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From Misdiagnosis to Prognosis: Autoethnographic Layered Accounts of Life with Mastocytosis

Gianina Shamarr Hayes
University of South Florida, ninah336@gmail.com

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From Misdiagnosis to Prognosis:
Autoethnographic Layered Accounts of Life with Mastocytosis

by

Gianina S. Hayes

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
in Curriculum and Instruction with an emphasis in
Adult Education
College of Education
University of South Florida

Major Professor: Wayne B. James, Ed.D.
Jeffrey D. Kromrey, Ph.D.
Janet C. Richards, Ph.D.
William H. Young, Ed.D.

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Dedication

Most of all, my dissertation is dedicated to God who so graciously lead me to the path which provided a platform to tell my story. Once engulfed in the chaotic confusion surrounding my illness, I now stand comfortably in full understanding of the purpose of my pain. Thank you Jesus, for the loving kindness you bestowed upon me.

I would be remiss not to dedicate my dissertation to my mother Regina Hayes and my grandmother Margaret Johnson (posthumously)—two women of strength and faith—who never once doubted me. If it were not for the two of you, I would have continued to believe the lies I was told about myself regarding my condition. Thank you for being there during the most vulnerable and perplexing moments in my life. Although you are no longer here Granny I can still feel your presence, gently guiding me toward my destiny.

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I would like to offer my sincere thanks to each physician who so graciously partnered with me as we approached a correct diagnosis. Though your names were hidden by pseudonyms, your acts of empathy and sound diagnostic decision making did not go unnoticed.

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Abstract

This study was an autoethnography authored in the form of layered accounts. It was based on my journey toward a correct diagnosis with the rare, orphan disease known as mastocytosis. The purpose of the study was to utilize my experiences to investigate mastocytosis from the perspective of an individual diagnosed with the disease. Furthermore, I investigated what ways and how much adult education philosophies and principles (e.g., humanistic, behaviorist, and adults' involvement in learning) may have been salient in my being correctly diagnosed to examine not only the disparities, but also the similarities in the way each physician I encountered approached the diagnostic process.

The layered accounts—written in three distinct layers—revealed my perception of my journey toward a correct diagnosis as blind, discouraging, and isolating (layers one). Also noted in layer one are detailed descriptions of my bouts with chorea (extreme, uncontrollable spasms affecting the limbs), which was rarely discussed in the literature. The responses of those around me (layer two) ranged from shock, genuine concern, uncertainty, judgement, dismissal, disbelief, humor, anger, hurt, and positivity. Pertinent literature on mastocytosis was juxtaposed with my experiences divulged in the first layer and highlighted similarities in the approach to the diagnostic process taken by the physicians who treated me and multiple disparities between what the literature states my experience as someone diagnosed with mastocytosis versus my actual experiences (layer three).

In addition to identifying the most salient adult education philosophies and principles in my journey to a correct diagnosis, this research identified parallels between the facilitator-learner relationship in adult education and the physician-patient relationship. The results implicate three principles and three philosophies salient to my correct diagnosis, along with one

philosophy and one principle which were the most salient. An overarching theme of self-directedness emerged along with a multiple disparities between what the literature states my experience should have been versus what took place as I sought medical care.

Chapter 1

Introduction

I remember hopping across the floor in the exam room of the doctor's office at the age of four. My pediatrician, Dr. Douglas (personal communication, 1983), turned to my mother and said "She's allergic to something, but I just don't know what it is." At the time, I had no clue what allergies were. The only thing I knew was sometimes I did not feel well. Throughout my early childhood I had dark, puffy, circles under my eyes, chronic constipation, and a recurrent upset stomach. Although several of my pediatricians were unable to specifically identify what was wrong, they offered the same possibility of me growing out of it as consolation to my mother. Eventually, I did grow out of it—or so I thought. What appeared to be maturation may have possibly been a period of remission.

At the age of 24 not only did some of my familiar symptoms return, they worsened. My dark puffy eyes were accompanied by swollen lips. The constipation and upset stomach turned into diarrhea and vomiting. My once smooth, uniformly colored skin darkened and became acne prone, rash prone, and highly sensitive. I often treated the symptoms as mere formalities, until one day I could no longer ignore them. I began experiencing seizure-like, uncontrollable spasms that affected my limbs and sometimes rendered me immobile. When I sought medical attention I either walked away undiagnosed, misdiagnosed, or told what I was experiencing was psychosomatic; some physicians who assumed psychosomatic associations were at play either prescribed counseling or antidepressants. Over time I developed a visceral mistrust of myself. If every physician who examined me was right and this was all in my head, I could no longer rely upon myself to make simple assessments such as whether or not any of my symptoms were

real. This incessant cycle of illness, doctor visits, and self-doubt continued for nearly five and a half years. It was not until 2009 that I was correctly diagnosed with mastocytosis. This is the story of my journey towards a correct diagnosis.

Mastocytosis is a stem cell disorder characterized by a surplus of immune cells known as mast cells; it exhibits a myriad of symptoms as well as morphological manifestations such as its two main forms which are cutaneous (affecting the skin only) and systemic (affecting organs other than the skin) (Hartmann, Bruns, & Henz, 2001; Horny, Sotlar, Valent, & Hartmann, 2008; “Mastocytosis Society of Canada”, 2011; Metcalfe, 1991). Mastocytosis may effect individuals “of all ages and genders”, and some may be diagnosed “with one or both forms of the disease” (“Mastocytosis Society of Canada”, 2011 “Defined,” para. 1). Although present in all ages and genders, research insists cutaneous mastocytosis primarily affects Caucasians (Hartmann, Bruns, & Henz, 2001; “Mastocytosis Society of Canada”, 2011; “Orphanet”, 2015; Woodward, 2003). Mastocytosis is also an orphan disease (OD) meaning it is either rare or a common disease that is often overlooked because it is not widespread in more developed countries; in many cases orphan diseases may be life threatening, and difficult to diagnose (*Medicine Net Online Dictionary*, 2012; Schieppati, Henter, Daina, & Aperia, 2008; Zhang, Zhu, Jacomy, Lu, & Jegga, 2011).

The classification of mastocytosis in reference to whether or not it is in its cutaneous or systemic form may be further refined by identifying whether or not systemic mastocytosis is functioning in an indolent or aggressive manner (Hartmann, Bruns, & Henz, 2001; Horny et al., 2008; “Mastocytosis Society of Canada”, 2011; Metcalfe, 1991). Aggressive systemic mastocytosis may potentially lead to other diseases such as malignant lymphoma, dysmyelopoietic and myeloproliferative disorders, mast cell sarcoma, and mast cell leukemia—often resulting in death (Hein & Hansen, 2005; “Mastocytosis Society of Canada”, 2011; Metcalfe, 1991). Despite the notion of indolent systemic mastocytosis being nonthreatening to a

patient's mortality, the Mastocytosis Society of Canada (2011) argues indolent systemic mastocytosis "is not a benign or minor diagnosis" and "is in many cases life threatening" (p. 2). Furthermore, "patients diagnosed with that stage [indolent systemic mastocytosis] experience continual escalation of current symptoms, and development of new symptoms they never used to have" ("Mastocytosis Society of Canada ", 2011, p. 2). Due to the difficulty associated with diagnosing and classifying mastocytosis, patients may endure symptoms for 10 years or more without a correct diagnosis, and without necessary treatment ("Mastocytosis Society of Canada", 2011).

Defining Orphan Diseases

An orphan disease (OD) may be defined as "a rare disease (according to US criteria, a disease that affects fewer than 200,000 people) or a common disease that has been ignored (such as tuberculosis, cholera, typhoid, and malaria) because it is far more prevalent in developing countries than in the developed world" (*Medicine Net Online Dictionary*, 2012, para. 1). It is estimated that roughly 8,000 ODs are in existence—some of which afflict young children, are genetic, and life threatening (Zhang et al., 2011). Because there is such a wide variety of ODs and so few patients who suffer from them, developing a public policy tailored to each OD is problematic (Zhang et al., 2011). It is this lack of infrastructure that makes it nearly impossible to develop "a universally recognised coding system"; this further impedes research by "preventing assessment of the economic and social effects of rare diseases" (Schieppati et al., 2008, p. 2039).

A lack of infrastructure and research concerning ODs may affect patients. According to Schieppati et al. (2008) it causes "diagnostic delays" (p. 2039). In fact, the results of the Eurordis Care Study conducted by Kole and Faurisson (2009) identifies "late diagnoses" as the culprits that delay "the beginning of adapted treatments and" having "severe, irreversible, debilitating and life threatening consequences" (Kole & Faurisson, 2009, p. 20). Kole and

Faurisson's (2009) research reveals the results of a questionnaire distributed to 18,000 participants across 17 European countries regarding the main causes of diagnostic delay in reference to eight ODs including: Cystic fibrosis, Crohn's disease, Marfan syndrome, Fragile X syndrome, Duchenne muscular dystrophy, Ehlers-Danlos syndrome, Tuberous sclerosis, and Prader Willi syndrome. The study reports patient outcomes ranging from late diagnoses to incorrect and no diagnoses. Specifically, 25% of participants reported a time period of 5-30 years elapsing between initial symptoms and a final, confirmatory diagnosis (Kole & Faurisson, 2009). Prior to receiving a definitive diagnosis, 40% of patients received an incorrect diagnosis—while others received no diagnosis at all (Kole & Faurisson, 2009). Moreover, several of the listed incorrect diagnoses resulted in superfluous medical interventions; these superfluous medical interventions range from providing 10% of patients with psychological care under the assumption that their symptoms were psychosomatic to 33% not receiving necessary treatment, and even performing surgeries on 16% of patients (Kole & Faurisson, 2009). One quarter of the participants sought second opinions from other regions of their country while 2% sought second opinions abroad (Kole & Faurisson, 2009). One third of study participants expressed dissatisfaction with methods utilized to communicate the diagnosis (Kole & Faurisson, 2009). Overall, the study delineates an arduous journey toward a correct diagnosis which was often reached by patients seeking "answers on their own, with little help from healthcare systems" (Kole & Faurisson, 2009, p. 42).

Mastocytosis as an Orphan Disease

Although not included in the Eurordis Care studies, Mastocytosis is an OD. I suffered from the symptoms and complications of mastocytosis for nearly five and a half years prior to receiving a correct diagnosis; this is consistent with both the Schieppati et al. (2008) research on delayed diagnostics, as well as Kole and Faurisson's (2009) Eurordis Care studies. During the five and a half year period, I incurred the same instances mentioned in the Eurodis Care 2

study—incorrect diagnoses, no diagnoses, and futile medical procedures (Kole & Faurisson, 2009). Hermine et al. (2008) note “the true incidence of mastocytosis is unknown, but the available evidence suggests that it is a rare disease, with a prevalence of no more than 0.3 per 10,000, which qualifies it as an orphan disease” (p. 1). Mastocytosis is a disease that is not widely recognized by patients or medical practitioners who often dismiss the disorder based upon their unfamiliarity with it (Campos-Castello, 2001; Hermine et al., 2008). In fact Campos-Castello (2001) suggests “orphan diseases need to be diagnosed early by specialists who have had patients referred to them by general practitioners” (p. 1). It is important to mention that Campos-Castello (2001) acknowledged the instances of late diagnoses associated with mastocytosis prior to both Hermine et al. (2008) and Kole and Faurisson’s (2009) research; Campos-Castello (2001) acknowledged the multitude of patients whose “initial recognition of the disorder is often delayed and late diagnosis occurs in 45% of these rare diseases that make up 10% of human illnesses” (p. 1).

Problem Statement

There is a lack of research conducted from the perspective of an individual diagnosed with the OD, mastocytosis. Despite the abundance of findings from the 12,000 patients who participated in Kole and Faurisson’s (2009) Eurordis Care studies, mastocytosis was not included on the list of the 18 ODs studied. Many of the questions answered concerning the gamut of diseases in their study have yet to be answered about mastocytosis. Though their investigation of ODs privileges meaning “to accord a higher value or superior position to” (*Merriam-Webster Dictionary*, 2015) and reports the experiences of the patients, the two authors were not patients. As a result, the patients who participated in the study provided guided responses to questionnaires as opposed to disclosing detailed accounts of the most salient course of events that transpired during their diagnostic delays. Furthermore, their study was quantitative—leaving little room for detailed descriptions of patient’s personal accounts.

Research establishes that patients with mastocytosis may wait 10 years or more to receive a correct diagnosis; the reasoning behind this delay in diagnosis is not addressed directly, but it can be argued few physicians are aware of the existence of mastocytosis and patients may have low health literacy (Campos-Casetello, 2001; Martin et al., 2009; “Mastocytosis Society of Canada,” 2011; Williams, Davis, Parker, & Weiss, 2002).

Purpose Statement

The purpose of this study was to investigate mastocytosis from the perspective of an individual diagnosed with the disease. It is imperative for “patients to express themselves and to report their voice” as opposed to an “epidemiological observational” approach which could conceivably dim the patient’s voice (Kole & Faurisson, 2009, p. 22). I also investigated what ways and how much adult education philosophies and principles (e.g., humanistic, behaviorist, and adults’ involvement in learning) may have been salient in my being correctly diagnosed to examine not only the disparities, but also the similarities in the way each physician I encountered approached the diagnostic process (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Guglielmino, 2008; Knowles, 1975). In addition to identifying the most salient adult education philosophies and principles in my journey to a correct diagnosis, this research identified parallels between the facilitator-learner relationship in adult education and the physician-patient relationship (Arseneau & Rodenburg, 1998; Boldt, 1998; Johnson & Pratt, 1998; Knowles, 1975; Nesbit, 1998; T’Kenye, 1998).

Rationale

As previously stated, Kole and Faurisson (2009) named the patient’s voice as a viable option for relaying important information as opposed to the common “epidemiological observational studies” that exist (p. 22). For instance, there are case studies of patients with mastocytosis that relay the symptoms and complications experienced by patients (e.g., Hein & Hansen, 2005; Siegert, Diebold, Ludolph-Hauser, & Löhrs, 2004; Sperr et al., 2002).

Nonetheless, the patient's perspective is based upon observational research and often interpreted in reference to a medical yardstick; in some instances, observational research alone can dismiss information-rich claims made by the patient, because they are inconsistent with medical norms (Kole & Faurisson, 2009).

An example of this is a case study conducted by Hein and Hansen (2005) where a patient expressed complaints about possible side effects after being placed on several medications to treat his mastocytosis. The following depicts the patient's experience:

The patient was then treated with loratadine 10mg daily, ranitidine 150mg daily, prednisone 20mg three times daily, and a-interferon 2b (IFN-a) 3.0 million subcutaneously three times weekly. While he initially had mild subjective improvement, his sense of weakness and his weight loss persisted and his laboratory data showed no evidence of regression. Eventually he became persistently nauseated and complained of diffuse myalgias thought to be secondary to his treatment regiment. After two months, he withdrew from treatment. The patient died one month after his treatment, four months after his diagnosis. (Hein & Hansen, 2005, p. 97)

Note how the patient complained about "diffuse myalgias" and nausea, but somehow those complaints were deemed "secondary to his treatment regiment" (Hein & Hansen, 2005, p. 97). The researchers were not clear about what steps were taken to determine his symptoms were not side effects of the medication. There was also no mention of an attempt to investigate the patient's claims. Furthermore, the patient "withdrew from treatment" after only a couple of months (Hein & Hansen, 2005, p. 97). Hein and Hansen (2005) were unclear as to why the patient withdrew. Perhaps the pain outweighed the benefits of the medication or maybe "his sense of weakness and his weight loss persisted and his laboratory data showed no evidence of regression" (Hein & Hansen, 2005, p. 97). More importantly, he "died one month after his treatment, four months after his diagnosis" (Hein & Hansen, 2005, p. 97).

I am not at all insinuating mistreatment was the cause of the patient's death. I am, however, questioning where the patient's voice was during this sequence of events. A reader who does not have mastocytosis may view this account in regards to its content in the absence of context and only glean the superficial *facts*. A sufferer of mastocytosis like me, on the other

hand, would more than likely consider the context in which the circumstances occurred. As a sufferer of mastocytosis, I have taken several of the medications listed in the above quote. And just as the study participant, I complained about nausea and diffuse myalgias only to be told that what I was experiencing was not a result of the medication. Also similar to the study participant, I lowered the dosage of certain prescribed medications and simply abstained from consuming others. My claims about the side effects were utterly disregarded by some physicians. Instead, I was politely informed that it was up to me to discontinue using the medication, but it was not recommended. Simply put, my claims and those of the study participant were noted, but not substantiated. For this reason, I have chosen not only to write about the perspective of a person diagnosed with mastocytosis, but more importantly as an individual who has been diagnosed with mastocytosis.

Significance and Usefulness of the Study

Mastocytosis patients endure a period of 10 years or more before receiving a correct diagnosis ("Mastocytosis Society of Canada," 2011). I was correctly diagnosed with mastocytosis after only a five and a half year diagnostic delay. Detailed descriptions of my journey to a correct diagnosis during my diagnostic delay may aid in arriving at speedier, correct diagnoses, and in turn prolonging patients' lifespans. I examined not only the disparities, but also the similarities, between my own experiences and the literature on mastocytosis. According to much of the personal communication between my physicians and I, some of my symptoms and complications were unique and antithetical to research findings on mastocytosis. This may encourage medical professionals to consider the high level of clinical variability mastocytosis presents rather than seeking classic cases divulged in the research (Bazan-Socha, Rudzki, Maciejewicz, Witkoś, & Szczeklik, 2001).

The parallels identified between the facilitator-learner relationship in adult education—which are expounded upon in the subsequent text—and the physician-patient relationship may

provide useful recommendations and implications for practice. Whether or not an individual has experienced a chronic illness, they have more than likely—at some point in their life—visited a physician. Traditionally, the physician-patient relationship has been perceived and treated as a parent-child relationship; the physician acts as the parent and the patient takes on the role of the child (Bodenheimer et al., 2002). Specifically, physicians are regarded as experts while patients are viewed as idle, uninformed beings who bring “little to the table besides their illness” (Bodenheimer et al., 2002, p. 2470). This perspective is especially common in reference to the patient-physician relationship when the patient has been diagnosed with a chronic illness (Bodenheimer et al., 2002). Although seemingly accurate, this traditional perspective (parent-child relationship) assumes that physicians are comfortable with taking all of the responsibility and patients are neither proactive about nor interested in collaborating with physicians to improve their health. In fact, some patients may desire and even pursue active roles concerning their health in concert with their physicians (Bodenheimer et al., 2002). Moreover, Bodenheimer et al. (2002) elaborate on an emerging paradigm where “people with chronic conditions are their own principle caregivers, [while] health care professionals—both in primary and specialty care—should be consultants supporting them in this role” (p. 2470). Due to this emerging paradigm, it may prove advantageous to exemplify adult education teaching perspectives from both the classroom and exam room perspective, while establishing parallels and connections between both environments.

A case for presenting this study as an autoethnography. Some may read this dissertation and wonder why I chose to write it as an autoethnography as opposed to administering a questionnaire to participants—similar to the research of Kole and Faurrison (2009). As the subsequent text in the review of literature reveals, autoethnography is a style of research and writing that exhibits multiple layers of consciousness and ties personal experiences to cultural ones (Ellis & Bochner, 2000). Kole and Faurrison’s (2009) research

calls attention to a culture within medicine that often neglects the voices of the patients with ODs, in favor of epidemiology. My personal experiences with mastocytosis offers further investigation into and analysis of said culture in reference to mastocytosis. Not to mention, autoethnography provides a human element that is often missing from the more sterile, clinical observations made to better understand patients. As I wrote each narrative chapter (Chapters 4 through 6) I did so in a manner that would draw the reader in to experience every instance of pain, frustration, confusion, and heartache I faced in the moment and evoke empathy.

From personal experience—participating in conferences and grand rounds at hospitals—mastocytosis patients are often reluctant to speak candidly about their struggles with disease—even with other patients. In fact “mastocytosis patients are not seen regularly by people outside their immediate family or caregiver except for those rare occasions when they are feeling well” (“Mastocytosis Society of Canada,” 2011, p. 3). Moreover, I have observed the same disinclination in my own behavior. I often avoid sharing my illness and any complications I endure with others to avoid garnering their pity. Writing this dissertation has placed me in a paradox which has proved cathartic for my soul, yet sully for my tough exterior.

In addition to the reluctance to speak out, amassing sizeable groups of mastocytosis patients for research purposes may prove daunting. For example, I attended an international conference held at Duke Hospital in 2010. There were patients from Germany, Russia, and several other countries including the United States (US). In most cases, a global inquiry should at least be able to accrue to an *n* of 200. A total of roughly 63 patients attended the conference. Further indicating the difficulty of acquiring study participants are the multiple resources cited in this dissertation, which are either case studies or contain a total of 113 participants or less with mastocytosis; these studies were conducted all across the globe from the US to Austria and Spain by physicians who possessed the medical records of mastocytosis patients—which are inaccessible to the general public (Garcia-Montero et al., 2006; Hein & Hansen, 2005; Nordlind

& Theodorsson, 1993; Schwartz et al., 1995; Siegert et al., 2004; Sperr et al., 2009). Overall, the medical community “does not know this disorder or mast cells nearly well enough to provide answers to all that patients endure and suffer” because it has “barely scratched the surface in fully defining, diagnosing and treating mastocytosis” (“Mastocytosis Society of Canada,” 2011, p. 2). My willingness to openly discuss my daily battle with mastocytosis may provide new insight for the medical community.

Consider the previously mentioned account of the deceased patient in Hein and Hansen’s (2005) case study. Perhaps there was more to be learned from the patient in addition to what was determined from the lab work. This autoethnographic research demonstrates what can be learned about mastocytosis and similar diseases outside of lab work. It also serves as a means of questioning and deconstructing the relationship between the general diagnostic process and health literacy as it pertains to mastocytosis. Moreover, I hopefully can add to the knowledge base of mastocytosis, make an impact (socially, personally, institutionally, organizationally) on both the medical community and community of mastocytosis patients, generate new ideas about the physician-patient relationship in reference to the diagnostic process, inform constituencies about mastocytosis, and examine the past—including my own experiences with mastocytosis (Gall, Gall & Borg, 2007; Newman, Ridenour, Newman, & DeMarco, 2003).

Research Questions

The following research questions guided the study:

- 1) How do I, as patient with mastocytosis, describe and perceive my journey toward a correct diagnosis?
- 2) How is mastocytosis defined by multiple academic and medical literature sources versus my personal experience?
- 3) How do multiple academic and medical literature sources delineate the general

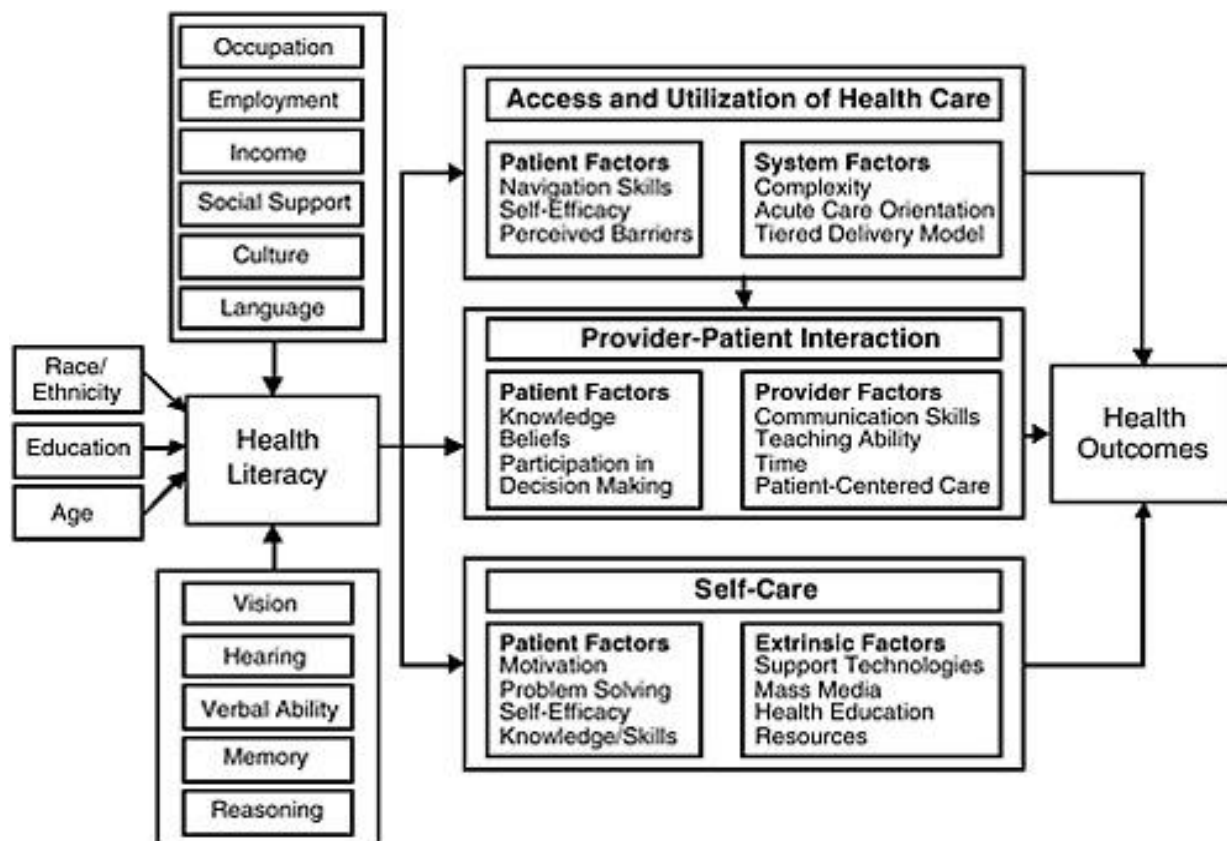
diagnostic process and how does this differ from my experience?

- 4) What parallels exist between the facilitator-learner relationship demonstrative of adult education, and the physician-patient relationship?
- 5) Which adult education principals and philosophies did I utilize while working with physicians to establish a correct diagnosis?
- 6) Among those utilized, which adult education principals and philosophies were most salient in arriving to a correct diagnosis?

Conceptual Framework

Some of the issues that may prevent patients from receiving a correct diagnosis found in the literature include a lack of awareness about the existence of mastocytosis on behalf of the physician and low health literacy rates among patients (Campos-Casetello, 2001; Williams et al., 2002; Martin et al., 2009; "Mastocytosis Society of Canada," 2011). Figure 1 depicts the relationships of health literacy and health outcomes.

In line with Paasche-Orlow and Wolfe's (2007) model concerning health literacy is the perspective of Bodenheimer et al. (2002) on collaborative care that credits the knowledge patients bring to the table as being equally as important as the knowledge of the physician. Although physicians are clearly experts in their field, only patients are experts about their own lives; consequently, acknowledging and improving health literacy is a must (Bodenheimer et al., 2002; Paasche-Orlow & Wolfe, 2007). Likewise, diagnosing an OD such as mastocytosis may further complicate both the health outcomes as described by Paasche-Orlow and Wolfe (2007) and the potential to establish the collaborative care recommended by Bodenheimer et al. (2002).



*Figure 1. Causal pathways between health literacy and health outcomes model. The 14 rectangles on the left (race/ethnicity, education, age, occupation, employment, income, social support, culture, language, vision, hearing, verbal ability, memory, and reasoning) denote a direct effect of sociodemographic, intellectual, and physical attributes on health outcomes. As a result of the patient's health literacy level, their ability to access and utilize health care, interact with their health provider or physician or engage in self-care equally determine health outcomes. From "The Causal Pathways Linking Health Literacy to Health Outcomes," by M. K. Paasche-Orlow, & M. S. Wolfe, 2007, *American Journal of Health Behavior*, 31, p. 19-26. Copyright 2007 by PNG Publications. Reprinted with permission.*

This autoethnography was built upon the framework of the gap between the accounts of mastocytosis in existing research and my personal experience.

Limitations

Two limitations come to mind when reviewing this study. This includes the incorporation of my perspective as an adult education major as a researcher rather than a medical student and the exclusion of co-researchers.

Perspective of an adult education major. Despite my inclusion of a detailed review of literature and some assistance from, Dr. Metcalfe, the fact remains I am not a medical student, nor am I a medical professional. My expertise is in education, which privileges me with the ability to procure, read, and comprehend less accessible, complex literature. Nonetheless, I have never experienced diagnosing or treating a patient with an illness. In light of this, it should be duly noted my perspective is purely that of a patient paired with theoretical concepts regarding mastocytosis and is absent of the physician's perspective and formal, medical education.

Exclusion of co-researchers. Most autoethnographies discuss the experiences of the researcher, through the eyes of the researcher exclusively. In some instances, researchers may opt to include two to three colleagues in what are known as duoethnographies and trioethnographies. Well written duo and trioethnographies require all writers involved to be capable of producing evocative, narrative-like, and thorough academic writing. In most cases, all three researchers are either in graduate school or recipients of graduate degrees. When I began writing this autoethnography, I did not know anyone who fit this description. In the case of Perez (2013), he conducted responsive interviews with three, purposively selected participants who shared similar experiences to his own, and to whom he referred to as co-researchers. From the data, he constructed individual portraits of each co-researcher as well as a group depiction. The utilization of duoethnography, trioethnography, and the heuristic approach with participants as co-researchers would have further enhanced the organic triangulation, which occurred from my interacting with 15 physicians by providing perspectives of more patients who each interacted with multiple physicians.

Definition of Terms

This section serves to define specific terms that are relied upon throughout the study. It also serves to provide the context in which the terms are utilized.

Aggressive Systemic Mastocytosis (ASM). The definition of ASM utilized in this study is the one proposed by Orphanet, a website dedicated to discussing rare illnesses and orphan drugs:

a severe and rare form of systemic mastocytosis (SM . . .) characterized by considerable infiltration of mast cells in different tissues. . . . Patients present with severe symptoms related to mast cell invasion and the intense release of mediators including syncope, recurrent flushing, diarrhea, pain, organomegaly [enlargement of organs] and organ dysfunction, impairment of hematopoietic function (which may result in disruption of the blood count ranging from isolated cytopenia to more or less marked pancytopenia), bone involvement in the form of osteoporosis with the risk of fracture, and malabsorption. (Orphanet, 2015)

Autoethnography. Ellis, Adams, and Bochner (2011) as well as Ellis and Bochner (2000) define autoethnography as an engaging and evocative style of research and writing that exhibits multiple layers of consciousness and ties personal experiences to cultural ones by identifying epiphanies, revelations, implications, and establishes sociocultural parallels to society and one's self that are meaningful to the autoethnographer.

Health literacy. This study relied on the definition of health literacy offered by the World Health Organization (WHO) (2015); they regard it as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways that promote and maintain good health” (p. 10).

Layered accounts. Ellis et al. (2011) and Ronai (1995) describe this form of autoethnography as one that juxtaposes the researcher's experience beside pertinent literature, data, and abstract analysis.

Researcher's experience (layer one). This is the first of three layers within the type of autoethnography known as layered accounts. It relays the experiences of the researcher in a narrative form (Ellis et al., 2011; Ronai, 1995).

Responses of others (layer two). This is the second of three layers within the type of autoethnography known as layered accounts. It takes note of how those around me responded to the events which transpired in my experiences (Ellis et al., 2011; Ronai, 1995).

Self-directed learning. Self-directed learning is described as “a process of learning, in which people take the primary initiative for planning, carrying out, and evaluating their own learning experiences” (Merriam, Caffarella, & Baumgartner, 2007, p. 110).

What the literature states (layer three). This is the third of three layers within the type of autoethnography known as layered accounts. It compares the experiences of the researcher to pertinent literature on the subject matter (Ellis et al., 2011; Ronai, 1995).

Glossary of Terms

Acute myeloid leukemia (AML). Is a rapidly progressive form of leukemia “in which the type of blood cell that proliferates abnormally originates in the blood-forming (myeloid) tissue of the bone marrow” (“American Cancer Society,” 2015).

Chronic myelomonocytic leukemia. Golub, Barker, Lovett, and Gilliland (1994) describe Chronic Myelomonocytic Leukemia as a form of leukemia marked by an exorbitant amount of white blood cells.

Cutaneous mastocytosis (CM). Also known as urticaria pigmentosa (UP), CM is defined as a form of mastocytosis that is relegated to the skin and primarily affects Caucasians (Hartmann, Bruns, & Henz, 2001; “Mastocytosis,” 2012; “Mastocytosis Society of Canada”, 2011; “Orphanet”, 2015; Woodward, 2003).

Hematologic disorders. *Mosby’s Dental Dictionary* (2008) describes hematologic disorders as “the diseases of the blood and blood-forming tissues” (p. 318).

Hypereosinophilic syndrome. The Mayo Clinic (2015) refers to Hypereosinophilic syndrome as “a group of blood disorders that occur when you have high numbers of eosinophils—white blood cells that play an important role in your immune system. Over time, these high numbers of eosinophils enter various tissues, causing inflammation and eventually damaging your organs, most commonly targeting the skin, lung, heart, blood and nervous system” (Patient Care and Info, Diseases and Conditions para. 1 under Definition).

Indolent systemic mastocytosis (ISM). According to Orphanet (2015), ISM (also known as smoldering mastocytosis) “is a benign form of systemic mastocytosis” which is “characterized by an abnormal proliferation of mast cells either only in bone marrow or in numerous tissues” (Rare Diseases Search section, para. 1 under Summary).

Mast cell leukemia. This study employed a definition of mast cell leukemia posited by Orphanet (2015) that regards it as a very rare “malignant form of systemic mastocytosis” which is “characterized, most of the time, by the presence of circulating mast cells” (Rare Diseases Search section, para. 1 under Summary).

Mast cell sarcoma. This term is “defined by a local destructive sarcoma-like growth of a tumor that consists of highly atypical mast cells” (Chott et al., 2003, p. 1013).

Mastocytosis. Although this study lists, compares, and contrasts several different definitions for mastocytosis, for the purpose of consistency, this study relied upon the definition provided by the Mastocytosis Society of Canada (2011):

A myeloproliferative neoplastic (mpn) stem cell disorder, caused by an over-abundance of good immune system cells called mast cells and the release of mast cell mediators. These cells may also be misshapen or malformed, further contributing to their dysfunction.¹ Mastocytosis presents in cutaneous (skin) and systemic (internal) forms. Patients of all ages and genders may present with one or both forms of the disease. (“Defined,” para. 1)

Myelodysplastic syndromes. These are known as “a group of diverse bone marrow disorders in which the bone marrow does not produce enough healthy blood cells” (Myelodysplastic Syndromes Foundation, 2014 para. 3).

Myeloproliferative disease. This term is known as a group “clonal hematologic diseases” resulting “from a transformation in a hematopoietic stem cell” (Campbell & Green, 2006, p. 2452).

Non Hodgkins lymphoma. Orphanet (2015) defines Non Hodgkins Lymphoma “a heterogeneous group of malignant tumors of the lymphoid system” (Rare Diseases Search section, para. 1 under Summary).

Orphan disease (OD). According to *Medicine Net Online Dictionary* (2012), this term is defined as “a rare disease (according to US criteria, a disease that affects fewer than 200,000 people) or a common disease that has been ignored (such as tuberculosis, cholera, typhoid, and malaria) because it is far more prevalent in developing countries than in the developed world” (Rare Diseases, Search section, para. 1 under Summary).

Orphan drugs. The definition of orphan drugs employed in this study comes from the Orphanet (2015) website that defines it as “drugs that are not developed by the pharmaceutical industry for economic reasons but which respond to public health need” and in some instances “a drug may also be considered as ' orphan ' since a substance may be used in the treatment of a frequent disease but may not have been developed for another, more rare indication” (Other Information, About Orphan Drugs section, para. 4 under What is an orphan drug?).

Systemic mastocytosis (SM). According to the Orphanet (2015) website, SM is “a heterogeneous group of rare acquired and chronic hematological malignancies that are related to an abnormal proliferation of mast cells in tissue, including bone marrow, with or without skin involvement” that “can be divided into indolent SM (ISM) and aggressive SM (ASM)” and primarily “affects Caucasians” (Rare Diseases Search section, para. 1 under Summary).

Vasculitis. Vasculitis is defined as “any of a group of disorders characterized by inflammation and necrosis of blood vessel walls” (vasculitis, 2008).

Organization of the Study

In Chapter 2 I examined autoethnography, mastocytosis, and the learning relationships between both facilitators and learners and physicians and patients. I then provided autoethnographic vignettes in the form of layered accounts describing my experiences as an individual with mastocytosis, the responses of others, and what the literature states about my experiences with mastocytosis in Chapters 3, 4, 5, and 6. Chapters 7 and 8 offered the findings and discussion respectively and included descriptive statistics comparing my lab results (i.e.,

bloodwork, biopsies, etc.) to datasets containing the lab results of study participants with mastocytosis. In Chapter 9 I provided the summary, conclusion, implications, and recommendations.

Chapter 2

Literature Review

The purpose of this study was to investigate the orphan disease mastocytosis from the perspective of a patient diagnosed with the disease. To enhance my understanding of my personal experiences with mastocytosis as well as my understanding of health literacy, the diagnostic process, and adult education principals and/or philosophies in informal and non-formal settings my research questions were answered via a method of autoethnography known as layered accounts; this involves comparing and contrasting my personal experiences to relevant literature (Ellis et al., 2011; Ronai, 1995). This review of literature examines autoethnography, mastocytosis, and relationships between facilitators and learners as well as between physicians and patients.

Autoethnography

Before attempting to explain what autoethnography is, it may be more appropriate to establish what it is not. Although autoethnography requires some aspects of autobiography, to say these two styles are identical is inaccurate. An autoethnography is not a *tell all* nor is it a historical account of events (Ellis et al., 2011; Ellis & Bochner, 2000).

Autoethnography is a style of research and writing that exhibits multiple layers of consciousness and ties personal experiences to cultural ones (Ellis & Bochner, 2000). Writing an autoethnography requires the researcher to “retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity” (Ellis et al., 2011, p. 4). To put this into perspective

Ellis et al. (2011) quoted Allen [personal interview, May 4, 2006] who clarified the role of the autoethnographer:

Look at experience analytically. Otherwise [you're] telling [your] story—and that's nice—but people do that on *Oprah* [a U.S.-based television program] every day. Why is your story more valid than anyone else's? What makes your story more valid is that you are a researcher. You have a set of theoretical and methodological tools and a research literature to use. That's your advantage. If you can't frame it around these tools and literature and just frame it as "my story," then why or how should I privilege your story over anyone else's I see 25 times a day on TV? (Ellis et al., 2011, p. 4)

Considering the above quote, it is the responsibility of the autoethnographer to "not only use their methodological tools and research literature to analyze experience, but also must consider ways others may experience similar epiphanies" (Ellis et al., 2011, p. 4). The autoethnographer "must use personal experience to illustrate facets of cultural experience, and, in so doing, make characteristics of a culture familiar for insiders and outsiders" (Ellis et al., 2011, p. 4)

Types of autoethnography. Ellis et al. (2011) discuss nine types of autoethnography, which are: narrative ethnography, co-constructed narratives, indigenous/native ethnographies, reflexive dyadic interviews, reflexive ethnographies, interactive interviews, community autoethnographies, layered accounts, and personal narratives. The type of autoethnography written is contingent upon the level of emphasis placed on "the study of others, the researcher's self and interaction with others, traditional analysis, and the interview context, as well as on power relationships" (p. 5).

Narrative ethnography. This form of ethnography is the result of a shift from observing participants to observing participation as a method for anthropological studies (Tedlock, 1991). While observing participation in this manner, "ethnographers both experience and observe their own and others' coparticipation within the ethnographic encounter" (Tedlock, 1991, p. 69). His proposed methodological shift reveals:

a representational transformation in which, instead of a choice between writing an ethnographic memoir centering on the Self or a standard monograph centering on the Other, both the Self and Other are presented together within a single narrative ethnography, focused on the character and process of the ethnographic dialogue. (Tedlock, 1991, p. 69)

Co-constructed narratives. These types of narratives delineate the essence of human interaction based on joint efforts to confront the “ambiguities, uncertainties, and contradictions” of functioning in friendships, intimate partnerships, and families (Ellis, Adams, & Bochner, 2011, p. 7). Such joint efforts and activities serve as the foundation for co-constructed narratives by conceptualizing relationships as “relationships as jointly-authored, incomplete, and historically situated affairs” (Ellis et al., 2001, p. 7). The writing process involves several authors who each write their own stories—based on epiphanies—followed by sharing and reacting to each other’s stories (Bochner & Ellis, 1995; Toyosaki & Pensoneau, 2005; Vande Berg & Trujillo, 2008).

Indigenous/native ethnographies. Indigenous/native ethnographies “develop from colonized or economically subordinated people, and are used to address and disrupt power in research, particularly an (outside) researcher’s right and authority to study (exotic) others” (Ellis et al., 2001, p. 6). Unlike its conventional predecessor, the more modern indigenous/native ethnography rejects the notion of subjugating those who are studied to the mercy of white, male, able-bodied, heterosexual, Christian, upper-to-middle class ethnographers (Denzin, Lincoln, & Smith, 2008).

Reflexive dyadic interviews. These types of interviews hone in on the emotional dynamics as well as the meanings which developed from the interactions of the actual interviews (Ellis et al., 2011). Unlike the majority of interviews where the emphasis is placed on the responses of the participants, reflexive dyadic interviews also consider the feelings of the researchers; this includes personal aspects of researchers such as their inspiration for conducting the research, any passionate reactions to the interviews, ways in which the researcher was transformed by the interviewing process, and familiarity with the subject matter (Ellis et al., 2011).

Reflexive ethnographies. Unlike its transactional relative, reflexive dyadic interviews, reflexive ethnographies focus mainly on the ethnographer (Ellis et al., 2011). This is exacted by

documenting how a researcher changes during the research process (Ellis et al., 2011). This may be presented in a narrative form known as reflexive/narrative ethnography that ranges from a biography of the ethnographer, to the ethnographer conducting a simultaneous study of his or her life in comparison to the lives of cultural members, to making the memoirs which depict the ethnographer's behind-the-scenes research the focal point of the investigation (Ellis, 2004; Van Maanen, 1988).

Interactive interviews. Often described as collaborative in nature, interactive interviews equip readers with an intimate portrait of how people react to sensitive subject matter; this is enacted by the investigators and the participants collectively probing sensitive subject matter through conversation (Adams, 2008; Ellis et al., 2011). Sensitive subject matter may include substance abuse or eating disorders (Ellis et al., 2011). This form of autoethnography emphasizes what is learned from the interaction between the researcher and the participant during the interview process; moreover, it offers information-rich stories from the participants (Mey & Mruck, 2010).

Community autoethnographies. Community autoethnographies read somewhat like an anthology. This form of autoethnography is written by combining the personal accounts of researchers to delineate how certain socio-cultural aspects of a community are expressed (Toyosaki, Pensoneau-Conway, Wendt, & Leathers, 2009).

Layered accounts. This form of autoethnography juxtaposes the researcher's experience beside pertinent literature, data, and abstract analysis (Ellis et al., 2011). Layered accounts are comparable to grounded theory in reference to how both methods present analysis and data collection as a simultaneous process while presenting relevant literature as a "source of *questions* and *comparisons*" as opposed to a "measure of truth" (Charmaz, 1983, p.117). Layered accounts differ from grounded theory by relying on reflexive accounts, introspective analysis, and the use of vignettes with multiple voices (Ellis, 1991).

Personal narratives. Personal narratives are noted as the most contentious of all autoethnographies; this is partially due to the absence of “traditional analysis and/or connections to scholarly literature”, which are staples in traditional sciences (Ellis et al., 2011, p. 7). In personal narratives, the academic and personal facets of the researcher’s life are discussed in a context where the actual researcher functions as the phenomenon (Ellis et al., 2011). Personal narratives attempt to make sense of life and self as they relate to culture; the researcher may connect with participants, and rely on them as co-researchers (Ellis, 2004).

Examples of autoethnography in health and adult education. Autoethnographies are capable of not only addressing general populations, cultures, and subcultures, but also specific fields of study (Ellis et al., 2011). This ties into the importance of accessibility.

Autoethnography in adult education. Autoethnographers—well versed in the field—may call unfamiliar subject matter to the attention of their colleagues; this is achieved by incorporating principles, practices, and philosophies from their field of the study to create social awareness while emphasizing distinct parallels between the author’s field of study and his or her personal experiences (Bochner, 1997; Ellis, 1995; Goodall, 2006; Hooks, 1994). For example, Brookfield (2011) and King (2014) each authored autoethnographies that incorporated adult education principles and practices as pragmatic applications for coping with their experiences.

Brookfield’s (2011) *When the Black Dog Barks: An Autoethnography of Adult Learning in and on Clinical Depression* provides a personal narrative about his experience with clinical depression, and how adult learning methods and perspectives may prove useful in the push to better understand clinical depression. King’s (2014) *A Journey with Chronic Pain: Self-directed Learning as Survival* provides layered accounts from which emerging themes of self-directed learning were analyzed and discussed. Each author provided thick descriptions of their experiences while incorporating commonly used terms from their field to relay comprehensible perspectives.

Autoethnography in health. In other instances, an individual who has no ties to a particular field of study may share her or his accounts of a unique experience to provide insight from their perspective to experts in a particular field. An example of this type of autoethnography is Cahalan's (2012) *Brain on Fire: My month of Madness*. This personal narrative—written in the form of a novel—divulged Cahalan's experience with a rare, incorrectly diagnosed disease that nearly claimed her life. Although not a doctor, Cahalan authored this story from the perspective of a patient; this provided insight for medical professionals which may prove useful for earlier diagnoses. Clardy (2013) who holds both a medical doctorate and a doctorate of philosophy, reviewed the book. It was Clardy (2013) who expressed the importance of an autoethnographic piece from the perspective of the patient in the following statement:

By describing both the subtle and dramatic changes from the eyes of the patient, from the earliest symptoms through late recovery, the book accomplishes what cannot be done at the bedside in five or even thirty minutes: it personalizes the disease; it brings the diagnosis from abstraction to reality, accurately portraying the desperation of the acute phase of the illness. Perhaps most important, it gives hope for recovery, but not unqualified by the long duration of the recovery period and the effort required to maximize recovery. (p. 1)

Defining Mastocytosis

As mentioned in Chapter 1, mastocytosis is an orphan disease (OD). Although the disease itself is rare, there does not appear to be a shortage of definitions for the disease.

There are multiple definitions of mastocytosis. Metcalfe (1991) defined it as:

a disease characterized by an abnormal increase in mast cells. Manifestations of the disease are provoked in large part by the resultant increase in mast cell-derived mediators, which have a variety of local and systemic effects. Mastocytosis is variable in respect to the organ systems involved, clinical manifestations, and association with hematologic diseases. (p. 2s)

The Mastocytosis Society of Canada (2011) defined mastocytosis as:

A myeloproliferative neoplastic (mpn) stem cell disorder, caused by an over-abundance of good immune system cells called mast cells and the release of mast cell mediators. These cells may also be misshapen or malformed, further contributing to their dysfunction. Mastocytosis presents in cutaneous (skin) and systemic (internal) forms.

Patients of all ages and genders may present with one or both forms of the disease.
("Defined," para. 1)

Horny et al. (2008) define mastocytosis as "an unusual clonal disease of the hematopoietic stem cell" (p. 686). Yet another definition is offered by Hartman et al. (2001) who concluded "mastocytosis is a rare disease characterized by an abnormal increase of mast cells in tissues. The skin is the organ most frequently involved, but mast cells also accumulate in the bone marrow, gastrointestinal tract, lymph nodes, spleen, and liver" (p. 143).

It is apparent in all four definitions that mastocytosis is a cellular disease. Upon closer look, however, subtle differences between the definitions may be detected. Out of the four definitions, the Mastocytosis Society of Canada's (2011) is the only one that describes it as myeloproliferative; this term implicates the disease in having adverse effects on "blood cells -- platelets, white blood cells, and red blood cells" that cause these particular blood cells "to grow abnormally in the bone marrow" regardless of whether or not it presents in its cutaneous or systemic form ("University of Maryland Medical Center", 2015). Only the Mastocytosis Society of Canada (2011) and Horny et al. (2008) mention the involvement of stem cells in mastocytosis.

Pointing out subtleties in how mastocytosis is defined may seem trivial to some, but in reference to reaching a correct diagnosis, classification, and a somewhat accurate prognosis, consistency is key. Multiple, inconsistent definitions of mastocytosis are not a new occurrence. In fact, disparities in definitions of mastocytosis date back as far as 1877. Metcalfe (1991) calls attention to this issue with the following statement:

In 1889 Nettleship described the typical lesions of mastocytosis, subsequently termed urticaria pigmentosa, in a report of an unusual form of urticaria in a two-year-old girl [1]. The initial report includes a description of a wheal that could be produced by scratching the lesion. At about the same time, in 1877, Paul Ehrlich first described connective tissue cells that possessed granules which he called "mastzellen," or overfed or overnourished cells. He later noticed basophils in the peripheral blood and realized that those cells were similar to mast cells. Subsequently, it was recognized that urticaria pigmentosa could be associated with symptoms involving, for example, the gastrointestinal tract . . . in 1949, Ellis clearly established that mastocytosis is a disease that can be systemic and involve internal organs. (p. 2s)

The subsequent text will further explain how multiple definitions can affect the diagnosis, classification, and prognosis for mastocytosis.

Diagnosis and classification of mastocytosis. As previously stated mastocytosis manifests in two general forms: cutaneous (relegated to the skin) and systemic (spreading to other organs) mastocytosis (Metcalf, 1991). To first diagnose mastocytosis and then determine the type, three main forms of testing are utilized: soft tissue biopsies, blood tests, and bone marrow biopsies (Sperr et al., 2002). If the patient exhibits identifiable skin involvement (i.e., hives and flushing) the physician may authorize a biopsy of the affected area (Sperr et al., 2002). If the skin is asymptomatic while other symptoms such as unexplained anaphylaxis are present, the physician may request a blood test to assess tryptase levels which are diagnostic indicators reflective of mast cell activation (Sperr et al., 2002). Normal serum tryptase levels for those not suffering from mastocytosis are less than one, and abnormal serum tryptase levels for sufferers of mastocytosis over 20 suggest systemic mastocytosis (Sperr et al., 2002). Mast cell activation alludes to systemic involvement and the potential for mast cell leukemia, therefore, necessitating chemotherapy (Sperr et al., 2002). If systemic involvement is suspected, a bone marrow biopsy will be taken from the patient to verify the findings of the blood test (Sperr et al., 2002).

Although the process for diagnosing mastocytosis appears to be basic, it is far more complex than imagined. One reason is physicians have a tendency to base the diagnostic process solely on an early hypothesis about what is being observed rather than reasoning which can often result in an incorrect diagnosis (Bodenheimer et al., 2002). Other issues that may prevent patients from receiving a correct diagnosis which have been found in the literature include a lack of awareness about the existence of mastocytosis on behalf of the physician and low health literacy rates among patients (Bryan, Swann, & Brittain, 2012; Campos-Castello,

2001; Martin et al., 2009; “Mastocytosis Society of Canada,” 2011; Paasche-Orlow & Wolfe, 2007; Williams et al., 2002).

Conflated use of classification schemata. Just as mastocytosis exhibits a high degree of variability “in respect to the organ systems involved, clinical manifestations, and association with hematologic diseases”, so does it vary greatly in how it is defined and categorized (Metcalf, 1991, p. 2s). This is possibly due to an absence of a consistent, widely used definition of mastocytosis and its many manifestations. This inconsistency in regards to classification was noted by Golkar and Bernhard (1997) who affirmed a “no satisfactory classification of mastocytosis has been presented” and “a ‘consensus’ classification showed that consensus is not always the most effective way to engender order” (Golkar & Bernhard, 1997, p. 1379). The World Health Organization (WHO) offers the most current classification scheme for mastocytosis; this classification scheme which was presented in 2008 followed 20 years after an earlier classification scheme offered by Travis, Li, Bergstralh, Yam, and Swee in 1988 (McNeil & Katelaris, 2011; Metcalfe, 1991). Metcalfe (1991) recommended the medical community seek to enhance the classification system which will permit “assessment of prognosis and therapy” (p. 2s). Metcalfe (1991) provides further details about the complexities of the mastocytosis classification process:

Classification of mastocytosis based on distribution of the lesions consists of listing which organs are involved, e.g., the liver, spleen, bone marrow, or gastrointestinal tract. The nature of the process is variously referred to as “benign” or “malignant”. It is thus often difficult to compare descriptions of mastocytosis in articles by different authors. For example, a person with a form of mastocytosis that has persisted for 40 years and resulted in severe gastrointestinal disease with malabsorption may be referred to by one author as having “malignant disease” because of the severity of the process. Another author may use the same term to describe a second patient who has manifested a mastocytosis process for only six months, but one which is rapidly progressive. Clearly, such definitions do not allow categorization for treatment and for assignment of prognosis. (p. 2s)

Classifications of mastocytosis. To resolve some of the inconsistencies within the classification scheme, Metcalf (1991) suggested the use of the Travis et al. (1988) classification

scheme. The National Institutes of Health (NIH) relied heavily on the research of Travis et al. (1988) which insisted the—then current—binary classification scheme of (cutaneous or systemic) ignored a multitude of categories, manifestations, and disorders associated with mastocytosis. Veritably, mastocytosis may present in four categories: Indolent Mastocytosis, Mastocytosis associated with a Hematologic Disorder with or without Urticaria Pigmentosa (UP), Mast Cell Leukemia, or an aggressive form known as Lymphadenopathic Mastocytosis associated with Eosinophilia which may also present with UP (Travis et al., 1988).

Indolent Mastocytosis, the first category of mastocytosis—known as Indolent or Type I Mastocytosis—may manifest as both cutaneous and systemic; in its cutaneous form, it may be diffuse or express as UP (Travis et al., 1988). In its systemic form, Indolent Mastocytosis may infiltrate the bone marrow and/or the gastrointestinal (GI) tract, and may or may not present with UP (Travis et al., 1988). This category of mastocytosis is named so (Indolent) due to its slow progression rate in comparison to the other three categories (Metcalf, 1991; Travis et al., 1988).

Mastocytosis associated with hematologic disorder, also known as Category II, is linked to three disorders and two forms of cancer. These disorders and cancers are dysmyelopoeitic disorders, myeloproliferative disorders, neutropenia disorders (chronic), acute non-lymphatic leukemia, and malignant lymphoma (Metcalf, 1991; Travis et al., 1988).

Dysmyelopoeitic disorders are characterized by hypercellularity—an excess of cells—of the bone marrow, and are often mistaken for acute myeloid leukemia (Bennett et al., 1976). Myeloproliferative disorders—also known as Myeloproliferative Neoplasms—are “clonal hematologic diseases” resulting “from a transformation in a hematopoietic stem cell” (Campbell & Green, 2006, p. 2452; “Lab Tests Online”, 2013). In other words, the body’s stem cells which normally produce to replace aging or dying cells begin to overproduce and release the new cells into circulation before they are fully mature; this results in an imbalance causing other mature

cells to either be overabundant or scarce (“Myeloproliferative Neoplasms”, 2013). Neutropenia disorders are marked by a decline in the number of white blood cells known as neutrophils (“Lab Tests Online”, 2014). Acute Nonlymphatic Leukemia—also known as Acute Myelogenous Leukemia, Acute Myeloid Leukemia, Acute Myeloblastic Leukemia, Acute Granulocytic Leukemia and Acute Nonlymphocytic Leukemia—“is a rapidly, progressive malignancy of both the bone marrow and the blood” (“National Cancer Institute,” 2015; “American Cancer Society,” 2015). Malignant Lymphoma is a cancerous “disease primary in the lymphatic system” which “includes the tumors diagnosed as giant follicular-cell lymphoma” (Nathanson & Welch, 1937, p. 598). Unlike Category I, Category II progresses more rapidly, and the rate of progression is contingent upon the specific hematologic disorder it is associated with (Metcalf, 1991; Travis et al., 1988).

Mast Cell Leukemia—also known as Category III—is not associated with any disorders or UP (Travis et al., 1988). It “is characterized by the leukemic spread of MCs [Mast Cells], with frequent and multiple organ involvement such as the liver, peritoneum, spleen, bone, and marrow” (Georgin-Lavialle et al., 2013, p. 1285). Even with treatment, patients with Mast Cell Leukemia have a low survival rate (Georgin-Lavialle et al., 2013; Metcalf, 1991).

Finally, Category IV or Lymphadenopathic Mastocytosis Associated with Eosinophilia is an aggressive and rapidly progressive form of mastocytosis; it is associated with eosinophilia which is a high level of disease fighting white blood cells present in blood or tissue (Golkar & Bernhard, 1997; Metcalf, 1991; Travis et al., 1988). This form of mastocytosis may present with or without UP, “occurs in the bone marrow, then the gastrointestinal tract, and then other organs” (Golkar, & Bernhard, 1997, p. 1379; Metcalf, 1991; Travis et al., 1988). Individuals who are classified as having “category IV generally live only 2-4 years without chemotherapy” (Metcalf, 1991, p. 2s).

The WHO criteria. The WHO asserted “additional clinical investigations should be performed to define the exact subtype of the disease” (Sánchez-Muñoz et al., 2011, p. 1157). To aid in the establishment of subtypes, the WHO suggests both one major and one minor criteria be met to determine if a patient has Systemic Mastocytosis. Johnson et al. (2009) further elaborates on this criteria:

The morphological identification of multifocal, dense infiltrates of mast cells [15 or more] in bone marrow or other extracutaneous sites, confirmed by tryptase immunohistochemistry or special stains, is the major criterion . . . In essence, this criterion is based on using the traditional morphologic approach to establish the diagnosis of systemic mastocytosis. The four minor criteria include: (1) 425% of mast cells with cytologic atypia (Figure 1c), (2) KIT mutation at codon 816, (3) CD117^b mast cells that aberrantly express CD2 and/or CD25 (Figure 1d) and (4) serum tryptase persistently 420 ng/ml. (p. 51)

The major criterion is assessed by biopsying bone marrow or other extracutaneous organs including the GI tract, liver, or spleen (“Me and my Mast Cells”, 2013). Those biopsies are then viewed under a microscope and carefully inspected for dense aggregates of over 15 mast cells in the pathologists/observer’s Field of View (FOV); in reference to diagnosing mastocytosis the specific FOV is the High Power Field (HPF) of view (“Me and my Mast Cells”, 2013; Siegert et al., 2004; Sperr et al., 2002). Multifocal simply means such dense aggregates must be noted in more than one location within the pathologist’s HPF of view (“Me and my Mast Cells”, 2013; Siegert et al., 2004; Sperr et al., 2002).

The first of the four minor criteria is assessed by utilizing the same biopsies mentioned in the major criterion and establishing that 25% of the mast cells in the biopsy appear spindle shaped (malformed) (“Me and my Mast Cells”, 2013).

The second of the minor criteria stipulates a patient must exhibit what is known as a cellular c-kit mutation—specifically c-kit D816V (“Me and my Mast Cells”, 2013). C-kit is a type of receptor/protein located on the outside of the cell membrane, and functions much like a sensor by sending and receiving signals (“Me and my Mast Cells”, 2013). Once it [c-kit] receives the signal—known as Stem Cell Factor (SCF)—the two bind with one another inciting

mast cells to split and replicate (“Me and my Mast Cells”, 2013). In the context of mastocytosis, the DNA of the c-kit is damaged; this damage referred to as a mutation, causes mast cells to replicate uncontrollably without the prompt from SCF, and results in the overabundance of mast cells called mastocytosis (“Me and my Mast Cells”, 2013). Although c-kit D816V is the specific mutation required to meet the second of four minor criteria, it is crucial to note c-kit may mutate into hundreds of forms (“Me and my Mast Cells”, 2013). Accordingly, absence of c-kit D816V does not insinuate the absence of mastocytosis (“Me and my Mast Cells”, 2013).

The third of the four minor criteria necessitate the presence of two types of proteins CD2 and/or CD25 on the membrane mast cells contained in the biopsy (“Me and my Mast Cells”, 2013). These particular proteins are both found on the surface of thymus (T) cells yet functions differently (“Me and my Mast Cells”, 2013). The CD2 protein serves as a molecular adhesive; this adherent protein literally enables cells to stick to one another, consequently expediting intercommunication among cells (“Me and my Mast Cells”, 2013). The CD25 protein serves as the alpha chain of the interleukin 2 (IL-2) receptor, and is a component of cell receptors of activated T and B cells (“Me and my Mast Cells”, 2013).

The Me and my Mast Cells (2013) website accurately explains the fourth of the minor criteria that involves tryptase levels in the blood. Tryptase is a mediator emitted by mast cells during the degranulation process; degranulation may be described as a detonation that emits biochemical mediators—such as histamine—from the mast cell prompted by an antigen. Blood test results revealing more than 20 nanograms of tryptase per milliliter of blood meet this minor criterion. In the instance a patient has been diagnosed with a hematologic disorder or blood cancer, this particular test is not suitable; patients who have blood cancer or other hematologic disorders may often have higher than normal tryptase levels unrelated to mastocytosis.

Newer algorithms for classifying mastocytosis. Questions and concerns rose about the utility of the WHO criteria (Johnson et al., 2009; Sánchez-Muñoz et al., 2011). The findings of a

study conducted by Johnson et al. (2009) reported difficulty classifying six out of 59 participants as having SM utilizing the WHO criteria:

our study supports the value of the WHO criteria for diagnosis of systemic mastocytosis by bone marrow examination with ancillary studies. However, bone marrow examination using WHO criteria is neither completely specific nor sensitive for systemic mastocytosis. In six patients with suspected systemic mastocytosis, bone marrow examination did not confirm the diagnosis. One patient in this study with a history of systemic mastocytosis, who did not meet the criteria for systemic mastocytosis, had a splenectomy performed before bone marrow examination that showed systemic mastocytosis. The ability to diagnose systemic mastocytosis appears to be particularly difficult in patients with an associated clonal hematologic neoplasm because serum tryptase levels can be elevated as a result, and therefore serum tryptase level cannot be reliably used as a minor criterion for systemic mastocytosis. . . . It seems likely that particularly high serum tryptase levels in patients with suspected systemic mastocytosis may be useful, and thus setting a higher cutoff level for serum tryptase level in patients with systemic mastocytosis with associated clonal hematologic non-mast-cell lineage disease may be helpful. (Johnson et al., 2009, p. 57)

In accordance with Johnson et al. (2009), Sánchez-Muñoz et al. (2011) not only questioned the reliability of the WHO criteria, but also why the Johnson et al. (2009) study is the only study in existence regarding the utility of the WHO criteria. According to Sánchez-Muñoz et al. (2011), “the utility of the WHO classification for the diagnosis and classification of mastocytosis has been prospectively evaluated in only one study , which suggests that the WHO criteria for systemic mastocytosis may still be associated with some false-negative cases” (p. 1158). In light of this, Sánchez-Muñoz et al. (2011) conducted their own study to “evaluate the utility of the WHO criteria for the diagnosis and classification of a large series of mastocytosis patients” (p. 1157). This study addressed the concerns about patients who “belong to the good-prognosis categories of the disease (e.g., cutaneous mastocytosis, indolent systemic mastocytosis, and well-differentiated systemic mastocytosis)” yet, “experience disease progression” due to the heterogeneous nature of the “good-prognosis categories” (Sánchez-Muñoz et al., 2011, p. 1158). These were the results of the study:

In this study, we retrospectively applied the current WHO criteria to the diagnosis and classification of a group of 133 cases suspected of mastocytosis and a heterogeneous group of 855 controls. Overall, no false-positive cases were found with only one case that could not be classified. However, despite this high diagnostic efficiency, 15 cases could have been more precisely classified. Most of these 15 cases corresponded to

well-differentiated systemic mastocytosis and patients with an overall picture similar to indolent systemic mastocytosis, who were classified as either cutaneous mastocytosis or aggressive systemic mastocytosis. . . . *However, it should be noted that false negative results were relatively frequently observed* [emphasis added], particularly in well-differentiated systemic mastocytosis where mast cells were round, usually with a clearly increased size, and they were fully granulated with frequent degranulation phenomena making them morphologically rather similar to normal bone marrow mast cells. (Sánchez-Muñoz et al., 2011, p. 1165)

Disease progression occurring in individuals with otherwise good-prognoses suggests a need for “refined criteria for an improved prognostic stratification of systemic mastocytosis” specifically “for cases at early phases of the disease” (Sánchez-Muñoz et al., 2011, p. 1158). Based on the results of their study, Sánchez-Muñoz et al. offer what they deem a more precise “algorithm that could be routinely applied for refined diagnosis and classification of the disease” (p. 1157). This proposed algorithm does not dismiss the WHO criteria, but rather modifies it (Sánchez-Muñoz et al., 2011). These findings notwithstanding, focus primarily on the accumulation of MCs in the bone marrow and appear to neglect the need to investigate the possibility of Systemic Mastocytosis (SM) with extracutaneous organ involvement without first establishing bone marrow accumulation (Sánchez-Muñoz et al., 2011). See Figure 2 to review the Proposed REMA algorithm for the diagnosis and classification of mastocytosis subtypes. The literature states SM “is characterized by clonal MC accumulation in bone marrow and other extracutaneous organs such as liver, spleen, lymph nodes, and the gastrointestinal (GI) tract” (Akin & Metcalfe, 2004; Behdad & Owens, 2013, p. 1220; “Me and my Mast Cells”, 2013; Sánchez-Muñoz et al., 2011; Sokol et al., 2010). Yet, Sánchez-Muñoz et al. (2011) then omitting other forms of extracutaneous organ involvement from a proposed algorithm is not only contrary to both the WHO and Travis et al. (1988) classification schemata, but also inconsistent with the definition of SM (Akin & Metcalfe, 2004; Behdad & Owens, 2013, p. 1220; “Me and my Mast Cells”, 2013; Sánchez-Muñoz et al., 2011; Sokol et al., 2010). Furthermore, patients like me who present only 2% bone marrow accumulation and serum tryptase levels ranging from 4.4 to 5.5 ng/mL—much lower than the necessary 10% bone marrow accumulation and 20 ng/mL

serum tryptase required to meet the criteria for SM yet present extracutaneous organ involvement—may be incorrectly classified as Cutaneous with UP (McNeil & Katelaris, 2011; Metcalfe, 1991; Sánchez-Muñoz et al., 2011).

According to Behdad and Owens (2013) diagnosing SM “with primarily GI presentation can be challenging and requires familiarity with this entity and a high index of suspicion” (p. 1220). An estimated 70 to 80% of patients manifest GI involvement along with SM (Cherner et al., 1988; Jensen, 2000). Sokol et al. (2010) point out an observable high rate of variability in reference to published works addressing frequency rates of GI manifestations:

The first major studies reported 20% of GI symptoms whereas most of later studies until 1985 reported a 40%–50% rate. Studies carried out since 1985 report a higher frequency from 60%–80%, making GI symptoms as frequent as pruritus among patients with SM. Several factors can contribute to this great variability in published series: the diversity of SM definition, the lack of consensus about GI symptoms definition and detection threshold, and differences in data collection (retrospective vs. prospective). (p. 1248)

Some of the more prominent features of GI manifestation of mastocytosis are abdominal pain, diarrhea, urticarian gastric lesions, malabsorption, nausea—and in fewer studies—GI bleeding, esophageal disorders, and peptic ulcers (Ammann, Vetter, Deyhle, et al., 1976; Borda, Uribarrena, & Riveropuente, 1983; Cherner et al., 1988; Clemett, Fishbone, Levine, James, & Janower, 1968; Horan, Sheffer, & Austen, 1990; Jensen, 2000; “Mastocytosis Society of Canada”, 2011; Metcalfe, 1991; Scolapio, Wolfe, Malavet, & Woodward, 1996; Sokol et al., 2010; Travis et al., 1988).

Unlike the four categories proposed by Travis et al. (1988) and utilized by the NIH, the WHO proposed seven categories in the classification scheme: “cutaneous mastocytosis, extracutaneous mastocytoma, indolent systemic mastocytosis, aggressive systemic mastocytosis, systemic mastocytosis associated with other clonal hematological non-mast cell lineage disease, mast cell leukemia, and mast cell sarcoma” (Sánchez-Muñoz et al., 2011, p. 1157).

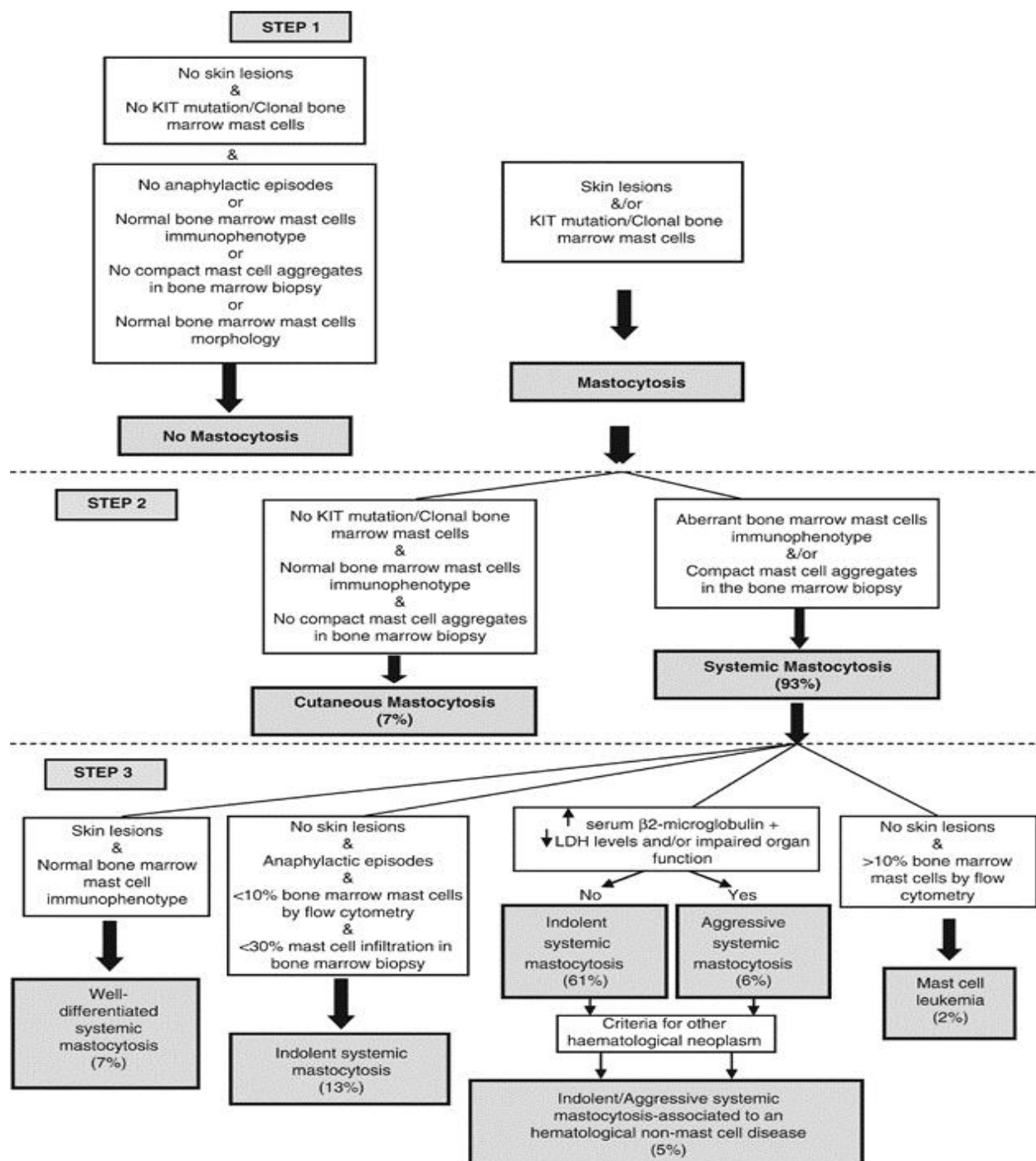


Figure 2. Proposed REMA algorithm for the diagnosis and classification of different subtypes of mastocytosis. The specific percentage of mastocytosis patients (n = 133) included in each category is shown between brackets. From The Evaluation of the WHO criteria for the classification of patients with mastocytosis by Sánchez- Muñoz et al., 2011, *Modern Pathology*, 24(9), 1157-1168. Copyright 2011 by Macmillan Publishers Ltd. Reprinted with permission.

Table 1 provides a side-by-side comparison of both classification schemata. Disparate from the earlier classification scheme proposed by Travis et al. (1988), the WHO placed cutaneous mastocytosis and indolent systemic mastocytosis in two separate categories (McNeil & Katelaris, 2011). Furthermore, Systemic Mastocytosis with an Associated Hematologic Disorder became Category III, and incorporated six rather than five hematologic disorders which are: Acute Myeloid Leukemia, Myelodysplastic Syndromes, Chronic Myelomonocytic Leukemia, Non Hodgkins Lymphoma, Myeloproliferative Disease, and Hypereosinophilic Syndrome (McNeil & Katelaris, 2011).

Acute Myeloid Leukemia is synonymous with Acute Myelogenous Leukemia (“Acute Myelogenous Leukemia”, 2014). Myelodysplastic Syndromes are “poorly formed or dysfunctional blood cells” resultant of a malfunction in the bone marrow (“The Myelodyplastic Syndromes Foundation”, 2013). Neutropenia Disorders—which fall under Category II of the classification scheme proposed by Travis et al. (1988)—also fall under the umbrella of Myelodyplastic Syndromes as a “hallmark feature” (“The Myelodyplastic Syndromes Foundation”, 2013). The third hematologic disorder associated with Systemic Mastocytosis from the WHO classification scheme, Chronic Myelomonocytic Leukemia, is marked by an exorbitant amount of white blood cells; it too falls under the umbrella of Myelodyplastic Syndromes (Golub, Barker, Lovett, & Gilliland, 1994). Non-Hodgkins Lymphoma is a form of cancer that begins in the white blood cells known as lymphocytes, and may be classified as a Malignant Lymphoma listed under Category II of the Travis et al. (1988) classification scheme (Nathanson & Welch, 1937). Myeloproliferative Diseases—as previously stated—are “clonal hematologic diseases” resulting “from a transformation in a hematopoietic stem cell”, and are listed on both the WHO, and Travis et al. (1988) classification schemata (Campbell & Green, 2006, p. 2452; McNeil & Katelaris, 2011). Hypereosinophilic Syndrome is attributed to an overabundance of white blood cells known as eosinophils (“Mayo Clinic”, 2015).

Table 1

Comparison of Classification Schemata Offered by Travis et al. (1988) and the WHO criteria

Category	Travis et al. (1988)		WHO criteria	
	Type	Subvariant	Type	Subvariant
I	Indolent Mastocytosis	<ul style="list-style-type: none"> • Skin only: UP, Diffuse Cutaneous Mastocytosis • Systemic: Marrow, GI, \pmUP 	Cutaneous Mastocytosis	<ul style="list-style-type: none"> • Urticaria pigmentosa (UP) • Maculopapular CM (MPCM) • Diffuse CM (DCM) • Mastocytoma of the skin
II	Mastocytosis with an Associated Hematologic Disorder (\pm UP)	<ul style="list-style-type: none"> • Dysmyelopoietic Disorders • Myeloproliferative Disorders • Acute Non-Lymphatic Leukemia • Malignant Lymphoma • Chronic Neutropenia 	Indolent Systemic Mastocytosis	<ul style="list-style-type: none"> • Smoldering SM (SSM) • Isolated bone marrow mastocytosis (BMM)
III	Mast Cell Leukemia		Systemic Mastocytosis associated with other Clonal Hematological Non-mast cell Lineage Disease	<ul style="list-style-type: none"> • Acute myeloid leukaemia • Myelodysplastic syndromes • Chronic myelomonocytic leukaemia • Non Hodgkins Lymphoma • Myeloproliferative disease • Hypereosinophilic syndrome
IV	Lymphadenopathic Mastocytosis with Eosinophilia (+UP) (ASM)		Aggressive Systemic Mastocytosis	
V			Mast Cell Leukemia	Aleukemic Mast Cell Leukemia
VI			Mast Cell Sarcoma	
VII			Extracutaneous Mastocytosis	

Note. Comparison of Adapted from “Systemic Mast Cell Disease: Analysis of 58 Cases and Literature Review,” by Travis et al., 1988, *Medicine*, 67(6), 345-368; “Classification and Diagnosis of Mastocytosis: Current Status,” by D. D. Metcalfe, 1991, *Journal of Investigative Dermatology*, 96, 2-4. doi:10.1111/1523-747.ep12468882.

It [Hypereosinophilic Syndrome] is a rapidly progressive form of mastocytosis, and shares a similarity with Lymphadenopathic Mastocytosis due to both being affiliated with eosinophilia

("Mayo Clinic", 2014). Nonetheless, they are placed in two different categories; Travis et al. (1988) placed Lymphadenopathic Mastocytosis in Category IV, while the WHO placed it as the sixth subvariant of Category III (McNeil & Katelaris, 2011).

Category IV of the WHO classification scheme is Aggressive Systemic Mastocytosis (ASM) in general (McNeil & Katelaris, 2011). Travis et al. (1988), on the other hand, specifically identified Lymphadenopathic Mastocytosis with Eosinophilia as a form of ASM in Category IV; again, the WHO categorized it as a subvariant of Category III. Mast Cell Leukemia Transitioned from Category IV in the Travis et al. (1988) classification scheme to Category V in the WHO classification scheme, and it is associated with Aleukemic Mast Cell Leukemia (McNeill & Katelaris, 2011). Unlike other forms of leukemia, Aleukemic Mast Cell Leukemia is malignant, but does not exhibit an elevated white blood cell count (Noack et al., 2004; Valentini et al., 2008). The WHO added two more categories which are Mast Cell Sarcoma and Extracutaneous Mastocytosis (McNeil & Katelaris, 2011). Mast Cell Sarcoma is "defined by a local destructive sarcoma-like growth of a tumor that consists of highly atypical mast cells" (Chott et al., 2003, p. 1013). Extracutaneous Mastocytosis is defined as having aggregates of 15 or more mast cells per High Powered Field (HPF) noted in a biopsy taken from an organ other than the skin (McNeil & Katelaris, 2011).

Symptoms and prognosis. According to the Mastocytosis Society of Canada (2011), mastocytosis involves multiple capacities of specialty medicine; resultantly, the patient is subjected to a long, complicated diagnostic process. In its systemic (affecting one or more organs in addition to the skin) form, mastocytosis may take an accelerated turn resulting in death (Hein & Hansen, 2005). Some of the symptoms of mastocytosis include but are not limited to: difficulty with foods and drinks, anaphylactoid reactions, gastrointestinal pain, bloating, unexplained medication reactions, enlarged liver/spleen, liver/spleen/bladder/kidney pain, enlarged lymph nodes, frequent urination, unexplained B12 deficiency, intermittent tinnitus

or hearing problems, tachycardia, diarrhea, vomiting, unexplained weight and hair loss, cognitive impairment, decreased bone density, mouth sores, shortness of breath, unexplained weakness, chest pain, vertigo, skin lesions or sores, skin rashes, and tremors (“Mastocytosis Society of Canada,” 2011).

As a sufferer of systemic mastocytosis, I have experienced all of the symptoms listed in the above paragraph. Much unlike the average 10 years plus—as reported by the Mastocytosis Society of Canada (2011)—it takes for a mastocytosis patient to be correctly diagnosed, I received a correct diagnosis after approximately five and a half years. Furthermore, according to my current team of physicians who are stunned by my ability to work and attend class fulltime, I am a functioning mastocytosis patient. The average of 10 years it takes to receive a correct diagnosis is not only indicative of low health literacy on behalf of the patient but also, indicative of a lack of awareness of the disease among physicians (“Mastocytosis Society of Canada,” 2011; Paasche-Orlow & Wolfe (2007).

In concurrence with Metcalfe (1991) The Mastocytosis Society of Canada (2011) goes into further detail to explain the variability of mastocytosis which “presents in cutaneous (skin) and systemic (internal) forms” and affects “patients of all ages and genders” who “may present with one or both forms of the disease” (“Mastocytosis Society of Canada,” 2011 “Defined,” para. 1).

With such little research involving this disease, it is not clear how it was determined that it is more prevalent in the United Kingdom (UK) (A. Attwater, personal communication, June 2009). According to statistical data in the UK, mastocytosis exhibits an even greater disparity in numbers than general statistics concerning orphan diseases. Cutaneous mastocytosis (relegated to the skin) affects only one in 1,000 patients in England and systemic mastocytosis (spreading to other organs secondary to the skin, [i.e., intestines, liver, spleen]) affects one in every 150,000 people (“National Health Services,” 2012).

Health literacy as a barrier. As mentioned in the introduction, a patient's ability to comprehend literature—such as reading and understanding lab results—can greatly affect their health outcomes (Paasche-Orlow & Wolfe, 2007). According to Williams et al. (2002), roughly 40 million Americans are limited in regards to health literacy. Health literacy in this context refers to the complexity affiliated with the “the language or treatment processes for the novice patient and resulting impact on the treatment process” (Bryan et al., 2012, p. 3). Consequently, this disparity in literacy translates to nearly one-third of the United States' (US) population (Martin, et al, 2009). In addition to this disparity between the population of the patients who are health literate and those who are not, is the disparity between primary physicians and specialists who are primed to diagnose and treat mastocytosis and those who are not (Bryan et al., 2012; Campos-Casetello, 2001; Metcalfe, 1991; Paasche-Orlow & Wolfe, 2007; Williams et al., 2002). It is essential for primary physicians to recognize when a specialist is necessary; failure to do so may contribute to the already estimated 45% of patients who receive late diagnoses (Campos-Casetello, 2001; Metcalfe, 1991).

Learner and Facilitator Relationship Roles in Adult Education

The research on mastocytosis implicates a divide, rather than a collaborative effort between physicians and patients. As previously stated, this divide is the result of low health literacy among patients and a noted lack of awareness among physicians (Bryan et al., 2012; Campos-Casetello, 2001; Martin et al., 2009; “Mastocytosis Society of Canada,” 2011; Paasche-Orlow & Wolfe, 2007; Williams et al., 2002).

Although the literature on mastocytosis offers recommendations for both patients and physicians to follow separately, the type of learning relationships that exist between patients and physicians is neglected. In this portion, adult education practices and perspectives such as adult learning, adult development, self-directed learning, transmission perspective, developmental perspective, apprenticeship perspective, nurturing perspective, and social reform

perspective are examined to establish parallels between them and medical practices. This will be enacted in an effort to translate learning in the classroom to learning in the exam room.

Adult learning. Adult learning may be defined as a an internal cognitive process heavily reliant on what the learner as opposed to the facilitator does in a learning environment; such learning can be both unplanned and incidental (Merriam & Brockett , 2007). Simply put, adult learning is in many ways a natural occurrence which does not take place in a vacuum and requires a certain level of autonomy in a learner-centered rather than teacher centered environment. Because adult learning can take place anywhere as Merriam and Brockett (2007) suggest, it is plausible that it can take place in a medical exam room just as it does in a classroom (Bodenheimer et al., 2002).

Self-directed learning. Self-directed learning is described as “a process of learning, in which people take the primary initiative for planning, carrying out, and evaluating their own learning experiences” (Merriam, Caffarella, & Baumgartner, 2007, p. 110). Within the field of adult education, self-directed learning is regarded as a hallmark for a suitable adult learning environment as a well as a necessity for successful learning outcomes (Knowles, 1975; Guglielmino, 1977, 2008). This is because self-directed learning is a cognitive process which often takes place in the absence of a facilitator (Tough, 1967). This requires a great amount of autonomy on behalf of the instructor to allow learners in the classroom to have control over their learning experience. Self-directed learning is closely related to self-motivation which is also an internal process where a learner does not require external incentive to engage in the learning process. Self-directed learning is also akin to self-management education which will be covered in depth in the subsequent paragraphs.

Relating the five teaching perspectives to physician-patient learning relationships.

In adult education, there are five perspectives on facilitating adults; these perspectives are developmental, transmission, nurturing, apprenticeship, and social reform (Arsenau &

Rodenburg, 1998; Boldt, 1998; Nesbit, 1998; Pratt, 1988; T'Kenye, 1998). Unlike most literature which often contextualizes best practices based on a favored theory, these perspectives are demonstrative of a thoroughly-researched analysis of pragmatic and philosophical orientations which influence adult educators (Arsenau & Rodenburg, 1998; Boldt, 1998; Nesbit, 1998; Johnson & Pratt, 1998; T'Kenye, 1998). The five teaching perspectives mentioned here exhibit aspects similar to the characteristics of physician-patient relationships. The following paragraphs define each of the five teaching perspectives and identify existing parallels between four of them and characteristics of physician-patient learning relationships.

Transmission perspective. This perspective is defined as “teacher mastery over content combined with expertise at incorporating various teaching skills to deliver that content” (Boldt, 1998, p. 81). Unlike a student centered environment, the transmission perspective is teacher centered (Boldt, 1998). This places the responsibility and creative control of organizing and structuring the course content on the instructor (Boldt, 1998). As a result, the facilitator of the course is required to be the Subject Matter Expert (SME) (Boldt, 1998). Despite the fact that “content expertise is undeniably of primary importance to transmission teaching, this perspective also focuses on transmitting knowledge and skills” (Boldt, 1998, p. 77).

The transmission perspective is reminiscent of the traditional perspective of the patient physician relationship where the physician is the SME and the patient acquires the knowledge that the physician renders (Bodenheimer et al., 2002; Boldt, 1998). Unlike the traditional patient physician relationship, the transmission perspective is proposed as an approach to increasing the effectiveness of learning by instituting tests and exercises repetitiously—wherein the traditional patient physician relationship allows physicians to maintain a position of power by concealing rather than the knowledge with patients (Bodenheimer et al., 2002; Boldt, 2002).

Apprenticeship perspective. Unlike the transmission perspective—which focuses on teaching and learning in formal environments (i.e. universities)—the apprenticeship perspective

focuses on teaching and learning in informal environments (Johnson & Pratt, 1998). From the apprenticeship perspective, the facilitator enculturates learners into “a group of people with a common sense of identity and purpose, and clearly defined roles, usually suggesting levels of authority and responsibility” which is referred to as a community (Johnson & Pratt, 1998, p. 43). The apprenticeship perspective sets itself apart from the other four perspectives because it merges the facilitator with the content (Johnson & Pratt, 1998). Specifically, facilitators are required to possess and exemplify the knowledge and principles of the community to which they belong (Johnson & Pratt, 1998).

The apprenticeship perspective exhibits an observable likeness to what Bodenheimer et al. (2002) refer to as collaborative care. Collaborative care credits the knowledge patients bring to the table and equates it with the knowledge of the physician (Bodenheimer et al., 2002). Although a physician is clearly an expert in their field, only the patient is an expert about their own life (Bodenheimer et al., 2002).

Developmental perspective. Dissimilar from the transmission and apprenticeship perspectives, the developmental perspective pushes learners to the forefront while content lays wait in the background—creating a learner-centered environment (Arsenau & Rodenburg, 1998). In this instance, learners are guided toward thinking and problem solving on expert levels (Arsenau & Rodenburg, 1998). Therefore, the facilitator is charged with the task of turning the learners into SMEs rather than maintaining their position as facilitator and SME (Arsenau & Rodenburg, 1998). In order to be an effective practitioner of the developmental perspective, the facilitator “must be able to build bridges between learners’ present ways of thinking and more desirable ways of thinking within a discipline or area of practice” (Arsenau & Rodenburg, 1998, p. 47).

In agreement with the developmental perspective, we find a post conventional view for teaching in the exam room known as self-management education (Bodenheimer et al., 2002).

Equally antithetical to the transmission and apprenticeship perspectives, self-management education understates conventional physician-patient learning relationships by providing “patients with problem-solving skills to enhance their lives” and ultimately promotes role expansion (Bodenheimer et al., 2002, p. 2470). Self-management education is also comparable to self-directed learning which affords learners the autonomy to engage, navigate and evaluate their own learning process (Merriam et al., 2007).

Nurturing perspective. The nurturing perspective is supported by the “belief that learning is most affected by a learner’s self-concept and self-efficacy” (T’Kenye, 1998, p. 49). Simply put, it is the facilitator’s objective to assist learners in becoming more self-sufficient and confident in their learning ability (T’Kenye, 1998). To meet this objective, learners must not only achieve success but, attribute it to “their own effort and ability, rather than the benevolence of their teacher or the serendipity of circumstance” (T’Kenye, 1998, p. 49).

Observable similarities exist between the nurturing perspective and self-management education. Just as a facilitator from this perspective will encourage students to become greater, more independent researchers—so does the physician instill self-confidence in patients to learn more about their own health (Bodenheimer et al., 2002; T’Kenye, 1998).

Social reform perspective. This perspective is known for espousing clear-cut and eloquent visions in the interest of social reform (Nesbit, 1998). The clear-cut and eloquent visions are often linked to an ideal that “is based on a core or central system of beliefs, usually derived from an ethical code (such as the sanctity of human rights), a religious doctrine (such as the sanctity of God’s law), or a political or social ideal (such as the need to redistribute power and privilege in society)” (Nesbit, 1998, p. 50).

Nesbit’s (1998) social reform perspective is backed by Donabedian’s (1968) push for quality care of patients which is based on the ethical code of putting the health and welfare of the patient first which is also referred to as the articles of faith. Donabedian’s (1968) clear-cut

vision of satisfied, informed and healthy patients is a call to action to reform the social aspects of the process of medical care. This is addressed by expanding the horizons of curative care (curing diseases) to pursue a holistic approach to patient care that includes educating patients and instituting intelligent cooperation which provides patients with the opportunity to use what they learn cooperatively with physicians to improve their health (Bodenheimer et al., 2002; Donabedian, 1968).

Teaching Hospitals and Clinics

Some of the parallels established in the aforementioned are noted and carried out in what are known as teaching hospitals and clinics. Hospitals and clinics that make an effort to teach patients through consultative methods are known as teaching or tertiary hospitals and clinics (Obajimi et al., 2013). Such medical facilities extend their services beyond the traditional curative approach to provide an interactive, consultative environment where patients become informed and well versed in self-management education (Bodenheimer et al., 2002; Obajimi et al., 2013). In said environments which are conducive to learning, patients are free to learn not only from physicians but, from their peers as well (Bodenheimer et al., 2002; Obajimi et al., 2013; Pratt, 1956).

How and what patients learn. Several people are aware they have an illness—yet they know nothing beyond how often they should take their medication and the correct dosage (Pratt, 1956). This is indicative of an imbalance in power between patients and physicians—where patients do not learn anything beyond basic information provided solely by the physician (Bodenheimer et al., 2002; Pratt, 1956).

As Pratt (1956) further elaborates, “the medical information that lay people learn from various sources, and the conditions under which they can and cannot learn such information, constitute vital problem areas both for those attempting to improve medical care and for those interested in medical sociology” (p. 29). To further investigate this observation, Pratt conducted

a study comparing three groups of individuals: those who are suffering from coronary thrombosis, those who know someone who is suffering from coronary thrombosis, and those who do not suffer from coronary thrombosis nor know anyone who does. Based upon the available data regarding the disease, the study investigated what patients learned from the information disseminated about coronary thrombosis in reference to President Eisenhower's (who suffered from the disease) prognosis as well as what was learned from associates and personal experience.

The study results revealed the number of individuals who had coronary thrombosis and answered questions regarding the disease correctly was slightly larger than the number of individuals who answered questions regarding the disease correctly and did not have the disease (Pratt, 1956). Pratt (1956) also noted "a significantly greater gain in information" acquired by study participants "with associates who had a given disease over those without such interpersonal contact with the disease" (p. 39). Furthermore, the disparity between the levels of awareness in participants questioned prior to Eisenhower's illness and participants questioned subsequent to his illness reflected similar findings to the disparity between those who had coronary thrombosis and those who never had it nor knew anyone who did. In fact, those who learned about the disease based on the experience of Eisenhower exhibited greater levels of awareness and answered questions correctly in far greater numbers than those who had the disease. Such findings implicate social relationships and mass communication are equally—if not more—influential than patient physician relationships on how and what a patient learns.

Pratt (1956) goes further in depth to explain the minor difference between the number of correct answers about coronary thrombosis provided by those who had the disease and those who neither had nor knew anyone who had the disease; the rationale offered by Pratt identifies the physician as the source of the type of information disseminated. For instance, some

physicians were more apt to divulge the practical aspects of the disease while others offered information concerning positive facts about prognosis and treatment. This particular study finding is reminiscent of the earlier disclosed teacher-centered transmission perspective—where the facilitator is solely responsible for the organization and dissemination of knowledge (Boldt, 1998).

The Medical Diagnostic Process

According to Elstein and Schwarz (2002), the medical diagnostic process—also known as clinical diagnostic reasoning—is relied upon as the general procedure utilized to first investigate and then determine the root cause of a patient's symptoms and complications based on one or more hypotheses. Although the diagnostic process is a hallmark in medical research, they offer an alternative view on its use. Furthermore, “diagnostic accuracy does not depend as much on strategy as on mastery of content” (p. 730).

Two paradigms for clinical reasoning. Elstein and Schwarz (2002) offer problem solving and decision making as two paradigms for clinical diagnostic reasoning. Both paradigms in this article focused heavily on the mistakes physicians make during the clinical diagnostic reasoning process. This is because “errors tell us a great deal about fundamental cognitive processes, just as optical illusions teach us about the functioning of the visual system” (p. 732). In other words, what appears to be working for clinical diagnostic reasoning may not necessarily be working but rather, it is simply traditional and familiar.

Problem solving. Elstein and Schwarz (2002) posit the problem-solving approach to clinical diagnostic reasoning is based on “hypothesis testing, pattern matching, or categorisation” (p. 731). They also identified errors which cause this particular paradigm to be unsuccessful when attempting to diagnose an illness. For instance, the physician may fail to propose a hypothesis that is correct. This is partly due to the formation of hypotheses being heavily reliant upon emerging patterns in and categorizations of the patients' symptoms; some

diseases may mimic others by exhibiting similar symptoms and, therefore, lead to presumptuous and steadfast hypotheses.

Decision making. This paradigm perceives clinical diagnostic reasoning as objective in nature by viewing “diagnosis as opinion revision with imperfect information” (Elstein & Schwarz, 2002, pp. 731-732). The decision making paradigm is starkly contrasted from the problem solving paradigm because it is more amenable to reformation prior to receiving the results of blood tests or biopsies (Elstein & Schwarz, 2002).

Implications for practice. Based upon what was discussed in the literature, practical implications may be noted. Consider the case study discussed in the introduction about a patient who suffered from systemic mastocytosis:

The patient was then treated with loratadine 10mg daily, ranitidine 150mg daily, prednisone 20mg three times daily, and a-interferon 2b (IFN-a) 3.0 million subcutaneously three times weekly. While he initially had mild subjective improvement, his sense of weakness and his weight loss persisted and his laboratory data showed no evidence of regression. Eventually he became persistently nauseated and complained of diffuse myalgias thought to be secondary to his treatment regiment. After two months, he withdrew from treatment. The patient died one month after his treatment, four months after his diagnosis. (Hein & Hansen, 2005, p. 97)

As previously noted the patient’s complaints were deemed “secondary to his treatment regiment”, without mention of how this determination was made or an account of further investigation into the patient’s symptoms (Hein & Hansen, 2005, p. 97). Furthermore, the literature does not disclose an investigation into the reasoning behind why the patient “withdrew from treatment” (Hein & Hansen, 2005, p. 97). Finally, none of the accounts from Hein and Hansen’s (2005) case study divulge any efforts by the physicians to educate the patient about their disease and the importance symptom management.

The above account of the deceased patient is indicative of why the physician-patient learning relationship should be honed and in some cases reformed. Perhaps there was more to be learned from the patient in addition to what was learned about the patient based on lab work. Bodenheimer et al. (2002) echoes this sentiment by noting “if physicians view themselves as

experts whose job it is to get patients to behave in ways that reflect their expertise, both will continue to be frustrated” (p. 2470). He goes on to say “once physicians recognize patients as experts on their own lives, they can add their medical expertise to what patients know about themselves to create a plan that will help patients achieve their goals” (Bodenheimer et al., 2002, p. 2470).

With the recommendations of Bodenheimer et al. (2002) in mind, Hein and Hansen (2005) could have taken the apprenticeship perspective by equating the importance of the knowledge the patient provided with their own expertise. From the combined expertise, a new approach to treatment that involved different medication than the patient received could have been devised.

This approach to medical research closely mirrors the earlier discussed, conventional, research methods utilized in social sciences prior to the era of postmodernism. In this case, a physician may serve as the researcher who authoritatively enters a culture in a very sterile removed manner in the interest of ethics and ironically exploits the culture by leaving and writing about them without mentioning any relational ties (Conquergood, 1991; Ellis, 2007; Reidmann, 1993). This sort of research-oriented colonialism may have led to the work of Kole and Faurisson (2009) who sought to conduct studies “for patients, by patients” (p. 22). In many cases—such as the Hein and Hansen (2005) case study—patients are subjected to tests and the only responses that seem to be of importance are in reference to how a particular medication performs or a disease runs its course. In such instances, the voice of the patient is silenced and overshadowed by their physiological responses to stimuli. Although the results of such studies are indeed informative and lifesaving, placing such heavy emphasis on quantifiable results may potentially foster an oppressive relationship between physicians and patients. In accordance with Freire’s (1993) theory of synchronization, the burden of initiating the process of dialogue is placed upon the oppressed. This is based upon the belief that oppressors may

exploit the integrity of their own power (Freire, 1993). As an oppressed patient, it is my responsibility to initiate the necessary dialogue to reconcile the gap between patient health literacy and physician awareness in reference to mastocytosis.

Chapter 3

Methods

The purpose of this study was to investigate mastocytosis from the perspective of a patient diagnosed with the disease. Autoethnography in the form of layered accounts was utilized as the method for this study. In this chapter I covered the many aspects of autoethnography including its use as a method, the history of autoethnography, and information on how to write an autoethnography. Also mentioned, are the things every autoethnographer should know about writing an autoethnography and the Institutional Review Board (IRB). I then covered topics such as validity, reliability, generalizability, caveats, the design of the study, assumptions, and data sources. Finally, I concluded this chapter by discussing my coding techniques in great detail, providing tables and figures to aid in my explanation.

Autoethnography as Method

As stated in the review of literature, autoethnography is a style of research and writing that exhibits multiple layers of consciousness and ties personal experiences to cultural ones (Ellis & Bochner, 2000). A well written autoethnography not only tells the story, but does so in a manner that is engaging and evocative by stimulating the memories of the readers in regards to what they have experienced (Ellis & Bochner, 2000). Ellis and Bochner's (2000) explanation of autoethnography clearly separates its characteristics from an autobiography. Overall, an autobiography divulges actual events that transpired in an individual's life without the intent of establishing sociocultural connections and implications that are meaningful to the autobiographer; an autoethnography, on the other hand, identifies epiphanies, revelations,

implications, and does establish sociocultural parallels to society and one's self which are meaningful to the autoethnographer (Ellis et al., 2011; Ellis & Bochner, 2000).

History of autoethnography. Historically, autoethnography has roots in the era of postmodernism (Ellis & Bochner, 2000). During the 1980s when postmodernism began receiving notoriety, researchers in academia instigated an inquisition into the ontological, epistemological, and axiological limitations of traditional research in the social sciences. It was traditional research that followed a trend of research-oriented colonialism. The term research-oriented colonialism is based on the works of Conquergood (1991), Ellis (2007), and Reidmann (1993) who liken the traditional, observational approach of research to a form of imperialism where a researcher authoritatively enters a culture in a very sterile, removed manner in the interest of ethics. Ironically, the researcher actually exploits the culture by leaving and writing about them for financial gain and academic acclaim without mentioning any relational ties to members of the culture (Conquergood, 1991; Ellis, 2007; Reidmann, 1993). For instance, a traditional researcher enters and observes a little known culture in what is deemed an underdeveloped society. Based on the traditional researcher's observations, definitive conclusions, and sweeping generalizations are made about the culture with no consideration for how the presence of the researcher affected members of the culture. Likewise, the researcher assumes his or her own perceptions were not influenced by members of the culture and, in turn, are unbiased because they refrained from participating in daily cultural operations. Simply abstaining from participating in daily cultural rituals does not make the observer any less visible and tangible, nor does it make the work of the traditional researcher more credible (Conquergood, 1991; Ellis, 2007; Reidmann, 1993).

Much of Conquergood's (1991) research was based on the works of Geertz (1988) and Rosaldo (1989) who addressed the grander scale of ethnography which gave birth to autoethnography. Rosaldo (1989) acknowledged:

The once dominant ideal of a detached observer using neutral language to explain “raw” data has been displaced by an alternative project that attempts to understand human conduct as it unfolds through time and in relation to its meanings for the actors. (p. 37)

Geertz (1988) further expounded upon the colonialist foundations of anthropological research:

The end of colonialism altered radically the nature of the social relationship between those who ask and look and those who are asked and looked at. The decline of faith in brute fact, set procedure, and unsituated knowledge in the human sciences, and indeed in scholarship generally, altered no less radically the askers’ and lookers’ conception of what it is they were trying to do. (pp. 131-132)

It was during this transitional period in research—mentioned by Geertz (1988)—when researchers began to realize “that different kinds of people possess different assumptions about the world—a multitude of ways of speaking, writing, valuing and believing—and that conventional ways of doing and thinking about research were narrow, limiting, and parochial” (p.

2). In fact, Ellis et al. (2011) rely on the works of several authors who attribute the “different assumptions” made by “different kinds of people” to:

race (Anzaldúa, 1987; Boylorn, 2006; Davis, 2009), gender (Blair, Brown & Baxter, 1994; Keller, 1995), sexuality (Foster, 2008; Glave, 2005), age (Dossa, 1999; Paulson & Willig, 2008), ability (Couser, 1997; Gerber, 1996), class (Hooks, 2000; Dykins Callahan, 2008), education (Delpit, 1996; Valenzuela, 1999), or religion (Droogsma, 2007; Minkowitz, 1995). (pp. 2-3)

Ellis et al. (2011) also point out how advocates of conventional and canonical ways of conducting research are in effect supporting “a White, masculine, heterosexual, middle/upper-classed, Christian, able-bodied perspective” (p. 3). Beyond the obvious sectarian implications of conventional approaches to social sciences, an implied sense of superiority emerges which discredits other ways of knowing by insinuating they are both unsatisfactory and unfounded (Ellis et al., 2011).

Based on the contradictions about what was considered acceptable research, researchers within the social sciences reexamined their traditional stance, and determined that if their research was more akin to literature rather than physics, the scope of the discipline could be widened (Bochner, 1994). This brings us to the hybrid of ethnography and

autobiography . . . autoethnography. Autoethnography is the very antithesis of the previously noted parochial, conventional approach to research in the social sciences (Ellis et al., 2011). According to both Adams (2005) and Wood (2009), autoethnography forgoes fixed definitions of what significant and valuable research looks like by opening and expanding the narrow perspective lens on the world. Through autoethnography, readers can acquire a greater understanding of the kinds of people studied in social sciences from their firsthand accounts as opposed to analyzed observations (Adams, 2005; Wood, 2009). Ironically, the perceived bias associated with the first person writing style of autoethnography serves to circumvent the bias which exists in the conventional approach.

How an autoethnography should be written. To gain a clear understanding of how an autoethnography should be written, consider its parents: autobiography and ethnography. By examining its parents the makeup of autoethnography becomes more transparent and—as a result—demystified.

Autobiography. An autobiography is written by retroactively and fastidiously writing about previous experiences; typically, the author's previous experiences were not lived through for the purpose of publication, but are instead amassed by utilizing hindsight (Bruner, 1993; Denzin, 1989; Ellis et al., 2011; Freeman, 2004; Wood, 2009). In certain instances, authors may even rely on personal interviews, journals, recordings, and pictures to assist them with recollection (Delany, 2004; Didion, 2005; Goodall, 2006; Herrmann, 2005). As previously discussed, epiphanies and revelations that greatly impacted the course of the author's life are referenced as reliable sources (Ellis et al., 2011). Some may question the credibility of epiphanies because they are viewed as relative, "self-claimed phenomena in which one person may consider an experience transformative while another may not" (Ellis et al., 2011, p. 3). To further explain the context in which epiphanies are utilized in this context, Ellis et al. (2011) rely on an earlier work of Bochner [1984, p. 595] which addresses the subject:

While epiphanies are self-claimed phenomena in which one person may consider an experience transformative while another may not, these epiphanies reveal ways a person could negotiate "intense situations" and "effects that linger—recollections, memories, images, feelings—long after a crucial incident is supposedly finished. (p. 3)

Not only should an autobiography be written in a way that will engage readers and cause them to reminisce, but it should utilize elements of storytelling such as plot development, character, and story progression (Didion, 2005; Ellis & Ellingson, 2000; Frank, 1995). Just as research requires researchers to seek and address a research gap, autobiography challenges writers to utilize their epiphanies—derived from personal experiences—to bridge the gap between similar, existing storylines (Couser, 1997; Goodall, 2001).

Although written primarily in first-person, autobiographies may intermittently switch to the use of second-person which allows readers to become an eye witness alongside the author as opposed to receiving a third party account of events (Glave, 2005; McCauley, 1996; Pelias, 2000). This affords autobiographers the advantage of allowing readers to experience what they felt rather than attempting to describe indescribable emotions (Glave, 2005; Pelias, 2000; McCauley, 1996). The use of third-person is an equally effective tool for autobiographers who wish to present findings and clarify the context in which certain interactions transpired (Caulley, 2008).

Ethnography. Ethnography studies the relational practices of a culture by becoming a participating observer who both takes notes on and engages in exercising the values and beliefs of the culture to help both members and nonmembers of the culture gain a better understanding of its ways (Geertz, 1973; Goodall, 2001; Maso, 2001). In some instances, the researcher may even opt to conduct interviews with members of the culture (Berry, 2005; Nicholas, 2004).

Ethnography has some anthropological implications; it was, nonetheless, the aforementioned research-oriented colonialism that functioned as one of many “imperialist underpinnings of anthropology (Asad, 1973; Ashcroft, Griffiths, & Tiffin, 1989; Miller, 1990), the discipline with which ethnography has been closely but not exclusively associated”

(Conquergood, 1991, p. 179). This resultantly tainted the image of ethnography in turn causing ethnographers to struggle both “acutely and productively with the political implications” associated with ethnography (Conquergood, 1991, p. 179).

For those ethnographers who were more reformistic in nature, this critical period of conventional autoethnography was described as “a *felix culpa*” or “fortunate fall” (Conquergood, 1991, p. 179). Unlike their traditionalist counterparts, reformistic ethnographers sought to reconsider ethnography by adopting the themes of “(1) The Return of the Body, (2) Boundaries and Borderlands, (3) The Rise of Performance, and (4) Rhetorical Reflexivity” (Conquergood, 1991, p. 180). The Return of the Body refers to privileging “the body as a site of knowing” (Conquergood, 1991, p. 180). Malinowski (1961) stressed the importance of returning to the body by stating:

It is good for the Ethnographer sometimes to put aside camera, notebook, and pencil to join in himself in what is going on. He can take part in their natives’ games he can follow them on their visits and walks, sit down and listen and share in their conversations. (pp. 21-22)

Boundaries and Borderlands allow the ethnographer to centralize “the peripheral instead of de-centering the ‘metropolitan typifications’ that they carried inside their heads (Rosaldo, 1989, p. 207)” (Conquergood, 1991, p. 184). The Rise of Performance opens the door to use “the language of drama and performance” to represent the performance aspects of humankind and social life (Conquergood, 1991, p. 187; Turner, 1986). Simply put, individuals are all performers in their own right in regards to the roles they perform in their social lives, etc. (Turner, 1986). Rhetorical Reflexivity challenges research-oriented colonialism by acknowledging “the pretense of looking at the world directly, as thought through a one-way screen, seeing others as they really are only when God is looking . . . is itself a rhetorical strategy, a mode of persuasion” (Geertz, 1988, p. 141). When an ethnographer brings a different culture into his or her own culture conceived viscerally in the essence of the ethnographer’s culture, the ethnographers’ terms dominate the terms of the observed culture (Geertz, 1988).

Jorgenson (2002) asserted that the purpose of ethnography is to equip both insiders and outsiders alike with an enhanced understanding of a particular culture by providing what is known as a “thick description.” He further elaborated by noting how such a description is developed by detecting patterns of occurrences, feelings, stories, and cultural experiences based upon field notes, artifacts, and interviews.

Autoethnography, the offspring. Just like its parents, autoethnography incorporates all the elements of artistic, reminiscent, thick descriptions to relay experiences that are both personal and interpersonal (Ellis et al., 2011). There is, however, one advantage that autoethnography possesses . . . a higher level of accessibility (Bochner, 1997; Ellis, 1995; Goodall, 2006; Hooks, 1994). Traditional research is often written to address facilitators, practitioners, and scholars within a field of study. And, often overlooks vaster, more diverse audiences (Bochner, 1997; Ellis, 1995; Goodall, 2006; Hooks, 1994). Increasing the accessibility of a work that is designed to make both personal and cultural experiences more meaningful may serve as a catalyst for inspiring social and personal change (Bochner, 1997; Ellis, 1995; Goodall, 2006; Hooks, 1994). Ellis (1995), for instance, superseded the confines of academic context by addressing all who have loved and lost in the autoethnographic novel, *Final Negotiations: A Story of Love, Loss and Illness*. Ellis (1995) described both her personal experience with losing a loved one, and how the cultural aspects of academia affected her relationship to the deceased as well as her grieving process. Such thoughtful integration can also be achieved by comparing and contrasting personal experience to existing research (Ronai, 1995, 1996).

Perhaps there are long standing beliefs fortified by years of quantitative research that have determined a particular phenomenon to be true laden with resolute definitions. Autoethnographers in response may compare and contrast their personal experience as a means for information rich data to both trouble and add to the existing body of knowledge.

Some of the leading authors of autoethnography are Reed-Danahay (1997), Ellis and Bochner (2000), and Anderson (2006).

According to Ellis et al. (2011), a well written autoethnography requires more than meeting format standards. To ensure a masterful work, autoethnographers must take responsibility for their personal influence on the who, what, where, when, and how as opposed to pretending to be completely uninvolved. This is antithetical to the sterile approach of observational research that was exacted based on a long-held belief that inserting one's self into a culture will develop bias. It should be considered that completely removing one's self during the observation process may be equally influential (Conquergood, 1991). An autoethnographer will immerse him or herself into the culture and acknowledge his or her ties and involvement; this is indicative of the ethnographic aspects of an autoethnography.

Autoethnography and the IRB. Practitioners of autoethnography should be advised despite their reliance on *self* as the data source, it does not meet IRB standards in regards to human subjects. This means the autoethnographer will receive notification from IRB, stating the study is effectively closed. Regardless of the introduction, review of literature, and my usage of layered accounts in this dissertation, I received the same notification from IRB. See Appendix A to view the closure of my study.

Validity. In the context of autoethnography, validity “means that a work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable, and possible, a feeling that what has been represented could be true” (Ellis et al., 2011, p. 10). Autoethnographic layered accounts address validity by triangulating multiple sources of relevant literature and utilizing them as a means to question and compare against the researcher's experience instead of viewing the literature as a verifiable truth (Chang, 2008; Charmaz, 1983). Furthermore, the autoethnography must be coherent, and serve as a mechanism to guide the reader through the world via the author's perspective (Ellis et al., 2011; Plummer, 2001). The

validity of an autoethnography is also reliant upon the usefulness of the story; in this regard, the autoethnography should offer helpful information to improve the lives of readers, participants, and even the author (Bochner, 2002; Ellis, 2004).

Reliability. Unlike its conventional social science counterparts, reliability in this facet refers to the author's credibility; this may also be referred to as dependability in qualitative research (Ellis et al., 2011; Lincoln & Guba, 1985). This means considering whether or not the events described by the autoethnographer could have actually taken place or if the autoethnographer has written such an incredulous piece "that the story is better viewed as fiction than a truthful account" (Ellis et al., 2011, p. 10). As noted below under *Caveats*, readers must remain cognizant of the fact the researcher's compilation of accounts are the result of recollections of specific events long after they transpired. Some may question my ability to accurately recall and disclose certain events from the past. Due to the degree of trauma I experienced during the divulged ordeals, they are forever emblazoned in my mind. To further reinforce the accuracy of my recollections, a timeline in the form of a table is included within the appendices, which provides the months and years of each experience disclosed (see Appendix B). This is accompanied by medical records which reflect my biopsies and blood drawings, which corroborate my recollections. To view my pathology report, which discloses the results of biopsies taken from my GI tract, see Appendix C. To view the results of my first tryptase drawings view Appendix D and to view the results of my bone marrow biopsy see Appendix E.

Generalizability. Again, a sharp contrast is made between the criteria for generalizability in traditional social sciences and autoethnography. In autoethnography, generalizability does not refer to *large random samples of respondents*, but rather to readers who compare their lives to those of the author's to determine whether or not the author adequately illuminated common, cultural experiences and processes (Ellis, 2004; Ellis et al., 2011; Ellis & Bochner, 2000; Ellis & Ellingson, 2000; Flick, 2010).

Caveats. Readers of autoethnographies should be aware they are written based upon the researcher's recollection of events as well as the "memories, images, feelings—long after a crucial incident is supposedly finished" (Bochner, 1984, p. 595). Thusly, the context in which quotation marks are employed throughout the text are different from the conventional usage of quotation marks in accordance with the American Psychology Association (APA) guidelines. The usage of quotation marks in autoethnography do not denote verbatim quotes from the researcher and those the researcher conversed with; instead quotation marks are utilized to differentiate and transition between points of view such as first, second, and third person. These "alterations of authorial voice" serve to produce thick, multidimensional descriptions of the researcher's experience (Ellis et al., 2011, p. 5).

Design

The autoethnographic research design utilized for this study served to juxtapose my experience with mastocytosis beside pertinent literature, data, and abstract analysis via a form of autoethnography known as layered accounts (Ellis et al., 2011). Most autoethnographies avoid the use of research questions. These layered accounts were guided by the following research questions:

- 1) How do I—as patient with mastocytosis—describe and perceive my journey toward a correct diagnosis?
- 2) How is mastocytosis defined by multiple academic and medical literature sources versus my personal experience?
- 3) How do multiple academic and medical literature sources delineate the general diagnostic process and how does this differ from my experience?
- 4) What parallels exist between the facilitator-learner relationship, demonstrative of adult education, and the physician-patient relationship?
- 5) Which adult education principals and philosophies did I utilize while working with

physicians to establish a correct diagnosis?

- 6) Among those utilized, which adult education principals and philosophies were most salient in arriving at a correct diagnosis?

As previously mentioned in the review of literature, layered accounts juxtapose the researcher's experience beside pertinent literature, data, and abstract analysis (Chang, 2008; Ellis, 2009; Ellis et al., 2011). Layered accounts are comparable to grounded theory in reference to how both methods present analysis and data collection as a simultaneous process while presenting relevant literature as a "source of *questions* and *comparisons*" as opposed to a "measure of truth" (Charmaz, 1983, p.117). Layered accounts differ from grounded theory by relying on reflexive accounts, introspective analysis, and the use of vignettes with multiple voices (Ellis, 1991).

An example of a layered account by Ronai (1995) interweaves her experience with remaining silent about the sexual abuse she endured as a child alongside studies regarding silence and sexual abuse. Ronai's article may be described as being structured in three distinct layers which are experience, the responses of others, and what the literature says about others who had experiences similar to Ronai's. The subsequent block quotes will demonstrate each of the three layers mentioned. First, Ronai (1995) recalls her experience with abuse (first layer):

My father did "it" to me, sometimes every night for months, unless we were on the road hitchhiking, or if he was in jail for the nominal 2 months to a year for some theft, or indecent exposure, or some other sex offense. (p. 400)

Next she relays the responses (second layer) of some of her colleagues to her intent to write an autoethnography about the sexual abuse she endured as a child:

Several people told me not to talk about these experiences. When I suggested my own experiences with child sexual abuse as a research topic, one sociologist advised me to investigate the general topic, using my own story as one of my interviews. In other words, he told me to bury it in other data. (Ronai, 1995, p. 402)

After noting several suggestions from her colleagues encouraging her silence, Ronai (1995) revealed a parallel between her experience and the literature by referencing Reimer [1977, p. 467]:

Social science researchers too frequently neglect "at hand" knowledge and expertise they alone possess in the engineering of their research ventures. They often ignore or treat as ancillary their own unique biographies, life experiences, and situational familiarity when these could opportunistically serve as important sources for research ideas and data. (Ronai, p. 402)

To further back her experience with research, Ronai (1995) not only included literature which addressed the behavior of her colleagues, but also discussed the trend of silence among sexually abused college students such as from Giarretto's (1982) study:

In a study of 1,200 college students (Giarretto, 1982), 26 percent reported being involved in sexual child abuse before the age of 13 and yet only 6 percent of the victims reported it. Giarretto concluded that most children do not tell anyone until many years later. Reasons included: fear that they will lose the love of a family member; feelings of low self esteem (i.e., "I deserve it"); fear of not being believed; fear of being blamed; fear of breaking up the family; fear of making family members mad; or simply being trained to obey adults. (Roani, 1995, p. 406)

The last two block quotes are both examples of the third layer that relays what the literature says.

The use of layered accounts not only divulges my experience, but also my diagnostic test results, which is used in comparison to quantitative studies regarding trends in test results of other mastocytosis patients. Some of the benefits of utilizing autoethnography as a research method as noted in the literature are the ability to provide information rich, first-hand details of events (Chang, 2008; Ellis, 2004; Holt, 2003). It was my intention to identify the disparities and similarities between my personal experiences and medical research to aid in determining the ontological, epistemological, and methodological aspects associated with the medical diagnostic paradigm when testing for disease (Punch, 2009). Moreover, I sought to identify examples of the existing parallels between the learning relationships between both physicians and patients and facilitators and learners—mentioned in the review of literature—within the layered accounts.

The layered accounts provided in this chapter describe the most salient events that occurred prior to my seeking medical attention and the reaction from my family. Each account divulges pertinent information comparable to the literature regarding heightened symptoms, and complications.

In accordance with autoethnography guidelines, the subsequent accounts are exceedingly detailed to exhibit multiple layers of consciousness and tie personal experiences to cultural ones in a manner that is engaging and evocative by stimulating the memories of the readers (Ellis & Bochner, 2000). Ronai (1995) described both her personal experience with sexual abuse, and how the cultural aspects of academia affected her perspective on conducting autoethnographic research as well as her relationship with herself. Similar to Ronai, my layered accounts offer insight into my working, academic, platonic, romantic, familial, faith-based relationships, my relationship with myself, and how they were affected by my experience with mastocytosis. Incorporating even the minutest details allows for identification of epiphanies and establishes meaningful, sociocultural parallels to society and one's self (Ellis et al., 2011; Ellis & Bochner, 2000). In fact, it is such detail and establishment of parallels that separates autoethnography from an autobiography (Ellis & Bochner, 2000). As an autoethnographer—well versed in what life is like as a sufferer of mastocytosis—I utilized specific accounts to call unfamiliar subject matter to the attention of my colleagues; this was achieved by incorporating principles, practices, and philosophies from the field of adult education to create social awareness while emphasizing distinct parallels between adult education and my personal experience with mastocytosis (Bochner, 1997; Brookefield, 2011; Ellis, 1995; Goodall, 2006; Hooks, 1994).

This chapter entails the most salient moments where my symptoms were heightened prior to seeking medical attention. The subsequent chapters cover my journey as I floated from physician to physician seeking a diagnosis and treatment for my symptoms. The remainder of

this chapter and subsequent chapters flow in a manner similar to Ronai's (1995) layered account. I began by recounting my experience (layer one), relaying the responses of others (layer two), and concluded with research comparable to my accounts (layer three). Ronai utilized asterisks to denote "a shift to a different temporal/spatial/attitudinal realm (Ronai, 1992)" (Ronai, 1995, p. 397). I too utilized asterisks, but for the purpose of indicating time lapses.

Assumptions. According to Perez (2013) "autobiographic research methods such as auto-ethnography . . . assume an insider perspective for the researcher" (p. 71). Perez's (2013) dissertation, which also utilized autoethnographic techniques, addressed both the role and assumptions of the researcher based on the works of Janesick [2004] and Gruppetta [2004]:

Janesick (2004) noted, the researcher is the primary research instrument in qualitative work. For this reason, qualitative researchers need to be explicit about the assumptions they bring to their research because doing so can enhance the study by providing a contextual frame for the reader to properly interpret the researcher's conclusions (Gruppetta, 2004). (p. 70)

In reference to the above statements, my role as the researcher was assumed in a manner that acknowledged the fact of my being an individual diagnosed with mastocytosis—a role that was accompanied by specific biases and assumptions. Due to this, I defined "my role as that of a researcher/participant rather than as that of a detached observer" (Perez, 2013, p. 70). As a researcher/participant, I fully comprehend that my association with the topic of this study was influential on the way I interpreted the emerging themes of this study. In an attempt to explicitly communicate my biases and assumptions I maintained my reflections in a journal. This journal consisted of video and written reflections that "provided opportunities for introspection about my researcher role throughout the study" (p. 71).

The primary assumption I brought into this study was my experience, being a patient with mastocytosis made me an insider and therefore equipped me with unique privileged information. Although there are case studies that reported symptoms relayed by the patients, the feelings of the patients on how they were being treated by medical staff, as well as their

feelings regarding their diagnoses and prognoses were scarce. The majority of the studies I read that did divulge the patients' feelings included patients with rare diseases other than mastocytosis. Only one of the studies addressed the feelings of patients with mastocytosis, and how it affects their social lives. Perez (2013) mirrored this assumption in his dissertation by noting "another assumption for this study is that my insider status has allowed me to contribute insights to the study that might be taken for granted by other researchers who have not lived the experience of visual disability" (p. 72).

Data sources. Due to the postmodernist nature of this study, my personal recollections were utilized as the primary data source to reflect one of the many ways of knowing (Wall, 2006). This is in accordance with Ellis (1991) who recommended introspection be employed as a data source. Relying upon my own recollections as a data source—in this context reexamined "the condition of representation and therefore [engaging] with figures of subjectivity that do not depend on representation as it has been understood" (Clough, 2000, p. 286). In addition to my personal recollections, peer reviewed articles, books, websites, personal communication with physicians, personal communication with family and friends, as well as my lab results (bloodwork, biopsies etc.) were relied upon as data sources. Dr. Metcalfe, who is quoted 33 times within this text, graciously read my proposal (Chapters 1 through 3) and offered corrections to my definitions and contextualization of medical terminology utilized within the text.

Coding techniques relied upon for recreated dialogue. Albeit the majority of analysis—when utilizing the research method of autoethnographic layered accounts—takes place simultaneously during the writing process, further analysis was necessary to assist in identifying the observable adult education principles and philosophies from my relationships with the 15 physicians mentioned in Chapters 5 and 6. This entailed the use of open coding of the first layer of each autoethnographic account which relayed my experiences with each physician; subsequent to open coding, pseudonyms were assigned to each approach code. The codes

were resultant of my reading Chapters 5 and 6 repeatedly until patterns began to emerge and coalesce from the described relationships between each physician and I during the diagnostic process. The pseudonyms served to personify the data properties represented by each code. Table 2 provides the list of open codes, categories of codes, and categories of data. Table 3 provides further information into which data properties made up each code along with some of the narrative excerpts that illustrate the properties of each code.

Table 2

Open Codes Used to Analyze Narratives

Open Code	Category of Code	Category of Data
PSA	Approach	Problem Solving Absolutism
PSC	Approach	Problem Solving Conclusive
DMD	Approach	Decision Making Democratic
Pre-T P	Phase	Pre-test Phase
Po-T P	Phase	Post-test Phase

I then, reexamined each open code along with its corresponding narrative excerpts until a portrait of my experience emerged as a sequence of amalgamated constructs. These amalgamated constructs were developed by weaving the narrative excerpts into the data properties providing condensed, organized depictions of my experiences. Each of the assigned pseudonyms was utilized twice to portray my relationships with the physicians in both the pre-test and post-test phases (see Table 3).

Table 3

Open Coding, Frequency, Data Properties, and Narrative Excerpts

No.	Approach Code and Assigned Pseudonym	Freq.	Phase Code	Data Properties	Demonstrative Narrative Excerpts
1	PSA (Dr. Castle)	4	<ul style="list-style-type: none"> • Pre-T P • Po-T P 	<ul style="list-style-type: none"> • Physicians' strict adherence to Elstein and Schwarz's (2002) problem solving paradigm • No referrals for second opinions • Condescending • Reluctant to share information • Resistant to my input • Parallels Boldt's (1998) transmission perspective • Parallels traditional perspective of patient physician relationship (Bodenheimer et al., 2002) • My determination to seek other opinions increase my health literacy, and do my own research 	<ul style="list-style-type: none"> • "Well I didn't have these issues before I took it." "So what, you're a doctor now?" He laughs in between sentences. "Ha, haaa! Listen, I don't want to pooh, pooh on your little theory, but birth control pills don't do that." "Sometimes Miss Hayes people develop what are known as idiopathic hives. The term idiopathic has some psychosomatic implications" • I mean, I've had an endoscopy before and all it showed was GERD. Do I need another one? I don't know. I just feel like maybe they were missing something, but you could be the ones to find it. Can you help me?" Dr. Lawrence looks over at Dr. Walters. "What do you think Dr. Walters?" His scowling transitions into a stone face. "We can prescribe some more hyoscyamine for now. Based on what I felt, there's no need for another endoscopy. What are your thoughts?"

Table 3 Continued

No.	Approach Code and Assigned Pseudonym	Freq.	Phase Code	Data Properties	Demonstrative Narrative Excerpts
2	PSC (Dr. York)	3	<ul style="list-style-type: none"> • Pre-T P • Po-T P 	<ul style="list-style-type: none"> • Physicians' certainty my symptoms were psychosomatic • Physician's certainty I was depressed • No referrals for second opinions • Reluctant to share information • Resistant to my input • Parallels Boldt's (1998) transmission perspective • Parallels traditional perspective of patient physician relationship (Bodenheimer et al., 2002) • Determination to seek other opinions increase my health literacy, and do my own research 	<ul style="list-style-type: none"> • His lips curl upward as he delivers his next insult. "I could always prescribe an antidepressant for you. I noticed you were on one in the past. Perhaps it's time for a refill." "It never ceases to amaze me how when a doctor can't figure out what's wrong with you, you must be depressed. I may be under stress Dr. Cole, but I'm not depressed." • "A sleep aid, Miss Hayes to my knowledge, Effexor is just a brand name for venlafaxine which is taken to treat depression. I'm not certain . . ." I hold my hand out in protest. "Whoa, whoa, whoa are you telling me, this man told me he was prescribing medication to help me sleep and without telling me, he prescribed an antidepressant?"
3	DMD (Dr. Sanford)	7	<ul style="list-style-type: none"> • Pre-T P • Po-T P 	<ul style="list-style-type: none"> • Parallels Arsenau and Rodenburg's (1998) developmental perspective • Exhibits signs of self-management education (Bodenheimer et al., 2002) • Willfully shares information • Determination to do my own research and increase my health literacy 	<ul style="list-style-type: none"> • "Alright, I'll hand these to you and you can take a walk with me to the lab." I place the brochures in my purse and follow her down the hall. "I'll see you in a couple of weeks Nina. Take care."

I then, continued the coding process by exercising axial and selective coding. From these efforts an overarching theme was determined. Table 4 depicts the next two steps in the coding process.

Table 4

Open, Axial, and Selective Coding for Narrative Analysis

Open Code and Assigned Psuedonym	Axial Code	Selective Code
<ul style="list-style-type: none"> • PSA (Dr. Castle) • PSC (Dr. York) • DMD (Dr. Sanford) 	<ul style="list-style-type: none"> • Conducting research on my own • Increasing my health literacy 	<ul style="list-style-type: none"> • Self-directedness fueled by my relationship with each physician

To provide a better understanding of how, as well as the order in which I analyzed the data, Figure 3 provides a concise visual depiction of the process. The arrows in the figure delineate how each step in my process flowed from one to the next, exhibiting an interdependence of sorts.

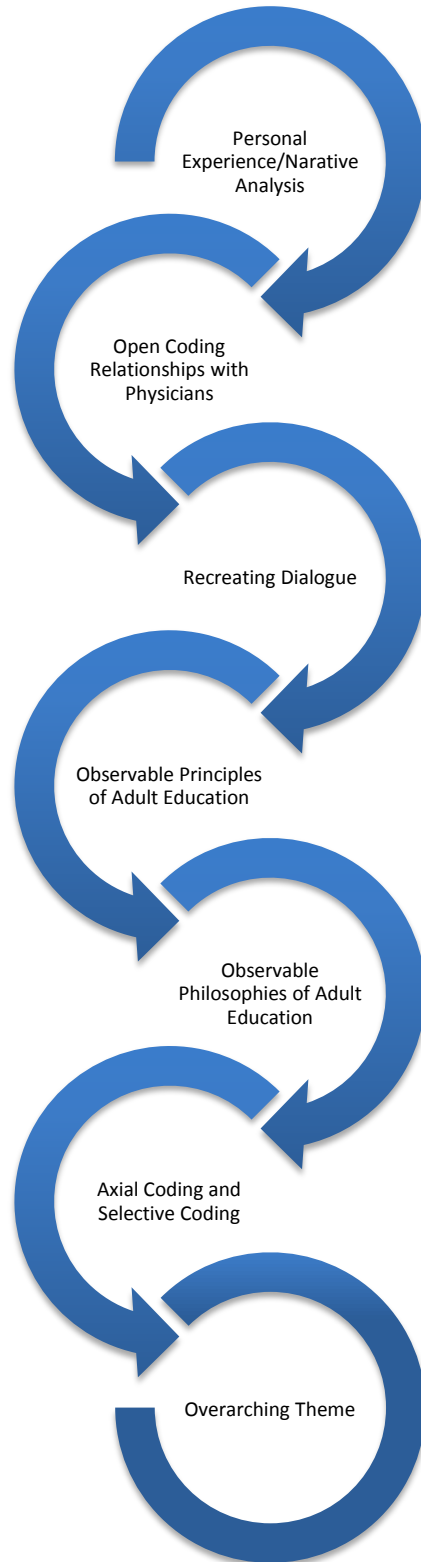


Figure 3. The overall coding process. This figure depicts the interdependent, step by step process used to code the data.

Chapter 4

My Experiences Prior to Seeking Medical Attention

The layered accounts provided in this chapter describe the most salient events that occurred prior to my seeking medical attention and the reaction from my family. Each account will divulge pertinent information comparable to the literature regarding heightened symptoms, and complications.

In accordance with autoethnography guidelines, the subsequent accounts are exceedingly detailed to exhibit multiple layers of consciousness and tie personal experiences to cultural ones in a manner that is engaging and evocative by stimulating the memories of the readers (Ellis & Bochner, 2000). Ronai (1995) described both her personal experience with sexual abuse, and how the cultural aspects of academia affected her perspective on conducting autoethnographic research as well as her relationship with herself. Similar to Ronai, my layered accounts offer insight into my working, academic, platonic, romantic, familial, faith based relationships, my relationship with myself, and how they were affected by my experience with mastocytosis. Incorporating even the most minute details allows for identification of epiphanies and establishes meaningful, sociocultural parallels to society and one's self (Ellis et al., 2011; Ellis & Bochner, 2000). In fact, it is such detail and establishment of parallels that separates autoethnography from an autobiography (Ellis & Bochner, 2000). As an autoethnographer—well versed in what life is like as a sufferer of mastocytosis—I will utilize specific accounts to call unfamiliar subject matter to the attention of my colleagues; this will be achieved by incorporating principles, practices, and philosophies from the field of adult education to create social awareness while emphasizing distinct parallels between the adult education and my personal

experience with mastocytosis (Bochner, 1997; Brookefield, 2011; Ellis, 1995; Goodall, 2006; Hooks, 1994).

This chapter will entail the most salient moments where my symptoms were heightened prior to seeking medical attention. The subsequent chapters will cover my journey as I floated from physician to physician seeking a diagnosis and treatment for my symptoms. The remainder of this chapter and subsequent chapters will flow in a manner similar to Ronai's (1995) layered account. I will begin by recounting my experience (layer one), relaying the responses of others (layer two), and concluding with research comparable to my accounts (layer three). Ronai utilized asterisks to denote "a shift to a different temporal/spatial/attitudinal realm (Ronai, 1992)" (Ronai, 1995, p. 397). I too will utilize asterisks, but for the purpose of indicating time lapses.

First Major Symptoms

There are far too many instances to recall where I succumbed to the symptoms of my once unexplainable illness. My journey to a correct diagnosis reads more like a series of diverse yet concurrent nightmares. Instead of describing every single incident, it is best to recount the most salient moments of my journey. This chapter will cover the first major symptoms I incurred as well as the reactions of family members prior to seeking medical attention from multiple physicians.

Mardi gras meltdown (layer one). It is Monday morning, February 7, 2005—the day before Fat Tuesday. I awake in my hotel room to the sound of my phone ringing incessantly. It is 5:03 a.m. and everyone knows I am on vacation. Is this an emergency? I slowly drag myself out of bed and trudge along the thin carpet across the dark room to the dresser where my phone is charging. I open my flip phone and answer "hello", but I am too late. They hung up. I scroll through my call history and notice five missed calls. I must have slept really hard. Three of the calls were from the news station and two from my immediate supervisor. What the hell? I

am on vacation. Is it impossible to have just one moment of peace? My best friend, Saida, sleeping in the adjacent bed, mumbles “who was that?”

“It was my job.”

“Why?”

“Who knows but, I’m not in the mood. There’s nothing I can do from here.”

I call my immediate supervisor back first.

“Hello ...Nina?”

“Hi Nancy, sorry I missed your call. I was asleep. Is everything ok?”

“Not exactly, the news station is crapping bricks right now.”

“Crapping bricks—for what—what did I do?” A phantom bubble rises from the pit of my gut to my chest.

“They’re pissed because you left during ‘sweeps’.”

“Nancy, they knew it was ‘sweeps’ when I filed for time off more than two months ago. I gave them the same dates I gave you, and you provided one of my coworkers as a replacement in my absence. I don’t, I just don’t understand. I followed procedure to the t. So what is the problem?”

“All I know is the news director called and fussed at me this morning. He said no one, absolutely no one leaves during sweeps.”

“What does that mean? I am contracted out to his company through yours. I work for you not him. He was pretty quick to that point out when I wasted time in the photo shoot only to find out my face would not appear on the billboard with the rest of the news crew. So let me get this straight; I am not important enough to be featured on a billboard but, I’m too valuable to leave during sweeps? How convenient. So what did you tell him?”

“I told him you followed protocol and you were reaping the vacation hours you earned.”

“Then what?”

“Then, the general manager called.”

“John called! Are you kidding me?” The bubble in my chest travels to my throat and morphs into a knot. Are they going to fire me? Why are they overreacting like this? The questions begin swimming inharmoniously, and colliding in my head. “So what should I do Nancy?”

“John said for you to get your butt on a plane and fly back immediately.”

“Who’s going to pay for that Nancy? I know I’m not. I flew here with Priceline tickets. They’re nonrefundable!”

“Relax, I told him you were probably sailing on Lake Pontchartrain somewhere and the reception was probably bad.”

“I hear you Nancy but, that’s easier said than done. I’m just . . .”

“Stop Nina, you did everything you were supposed to do. I’ll handle Brendt and John. Do not return their calls. Just let me do my job, and enjoy your vacation.”

“Thanks Nancy, I just can’t believe this is happening right now.”

“Don’t thank me. Just bring me something back”

“I will.”

I closed my phone and made my way back to the bed. Saida sits up in her bed.

“Dude, what happened?” Her empathy is genuine. We both work at the same station; she knows exactly what I am dealing with.

“The news director and general manager want me to get on a plane and fly back immediately.”

“I heard you say that on the phone. So what are you going to do?”

“Nothing, Nancy said to let her handle it.” Do they have any idea what it’s like be me—a pseudo celebrity? I’m not famous. I’m just a highly recognizable nobody; that means I get all the recognition of a celebrity with a fraction of the respect.

Unlike my syndicated counterparts who appear on national news shows, I am close, tangible, and apparently disposable. Pseudo celebrities are not worthy of a stylist or a makeup artist. We pick out our own clothes and do our own hair and makeup before we go on camera. By the way, none of those things are free either. You cannot begin to fathom the concept of a tight budget until you spend \$150 per month on Bobbi Brown makeup, and \$250 a month on clothing and hair products from a \$25,000 salary. As a single woman, with no children, who does not own a home I barely clear \$19,000 after taxes.

Apparently they forgot working for them only makes up a third of my day. The company that contracts me out to the news station requires all fulltime employees to work a split shift. This means when my shift ends at the news station by 8:30 am, I have a second shift from 3:00 to 7:00 pm providing traffic for five different radio stations. Yes, five! And since \$19,000 net pay is not enough to cover my rent while maintaining my image (hair, makeup, and clothes) I kept my midday shift at the radio station from 10 am to 3 pm. Now I am sure you are wondering, how on earth I can make it to my third shift when one ends as the other begins. During the 1:50 pm commercial break of my radio show, I run down the hall to the voice tracking room to prerecord the last hour of my show—which takes roughly 20 minutes. Then I have 50 minutes to remove my makeup, change into comfortable clothes, and grab dinner before heading to my third and final shift. Oh, and let's not forget, my apartment and my jobs are in three different cities—THREE! I live in High Point North Carolina, the news station is in Winston-Salem, and both the radio station and traffic buildings are in Greensboro. Just in case you didn't know, tardiness is the kiss of death in communications. Unlike a nine to five where I can call my boss and say I'm running 10 minutes late several hours of notice are required to fill my slot. Think about it. When is the last time you turned on the television and saw a message saying the 6:00 news will begin at 6:05? There is no room or forgiveness for error. Five days a week I maintain this circus act and this is how they treat me on my first paid vacation! A dull warmth takes form

in my chest and intensifies as it migrates to my forehead. Anxiety, fear, and anger are all brewing as I slowly rub my temples in a circular motion. “Shit, what if I don’t have a job to go back to?”

“They won’t fire you. You’re the best traffic reporter in the viewing area. Besides, if they’re making this much of a stink they obviously need you for ratings.”

I sigh deeply. “Yeah, I guess you’re right.”

“Cheer up, this is Mardi Gras! Tonight we’ll have some gumbo and hurricanes. You’ll forget all about this bull. But for right now, let’s get dressed and walk over to Café Du Monde. Those beignets are calling my name.”

We change clothes to and head to Bourbon Street to enjoy the festivities of the night. I don’t recall seeing this many people on the streets when I was at the 1996 Olympics in Atlanta. A pungent bouquet of scents densely populates the air—each competing for recognition: fresh water, sweat, creole seasoning, seafood, musk, alcohol, horse feces, sugar, urine, and breath. A sea of faces smiling, laughing, ogling, and glassy smirks toiling with drunkenness rush the shores of the French Quarter. The screams of the crowd are answered by the clanking of plastic beads and underscored by live jazz, hip hop and pop. My senses are in a state of information overload. I could easily become just as inebriated from overstimulation as I could from drinking, but I am immune. I want to lose myself in the sights, sounds, and smells, but an utter disconnect compromises my engagement. So I reach for my mask. It is shiny and colorful, but it is not decorated with glitter or paint. It is bedazzled with smiles, laughing, and dancing. Friendly conversation and quick wit serve as gold trim which provides a finishing touch. They cannot see me; I am a part of the crowd now. The visceral sense of foreboding churning in my spirit is invisible to them, yet all too apparent for me. Something is coming,

something life changing, but not enriching. It's all clear to me now. I didn't have a seizure the other night; I had a warning.

I awoke to an unfamiliar feeling. I know I had a couple of drinks last night, but not enough to cause a hangover. My eyes struggle to shift though what feels like a pool of mud, eliciting an intense throbbing in my head with each movement. Sluggishly I rise to a sitting position, turning my legs to the side of the bed as I stretch them outward and gingerly plant my feet on the floor to rise to standing. I wince as the weight of my body presses the tender soles of my feet. Every part of me aches, my bones, muscles, stomach, and eyes. Even my tongue and gums are sore. Slow, careful, baby steps guide me through the dark room to the bathroom. The sun isn't even up yet. Why am I awake? My fingers glide along the textured wall paper searching for the light switch as I lean against the cool door frame. Click, the blinding light assaults my eyes moving me to squint. My pace quickens as I turn my back and flop down on the toilet. Resting my face in the palms of my hands to block the light, I straighten my knees. My feet praise me for the short break. I flush and stand. The warm water and soap are soothing to my hands. I quickly glance at myself in the mirror. Wait! What the . . . ? My complexion is beet red and splotchy, and my familiar features are distorted. Staring back at me are red eyes with swollen upper eyelids, inflamed lips, and the nose of a pregnant woman stretched nearly a third wider than normal across my face.

I rinse the rest of the soap off my hands, and feverishly splash water on my face. This cannot be real. I look up to view my drenched face. The warm water only reddened it. Is this an allergic reaction to something? The only things I am allergic to are shrimp and latex, and I did not come in contact with either of them. Benadryl is the only allergy medicine I have, and there's no way I'm going to take it now. It will be time for breakfast in a few hours and I'll never wake up. Determined to sleep it off I stammer back into bed.

“Nina! Nina get up! I’m out of the shower. It’s your turn. Hurry up we’re going to miss breakfast.”

Feeling just as awful as I did a few hours ago, I sit up and rub my eyes.

“Whoa! You must have slept hard. Your face is puffed! Want me to get some ice to take the swelling down?”

“Yeah, sure, that would be great.” I make my way to the shower anticipating the comfort of the warm water on my aching body. Before turning the water on, I take another look at my face in the mirror. There is no change except a couple of pimples joined the fun. “Great, just great.” I step into the shower contemplating clever makeup tricks to cover this monstrosity. Too much contour in the daytime will make me look like Dracula. Concealer will tone down the redness, but it may make the puffy areas look even puffier. “Uuuuggghh!” I take my frustration out on my skin, scrubbing harder and harder as I replay yesterday’s conversation with my boss in my head. Was she really handling the situation? Should I call the station anyway? No, no always follow the chain of command, always.

“Nina are you alright?”

“Yeah, I’m just tired.”

“I sat the ice by the sink. Hold it against your face for a few minutes when you get out. And don’t take all day in there.”

“I’ve only been in the shower for two minutes.”

“You know you take forever.”

Pull yourself together girl. You’re on vacation. I turn off the water and snatch the curtain back. Hurriedly, I scoop two generous handfuls of ice and press them firmly to my face. The heat from my skin sends trickles of freezing water down my neck and chest. This better work or I’m going to walk around looking like a Muppet.

“Are you out of the shower yet? It’s lunchtime.”

“Shut up I have ice on my face!” We both laugh. I drop the ice in the sink and look up. There is some improvement, but I still look like a Muppet. I slather lotion on my face. What to do, what to do. Bronzer, that’s it. I’ll brush some bronzer on my face. It will even out the redness and cover these pimples. I complete my transformation with mascara and lip gloss. “Hey Saida come here and tell me how this looks.” I hear her sigh deeply on the way to the bathroom.

“You’re 25 years old and you need me to tell you how you look in your makeup?”

“Uh, were you 25 when you asked me how your outfit looked last night?” Anyone else would have escalated this witty exchange to an argument. Only we can banter this way and not be offended.

“I hate you.”

“Player, hater, hater” I sing in a high pitched voice as she walks into the bathroom. Her eyes settle on my face. Her expression is fixed as she nods her head.

“Okay.”

“Okay what? Okay good, okay bad, what?”

“Well you don’t look bad Nina. You just don’t look like your normal self, and it really shouldn’t matter. No one knows you down here and no one knows you’re on TV. So they can’t compare how you look today to what you normally look like. I mean . . . there’s only so much you can do right? We tried the ice and it kiiind of worked. Plus, the bronzer is helping some with the redness.

“Cut the crap, I look like who shot John.” An awkward silence sets in.

“You’re pretty on most days.” We erupt into laughter. This raw, unfiltered honesty is exactly why we are friends. She provides the loving candor I grew up with in my home and among my childhood friends. It is a rare, familiar trait I still seek in my adulthood friendships.

Anyone can lie to you, but a true friend tells you what you need to hear rather than what you want to hear. I needed to hear my eyes were not deceiving me, and I could either wallow in it or embrace it and have fun. I choose to embrace it.

During the drive to the airport, a fuzzy chill begins creeping up my right side. What is this? While boarding the plane I begin to struggle with my coordination. My once effortless and confident steps are now deliberate and focused as I make my way to my seat. Left, right, le-leffft, damn it! Don't fall! Even the little drill sergeant living in my head is frustrated. The fuzzy chill evolves into numbness and tingling as I grapple with the seatbelt.

"Dude are you alright? You look like an old lady over there."

"I don't know. I can't feel my right side."

"You're right side? Like your whole right side?"

"Yeah, it's like someone drew a straight line down the center of my body. Wait, what if I'm having a stroke? No, that would be the left side right? Besides I'm only 25 years old, I work out like a maniac, and I have a very healthy diet. Maybe I sat too long on the ride to the airport. Yeah, that's it. I sat too long and my right side went to sleep." As I continuously spew explanations for my condition, I can see the concern growing on Saida's face.

"Should we get off and head to emergency or something? All of those things you said make sense but, you have been stressed out this entire trip. Stress causes strokes and you're never too young to be stressed."

"No, I'm ok. I just need to get this whole fiasco rectified and everything will go back to normal." The swift syncopated rhythm of my heartbeat is joined by the steady beat of the tremor in my gut. Is this a sound check or live concert? I'm too young! There is no way I could be having a stroke. No way. Wait, my uncle had a heart attack at 27 from stress. I'm only two years younger than he was. God, stop thinking about this. The chaotic collisions of my

opposing thoughts rival the turbulence on the plane. If it is not a stroke, I'm going to give myself one before we land. I begin breathing deeply, toiling to center myself. That's it, the Twenty Third Psalm. Yes, yes, it always works when I meditate. "The Lord is my shepherd. I shall not want. He maketh me to lay down in green pastures. He leadeth me beside the . . ." Psalm 23:1-2 (King James Version).

I awake jolted by Saida gently shaking my arm.

"Nina, are you ok?"

"Mmm, ahem, yeah I guess I slept pretty hard."

"Come on, we have to catch our connecting flight."

I focus my eyes on the seat in front of me until the blended colors became a distinct blue and red pattern on the cloth. Quickly, I run my fingers across the seatbelt buckle which should feel cold and unyielding. Nothing, I feel nothing. I can move freely, but not without a conscious effort. Only my own awareness informs me I am touching anything.

"Is your right side still numb?"

"Yeah." I brace myself on the arm of the seat with my left hand and stood up.

"Nina, I'm worried. I don't like this."

"I'm okay. Look, if it doesn't go away by tomorrow, I'll do something about it. It's not as bad as it looks." Stop talking you need to maintain your concentration. I cannot believe I am coaching myself on how to move naturally, but I have to. No matter what I have to get home and prepare for work. Well, if I'm not fired already. All I have to do is make it through the airport to my next flight, and I can sleep on the plane again. I desperately try to polish my ill-contrived movements under Saida's watchful gaze. You can do this Gianina. It's mind over matter, nothing more. Alas, victory! We make it to the gate just in time to line up for boarding. I hold onto the tops of the vacant seats on the plane, steadying myself as I maneuver through the

cramped aisle. I'm almost there, just a few more steps. I flop in my seat, slowly melting into its contours desperately seeking a comfortable position to ease the numbness. There isn't one.

The drive from the airport to my mother's house is rather quiet. Saida and I always have something to talk about. This time the words are few. Maybe she's thinking about how she had to load my suitcase in the car. Me, the girl who benches 120 pounds and squats 190 cannot lift a 48-pound bag! Buried deep beneath my obvious gratitude for her help is shame.

"So what's next girl? We have to do this again next year. Maybe we can go to o York, Atlanta or DC. You know I know all the hot spots in Atlanta and DC." Perhaps these propositions I am making will lighten the mood.

"Before we go anywhere we need to figure out what's going on with you first."

"Yeah, and whether or not I have a job to cover the expenses." She turns the radio up as one of our favorite songs is playing. Neither one of us are in the mood to confront this reality now, but there is still unfinished business. How do I explain this to my mother, and my grandmother? They're practically clairvoyant; if I don't tell them everything, they will get the truth out of Saida. I can't avoid it, I parked my car there. It was nearly \$100 cheaper to fly out of the Raleigh Durham airport than the Greensboro airport which is closest to where Saida and I live. Before our trip, I parked my car at mom's house and Saida and I rode to the airport from there in her car. If I wasn't so frugal I wouldn't be in this mess. I could have taken a roundtrip from Greensboro, and driven back to my apartment in High Point. No one would have been the wiser.

Mom only lives an hour and 20 minutes away from me and the drive to my apartment on Sunday is always an easy one. Easy or not, driving with a barely mobile right side is probably not the best idea.

I know my family loves me and they would want to know if something is wrong, but now is not the time. Granny is battling a rare form of bladder cancer. The doctor's found it only a year after my grandfather—whom we lovingly referred to as Poppie—passed in 2002. Chemo treatments helped prevent it from spreading, but could not reverse the damage; her bladder was unsalvageable. When they removed Granny's bladder, several pieces of her spirit went with it. Her confidence, her independent nature, and her zeal for life were all stolen by the surgeon's incisions. The surgery left her with a urostomy bag. Half of her soul was already with my grandfather. What remained was a keenly insightful, loving, kind, and grateful, but broken individual.

Sometimes Poppie (my grandfather) comes to her in her dreams, telling her how wonderful it is on the other side. What if she gives up and decides to go with him? I know Granny never wanted to go through with the surgery. Granny told me she did it for us, and if she had her own way she would have let the cancer run its course. Her normal routine of dressing herself, driving and running errands became laborious chores. She now has to meticulously inspect her garments, making certain the cut of her shirts and elasticity of her pants waistbands are accommodating to this new foreign appendage. Preparing herself to rip a bandage off daily, only to replace it with another bandage on top of her already raw skin it. The driver's seat and seatbelt had to be adjusted just so. She had to sit close enough to reach the wheel without pressing the bag against the seatbelt, yet far enough away to keep the steering wheel from hitting the bag. She also had to space the straps of the seatbelt to keep them from pinching the bag. Eventually, Granny stopped driving. Even in her sleep peace eludes her. Lying in the wrong position or rolling over too abruptly could rupture the bag. Numb and afraid or not, I have all of my organs and I am not on chemo. There is no way I'm going to tell Granny about this. I silently pray, begging God to restore the feeling in my limbs. I guess He is busy.

Saida parks on the grass, under the tree so the three cars in the driveway can come and go without having to move her car. I take a deep breath and close my eyes. In a matter of minutes everyone will know something is wrong.

“Don’t worry Nina. I’ll get your bags out of the trunk. Do you need me to help you out of the car?”

“No, I got it.”

Slowly, I open my car door and gingerly twist my languid body to the right. While steadying myself with my left hand on the car door I slowly rise to a standing position. Out of the corner of my left eye, I see my uncle Kimothy walking toward us with his arms outstretched. Straighten up and smile Gianina. Straighten up and smile.

“Hey ladies, how was your trip? Did you bring me back some gumbo?” We both laugh. He walks over to my side of the car first to hug me. My heart begins to race. Don’t put your weight on him. Stand up straight when he hugs you or you will fall. I smile hardily as he leans his long slim frame down to embrace me. He kisses my cheek and leans back to look at me.

“How are you doing baby?”

“Good, good.” I search his eyes to see if he is buying it. He grins and quickly moves on to Saida.

“Saida! What’s going on girl?”

“Nothing much Uncle Kim, I’m just trying to enjoy these last few days of my vacation before I head back to the rat race.”

“I heard that. I tell you what; we are going to have a ball while you’re here. There’s food and beer inside, and Monica whipped up a batch of apple martinis. So, I’m going to take these bags and you two go in, fix a plate, grab a drink, put your feet up and tell us all about your trip.”

He grabs both of our enormous suitcases like they are pillows and heads toward the side door. I watch him until he clears the corner to move. I hear the screen door creak slowly. I can tell by the drawn out length of the creaking sound it is Granny opening the door.

“What’s taking you girls so long to come inside?” Her tone exudes an unquestionable intuitiveness. Think before you answer Gianina.

“Oh, we’re coming Granny, just stretching.” I stand still out of her line of sight, anticipating the loud clank of the screen door closing. It never comes. She is waiting, waiting to inspect me with her eyes. One glance will tell her everything she wants to know. There is only one thing left to do, drop the act.

Saida glances at me with a raised brow. I reply with a shoulder shrug preceding a concurrent sigh and head shake. Hesitantly, I plod along the front lawn making my way to the side door. “Hi Granny.” She studies me intently as I approach the stairs and calls me by one of my many nicknames.

“Hi Toot” she says coolly. “Are you stiff from the flight?” I know the drill. I want to protect her by saying yes. She does not need to know what I am going through right now, but answering untruthfully will result in a psychological cataclysm. Most people call out the obvious. Not Granny, she strategically poses rhetorical questions and analyzes every facet of your response. Her piercing gaze—like a heat seeking missile—actively pursues telling gestures in body language. While listening to the details of your story she maintains a calm yet stern demeanor, never letting on she is taking note of the inconsistencies. For the grand finale she baits you with a second round of rhetorical questions allowing you to fall into every gap you left between accounts. She then sinks deeper into her calm as you struggle to dig yourself out of your own hole. Exhausted, vulnerable, and utterly embarrassed you reach for the only option left . . . the truth. It is then and only then when she will offer you her hand. Take it and she will

extend mercy and protection. Reject it and your doggedness will result in a lifetime of alienation. No one keeps secrets from Granny, no one.

“No ma’am, I’m a bit numb on my right side.” I maintain eye contact with Granny, allowing her full access to examine me at her leisure as I pull myself up the stairs. She opens her right arm while holding the door open with her left.

“Hurry up I’m letting all the heat out of the house” she jokes. We both laugh as I make it to the top step. She hugs me close with her right arm and kisses my cheek. “Get in the house. It’s cold out here.” I walk into the kitchen with Saida and Granny following close behind conversing.

“Hi Sweetie Girl!” My mother beams as she enters the kitchen.

“Hi Mommy!” Her eyes shift to my feet and slowly work their way up to mine. The upward curling motion of her lips is intercepted by concern which blocks her smile from reaching its full potential.

“What’s wrong? Why are you walking like that?”

“Oh I’m just a little numb that’s all. I’m sure it will pass.” Hastily, she walks toward me, all the while scanning me from head to toe attempting to diagnose the problem. She embraces me tightly and plants a multitude of kisses on my face.

“Muah, muah, muah, muah, mmmuah! It’s so good to have you home Tootie.”

“It’s good to be home.” As Mom makes her way over to greet Saida my aunt Monica enters the kitchen touting yet another one of my nicknames.

“Hiiiiii Justin!” Following close behind, peeking around her left hip is her son, my first cousin, my heart Kyndall. Kyndall is only five years old going on 21. He bats his eyes sheepishly at Saida, and quickly shifts his gaze in my direction to address me by his preferred nickname.

“Hi Roastie.”

“No, you’re Roastie” I jokingly bellow back.

“No, you’re Roastie, you’re Roastie, you’re Roastie!” His giggle breaks the rhythm of his speech pattern as he jumps sporadically like a firecracker, while pointing his tiny index finger toward me. Before I became Roastie, I was Gigi. The name Roastie is his brainchild. At the age of three he made the astute observation that while the rest of the family ate red meat, I always ate roasted turkey or chicken. He questioned my Aunt Monica about this perplexing occurrence. “Mama, why does Gigi always eat roasted chicken? Can’t she eat the steak and ham?”

“You should ask her bump.”

He skipped over to me with an expectant gaze. “Okay, umm Gigi how come you only eat roasted chicken? You always eat roasted chicken Gigi.”

“Well Kyndall, I don’t eat red meat or pork because I am trying to be healthy. So, when you eat steak or ham I choose to eat roast chicken or turkey.” His eyes widened like saucers as his plump cheeks reddened. He began jumping up down yelling “Ooh! Ooh! You’re Roastie! You’re Roastie! You’re Roastie!”, and took off running to tell the rest of the family. Two years later, I am still Roastie.

Anticipating Kyndall running toward me for a hug, I stagger down into a kneeling position bracing myself on the kitchen countertop. I wince as the force of his tiny frame collides against my chest. He hugs me tightly.

“I missed you Roastie” he says.

“I missed you too Roastie” I reply.

“Uh, what is that?” My Aunt Monica asks in her infamous smart-alecky tone.

“I’m just a little numb is all.” I tap Kyndall on the back signaling him to give me room as I dig my left heel into the floor and use my left hand to pull down on the countertop and rise to a standing position.

She scowls, extends her right arm, and twirls her perfectly manicured hand with spread fingertips clockwise. “That, what is that?”

“I just said I was numb.”

“Wow! So it makes you move like an old lady?”

“Apparently so, but it’s no big deal.”

“Mm hmm.” she scoffs as she eyes me from head to toe. Everything about her, her words, her gestures, even her posture are mocking. She is the quintessential wisenheimer, but with a twist. Her sharp quips are paradoxically paired with concern. If you look closely, you will find her stern expressions are actually cleverly disguised smirks. Although our exchanges are sometimes unpleasant, it comes from a good place, a place of love. Off-putting to some, her sarcasm was a familiar comfort to me which graced me with the impenetrable skin I don to this day. Monica, the baby of five, is only 14 years older than I am. To say teenagers and toddlers do not mix goes without saying. As a child I would approach her bursting with excitement “Monica! Monica! Look what I made in school today!” Her monotone reply of “beautiful” initially deflated my pride, but eventually instilled me with tenacity. I graduated from pouty lips and tear tracks to “Fine, I’ll go show Granny.”

Eventually, I developed my own smart mouth and embraced the quick wittedness passed down to me from both Monica and the original queen of snarky remarks Granny. Most people who know me are completely unaware of this trait. I guard it with my life until someone comes along who seems to find pleasure in incessantly harassing me. Months go by, and each time I offer a gentle word of caution followed an exit, praying my efforts will inspire them to change their approach. Most take heed, but sadly, there is always one. There is always one person who cannot take the plethora of hints I spoon feed them all along and then it happens. They disrespect me for the last time. Instead of turning to exit, I turn to face them, plant my feet, and intrepidly unleash an arsenal of indignities. These are not indignities in the traditional sense

of hurling expletive laden insults for the sake of injury, but rather truthful observations characteristic of my antagonist's unacceptable behavior. The piercing reflection of their own truth seizes them. Those who are moved to speak often respond with "I can't believe you just said that to me!" At this point there is nothing further left for me to say. I said my peace. What they do from this point is up to them. The many pieces of me loving, thoughtful, loyal, investigative, and even wiseass are all sitting in this room. Anyone who knows my family knows me.

It is 4:02 in the morning and I am still awake. Mom is fast asleep unaware of my sleep deprived night. Some of us doubled up for our sleeping arrangements. Mom and I are in her room. Monica, Kimothy and Kyndall are on the pullout couch in the den, and Granny is in her room. Saida left last night to prepare for the week. The numbness has now progressed to a painful, prickly sensation. Gingerly, I run my left hand across my right side pausing intermittently to twiddle my fingers against my cold skin. The line drawn down the center of my body has now become more distinct, polarizing my right side which feels frostbitten and my left side which is warm and responsive. Careful not to wake Mom, I roll on to my left side facing the cherry wood highboy. I know I should go to the doctor, but I cannot. Not right now.

A thump followed by two, long, high-pitched creaks come from the distance. Granny is awake. The pace of her footsteps quickens as she attempts to rush through the clamor of the inevitable hardwood floor concert. I release the tension in my left side, roll on to my back and close my eyes. The painful tingling sensation intensifies as I contend with my racing thoughts. I need to go to the doctor. Oh my God, what if I have to go to emergency? But what if Granny is sick and has to go to the hospital? No, no, just stay still. Stay still and keep your eyes closed. I can sense her presence at the bedroom door, pausing to lovingly inspect me once more. I began to count in my head, one one thousand, two one thousand, three one thousand, four one

thousand. Defiantly she chokes back a muffled cough, awaiting any sign of movement. Six one thousand, seven one thousand, be still Gianina. Presumably, satisfied she resumes her hurried steps down the hall toward the bathroom. I wait until I hear the door close behind her to release a deep sigh. The light trickle of her urine flowing through the narrow tube of the urostomy is amplified by the silence of night. All I have to do is maintain my position when she comes out and I am home free. The toilet flushes preceding the rushing sound of water streaming from the faucet and landing in the sink.

Startled by the noise my mother's head pops up from her pillow. "Is that Mom?"

"Yes ma'am."

"Is she alright?"

"I think so. She probably just had to use the bathroom."

"Okay."

The door swings open spreading the bright light across the portraits hanging in the hallway, and reflecting it into my mother's room. "Are you okay?" we ask in unison.

"I'm ok. The question is are you?"

"Oh Mom, you know I'm fine" my mother replies.

"I was talking to Toot." Now my mother rolls over abruptly to look at me.

"Are you okay, Tootie?" My mother asks.

"Yes ma'am."

"Did you sleep good?"

"Yes ma'am." Granny leans against the doorframe holding a napkin over her mouth as she coughs and clears her throat.

"Mmm hmmm! You wouldn't lie to Granny would you?" She tilts her head down and peers at me over her high cheekbones. A lump forms in my throat rolling around as I struggle to

swallow. She knew I was awake the whole time. She baited me and I fell into my own story gap.

"I'm just tired from my trip."

"And your numbness?"

"I'm still a little numb, but I'm alright. You're the one who is in chemo, Granny."

"God takes care of me. So don't worry. Granny is going to be fine, and I can check on you anytime I feel like it little girl."

"I guess you heard that. Now go to bed!" My mom says to me jokingly.

"I'm in bed."

"Then go to sleep." We all laugh and call it a night.

I wake up to the sound of footsteps and creaking floors. Uncle Kim, Monica, and Kyndall are leaving today at 9:00. I told them yesterday I would get up and make beignets for breakfast before they left. Am I still numb? Wait, let me check. Frantically, I reach over my chest to squeeze my right arm. As I quickly work my way from shoulder to forearm I realize I can feel. Yes, I'm back! What time is it? Only 7:27 perfect! I roll on to my left side and begin to swing my legs toward the edge of the bed, but something is off. I pull back the sheets, look down and realize my right leg is stuck in an awkward position. My knee is bent with my thigh angled backward as if I were jumping a hurdle. "What the hell is going on?" Oh my God, did I just say that out loud?

"Justin did you say something?" I should have known Monica's bionic ears would hear me.

"No, just thinking out loud!" Breathing heavily I begin feverishly squeezing and poking my leg. I anticipate the familiar throbbing sting which plagued me all night, but it does not return. Nothing, I feel nothing. I dig my nails into the flesh of my calf, still nothing. With both

hands I straighten my leg and cumbersomely rake my limp leg over the flannel sheets and drop it over the edge of the bed. The loud thud it makes against the side of the bed breaks my shock. Hot tears stream down my face landing in the creases of my lips. My mother calls to me from downstairs.

“Tootie, you’re up already?”

Using every ounce of concentration I can muster, I focus my attention on my feet and desperately try to wiggle my toes. My foot responds with a weak, lethargic tremble. “Uh, yes, yes ma’am!” Immediately I wipe the tears from my face. Should I ask for help? No, I don’t need help. What would I do if I was not at Mom’s? I live alone. If I were at home in my two bedroom apartment with no one to call on, what would I do? I would get around by any means necessary. I lean on my left side and brace myself with both hands on the edge of the mattress. With one quick motion, I twist my body around, facing the bed with all of my weight on my left leg. I guess all those years of dancing paid off. Moderately balanced I hop on one foot turning with each hop until I face the dresser. Now steady, I continue hopping toward the foot of the bed making and making an L shape as I head toward the en suite.

“What is all that noise up there?” Granny shouts from downstairs.

“Nothing, I’m up.” Short of breath I prop myself against the sink to contemplate how I’m going to shower and use the toilet without breaking my behind. Fortunately the toilet is adjacent to the sink. With both hands on the edge of the sink, I push off and spin on my left foot until my back is to the toilet. With my left hand remaining on the sink, I use my right hand to lift my nightgown, pull it to my mouth, and clench it between my teeth. I then grasp the toilet tank with my right hand and slowly lower myself down on to the seat. A few seconds of finagling allow me to adjust to a comfortable sitting position. After I finish, I hoist myself up via the sink and tank again, and hop until I am ideally positioned to wash my hands, and brush my teeth. Most people wait until after they eat breakfast to brush their teeth. This is a no, no in my family.

Greeting loved ones with morning breath is form of disrespect. I spit the toothpaste out and look deep into the eyes of my own reflection. I always thought there was good soul inside of me. Was I wrong? I must have done something wrong to end up where I am now. I believe in God, go to church, and pay my tithes. Is this my punishment for going to Mardi Gras? I didn't flash anyone, do drugs, fornicate, or anything. At my worst I had a few drinks and danced. I do the same thing here in North Carolina and God has not smote me yet. Perhaps being in the presence of sin was enough to make me guilty by association. Whatever I did, I have to figure it out and make sure I never do it again. "Father, if you're angry with me please tell me what I did wrong. Whatever I have done, I'm sorry." My face begins to contort in preparation for more tears. This time, I successfully choke them back. I am not worth my own tears. I did this to me, no one else. I knew I should not have gone to Mardi Gras.

I turn, grab my towel and hop toward the shower. Thank God Mom does not have a tub in her bathroom. I don't know how I would get my leg over the edge. I pull back the powder blue curtain, hop over low the tiled edge of the shower, and turn the water on. Hastily I rest my right shoulder against the cool shower wall providing partial relief for my strained left leg. The hot water is a welcome comfort to my body with the exception of my right leg which still has no sensation. I apply my facial cleanser to my cheeks, attempting to wash away my worry, rubbing harder and more intently at the reemergence of each concern. I work up a lather with my washcloth and begin scrubbing my upper body paying close attention to my neck and shoulders as I massage the tension away. Bracing myself with my right hand on the wall I work my way down to my flaccid leg, and tenderly rub it in a loving circular motion. Will it ever be normal again? I complete my bathing ritual, turn the water off and carefully hop onto the bathroom rug to keep from slipping on the tile. I am almost there. All I have to do is lotion down, and get my clothes on.

Thoroughly moisturized, I hop out of the bathroom and toward my suitcase at the foot of the bed to pull out something to wear. A quick side glance at the clock informs me it is now 8:03. Oh my God! All of this hopping around has cost me over 30. Suddenly I hear footsteps coming up the stairs. Before I can contemplate my next move, there is a knock at the door. "Shit." I utter under my breath. "Who is it?"

"It's me." Mom's soothing voice sails through the door. I flop down on the bed, clothes in hand and scramble to put on my bra.

"Just a second."

"Girl, it's just me." The hinges creak as the door swings open.

"Mom!"

"What are you doing up here? All we hear is a bunch of banging around on the ceiling. It sounds like there are five other people up here with you. Are you exercising or something?"

"No, I'm not exercising. I'm just trying to hurry up and get dressed so I can make breakfast before Monica, Uncle Kim, and Kyndall leave."

"Well you better hurry up. Their bags are packed and they just loaded them in the car."

"But it's not even nine o' clock. They're not supposed to leave until ten."

"Don't get upset Gianina. They will probably just pick up something to eat on the road."

"But I bought a box of beignet mix and some chicory coffee from Café Du Monde while I was in New Orleans. I was going to make breakfast for everyone this morning. Tell them I'll be ready in a few minutes."

"Alright I'll tell them, but trust me, they are ready to go." Mom leaves the room and heads downstairs. Thank God she didn't notice my leg. I snatch my shirt down over my head and lean forward on the edge of the bed to fit my feet through the leg holes of my panties. Slowly I guide them up both legs to my mid-thigh, lie back on my towel, bear down on my forearms, and raise my pelvis to pull them into their correct position. Now the pants, this is

going to take some creativity on my part. Maybe if I treat them like pantyhose, I can get them on. I lean forward placing my jeans on the floor and begin rolling each pant leg up to the waist. Slipping each foot through, I then slide them to their stopping point which is my knee. Tightly grasping the waist of the jeans, I lie back on my towel again, repeating the process of bearing down on my forearms and lifting my pelvis as I wiggle my way in. Out of breath, I sit up, roll my pant legs down to my ankles, and put on my socks. "Yes!" Now I just have to make it downstairs. I push off the bed with both hands onto my good leg and hop toward the door. A glimpse of myself in the dresser mirror reminds me to fix my tousled hair. I hop to the dresser to brace myself as I use my right hand to rake through my tresses. Resuming my hopping marathon, I head out of the bedroom door down the hallway and abruptly stop at the top of the stairs placing my left hand on the wall. I did not factor in the stairs. Think fast Gianina. How are you going to get down these steps without falling?

Mom comes around the corner at the bottom of the stairs. "What are you doing Sweetie Girl?"

"I'm coming downstairs."

"Well come on." I look away for a moment and then directly at her.

"I can't move my leg."

"What! What do you mean you can't move your leg? What's wrong with it?"

"I don't know. When I got up this morning it was limp." Her face went blank as if she had seen a ghost.

"You mean it was numb when I came upstairs to check on you and you didn't say anything?"

"I'm okay."

"Not if you can't move your leg you're not." She starts up the stairs. "Let me help you."

"No, I can do it."

"Gianina, you're going to fall."

"No, I'm not. If I was in High Point, you wouldn't be there to help me down the stairs."

"But I'm here now."

"It's okay, I got it." Frustrated with my stubbornness, Mom looks down and throws her hands up. I grab the left stair rail with both hands and steady myself before reaching for the right one and push down. Tightening my abdominals and pelvis, I lift my left leg and lower it down to the first step. My right leg dangles loosely and grazes the edge of the step on the way down.

"What's going on in here?" Monica takes her place beside Mom.

"Gianina can't move her leg."

"What the hell? Is it still asleep?"

"No" I reply. "It's just limp."

Monica folds her arms and leans back disapprovingly as she observes me systematically making my way down the stairs. "Well what do you think caused it?"

"I don't know. It was like this when I woke up." Finally arriving at the bottom of the stairs, I maintain my grip on the rails and take a breath. "Well, that was a workout! Who's hungry?" I quickly hop on one leg past Mom and Monica and into the kitchen to avoid further questions. "Morning Granny!"

She whips her head back in disbelief. "What's wrong with you?"

"Oh my leg went limp." I reply casually.

"It went limp? It won't move at all?"

"No ma'am, but it's okay. It's not a big deal." I quickly change the subject to redirect her focus. "Remember when I called you and told you about those delicious beignets and coffee I had in New Orleans?"

"I remember."

“Well, I brought a couple of boxes of the mix and two coffee cans back. That’s what’s in the bag by the stove. I’m going to make them for breakfast. You’re going to love them.”

Determined I hop across the kitchen under watchful eyes to wash my hands. I dry my hands and push down on the countertop with my left hand as I reach with my right to grab a mixing bowl. “Alright I need some water, a wooden spoon, a rolling pin, cutting board to roll them out on, oh and a little flour to keep it from sticking. Beignets! Beignets! Beignets!” My bubbly approach to skirting the issue is met with silence. I turn my head and realize Mom, Monica, and Granny are collectively staring at me. “Right” I say as I slowly turn back to face the mixing bowl and begin cooking.

Uncle Kim walks in through the side door with Kyndall close by. “What’s going on Scrilla?”

“Nothing much Uncle Kim. How are you this morning?”

“I am fantastic, baby!” He says as he peers over the top of his glasses and points in my direction.

“Good morning, Kyndall.”

“Good morning, Roastie.”

Uncle Kim turns to Monica. “Alright the truck is warmed up. Let’s hit it. We have a long drive ahead of us.”

“Hit it?” I reply. “As in leave right now? Uncle Kim it’s 8:50. You said you were leaving at 10:00 today.”

“I know, but we’re packed and ready to go.” They were always doing this, rushing for no good reason at all. What difference is it going to make if they leave now or an hour from now? It’s Saturday.

“But I brought back all this stuff from New Orleans to cook for you. It won’t take long. All I have to do is add water. Please just give me a few minutes.”

“Baby we have to hit the road. I appreciate what you’re doing, but we need to get out of here.”

Completely deflated, I hop across the kitchen and reach down into the lower cabinet to pull out a cast iron skillet. “Fine, I’ll just make enough for Mom, Granny, and I.” I mutter while in motion.

“What are you doing?”

Monica sighs before chiming in “Her leg went limp on her this morning.”

“Went limp? What do you mean it went limp?” My God, how many times am I going to have this conversation today?

“Yesterday it was numb and today I can’t move or feel it at all. Look, it’s okay. I’m okay. Just come give me hug and have a safe trip.” His furled brow affirms his disdain. Not just for my condition, but for his schedule. Uncle Kim is a planner. The only thing that makes him happier than keeping his plans is carrying them out earlier than expected.

Monica heads toward the kitchen table and takes a seat. “We can wait a few minutes Kim. Just turn the truck off. We have time.” Uncle Kim continues to stare at me, brow furled. Finally he breaks his gaze and walks out to turn the engine off. Kyndall looks on with a confused expression while I frantically try to continue as if nothing is wrong.

“What can Granny do to help?” I look to my right and see Granny lovingly watching me struggle to complete what would normally be an effortless task for me.

“Oh, you don’t have to help Granny. This is my gift to you. You need to just sit back and relax while I do the cooking.”

“I want to help.” Her tone of voice turned a would-be plea into an edict.

“Yes ma’am. Would you mind making the coffee? It’s a lot different than regular coffee. You mix it half cream and half coffee so . . .”

“I can read the instructions.” She says sternly.

“Yes ma’am.”

Mom steps in and renders her services as well. “And what can I do to help you with the beignets, Miss Tootie?”

“You too huh? Would you mind handing me the oil, the flour bowl, and measuring the water? I just need seven ounces of water.”

“No problem.”

Uncle Kim walks back in from outside and takes a seat at the table. I pour the oil into the preheated pan and begin stirring the beignet mix in the glass mixing bowl until it forms a round sticky ball. I generously dust the cutting board, and rolling pin with flour, and finally coat both of my hands in flour. The intense aroma of the chicory coffee intertwines with the light scent of the warm cream heating on the stove and fills the kitchen.

“Wow! Now that smells good!” Mom says as she crosses into the breakfast nook.

Granny seconds the notion. “It sure does!”

I ferociously attack the dough with the rolling pin, using the weight of my body which would normally rest on my limp leg to spread it out to just the right thickness. Using the floured rim of a glass, I cut the dough into perfect round pieces. Carefully, I drop each piece into the hot oil and watch it bubble. “Oh wait, I forgot the powdered sugar.”

“Top cabinet to your right” Granny says. I lean against the countertop and stretch my right arm to reach and pull down the bag of sugar. I take the tablespoon next to the stove and lightly ladle the bubbling oil over each beignet to ensure doneness.

“The first batch is almost done” I announce. Using my left hand, I roll the cut dough into a ball, and quickly begin rolling it flat again. Monica and Uncle Kim silently watch as I cut the dough a second time. I sneak a peek at the clock on the microwave it is only 9:15. I’m still on time. I spoon the first batch out of the hot pan and onto a plate lined with napkins to drain the oil. The second batch goes in and I dust the first batch with powdered sugar. “Okay, everyone

can make their own coffee. Just remember to use half coffee and half cream or it will be too strong.”

Mom stands up and walks toward me. “We’ll fix our own plates. Come sit down. You did enough this morning.”

“I will as soon as I pull this second batch out of the oil I’ll . . .”

“Sit your aspirin tablet down.”

“Ha, ha, okay, okay I’ll sit down.” I hop over to the table as Kyndall watches intently. My mom rescues the second batch of beignets from the hot oil and starts tearing napkins off the roll.

“Tootie, how many do you want?”

“Three please.”

“Alright, three beignets coming up with a cup of coffee.” I watch as everyone lines up to fix their plates and pour their coffee. Monica brought Granny’s plate. We all waited for Mom to sit the second batch in the center of the table before we bowed our heads and said grace—lead by Granny of course.

“Heavenly father, we thank you for allowing us to gather as a family. We ask that you bless this food, allow it nourish our bodies, and please don’t let it make us sick or fat.” Snickers exchange across the table. We always believed God has a sense of humor. “Amen.”

“Amen.” We all say in unison.

Granny takes the first bite. “Mmm, mmm, mmm melt in your mouth.”

“Thanks Granny!”

“Wow, their like donuts.” Monica says as she turns it over in her hands to inspect it after her first bite.

“Mom what do you think?” I say as I place my coffee cup down on the table.

"I'll tell you in a minute. I'm still enjoying this coffee. Next time I will use a little less cream. You know I like my coffee strong." I watch as she bites into a beignet. She closes her eyes while she chews. This is a very good sign. Mom only closes her eyes when she really enjoys something. "Girl, these are the bomb."

"Thanks Mom!" I won over three out of five. All I need are two more stamps of approval. Kyndall was patiently waiting for his to cool. And Uncle Kim is a picky eater. He likes what he likes and nothing more.

"Baby these are delicious."

"What? You really like them?"

"Oh yeah, and the coffee is on point."

"Thank you Uncle Kim."

"Can I have one now please?" Eager to partake Kyndall turns to Monica awaiting her permission.

"Yes bump, it should be cool enough now." He smiles, grabs a beignet with both hands and takes a bite.

"Mmm Roastie these are good!"

"I'm so glad you like them Kyndall! That just makes my day." There is a brief moment of silence while we eat. For a brief moment I forget all about my leg and indulge.

Mom breaks the peaceful silence. "I know you don't want to hear this Gianina, but it has to be said. I understand you think this will pass and everything will be okay, but you need to go to the doctor."

"Yes you do!" Everyone bellows in unison.

"All of you are concerned about me and I get it, but for starters I am over 60 miles away from doctor. In addition to the distance, it's Saturday. The doctor's office is not open on Saturday, and I'm not going to emergency. It's not that serious."

"I know you think it's not that serious Gianina, but this could be a symptom of a bigger issue. You don't know what this is or why it's happening or do you?" Everyone turns to face me anticipating my answer. At a loss for words, I sit quietly and stare back.

Granny turns to me "Little girl, did you hear Monica?" Oh no, that's two Gianinas and one little girl. When the nicknames stop I know they mean business.

Should I tell them about the seizure I had in my sleep before I went to New Orleans? It will probably just raise more cause for concern. Besides, how can I tell them anything if I don't know anything yet? "I heard her Granny and no I don't know what's going on."

"Do you think someone put a root on you while you were in New Orleans?"

"A root Granny, really?" I lean my head back and laugh while Granny remains stone faced. She is a very superstitious woman. To this day she believes a woman who was jealous of Big Mama (Granny's mom) cast a spell on her to make her hair fall out. Big Mama had long, flowing hair. A woman in her neighborhood constantly begged to let her brush it. One day Big Mama gave in. Some of the locals claimed she took hair out of the brush, performed some sort of ceremony and buried it in a graveyard. Shortly after, all of Big Mama's beautiful hair began shedding until she was left with barely two inches of length. This made Granny very diligent about proper hair disposal. To this day none of us are allowed to throw shedding hair in the trash can. Whenever we clean our combs and brushes it is mandatory for us to remove every strand of hair and flush it down the toilet.

"Did you flush your hair down the toilet? A maid could have come in and taken it."

"Yes ma'am I always flush my hair."

"I'm just checking."

"Trust me this will all be over soon. I'm okay."

Mom leans in and locks eyes with me. “All I know is if you can’t move your leg before tomorrow, you will not be driving back to High Point or going to work. Are we clear?” The tone and depth of her voice ooze authority.

“Yes ma’am.” Monica, Uncle Kim, and Kyndall hug and kiss us all goodbye. We all wave and blow kisses as they slowly back out of the driveway.

Mom turns to me and goes right back into business mode. “Alright Gianina, I’m going to start a fire. You’re going to go downstairs, prop that leg up on the ottoman, and relax.”

“And Granny is going to heat some towels in the dryer and put them on your leg.”

“Granny you don’t have to do this. You need to rest more than I do. If anything I should be heating up towels for you.”

“Little girl, I’m going upstairs to get some towels out of the linen closet and when I get downstairs you better be sitting down with that leg elevated. Do you hear me?”

“Yes ma’am.” I go downstairs and elevate my leg as instructed. After nodding off maybe twice and roughly four applications hot towels I slowly regain feeling and movement in my leg.

Responses of others (layer two). There were several occasions when I was overwhelmed by the stress of my symptoms. I purposely avoided informing my family of what was happening to me, because I felt Granny’s health issues were more severe and consequently took precedence over mine. The responses of both my family and my best friend as they witnessed my symptoms were an assortment of shock, genuine concern, uncertainty, disbelief, humor, and positivity. Conversely their (family and best friend) responses to my concerted effort to keep my symptoms private ranged from anger to hurt.

Saida attempted to mask her initial shock with humor by wisecracking about my appearance and self-consciousness about it. She followed up by exhibiting genuine concern

and ultimately offered positive reinforcement by calling my attention to the freedom in being in an environment where no one knew me, and how I was a valued asset to the television station.

My family members did not react collectively. I noticed a polarization between my Mom and Granny's reactions versus my Aunt Monica and Uncle Kimothy's reactions after the initial shock of witnessing my symptoms wore off. Although there was a general consensus of concern on both sides my Aunt Monica and Uncle Kimothy seemed to remain more in a state of uncertainty of how to help me and disbelief of what they were seeing. Mom and Granny, on the other hand, were quick to offer physical relief for my symptoms by elevating my leg and keeping it warm. My aversion to divulging the severity of my symptoms was collectively met with anger and hurt. Perhaps my family interpreted my attempt to protect them from more stress as my not trusting them to support me in my time of need.

Comparing my experience to the literature (layer three). My own denial of the severity of my symptoms was not unique to my situation. In fact, sufferers of chronic illnesses often attempt to explain early symptoms away out of concern for how it will affect those around them (Bury, 1982). Bury provides an example of this type of denial exhibited by participants with rheumatoid arthritis in his study by reporting:

No one in the study group recognised the first signs as indicating rheumatoid arthritis. In the first instance impairments (a swollen finger, early morning stiffness) were merely regarded as a nuisance, and were seen as a result, for example, of exertion in decorating at home. They were not, even in retrospect, seen as a warning. The only kind of explanation called for was a "proximal" kind. That is, common sense partially furnished the answer, particularly in terms of the immediate external environment But the externalising and localising of the sources of discomfort became more problematic as the illness unfolded. (1982, p. 170)

Similarities between the shifting of the dynamics of my relationships with my family and friend, and those who participated in Bury's (1982) study are apparent. According to Bury, chronic illness "brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support" (p. 169). Just as I attempted to hide my symptoms and fear, so did some of the

participants in the study who were able to “hide their symptoms or disguise their effects for long periods” (Bury, 1982, p. 170).

It should be noted, my symptoms were heightened after I was faced with the threats of losing my job and my family finding out about my symptoms. Moreover, the day-to-day stress of never having privacy and always being judged by viewers may have been major factors. Stress is a known trigger for mastocytosis symptoms (Theoharides, 2002; Theoharides et al., 2009). In fact, “the mast cell has been considered an immune gate to the brain, as well as a sensor of environmental and emotional stress” (Theoharides, 2002, p. 106). Patients have reported “when anxiety rises, they know there will be a flare-up in symptoms, which may include flushing of the skin, intestinal upset, palpitations, migraines, and changes in mood and cognitive function” (Theoharides, 2002, p. 103).

Much of the delicious cuisine I enjoyed while in New Orleans consisted of high histamine foods such as tomatoes, most citrus fruits in general, some shellfish, gluten, wheat, red wine, and beer (Böhn, Störsrud, Törnblom, Bengtsson, & Simrén, 2013; Fukunaga et al., 2012). Angioedema, a form of swelling which “affects deeper layers in your skin, often around your eyes and lips” may explain my distorted facial features at Mardi Gras (Mayo Clinic, 2015). Angioedema results from an overabundance of histamine which may be triggered by food or even emotional stress (Mayo Clinic, 2015).

Although rare, in some instances mastocytosis may “affect the central nervous system” (Kanekura et al., 2001, p. 451). Two case studies cover mastocytosis patients who experienced involuntary seizure-like movements known as chorea (Iriarte, Mateu, Cruz, & Escudero, 1988; Kanekura et al., 2001). According to The International Parkinson and Movement Disorder Society (2015) “chorea is an abnormal involuntary movement” which is “brief, abrupt, irregular, unpredictable,” and “non-stereotyped.” In another case study conducted by Afrin (2013), four out of the five mastocytosis patients in the study reported “diffusely migratory tingling/numbness

paresthesias” (p. 2). These case studies may provide some insight regarding the numbness and tingling, as well as the seizure like movements I experienced in bed prior to my vacation.

Chapter 5

Floating from Physician to Physician

The purpose of this study was to investigate mastocytosis from the perspective of an individual diagnosed with the disease. In an effort to relay this perspective, this chapter disclosed the series of events that transpired while I sought a diagnosis. This includes multiple misdiagnoses, superfluous prescription medication, complete dismissal of symptoms by some physicians, and some physicians who were unable to correctly diagnose me yet did their best to quell my symptoms.

The layered accounts provided in this chapter describe the most prominent events that occurred while actively seeking medical attention over the course of roughly four years and the reactions from several physicians, my family, friends, and coworkers. Each account divulged pertinent information comparable to the literature regarding heightened symptoms, and complications. Just as in Chapter 4, the subsequent accounts in this chapter were written in accordance with autoethnographic guidelines meaning they are exceedingly detailed to exhibit multiple layers of consciousness and tie personal experiences to cultural ones in a manner that is engaging and evocative by stimulating the memories of the readers (Ellis & Bochner, 2000).

This chapter entailed my journey as I floated from physician to physician seeking a diagnosis and treatment for my symptoms. During this period I lived in High Point, North Carolina and later moved to Charlotte, North Carolina. The remainder of this chapter along with Chapter 6 will flow identically to Chapter 4 which mirrors Ronai's (1995) layered account. I will begin by recounting my experience (layer one), relaying the responses of others (layer two), and

concluding with research comparable to my accounts (layer three). Again, asterisks were utilized denote time lapses

The Numbness Returns (Layer One Part I)

It is Wednesday afternoon and I am standing at the entrance to my job. I always have to take deep breathes and collect myself before I enter the office. I am only Gianina Hayes when I go to bed at night and wake up in the morning, but during the day I transform into my alter egos. When I am on the news, I am Nina Hayes. On the radio I am simply Nina. And here, I am someone entirely different—a robotic yet friendly alter ego known as Lisa Coleman. I reach for the door handle. Wait, just one more deep breath. “Jesus help me.” Primed for the pandemonium, I open the door and head straight for the bathroom. I stand in front of the mirror, pull my makeup remover wipes from my duffel bag and commence to rubbing away two layers of expensive television foundation from my stifled skin. As each wipe lands in the trash I calculate how much money I am disposing of. Hmm, two wipes saturated in makeup front and back. I’m guessing \$10 worth of makeup is staring back at me from the trash.

Next, I carefully remove several bobby pins used to secure my wig. This wig is another expensive necessity essential for my protection. Between the disturbing letters, creepy phone calls, flowers, and the occasional male viewer I catch tailing me during my drive home, the wig and makeup serve as a disguise. Sometimes I use one of the company cars to further confuse my suiters. Most of the time my disguise works perfectly. I can usually shop and pump gas unnoticed without it. Although my makeup is purposely three shades darker than my natural hue, and my wig is roughly four inches longer than my real hair, there is always someone who is not so easily fooled. Sometimes they are polite and sometimes not. The unsolicited comments range from “I watch you every morning” to “wow, you’re much smaller in person!” When did “you’re much smaller in person” become a compliment? Were you sitting at home calling me a fat pig until you met me today? Those two comments usually come from women. The men, on

the other hand, are often inappropriate in regards to their timing and invasion of my personal space. I can recall several times when I was on a dates and male viewers spoke to me as if my dates were not even present. Once a man got so close in face I had to lean back and put my hand in between us to keep our lips from touching. It seems next to impossible to find a man who can handle the unwarranted attention I attract and not blame me for it. As a result, I have been single for over a year and a half now. Maybe I need to start dating guys outside of my viewing area.

I pull the two pins holding my own hair in place out and shake my head from side to side allowing it to cascade over my shoulders. Layer by layer I begin removing the rest of my armor. Meticulously I fold the stockings, skirt, camisole, button down shirt, blazer, and place them in my duffle bag on top of my high heels. Now the most dreaded part, I pull my right bra strap until the cup gives way and close my eyes tightly as I gently peel away the two non-latex band aids forming a cross over my nipple. My raw, red, sticky, skin protests my efforts until I reach the cloth-lined center. Suppressing your nipples is a little known trick of the trade for women in the industry. To protect the expensive equipment at news stations, thermostats are kept at unbearable temperatures to prevent overheating, which in turn makes all of us female workers accountable for our body's natural response. Appearing on camera with erect nipples can result in suspension or even termination if it happens too many times. I guess no one was intelligent enough to suggest installing a separate thermostat for the equipment room or the higher ups would rather I spend money on band aids then spending the necessary money to make female employees more comfortable. After removing the second set of band aids from my left breast, I dab away the tiny specs of blood and apply witch hazel followed by Vaseline. The initial sting succumbs to a soothing finish. I reach back into my duffle bag and pull out my jeans, t-shirt, and flats. Thank God my afternoon shift is casual.

Fully dressed with little time left, I race down the hall to the office, flop down in my seat, and plug in my head phones. "What's up everyone?"

Asia answers back first "Hi Nina Weena."

"What's up?" Jake and Mara answer back in unison.

"Have you heard about any accidents on the scanner yet?"

Asia calmly replies without looking up "Just a 10, 50 PI [Police code for accident with Personal Injury] on the corner of Lee and Elm street, but other than that nothing." At first I was overwhelmed by the foreign lingo, but over the course of a few weeks I learned to love it. Being successful at this job requires a sharp memory and a keen ear to distinguish the police codes as they escape through the static of the scanners. I quickly write down the accident and begin organizing my spots. Nearly all reports are followed by a 10 second spot which is a one paragraph commercial provided by a sponsor who pays the company to have us read them at certain times of day on the station of their choice. Forgetting to read a spot or reading the wrong spot for the wrong station is blasphemy. Sometimes I spend a major part of my day trying to rearrange the schedule of the spots to make up for one I missed by reading it at a later time and logging my mistake. Oh, and did I fail to mention the log? As I read each spot, I am required to mark it off on a log sheet as a record for the sales department.

As the voices on the scanners fight their way through the faulty reception, I simultaneously listen to two separate receivers. One is connected to my coworker Percy who views accidents from an airplane and the other to Sheldon who views accidents on the ground from a company car. As if this were not enough, I keep my ears open for a man named Chuck who sends word of accidents in outlying areas through a Nextel cell phone with a walkie talkie feature.

The clock to my right seems to tick faster than its normal pace as the top of the hour approaches for my first report. I put my headphones on, flip the switch on the Integrated

Service Digital Network (ISDN) line, pot [increase the volume] my microphone up, and ask the disc jock if he is ready for his first report. On cue I accurately describe the one accident in progress along with alternate routes and updates on the traffic flow followed by a 10 second spot for a local car detailing shop. The pace of this rhythmic pattern quickens as the day progresses. More and more accidents begin pouring in through the scanners, ISDN lines, and cell phones leaving me little to no time in between reports. The reports become more difficult to deliver as I attempt to drown out my colleagues whose voices trail off in the background as I simultaneously deliver my report. Time, the most important thing is to keep time. Each of the five radio stations has a designated time for me to provide their traffic reports. Sometimes if they are not ready at the specified time, I have to disconnect and move on to the next station. This puts me back into the conundrum of making up for spots I missed in my log. I remember when I brought Mom in to show her what I did for a living. She covered her ears with her hands, shook her head, and walked outside muttering under her breath “I would go damn crazy working here.”

The incessant cycle of madness that led the day has now come to an abrupt halt. The scanners have stopped spewing their blaring noise through the speakers and the Nextel ceases to chirp. It is finally quiet. Asia and Mara are gone for the day leaving only Jake and I behind to shut down. I am ready to go home, but I need a few minutes to collect myself before I make the drive. I unplug my headset and rock back and forth in my chair staring at the foam padded walls of my cubicle. An unfamiliar rush surges through my body and within moments I am slumping in my seat. “What the hell?”

Jake pushes his chair back and peeks around his cubicle. “Shit! Nina, are you alright?”

Dazed from the shock of what is happening I look down at my flaccid arm dangling by my side. “I don’t know! I can’t feel my left side!” Breathe Gianina, just breathe. I try my best to

foster calming thoughts recalling my rapid recovery from my New Orleans trip, but this is different. This time it's my left side. What if I really am having a stroke?

"Nina, do you think you're having a stroke?"

"I don't know. No, no I can't be. There's no way I'm having a stroke."

"Smile for me."

Fear hinders my usually effortless smile from immediately forming.

"I'm calling 911, you're having a stroke."

"I'm not having a stroke, Jake! I'm just scared! Please don't call 911. Just, just give me a minute! Give me a minute, Jake." The thought of going to a hospital sends my heart pounding. I can't go to a hospital. They never listen when I tell them I am allergic to latex. After the fiasco I had earlier this year, I am not sure I will ever be able to trust a doctor or nurse when latex is involved. During an annual eye exam, one of nurses touched my bare eyes with latex. My eyes started burning and my throat started rubbing together and she froze. She froze! I had to go out in the hallway and flag down another nurse to help me. Never again will I put myself in that position. Since that unforgettable ordeal I have searched high and low for a latex allergy bracelet. No one seems to carry them. What is the medical supply industry waiting for, for one of us to die?

I do not have time to explain my aversion to going to emergency to Jake. He is just going to have to accept my resistance and move on. I place my right arm on my desk and slowly push myself to a standing position. Last time it was my leg. A limp arm should be a piece of cake.

"Nina what are you doing? Sit down!"

"I'm going to Urgent Care."

"How are you going to get there?"

"I'm going to drive."

“Drive, are you out of your mind? How are you going to drive if you can’t move your left side.”

“Watch me.” I hoist my purse onto my right shoulder and walk toward the door. I pause upon realizing I left my duffle bag. Now I have to ask him for help. Reluctantly, I open myself to his willingness to help. “Jake.”

“Yes” he sings expectantly.

I chuckle before responding. “Ha ha! Would you please carry my duffle bag for me?”

Jake lets out a deep breath. “I thought you were going to say call 911. I can’t believe you’re still doing this. This is crazy. You’re crazy!”

“Pleeeeeease, Jake I don’t have much time. They close soon.” Jake grabs my bag and holds both the door to the office and the door to main entrance open for me as I clumsily hustle through.

“If you pop the trunk, I’ll put your bag in for you.”

“Right, my keys!” I drop my purse on the hood of my car and use my right hand to unzip and search. After what seems like endless tussling, I locate my keys in the side pocket of my purse. “Sorry I don’t have a fob.” I toss the keys to Jake. He catches them, opens the trunk and drops my duffle bag in. I hold up my right hand waiting for him to toss them back.

He gives me the side eye, as he walks toward me. He shakes his head as he puts the key in the lock and opens the door. “Get in.” I hold on to the roof of the car with my right arm and swing my body into the seat. Jake reaches across me and puts the key in the ignition, while I position myself semi-comfortably in my seat. “How are you going to get out of your car by yourself when you get there?”

“That’s for me to figure out, and Jake . . .”

“Yeah.”

“Thank you.” He shoots a half grin and nods before looking down at the curb. In a frenzy I tussle with my seatbelt, stretching and retracting it multiple times with my good arm before securing it in place. I adjust my mirrors to accommodate this unusual contortion and start the engine. There is no turning back now.

After what seemed like a lifetime of driving, I arrive at Urgent Care. The parking lot is mostly bare, leaving the perfect parking space near the front entrance. I release the seatbelt and start working my way out of the car. Pushing down against the seat, I twist my body until I am facing the car door and my left side is leaning against the seat. Using the index and middle finger of my right hand I pull the door handle and kick the door open with my right leg. I drop both legs over the door seal, and reach out and up to grab the roof of my car to help lift myself to standing. A mild, tingling sensation tickles my left leg as I firmly plant my feet. I shake my leg to see if it has sided with my left arm in the case against me. It responds more like I gave it a suggestion as opposed to a command. Hopefully I get inside before everything goes limp. I push the lock button on the door and slam it shut. Limping frantically with my arm dangling aimlessly, I pass the high curb and opt to walk up the ramp. I take a few breaths and lean against the brick wall to compose myself before pulling the door handle. How long will it take them to find out what’s going on with me? What will they find? I limp through the empty lobby toward the sign in sheet and grab the pen. The sign-in sheet continuously slides away from me as I attempt to fill it out.

The clerk at the front desk acknowledges me without looking up. “After you sign in, please hand me your insurance card.”

I could feel my cheeks turning red from the embarrassment of fiddling with the pen and paper. “I’m sorry to bother you, but I can’t move my left arm. Would you mind holding the sign-in sheet still while I write my name?”

She pauses and locks eyes with me. Her facial expression relays both concern and disapproval. "Sure, no problem."

The judgement in her eyes is apparent. I know exactly what she is thinking. Why didn't I go to the emergency room? Who in their right mind goes to Urgent Care with stroke symptoms? What she does not understand is I came specifically for Dr. Adams. He has been my physician since my freshman year in undergrad. In fact, it was Dr. Adams who discovered my latex allergy. If there is anyone I trust with my safety, it's him. I look at the clock and write down the time on sign in sheet. It is only 13 minutes until closing. Leaning forward against the smooth wood, I hoist my purse on top of the front desk to pull out my license and insurance card.

The woman at the front desk stares at me as I fiddle with my wallet using only my right hand. "Here, let me help you."

"Thank you." I take a deep breath and talk her through the intricacies of my wallet. "My ID is in the front under the plastic overlay and my insurance card is three slots back behind my AAA card."

"Good thing you're organized." She smiles and takes both cards.

As she takes her seat, another female staff member walks over. "Hi, what's going on here?"

"Uh . . ." The front desk clerk pauses to look at my ID. "Miss Geee-aww-nee Hayes can't feel her left side."

"Oh you poor thing! You think maybe you should have gone to emergency?"

"With my latex allergy, I'm leery about putting myself in other people's hands. Dr. Adams knows about my allergy and always keeps latex free gloves handy. Plus, I really hate having to explain myself to strangers when I don't feel well."

"You should get a medical ID bracelet. That way you don't have to explain yourself."

“Well, maybe medicine is not that progressive yet. I’ve been everywhere and I mean everywhere searching for a latex allergy bracelet. The only ones available are penicillin, diabetes, asthma, Alzheimer’s, etc. If latex allergy ID bracelets exist, they’re a well-kept secret.”

“Really, imagine that.” The sarcasm in her voice is apparent. “Well, you just go ahead and have a seat. We’ll call you back shortly.”

The front desk clerk places my ID and insurance card back into my wallet for me. “That will be 30 dollars Miss Hayes. Would you like to pay with cash, check or card?”

“Card please. It’s in the first slot behind my license.”

“I see it.” She swipes my card and slides it back into its rightful crevice. “Just sign here please.” She holds the receipt steady as I scribble my name across the dotted line.

“Thank you.”

She waves her palm. “Oh, you’re welcome.” I limp away and lean against the wall allowing my numb arm to dangle freely. The sarcastic woman—presuming I am out of listening range—faintly whispers to the clerk. “Isn’t that the traffic girl from Channel 12?”

“Yeah.”

“I thought so. She’s a lot smaller in person.” She flashes a counterfeit smile at me and disappears behind the bookshelves.

The clerk stands and leans over the front desk. “Oh, you can have a seat. He’s with a patient now. It may be a few minutes.”

“Thanks, but I would rather stand. My leg is starting to feel a little numb too. If I sit, you might have to come around that desk and help me get back up.”

“Ha, ha! Well, if you do decide to sit, I’m just a holler away.”

“I’ll keep that in mind.” It’s rather ironic how everyone thinks I should have been rushed to emergency, yet there is no rush to examine me. If this is as urgent as they suggest, perhaps a nurse should check my vitals while I wait.

I guess my tunnel vision from the front door to the front desk got the best of me. I did not even notice of the gentleman sitting in the corner of the room, staring at me intently. Dear God, not today please. His dirty, red ball cap is tilted back just far enough to showcase his unkempt eyebrows and rugged features. He has not even blinked since I noticed him. Either he is intrigued by my condition, he knows who I am, or both. Please let it be the former. I am not sure what is worse, the fact he is staring or the silence accompanying his fixed gaze. By now a regular viewer would have spoken to me or maybe even posed some ridiculous question about the weather. I will never understand why people ask me about the weather as if knowing alternate driving routes equips me with some sort of meteorological insight. When I politely remind them I report traffic and not weather the usual response is “I know.” I know, seriously? It is as if some powerful urge to say something no matter how irrelevant outweighs common sense. More importantly, what is the big deal? I report traffic! I am not an actress or a singer. I am a regular, run of the mill traffic reporter. Now this guy, he’s a special case. He slouches in his chair sinking deeper into his unapologetic gaze. Utterly creeped out, I turn my gaze from him and direct it toward the paintings—or shall I say printings—on the wall. Maybe art is placed on the walls of clinics for this very reason. It gives patients something to focus on until their names are called.

A brunette woman walks through the door from the rear wearing a short, pink skirt and a black halter top. I hope he is waiting for her so he can leave and stop staring at me. At least her presence should move him to be more respectful. As she walks over to the front desk, I spy him out of the corner of my eye. He is still looking! The nerve of this guy is uncanny. If this happened two years ago, the old me would have glared back at him until his skin melted, but self-defense—even when it is not physical—is career suicide in this business. I will be known as the bitchy traffic reporter who does not care about her viewers. So I lean against the wall and silently endure his ocular assault.

The woman shoves a prescription order in her purse and turns toward him without even looking up. "Come on Daryl. I'm hungry let's go get something to eat." I frown and set my eyes on the door to circumvent his unbroken, abashed gaze. Will someone please hurry up and call my name. She looks up and takes note of his inappropriate ogling. She then looks me up and down as if I am somehow responsible. "Daryl, did you hear me? I said let's go!"

"Coming." He quickly snaps out of his gawking, stands, and switches his gaze to the floor as he walks toward her. No further words are exchanged just heated glances between the two of them as they both walk out the front door. I send a peace offering in the form of a smile to her. The last thing I need her to think is that I actually wanted that disrespectful, excuse for a man. Sadly, the damage has been done. She glares at me one last time before walking out.

Traces of their argument filters into the waiting room. "I swear I can't take you anywhere Daryl." The front desk clerk perks up, looking at me and then at the door.

"What? What are you talking about?"

"You know exactly what I'm talking about. Get your ass in the car!"

"Tsk, ts, ts." The clerk shakes her head and plops back down in her seat.

I sigh deeply and close my eyes. If I thought I could sleep through this, I would just go home. Finally the rear door opens and a nurse with a clipboard steps forward. "Gee-aww-nuh Hayes." I push away from the wall and walk toward her. Her neck snaps back as she takes note of my freakish hike. She does her best to look unfazed and changes the subject. "Uh, umm, did I say that right?"

"No, but it's close enough. It's a whole lot better than Guy-uh-nigh-nuh. That's probably my least favorite pronunciation."

She smirks and looks down at her clipboard as I cross the threshold into the hallway. "So how is it pronounced? I want to make sure I say it right"

“Juh-nee-nuh. It’s Italian. So, you kind of roll the G-I-A together and it makes a Juh sound.”

“Oh ok, interesting.” She nods repeatedly attempting to ease into the inevitable question. “So, what’s going on here today?”

“My upper left side went numb, and I’m starting to have a hard time feeling my left leg as well.” My words become breathy as I drag myself to the weighing scale. “Hey, if I hop on this thing is it going to break? I really can’t afford to pay for it if it does.”

Her head rocks back as she laughs silently. “A sense of humor at a time like this, we’re going to get along famously. Don’t worry we can skip your weight for today. I’ll just take your blood pressure. We’re going into the last exam room on the right okay?”

I pick up the pace eager to make it to the room and rest. “Okay.”

“So you just went numb out of nowhere?”

“Yes.”

“Were you doing something like a strenuous activity?”

“No, argh.” I grunt as I hoist myself onto the exam table. “I was just sitting at my desk at work.”

“I looked through your chart and I didn’t see a history of neuropathy or diabetes.” She pulls the blue blood pressure cuff from a wire basket screwed into the wall and lays it next to me on the table. She then lifts my lifeless arm and rolls up my sleeve. “My goodness your arm is cold. Can you move it at all?”

“No.”

“You poor thing, has this ever happened before?”

“Yes, a few weeks ago after my vacation, but it was my right leg then. I thought maybe I sat on the plane too long or something. Then, this happened.”

“Hmm, I’m going to take your blood pressure.” She wraps the blue cuff around my arm and pumps away. “One fifty-five over a hundred. That’s not good.”

“Oh my God! Do you think I’m having a stroke?”

“I’ve been listening to your speech and watching your facial expressions. I’m pretty certain you’re not having a stroke. Sometimes when the body is under duress blood pressure can become elevated.”

I look away at the wall. “What do you think it is?”

“I don’t know. I’ve never seen anything like this before. I’m going to step out. Dr. Adams will be with you shortly okay?”

“Yeah, okay.” I begin mulling over my every move in New Orleans. Did I consume too much sodium? They season their food heavily down there. Maybe it has something to do with the seizure I had in my sleep. What if I have epilepsy? No, it wasn’t a seizure. It could have been a nightmare or something. I did have night terrors as a child.

The door opens and in walks Dr. Adams smiling and pleasant as ever. “Hello Miss Hayes.”

“Hello Dr. Adams.” Even in a moment of such uncertainty, I cannot help but smile back at him. Dr. Adams is a very large man. He looks to be about six foot four and approximately 275 pounds. He wears dark, thick rimmed glasses which compliment his chestnut brown hue.

“So what do we have going on today? I hear you have some numbness on your left side.”

“Yes.”

“You can’t feel anything, anything at all?”

“I have some feeling in my left leg, but from the waist up to my neck nothing.”

“And your blood pressure, it’s really high today. You know we’ve talked about this, Miss Hayes. You might have to start taking something for your blood pressure.”

"I know, I just think if I work out more and adjust my diet everything will level out."

"Adjust your diet? You're already this big around." He smiles and holds up his pinky finger."

"Very funny, Dr. Adams."

He dries his hands with a paper towel after washing his hands at the sink. "All jokes aside Miss Hayes, I think there may be an issue with your circulation. I'm going to do a quick test and we will take it from there." He walks toward me, picks up my left arm, and works his way up from my wrist to my shoulder squeezing and releasing. "Can you raise your arm?"

"No."

"Just try for me. Give it your best shot."

My right side tenses as I struggle to move my left arm. My fingers on my left hand tremble slightly, but no significant movements. He pulls out his reflex hammer and taps away at my knee. "Well, there's some movement here. Not as much as I would like, but it's promising. Your upper left side, however, is a major concern for me. I'm going to have you take off your shirt and undergarment and put on a robe. You can keep your pants on. I'm just going to take a look at your spine."

"Wait, what do you think is happening."

"I wouldn't be too worried. My guess is it's just a pinched nerve. People get those every day."

He turns and walks out of the exam room closing the door behind him. I tug away at my shirt, desperately trying to pull my cold, limp arm through the sleeve. What was I thinking? Maybe I should have asked him to send Karen in to help me. Mom often criticized my independence. According to her I am self-sufficient to a fault. I can hear her now. "No person is an island Gianina. It's okay to ask for help." Maybe I should have asked this time.

“Knock, knock Miss Hayes.” Karen lightly taps on the metal door frame and pokes her head into the room. “Dr. Adams thought you could use some help undressing.”

My customary poker face eludes me as I look up with my arm stuck in the sleeve. “Yes, I could use a little help please.”

“You look like a kid who got caught with her hand in the cookie jar.” We both laugh while she guides my arm through the twisted fabric.

“Yeah, I guess I do. It’s kind of hard for me to admit I need help sometimes. I feel like I live alone and if I were home no one would be there to help me. So, it’s in my best interest to figure it out on my own.”

“But right now, someone is here to help you. There’s no shame in this Miss Hayes.”

“You know you can call me Nina right? Dr. Adams calls me Miss Hayes as a joke because he’s known me since I was a freshman in college and he watched me grow up in a manner of speaking.”

“Oh, well are you comfortable with Nina?”

“Quite.”

“Then I’ll call you Nina.” She pulls my right arm through the other sleeve and then slides my shirt over my head. “I’ll just hang this over the arm of the chair.” She lays the shirt down gently and stands in front of me with her head cocked to the side. “I’m pretty sure he’s going to want you to take this bra off too. Are you comfortable with that?”

“Yes, he told me to remove it. Come to think of it, it’s probably best for both of us. I’m afraid if you don’t help me take this thing off I may be forced to shower and sleep in it tonight.” We both snicker. “Don’t get me wrong, I do sleep in a bra every night but, not with underwire.”

“I hear you girl. Gravity doesn’t care if our eyes are closed.” Karen reaches both arms around me and looks over my shoulder as she unfastens each hook. “You need a man for this.”

“Then it will never get unfastened.” We break out into laughter again. Our humorous exchanges decelerate my racing thoughts. Maybe this is not as bad as I thought. Dr. Adams will locate the pinched nerve. I will wear a sling for a few days and voila. I use my right arm to cover my bare breasts as Karen folds my bra and places it on top of my shirt in the chair. My left breast feels frigid and doughy while the right is warm and pliable. This cannot be permanent. It just can’t be. What if I’m partially paralyzed? Wait, wait, God would never let something like this happen to me. On the other hand, bad things happen to good people all of the time. What if this is one of those times?

Karen pulls out the drawer under the exam table and grabs a robe. “I’ll put your left arm in first.” She gently lifts my left arm and funnels it through the sleeve of the robe. I help her along by guiding my right arm through the other sleeve and straightening the neckline. “Are you cold Miss, I mean Nina? It’s kind of hard to tell with this dividing line you have going down the center of your body here.”

“Honestly, I don’t even know if I’m coming or going right now. My right side feels warm to me so I’m going to go with it.”

“I just wanted to be sure because I saw a few goose bumps when I helped you into your robe. I thought you might be a little chilly.”

“I think I’m just scared.”

“I’m sure you are. I don’t know how you’re keeping a smile on your face right now. Dr. Adams probably would have had to bring in some smelling salt to revive me if my left side went numb.”

“Let’s just say I’m crying on the inside for now. I’ll probably let it out in my car or when I get home. I can’t pass out though because there’s no one there to revive me.”

Dr. Adams walks in with a folder in his hand as we laugh. “Whatever Karen said about me, it’s not true.” Our laughter intensifies. “Alright Miss Hayes let’s take a look at your spine

and see what's going on. Do you think you can move to the foot of the table with your back to me or do you need some help?"

"I'm probably going to rip this paper to shreds trying to scoot. So, I'm going to go with help."

"Karen, do you mind?"

"Not at all Dr. Adams." Karen grabs the stepstool from across the room and helps me down from the table. She then places the stepstool at the foot of table and walks me over to it. I step up with my right foot and sit down on the edge of the table with my back to Dr. Adams. "I should have thought of this when you first came in Nina."

"I thought about it Karen. I just wanted to do things the hard way. I'm stubborn and tenacious. Isn't that right, Dr. Adams?"

"I'm staying out of this one, Miss Hayes" he says smiling. "Do you think you can scoot all the way to the right? Sorry, I can't really get to your back from this angle." I use the stepstool to get down again, and Karen quickly moves the stool to the right. I step back up and sit on the edge of the exam table again. "That's perfect! I know you have a loss of sensation on your left side, but I want you to try your hardest to sit up straight."

I adjust my posture, stretching my head and neck, and lengthening my spine as if I were about to do Pilates. "Alright I'm ready."

"You're sitting up straight Miss Hayes?"

"Yes, but by your tone I'm guessing not straight enough."

"Well, it's just . . . well, your right side is higher than your left."

"Is that a bad thing?"

"It can happen with a pinched nerve, and I'm pretty sure that's what this is. Karen, you can stay right there in case I need you again, and Miss Hayes, I'm going to need your

participation as well. I'm going to poke on certain areas of your spine and I want you to tell me whether or not you feel it."

"Sounds easy enough, I'm ready when you are."

He steps behind me. "Ready?"

"Yep." A few seconds pass before I feel a light tap on my back." I felt that."

"Okay good."

"I felt that too. It felt a little strange though."

"How so?"

"It was a kind of tingly."

"Tingly? Hmm."

I wait a few seconds and then a few more. Maybe he is taking notes on the tingling sensation. "What's going on? Are we taking a break?" He does not answer. Impatiently I turn my head to face Karen. Her brow is furled as she looks at Dr. Adams. "Hello" I sing jokingly.

Dr. Adams walks around to face me. The look on his face is an intermingling of pity and disarray. In a broken voice he announces "I just poked your vertebrae in four places and you didn't even feel it."

I respond optimistically. "Well I felt it two out of the four times. That's not terrible, right?"

He leans in closer. "I poked you four times after the two initial pokes." He snuffles and adjusts his lab coat. "Would you excuse me for a moment?" Without another word he rushes out of the room.

"Wait, what does this mean? Karen, I don't understand. That's normal for a pinched nerve right?"

"I'm not sure Nina."

My voice begins to crack. "Then why is he so upset? He's a doctor. He sees stuff like this all the time." I know Dr. Adams has always viewed me like his own daughter, but I never thought he would react so strongly.

"I'm going to check with him and find out what's going on and I'll be back."

"Yeah, it's not like I'm going anywhere right?" Neither of us laughs. I look up at the ceiling. "Dear God, what have I done to offend you? Am I going to be permanently disfigured at the age of 24?" I repeat the Twenty-third Psalm in my head, nearly completing my second cycle before a knock at the door interrupts me.

"Miss Hayes, can I come in?" It was a man's voice, but not Dr. Adams'.

"Yes, come in." I turn my head, but he is not fully in my line of sight. His frame is slightly above average size, but I cannot yet make out his features. He walks around to face me.

"Hi, I'm Tito."

Stunned by his favorable features I delay my response as I take him in visually. He is about six feet tall, with olive skin, and short dark hair. His almond shaped, dark, eyes seem to gleam through the lenses of his rimless glasses and are kind yet penetrating. I feel as though he can see into me. His clean shaven skin is immaculate and glides over his high cheekbones complimented by his full pink lips. Why would God send someone this attractive to me on my worst day? Is this a cruel joke or maybe this is my answer to the Twenty-third Psalm? Maybe bad news from such a specimen will dull the shock. "Hi Tito, it's nice to meet you. Did Dr. Adams send you? What, uh, what did he say?"

"All I know is he told me to get some x-rays and you might need some help getting around. Can I help you down from there?"

"Karen left the stepstool. I think I can manage." Gees, what was I thinking? I should let him help me. This is bad for my image; what if he watches the show? One thing I never

learned how to do is drop my handkerchief, so to speak. I wobble, nervously trying to maintain my balance as I step down onto the stool.

He immediately steps in and cradles me. "Here, let me help you." Our eyes lock momentarily as he helps me regain my footing.

I abruptly avert my eyes to the floor breaking the spell. "Thank you. I'm sorry, I'm just not used to accepting help from people."

His eyes chase mine until they are cornered. "That's what I'm here for, to help you." I swallow hard and nod. "It's your left side right?"

"Right, I mean yes. Oh my God, let's not turn this into a rendition of *Who's on First*."

"I know right? I mean left." We look at each other and laugh as he walks around to my left side. "Wait, I have an idea. I'll be right back." I wonder what he will come back with a crutch, maybe a cane. A faint rumbling approaches from the hallway. It suddenly stops and Tito pushes the door open. "Need a ride?" He says smiling. Behind him is a long metal cart with high arched rails on two sides. "We use this to move heavy equipment. I figure I can get you to the x-ray room much faster if we wheel you in and given your aversion to help, I thought a wheelchair might be insulting."

"You thought right." I limp toward Tito keeping my eyes on the cart. Too much eye contact after such a thoughtful move could be a mistake. I grab the front rail with my right arm and hold steady as I lift my right leg.

"Go ahead, I got you." I look down to see him supporting my left arm.

"Are you sure? I can't feel a thing."

"Trust me." Blindly, I place my weight into what felt like a void as he lifts me onto the cart and places both of my hands on the front rail. "You're all set. Are you ready?"

"Yes." I answer smiling.

"Hold on." The low rumbling sound returns as Tito wheels me down the hallway. Along the way, I look into each examination room. They are all clean and empty, adequately prepped for Monday morning.

"It looks like I closed the place. Do you have the time Tito?"

"It's about a quarter pass seven."

"A quarter pass seven, you closed at six. I'm so sorry."

"For what, it's not like you asked for this to happen."

"I'm sure you had plans for the weekend."

"Not really. Besides, I'd rather be here doing what I love anyway." He stops the cart at the next to last door at the end of the hallway.

"You really enjoy helping people?"

"Yeah, even the ones who don't want my help like you." He winks before turning to open the door all the way and flipping on the light switch. "We're here" he beams.

"You know you're a hot mess right?"

"Only the best for my patients." He walks toward me with outstretched arms. "Come on."

"Are you kidding me? What happened to helping me down one leg at a time?"

"We don't have time for that. Your being here is interrupting my weekend plans remember?"

"Very funny." Reluctantly, I let go of the rail.

He wraps his arms around my waist and looks into my eyes. "It's okay, don't tense up. Just relax."

"I'm heavier than I look."

"I'm stronger than I look." Effortlessly, he picks me up and places my feet firmly on the floor. "See, you're light as a feather."

I smirk and look away as he guides me into the room. He positions me on a tape mark on the floor. "How long before the x-ray tech arrives?"

"I am the x-ray tech." Shocked I blink several times. "What, you thought I was a nurse?"

"Well yes, you're so attentive."

He swaggers and looks down. "It comes with the territory. So here's the procedure, I'm going to fit you with a vest. I'll warn you, it's kind of heavy. In between x-rays I'm going to have you face different directions so I can see your spine from different angles. I know you can't move well right now. So, I'll help you face the appropriate direction. And FYI, this will go much faster if you don't fight me."

"Ha, ha, ha." I reply sarcastically. Tito fits me with the vest and steps back to turn on the machine.

"Stay perfectly still. I'm going to step out and I'll come back in after it stops okay."

"Okay." Although my body is still, my mind is in perpetual motion. This is really happening. I am standing here being x-rayed without a clue as to what's wrong. Is this permanent or reoccurring? What if I still can't move Monday morning? What will I tell my boss? Is Jay genuinely attracted to me or is it just benevolence? I can feel myself breaking and desperately trying to hold it together.

Tito walks in and holds my arm as he turns me to face right. "Are you alright?"

"Yeah, just, just thinking."

He looks into my eyes for confirmation, but comes up empty. I have none to offer him, just empty words. "Okay, just two more after this one." He pushes a button and leaves the room again. The rushing thoughts begin swirling on cue. I'm much too young for this to happen to me. I've never been married and never had children. Come to think of it, I've never been pregnant before. I don't even know if I can have children. Is this how the rest of my life will be—no meaningful living—just an unproductive, codependent existence? Hot salty tears trickle

down my face landing in the corners of my mouth. I turn away to wipe my face as Tito walks back into the room. This time he is silent. He maneuvers me into the next position, pushes the button and leaves. Now certain this sappy display has destroyed any attraction he may have had to me, the trickling graduates to streaming. I hear the door creak as Tito walks back in. I turn to settle into my final position hoping to discourage him from assisting me, but he continues in my direction. I turn my head away in shame. I'm already facing the right direction why is he still coming? Tito places one hand on my shoulder and with the other pulls out a handful of folded tissue. Eager to end the humiliation, I reach for the tissue, but he pulls away. I face him, with squinted eyes perplexed by this uncivil gesture. He leans in inches from my face and dries my tears. I respond with more tears followed by sniffing and giggling. The once soft and fluffy tissues morphs into a soaked wad of mush, which he places back into the pocket of his scrubs. He removes the heavy vest from my shoulders and escorts me back to the cart. During the walk over he explains the next steps. "I'm going to take you back to the exam room where you can change clothes. During that time Dr. Adams and I will look over your x-rays and decide what needs to be done from there. It shouldn't take long."

"Got it." I nod in agreement. "Is Karen still here?"

"Yes, do you need her?" He picks me up by my waist and stands me on top of the cart.

"I'm pretty sure I'm going to need some help getting back into my shirt."

"Man, I didn't even think about that. I will be sure to send her in to help you. Since you brought it up, what are you going to do when you get home? I mean, do you have someone to help you?"

Fully aware of the double meaning of his question, I look down and smile. "I have no earthly idea, and, no, I don't have anyone to help me." He smiles and looks away to collect himself. The cart stops in front of my exam room and he lifts me off the cart by my waist once more before walking me into the room. "Thank you."

“There’s no need to thank me. I’ll send Karen in and I will be back shortly.” I respond with a smile and wait until he exits. As soon as the door closes, I tug at the left side of my robe until the sleeve slides down to my wrist. I then pull at the collar twisting from side to side, trying my best to make it slide off the other arm.

There is a knock at the door followed by Karen’s voice. “Need some help in there girl?”

“You know I do.”

She glides in and immediately starts helping me with my robe. “You just couldn’t wait could you?”

“I thought I would at least get things started. You need to go home and so do I. I am tired.” I shield both of my breasts with my right arm while she throws the robe in the hamper and unfolds my shirt

“I just want to make sure. We decided against putting the bra back on in case you can’t take it off when you get home right?”

“Right.” We return to our usual ritual of tugging, pulling, and maneuvering until the shirt is on both arms and around my neck. A knock at the door interrupts our progress.

“Nina are you decent?”

“Just a minute Tito, I’m almost done with her.” Two more harsh tugs and a twist settle the shirt into its correct place.

“Thank you Karen, I could not have gotten through this day without you.” She leans in and hugs me.

“It was my pleasure. I sure hope you feel better.”

“Me too.”

“Take care Nina. Alright Tito, you can come in now!”

Tito timidly creeps in with a manila folder hiding his face. “You sure you’re decent?”

My response is chopped by laughter. “Yes, I am. So what’s in the folder?”

"The results of your x-rays."

"Already, did you locate the pinched nerve?"

"Dr. Adams and I discussed the results. He will explain everything to you. I'll walk you to his office."

I have never been called to sit in a doctor's personal office before. Are there two pinched nerves? Maybe I need physical therapy or something. None of this makes sense. Why can't he just tell me what he saw on the x-rays? As we walk down the hall a burning question festers in my mind. Should I wait until after I talk to Dr. Adams? No, the time is now. I need to know now. "So Tito . . ."

"Mm hmm."

"When you knocked on the door to see if I was decent, you called me Nina."

"Yeah."

"I never introduced myself to you as Nina. You called me Miss Hayes from the moment you introduced yourself to me up until just now."

"So what are you getting at?" I respond with a head tilt and a raised brow. "Okay, so yes, I know who you are. I watch you every day. It took me a minute to figure out it was you though. You're a lot smaller and lighter skinned in person than you are on TV. Oh and FYI, I like your real hair better than . . . what is it a weave or a wig?" Unlike most viewers I encounter, I find his candor refreshing. A half grin forms on my face. "Oh God, I hope I'm not offending you."

"It's a wig and no I'm not offended, just embarrassed."

"Embarrassed by what? Lots of women wear wigs"

"Not the wig, I'm embarrassed by everything you saw today."

He turns to face me as he knocks on Dr. Adams' door. "Trust me I've seen much worse, and, in case you're wondering, I still think you're beautiful." I cover my face with my hand as warmth rushes to my cheeks.

"Come in, Miss Hayes." I notice a difference in Dr. Adams' tone as I walk in. It is devoid of his usual inflection. Tito nods his head at Dr. Adams and closes the door. This cannot be good.

Dr. Adams looks down at a gold envelope, and without making eye contact extends his hand toward one of the chairs across from him. "Have a seat, Miss Hayes."

"Just go ahead and tell me, Dr. Adams. It's me remember? You have been my doctor since what, freshman year in college. I know you have a wife and kids and you need to get home like yesterday. So go ahead tell me how long I need to wear a sling and we can both get out of here."

He shifts in his chair, clearly unamused. "Your x-rays were normal."

"Whew! Thank God! You made me wait and worry for this? Aww come on, fix your face, Dr. Adams this is good news right?"

"Not exactly, the fact remains you can't feel your upper left side."

"So, then we have to try another procedure to locate the pinched nerve right?"

"I'm not so sure this is a pinched nerve we're dealing with here. I even took a close look at your spine for fractures. I didn't see so much as a spur."

"Sorry, I don't follow."

He pulls his glasses off and rubs his eyes. "I think this could be a neurological issue."

I close my eyes and clear my throat. "A neurological issue, so you do think I had a stroke?"

“In my opinion I don’t think you had a stroke, but I’m not at liberty to say what is really going on with you. Only an specialist can determine that. I’m going to forward these x-rays over to a neurologist.”

Suddenly I realize what I forgot to tell him. The seizure, maybe all of this has something to do with the seizure. “Dr. Adams, what about seizures?”

“What about them?”

“They’re neurological right?”

“Yes, did you have a seizure today? Why didn’t you tell me?”

“No, not today, and I’m not even sure if it was a seizure. I woke up in the middle of the night. My legs and arms were kicking and flailing on their own and I kept repeating no, no, no over and over. I tried, but couldn’t stop. Plus, this is the second time I went numb. Last time it was my right side and my right leg was flopping around like a noodle, kind of like my arm is today.” His empathy is apparent as I share my account. “Do you think any of this is related?”

“I uh, I honestly don’t know Miss Hayes. Only a neurologist can provide a definitive answer. I called and made an appointment for you with Dr. Mathews. I did my best to escalate it based on your condition, but Dr. Mathews is a sought after neurologist. He’s booked for the next three weeks.”

“What am I going to do until then?”

“Unfortunately, I can’t prescribe anything because you’re not in pain and I don’t know what’s wrong. The best advice I can give you is to use a warm compress, maybe a hot bath, and lots of rest. Do you have anything at home to help you sleep?”

“Yeah, I have sleepy time tea and red wine. I think I’ll take a shower instead of a bath. I might not be able to get out of the tub by myself.”

“If I were you, when I get home I would take a hot shower, drink either the tea or wine and lay down with a heating pad or hot towel.”

I look down at my feet planning the order of my uneventful night and developing a plan of action to placate my family when they ask how my day went. "I guess I better get going so I can get started." I slowly lift my eyes to meet his only to notice he is still looking down at the envelope. A sense of helplessness radiates from him. For the first time ever, Dr. Adams cannot rescue me.

He finally looks up and leans across his desk to shake my hand. "Good luck Miss Hayes. I'll be interested in knowing how things turn out."

I firmly grip his hand as we shake. "Thanks Dr. Adams."

"Are you going to be alright?"

"You know me, I will always be alright." Our eye contact is brief without an ounce of reassurance. If he is this worried, it must be bad. I turn and walk out of the office to check out.

The front desk clerk is gone and the lights behind the desk are dim. "Hello, is anyone here?" No one answers. I lean forward across the desk to look, still no one.

Tito enters the lobby from the rear door. "Oh, everyone's gone for the day. Don't worry about checking out. You can schedule a follow up after you see Dr. Mathews."

"Okay then, I'll be sure to make an appointment later. Thank you for everything Tito. I'm going to go home and try to forget all about this monstrosity of a day."

"Wait, I'll walk you out." He runs ahead of me to unlock the front door.

"So you're not really walking me out, you're letting me out."

"Well I could have stood there and laughed while you kept pulling on the door, but I think this is much nicer." He stands aside and holds the door open until I cross the threshold. I stay on the sidewalk until I reach my car. I plop my purse down on the hood to use my one good arm to search for my keys. "Here let me get them for you."

"You really don't have to do this."

"How many times are we going to have this conversation?"

I step back and hold my right hand up in a submissive stance. “Go for it.”

He reaches in and begins sifting through my bag of secrets. Pads, tampons, and receipts roll across his hands like waves until he makes his way to the bottom. His hand becomes motionless as if it is caught on something. He looks up and smiles. “Nice bra.”

“What? Oh my God, I forgot it was in there!” I bury my face in my right hand peeking at him through my fingers to gauge his reaction.

“Don’t worry, I have sisters.” He holds my keys in the air as if claiming a Cracker Jax prize and opens the driver’s side door. “Your carriage awaits.”

“Okay, you’ve been funny all day. Now you’re burgeoning on corny.”

“Haven’t you heard? All of the good guys are cornballs?”

“Spoken like a true cornball.” He chuckles as he gently guides me into my seat. I position myself to sit as comfortably as possible before he straps me in. Tito hands my purse to me and then crouches down by the door seal.

“Can I take you out sometime?”

“What?”

“You heard me.”

I close my eyes and shake my head vigorously in disbelief. “Let me get this straight. After all you saw today, you want to take me out on a date?”

“Yes.”

I open my eyes and stare deeply into his, searching for a cleverly hidden agenda. “And what if my arm is still flapping in the wind, then what?”

“Then I’ll have an excuse to hold you close without feeling like a creepy pervert.”

“Not too close, I can still slap you with my right hand.”

“You can, but you won’t because I’m a good guy.”

“Are you?” He nods his head. Then please explain to me the ethical implications of what you’re doing right now. Can you get in trouble for going out with a patient? More importantly, is this something you do all the time—asking out every sick girl who walks through the door?”

“Technically, you’re not my patient because I’m not a doctor. I’m an x-ray technician. To answer your second question, no I don’t ask out every sick girl who walks through the door just the hot ones like you.”

I smile and tilt my head. “What do you want from me Tito?”

“I don’t know. The only thing I do know is I want to see you again and not here like this. For right now, let’s just start with your phone number. If our date sucks you never have to call me again. Deal?”

“Deal.” I watch him as he programs my number into his flip phone.

“I’ll call you soon. This is the right number isn’t it?”

“Yes Tito.”

“It better be.” He smiles one last time before stepping aside for me to close the door.

“Think about where you want to go on our first date. Oh, and be safe on your drive home.”

“I will.”

I pull into the parking lot of my apartment complex dreading the hike up the stairs to my place. The details of my inevitably mundane evening plays in mind. Today’s fiasco interfered with my free Friday night rituals of either hanging with friends or a Blockbuster movie marathon. Outside of paying my rent and utilities, makeup, clothing, groceries, student loans, and a personal loan from Beneficial, I cannot afford the luxury of cable. I let out a deep sigh at the thought of falling asleep to a fuzzy local channel or a DVD I’ve seen a dozen times from my own collection.

My phone rang three times on the way home from the doctor's office. I could tell by the ringtone that two of the calls were from Mom. No matter how many times I tell her I am alright, she would jump in her car and be here in minutes. Granny needs her more than I do right now. I lightly bang my head against the steering wheel. "Damn it! Damn it! Damn it! Get it together girl. You've been taking care of yourself for this long. Today is no different." Looking up at the night sky, I beg God for divine intervention. "Father please give me strength."

Careful not to get my arm caught, I lean to the right and unhook my seatbelt. I slide the key out of the ignition and reach across my chest to open the door. Purse in hand, I twist my lower body toward the door, drop my legs over the door seal, and stand wobbling from side to side. I look back at the trunk of the car over my shoulder. My duffle bag will have to wait until tomorrow. There is no way I can lug it up the stairs tonight. I hit the lock button and close the door behind me. Wary of alerting my neighbors, I tiptoe quietly through the hallway toward the steps. The concrete floors and high ceilings in the hall amplify even the slightest hint of noise. The last thing I need is for one of my neighbors to come outside and ask what is wrong. While I could definitely use the help, I'm just not in the mood to provide a recap of today's events. I brace myself with my right hand against the painted, wood wall as I go up the stairs. The slow, arduous climb comes to an end as I pause at my door and slip the key into the lock.

I turn the key and walk inside, dropping my purse on the floor, and quickly locking the door behind me. Steadying myself on the chair by the foyer I kick off each shoe. I yank the waist of my jeans with my right hand repeatedly until the button gives way and the zipper slides down. There is no way I can get out of jeans without falling. I need to lie down. I limp down the hall of my apartment toward my room. I flip the light switch, turn to face the vanity and flop backwards on my bed quickly pushing my jeans and underwear down in chorus as I wiggle my way out of them. I get them just below my knees before I sit up and roll both garments down to my ankles. I stop to catch my breath. "You're almost home free Gianina. Don't stop." Using

my right thumb I hook the hem of my right pant leg and free my foot. The same method proves successful on the left leg. I lie flat again, shaking my legs feverishly until I hear the thud of my clothing hitting the floor.

Now comes the hard part, my shirt. I grab my left arm, assuming the role of puppeteer until it is perfectly positioned above my head. Slowly I pull and stretch the cuff of my sleeve until my elbow nears the seam at the shoulder. I pull and tug at my sleeve to no avail. My arm is stuck. Grief washes over me as I look up at the popcorn ceiling. I am 24 years old, home alone on a Friday night, and I can't undress myself. Humph, I used to be worried about having to put up with some guy's insecurities. Now I have to wonder if anyone is going to want me at all like this. Tito seems sincere, but can I really trust him? He's probably a player. Who the hell would want to deal with this every night? I guess it's just you and I God.

Overcome with anger and determination, I reach across my body and roll the waist of my shirt up to meet my entangled arm. I slide and wiggle toward the edge of the bed until my cold clammy arm pops out of my shirt. I snatch the collar of my shirt over my head and vigorously shake my right arm flinging my shirt across the room. "Thank you Jesus."

I roll up to a sitting position and rock forward to standing. While limping toward the bathroom, I catch a glimpse of myself in the mirror of the vanity. My left shoulder sits noticeably lower than my right. Twisting my waist from side to side I watch my left arm swing loosely like a wet noodle. No wonder Dr. Adams was at a loss for words.

I continue my journey down the hall into the bathroom, flip the switch, and grab a butterfly hair clip off the countertop. I flip my hair forward and gather my hair with the large clip. Eagerly anticipating the warmth of the shower, I hurriedly turn the knob and adjust the temperature. The soothing feeling of the water tapping on my skin provides comfort to all but my upper left side. Even under the steaming hot water, my left side is colder than a slab of marble. I grab my cleanser and begin my bathing routine. Nearly done bathing, a hunger pang

interjects swaying me to quicken my pace and answer its call. I rinse all of the soap away, turn off the water and douse myself in body oil. I rub the oil into my skin with my right hand and haphazardly drape myself with my towel.

The hunger pangs are now joined by loud rumbling and gurgling noises. I pump my facial lotion in my hand and slather it on my face and neck. The leftover pizza from yesterday sounds good. The sound of Mom's ringtone beckons from my room. I stand in the hallway looking in both directions weighing my options. Should I answer and tell her what happened or just call her tomorrow? I take two steps toward my room. Suddenly, there is silence. "Sorry Mom, we'll talk tomorrow when I'm feeling better." I make my way toward the kitchen when a cool sensation creeps along my legs. The feeling becomes colder and fuzzier with each step, steadily progressing to my torso. My limbs feel taught and achy as if hooks are concurrently pulling on each muscle fiber. Flashes of color splash across the white walls making it difficult for me to focus. I stumble to the middle of the hallway as my knees buckle. I swing my right arm reaching for the doorknob to the linen closet to break my fall, but I miss landing face down on the carpet. My once languid left arm now twitches uncontrollably and my left leg kicks the wall violently. "Help me. Pleeease, h-h-help." My lethargic tongue, quivering lips, and twitching cheeks muffle my voice into a mushy whisper. It's no use. Who's going to hear me if I can barely hear myself? My heart pounds at 100 miles an hour. I watch in horror as my own body betrays me. Angry tears stream down my face as my body continues to writhe in random, arrhythmic, motions for what seems like an eternity. Without warning everything stills including my demanding stomach which was quieted by the trauma. Pain racks my body from head to toe. Even my once numb left side screams for relief. Forget dinner, I just want to go to bed. I lift my head from the carpet and realize none of my limbs are joining the effort. Everything below my neck is dead. "I can't move!" My instinct is to call for help again is thwarted by the reminder that I am nearly naked. Is this how I want to be found by the ambulance—face down

on the carpet barely covered in my towel? I'm so tired. How did I get so tired? I turn my head to face the baseboard wiping my tears into the soft carpet, and stare at the details of the brush strokes in the paint until I drift off to sleep.

An audience for my seizures. Isolation has become a form of solace for me. Avoiding people and public places for fear of having a seizure is the only insurance for concealing the truth—the truth about my slow descent into madness. My body is no longer mine, but rather an abusive partner who beats me in private and is a perfect gentleman in public. An entity in its own right, it became the boogey man of my adult life. If it were not for the bruises from accidentally hitting myself during the seizures I would not believe me either. Although he [my body] batters me relentlessly I cover for him, telling friends I fell or bruised myself exercising. Unlike a real life abuser, he will never be convicted or sentenced lest he take me with him.

He [my body] controls everything, including my love life. Tito pulled out all the stops on our first date, but the threat of him [my body] tracking me down looming over me kept me distant and despondent. I knew it was just a matter of time until he came looking for me—enraged because I did not come home right away. The only thing Tito can offer me is comfort while I take the beating. What if Tito grows tired of doing that? I'm already cracked. If I let Tito in and he leaves me now at my most vulnerable, I will shatter. My reluctance and anxiety slowed our communication to an awkward crawl. I returned Tito's calls more and more infrequently until I stopped returning them altogether. How could I burden a man I barely know with the task of protecting me from me? Tito is better off without me.

Mom and Granny are on their way to see me and my place is a mess. My apartment is normally spotless, but lately my body has made it nearly impossible to follow my usual regimen. I had three seizures in between shifts yesterday and one already this morning. I rub my aching forearm as I stare at the two-day old pile of laundry and dryer sheets I dumped on my sloppily

made bed. My furniture hasn't been dusted in over a week and the carpet is in serious need of vacuuming.

Another feeble attempt to fold my clothes leaves me frustrated as my uncooperative fingers stubbornly curl inward making fists. He beat me bad enough this morning. These are just a few shoves to remind me who is boss. The familiar sound of the Lincoln, car door slamming echoes outside my bedroom window. I drop my pants on the floor in frustration and rush to the window, peeking through the blinds for confirmation. Mom walks around to the passenger side as Granny slowly eases out of the car. "Shit!" Embarrassment and disappointment set in as I look around at my dirty room. I need everything to be perfect; as long as everything looks perfect they will not ask questions. Worst of all Granny has asthma, she is on oxygen, and chemo. She certainly does not need to breathe in dust.

Granny's unmistakable, rhythmic knock on the door beckons. I frantically shake my hands in an attempt to free them from their loosely locked positions as I walk into the living room. The grip on my fingers lessens slightly leaving my hands in somewhat of a scooped position; they are not well coordinated, but functional. I adjust my posture head up, back straight, and shoulders back. I quickly rehearse my lines in a low whisper. "No, no everything is great. Trust me I'm fine." The rhythmic knock begins again. I focus my efforts to twist each lock before turning the knob with both weak hands.

Granny's arms are already outstretched "Hi Sugarfoot!"

"Hi Honeybun!" I respond. She hugs me tightly and steps aside for Mom to get a hug.

"Hi Tootie Fruitie!"

"Hi Mommy!"

Mom leans in to hug me, but steps back. "Why are your eyes red? Have you been crying?"

"I was going to ask her the same thing."

"It's not a big deal. I'm just tired and I wanted everything to clean before you got here."

Granny kisses me on the cheek and grabs my arm tightly. "Now you know Granny doesn't care about that. What's wrong with you?"

"I know, but everything is dusty and you have asthma. I tried to dust, I just didn't have time."

"What's wrong with your fingers?" I look up to see Mom horrified pointing at my hand. "Why are they curled up like that?"

When did they tighten back up? "I uhhhh" Mom and Granny have been here all of 30 seconds and I have already been caught. If I try to cover it up, I'll just look stupid. They will never go for it. "I uh, I've been, I've been having seizures. At least I think"

"Seizures!" They exclaim in unison.

"What do you mean you've been having seizures?" Mom walks toward me.

Granny grabs my arm again. "And you didn't tell anyone? Why? You know you can always tell Granny." My mouth is agape searching for the least offensive explanation for my secrecy. Before I can pull my words together, Mom puts her hand on my back and guides me to the couch.

"Sit down; we need to talk about this."

All eyes are on me as I look down at my curled fingers and breathe deeply. "It started just before I went to New Orleans. The night before the flight, I woke myself up twitching and shaking repeating the same word over and over 'no, no, no' and I couldn't stop. I tried, but it just kept happening. I guess it lasted around two minutes or so. When it was over, I was really sore and tired. I went right back to sleep in a matter of minutes. Then it got worse. Remember when I came home and my leg was numb?"

Mom leans in closer. "Yes, I remember."

"Me too" Granny responds.

"Well, a few weeks later the same thing happened at work except it wasn't my leg. It was the upper left side of my body." My voice breaks as I relive the event. "I slumped at my desk. I thought, I thought I was having a stroke."

"Oh no, you had a stroke and didn't tell us!"

Granny chimes in and strokes my frail hand in support. "Let her finish, Regina."

I lower my volume to a whisper to control my tears. "No, I didn't have a stroke. The doctor took x-rays because he thought it was a pinched nerve, but it wasn't."

"What was it?" Mom demands.

I pause and sniffle. "He thinks it's neurological. So, he sent me to a neurologist."

"What did he say?"

"He thinks I have either Multiple Sclerosis or Parkinson's."

"My God, my God! Gianina you don't keep stuff like this to yourself, you tell us! Do you hear me? Jesus! Why would you keep something like this from us?" The anger in Mom's voice makes me hesitant.

"Regina, go easy on the girl."

"I'm sorry, but she knows better. Wait a minute, let's get back to the seizures. When was your last one?"

"This morning."

"You had one this morning?"

"Mm, mm, mm." Granny shakes her head in disbelief.

"You know we're always here for you, no matter what. You do know we're here for you, right?"

"Yes ma'am."

"Then why Gianina?"

The wells in my eyes overflow as I turn to face Granny. “Because it’s too much! It’s just too much! How can you focus on helping Granny get well if you’re too busy being worried about me?”

“Gianina it doesn’t matter. I”

“Yes, it does Mom!” Granny squeezes my hand tightly. “You took care of Poppie until his last breath, now Granny’s sick.”

“And!?”

“And? Huh, aren’t you tired Mom? You have taken in more friends and family members than a homeless shelter. Monica lived with us for a while. So did Uncle Tim and Uncle Tony. Janaya lived with us for three school years. Anwan lived with us off and on, for what, a year? Then there was Keisha, Mitzie, oh and David. When do you get a break? You’re always telling me how no man is an island, but maybe you need to start telling yourself that. Mom, you can’t take care of everybody.”

I watch the tears drop from Mom’s eyes. I don’t think she ever took note of how much she’s done. She just did what needed to be done to hold the family together. Her silence tells me she understands my rationale. My secrecy wasn’t defiance, it was consideration.

Mom’s voice quivers. “I understand, but don’t you ever do this again.”

“Yes ma’am” I whisper.

Granny interjects “Did the doctor run any tests?”

“Nothing major. It was just a consultation. He asked me to walk around the room a bit, scratched my feet and hands with a needle, and had me to stare into a light. He saw some abnormalities with my equilibrium. So, I’m having an MRI next week. Maybe that will reveal something.”

Granny gazes into my eyes intently. “Well, one or both of us need to be there during your MRI.”

"It's really not a big deal Granny. All I have to do is lay there until it's over."

"I know what an MRI is. I've had several. My question is what if the results are not good? Then what, are you going to sit there and process it all alone? I know you're tough, but you need someone there with you."

"Yes ma'am."

Mom wipes the tears from her face. "Have you eaten?"

"Not yet."

"You mean you skipped breakfast?"

"I wasn't hungry and I knew you would be here soon. I'm hungry now though."

Mom shakes her head and laughs. "Do you want breakfast or lunch?"

"It doesn't matter."

"Girl make a decision."

I turn on the couch and face Granny. "Granny what do you have a taste for?"

"No, Granny's not choosing today you are. I don't care where we go as long as we stop by Krispy Kreme when the hot light is on before we leave town." Mom and I burst out laughing. No one loves Krispy Kreme donuts more than Granny.

"Okay, okay, I would like breakfast please. There's an IHOP down the street. We can go there if it's alright with both of you."

"It's fine by me. Mom what about you?" Mom looks to Granny for approval.

"Didn't I tell you I don't care as long as we go to Krispy Kreme after? Gianina we have to get your mother's ears checked."

Mom and I crack up as we stand to our feet. I offer my arm to Granny. "Let me help you up Granny."

“As weak as your little hands are I should have helped you up. Granny’s not that weak yet. I can get up on my own.” I stand aside as she builds momentum rocking back and forth. She eventually stands to her feet and we all exit making our way to the car.

Feeling 20 pounds lighter I hop in the back seat right behind Granny, and proceed to offer directions. “Okay Mom after you pull out of the complex, you’re going to make a left at the second light and it’s right there in the shopping center.”

“Wow, it is close.”

I strap in and sit comfortably for no more than 20 seconds before my limbs grow cold. My wrists flip back while my fingers forcefully curl inward. My teeth clench tightly as my fingernails pierce the skin of my palms. “No, no, not now” I whisper.

“Not now what?” Granny rebuttals. I should have known she would hear me.

“I’m okay. I’m okay.” My body goes limp as I slump sideways in my seat. My hands loosen their grips as my wrists straighten and my fingers uncurl to reveal lightly bloodied crescents on my palms.

Granny whips her head around. “Regina pull over, pull over!” I feel the car shift abruptly. “Toot, are you having a seizure? Toot, can you hear me?”

I struggle to respond as my arms constrict tightly against my torso—squeezing my ribcage. A grunt escapes my lips as my right arm shoots out in front of me and I shake uncontrollably. My left arm flails wildly striking me in my chest and face.

“Mom, is she having a seizure?”

“Yes, I think she is.” I hear the zip of Granny’s seatbelt and suddenly she is turned around leaning over me. “Oh no, I got you Toot.” A look of horror grips her face. Instinctively, she grabs my flailing arms to prevent me from hitting myself. Her weight bears down on me exacerbating the nearly unbearable pain.

Uncertain what feels worse—hitting myself or being pinned down—I opt for release.

“Granny, it hu-hu hurts.”

“I know I won’t let you hit yourself. I got you.”

The car door to my left opens and Mom slides in next to me. “No when, when you hold me down.”

“Mom, I think it makes it worse when you hold her down, she’s saying”.

“Well, if I let her go Regina, she’ll hit herself.”

“Hit herself?”

My back jerks into an arched position. My chest writhes rapidly as my stomach and back muscles play tug of war with my torso. “Please let go.” Reluctantly Granny releases me and my arms swing violently nearly hitting Mom.

“Jesus!” Mom exclaims as she scoots back.

“I’m sorry Mom.” Sobbing frantically, I focus on the ceiling of the car to keep from looking at Mom and Granny’s faces. I hear them sniffing as they watch in disbelief. Instantly my entire body relaxes.

Mom scoots in close and cradles me. “Your arms are cold! Mom, feel her arms.”

Granny places her hand on my arm. “Like a block of ice. Do you want Granny’s sweater?”

Exhausted, I reply “No ma’am, I’m not cold.”

“I’m touching your arm right now. I know you’re cold.”

“I can’t feel it.”

“Can’t feel what?”

“Anything.”

Granny reaches down and begins squeezing my forearm systematically from wrist to elbow. “You can’t feel this?”

“No ma’am.”

Her brows furl in disappointment as she shakes her head. “Mmm, and you weren’t even going to tell us.”

“Gianina, this is bad. You have to see a doctor” Mom says.

“I am, you forgot?”

“No, I mean right now Gianina.”

“Mom, it’s Saturday. The only thing open is Urgent Care and Dr. Adams is the one who set up the appointment with the neurologist. So, he couldn’t help me even if he wanted to. Besides, this one wasn’t that bad.”

Mom and Granny answer in chorus. “Wasn’t that bad?”

“At least my legs didn’t kick. They just twitched a little.”

“You mean on top of all that your legs kick too?” Mom’s facial expression reads both empathy and puzzlement as we all sit in awkward silence.

Granny breaches the quiet. “You still hungry Sugarfoot?”

“No ma’am, I lost my appetite and I’m really tired.”

“I know you’re tired, but you need to eat something Tootie. You haven’t eaten all day.” Mom leans down and kisses my forehead.

“Okay, I’ll eat something, but please don’t make me go in.”

“You need to sit down and eat Tootie.”

“Mom, you don’t understand. Everyone here knows me.”

“If they’re fans and avid viewers, they’ll understand.”

“No, they won’t. Not everyone who speaks to me is a fan. Some people are just nosy and like to gossip. I’m numb already. I don’t know what I’m going to look like when I try to walk. What if people start whispering or worse, asking me questions? What am I supposed to do? Tell them what happened. I have no privacy as is.” I shake my head as I close my eyes

visualizing the awkward stares from strangers as I make my way inside the restaurant. “I can’t Mom. I just can’t.”

“Okay Tootie.” Mom runs her fingers through my hair and tilts her head back, letting out a deep sigh as she looks toward the ceiling.

“You just give Granny the order and I’ll go in and get it. These crows don’t know me.” I let out a strained giggle as I feel myself drifting off to sleep.

My First Misdiagnosis (Layer One Part II)

As I sit in between Mom and Granny in the cold quiet lobby, I do my best to burry my frazzled nerves beneath my hopeful smile. The climate is far more solemn than a family practice waiting room. There are no children playing, and none of the patients are smiling. The weight of the atmosphere is a cruel reminder that what ails me may not be so easily rectified with an over the counter pill for a couple of weeks. It could possibly be incurable and debilitating. Based on my seizures, insomnia, vomiting, diarrhea, and excruciating bone and muscle pain Dr. Mathews was convinced I was suffering from either Multiple Sclerosis (MS) or Parkinson’s disease. He wasn’t available the day I had my MRI to immediately discuss my results. So, here I am on my third visit to his office. I just want answers, answers to end this nightmare.

The nurse calls my name “Guy-uh-nigh-nuh Hayes.” I tremble on the inside as I walk toward her. Mom opts to go in with me while Granny stays in the lobby. Granny’s remarkable resilience allowed her to travel an hour and a half with Mom to be there with me. Her already deep set eyes seem to sink further into her newly slim face. She should not be here fighting for me; she has her own health battle to fight. As I walk toward the nurse, I mask my guilt by donning a forced smile and waiving at Granny. It should be me visiting her in her time of need, not the other way around.

Mom and I only wait a few minutes before Dr. Mathews walks in. He smiles and greets both of us. "Hi there Miss Hayes, who is this young lady you brought with you?"

"This is my mother Regina. Mom, this is Dr. Mathews." I watch as they shake hands and nod.

"It's nice to see you have some support here with you, Miss Hayes."

"Yeah, I have a great support system" I respond.

"I won't waste any time here ladies. I'm not sure if the nurse already informed you, but the initial tests were inconclusive. The only way to be sure that you don't have MS or Parkinson's is to have a spinal tap."

I respond without hesitation. "Okay sure. When do you want to do it?"

He looks at me expectantly. "Right now if you're up for it."

I consider his proposal in my head. My pain threshold is rather high. In fact my martial arts instructor often paired me with male sparring partners because I was strong enough to handle them. This is going to be a piece of cake. Besides the sooner I do this, the sooner I find out what is wrong with me. "Let's do it." I stand eagerly, stretching before reaching the exam table. I hop up and sit comfortably on the exam table and I notice Dr. Mathews reaching for the latex gloves. "Wait! I'm allergic to latex! Did you forget?"

He looks down at the gloves in disappointment. "I did. I'm so sorry Miss Hayes. I'll go down the hall and get some vinyl gloves."

Mom flashes a concerned look my way as he leaves the room. "I guess I'm going to have to be on high alert today. Does he realize how severe your allergy is?"

"Yes, it's on my chart. He just forgot. Everyone forgets."

He returns to the room with a somber expression. "It looks like we're fresh out of vinyl gloves."

Great, I was so ready to get this over with. “Fresh out, how are you going to do the spinal tap?”

“Well, I have an idea. We have some sterile sheets in the next room. I can put one of sheets against your spine as a barrier while I locate the point of insertion. The last thing we need is for you to go into anaphylactic shock. How does that sound?”

“Huh, that’s fine. I mean as long as you get what you need and I don’t get sick”. He exits again.

Mom crosses her arms and leans back in her chair. “Mm, mm, mmm.”

I plead with her to censor her judgement. “Mom.”

“I’m not saying a word, but you’re better than I am. I wouldn’t trust someone who doesn’t have your essentials available. He knew you were coming today. He should have had your vinyl gloves ready.”

“Mom.”

She crosses her legs and looks away. “Nope, you’re grown. You do what you want to do. I’m just saying what I would do that’s all.”

I shake my head chucking at her comical gestures. Mom shakes as she laughs silently with me. We immediately straighten up when he returns with the sterile sheets. The nurse follows behind closely, pushing a cart topped with several small components including the thickest needle I have ever seen in my life. I am not even afraid of needles, but this one is huge. Sensing my concern, he spills the proverbial disclaimer. “I know it looks bad Miss Hayes, but I have done this a thousand times. Once I numb you up, you won’t feel a thing. It’ll be over before you know it.”

I take one last glance at the gargantuan needle before responding. “Hey, the sooner the better right? Do I need to put on a robe?”

"No, there's no need to undress fully. You can remove your shirt and leave your bra on and maybe slide your pants down a bit."

"Okay." I do as instructed.

"How should I lay?"

"If you would, lay on your right side facing the wall please." I lay flat and roll onto my right side awaiting more instructions. "Are you ready Miss Hayes?"

"Yes."

"What about you Regina? You all set?"

Mom responds coolly. "I'm ready whenever she is."

"Alright it looks like we're ready to go." There is a brief silence followed by a cold alcohol wipe gliding up and down the center of my back. "You're going to feel a little prick and then a slight burn. It's just the anesthesia."

"Okay." True to his description I feel the prick and shortly after the burn. That was nothing. I have endured worse burns from the sun. I can't believe the woman on I saw on TV was screaming from this. I guess it was just good acting.

"Now Miss Hayes, I'm going to insert the larger needle. I need you to pull your knees into your chest in a fetal position and stay perfectly still. I'm looking for what I call the sweet spot. When the needle penetrates the sweet spot, you'll feel a sharp electric like current through your leg. Whatever you do, don't move! I can't stress this enough. Don't move!"

"I'll be a perfect statue." I draw my knees tightly into my chest and hug them. The warm fabric grazes my skin as his fingers gently press against my back searching along my spine through the sheet. "Ok, just a little pressure here." A small pinch rapidly grows into an arresting ache.

"Miss Hayes, is that it?"

The urge to scream arises, but once it reaches my lips only a gasp escapes. Within seconds my mascara and eye shadow muddy my tears blurring my vision. Instinctively, Mom rushes to my side. She places her hand on mine and then rubs my head.

I catch my breath whimpering a late response. “No, that’s not it.”

“Oh boy, I’m sorry Miss Hayes. I’m going to have to try a different spot alright? It’s so hard to gauge through this sheet. Ok stay still. Here we go.” The second insertion is even worse. Why isn’t the anesthesia working? I begin repeating the Twenty-third Psalm in my head to deaden my cognizance, but I am quickly awakened by Dr. Mathews. “Miss Hayes, is that it?”

“No” I whisper. Mom forcefully clears her throat, desperately trying to maintain her composure. I exhale as he slowly retracts the needle from my back.

He apologizes profusely, burgeoning on dishevelment. “Gee I’m so sorry. I’m really, really, sorry Miss Hayes.” His quivering voice becomes analogous to his trembling fingers as he continues down the path of my spine. I am not certain what I fear most now, my accidentally moving or his unsteady hands driving the needle in too far. “I promise this never happens Miss Hayes. It’s just this darn sheet.” I take relief in the brief moment of silence offered while he collects himself. “Okay, one more time.”

I grunt as an intense knife-like heat surges through my left leg with the strength of an electric current. “Uhhh! That’s it, that’s it, take it out.” A new wave of thick, mascara ridden, tears blur my vision drenching the paper on the exam table.

“You felt the shock?” Dr. Mathew pauses awaiting my response.

“Yeah, you can take it out now” I murmur. I feel the needle turn slightly.

“Actually I can’t Miss Hayes. I need a sample of your spinal fluid to send to the lab. Sorry, I should have explained this part to you. I’m sorry if I’m hurting you. I’m trying to keep the needle still while I attach the collection tube.” I feel a slight jerk as he attaches the tube. “I just need you to lay here for a short while, until the tube is full.”

“Okay.”

Mom continues to rub my head. She leans down and kisses me. “It’s alright Tootie. It’ll be over soon.” Embarrassed by my inability to control my tears, I squeeze my eyes tightly together. Somehow my effort to hold back my tears elicits more. The time seems to pass slower than normal as I lay on the table for what seems an eternity.

A light breeze brushes my back as Dr. Mathews reenters the room. “Let’s see how we’re coming here.” I feel the needle painfully shift in my back.

“Uhh!”

“Sorry, sorry, I just wanted to see how much fluid we collected. Oh boy.”

“What’s wrong?” Mom asks.

“Honestly I don’t have nearly enough fluid. I’m thinking maybe if I try to angle the needle I can get a little more fluid. Let me know if I hurt you too bad.” I quietly wince as he maneuvers the needle. Mom’s fingers stop mid stride at the crown of my head awaiting the end result. “Huh, I can’t even get another drop.”

Mom steps in on my behalf. “So what is the next step?”

“Well I do need more fluid, but I’m afraid that if I leave this in any longer the pain is going to put her out. I guess this will have to suffice. I think I’ve hurt you enough today Miss Hayes. Wouldn’t you agree?”

“Yeah.” The tension in my back releases as the needle slides out.

“You can stretch your legs out now but don’t sit up. It’ll give you a killer headache. I’ll be back in a little while with a soda for you to drink.”

I roll over in agony to face him. “No thanks, I don’t drink soda.”

“Oh it’s not refreshment. It’s a good source of caffeine. The caffeine will help with the pain. What kind of soda would you like?”

“Do you have Dr. Pepper?”

"No, but we have Coke. Is that alright?"

"Yes, Coke is fine." I wait a few seconds assuring he has left the room. I look up observing Mom's glistening cheeks. Her water proof makeup is still flawlessly in place undisturbed by her tears. "You can sit down now Mom. I'm okay."

She sniffles and clears her throat. "Ahem! I'm fine where I am. You just relax." Her voice and soft touch soothes me as I close my eyes and breathe deeply.

Dr. Mathews enters the room soda in hand. "Alright Miss Hayes, I need you to sit up very slowly and drink this for me. Better yet, could you lie on your side and drink it?"

I rest my head against the palm of my hand and take the soda from his hand. My hand trembles as I bring the cup to my lips for a sip. "Here, let me." Mom takes the cup and tips it steadily allowing a light stream to funnel into my mouth.

I close my lips and push them forward signaling my need for a break. Gulping down the last bit in my mouth, I look up and smile. "Thanks Mom."

"You're welcome Sweetie Girl. You want some more?"

"Yes ma'am." She tips the paper cup back against my mouth. I part my lips allowing the cool beverage to sooth my throat as I listen to Dr. Mathews.

"You handled this very well considering the circumstances Miss Hayes. I am so sorry that we did not have any gloves on site for you today." I wave my palm expressing my dismissal of any hard feelings.

"I'm certain your bloodwork will go much smoother than this, ha, ha."

Soda spills on the carpet as I shrink back from the cup. "Bloodwork, what bloodwork?"

"Oh, well the spinal tap won't tell us everything. We need to draw some blood as well."

I push myself into an upright position. "Wait Miss Hayes! You can't sit up yet. You'll get a headache!"

I extend my right arm. "Here this one has the better vein. I'm tired and I just want to get it over with."

"Oh that's great it's just uh, we don't draw blood here."

"What do you mean you don't draw blood here? You said I needed to do bloodwork in order to determine what's going on."

"Well, yes you do. It's just that bloodwork is done in the building just across the parking lot". I look down, sigh, and shake my head. Why didn't he tell me this beforehand? It would have made even more sense to have my blood drawn first and the spinal tap afterward.

"Can you handle that today Tootie?" Mom chimes in.

"It's not like I really have a choice at this point. I already missed work this afternoon. There is no way I'm going to miss work again to come back here for bloodwork."

"Whoa, Miss Hayes, I wouldn't recommend that you go to work tomorrow."

"You don't understand Dr. Mathews. I have to be there."

"Gianina I'm going to side with Dr. Mathews on this. You need to stay home."

I rest my head in my hand and massage my forehead with my fingertips. "Let me ask both of you a question. What time does the 6:00 news start?"

Dr. Mathews looks puzzled and answers reluctantly "siiix o'clock."

"Yes, the 6:00 news starts precisely at 6:00, not 6:01, not 6:02, but 6:00 on the dot. And during the holidays, do we cancel the news or show reruns because it's Christmas?"

Mom lowers her head and quickly looks back up. "Gianina . . . "

I continue on, blocking her from interjecting. "No, we don't. Rain or shine, snow or sleet, Christmas or Thanksgiving, it doesn't matter we are still on TV. Is your practice open on Christmas, Dr. Mathews?"

"Ahem, no, no it's not."

“Hmm, must be nice. And Mom, when you’re sick you can just break out your laptop and work from home. I can’t report traffic from home can I?” Mom responds with a frustrated sigh. “Do you know the most disturbing part of all of this? Both of you earn what, more than four times my salary. I only make \$25,000 a year before taxes and I can’t even miss one day without hearing about it. Did you forget how they treated me when I went on vacation, vacation that I earned and applied for months in advance? Did you forget about that?”

Mom cocks her head to the side and responds calmly. “No, I remember.”

“Then can we please just get this over with so I can get some rest and be fresh for tomorrow?”

Dr. Mathews quietly walks over and grabs the step stool, placing it under my feet.

Mom guides me down onto the carpet. “I’ll drive you over. Let’s get your shirt back on.” I stand still as Mom dresses me like I was four years old again. I know she is agitated with me, but I cannot help but smile at her as she helps me into my blazer. She eventually smiles back. “Here let me get your soda. You need to finish that.”

“Your mother is right Miss Hayes. You’re going to need the caffeine.”

“Okay, I will. I’m just not a soda drinker, sorry.”

“No, don’t apologize. That’s a good thing. I wish my other patients were as diligent about their diet as you are.”

“Thanks Dr. Mathews.”

“You’re welcome. Oh, and good luck to you Miss Hayes. We’re going to do everything we can to help you.”

He extends his hand for me to shake. “Thanks Dr. Mathews.”

He turns to Mom. “It was nice meeting you, Regina.”

“It was nice meeting you as well Dr. Mathews.”

“Check out is just down the hall on your right.” Dr. Mathews hands my paperwork to Mom.

“How soon should Gianina expect her results?”

“Anywhere from two to three weeks. We’ll contact her.”

“Okay thanks again, goodbye.” Exhausted from my back-to-work speech, I simply wave and smile at Dr. Mathews on the way out. Mom guides me by my arm down the hall holding my paperwork and soda until we reach the desk.

“Hi there, how are you ladies today?”

Mom and I answer in unison. “Fine and you?” We look at each other and laugh.

“Oh, you’re definitely mother and daughter.” She pops her chewing gum in between giggles. “Me and my girls do the same thing. The most widely used word in our vocabulary is jinx.”

“I guess the apple doesn’t fall too far from the tree does it?”

“It sure doesn’t. I’ll take that paperwork for you ma’am.” Mom hands her the paperwork.

“Alright, that will be \$20.” I reach for my purse to pull out my wallet.

Mom pauses and looks at me sided eyed. “What are you doing?”

“I’m paying for my visit.”

“No you’re not. Girl put your little wallet away. I’m paying today.”

“But, Mom . . .”

“What did I say?”

Normally I would protest and rush to pull out my card before she could get to hers, but today I have argued enough today. “You got it.”

“Thank you ma’am.” She smiles and hands her card to the clerk. “By the way, I have to take my daughter to have blood drawn today. Where is that building exactly?”

“Just one moment.” The clerk types the card numbers into the computer and hands it back to Mom. “It’s the long, white building right across the parking lot. You can’t miss it.”

“Alright, thank you.” The sound of the document-sized receipt printing in the bubble jet printer sends throbbing pains through my head. I rub my temples with my fingertips and then I remember Granny is in the lobby. She can’t see me like this. I have to pull it together. In a frenzied burst of energy, I wipe my face checking my hands to see how much mascara has come off with each wipe. Why does TV makeup have to be so thick? I fluff my wig and put my shoulders back while Mom signs the receipt. She looks up with a half grin, tucks her copy of the receipt away and digs around in her purse. “Come here.” Mom smiles as she wipes my face with a tissue.

“Thank you.”

“You’re welcome Sweetie Girl.”

I wait a few moments while she wipes. “Did you get it all?”

“Yeah, wait one second. Okay, that’s better.” She offers me her arm as we turn to face the exit door.

“It’s alright Mom. I can make it.”

“Girl come here!”

“I got it. Please just let me walk on my own.”

“One day you’re going to learn how to accept help. Here.” She holds the door open for me. I see Granny’s joyful yet inquisitive face. She is inspecting me again; I can feel it. Her gaze deepens as she looks me up and down. My poker face crumbles as the pain radiates from my back to my throbbing temples.

She finally speaks. “Are you alright Toot?”

“Yes ma’am.”

“Mm, mm, mm telling stories again?”

“Granny, I’m okay.”

Her eyes narrow as she exhales through her nose. With her eyes still fixed on me she addresses Mom. “Regina, is she alright?” I look at Mom, praying she will cover for me. Mom closes her eyes and shakes her head. My silent expression implores her silence. She tightens her lips and looks at me with the wells of her eyes filled to capacity. “Come on let’s go.”

Granny never takes her eyes off me all the way to the car. “Regina, what did the doctor say? Is something wrong with Gianina?”

“He’s not sure yet.”

“I don’t understand why you’re so upset. No news can be good news.”

“I just don’t want to talk about it right now mom. Right now we have to take her to get some bloodwork done. I’ll tell you about it later.” As I step down from the curb, the shock from the impact shoots up my back and into my neck. I pause and rub my hand across my spine. I can’t cry in front of Granny. I just can’t. My body shakes from the pain. “I told you good to let me help you!” Mom presses the fob twice to open all the doors and slowly walks me over to the rear passenger side. “Can you lean up against the car for me?”

“I’m sorry Mom.” I look deep into her eyes searching for absolution.

Her voice breaks. “It’s okay, just learn to take my help when I offer it. There’s no shame in asking for help okay.”

“Yes ma’am.”

Mom gingerly guides me into the backseat as Granny looks on puzzled. “I wouldn’t sit up if I were you Gianina. I think you should lay down just like the doctor said until we can get your bloodwork done.”

Quite bothered from her exclusion, Granny questions Mom again. “What’s wrong with her Regina? She was fine in the lobby.”

Mom lays me down on my right side and places my feet up on the seat. “He gave her a spinal tap.”

“What? A spinal tap? Oh no, I heard those were painful!?”

Mom snuffles and clears her throat. “Yes, they are.”

Looking more concerned than ever, Granny rushes to the passenger seat and turns completely around, resting her weight on her knees.

“Granny what are you doing?”

“Hush, just close your eyes.” She begins reciting The Lord’s Prayer while rubbing my arm from shoulder to wrist stopping in between verses to reassure me. ‘Our Father, which art in heaven’ . . . it’s going to be alright (Matthew 6:9, KJV). “Hallowed be thy name. Thy kingdom come, Thy will be done on earth as it is in heaven” . . . Granny’s here (Matthew 6:9 – 10, KJV).”

Her prayers and gentle touch move me to full on sobbing. I hold my tongue until she finishes praying. “It’s not fair Granny.”

“What’s not fair?”

“You’re sick. You should be at home resting, not here with me. I know your knees have to hurt by now. You don’t have to”

“Hush, that’s what Granny’s here for. You know I have to check on my Sugar Foot.” I laugh through my snuffles as she smiles back at me.

Mom’s tone sharpens as she pinpoints our intended destination. “This place isn’t across the parking lot. It’s across the damn street. Do they know the difference between a parking lot and a street?” I feel the car come to a halt and Granny pats me on my shoulder before slowly turning around to get out of her seat. Mom abruptly opens her door. “Don’t you move a muscle until I come back there and get you.”

“Yes, ma’am.” I lay perfectly still until Mom opens the door and sit up raising my arms out in front like a child, allowing her to pull me toward her.

After bringing me to the edge of the backseat, Mom takes hold of my legs and swings them over threshold of the car door. "Alright, on the count of three, I want you to put your feet down and I'm going to stand you up slowly. Ready? One . . . two . . . three." I grunt and take a deep breath as my feet hit the ground. "Did that hurt?"

"Just a little, but I'm okay."

"You always say that, even when you're not."

Granny watches as Mom walks me over to the curb. "Regina, take her to the ramp so she won't have to step up and hurt her back again."

"Good idea Mom."

"You girls think and move too slow. You need to get it together so you can keep up with Granny."

Mom and I both laugh as she walks me to the ramp. "Wait one second Gianina. I forgot your soda." Mom runs back to the car and gets my Coke. "I want you to know we are not setting foot in that place until you drink this down."

"I know, I know, I just hate soda."

"It's either this or be in pain." Mom shoves the cup in my hand. I gulp it down, releasing a silent belch.

"All done."

"Good, after this I can make you some coffee and give you some Advil."

"Yes, coffee would be much better."

"Alright, let's go inside."

Granny holds the door as I drag my feet to avoid impact while walking. The lobby is enormous, almost hotel lobby like. The concrete floors are speckled with the proverbial tall, green plants near the elevators. The echoes of voices stir in the overcrowded space. The high volume of conversations, footsteps, and phones ringing bellow like thunder in my aching head.

A man sits hunched over in his chair, trembling—his rigid contorted fingers pressed against his chest. If Dr. Mathews is right that could be me in a few years.

There are only two seats left by the window. Mom takes charge and delegates immediately. “Gianina, give me your ID and your insurance card so I can check you in. Mom, you take Gianina over there and get those last two seats.”

I open my wallet and pull out the requested items. “Here you go.”

“Thank you. Now go sit down.” Mom squints her eyes and makes a funny face before walking away. Granny walks me to my seat. I turn around and grasp both chair arms, slowly lowering myself down.

“You got it Sugarfoot?”

“Yes ma’am.” I breathe out heavily once my body makes contact with the seat and sends a shooting pain up my spine.

Mom walks back over and hands my cards to me. “How are you coming Tootie?”

“I’m hanging in there.” I begin scanning the room, praying no one recognizes me. The last thing I need is for someone to ask me for an autograph or worse, ask me what is wrong.

“Good, it shouldn’t be long.”

Thirty minutes have passed and no one has called my name. I lean forward in my chair rocking from side to side to alleviate the stress on my back.

Mom stands with her arms crossed in frustration. “I’m going to go over there and ask them what the holdup is. They can’t have my child sitting out here this long.”

Granny reaches over and rubs my back. “Yes, you better go check on things Regina. I’ll sit here with her.”

. My vision blurs from the pain as I watch Mom walk quickly over to the front desk. Although I cannot hear the conversation clearly, it is obvious that Mom means business. The

clerk makes a phone call and hands Mom some paperwork. She then begins pointing as if she is giving Mom directions. Mom looks toward Granny and I and motions for us to come over. Whatever she told the clerk worked. Granny helps me out of my seat and we walk together slowly over to Mom. "She said we need to go through the double doors near the entrance. How is your pain Tootie?"

"I'm okay."

"No, I can tell you're not. Can you hold on a little longer?"

"Yes ma'am." My blurry vision pushes me to hold Granny's hand tighter. We walk through the double doors and turn left. Standing there is a woman behind a podium, much like a hostess in a restaurant. She is average height and mildly stout. Her headset is perched on top of her short, perfectly coiffed, salt and pepper hair which appears to be supported by two full cans of hairspray. Her thin rimmed, reading glasses rest near the tip of her nose. I watch as she nods her head, looking down and speaking into the mouthpiece of her headset.

"Okay, yes, yes . . . no problem." Caught off guard, she looks up and greets us. "Hi, how may I help you?"

"I'm here for my daughter's bloodwork."

"Last name please."

"Hayes."

"And first name please."

"Gianina."

"Hmm, can you spell that please?"

"Yes, G-I-A-N-I-N-A."

"Oh, how unique. Yes, yes, I have her right here. Please have a seat in the waiting area behind me."

"I beg your pardon? We just waited for over 30 minutes on the other side." Mom's calm yet assertive tone startles the woman.

"I'm sorry ma'am, this is just procedure."

"You will have to excuse me if I do not understand the purpose of two waiting rooms for patients."

"Well, she has to file her insurance." Her half smile reveals her discomfort with being questioned.

"I gave her insurance card and ID to the front desk on the other side."

"Right, but on this side she has to go over it with a case worker to explain coverage."

I can sense Mom's anger, but as always she maintains her cool. The woman gulps as Mom shoots a scathing glance that could cut glass. "Come on Gianina."

I trudge along to my seat. Unlike the chairs in the first waiting room, these chairs are wooden and have no cushions. I slowly inch my way down into the seat, hoping to avoid the shock from the impact, but my efforts are in vain. The pain travels up my spine and to my head within seconds. I roll my lips into my mouth and bear down on the backs of them with my teeth to keep the moan from escaping my lips. I lean forward and hug my knees, rocking from side to side to alleviate the pressure. I feel Granny's hand gliding down my back attempting to comfort me. I see Mom's foot tapping in her leather mules. "Is she okay Mom?"

Granny answers on my behalf in a low whisper. "No."

"I just don't understand why we need to wait again." I can feel the heat coming off of Mom. Unable to sit any longer, I stand hoping to ease the pain. I stumble twice before regaining my balance. "Tootie!" Mom rushes into action and puts her arms around me as I tremble from the pain. "You need to sit down sweetheart."

"Mom it hurts too much to sit, I have to stand up for a while."

"That's it." Granny heads over to the hostess.

“Mom what are you doing?” Mom’s words seem to fall on deaf ears as Granny marches toward the lady at the podium. This time I am standing in close enough proximity to hear the conversation. “Excuse me, but I do not recall your name. What is it?”

“Oh, it’s Shirley.”

“Well Shirley, I understand that there is a wait but I don’t think my granddaughter can hold on any longer.”

“Well, Mrs. uh . . . “

“Margaret, you can call me Margaret.”

“Well Margaret everyone has to wait.”

“I understand that, but I don’t think you understand. She just had a spinal tap.”

“A spinal tap, when?”

“About an 45 minutes ago across the street and she’s in tremendous pain.”

“Oh my goodness, we didn’t know.”

“You mean the doctor did not call to forewarn anyone?”

“No, he didn’t.”

“Let me see what I can do to speed this up for you.” Shirley disappears behind a partition for a few minutes. She emerges blank faced, walks toward Granny, and places her hand on her shoulder. “I’m so, so sorry she can go back now.”

“It’s alright, you were just doing your job and you didn’t know.” Granny and Shirley turn to face Mom and I and motion to us come on.

“Come on Tootie. Can you make it?”

I take a deep breath and smile. “Yes ma’am.”

Shirley leads the three of us behind the partition and introduces us to a tall slender woman. “This is Tawny.”

Tawny shakes Mom and Granny's hands before making her way to me. "Oh my goodness, you don't look like you're feeling good at all."

"Hmm, I'm okay."

"Well someone should tell your body. Look at how you're standing. Let's go ahead and take care of this insurance so you can get out of here. Why don't you have a seat right here and we'll get started?"

"Actually, it hurts worse to sit. Do you mind if I stand?"

"No, not at all." I rock from side to side, hugging myself as I answer each of Tawny's questions. She then prints out a long document and staples it together. "I need your signature on a couple of these pages. Do you think you can do that for me?"

"Yes." I wince as I lean over the desk and pick up the pen to sign.

"Alright, and one more signature here, another one here, and one last one here." I sign and slowly roll up to a standing position. "Okay, this should do it. You should hear your name called very soon. As a matter of fact, it should be the very next name you hear. I sure hope you feel better." Tawny leans across the desk and shakes my hand. We exchange a smile.

"Thank you, Tawny."

"Oh, you're welcome and again we're sorry. Had we have known you had a spinal tap, we would have done our best to move you through quicker." Granny and Mom thank Tawny again before we return to the waiting area.

As soon as I lean myself comfortably against the wall, I hear the familiar articulatory assault on my name. "Gee-ah-nee Hayes." That is the funny thing about having an Italian name; you never know what rendition of it you are going to hear.

Mom turns to Granny. "Mom I'm going to go back with her. Are you going to be fine out here?"

"Girl go ahead. I'm fine. Sugarfoot . . ."

"Yes ma'am." I answer softly.

"Granny will get you some hot, fresh Krispy Kreme after you give this blood okay."

"Okay Granny."

"Come on sweetie girl." Mom pulls me close to her as she ushers me toward the nurse.

She greets us with a perplexed look "How do you say your name?"

"You can just call me Nina."

"Oh yes, that's much easier. Follow me please"

She leads us down a short hallway to a room on the left where another nurse is standing—a very pleasant with a thick sugary accent. "Oh my goodness, look at you. We need to get this over with quickly. Hi, I'm Nancy." She nods and speaks to Mom briefly.

Completely drained of energy, I whisper to the nurse. "I'm allergic to latex."

She nods and reaches for a blue vinyl tourniquet. "No problem, I got you covered girl. They're running quite a few tests on you today hun. You might want to get some juice or something sweet to eat after this."

"My Grandmother is getting me some Krispy Kreme donuts after this."

"Whoo hooo, IT don't get no better than that. I sure wish my Grandma was still living. You better cherish these moments."

"I do."

"Good. Have a seat in that chair over there and pull the arm down over your lap."

I do as I am told while Mom watches from the door. She wipes the crook of my elbow with an alcohol pad. "Before you start, I should tell you I have small veins and they roll."

"Hun, I've been doing this for a long time. If anyone can make you bleed, it's me." She smiles before tightly securing the tourniquet around my bicep. With her middle and index finger she taps excitedly, squinting her eyes as she looks for a vein. "Hmm, you weren't kidding were you? Let's try the other arm." Upon the release of the tourniquet I take the opportunity to adjust

my sitting position and yet again release the strain on my lower back. Nancy quickly ties up my left arm and taps again. "Where are your veins, girl?"

"I told you." I whisper quietly.

"Wait, I see one. It's a skinny little something. Let's see what we can do here." Nancy gently inserts the needle. As expected, nothing comes out. She angles the needle slowly guiding it in and out. Normally, I would frown and ask her to take it easy, but the pain of the needle pales in comparison to my aching back and throbbing head. "Well I'll be. You're just determined to call my bluff aren't you?" I simply smile and sigh. "Okay let's try the other arm again. If this one doesn't work we're going have to go into your fist okay?" I nod in agreement as she starts the process all over again on my right arm. The needle pierces my skin. Even Mom leans in as we all wait expectantly. Finally, the tube fills with blood. "Whew, you sure don't like to bleed do you hun"? I gently shake my aching head. "This shouldn't take long at all. I watch as she removes the first vial and replaces it with a second, then a third, a fourth, a fifth, a . . . dear God how much blood is she going to draw?

I awaken to a violent shake. "Hmm?"

"I'm sorry I had to shake you like that, but you dozed off and you were leaning hun. I didn't want you to bend the needle in your arm. Then we'd really be in trouble". She withdraws the needle and quickly bandages my arm.

"Tootie are you okay?" I turn my head to face a blurred image of Mom. I shut my eyes tightly and open them widely repeatedly to regain my focus. Mom's familiar features slowly come into view.

"Yes, ma'am." I respond quietly.

"We're all done now hun. There's no need to check out. You just head on out to your car. You make sure you get somewhere and lay down, and enjoy those Krispy Kreme donuts, you hear?"

I smile fondly at the nurse as I struggle to stand on my own. "I will." Both dizziness and nausea vie for my attention and are swiftly upstaged by nausea.

I rub my stomach as Mom embraces me and steers me toward the exit. "I got you Sweetie Girl." As we near the lobby, the urge to straighten up and put on my happy face for Granny strikes me, but my body is unable to comply. At best I can simply refuse to cry. When we reach the lobby Granny is already standing, waiting for us. No words are exchanged. She simply walks alongside Mom and I, rubbing my back as we make our way to the car. Mom goes through the usual ritual of helping me into the backseat where I lay flat. I count the tiny cracks on the back of the leather seat until I fall asleep.

"Sugar Foot, I know you may not feel like it, but I need you to eat this donut for me." I open my eyes to see Granny standing by the open rear car door holding an open box of donuts. "Do you need Granny to help you up?"

"No ma'am, I can do it." I slowly push myself up and scoot toward her. "Where's Mom?"

"I'm right here Tootie Fruitie." I turn my head to find her sitting in plain view in the driver's seat. I guess I am so disoriented I did not even notice her. "Are you still in pain?"

"It's not that bad."

"Liar." Mom flashes her half, can't fool me smile in the rear view mirror at me.

I return the expression as I take the napkin from Granny's hand. "Thank you Granny."

"You're welcome. They're hot and fresh—melt in your mouth." I take the napkin and wrap it around a sticky glazed donut. The heat from the hot glaze penetrates the thin napkin and adheres to my fingertips. I begin repositioning myself in my seat. "Get two or three. There's a dozen in this box."

"I'm not very hungry Granny."

"I know Sugar Foot, but you need something sweet. Your mom told me you gave a lot of blood today. You know Granny knows all about giving blood. Please, eat another one for me."

Unable to resist her loving persuasion, I hold my hand out for another napkin. Granny hands it to me and I reach in to grab yet another sticky treat. "Thank you Granny."

"One time is enough."

"Yes ma'am." I hold both donuts in one hand and return to the process of repositioning myself.

"What are you doing?" Mom says.

"I'm getting back in my seat so you can drive."

"Oh no, we are not going anywhere until you eat those donuts. Just relax and enjoy. There's coffee up here for you and the whole nine."

"Yes, but we have to get Granny back. Granny I know you must be tired."

"Don't worry about Granny. God will take care of me. Besides we're spending the night."

"You're spending the night?" I smile as I bite into the warm donut.

"I know you didn't think we were going to leave you alone like this did you?" Mom reaches back and hands me a cup of coffee. "Here you go Sweetie Girl."

I accept the thoughtful gift. "Thanks Mom, but you didn't pack any bags."

"Girl we went to Walmart while you were sleep and bought contact fluid, toothbrushes, and all. You were knocked out."

I grin with excitement. "We're going to have our own slumber party."

"We sure are." Mom says happily as she bites into a donut.

"Now while we're sitting here we need to discuss this idea you have of going to work tomorrow. I really think you should stay home."

“Mom, we’ve been through this. You know if I don’t show up, they have to find someone to replace me. I am the only one trained to report traffic on a Chroma key wall (green screen). That means whoever they send will have to do audio only reports. Thomas hates audio reports. His whole reason for hiring me was to avoid them.”

“I understand, but this is about your health Gianina! You’re not well. No one even knows what’s wrong with you.”

“I can do it.”

“Really?”

“Yes.”

“So you mean to tell me you can drive with the pain you’re in right now?”

She has a point. I drop my head in silence. “I almost lost my job over paid time off—time off that I earned.”

“I know.”

“If they were mad over that, what do you think they’ll do if I call in sick? It’s too soon.”

Mom lets out a heavy deep breath. “Alright I’ll make a deal with you. If you feel like you have to go to work. I’ll drive you.”

“You can’t drive me. You have to work tomorrow too.”

“Honey, my laptop is in the trunk, and I already called Frank and told him what was going on. So do we have a deal Gianina Hayes?”

“Yes ma’am.”

“Alright, let’s get you home and ready for tomorrow.”

The lab results. I lean forward across my lap, fingers tightly clasped while I anxiously tap my feet on the thin carpet in the exam room. Dozens of disorders and diseases flood my mind as the suspense builds: Multiples Sclerosis, Parkinson’s, epilepsy. God, what if it is a brain tumor? Why couldn’t he just call me with the results first and then schedule a visit to

discuss details in person? I immediately begin rehearsing pertinent questions in my head. How does this affect my lifestyle? Will I have to take medication for this? Does it require surgery? Is it curable? I know once he starts talking I am going to forget all of these questions. More importantly I have to exercise control. No matter what he says, I will not freak out. You got this Gianina. Be stoic, rational, and choose your words wisely.

“Miss Hayes!” Dr. Mathews walks in beaming.

I immediately sit up and place my fidgety hands on my thighs. “Hi Dr. Mathews.”

“And how are you today?”

“Anxious.” Did I really just say that? Where is your stoicism woman? Stay calm and collected.

“Anxious huh? There’s no need for that.”

What is up with all the small talk? He knows why I am here. Why can’t he just tell me what is wrong? “Sooo, Dr. Mathews uh, what did you find?”

“Well . . .” My heart races in anticipation. He pauses and opens a manila folder, slowly flipping through my results. Get on with it already. He pauses at the fourth page, rubbing it in between his fingers. “Miss Hayes I am happy to report you are one of the healthiest people I have ever seen.”

“I beg your pardon. Healthy, I’m sorry but I don’t follow.”

“I mean healthy as in your blood count, creatinine, and glucose are all normal. And your cholesterol—I’ve never seen such great cholesterol. Your HDL is above 80. Do you know how hard it is to get your good cholesterol that high?”

Why is he talking about general testing? What about the Parkinson’s and MS? “Dr. Mathews I thought you were testing me for other things like MS and . . .”

He cuts me off. “Oh yes, yes, I tested you for all of those things. In fact I even tested you for HIV.”

"HIV, why did you test me for HIV and what were the results of the other tests?"

"Well Parkinson's MS are not diagnosed through bloodwork."

Not diagnosed through bloodwork. Stay calm and collected Gianina. "I don't understand. Why was the bloodwork necessary if you didn't need it to diagnose either of the two diseases you were certain I had?"

"I know it probably seems excessive from your standpoint, but it was necessary to rule out any other diseases."

"Remember we did a series of test including an MRI prior to the lumbar puncture. It was the MRI and the lumbar puncture that ruled out MS. I just wanted to be absolutely certain and based on everything I found collectively, I am inclined to believe that you are in perfect health."

I squint my eyes, reflecting on the two seizures I had this morning before I got dressed. How could he say something like this? "But Dr. Mathews, I just had two seizures this morn . . ."

"Whoa, whoa, let's be careful with our terminology here. I would not classify these uh, episodes you are having as seizures."

"Then what would you call them because they are definitely not figments of my imagination?"

He rubs his chin with his thumb and index finger. "Based on your description you are lucid during these episodes and you can remember everything afterward. Let's just call them jerking fits."

His condescending tone sends a rush of heat from my stomach to my chest. I don't give two shits about whether they are seizures or jerking fits. All I want to know is how to make them stop. To top it off he has the nerve to call me healthy, healthy—after all I have been through. He may as well just call me a liar. "Well whatever they are, Dr. Mathews, could you please give me something to make them stop? I know I haven't had a so called jerking fit in front of you, but I assure you I am not making this up."

“Oh no, I would never accuse you of making up something like this Miss Hayes. I just think the cause could be something else altogether.”

Now we’re getting somewhere. I knew he was hiding something from me. “Something like . . .”

“I noticed on your list of prescription medication you take an oral contraceptive known as Yasmin. Correct?”

Utterly confused I respond hesitantly. “Yes, I do.”

He pushes his glasses higher on his nose. “Well I’m going to advise you not to take it anymore.”

“Why?”

“To tell you the truth Miss Hayes, you’re not the only woman who has come into my office with strange symptoms while taking those pills. Personally, I think it’s a nightmare drug and women should steer clear of it altogether.”

Finally, the root of the problem is exposed. “So you think the pill did this to me?”

“Well I think it’s certainly a factor, but I don’t want to blame everything on the pill.”

I lean in and slowly nod my head signaling my desperation to be on one accord with him. “So, you’re saying there is something else going on?”

“Although there is no sign of MS, Parkinson’s or epilepsy, there are two flags on your labwork.”

Will you get to the point already? Just say it for God’s sake. “Flags, what kind of flags?”

“For starters, your melatonin levels are rock bottom and your serotonin was so unremarkable that it was immeasurable. You also have some considerable inflammation.”

“Melatonin, isn’t that an herb or something people take to sleep?”

“You’re absolutely right. Yes it is, but it’s also a naturally occurring hormone in the body. I suspect your insomnia is linked to your low melatonin levels.”

“And serotonin, what is that exactly?”

“Serotonin is a naturally occurring chemical in the body tied to your mood.”

“My mood, what does my mood have to do with anything?”

“Well, let me ask you this; are you depressed?”

Depression, is he joking right now? “Depressed? No, I’m not depressed!” The expression on his face informs me I am burgeoning on aggression. I exhale and lower my voice. “I’m sorry Dr. Mathews, but I am not depressed. What I am is tired and frustrated. Not only am I having these jerking fits as you call them, but I haven’t slept in four days, four days. I nodded off on my way to work this morning. Now I may not know what is wrong with me, but what I do know is that I’m not depressed.”

He softens his tone and redirects. “I understand that Miss Hayes, but you work in a high stress environment. Although I’m not at liberty to name names, you’re not the first news personality I’ve treated. Believe me I’m not saying that these things are not happening to you. I just think that the culprits are stress and those horrible birth control pills that you are on. Like I said, those Yasmin pills are a nightmare drug. I wouldn’t be surprised if a class action lawsuit is filed against them in the near future. Most importantly, lack of sleep can make the body do funky things. I think once we can get you sleeping again and off of those God awful pills you will start to feel better.”

“What about the seizures?” He smiles as he raises his eyebrows and tilts his head forward. I quickly correct myself before he has a chance to. “I’m sorry I mean the jerking fits or muscle flailing—whatever you want to call it. Will it stop too?” He knows what I’m trying to say. Just because I can’t articulate it with the proper terminology doesn’t mean he needs to correct me repeatedly. “It’s not just painful and embarrassing. It’s incapacitating. Whenever it happens, I get weak and either fall asleep or lose consciousness. Did I tell you it happened to me at work in the editing bay? What if I’m live on camera next time? Oh my God, I could never

show my face again.” I pause and envision the negative backlash from the rumors that would start about me. Someone will probably assume it is drugs or alcohol. Before you know it, the public will start vetting me like they did the weather man on Fox News.

“Miss Hayes, Miss Hayes.”

I snap out of my nightmarish daydream. “Yes.”

“I was saying once you start sleeping, I believe your body will balance itself out and the flailing will stop. So, I’m going to prescribe some medication for you okay?”

“Okay.” I always prided myself for taking a more holistic approach to my health as opposed to treating each ailment separately with a pill. I eat healthy, exercise regularly, take vitamins, and now I am on my way to becoming a cliché pill popper. I sigh and accept my new fate. “What should I take?”

“For the pain, let’s try Percocet.” He looks down as he writes the prescription. “And to help you sleep, I’m going to prescribe Effexor. Here you go.” He hands me the small sheet of paper.

Although I am holding a possible cure in my hands I cannot ignore the unrest in my gut. “Dr. Mathews I respect and appreciate your recommendations, but are there any natural alternatives? It’s just that . . . well, this is a lot of medication. I have never in my life been on this many drugs at once. Couldn’t I just take melatonin instead of the Effexor?”

He pauses, leans his hip against the exam table, and crosses his arms. “I understand your concerns, but the objective here is to get you well again. Melatonin can be effective for someone who needs a few extra hours of sleep or to fall asleep sooner, but your case is rather extreme, wouldn’t you say?”

I look down at his illegible scribble on the paper. “Yes, I guess you’re right.” I shake his hand and walk away. A dismal heaviness slows my pace as I walk out of the exam room. It has

to be more than just the birth control pills and stress. I am not an expert, but I know my body.

He is wrong.

Dumping the pill. After mulling over Dr. Mathews' concerns about the birth control pills I was on, I decided to stop taking them. I threw them in the trash last night, praying God would give me another avenue to lighten my cramps and cure my Polycystic Ovarian Syndrome (PCOS). The next order of business is to call Dr. Roberts, my gynecologist. He was so adamant about my needing those pills to prevent future issues with infertility. I left a message early this morning informing the nurse of my decision to discontinue taking the pill. She told me she would relay the message and contact me back with any suggestions from Dr. Roberts.

I turn the air conditioner off, roll down the windows of my car, and open the sun roof allowing the wind to whip my hair. The sun kisses my face providing a glimmer of hope as I visualize a symptom free life. "I'm going to get my life back!" No sooner than I begin to unwind my cell phone rings. I pull it from the cup holder and look at the number across the screen. It does not look familiar, but something tells me I should answer. I use my thumb to flip my phone open and answer. "Hi, can you hold on a minute? I need to roll my windows up."

"Yeah, that's fine."

The voice sounds strangely familiar, but I cannot quite put my finger on who it is. I quickly close the sunroof, roll the windows up and turn the air conditioner back on. "Okay, sorry about that. Umm, to whom am I speaking with?"

"It's Dr. Roberts."

"Dr. Roberts, wow I wasn't expecting to hear directly from you. I thought the nurse was going to call me back with any suggestions you may have offered. I'm glad you called me called me directly. This way there won't be any confusion."

“Right, so what is this I hear about you not taking the pill anymore?” His tone is curt and snarky. He was a bit terse during my last two visits, but I overlooked it in the interest of focusing on my health.

Uncertain of why he is being so rude, I soften my tone hoping to lighten the mood.

“Well, I have been having some rather disconcerting side effects.”

“Side effects, side effects like what?”

“If you recall my last visit I told you I got nauseous every time I smelled chicken, my vaginal region is noticeably swollen, and I’m having issues with acne. I had to see a dermatologist a few days ago. My face looks terrible.”

“And?”

“Ha” I laugh to calm my nerves. I can feel myself preparing to engage him in verbal warfare. I really do not want to do this today, but he is asking for it. “And . . .” Hold it together Gianina. Don’t go tit for tat. “I have been having insomnia and strange jerking fits that are so severe that I have been placed on prescription medication.”

“And what, you think it’s the pill?”

“Well I didn’t have these issues before I took it.”

“So what, you’re a doctor now?” He laughs in between sentences. “Ha, haaa! Listen, I don’t want to pooh, pooh on your little theory, but birth control pills don’t do that.”

“Pooh, pooh? Listen, I don’t know who you think you’re talking, to Dr. Roberts, but it better not be me. And for the record, the theory is not mine. The little theory as you call it came from a Neurologist who informed me he has treated several women with similar symptoms to mine and they were all taking Yasmine. In fact, he referred to it as a nightmare drug.”

“A nightmare drug, really? So let me get this straight, you went to someone who studies the human brain to tell you how your ovaries should function? Huh, I guess I’m in the wrong profession. I should’ve taken this OBGYN specialty and just went out and started performing

open heart surgeries. Kuddos Nina, yeah that's spot on. Look I'm just trying to help you. If you want to be infertile and lose your chance at motherhood that's your business."

I pull the phone away from my ear and squeeze it while I glare at it. I held back long enough. His smug ass is going down. "Help me, that's highly debatable Dr. Roberts. You know Dr. Roberts, I've been thinking . . ."

"Thinking huh, oh please enlighten me Nina."

"Yes I've been thinking and I have another little theory perfectly packaged with a big, red bow just for you."

"And what would that be?"

"Well, you did provide the same diagnosis and prognosis for two completely different women. Not to mention, you prescribed the exact same medication for both of us."

"What two women?"

"Me and my best friend Saida. Oh, I'm sorry. Have you prescribed Yasmine for so many women that you can't keep track?"

"What's your point Nina?"

"I don't know Dr. Roberts. What is my point? Why don't we discuss it over dinner? You can pay for it with that hefty kickback you're getting for convincing your patients they all have PCOS."

"Kickback, what do you, uh what do you mean kickback?"

"You know exactly what I mean! What respectable doctor who took the Hippocratic would argue with a patient about taking a birth control pill when he could simply prescribe another brand? I'll tell you what kind of doctor would do that, one who is more concerned about his pockets than his patients. You're a sellout! Do you have any idea what you and your unethical principles have cost me? Do you? Oh, and before you fix your mouth to make another smart ass comment I suggest you take a moment to remember who I work for. I could

be at your door with a camera crew in two hours flat.” I can’t believe I just did that. I have never played the news card before, but this man has to be stopped.

He quickly back pedals. “Listen, listen if you are not comfortable taking these pills I am certainly not going to force you to take them. It’s your decision.”

“Wrong Dr. Roberts, it’s not just my decision. It’s the decision of every woman who walks into your office. I’ve already spoken with Saida about the side effects of this pill. She’s having some issues with it as well. So, not only are you going to take the same stance with her that you’re taking with me, but you’re going to take that same stance with every woman who is under your care. If I ever hear that you so much as suggested a woman take this pill for PCOS, I will bring her to the news station and have her share her story with our entire viewing area. Are we clear?”

“Look I don’t want any trouble.”

“Then stop making it!” An awkward silence persists for roughly 10 seconds.

“Listen, your follow-up visit will be free, no copay okay?”

“Follow up, after what I’ve been through. You must be out of your mind. You’re lucky I don’t sue you.” I break yet another awkward silence. “Goodbye Dr. Roberts.”

“Click.”

Side effects of Effexor. Four weeks have passed since I began taking medication and I am riding, what seems to be, a roller coaster toward recovery. The jerking fits have slowed down from three to four times a day to only once a day, but my vitality is another story altogether. Never have I been so fatigued. Just the other day I slept through my alarm and was two hours late for work. If it were not for Lila, the morning producer, calling my cell phone repeatedly I would have slept the day away.

Possibly the most shocking of all is my dramatic weight loss. My size six clothes are now baggy. Even my undergarments—which were once taut—ripple and gape around my bust

and rear. I look into the mirror sifting through this physical plane of confusion, desperately seeking a shred of familiarity. Who is this skinny woman staring back at me? It's no wonder I am so thin given my nearly nonexistent appetite. Just one small meal a day makes me feel like I've gone back for seconds at Thanksgiving dinner. I pray this is just a temporary adjustment period.

Fissures. A painful jerk in my intestines causes me to swerve while driving. "Whoa!" I regain control of the wheel and position myself in my respective lane as the woman next to me honks her horn. My insides feel like I swallowed a brick. It must be something I ate. I reflect on my usual patterns and realize it has been over a week since I had a bowel movement. A whole week, how did I let an entire week go by unnoticed without having a bowel moment. Normally I have a movement once or twice daily. Perhaps my low appetite is to blame. Whatever is happening right now I know I need to get home fast. My knuckles whiten as I tighten my grip on the steering wheel. "Uhh!" I lean forward and clench the wheel even tighter as the pain barrels down again. "Hold on, you're almost home girl."

My wheels screech as I skid into my parking space. I turn the car off, snatch my purse out of the passenger seat and bolt out of the car. I sprint toward the stairs and shield my tender belly with my forearm as I climb. The door key, why didn't I get it ready before I jumped out of the car? Nervously I sort through my keys. Another sharp pain stuns me. I stop for a moment and collect myself. I hear a voice through the door across the hall. Oh no, it's Jason. I cannot have him asking questions right now. "Come on, come on" I whisper as I continue to sift through my keys peeking over my shoulder intermittently. "Got it" my unsteady hand struggles to get the key into the lock. "Damn it, come on." I hear the lock on Jason's door snap. My heart races as I use both hands to help guide the key into the lock. The hinges on Jason's door creek echoing loudly across the breezeway. With one swift motion, I twist the key and doorknob simultaneously while pushing the door open. I lightly close the door behind me and lock it. The

loud slam of Jason's door quickly follows causing the pictures on my wall to gently sway. I made it.

Quickly I step out of my shoes and rush toward the bathroom. I unbuckle my pants and snatch both my pants and underwear down to my ankles concurrently. The pain worsens as it travels further into the pit of my gut. Now cradling my stomach with both forearms, I rock back and forth on the toilet, as a pain that can only be described as fiery razor blades shoots through my rectum. "Oh God!" I scoot forward on the toilet seat and look back at my feces swimming in bright crimson water. "What the . . . wait am I on my period? No, I can't be. My period is not due for another two and a half weeks. Oh no!" That means the blood could have only come from one other place. I pull the toilet paper, wrap it securely around my hand, and reach back to wipe. "Ahh!" Even the soft tissue tears my tender skin. I close my eyes tightly as I bring my hand forward for the verdict. "Please don't let it be bloody. Please don't let it be bloody." I open my eyes to see the blood-soaked tissue.

In complete shock, I abruptly stand and throw the tissue into the toilet. Consumed with raw emotion I look up and begin questioning God. "Why, huh? Why? Why won't you give me a break? What have I done that's so bad that I have to deal with this? I know have a temper, but my God do I deserve all this? What the seizures, the numbness and tingling, the partial paralysis wasn't enough? What I have colon cancer now too?" My body trembles as I count my good deeds on fingers. "I go to church. I pay my tithes. I, I, I give money to the homeless. I try my best to follow your teachings. As a matter of fact I'm celibate . . . celibate! Do you know how hard it is to wait on you for a husband in world where no one wants to wait for sex? I may not be perfect, but I'm a good person! Is this what I get for being good? What more do you want from me Lord? How much more do I have to take? Answer me!" I bang my head against the bathroom door as I come to the realization of what I've done. I just yelled at my most trusted friend. "Please forgive me. I'm so sorry God. I never should have yelled at you. I just

don't understand. You said you would never give me more than I can bear and this, this is too much. It's too much." The weight in my chest chokes me allowing only silent cries to escape my lips as the steam from my hot tears blurs my vision.

A warm tickling sensation down the inner back side of my thigh draws me from my bawling stupor. I must have let a mosquito in. I slap my thigh and draw back my hand expecting to see the squashed culprit. Instead my palm is smeared with blood. I duck shuffle back toward the toilet, grab a wad of tissue, and lightly dab the affected area until the last tissue comes back clean. It's too late to make it to Urgent Care and I'm not spending a penny to sit in emergency all night. I pop the top off of the Vaseline and lightly swipe a clean piece of tissue across the greasy substance. I look at myself in the mirror as I lightly dab the glazed tissue on my bottom. Will I live to see 30?

Memory loss. "Where are they? Where are they?" I mutter to myself as I sift through my closet searching for my favorite pair of jeans. "I know I'm not crazy. My closet is color coded. They have to be right here in this section." I continue my frantic search, jumping up and down snatching the folded clothes from the top shelf and tossing them over my shoulders. Saida's on her way and I'm not even dressed. One of my coworkers Milton is having one of his legendary barbecues and I was in charge of the vegetarian cuisine. I spent so much time preparing the food I did not even lay out my clothes. A knock at the door reminds me my time has run out. "Uhhh!" I rush to the door in my nightgown and look through the peephole.

Saida's holds her face close to the peephole warping her soft features. "You know who it is!" I open the door and step aside to let her in.

"You mean to tell me it's noon and your still not dressed."

I immediately walk to the kitchen to see if the casserole is cool enough to transport. "Hey don't judge me. I overslept and I've been cooking since I got up."

"Cooking, cooking what?"

"Oh, I didn't tell you?"

"Tell me what?"

"Milton put me in charge of the vegetarian food. It's still too hot to put in the car. Want to taste it?"

Saida peeks under the foil. "Looks great, but no thanks, I already told you I grew up on tofu and all that stuff, and I'm over it. Everything I eat now has parents."

"Huh, your loss."

"No, my loss is waiting on you when we're already late. You want to tell me why you're not dressed yet."

"I told you I was cooking."

"My point exactly, you were cooking. The food is done, yet here you are with all your goodies hanging out of your gown. What's the problem?"

"Come with me." I walk down the hall toward my bedroom. "I can't find my jeans. Maybe you can help me."

"Which pair?"

"My favorite ones, you know the low rise with the stripes." I stop at the entrance of my closet when I realize Saida is no longer behind me.

She stands still in the doorway with a look of bewilderment. "What the hell happened in here dude?"

"What are you talking about?"

"Um, your room."

I begin sifting through my clothes in the closet again. "What about it?"

"Are we looking at the same room?"

"I told you I was looking for my jeans." I continue my tirade of hanger sliding and clothes tossing when I feel Saida's hand on my shoulder.

"Come here."

"What? I'm trying to find my jeans."

"Look."

"Look at what?"

"Your room, it's a hot mess." I look around the room and notice clothes strewn everywhere. My dresser drawers are open with clothes overflowing from them. I was so consumed by trying to find my jeans I had not even noticed. "Nina, this isn't like you at all."

"I know." I plop down on the bed and sigh. "I just never seem to know where anything is anymore and I always used to know where everything was." I shake my head in disappointment. "Do you know how many times I leave my room to get something and I can't remember what it was or how many times I've lost and found my keys this week alone?"

"Well sometimes we forget things. I mean, I forget sometimes too."

"It's not just forgetfulness. Sometimes I feel lost. It's like I know I have something to do, but I'm not sure what it is. I can't explain it. It doesn't even make sense to me. I'm doing everything I'm supposed to, but something just isn't right"

"Saida wraps her arm around me. I know you've been having a hard time lately. Soo, I brought you these." She dumps a bag of clothes on my lap.

"Where did these come from?"

"I had this bag in my hand the whole time and you're just noticing it. You need coffee. As a matter of fact I'm going to make some while you get dressed. And hurry up, I'm going to need some liquor after all this. Hold on, you did remember to take a shower right?"

"Yes, I remembered to take a shower, but I forgot what a smartass you are. Remind me to slap you when I get dressed."

"Whatever, me . . . coffee, you . . . dressed!"

"Wait."

"What?"

"Thanks Saida."

She turns and smiles. "No problem homey. Now hurry up! I'm hungry."

Weight Loss and Accusations. I clasp my hands tightly overtop my crossed legs anxiously waiting for my news director Jeff to turn around from his computer and face me. "Juuuust a minute Nina, I'll be right with you after I finish this email."

I begin racking my brain, desperately trying to determine why I am here. Tom never calls me into his office unless it is to praise my performance level or offer constructive criticism, but lately my performance level has suffered greatly. I slept through half of a shift, not to mention the vacation in New Orleans debacle. Is he going to fire me? I should have seen this coming. "No problem Tom." No matter what he says, I will hold my head high and shake his hand on my way out. I can scream in the car on the way home. Ooh, I completely forgot about the jerking fit I had a few weeks ago. Although the meds are improving the jerking fits, it has not stopped them. I am sure word got back to him. There is no way to accurately articulate everything I am experiencing. So, I simply inform my coworkers that I am unwell. Having a jerking fit at work was the most embarrassing thing I have ever experienced. I remember the looks on the faces of my coworkers.

I had just given my third report for the morning and walked back to my desk. As I placed my hands on the keyboard the conversant, cold, tingling sensation began creeping up my legs. My next report is in a matter of minutes. There is no way I am going to allow myself to be seen like this on live television. My legs continue to lose sensation as I walked over to the producer's desk. "Lila."

"Yes." She answers while typing feverishly.

"My legs are cold. I'm uh, I'm afraid something is going to happen. Would you please cut my next report?"

She spins around quickly in her desk chair and faces me with furled brows. "Yeah, no problem at all. Are you alright?"

"Yeah, I just need a moment." The tingling reaches my hips weakening my legs. I have to get out of there fast. "I'll be in the editing bay if you need me."

"Okay." She answers hesitantly.

Bruce a member from the floor crew rushes to my side. "Are you okay Nina?"

"I just need to get to the editing bay and sit for a minute." Bruce was a tall, pale, dark haired man. He once told me he was what was known as Black Irish in his homeland. Although we could not be any more different appearance wise, we found common ground through our socially constructed labels.

Bruce walks with me to the editing bay and helps me into my seat. "I'll grab a chair and sit with you for a minute."

The cold tingling sensation spreads to my waist. It's only a matter of time. He has to leave. I can't let him see this. "No Bruce, I'm fine. I just need a moment to myself."

His quiet stares questions my honesty. "If you say so, I'll be down the hall if you need me."

I swallow hard and nod. He leans against the door frame staring at me for what seems like an eternity. Why won't he just leave? God, I can't feel my chest. "Bruce I'm fine, just go." He hangs his head before turning to walk out. Within seconds my neck snaps back and my muscles contract painfully squeezing my ribcage causing me to gasp for air. My right arm flails violently hitting the wall prompting me grunt. "Uhh!" No . . . no . . . no why couldn't I hold it in? Someone probably heard me. My rogue arm swings over and slams down on the control panel, while my fingers randomly strike buttons. Loud popping noises ring out from my spine as my back painfully arches pulling my body away from the chair. My chest heaves with enough ferocity to break through my skin. Succumbing to my body's hostile takeover I sporadically steal

gasps of air. Two figures appear by the door in my peripheral. How long have they been standing there? “Don’t look” I whimper. One sharp jerk sends me falling from the chair. I close my eyes tightly in anticipation of the impact. Suddenly, I feel myself being lifted slowly back into my chair.

I open my eyes and find myself suspended in Sherry’s arms. The full wells of her eyes glisten through her glasses. “I got you Nina.” The painful contractions and twitching worsen as she grips me tightly, repositioning me in my chair. Still gasping for air I plead with her to ease up. “Please, please not too . . . hard. It . . . makes it worse.”

Sherry smiles and loosely holds her arms around me like a basketball goal guiding me back into my seat. My arms resume their ferocious assault on the control board, banging my hands and forearms against joysticks, knobs, and buttons. She leans in and gently kisses my salty cheek. “I won’t let you fall.”

Another presence hovers over me. Unable to turn my head fully, I strain my neck and fight to see who else has witnessed my humiliating ordeal. I clear my throat pushing the knot down just far enough to speak. “Bruce.” Wide eyed, he stands in silence taking in my vulnerable state before storming off. I breathe in through my nose and blink my eyes repeatedly as my movements become less volatile. My vibrantly twitching fingers go limp and curl inward as my back muscles and chest relaxes. “Thank you Sherry.”

She flashes a half grin heavy laden with concern. “You don’t have to thank me. Is there anything I can do?”

It is too late to be ashamed. My secret has already been revealed. Not asking for help at this point would be absurd. “Actually yes, there is. I just need to close my eyes for a few minutes. Would you please walk with me to tell Lila to cut the next segment as well? And, if you don’t mind, could you walk me over to the archives room. I can’t lay my head down on this control panel and it’s too bright at my desk.”

"It's not a problem Nina. Just let me know when you're ready."

Enervated from the contractions, I rock back in the chair as Sherry pulls me to generate the necessary momentum to stand. Sherry takes my hand guiding me with each small, shaky, and uncertain step toward the newsroom. Hopefully Lila will not be upset. I use my free hand to fan my face and hopefully cool my burning, teary eyes. As we turn the corner, I see Bruce wiping his eyes. I drop my head in shame as we turn the corner and cross the newsroom floor and approach Lila's desk. "Lila."

"Yes." She abruptly swivels in her chair to face me. "Oh my God what happened? Are you shaking?"

"I"

Before I can finish my sentence, Sherry speaks on my behalf. "She had some sort of seizure or something. I think she needs to sit the next one out."

"Sure, sure, whatever you need Nina. Are you going to be okay?"

"Yeah, I just need to lay my head down for a bit, Lila. After that I'll be fine."

"Okay hold on." She swivels in her chair again and faces her computer screen.

"According to the rundown, the next segment was your last anyway. So, take all the time you need. It's not a problem." Lila looks me up and down. "Are you sure you're okay, Nina."

I nod before responding. "Thank you."

"No problem Nina."

I stare off into the distance as Sherry walks me to the archives room—carefully staving off all eye contact to avoid further discussion with my coworkers.

I walk through what seems like a maze of stares; some are concerned and saddened, while others are outright judgmental. The heavy whispers fill my sensitive ears like water.

"What's going on with her?"

"I don't know, but she's lost a lot of weight."

“Yeah, she’s really skinny.”

“Do you think she’s anorexic or something?”

“Probably, you know I haven’t seen her eat in a while.”

I recognize one of the voices. It is Tara, one of the field reporters at the station. She quickly shushes the intern she is gossiping with as I get closer. These two must have learned how to whisper in a helicopter. Completely oblivious to the fact that I heard her, she stands and addresses me. “Hey Nina, is there anything I can do to help?”

I quickly reflect on her snide, backhanded compliments about African American hair and how I should wear false lashes because mine were too short. Kate, the morning news anchor, always intervened in the midst of Tara’s underlying verbal assaults. If it were not for Kate, I probably would have allowed Tara’s words to take root. It became clear to me sometime later that her words were not simply skewed observations, but were grounded in jealousy. She had a crush on a coworker who I sometimes socialized with in between reports. Somehow, she perceived our interactions as a threat. I could have easily told her I was not interested in him nor was he interested in me. Truthfully, he had a thing for my best friend Saida and all of the laughing and joking between us, which she found so threatening, was actually about he and Saida. Instead I chose to let her think whatever she wanted. I spent my whole life caring about what people thought. I will not give her, of all people, the satisfaction. “No, I got it.” My flat answer and cold stare relay my awareness of her conspicuous conversation.

The intern’s green eyes widen as she looks at me and then Tara. Tara clears her throat and looks down as she fidgets with her sleeve. “Ahem, okay just let me know.” She holds on to the edge of her cubicle, watching as I continue.

“Tara I think she heard us.”

I finally reach safety. Sherry walks me into the dark room and slowly helps me down into the chair. “There you go Nina.” She smiles before turning me around in my seat to face the desk.

“Sherry.”

“Yeah.”

“I know I already said it, but thank you.”

“Don’t mention it.” She pats me on the back before leaving. No longer able to fight the fatigue, I stack my forearms on top of one another to make a pillow for my head. I just need to rest and everything will be fine.

“Nina! Snap, snap! Earth to Nina!” My daydream is interrupted by Tom jokingly shouting my name and snapping his fingers.

“Oh, sorry Tom.”

“Thought I lost you for a minute.”

“Well, you found me.” I answer nervously.

“Do you know why I asked you to be here today?”

Stay calm and choose your words wisely. “No, no, I do not.”

“I asked you to be here today because I am concerned about you.”

This is worse than I thought. He thinks I’m weak. He would probably rather dispose of me than waste his time waiting for me to get better. I have to plead my case. “Tom I know it looks bad—my health situation and all, but I am slowly and steadily getting better. I am on medication now and that situation I had a few weeks ago, I’m nipping it in the bud. Trust me I am doing everything in my power to make sure it never happens again.”

He furls his brows as he sits back in his chair, forming a pyramid with his hands. “Make sure what never happens again Nina?”

Bewildered, I shake my head and question his question. "I'm sorry Tom what are you talking about?"

"Wow, um I asked you here to talk about your weight."

"My weight?"

"Before you go off onto a tangent, I am not necessarily talking about your weight, but rather the lack thereof."

"I beg your pardon."

"Nina, how do I put this? I think you've gone too far on your diet."

"Diet, Tom I'm not on a diet."

"Are you eating Nina?"

"Am I eating? Of course I'm eating."

"I know there is a lot of pressure to be thin in this shallow industry and sometimes it can cause you to do unhealthy things to yourself."

"Wait a minute. You don't think I'm anorexic do you Tom?"

He grimaces and cocks his head to the side. "According to your coworkers, you haven't put in a breakfast order in weeks."

As much as I hate to admit it, he is right. My appetite is nearly nonexistent these days. "It's not that I am starving myself Tom. I'm just not hungry and I'm tired all the time. I think its these sleeping pills."

"Sleeping pills?" He leans forward in his seat.

"Yes, my doctor prescribed them. Remember the day you said I was dragging on air?"

"Yes, you were definitely out of it."

"I had a spinal tap the day before. I don't know what's going on Tom, but it's not good. My neurologist's theory is if I can win the battle against my insomnia the jerking fits will stop and I can get my life back."

Tom stares deeply into my eyes, searching for truth. “So you’re not starving yourself?”

“No.”

“And you’re not bingeing and purging.”

“No, I hate regurgitating. The only time I do is when I’m sick.”

He nods his head looking down at his desk contemplating my explanation. “Here I was calling you into my office to discuss an eating disorder and you’re dealing with a major health issue. Nina I’m sorry.”

“No, please do not apologize. It’s nice to know you are concerned.”

He nods his head again formulating his next question. “So we’ve established that you don’t have an eating disorder, but can you do something for me?”

I pause for a second, unsure of what I am about to agree too. “Sure Tom.”

“I know you say you’re not hungry, but I really don’t think you understand just how much weight you’ve lost. I heard the producer tell you last week that you’re wasting away.”

“Yes, she did.”

“Before you leave today, run into the archive room and watch some recent footage of yourself. No offense to you, but if the camera adds 10 pounds and you still look skinny on TV that’s not a good thing. And if it’s not too much to ask even though you’re not hungry, can you at least try to eat more?”

“Yes, Tom I’ll try to eat more.” He stands up, signaling my dismissal. “Nina I’m glad we had this talk.”

I reach out my right hand to shake his. “I am too. Thanks for your concern, Tom.”

“Anytime Nina, anytime” he chuckles and sits back down as I leave his office. I never knew I was being watched so closely by upper management.

The truth revealed. I hold the white paper blanket over my bare thighs as I sit upright on the exam table. This is the part I hate most, the waiting—waiting to see the doctor, waiting

on test results, waiting for something to make me feel better. The waiting never seems to end.

Hopefully Tito is not here. I have not returned his calls in over a week.

A sigh of relief escapes my mouth as Dr. Adams walks in with an unknown female nurse.

“How’s it going Miss Hayes?”

“Uh, it’s going, how are you Dr. Adams?”

“I’m doing great. This is Lucy. Lucy, this is Miss Hayes.”

“Hi how are you?” She peeks around Dr. Adams’ massive frame and waves.”

“Hi there” I respond.

“Let’s see here Miss Hayes, your chart says you’re here for . . . oh no, rectal bleeding. Is that right?” He sits on the stool as he further examines my chart.

“Yes.”

“What’s going on back there?”

“I don’t know. I’ve been really constipated lately.”

“How bad, like you skip a few days?”

“Try a week plus.”

He slaps my chart down across his lap. “A week plus! That’s a no, no!”

“I know, that’s why I’m here.”

He makes the proverbial tsk, tsk noise as he continues to flip through my chart. “Ah, I’m pretty sure this is the cause. I see you listed Percocet as one the medications you’re on right now. Actually I stopped taking it after a week. It was too hard to stay awake. I only listed it because I did take it at some point and I wasn’t sure if it was still in my system.”

“Hmm, how long has it been since you’ve taken Percocet?”

“Uh, about four weeks maybe.”

“It shouldn’t be in your system any longer then. That was my first guess, but I can tell

you that some antidepressants are known to cause constipation—although I’m not familiar with the side effects of this one.”

I frown at the thought of this irrelevant statement. “Antidepressants, you know I don’t take those Dr. Adams.”

He pushes his glasses higher on his nose leaning in closer to view my chart. “Maybe I’m misreading your handwriting, but it looks like you wrote Effexor.”

“Yes, I did. It’s a sleep aid.”

“A sleep aid, Miss Hayes to my knowledge, Effexor is just a brand name for venlafaxine which is taken to treat depression. I’m not certain”

I hold my hand out in protest. “Whoa, whoa, whoa are you telling me, this man told me he was prescribing medication to help me sleep and without telling me, prescribed an antidepressant?”

A bit flustered by my suggestion, he shifts on the stool and rephrases. “Well do you think maybe you misspelled it?”

“Absolutely not, I read the name directly off the pack while I was in the lobby to make sure I spelled it right. Here, I’ll get it out of my purse.” I jump down and wrap the paper blanket completely around my waist to cover my backside. With one hand I unzip my purse, pull out the pack, and proudly present the evidence. “See I told you, E-F-F-E-X-O-R.”

He reviews the pack sliding the pill case out, sliding it back in and carefully reading the label. He shakes his head and hands the box back in disbelief. “Yes, this is definitely Effexor.”

The alarming confirmation sends a rush of heat from my chest to my head. “So he lied?” Lucy’s eyes widen as she waits for Dr. Adams’ response.

“Well I wasn’t there. I can’t exactly say he lied.”

“You don’t have to say it. That’s exactly what he did. He lied. I knew he didn’t believe me. Here I am looking for help for my jerking fits and insomnia and I end up being underweight,

constipated, with no appetite, blood in my stool, and I can barely wake up in the morning to go to work. Oh yeah, he's helping me alright."

"I'm uh, I don't even know what to say about this Miss Hayes. This is a lot to take in. Are you alright?"

An intense pressure settles around my eyes. I am absolutely furious, but I have no tears left. I'm all cried out. "How could I have been so stupid, Dr. Adams? I didn't even read the information packet from the pharmacy. I just took his word for it. I mean I know I'm busy, but that's no excuse. I should have read more than just the dosing, but he's a doctor. He's a doctor. He's supposed to have my best interests at heart right?"

"I'll uh, I'll look into this Miss Hayes. For right now we need to focus on what's going on with your rectum. I know you're angry, but could you please lay down so I can take a look?"

"Yeah, yeah, I'm sorry." I stand on the step stool and plant myself on the exam table." I lift my legs, swing them around onto the table, and lay back. "I can't believe he lied." I whisper as Dr. Adams snaps his gloves over his wrists. I never have to waste my time asking him if the gloves are latex free. He always remembers. He's the one who realized I had a latex allergy in the first place.

"Any more issues with numbness and tingling like last time?"

"Yes, just not as frequent."

"What about the jerking and twitching?"

"It's just like the numbness and tingling. I still have it, but not as frequent."

He sits on the stool and glides to the foot of the exam table. "Well that's progress, because let me tell you, I didn't know what to think the last time I saw you. I certainly hope this stops altogether."

"Yeah, me too."

I hear the click of the stirrups as he snaps them into place. “Okay Miss Hayes can you slide down to the edge and put your feet in the stirrups for me?”

I do as instructed and stare at the ceiling mulling over my ignorance. How did this get passed me? “Ow!”

“Is that tender?”

“Yes, very.”

“Hmm.” He pulls the gloves off and tosses them in the trash.

“That was fast. What’s down there? What did you see?”

“It appears you have anal fissures.”

I take my feet out of the stirrups and sit up. “Anal fissures, what are those?”

“They’re basically sores on the anal mucosa.”

“Sores on my anus, I don’t understand how this happened. Do I have colon cancer or something?”

“No, no, nothing like that.”

Dr. Adams’ calming fatherly presence provides zero solace. I need answers. “Then what?”

“Well you did have some complaints about constipation and bloody stool. Sometimes the stool can harden and when it’s finally expelled it can tear the anus on the way out.”

“So I ripped myself open defecating?”

“Exactly.”

“I don’t understand. How did my stool get this hard in the first place?”

“My guess is the Effexor. Antidepressants can often cause severe constipation and stool hardening.”

“What can we do about it? Can I get some Preparation H or something like that?”

“No, that won’t really help. A little nitroglycerin should do the job.”

I frown at the notion of putting such a toxic sounding agent anywhere on my already damaged body. “Nitroglycerin?”

He chuckles in response to the questioning tone in my voice. “Ha, ha I know it sounds bad, but it will help.”

“What are the side effects?”

“Well, it can cause headaches.”

“Headaches, you mean to tell me something I apply on my rear end can make my head hurt?”

“It’s been known to happen.”

“So I can either have a bloody butt or an achy head? This just gets better and better. You know Dr. Adams, I’m not sure what’s worse the fact he lied or the fact that I now have to take medication with side effects to cure the side effects of the medication he prescribed.”

He hands me the scrip and pats me on the shoulder. “Well, let’s see if we can make you better.”

Withdrawal from Effexor. Only 15 minutes are left until my next report and I still cannot remember where I placed the list of traffic accidents. I dig my fingertips into my temples and begin rubbing intensely. “God, where did I put that paper?” A light breeze disturbs my wig followed by a hand on my shoulder. Startled, I release my temples and turn to find Kate.

Her friendly smile lessens my dismay. “It doesn’t count unless you answer yourself back.”

“What? Oh God, I was talking to myself wasn’t I? I’m sorry. I probably should have started with good morning or hi. Let me try this again. Hi Kate.” I flash a bright smile and a corny fan wave.

She returns the hokey gesture. “Hi Nina!” She pulls an empty chair up to my desk and sits next to me. “Do you mind if I sit with you for a minute? You look stressed.”

“Uh you have no idea, please have a seat.”

“What’s going on?”

I lay both hands flat on my desk. “I can’t find my list of accidents for my next report.”

“Oh, it’s right up front.”

I stand and look toward the front of the room. “Up front where?”

“You taped it on the stand near the Chroma wall so you could see it, remember?”

“Oh, oh yeah.” I sit back down and shake my head—embarrassed by my absent mindedness.

“Wait, do you have to add any new accidents to the list?”

“No.”

“Well, we’ve got what four minutes?”

“Yeah, what’s up?”

“I was going to ask you the same thing. You have one of the sharpest memories I’ve ever seen. I have never known you to tape a cheat sheet anywhere. You always memorized your accidents.”

I unclamp the microphone battery pack from my waist and turn it off, signaling her to do the same. Kate nods and quickly turns hers off as well. “I know, I know it’s driving me crazy. I think it’s these pills. I stopped taking them, but they probably haven’t worked their way out of my system yet. The side effects are the worst.”

She smiles knowingly. “Ah, so we’ve graduated to pills have we? Don’t worry pill popping is more common than you think in this business. Not the illegal stuff, but you know valium, sleeping pills, and diet pills the usual. Sleeping pills are the most common. Every news personality goes through a period of insomnia. Personally, I think it’s the fear of not waking up on time that keeps most of us awake all night. So what did they have you on Ambien, Lunesta.”

I lean in and whisper. “It was an antidepressant called Effexor.”

She leans forward in her chair and taps me on my thigh. "Oh, you're on Effexor."

"Shhh! Just tell the world why don't you?"

Kate covers her mouth with both hands as we giggle. "Sorry I didn't mean to say it that loud" she whispers.

"You said it like you've heard of it before."

"I have." She looks around the room and then scoots in closer. "Owen was on it."

"Owen, who's Owen?"

"Oh that's right, he quit before you started working here. He was one of our field reporters. So how did you ween yourself off of them?"

"Ween, I didn't ween myself off. I threw them in the trash." I sit back in my chair and pridefully cross my legs. "I have willpower."

"Yes and apparently you're completely clueless too. Are you crazy? You don't stop taking antidepressants cold turkey. No wonder you've been so clumsy lately."

"Wait, what do you mean I've been so clumsy lately?"

"Nina, you think we all haven't noticed you stumbling around the station."

"And you think that's from the Effexor?"

"Oh God yes, Owen did the same thing. I used to watch him stand by his desk with his arms out like he was surfing."

I rub my nose nervously. "That explains a lot. Truth be told, I have been struggling lately. I have the worst vertigo. Just the other day I parked my car and was freaking out because I thought I was still moving. The nausea, the nightmares, it all makes sense now. I was so focused on getting rid of the side effects, I never even considered the possibility of withdrawal symptoms."

She glances down at her watch and then back up at me. "So how long have the brain zaps been going on?"

“Brain zaps, what are those?”

“Trent told me he was talking to you yesterday and mid-sentence your eyes rolled back and you started shaking.”

I drop my head down in my hands. “Oh my God, is that what that was? I thought my jerking fits were coming back. It sounds like a . . .”

Kate completes my sentence. “. . . wind tunnel in your head.”

“Yes! And it feels like . . .”

“. . . you’re being electrocuted.”

“Yes! How do I make it stop?”

“Honestly, I don’t know.”

“Well, what did Owen do to make it stop?”

She sighs and taps her fingers on my desk. “Owen tried to get off of it. He really did, but the withdrawal symptoms were just too much. So he kept taking it. He said he felt like he was going insane without it.”

My heart sinks as I ponder the possibility of worsening symptoms over time. I know I have a long road ahead of me, but I have to stop. I can’t continue on like this.

“Two minutes and we’re live!” Kate and I stand and look at each other after both getting the message in our IFBs (Interruptible Foldbacks) and walk over to take our places.

“You know if you ever need to talk Nina, I’m here. You don’t just have to wait until you’re here if you have something on your mind.”

“Thanks Kate. I’ll keep that in mind.”

“You’re welcome.” She smiles and quickly powders her face before taking her seat at the news desk.

“One minute everyone. One minute to live.”

Reemergence of symptoms (Layer One Part III)

It has been about a year and a half since my last major jerking fit. Every now and then my limbs twinge and go numb, but for the most part I am healthy again. I have resumed my usual activities and I am no longer dependent upon medication. I have since taken a position at a different news station for better pay. Things could not be better. It's almost too good to be true.

Anaphylaxis. I breathe deeply into my diaphragm as Alyssa counts down in my IFB cueing me in for my next live traffic report. "Five, four, three, two"

"It's a busy day on the highways today. An accident with injuries in uptown on Tryon and Trade is blocking the left lane of the intersection. Also, keep in mind it's Nascar season and both I-85 North and South have regressed from being highways to parking lots. Expect bumper to bumper traffic from the Kannapolis exit all the way to Tryon until approximately eight o'clock tonight. Independence and The Brookshire are slow, but at least moving and I-77 South is riddled with stop and go traffic caused by onlooker delays from an overturned vehicle on the side of the road." The red numbers at the base of the remote controlled camera countdown like a shot clock alerting me to the three seconds I have left. "With your News Fourteen Carolina update, I'm Nina Hayes." I wait until the clock drops to zero and I hear Alyssa's voice in my ear again.

"Alright Miss Nina, you're clear."

"Alyssa, I know my next report is in 10 minutes, but I may need a few extra minutes."

"Uh oh, is your stomach still giving you grief?"

"Yes, I have no idea what's going on. It feels like someone lit a match inside me."

"Oh goodness, well if you can get through this next report you know you have thirty minutes between it and the one that follows."

"I'll try to make it."

"I know you will. You're a trooper."

"Thanks Alyssa, what would I do without your words of encouragement?"

"Um, be sad and pout until I come back."

"You forgot scream and throw a tantrum like a toddler."

"Oh that's a given." Her infectious laugh pours through my earpiece.

We both laugh as I rub my stomach on my way back to my desk. The entire news room is abuzz with scanners, camera men running to grab their gear while the producers remain glued to their desks constantly updating and adjusting the rundown to accommodate live shots and time constraints. I rock back and forth in my chair with my arms wrapped around my waist attempting to soften the agony. My cube mate Kenny takes note of my discomfort. "Nina are you okay?"

"Yeah, mm hmm, I just mm hmm, I don't feel well." My throat feels scratchy and clogged as a metallic taste fills my mouth. "Mm hmm, Kenny would you excuse me for a minute?" Recognizing the familiar symptoms I snatch my mic off and grab my purse. My throat is closing. I'm going into anaphylactic shock. Nearly to the bathroom I feel the sides of my throat rub together. I break into a sprint and burst through the news room door. Just a few feet away from the bathroom, I rifle through my purse for my EpiPen. Now choking I push through the bathroom door and fidget with the button on my slacks until I rip it off. I snatch my pants down to my knees and jab myself harshly in the thigh counting to 10 just as I was taught. A loud gasp escapes my lips as my throat releases its tight grip. Repeated coughing and brief hyperventilating follow the gasp as I gradually regain my breathing pattern. My lunch crawls into my chest and makes its way to my throat. I turn to face the toilet and snatch the locks of my wig back as I heave up the contents of my stomach. In between heaves and coughs, the shuffling of feet breaks through. I realize I am not alone.

“Nina are you alright in there?” The voice sounds fondly familiar, but I cannot make it out.

Fighting the residual dry heaves I respond. “Who’s there?”

“It’s Tara. I saw you running through the news room. I wanted to make sure you were okay.”

Shocked by her volunteering to assist me, I instinctively try to dismiss her. Tara sits on the back side of the newsroom. We barely said two sentences to each other since I started working here. Where is this coming from? “I’m fine Tara. I don’t want to hold you up. I’m sure you have to get back to your desk.” Weakness inches up my legs stirring a trembling inside.

“Are you sure?”

My lips quiver as I form my lips to respond. Not here, I cannot have a jerking fit here. I have not had one in months. “Wait, I hate to ask but I do need your help.”

“What can I do?”

The trembling builds and subdues my jaw causing me to stutter. “I-I-I n-need you to p-p-please walk me back t-t-t-to my desk.”

“Sure no problem, I’ll walk you back in. I’ll be standing here when you come out of the stall.” I fix my torn pants as best I can with my unsteady hands, tucking my loose waistband into the band of my underwear and masking the dishevelment by pulling the hem of my sweater below my waist. “If you don’t mind my asking, what’s wrong?”

“I h-had an allergic reaction to-to-to something and I u-u-used my Epi p-pen . . .”

She quickly interjects. “Oh, that’s why you’re stuttering. You had an epi shot.”

It all became clear, I was not having another jerking fit. I was reacting to the EpiPen. How could I forget the side effects of epinephrine? Trembling, nausea, sweating, and rapid heartrate just to name a few are all a part of the process. Thank God, I cannot take the

embarrassment of another jerking fit at work. I unlatch the stall door and timidly look up at Tara. “Th-tha-ank you.”

She smiles and nods before holding the bathroom door open for me. Beads of sweat form on my forehead as Tara takes my arm and guides me to the newsroom door. “Girl you are shaking. Go ahead and put your weight on me, I gotcha.”

I close my eyes and sigh deeply while she opens the newsroom door. I know everyone is going to have questions. I look to her as she holds the door. “Please d-don’t t-t-tell . . .”

“Don’t worry I won’t answer any questions. I’m just going to get you to your desk and you can answer questions later if you want to. Oh, and this probably goes without saying, but you probably should skip your next segment.” We both smile as I walk through the door and journey to my desk. I fix my gaze on my desk all the way at the front of the newsroom in an effort to avoid the agape mouths and widened eyes peering over the cubicles. I catch John, the cameramen, in my peripheral mouthing “what’s going on” to Tara as we trudge pass. She shakes her head and grimaces in response—accurately communicating now is not the time. He nods and looks away as he returns to his seat. Halfway to my seat, I spy Kenny watching as Tara and I make our way back. The cold beads of sweat on my forehead trickle down into the creases of my eyes. The salt irritates my contact lenses and triggers me to blink. Now positioned in front of my desk, Tara holds me steady as I lower down in my seat.

Kenny turns in his chair to face me. “What’s going on?” Pressed for time I turn to Tara and nod, signaling her to explain while I call the production room. I tune them out as I try to control my tremor to make the call. My shaky hands hesitate in between each number as I carefully dial each one.

She answers after the first ring. “Don’t worry Nina, it’s already taken care of. Just let me know if you need me to cut the next segment after this one too.”

A feeling of relief washes over me “Thank y-you Shhhhante.” Todd’s piercing gaze weighs on me as I open my desk drawer and pull out a napkin to wipe the sweat from my face. The pressure of being watched makes my trembling all the more apparent. I grab a pen and execute a choppy slide to get the scrap paper on my desk front of me. Looking at my computer screen I notice two new traffic accidents added to the list from Metro Networks. I funnel all of my concentration into my hand, attempting to legibly write down the new accidents. The result is messy scribble fit to rival a toddler with a pack of fat crayons. I sigh and shake my head in frustration.

Todd takes note and offers a word of advice. “Nina, maybe you should just go home. Marshall is on vacation. He won’t even know.” Marshall is our news director, a hardnosed, sarcastic, chauvinistic, slave driver whose favorite pastimes are nepotism, discrimination, and overall creating a hostile work environment. If he were here now, he would probably be hovering over my desk badgering me about how much time I need to get back in front of the camera. Most dismiss the notion of chauvinists still existing in today’s newsroom. To those individuals, I say until you have watched your boss extend the curtesy of calling your male coworkers into his office to express his displeasure versus screaming at the top of his lungs in the center of the newsroom at your female coworker—to the point of eliciting tears—keep warm in your little utopias. If you ask me, my determination not to cry provoked a challenge in him along with some of my male counterparts. The perplexity is evident in his eyes when he looks at me. It must plague him to no end wondering what it will take to streak Nina’s mascara. The answer for today is sweat following an EpiPen injection. He can have my silence, my anger, my cynicism, and my sarcasm, but my tears belong to me.

“It w-would be niiice but, I c-can’t drive l-like this. I j-j-just need to put muh-muh-my hhhhead down until the sh-shaking stops.” Todd silently nods in agreement. I lay my head on

my desk for roughly 30 seconds and my phone rings. I see the number from the production room across the caller ID.

"Your mic must be close by you. We heard everything and don't worry about your next segment. Just take it easy until your strong enough to drive home."

"Th-thanks Alyssa."

"No problem Nina."

I hang up the phone and lay my head on my desk once more. I wonder how Granny is doing today. She had chemo. This little fiasco I am facing more than likely pales in comparison to how she is feeling. I awaken suddenly to drool running down my cheek. Startled I sit upright to discover a splitting headache. I hold both of my hands out in front of me. The tremors are gone. I grab my mirror and a tissue to wipe the drool off my face. Mascara tracks extend from my eyes to my chin. The wipe of my tissue exposes my natural hue hidden deep under my layered foundation. I wipe as much of the mascara tracks away as I can before jostling the mouse to wake my computer and check the time. "Seven forty-five!"

Todd walks behind me. "Yeah, you were knocked out." I turn in my chair to face him forgetting all about my smudged makeup. "Damn girl!"

"Shut up Todd."

"At least you're not stuttering anymore, but seriously damn!" I cock my head to the side and shake, releasing laughter. I could not ask for a better cube mate than Todd. He was always concerned and never ceased to have something interesting to discuss.

"It's a good thing it's dark out. I can go straight home without anyone seeing my face."

"Yeah, don't make any stops."

"Screw you Todd."

"Not until you wipe that makeup off." He sticks his tongue out like a fourth grader before turning to walk away. "Goodnight Nina!"

“Whatever man, I’m out of here.” I cradle my aching head in my left hand as I stand and shut down all my equipment. Tonight I will use the usual excuse when Mom and Granny ask why I sound so bad. I’ll just tell them I am tired.

The allergist. After having to use my EpiPen at work last week, I made it my mission to find an allergist. I racked my brain trying to figure out when, where, and what I touched which may have been latex. Could it have been remnants of a pencil eraser on one of the desks in the editing bay or maybe my takeout was cross contaminated with bananas. Bananas are a well-known cross allergen of latex (Mikkola, Alenius, Kalkkinen, Turjanmaa, Palosuo, & Reunala, 1998; Allmers, 2012). Perhaps latex is not the only thing I am allergic to.

According to the young lady who booked my appointment for today, I will know the answer to all of these things before I leave the doctor’s office. If someone saw me driving with these Google Maps directions tightly clenched in my hands they would think I was a fraud. The truth is traffic reporters are only trained to locate and discuss accidents on major roads and highways, and this place is just two blocks from a cul de sack. Who would have thought to place a doctor’s office here? I double check the street number before pulling into a miniature parking lot and finding two empty spaces near the entrance. The architecture of the building reminds me of a 1960s mod home—ranch style with monkey grass and mulch lining the curved, covered entrance. I step up onto the raised sidewalk and open the double doors. The 1960s mod theme persists in the interior with wood walls and burnt orange carpet leading to another set of wood grain double doors. I pull the cold steel handle of the heavy door which opens to a large lobby filled with several groups of dark brown leather couches and chairs, each arranged by round wooden coffee tables covered in perfectly displayed magazines. The light peeking through the blinds creeps along the floor and compliments the warm tone of the carpet. As I make my way to the front desk, I notice two small children giggling and splashing in the stone fountain against the wall. I wonder if they have allergies too.

The front desk is unlike any other front desk in a doctor's office I have ever seen. It too, like the front entrance of the building, is round. It matches the wood grain pattern on the walls perfectly. Both the desk and the area around it are open. The proverbial glass sliding doors which separate the clerks from the patients are absent. The lady at the front desk greets me with a smile. "Hi there, what can I do for you?"

"I have a 10:30 appointment with Dr. Greer."

"What's the name?"

"Hayes, Gianina Hayes."

"Hold on a sec. Yes, I see you right here. I just need your insurance card and ID please."

"Sure." I pull the two items from my wallet and place them on the desk.

"Please sign in right here while I make these copies, and I'll be right back." Upon reviewing the ballpoint pen placed on top of the sign in sheet I notice the latex grip around the base. This is a bit disconcerting considering this is supposedly an allergy clinic. I reach into my purse to pull out my own pen. "Oh, there's a pen right there."

"I saw it, but you see the grip around the base?"

"Yeah."

"The grips on pens like these are usually latex and I don't want to take any chances today."

"Oh, are you allergic to latex?"

"Yes I am."

"Okay I didn't know that." She picks up the pen and twirls it around examining it. "We'll have to keep that in mind. Hey Laura!" A tall red head turns around.

"Yeah."

"Did you know these grip pens were latex?"

"No, I didn't."

"I didn't either. This woman just told me. We may need to get a pack of plain pens to use up here. This could be a problem in the future."

"Yeah, we sure don't need any lawsuits. Thanks for telling us."

"Oh sure, no problem."

The clerk reaches down and grabs a clipboard with a rather thick stack of papers on top. "Good thing you brought your own pen. I was about to hand you another grip pen."

"I know right?" I take the clipboard from her and begin flipping through the pages. If I would have known there would be this many questions to answer, I would have come 30 minutes early instead of 15."

"Yeah, it's a lot. Don't worry if you don't finish. When they take you back, the nurse will ask you the remaining questions and fill them in for you."

I smile and nod my head. "Good to know."

"You can have a seat anywhere and relax while you fill it out."

"Thank you."

"You're welcome."

I search for an empty seat with privacy for me to divulge my personal information on paper. Relieved by the fact no one has recognized me yet, I plop down on an empty couch near a window. The sunshine on my face warms my cold skin. I go through each question answering it to the best of my ability. A small glimmer of hope builds inside of me. This could be the answer to my prayers. I may actually find a solution for my allergies.

"Gee-uh-nee-nee Hayes." The nurse who calls my name surveys the room from left to right. She looks in my direction as I stand and walk toward her. As I near her, I anticipate the usual question which she poses immediately. "Did I say your name correctly?"

"No, but it's not a big deal. No one does. You can just call me Nina."

“That’s much easier. I think I will.” She grins as she walks me over to the scale and takes my weight. “Wow 149, you don’t look like you weigh that much. What are you like a size six?”

“Yes I’m a six.”

“You must have a lot of muscle under there girl.”

“I guess so.” I follow her down the hall and turn the corner where I watch the tile turn to thin carpet, which is also unusual for an allergy clinic; people with allergies are often taught to stay away from carpet. We hang a left where she leads me into the first exam room on the right. We walk in and follow the usual script of taking blood pressure and temperature.

“Your pressure is kind of high.”

“What is it?”

“One thirty-nine over 88, is this normal for you?”

“Yes.”

“Have you taken any allergy medication recently?”

“Um, yes I took a Benadryl yesterday.”

She whips out a pen looks down at the paperwork in her folder. “What did you take it for hun?”

“I broke out in a rash earlier this week and I couldn’t stop wheezing and sneezing. Plus my lips and eyes were really swollen.”

“Well, that’s not good. Do you know what caused it?”

“I have no idea. This happens to me a lot. The only thing I know I’m allergic to is latex and latex is practically in everything. I’m always trying to figure out what I touched.”

“Yeah, latex is in a lot of things from clothes to medical supplies. It’s almost impossible to get away from it.”

“Tell me about it.”

"It says here on the paperwork you gave me you carry an EpiPen. Have you ever used it before?"

"Yes."

"When was the last time you used it?"

"Last week."

"What happened?"

"I was at work. I became really nauseous and all of a sudden my throat starting rubbing and then it closed."

"And you don't know what triggered that either?"

"Not exactly, I had my suspicions about remnants of a pencil eraser on top of a desk I had to use, but I'm still not certain."

"Okay, I'll share this with the doctor and he'll be with you shortly."

"Alright, thanks." As she leaves the room, I wrap my arms tightly around myself to combat the cold and begin planning my weekend regimen. I need to do laundry tonight. Oh yeah I have a hair appointment tomorrow and, of course, I need some groceries. Maybe I should wait on the laundry since I am supposed to meet up with the girls tonight. While mulling over the mundane details of my schedule, I feel a presence. I look down and see a small boy standing in my room wearing nothing but a pull up. I recognize him as one of the children who was playing in the fountain in the lobby. He looks to be about two and a half to three years old. His pale skin gleams underneath his blonde curls which sweep his forehead and kiss his brow bone. His large, round, blue eyes speak volumes of curiosity. He rocks from side to side on the heels of his pudgy bare feet with his hands behind his back looking at me with his head tilted forward. "What are you doing in here?" I ask enthusiastically.

"Where my dister?"

"Oh, you mean your sister?"

"Yeah, where my sister?"

I could not help but laugh before responding. "I don't know where your sister is sweetheart. I think you should go find mommy and put some clothes on. It's cold out here."

He rocks a few more times, and then pauses donning a sly smile. "Bye, bye!" He waves and bolts out of the door.

The adorable and humorous image is difficult to remove from my mind. I find myself still laughing several minutes later when the doctor walks in. "Hello Miss Hayes, I'm Doctor Cole."

"Hi Dr. Greer, it's nice to meet you."

"Nice to meet you as well. Did one of your coworkers refer you to me?"

"I beg your pardon."

"No need to be coy, a lot of your coworkers are my patients. You do work at News 14 right?"

"Right."

"Yes, you're Nina Hayes. I recognize you." Perhaps the concern on my face is far too apparent because he quickly attempts to smooth things over. "Don't worry you're in good hands."

"Um, okay."

"So what's going on here?"

"Well, I keep having allergic reactions, but I am not sure to what."

"And these allergic reactions, what happens when you have them?"

"It depends, it can range from swollen lips and eyes to itchy rashes and anaphylaxis."

"Mm, not good. It says here your throat closed up last week and you used your EpiPen. Is this correct?"

"Yes."

"And the only thing you are sure you're allergic to is latex."

“Yes.”

“And how did you find out you were allergic to it?”

“By being responsible.”

He looks up puzzled at first. After a few seconds, his eyes widen as he leans his head back and opens his mouth in an, ah ha position. “Oh, what an eloquent way to put it.”

“Thanks, I try.”

“So after you saw what was happening down there, you went to see an allergist?”

“No, I went to see my gynecologist who knew exactly what it was, but still ran a myriad of tests to rule out all other possibilities. In fact he instructed me to hold a latex glove in the palms of my hands, count to 20, rub the glove all over my hands, and then wash them. My hands broke out in a burning, bright red, rash with what looked like sores in in under three minutes.”

“Interesting, I bet that was a relief for you.”

“For me and my boyfriend, he was on my hit list.” I wait for him to laugh, but he does not. Not even a chuckle comes out of this guy.

“Miss Hayes, have you ever had a scratch test?”

“No I haven’t. What is it? Will I be awake for it?”

“Oh yes, you’ll be awake. The test is exactly what it sounds like. I will have you lay on your stomach and we will mark your back with a grid. On the grid we will mark you and then scratch each area with small amounts of various allergen extracts. Sometimes there is an immediate reaction. Sometimes it can happen a few minutes or even a few days later.”

“So let me make sure I understand this process. For example, I told you I am allergic to latex. So you are going to mark an area on my back and scratch it with a latex extract to see if I react?”

“Precisely.”

“So what happens if my throat closes up again?”

"It's rare, but if it does occur you're in good hands. We have a multitude of EpiPens and allergy medication to stop the reaction in its tracks. Any other questions?"

"No, I can't think of any."

"Alright, I'll step out. You can remove your shirt and bra and lay on the table. I'll send the nurse in to perform the test, and I'll come back and review the results."

"Alright."

"I'll see you shortly Miss Hayes."

I wait for him to close the door before removing my clothing. This sounds like a quick and simple test. I can get it over with, grab some lunch, and then head back to work for the other half of my split shift.

A soft knock beckons at the door. "Come in."

"Hi Miss Hayes, I'm Cindy"

"Hi Cindy." I turn my head and see a petite blond woman, wearing pink scrubs, with her hair pulled loosely in a ponytail.

"I'll be administering the scratch test for you. Are you cold?"

"Freezing, is it obvious?"

"Yeah, you look like you're shaking a bit, and you're covered in goose bumps. I can put a blanket over your lower body, but I can't cover up your back because that's where I will perform the test."

"Anything will do at this point."

"Alright." She leaves and comes back with a white blanket and drapes it over my lower body. "Okay Miss Hayes, I'm going to clean the area with alcohol first and then I'm going to start drawing the grid."

"I'm ready when you are." She swipes the cold alcohol pad on my back with upward strokes.

“Now you’re going to feel me mark the areas we’re going to scratch.”

“Okay.” Light strokes of a writing utensil, perhaps a marker, dance along my back.

“Wow you’re fast.”

“Well I’ve been doing this awhile. At a certain point, you develop a rhythm.”

“Please don’t forget to include latex.”

“It’s already done.” The joy in her voice impresses her love for her job. “So now I’m going to swipe a small amount of allergen on each area I marked.” Light cold taps travel along my back. This time they are much slower with pauses in between. “Alright here comes the scratch part. You’re going to feel light scrape on each area no more painful than a fingernail. In fact you may not even feel it at all. Just let me know if you need a moment before I start.”

“I’m not squeamish you can start whenever you’re ready.”

“Alright, here we go.” A slight clawing sensation grazes each area on my back followed by a plunk sound as she drops each pen in what sounds like a plastic container. “Now that didn’t hurt at all did it?”

“No, it didn’t.”

“You would be surprised how some people overreact about this. You would think I used a scalpel on them or something.”

I turn my head to fully engage her. “Well you know, some people have a fear of needles.”

“Look at this little old thing. It’s not even a needle. It’s a lancet.”

I laugh as I view the tiny point no larger than the end of a thumbtack. “I’ve seen bigger tips on pencils. You want to see a big needle? Have a spinal tap.”

“You had a spinal tap?”

“Yes, a few years ago.”

“Wow, I hear those can be painful.”

“Oh trust me, it was. FYI you’re really good at your job. You’re courteous and patient. Those two qualities seem to be lacking in some doctor’s offices these days.”

“Aw, thank you so much.” Her eyes light up as she smiles. “I’m going to get the doctor and I’ll be right back. Just lay still for about 15 minutes and we’ll take a look at your back to check for any reactions.” I hear the door close behind her as she exits and suddenly the door creaks open again. “Oh and by the way, I loved the peach you had on yesterday. And I hope this doesn’t offend you, but you’re much smaller in person.”

My head rocks back as I laugh. “Thank you.” Had anyone else made those comments, I would be offended. Somehow her delivery softened the blow. I take a look at my watch. It’s 11:15 already and I still have to find time to grab lunch before returning to work at 2:30. I haven’t eaten since I had breakfast at 2:45 this morning to make it in to work by 3:30 am. No wonder I have a headache. Maybe I should have asked for the rest of the day off. Nah, bad idea, I am new here and still trying to prove myself. I need to save this for a day when I am really sick. I resist the temptation to wrap my cold upper body in the warmth of the blanket Cindy gave me. Time marches on as I nervously gaze at my watch. Fifteen minutes become 30 and 30 minutes quickly approach 40. Fretful as the time slips away, I stand and cover my chest with the blanket as I approach the door. I open it and lean my head out concealing myself from my shoulders down. Looking in both directions I call out for anyone who will listen. “Excuse me, is anyone around? Hello.” I do my best to maintain a soft tone as usual to avoid the bitch label which could brand me for life.

A tall woman, with short dark hair, and print pattern scrubs comes around the corner timidly. “Yes.”

“Hi, I’m so sorry to bother you. Uh, Dr. Greer was supposed to be back to check the results of my scratch test. It’s been almost 45 minutes. Normally I am a very patient person,

but I work a split shift and I have to be back at work very soon. I would truly appreciate it if you could relay the message for me.”

Her blank stare followed by a series of eye bats and half smile signify my soft tone has no bearing on her cynical body language. “I’ll try to find him for you.”

Instinctively, I want to match her tit for tat, but wisdom bridsals my temperament prompting me to smile and say, “Thank you.”

I close the door and return to my previous position lying on my stomach. It is now 12:02 pm. Even if I leave now, I will be caught in the lunch rush traffic. There go my plans to eat healthy today. My only hope at this point is fast food. I guess moving my cheat day 24 hours sooner can’t hurt. Twelve o’ five, and still no sign of Dr. Greer. He said he recognized me and knows several of my coworkers. If he is an avid viewer, he should be aware I work a split shift. At 10 minutes after 12, I stand to my feet and begin gathering my things to get dressed. A knock at the door stops me in my tracks. “Just a minute, I’m not decent.” I grab the blanket and cover my chest. “Okay, you can come in.”

Cindy walks in first greeting me with a smile with Dr. Greer standing tall behind her. “I hear you were looking for me, Miss Hayes. You weren’t going to leave were you?”

“Please don’t be offended, but yes. I work a split shift and I have to be back to work really soon. I haven’t even eaten lunch yet.”

“Well it’s lunchtime now. Eating an hour later won’t kill you. It’s not like you’re eating extremely late or something.” His eyes squint as he delivers the judgmental statement.

“Well, when you eat breakfast at 2:45 in the morning while everyone else is asleep like I do, lunchtime is in between 9:30 and 10:00. And dinner, it usually takes place around 4:00 at my desk via takeout. Given the fact my appointment was scheduled for 10:15 this morning, I had every intention of eating a late lunch—just not this late.”

“Hmm” he replies blank faced. “You can hop back on the table so we can get you out of here then. I mean if you still have time to stay.” His expression and tone elicit an all too familiar, yet foreboding nostalgia. I had no intention of challenging him, just his incorrect preconceived notions; it is now more apparent than ever I overstepped my boundaries as his patient. No matter what I say or how polite I say it, he has already made up his mind about me. I laugh and shake my head as I position myself back on the table for him to view my back. His presence looms over me while he observes my back. “Well Miss Hayes, it doesn’t appear you have any allergies.”

“I beg your pardon? What about the latex? I’ve had multiple reactions to latex throughout my life.”

“Actually, now that you mention it the latex looks to be inconclusive.”

“So what do I do now?”

“The scratch test is only part of your evaluation. We’re going to do some bloodwork today as well and see what we learn from it.”

“How long will it take for the results to come in?”

“You should hear something from us in roughly three weeks. So, you can go ahead and get dressed. Open the door when you’re finished and Cindy will show you where the lab is.” He turns to walk away.

“Wait.” I extend my left hand toward him to keep from rolling over and exposing myself.

“Yes.”

“I know this isn’t the best angle or the correct hand, but I’m trying to shake your hand.”

“Oh, hmm, okay.” The limp handshake confirmed my concerns. His desire to interact with me is now minimal at best.

After quickly getting dressed, I open the door to find Cindy standing there. “You ready Miss Hayes?”

"I am."

"Follow me please." We hang a right out of the room and a left at the end of the hall.

"It's the second door on the left. Good luck Miss Hayes."

"Thank you Cindy. It was a pleasure meeting you. I hope the rest of your day goes well."

She smiles from ear to "Thanks, you too."

I step into the room and see a women with her back turned facing a computer screen.

"Go ahead and have a seat. I'll be right with you."

I quietly take a seat in the chair, and quickly begin assessing the room for danger. The white tourniquet on the table to my right is clearly latex. Even the bandages are latex. I scan the table looking for non-latex alternatives. None are visible. I spy the collection of gloves on the wall. Although they range in size from small to large they too are all latex. For an allergy clinic, this is quite disappointing.

The woman finally spins around in her chair. "Hayes?"

"Yes."

"Alright looks like we're ready to go. Lay your arm on the rest for me and I'll grab the tourniquet."

"Before we get started, did anyone tell you about my latex allergy?"

"Well it says here your latex reaction was inconclusive. I guess we should be cautious huh?"

"I would definitely prefer it."

"Well if you do have an allergic reaction, this is definitely the place for it. We're well stocked antihistamines and EpiPens. Just to be on the safe side I'm going to grab some vinyl gloves." She glides on her wheeled stool across the room, opens a drawer, and pulls out a pair

of purple gloves. The color is a sure sign they are latex free. She glides back in my direction while fitting her hands into the gloves. "Now we can get started."

"Sorry, I need a different tourniquet as well."

"A different tourniquet, I'm pretty sure this one is fine."

"Actually, the non-latex tourniquets are blue and the white ones like the one on the table are latex."

She tilts her forward and looks down at me over the top of her glasses. "You sure?"

"Absolutely sure."

I watch as she glides across the floor again, pulls out the drawer and begins fumbling through it. She pulls out what looks like a blue roll of tape, wrapped in plastic with a white label and positions her glasses to read it. Next she grabs a white roll and repeats the procedure.

"Hmm, I guess you were right. The blue ones are non-latex." She rolls back to me, unwraps the tourniquet, and quickly wraps it around my arm. "Alright make a fist for me." She taps the crook of my elbow with two fingers. "Come on now. There's got to be a vein in there somewhere." She continues to tap unsuccessfully. "Let's try the other arm."

I lay my other arm across the rest. "Just so you know this happens a lot. My veins are small and they roll. So, even if you find one, you may have difficulty penetrating it."

"Thanks for the warning." She wraps the tourniquet on my left arm and begins tapping away. "Hmm, it's not much of nothing, but it will have to do." She swabs the area with alcohol and removes plastic casing around the needle. Steadying my arm with her left hand, she carefully guides the needle into my flesh with her right hand. The clear tube attached to needle remains clear. She pulls back and guides the needle in from another angle, still nothing. "One more time okay."

"No problem." She pulls back slightly still allowing the tip of the needle to remain inside and pushes from a different angle. A tiny bubble forms at the insertion site.

“Oh we definitely don’t want that! Let’s try the right arm again.” She carefully slides the needle out and hands it to me. “Sorry, but you could you hold this for me?”

“Sure.”

“I hate to ask, but I don’t want to lay it on the germy table and then reinsert it you know?”

“I understand and agree whole heartedly.” I hold the needle in my left hand while she unties the tourniquet on my left arm. She quickly switches sides and wraps the tourniquet around my right arm again.

“Come on now, we need some blood today.”

I look at the clock on wall while she relentlessly taps. It is now 12:41. Dear God please speed this up so I can go. At this rate, I will not even have time to wash off and reapply my makeup. The pinch of the needle breaks my thought pattern. I lean back and relax while she continuously guides the needle in and out at different angles. “Bleed child!”

“I told you. You may have to take it from my fist. Most phlebotomists do.”

“Nope, wait looks like I got it! Bleeding you is a fulltime job!”

“I know it was difficult, but you did well.”

“Well thank you.” She switches vials for the fourth time.

“How many do you need?”

“Just one more and we’re all done.” She removes the full vial and snaps on the last empty one. I watch until it fills and she removes it. “Okay, let’s bandage you up and get you out of here.”

“I forgot to tell you all those band aids are latex.”

“You know what, they sure are. I’ll just use a little gauze and some paper tape.” She places the square piece of gauze on top of needle before sliding it out. “Press on this for me.” I apply pressure to the area while she tears off two white pieces of paper tape. “Let go for a

second.” She secures the tape to the gauze and adheres the two pieces to my skin. “You’re all set. Just take this paperwork to checkout and you can make a follow-up appointment.”

“Thanks. By the way, I never got your name.”

“Oh, sorry about that, it’s Nancy.”

“Thank you Nancy. I appreciate your patience.”

“You’re welcome, I appreciate yours as well. Most people would have gotten out of that chair after the third poke.”

I smile and wave as I walk out the door. If I hurry, I can get a mandarin orange chicken salad from Wendy’s. It’s fast, but at least it will be healthy.

I have not even done my first report for the afternoon and I am already ready to go home. Falling asleep last night was next to impossible. All I could think about was Granny and how much I wanted to settle down and have children before she dies. Here I am 26 years old and no legacy other than my career. Can I even call my career a legacy? Sure I am on TV, but I am not syndicated. I was the producer and cohost of the number one radio show in my listening area, but it too was not nationally syndicated. Even in the midst of what everyone around me deems to be my successes, I see failure. Sure I have met celebrities, received free gifts, and VIP access to any nightclub in my city, but what I am leaving behind? Granny married the love of her life, bore five children, had six grandchildren, and stayed with her husband until he passed away. She always says “That job isn’t going anywhere.” I understand her completely, but who will look after me if I walk away from it? Men like Poppie who will work to take care of his wife and children are not in abundance these days. In fact, I see more men trying to find ways to get all of a woman’s time and energy with zero commitment on their part. Finding a deep connection in this cesspool we call the dating scene often leaves me feeling hopeless. Being celibate for over three years now is a testament to my giving up on

relationships and love. With the threat of Granny's death looming over me, my conscious decision to put love on the back burner feels like a mistake.

I look at the time on my computer screen. My first report is half an hour away and I am struggling to stay awake. Not sleeping last night really took its toll on me. An afternoon cup of coffee should do the trick. I grab my purse to head toward the break area and feel my phone vibrating. Please don't let it be about Granny; my heart can't take this today. I unzip my purse and notice an unfamiliar number. The area code is local. So, it is definitely not a telemarketer. I flip the phone open and answer as I walk behind the news desk. "Hello."

"Hi, I'm trying to reach a Miss Gee-uh-nee-nee Hayes."

Unfazed by the commonplace butchering of my name I answer calmly. "This is she."

"Miss Hayes this is Laura from Landon Care Facility. Sorry it took so long. I have the results of your recent bloodwork."

"I was beginning to wonder. It has been more than three weeks. I figured it was a good sign. If something was wrong, you probably would have blown my phone up. Okay, I'm ready. What are the results?"

"Well you don't appear to have any allergies, but we do have a concern."

"Which is . . ."

"There seems to be a lot of inflammation in your blood."

"Inflammation, what does that mean?"

"Well Miss Hayes, I'm sorry to tell you, but we're inclined to believe you have lupus."

"What?" I stop midstride and try to maintain an impeccable poker face in the center of the newsroom. "Laura would you please give me a moment? I need to get somewhere quiet."

"Sure, I understand." As I turn to walk toward the exit, my mind is flooded with the memories of my childhood friend Kia. I just lost her a year ago to lupus. She was only 25 years old. She suffered immensely before her passing. Will I suffer the same way? Hopefully my

coworkers think my heavy breathing is from my quick steps and not my fear. Finally, I reach the door and push it open aggressively. I rush to the other side and wait until it slams shut behind me.

“Sorry Laura, now could you run that by me again?”

“Yes, uh based on your test results, we think you may have lupus.”

I sigh deeply. “You said I may have lupus. So you’re not certain.”

“We cannot say with certainty. We are going to review the lab results again to see if we can rule it out. Sometimes inflammation is just inflammation, but given your symptoms and absence of allergies we want to be sure. We just didn’t want to leave you hanging. Miss Hayes, are you there?”

“Yes I’m here. Sorry, I’m just taken aback right now. This is the last thing I expected to hear.”

“I’m so sorry to be the bearer of bad news. I hate making these kinds of phone calls.”

“It’s not your fault, Laura. You didn’t give me lupus.” My nervous stomach begins to quiver recalling Kia lying peacefully in her casket. “Well how long do you think it will take to find out what’s going on conclusively?”

“Honestly, I’m not certain. We will definitely call you when we know something. Okay?”

Fighting my tears encourages my nose to run. I sniffle before replying with an unconvincing “Okay.”

“Have a great day Miss Hayes and again I’m sorry.”

“I’ll try thanks Laura.” I close my eyes as I fold my phone. The time shines through the little window on the front of my phone. I cannot cry here, never here. I open the door and walk back inside. It’s 20 minutes before my next report, just enough time to get this cry out in the bathroom, and grab some coffee before I go live. I rush through the newsroom avoiding eye contact until I burst through the rear doors and reach the safety of the bathroom. Heat

consumes my eyes as I look under the stalls ensuring I am alone. I enter the middle stall and permit myself to wail. Normally I cry silently, but the sound escapes uncontrollably. "God, what is happening to me? Why are you so angry with me? Whatever I've done or am doing please show me and I'll stop. I don't, I don't understand." Wrapping my arms around myself I lean against the wall of the stall and release the last round of tears. I picture Poppie in full uniform, donning his pristine ribbons standing at attention. The time for crying has passed and now it's time to move on. I clear my throat as I regain my composure and begin carefully dabbing my eyes to keep from disturbing my makeup. I unlatch the stall door and check my makeup in the mirror. My mascara stayed put, but my eyeliner is smudged, an easy fix. Quickly I discard the wet tissue and exit the bathroom. Making a beeline to the coffee maker, I fill my cup with copious amounts of powdered cream and pour the hot stale coffee into the Styrofoam cup. We have some of the most disgusting coffee I have ever tasted. Even when it's fresh it's nasty, but all I care about is staying awake. I stir it until the resistance in the bottom of the cup gives way and produces a light mocha color. Speed walking toward my desk the coffee swirls in the cup, overrunning the rim and burning my hands. When are we going to invest in some coffee lids? I place the coffee on my desk and wipe my wet hand before powdering my face. I reach around to the small of my back to turn on my IFB, and pull my lapel mic under my blazer and clip it on. "Hi Alyssa, are you there?"

"Yes ma'am. Your 20 seconds out." Her pleasant voice is calming and reassuring.

"Thanks Alyssa." After this report, I have to call someone, someone who won't tell my Mom or Granny. More importantly I need to tell someone who can handle it. Saida is still reeling from what happened in New Orleans. Telling her would be a bad idea. Monica and Uncle Tim will push me to tell at some point. Uncle Cook, on the other hand, will tell Mom and Granny before I can even hang up the phone with him. Uncle Kimothy always said I could tell him anything and he could keep a secret. I think it's time to call in a favor.

“Five, four, three, two . . .”

It is 10 am, and I am sitting in the lobby of the Landon Care Facility waiting for my name to be called. A week after receiving the disturbing news of my inflammation, I was asked to come in to review my results with Dr. Greer. Hopefully this will be over soon. I really don't want to rush the way I did last time.

After roughly 20 minutes of waiting, I hear my name. “Hayes.” I guess she wanted to spare both of us the embarrassment. I follow her as we make several turns through the long hallways. “We won't be needing your weight or vitals today Miss Hayes. We're just discussing results okay?”

“Sounds good to me.” We walk pass several exam rooms and straight toward a closed door. As we near it, I can make out Dr. Greer's name. The last time I went into a doctor's personal office it was to receive bad news.

The woman calls his name as she knocks lightly on the door. “Dr. Greer.”

“Come in.” He never looks up to acknowledge me as she opens the door and ushers me in.

I reach across the desk to shake his hand before taking a seat. “Hello Dr. Greer.” Oblivious to my hand hanging in front of him he continues to look down sorting through papers. “Ahem.” My deliberate throat clearing gets his attention.

“Oh yeah, sorry.” He gives me the same brief wet fish handshake he did last time when I left. “Have a seat. I have your results right here, it shouldn't take long.” He flips through the folder until he locates the lab results. “It appears both your scratch test and bloodwork were normal.”

“Normal?”

“Yes.”

“Just last week I received a disturbing phone call from your facility stating I may have lupus. Now you’re telling me none of this is a concern anymore.”

“Yes.”

His blank face and one word answers appeal to my snarky side. “Pardon me if I’m bothering you with these unnecessary questions about my health, but do you have an explanation of what may have caused the inflammation?”

“It really doesn’t matter because we double checked and it’s not lupus. Lots of things can cause inflammation.”

“Riiiiight, so when I break out in hives, can’t breathe, break out in strange rashes, and have these weird jerking fits, you don’t think they’re linked to anything?”

“Let’s not get all worked up here.”

“Perhaps if you weren’t so obviously underwhelmed, I wouldn’t have to be. Do you have any idea what I have been through Dr. Cole?”

“I am not saying none of this has a cause Miss Hayes. I am simply saying it may not be the cause we were looking for. News is a very stressful job.”

“Wow, the news speech again, why do doctors think my job is the root of everything?”

“When I said I treat quite a few of your coworkers, it wasn’t an exaggeration. Although I’m not at liberty to say what any of them are being treated for I can tell you the stress from the industry is definitely a factor. Think about it, your scratch test was clear and so was your blood work.”

“Correction, my scratch test was not clear. I called your office two days later and reported two large welts on my back. Did anyone bother to put it on record?”

He laughs condescendingly while shaking his head. “Miss Hayes, you weren’t even sure where they fell on the grid.”

“Well it’s probably because I bathe thoroughly Dr. Cole. If you advised me about the possibility of delayed reactions I would have scrubbed more gently. Do you remember discussing delayed reactions with me, because I don’t?”

“You laid on the table for 45 minutes. That was an adequate amount of time to establish whether or not you would react.”

“So you knew I had a reaction after I left your office and you made no provisions to see me again? Hmm, you know I find your perspective interesting considering the triage nurse I spoke with said delayed reactions can occur anywhere from a couple of hours to two days following exposure. Perhaps the two of you should compare notes.” I cross my legs and lean back comfortably in my chair awaiting his response.

My nice nasty approach throws him, but does not prevent a rebuttal. “That’s not the point Miss Hayes.”

“Then what is the point Dr. Cole?”

He lets out a deep sigh. The kind your parents let out when you are about to receive a lecture. “Sometimes Miss Hayes people develop what are known as idiopathic hives. The term idiopathic has some psychosomatic implications”

“I know what idiopathic means Dr. Cole. In fact I know what psychosomatic means as well, and before you patronize me any further than you already have, let me inform you I am college educated. Therefore, I don’t need you to pause and explain your big flowery terms. Furthermore, your use of the terms idiopathic and psychosomatic is nothing more than a condescending way to call me a hypochondriac. If you insist on insulting me to my face Dr. Cole, don’t hide behind euphemisms be forthright about it.” An awkward silence fills the room. His eyes narrow as he breathes heavily through his nose. “I’m sorry, should I define euphemism for you?”

His lips curl upward as he delivers his next insult. "I could always prescribe an antidepressant for you. I noticed you were on one in the past. Perhaps it's time for a refill."

"It never ceases to amaze me how when a doctor can't figure out what's wrong with you, you must be depressed. I may be under stress Dr. Cole, but I'm not depressed. Save your prescription for someone who actually needs it. And don't worry about scheduling a follow-up appointment. You won't be seeing me again." I snatch my purse out of the chair next to me and offer him my hand to shake. He stares at it momentarily and looks up at me.

"Good day Miss Hayes."

I smirk and retract my hand. "Good day Dr. Cole."

Fatty liver. I wake up coughing and swallowing hard trying to keep my food from creeping up my throat. A deep dull pain radiates from my sternum to my back making it difficult to breathe. I slow my breathing and continue to swallow hard hoping the food will retreat and return to its rightful place. The bitterness from the bile sours my mouth leaving a sharp twang on my tongue. My alarm clock reads 1:00 am. I have to be awake in an hour and a half to go to work. It seems like I just closed my eyes a few minutes ago. I climb out of bed and walk to the kitchen to get a ginger ale out of the fridge. I recall this very same ritual as a child, waking up in the middle of the night with the taste of bile in my mouth and food creeping up my throat. I would climb out of bed and go downstairs to get one of Poppie's Diet Pepsis out of the fridge. No matter how hard he was snoring, he always heard me. "Is your food in your chest again Toot?"

"Yes sir."

"Drink one of Poppie's Pepsis."

"I already have one. Thanks Poppie."

"Let me hear the sound."

I let out the proverbial refreshing drink sound from soft drink commercials. "Ahhhhhhh!"

"You know not to do that at the table right?" He says jokingly.

"Yes sir."

"Why?"

"Because it's bad etiquette."

"That's right." He would come in and hug while I let out multiple quiet belches relieving the pain and pressure. "Wait a few minutes before you lay back down so your food won't come back up okay."

"Okay Poppie."

I pause in between sips remembering how understanding, yet comical Poppie was. He never missed an opportunity for a teachable moment. Just as I did in my childhood, I let out small quiet belches, but this time the pressure does not subside. The food continues on its upward path. I quickly put the ginger ale on the counter, run into the guest bathroom, and lift the toilet seat. I lift the seat just in time. Forceful heaves initiate painful muscle contractions as yesterday's dinner evacuates. A few dry heaves and coughs indicate I am free to back away from the toilet. I flush and lean against the tub with my legs sprawled across the cold tile breathing deeply. The pain in my sternum is excruciating and unrelenting. Maybe I should call in. This will give them enough time to find a replacement for me. I peel myself from the floor and turn on the faucet to rinse the residual food particles from my mouth. The light from the kitchen provides a dim glow allowing me to make out my tired swollen eyes in the mirror. I definitely need to call in. I can't go on camera looking like this.

With my mind made up, I return to the kitchen to get my ginger ale and take it to back to bed with me. I flip my phone open and make the dreaded call to Terry and ask for the morning off. My apprehension has nothing to do with Terry. It's the news director Marshall who I am concerned about. He is not very receptive to fill ins. No matter how good my replacement is, he always has something negative to say. I guess it is just his way to live in a state of persistent

dissatisfaction. For some reason he is under the impression I should never ask for a day off.

Never mind the fact I arrive at work six hours before him and leave two hours after him.

I can hear the yawn in Terry's voice as he answers the phone. "Hello."

"Hi Terry, it's Nina."

"What's going on Nina? Sounds like your throat is sore, are you sick?"

"Yeah, I'm having trouble keeping my food down. I thought it was just indigestion, but I am in tremendous pain. I think it may be a bug or something. Do you think someone can fill in for me please?"

"Sure Nina, no problem."

"I hate to put you through this. I'm sure everyone is lined up to interact with Marshall."

"You let me worry about Marshall, and you focus on feeling better."

"Thanks Terry."

"Just so you know Nina, Marshall is not the type to compliment anyone. He only makes complaints. Unlike the reporters I sent him in the past, he's never complained about you."

"Are you serious?"

"Yes."

"Then why is he so rude to me?"

"Because he's an asshole."

"Don't make me laugh. I'm going to throw up again."

"Ewe gross, not on the phone."

Even the light chuckle I let out makes my stomach hurt even worse. "Thanks Terry."

"No problem, just give me a heads up if you need coverage for the afternoon shift too okay."

"I will." I strike the end button on my phone and reset my alarm to wake me at 6:30 instead of 2:30. Unable to lay comfortably, I position myself upright in bed and turn on the TV.

The pain escalates and the creeping sensation in my throat returns. I quickly scramble out of bed and into the bathroom. I lift the toilet in anticipation. I heave violently releasing yellow mucous like fluid from both my nose and mouth. The bitterness is even stronger than the first time I regurgitated. I curl my legs on the bathroom carpet square to protect them from the cold of the tile while I rest against the tub. The pain is worse than ever, almost paralyzing. I use my closed left fist to tap against my chest hoping to release another belch, but it never comes. Several minutes pass before the pain lessens a level tolerable enough for me to stand. Slowly and hunched over, I walk to the sink. Water won't do, this time I need Listerine to flush this taste out. I swish my mouth out and return to bed. Still unable to lay flat I reposition myself and lean my head back against the headboard, falling asleep with the TV on.

Sitting quietly in the lobby of the Urgent Care facility I take note of my surroundings. This Urgent Care is a far cry from the one I frequented in Greensboro. The cheap furniture and dated magazines on the scarred coffee table are reminders of what side of town I am on. Finally my name is called and I am escorted to the back by a young African American woman in colorful scrubs. "Did I say your name right?"

"Don't worry about it. No one does. You can just call me Nina if it makes it easier."

"Sorry, it does" she chuckles. "I'm Sherry by the way."

"Nice to meet you Sherry."

"First let's get your weight."

I place my purse in the nearby chair and step onto the scale. Expecting my weight to teeter within the 140-149 range as usual, I was shocked to see her move the large bracket to 150. "One fifty, when did this happen?" I watch in amazement as she uses her index finger to push the smaller bracket to the right. I count aloud with each pound. "One, two, three really? Four, five, six, and a half, you're telling me I weigh 156 pounds?"

“Hey, I’m not telling you this. The scale is. You look like you’re in shape to me. Plus you know we sisters carry a bit more muscle anyway.”

“I hear you, but this is unusual for me. I’ve never weighed this much. Even when I was flabby I weighed less than this.” Utterly disgusted I step down from the scale, grab my purse and follow Sherry into the exam room.

“Let’s get your temp and blood pressure.” She inserts the thermometer in my mouth and reaches for the blood pressure cuff. The thermometer beeps as she presses the Velcro together. “Hmm, are you cold Nina?”

“No more than I normally am. I’m generally a cold natured person. Why do you ask?”

“Your temperature is a little low.”

“What is it?”

“It’s 97.2. We usually like to see it in between 98 and 98.6.”

“Did you drink something cold before you came back?”

“No, actually I finished a cup of coffee in the car before I walked in to help me stay awake.”

“Strange, well I’ll take it again after I get your blood pressure.” She pumps away while I give the room a once over with my eyes. It is small, but very clean. My only complaint is the paper thin walls. I can hear every word the doctor and patient are saying next door. I will be sure to speak softly when it’s my turn. “Alright 142 over 95, you do realize your hypertensive right?”

“Yes, I do. It’s probably my fault. I haven’t been feeling well lately, and I slacked off on working out. It probably explains my weight gain too.”

“Have you thought about medication for it?”

“No, I’m certain I can regain control through diet and exercise.”

“Alright, but if it gets too bad, we need to start you on something. Hypertension is a silent killer Nina. Let me take your temperature again.” She disposes of the first sheath covering the thermometer and replaces it with a new one. “Open and lift your tongue please.” I do as instructed and wait. The thermometer beeps again, and she pops her lips as she checks it. “I have never seen this before! It is still 97.2. Has this ever happened to you before?”

“Only at home, I thought maybe my thermometer was off.”

“Hmm, I’m going to read up on this after you leave. So what brings you in today Nina?”

“I’m having terrible stomach pain. It’s not as bad as it was last night and this morning, but I’m still in pain.”

“Yeah, I noticed you were walking a little funny when you came in. Was it because of your stomach?”

“Yes.”

“And on a scale of one to ten how bad is it?”

“It’s about a seven. Last night and this morning it was 10 though.”

“Did you have any vomiting or diarrhea?”

“Vomiting.”

“When was the last time you vomited?”

“Around 1:45 this morning.”

“Okay, I’m going to give this information to the doctor, and I’ll she will be in shortly. I hope you feel better Nina, and we’re going to work on getting your temperature up and blood pressure down.”

“Yes we are. It was nice meeting you, Sherry.”

“It was nice meeting you too Nina.”

The effects of the coffee begin wearing off and I lean back on the exam table. As my belly sinks down the pain in my sternum resurfaces. I rollover to my side to release the

pressure, and lay in wait watching the door intently. After roughly 10 minutes, the door opens and in walks a petite Indian woman. She looks to be around five feet tall. Her thick, dark eyebrows frame what appear to be kind eyes and her long, black braid cascades over her shoulder dangling at her waist. Please God, don't let her be another Dr. Cole. I'm not in the mood to argue today.

"Hello Miss Hayes, I am Dr. Sharma."

"Hello Dr. Sharma, you can call me Nina."

"Okay Nina, how are you today." She walks over to the sink to wash her hands.

"I'm not terrible, but I could be doing much better."

She dries her hands as she approaches me. I begin to sit up. "Oh no, you can stay right where you are. Just lay flat on your back for me please. I hear you have a colicky stomach today."

I wince as I reposition myself on my back. "I've only heard the term colicky used when referring to babies."

"Oh, adults can be colicky too Nina. You look like you are in pain. Does it hurt to lay on your back?"

"Yes, very much."

"Interesting, and how would you describe the pain?"

"You mean the location?"

"Well, that too, but is it sharp or dull? Does it radiate?"

"It is a deep, dull, ache and it radiates from my sternum to my spine. It's hard to sit or lay in certain positions."

"I see, I am going to raise your shirt and press on your stomach and you tell me if it's tender."

"Okay."

She begins at my lower abdomen, pushing down with both hands while moving them in a circular motion. “Do you feel anything here?”

“No.” She slowly works her way up without resistance until she reaches my upper abdomen. “Ouch!”

“Is it tender here?”

“Yes, very!”

“Okay I’m sorry, but I have to continue.” She moves on to the upper right side which is even more tender than the center.

“Ow, ow!”

She releases the pressure and backs away “I’m so sorry you are hurting like this Nina.”

“It’s okay.”

“I must say I am very concerned about the region where you are experiencing this pain as well as the level of pain you are in. I read that you vomited this morning.”

“Yes, twice.”

“Has this ever happened before?”

“As a child I would wake up with indigestion. It felt like my food was creeping up into my chest. I would just get a soda to help me belch and then I was fine. I never had pain like this though.”

“Okay, so this is new. Would you mind sitting up for me please?”

“Sure.” I am unsure if it is due to Dr. Sharma pressing on my stomach or just the contraction of my abdominals, but sitting up proves difficult.

“I want you to take some deep breathes for me while I listen.” She places the stethoscope on my abdomen. I breathe in deeply and feel an intense pain. “Does it hurt to breathe deeply?”

“Yes” I whisper.

"I'll go quickly. Just a few more times for me please." She moves the stethoscope two more times on my abdomen and makes her way to my back. "Breathe, and one last time breathe please." I lean back on my hands to collect myself for a few seconds. "Nina, I am very concerned here. I think this is more than just a colicky stomach we are dealing with."

"What is it, my lungs? I used to wait tables there were a lot of smokers in those two restaurants."

"No your breathing is fine. I think it hurts when you breath because the problem is your liver."

"My liver, how is this possible?"

"I am not sure yet, but I would like to do three things today. First I want to get your Body Mass Index (BMI), do an ultrasound, and draw some blood. From there I can decide what to give you for your pain." Dazed, I pull my shirt down and step down from the table. "Follow me this way please." I reach for my purse on the way out. "Oh, you can leave it here. We're just going down the hall."

"I keep an EpiPen on me at all times, and I never like to be too far away from it. I hope you understand."

She responds with a concerned smile. "I do understand. Please, by all means take it with you." We make a right out of the exam room and walk straight ahead into an open room. "You can place your purse in the chair right here." I turn around after laying my purse in the chair and am met with an unfamiliar device. Dr. Sharma hands me a black device which looks like a cross between a portable video game and half of a steering wheel. "Place your hands on the metal leads along the handles please."

"Before I do, what is this?"

"Oh, this is the BMI calculator."

"This thing, what happened to the scapula under the shoulder blade?"

“That’s old school, we’ve come a long way.”

I take a deep uncertain breathe before wrapping my hands around the handles. “Okay.” Roughly 10 seconds pass before it beeps. I look down at the screen in amazement. “Forty-two percent, that’s impossible! I haven’t been above 25 % since my early teens. Is it accurate? I mean I’m a 36 double D and my thighs aren’t exactly on the small side. How do we know it’s not calculating my lady parts?”

“Trust me Nina, it is accurate. It may be picking up on visceral fat.”

“Visceral fat, but visceral means deep doesn’t it? Are you saying I have fat under my fat?”

Dr. Sharma holds her hand over her mouth and laughs. “That’s actually a good way to describe it Nina. Please let’s move on to the ultrasound.” Damn, how fat do I have to be to have fat under my fat? Well I did go from a size six to an eight so it makes sense. As soon as this pain subsides, I’m going on a strict diet and exercise regimen. She motions for me to follow her again.

We turn right and walk two doors down. “Alright Nina you can keep your shirt on if you like, but I would suggest rolling it up to your neck. Please unbutton your pants as well and roll them down to your hips.” I follow suit and grimace as I try to lay comfortably on my back again. “Nina have you ever had an ultrasound before?”

“No, I haven’t.”

“It’s very simple. I am going to place a little jelly on your stomach and roll a handheld wand across it. Just like when a woman is pregnant and we want to see the fetus.”

“Will I feel anything?”

“Maybe a slight tickle, but nothing more; if anything the cold jelly will be the most uncomfortable part.”

“Let’s do it.” I look down and watch her squeeze the thick, shiny jelly on my stomach and then place the wand in the blob of jelly. She squints and then widens her eyes before leaning back in her stool. “What is it Dr. Sharma?”

“It’s just as I suspected, but worse.”

“What do you mean worse?”

She pulls the screen to face me. “Do you see this area here?”

“Yes.”

“This is your liver.”

“Okay.”

“Do you see all of these thick dark lines?”

“Yes.”

“That is the fat surrounding your liver.”

“Fat, I don’t understand.”

“This fat we are seeing here should not be there at all. Nina, you have what is known as fatty liver. I am willing to bet this why you are nauseous and in so much pain.”

“So what would cause this?”

“A number of things: excessive alcohol consumption, high cholesterol, diabetes, obesity, pregnancy, hepatitis, etcetera. I don’t want you to panic Nina. This is reversible. You are not doomed to have fatty liver for the rest of your life. Something as simple as a change in your diet can fix this.”

Her positive reassurance falls on deaf ears as I run down the list of possible causes and how each relates to me. “I’ve always had good cholesterol. Doctors always rave at how high my HDL (High-Density Lipoprotein) is. I only drink occasionally and not excessively. I have been tested for diabetes before and my blood glucose was fine. I’m certain I don’t have

hepatitis although my last test was a few years ago. I'm not obese. Well, based on my BMI I guess it's debatable. What else did you say? Oh yeah, pregnancy, I'm definitely not pregnant."

"Are you certain?" She smiles slyly.

"I've been celibate for quite some time now. So unless God has afflicted me with the lengthy gestational period of an elephant, I'm definitely not pregnant. You're welcome to scroll down and view my empty womb if you like." She laughs and slides the wand to down to my uterus. "Wow, you didn't believe me."

"Nina, women get really sensitive about this topic and they are often in denial about it. You would be surprised. It appears you, however, are absolutely correct. There is no baby in sight."

"I told you."

She looks down and laughs. "Yes, you did. Here, take this napkin and wipe the jelly off. I am going to leave you now. Sherry is going to come in and give you some information packets about fatty liver, high liver enzymes, and a corrective diet. She's also going to walk you over to have blood drawn. Afterward, you can schedule an appointment to come in and discuss the results with me. In the meantime, I am writing you a prescription for hyoscyamine. This will help with the colic. It can make you both drowsy and dizzy. So, please do not take it before driving and I would not recommend you returning to work until the pain subsides. Please drink plenty of water and try to avoid alcohol and fatty foods until I see you again." She pauses and holds my hand tightly. "Good luck Nina."

"I will, thanks Dr. Sharma."

"You're welcome."

I wipe the cold sticky jelly from my stomach, pull up and button my pants, and sit up to pull my shirt down. The pain is still intense and now joined by hunger pangs. I realize I haven't eaten since yesterday.

Sherry walks in smiling with a handful of brochures. "How are you doing, Nina?"

"I'm fine, just a little taken aback right now."

"I heard, I'm sorry about your liver, but it's reversible."

"Yeah, she told me, but it doesn't make it any less disappointing you know?"

"I know, I know. Well, try to avoid fatty foods, anything fried, raw oysters, high amounts of sugar and salt, and I'm sure I don't have to tell you to avoid alcohol."

"Not at all, alcohol is not even an issue for me. I only drink twice a week anyway. You know Thursday nights at Therapy Lounge."

"Girl yes, the martinis are on point."

"I know right? Other than Therapy, I have a glass of red wine with my meals."

"You're definitely not doing much, but for now just avoid it altogether."

"Trust me, after what I saw today it won't be a problem."

"Alright, I'll hand these to you and you can take a walk with me to the lab." I place the brochures in my purse and follow her down the hall. "I'll see you in a couple of weeks Nina. Take care."

"You too, bye Sherry."

I stare at the anatomy chart on the wall while shaking my right leg nervously. It has been two weeks since my blood was drawn and no one called to provide my results. I always get tested for the usual stuff. I never miss a pap smear, cholesterol check etcetera. Who would have ever thought to check my liver? I am so glad I found Dr. Sharma and not another Dr. Cole. The anxiety builds with time. My fingers begin expressing the same anxious sentiment of my nervous legs, briskly tapping on the armrests.

Not a moment too soon, the door swings open. "Hello Nina!"

"Hello Dr. Sharma, how are you?"

"I am well. How are you today?"

"Nervous, can't you tell?"

"I most certainly can. Please try to relax. How is your stomach today?"

"Much better, I followed the diet and did everything you said."

"Yes I heard you lost six pounds since I last saw. That's quite remarkable."

"Thank you."

She takes a deep breath and pulls the stool to sit right in front of me. This is not a good sign. "So are you ready for your results?"

"Do you really have to ask?"

She covers her mouth and laughs. "Okay Nina, you tested negative for hepatitis."

"Yes!" I clasp my hands in a prayer pose and look up. "Thank you Jesus!"

"We also ran an AIDS/HIV test as procedure which is also negative."

"Oh, I could have told you I was negative. I was tested after my last breakup. I haven't been with a man since."

"I am pleased to hear this, but I just wanted to rule out all other possibilities."

"I understand."

"I do have some concerns though."

"Like?"

"Well, your melatonin, serotonin, and iron are quite low." I nod in agreement. "You do not look surprised."

"No, this happened a few years back when I started having some weird jerking fits. They looked a lot like seizures, but I was wide awake and able to recall them."

"Really, what did you do about them?"

"The doctor just gave me antidepressants. I don't think he believed me. It's not like I can make myself have a jerking fit in front of him."

"I'm sorry to hear this. It saddens me when I learn how many patients are given antidepressants when they do not need them. Sometimes as doctors we must accept when we are ill equipped to properly diagnose someone. Everything does not require a pill." She shakes her head in disbelief and returns to reading my results. "My biggest concern is although you do not have hepatitis, your liver enzymes are quite high. They read like someone who has cirrhosis of the liver. From what I can tell, it is just fatty liver and nothing more."

"Is this a serious problem?"

"It's not favorable, but it is not detrimental either. Based on the fact you are not a heavy drinker and you do not have hepatitis, I am not concerned. I think as long as you continue to avoid fatty foods, exercise and lose weight you will be fine. However, I am quite concerned about your stomach pain and complaints about vomiting at night."

"What do you suggest?"

"I think you need an endoscopy,"

"So I know what a colonoscopy is, but I'm not sure what an endoscopy is."

"It's quite similar, but on the opposite end. Instead of entering through the rectum, the tube will be inserted into your mouth and down your throat to check for upper gastric abnormalities. This may give us some insight as to what may be causing these issues."

"It sounds like something that will require me to be sedated which means I am going to need a ride and some time off work."

"You are absolutely correct. I would like for you to have this done in the next four to six weeks. I am going to refer you to Dr. Vincent. I have some paperwork regarding your referral. I want you to take it to Mission General Hospital and make an appointment with Dr. Vincent. In the meantime, read over these brochures about endoscopy and what to expect. Do you have any questions?"

"No, not right now."

“Should you have any, please do not hesitate to call alright.”

“I won’t”

She turns abruptly. “Oh yes, do you need a refill on the hyoscyamine?”

“No, I still have some left.”

“Good only take it as needed. Hopefully you will not need it again anytime soon.”

“I hope I don’t either. I was in excruciating pain.”

“Wait, I do have a question. You said my iron is low. I’m not anemic, am I?”

“No, but you are at the bottom of the range. If your iron level declines even a little you will be anemic.”

“I was asking because my aunt is anemic and all of the women in my family have very heavy menstrual cycles.”

She rocks her head back and her mouth opens in an ah ha formation. “This makes perfect sense. Heavy bleeding can definitely cause low iron. I suggest taking Geritol during your cycle. It may help maintain healthy iron levels. Any other questions?”

“No, you have addressed all of my concerns. Thank you so much Dr. Sharma. It is so nice to meet a doctor who actually listens and believes me. You have been beyond helpful.”

“Oh I’m so glad I could help.”

The first endoscopy. I hold my head down as Mom and I walk quickly into the hospital. “Girl hold your head up! I taught you better than that.”

“Mom, I don’t want anyone to recognize me.”

“This is different, you’re in the hospital. No one is going to bother you here.”

“Mom, do you remember the time I went to pick up a pizza? I didn’t have my wig on, no makeup, I was wearing my glasses, and I had on a sweat suit. I just knew I went unnoticed and as soon as I turned around to leave he said he watched me every day and to tell Shauna—the afternoon anchor—he said hello. Did you forget about that?”

“No I didn’t forget, but I sure would not allow it to cause me to walk around with my head down.”

“I hope you’re right, but just in case, I prefer to keep my head down.”

“Okay, I am not going to say another word, but you look crazy.”

“Then I’ll be crazy and inconspicuous.”

Mom glares at me for a moment. “Humph.”

As we near the front desk, I rehearse polite yet concise responses in my head to evade overly long conversations with nosy viewers. An attractive young man sits behind the counter, while two of his coworkers answer phone calls. “Excuse me.”

He smiles brightly. “Yes ma’am.”

“Would you mind telling us how to get to gastroenterology?”

“Not at all, is this your first time at Mission General?”

“Yes, it is.”

“No problem, I can help you out.” He stands and gestures with his hands illustrating each turn. “What you’re going to do is go straight all the way through those double doors, hang a right, and then make the second left. The waiting room will be right in front of you, you can’t miss it.”

Mom and I answer in unison. “Thank you.”

“Oh, you’re welcome.”

We follow his directions making our way toward the waiting room. I do my best to tuck my chin in just enough to hide my face without compromising my line of sight. I made it past the front desk clerk. Please God, don’t let anyone recognize me. Desperate to fight the fatigue, I vigorously rub my eyes and slap my cheeks. “Are you alright Sweetie Girl?”

“Yes ma’am, I’m just tired. I think it’s from fasting.”

“Oh, that’s right. You haven’t eaten since 8:00 last night and it’s almost lunchtime. I bet you are tired and hungry.”

“Yes I am. Come to think of it, I would normally be taking a nap in between shifts this time of day.”

Mom pulls in close and wraps her arm around me as we walk. “Just think, after this we can get something to eat and you can get some rest.”

I rest my head on her shoulder. “I can’t wait.”

We enter through the double doors leading to the waiting room and approach the front desk. This time we are greeted by a woman with chin length gray hair and very sharp features. I look down at her over the high desk and watch the sunlight dance off the diamonds in her rather large, yet tasteful wedding ring. Her eyes remain glued to the computer screen as she greets us. “How can I help you today?”

“Hi, I’m having a procedure done today.”

She immediately looks up, squinting her eyes at me before posing her next question. “Alright, last name please.”

“Hayes.” I slide my paperwork out of the large white envelope and present it to her.

“Hayes, Hayes” she flips through a thick white binder until she reaches the H’s. “And your first name please.”

“Yes, it’s Gianina with a G.”

She looks at me strangely and smiles. “I’m glad you told me. The first letter that came to mind was J.”

Mom places her hand on the countertop and laughs. “Don’t worry you’re not the only one.”

She stands and places the binder on the countertop in front of me, pointing to the blank space next to my name. “Sign here please.” I hand her my paperwork before rescuing the

dangling chained pen, swinging over the edge of the desk. “Thank you, Miss Hayes. I’ll have you all checked in, in just a minute. Go ahead and have a seat anywhere you like and I’ll come to you and go over everything before we send you back okay.”

“Okay.” I quickly sign my name before Mom and I walk to our seats.

As soon as we sit, Mom leans in whispers to me. “She sure was looking at you funny, wasn’t she?”

I lean back and silently mouth my answer back to her. “I know.”

Mom crosses her legs and leans back in her chair. “Mm, I wonder what that was all about.”

I quickly forget about the awkward exchange and focus my thoughts on Granny. She wanted so badly to be here for me, but chemo and germy hospitals don’t mix. With her low immune system, she could pick up anything here. Mom leans in and whispers again. “Here comes your friend.” I look up and notice the woman from the front desk walking toward us with a stack of papers. I do my best to hold in my laughter as she draws nearer. “You’re a mess Mom.” I whisper back to her.

“Alright Miss Hayes, we need to have you sign a few forms.”

“Sure, no problem.”

She closes her eyes and rocks forward before removing her glasses. “I’m sorry, but I just can’t shake the feeling that I know you from somewhere.” Oh no, I knew it. Think fast Gianina. “Have we met before?”

“No, not that I recall.”

She blinks several times before putting her glasses back on. “Hmm, it’s so strange. Your voice, it’s so familiar. I just can’t put my finger on it.”

She’s nearly on to you deflect Gianina, deflect. “You know I get that a lot. Some people have familiar faces and I guess I’m one of those odd balls with a familiar voice.”

She stares at me intently for a moment rubbing her chin before leaning back in her chair and giving me a once over. Damn, she knows who I am. "I guess it'll come to me later."

I sigh quietly inside as I smile at her. "I guess so." I look down and begin reading through the paperwork.

"Oh, no need to do all that, I marked all the spots where you need to sign and I'll summarize everything for you."

"I appreciate that . . ." I pause and look down at her nametag. " . . . Susan, but I don't sign anything without reading it first."

She places her hand over her mouth and giggles. "I understand completely. I like to know what I'm signing too."

As I reach the fourth page, I note a gross discrepancy. "Um, Susan."

"Yes."

"It looks like I'm scheduled to be viewed through the wrong end."

She raises her eyebrows. "I beg your pardon."

"According to this form, I am scheduled to have a colonoscopy today. I signed up for an endoscopy, as in down my throat."

Astonished, she leans over me and mouths the words as she reads silently. "My goodness, it's a good thing you did read the paperwork for yourself. May I?"

I pull my hands away allowing her to take the paperwork from my lap. "I am so sorry about this Miss Hayes. I'm going to take this back and make sure that everyone is aware of this error before we send you back. I can't believe this."

"Thanks Susan." She shakes her head incredulously as she walks away, further inspecting the forms.

As soon as she is out of range, Mom turns toward me smirking. "That's a damn shame." We both shake desperately trying to conceal our laughter. Mom leans in close to my face. "You

are certainly better than I am. After a mistake like that, I would have cancelled and gone home. This is hospital. Anatomy is their specialty and they don't know your behind from your mouth." Our jaws tremble as we continue struggling to hold our laughter in. We collect ourselves and return to our upright positions. "Seriously Tootie, do you want to get out of here?"

"No ma'am. If it was just a routine procedure I would, but you have no idea what it's like for me when I try to sleep at night. I have the worst stomach pain. Sometimes it's so bad I can barely move. Getting out of bed at 1:00 am to vomit when I have to get up in two hours to go to work, it's killing me. I can't go on like this. I'm tired Mom."

She looks at me lovingly and places her left hand on mine. "Okay sweetie girl. Whatever you want to do I'll be here for you."

"Thanks Mom."

Mom leans in again. "Susan was seconds away from figuring out who you are."

"I know. You see I deflected all of her questions."

"Yeah, I have to give it to you. You did a really good job. She probably does what I do in the mornings. I don't have time to sit and watch the morning news, but I turn it up and listen while get dressed. She probably hears your voice every day, but cannot place your face."

"You're probably right. If you don't mind, I'm just going to take a quick nap."

"You go right ahead. I'll wake you up when she comes back."

No sooner than I began to drift off I feel a gentle nudge from Mom. "Here she comes. I hope the paperwork is correct this time." I squeeze my eyes tightly and blink several times to adjust my blurry vision. Just before Susan enters within range Mom utters under her breath. "I tell you what, after you read through it, I'm going to read through it next."

Susan stands directly in front of me and sighs before handing me the paperwork. "Miss Hayes, again I am so sorry. This is a brand new set of forms. I looked everything over and it looks correct now, but please feel free to give it a once over yourself."

I gladly accept the paperwork. “Thank you Susan.” She takes a seat next to Mom and begins chatting with her as I carefully read each page, paying close attention to the fine print. If they don’t know which end they’re entering, God only knows what other mishaps are in store for me.

As soon as I get to the last page Mom abruptly ends her conversation with Susan. “I don’t mean to cut you off, but would you excuse me for a moment?”

“Oh sure, go ahead.”

Mom turns toward me and snatches the paperwork out of my hands. “Thank you ma’am.”

“Mom!”

“Don’t mom me, I told you I was going to read through this after you were finished. You’re tired and sometimes you need a fresh pair of eyes to catch mistakes.” She makes her proverbial deal-with-it face and begins reading through each document.

Susan leans in and concurs. “Isn’t that the truth? Listen to her, this is the best advice you’ll ever get. I sure wish my mom was still around to give me sound advice like yours.”

Mom nods her head as she reads each page slowly before handing the forms back to me. “Okay you can sign.”

“Are you sure? You know I’m tired.”

We both snicker. “Girl, stop wasting Susan’s time and sign those forms.”

I whip my pen out of my purse, quickly sign the forms, and hand them back to Susan. “Here you are Susan. Thanks for taking care of this for us.”

“Oh no, thank you for catching it. This could have been a fiasco. I’m going to take this back and process it. Your name should be called in a bit and we’ll take you back for prep. Do you have any questions?”

“No, I don’t have questions.”

Susan turns and faces Mom. "What about you, Mom, any questions?"

"No, but if I think of any, I will let you know."

Susan turns back to me. "Okay, I'll go ahead and get this started. I hope you don't mind my saying so Miss Hayes, but maybe you should consider voice over work or maybe even radio. You certainly have the voice for it."

"You know Susan I will have to give it some thought." She smiles and walks away. Mom turns to me and snickers before facing forward to watch the TV mounted on the wall.

I plant my forearm on the armrest and support my head in the palm of my hand. Another gentle nudge awakens me from my slumber. I open my eyes widely and stretch. "Are they ready for me?"

"Yep, they just called your name. Do you need me to help you up?"

"No ma'am." I stand and stretch one last time before looking at the clock on the wall. "Twelve thirty!"

Mom laughs as she pulls her purse onto her shoulder. "Yes, you were knocked out."

"I'm not talking about that. My appointment was set for 11:15."

"Well they probably had to discuss the mistake they made. You never know what may have gone on back there. Look, we can discuss this later. Let's hurry up and get you back."

As I walk toward the nurse holding the door open, reality suddenly sets in. I am about to be fully sedated while someone shoves a tube down my throat and into my stomach. The only thing I have ever been sedated for was the removal of my wisdom teeth. This is different. No one was poking around at my insides.

The nurse flashes a coy smile at both of us. "Right this way please." I turn and wave to Susan before following her. Susan hunches her shoulders and waves back excitedly. I wonder if she will see me on the news in the near future and think back on this moment. Will she think I am a jerk or will she respect my right to privacy?

As we walk down the long hallway, a male nurse looks me up and down and then at the nurse leading us and smiles. A female nurse walks passed us and does the same. "Mom flashes a confused look at me. I whisper in her ear. "Either they recognize me or they had a good laugh about the mix up."

She grins and nods her head. "It was a mix up alright."

We enter a small room with four chairs and a gurney centered under a bright light. The nurse turns and faces us. "Ladies I am so very sorry about the wait. We were informed about a major error with your paperwork. Although you requested an endoscopy, it was somehow misconstrued and you were scheduled for a colonoscopy."

I drop my head and smile. "I know I'm the one who caught the error."

She holds her hand over her open mouth in embarrassment. "Oh no, that is the worst. For the record, I didn't do it."

Mom shakes her head. "I've never seen anything like it."

"I'm Shantel by the way."

"Nice to meet you Shantel. I'm . . ."

"I know who you are Miss Nina Hayes. I watch you every morning. You're even pretty without your makeup and hair."

My stomach drops down into my hips. "Wow, um, thank you Shantel."

"You can just imagine the buzz back here when everyone realized we messed up Nina Hayes's paperwork. Oh my God! It was pandemonium. No one wants to be on the news for something like this. Can you imagine?"

Well, there goes my chance to plead with her not to tell anyone who I am. Now I'm pigeon holed into being political. "Everyone makes mistakes. Whoever made the error, tell them I said we are all human. Besides, it's been rectified. It's all water under the bridge now."

Shantel smiles from ear to ear. “You’re so sweet. I can’t wait to tell everyone you’re not a diva. I mean you’re fierce, but you’re not rude. You know what I mean.”

“I do and thank you. You’re too kind.”

“Well, I don’t want to hold you any longer. We have to get you prepped. There’s a robe and a pair of socks on the gurney.” She flips her wrist and drops her chin. You can leave your pants on since we know which end we’re going in now. Okay!” We all laugh. “Well I’m going to leave now. If you need to go to the bathroom, there’s one right over there to your left. The anesthesiologist should be in shortly. Is there anything else I can do for you . . . Nina?” She grins hard and shrugs her shoulders up to her neck.

“No, thank you Shantel. You’ve been very helpful.” She smiles and waves giddily as she backs out of the room, closing the door behind her. I quickly face Mom. “And you were wondering why I was walking around with my head down. That’s two people so far. This is so embarrassing.”

Mom sighs and shakes her head. “I see what you were talking about, this is a trip.”

“But Mom, I have told you about this several times.”

“I guess this is one of those situations where you have to be there. Now I’m here and I get it, but you shouldn’t be embarrassed Gianina. People go to the doctor all the time.”

“Yes they do, but how many of them encounter a bunch of strangers watching their every move? What if they start talking? I know it’s just an endoscopy, but it’s my personal business.”

Mom laughs “Gianina if you look at it, it’s really flattering.”

I scoff at the notion. “You still don’t understand what it’s like for me. This is the kind of stuff that sparks rumors. God only knows what this can turn into.”

“Don’t get upset Gianina. The last thing you need is stress before your procedure. Now hurry up and put that robe on before the anesthesiologist comes back.” I quietly walk over to

the bed and begin undressing. "Here, let me help you. We don't have much time." Mom takes my shirt out of my hands and quickly folds it. I hand her my bra before putting on the robe. I pull my shoes and socks off and put on the hospital-issued socks laid out on the gurney. "Don't forget your jewelry."

"Oh, yes ma'am." I reach behind my neck and fidget with the clasp on my necklace.

Mom steps behind me. "I got this. Take your earrings off." Just as I unclasp the second earring, there is a knock at the door. "Just in time." Mom picks up my things and walks toward the door. "Come on in" she says pleasantly.

In walks a very tan woman with short brown hair. "Hi I'm Candace." Her voice is soothing. As she gets closer, I can see into her kind brown eyes. Something about her screams trustworthy.

"Hi Candace, I'm Regina."

"Nice to meet you Regina. I'm going to go out on a limb and presume the young lady in the robe is our patient Miss Hayes. Either that or you're just into hospital fashion."

"You presumed correctly Candace. I am a hospital fashionista and please call me Gianina." Maybe if I give her my full first name she won't put two and two together.

She laughs heartily. "We're going to get along just fine."

I sit comfortably on the gurney and watch Mom as she pulls a book out of her purse. She is one of the most voracious readers I know. No matter where we go, Mom is always prepared to pass the time with a good book. Alexander Deveraux with an occasional Terry McMillan novel provides her fix. I quickly redirect my attention toward Candace. "Candace, are you the anesthesiologist?"

"Oh no, you'll see her a little later. I came in to get your IV started and check your vitals."

"Oh, okay."

She walks across the room and pulls the rolling stool to my bedside. “First I need to take your temperature and check your blood pressure.” She wheels the cart over and slides the thermometer into its protective sleeve. I open my mouth instinctively and clamp down on the thermometer. She gently grabs my arm and wraps the blood pressure cuff around it. The thermometer beeps. “Hmm 97.2, that’s a little low.” She pulls the thermometer out of my mouth and discards the cover. “Are you cold?”

“Yes, but even if I wasn’t my temperature is a little low sometimes.”

“This is the first I’ve heard of this.” I look over and see mom giving me the side eye.

Candace responds calmly. “Usually we like to see the ideal temperature of 98.6, but it’s not a big deal. I wouldn’t give it too much attention.” The cuff tightens around my arm. “Well let’s see if we can raise your body temperature a bit.” She walks over to the closet and pulls out an extra blanket. The blood pressure cuff lets out a loud hissing noise as she approaches. “Let’s take a look at your blood pressure.” She turns the cart to view the reading. “Oh my goodness, are you nervous about your procedure dear?”

“I am a bit apprehensive, yes.”

“Well, it shows. Your blood pressure is 143 over 95.”

Mom chimes in from her seat. “Not good.”

“Look at me Gianina. Everything is going fine. Just take some deep breaths for me.” I close my eyes and breathe deeply. The Velcro pops loudly as she removes the blood pressure cuff. “Now get under the cover for me.”

I pull the covers back and slide in between the cool sheets. “It’s even colder under the covers.” I roll over onto my side and my knees toward my chest in a fetal position.

“Maybe this will help.” Candace unfolds the blanket and shakes it a few times before spreading it evenly over me. “I’ll get . . .” Out of nowhere, a male nurse barges into the room,

anxiously leaning forward and tightly clasping the door handle. Mom flips her book over in her lap in silence and Candace turns around abruptly. "May I help you?"

He looks directly at me, with a knowing smile. "No, wrong room sorry."

"Well, make sure you knock next time."

He apologizes to Candace, all the while maintaining eye contact with me. "Sorry." He cocks his head to the side and backs out of the room while mouthing "bye" to me. This just escalated from flattering to disrespectful and creepy. Not that I minded his curiosity, but he could have at least knocked. What if I was undressing?

Candace removes the cuff from my arm. "Well that was strange. What kind of person just walks in and doesn't knock?"

"Fans who watch her on the news."

I turn and glare at Mom. "Mom." If she did not know who I was before, she certainly knows now.

Candace leans back and takes a closer look at me. "I thought you looked familiar. You're that traffic reporter, aren't you? Wait don't tell me, Tina, no, no, it's Nina . . . Nina Hayes right?"

I sigh deeply and pull the covers tightly. "Yes, that's me."

"Oh my goodness, I can't believe I didn't recognize you." Her eyes sparkle as she makes the connection. "Well, that still doesn't excuse his behavior. Everyone's entitled to privacy. You're rattled as it is and I certainly don't want your blood pressure to climb any higher. Don't you worry, Nina. I'm going to take real good care of you, just relax and breathe." This time we are interrupted by a knock at the door. "Ah, that's probably Rhonda checking to see if you're ready to go back. Come in."

A young, female nurse pokes her head into the room and looks around before locking her eyes on me. A look of shock wipes across her face. "Oh" she whispers.

“Move girl!” Another voice emerges behind her as another nurse standing behind her neck to see over her. “I can’t see.”

Clearly annoyed Candace places her hands on her hips. “Do you ladies need something?”

The one in front answers. “No, no, wrong room, sorry.” She nudges the woman behind her before backing out of the room. As she closes the door I hear them whispering. “See I told you it was her.”

“This is absurd!” Candace races to the door. “We’re not going to play this game all day. The next person who knocks on this door is going to need a key.” She twists the lock until it clicks and returns to my bedside. “Let’s get this port in dear. Do you have a preference of which arm?”

“Um neither, I have the smallest, rolling veins ever. It may be better to put it in my fist.”

She holds my right arm in her hands and begins to examine the crook of my elbow tapping away with her index and middle fingers. She repeats the process on my left arm. “Yeah, they certainly are small. I mean nothing is popping out.” Gently she takes both of my hands into hers, shifting her eyes between the backs of both of my hands. “Well your veins look much better in your hands. Are you sure want me to do this? It hurts much worse in the fist.”

“I’m sure, I have a pretty high tolerance for pain and we’re already behind schedule.”

“As long as you’re alright with it, I’ll go ahead.” She opens the drawer of the nightstand and pulls out white latex gloves.

“Wait! I’m allergic to latex!”

“Oh goodness, that’s right. I think there’s a box of vinyl gloves in here somewhere. I’ll be right back.”

As she walks across the room mom joins the conversation. “Yeah, we have to be extremely careful with her and latex. She goes into anaphylactic shock.”

Candace continues rummaging through the cabinets. "You know it's really sad. You would think with all the people who are suddenly developing latex allergies, there would be a greater effort to make vinyl gloves more abundant and easily accessible in hospitals. Whenever a latex-intolerant patient comes to the hospital, we have to go on a treasure hunt. It's a shame." She squats down and checks the bottom cabinets. "Ha! We're in luck." She stands waving a box of vinyl gloves in the air. "Alright, let's get this show on the road!" Candace executes her victory march across the room and suddenly, there is another knock at the door. Mom covers her face with her book and laughs.

"It's not funny Mom."

She drops the book. "Maybe not to you, but I think it's hilarious. Mm, mm, mm."

Candace cuts her eyes in the direction of the door. "That had better not be another nosy person trying to weasel their way in here." The door handle giggles up and down. "Who is it?"

"It's Rhonda, I'm checking to see if the patient is ready."

Candace holds her finger up. "One moment Nina, I promise I'm going to get you prepped."

"Keep doing what you're doing Candace. I'll open the door." Mom stands, unlocks the door, and lets Rhonda in. "Hi I'm Regina."

Utterly confused, Rhonda enters the room timidly. "Hi Regina, I'm Rhonda. Um Candace, why was the door locked?"

The gloves snap as Candace pulls them tightly over her wrists. "We had a couple of uninvited visitors trying to sneak a peek at Miss Hayes here."

Rhonda leans back in her stance and snickers. "Really? I heard a lot of the nurses and residents talking, but I didn't think they'd have the nerve to actually walk in here. That's just wrong."

"You should've seen them, Rhonda. They were acting like little children."

Rhonda approaches the bed. “Miss Hayes, on behalf of the medical staff at this facility, I would like to apologize. Unfortunately, we do not receive training on star struck prevention.”

I laugh and shake my head. “This would make much more sense if were actually a star, but I’m just a traffic reporter. This is insane.”

“Your modesty is refreshing, but the fact remains you are on television Miss Hayes. And for some people that spells star.”

“I hear you, but it still makes no sense to me.”

“Goodness, where are my manners? Miss Hayes, I’m Rhonda. I’m you’re anesthesiologist.”

“Nice to meet you Rhonda. You can call me Nina.”

“Nice to meet you Nina. As soon as Candace gets your IV port in, we’re going to wheel you back. I’m going to put a heart monitor on you, and then I’m going to inject you with Demerol. After the procedure is over, Candace will wake you in the recovery room and you can go home. She turns sideways to make eye contact with Mom. Regina, I’m assuming you’re the mother.”

Mom smiles proudly. “Yes I am.”

Rhonda looks back at me. “It must be nice to have such loving support. You would be surprised to know how many people come in here alone and have to wait for several hours after their procedures for someone to pick them up. It’s really sad.”

“Yeah, I’m blessed. I have a great mother and a wonderful family.”

Mom smiles back at me. “Well, when you have a great child, it makes it that much easier.”

“Well Candace, I’m going to leave you to it.”

“Actually, I’m all done Rhonda.” Candace holds my arm up, presenting the port on the back of my hand.

“Well that was quick and you didn’t even make a sound Nina. Most people yelp when the IV goes in.”

“After having a spinal tap that took several tries to find the right spot, nothing seems to hurt much.”

She crosses her arms and walks toward me. “Goodness that sounds horrific!”

“It was far from pleasant.”

“Well you don’t have to worry about a thing. When I get through with you, a hurricane could hit and you wouldn’t even know. Candace, would you mind helping me unlock these wheels?”

“Not at all.” They both bend down and release the locks. “Now Regina, I’ll take her things from you if you like and you can make yourself comfortable in the waiting room.”

“That’s alright. I’ll hold on to them.” Mom gathers her things and walks over to me. “I’ll be praying for you Sweetie Girl. Remember to relax.” She leans down and kisses my cheek before backing away for Rhonda and Candace to push the gurney out of the room.

A sudden feeling of deep seated unrest forms in my belly. Either something is wrong or something is about to go wrong. I wave at Mom and smile, skillfully suppressing my fear. Dear God please do not let it be something with work again. No matter how much notice I give, the moment I put in for time off Marshall has a conniption. I wonder what kind of complaint he’s going to come up with this time. Even my anxiety is no match for my fatigue which attacks ferociously. “Rhonda.”

“Yes Nina.”

“I’m going to take a short nap. Will you wake me when you’re ready to start the anesthesia?”

She laughs and looks down at me. "You're already sleepy before I even inject you, a patient after my own heart. By all means Nina, close your eyes and I'll wake you when it's time." I sink my head deep into the pillow and repeat the Twenty-third Psalm.

A feeling of light pressure on my chest awakens me. I look down and notice a woman placing leads on my chest. "Hi there, hope I didn't startle you. This is just a heart monitor." I nod my head and return to my much needed nap.

"Miss Hayes."

I struggle open my eyes, and sit up seeking the masculine voice calling my name. "Hello."

"Hi there."

"Oh, hi Dr. Vincent."

"Somebody's sleepy."

"Exhausted."

"That's good. The anesthesia should take affect much sooner. Rhonda should be with you very shortly."

"Right here!" Rhonda walks in beaming.

"Do you have any questions before we begin?"

"No, I'm ready."

"Okay, let's get started." Dr. Vincent walks as Rhonda sits bedside.

"How are you feeling Nina?"

"Tired and hungry."

"I know I apologize for how long you had to wait, but we'll be done with you sooner than you know." I nod as I watch her grab a syringe from the tray. "Nina, can you count down from 10 for me?"

"Mm, hmm, ten, nine, eight, seven, si . . ."

“Nina . . . Nina . . . Nina.”

I hear my name in the distance followed by a gentle shake to my shoulders. Bright light sends a throbbing ache to the backs of my eyes. I squint and blink impatiently, desperately trying to decipher the shapes through the blurry haze. “Mm, my head hurts.” A sore, tenderness circulates down my throat. “Ahem! What happened to my throat?”

“A little soreness after an endoscopy is normal.” My eyes partially come into focus. It looks like Candace.

“Hi Candace.”

“You recognize me. That’s a good sign.”

“Hi Tootie Fruitie.”

“Mom?”

“I’m right here. Can I get you anything?”

“No ma’am.”

I search the well-lit room, squinting and opening my eyes repeatedly. I hone in on the open door where a woman is standing in the hallway. “Who’s that?”

Candace turns and barks across the room. “I told you to let the woman rest! You guys are shameless!” The woman in the hallway quickly disappears. “I can’t believe these people. We’re supposed to be professionals.” I look toward each side of me and notice an empty bed on my left. To my right the curtains are drawn with the silhouette of what appears to be a man lying in bed penetrating the thin, white fabric.

“Where am I?”

Candace answers calmly. “You’re in the recovery room dear.” I immediately sit up further aggravating my aching head. “Not so fast Nina. I still have to remove your IV. Don’t worry, it doesn’t hurt coming out. It actually feels good.” She takes my hand and presses down

on the port while slowly pulling off the tape. She then grabs a piece of gauze, places it over the entry sight, and gingerly slides the port out of my vein. “See, not so bad. What am I telling you this for? You barely felt it when I put the port in.” Candace grabs a roll of tape and secures the gauze tightly. I lift my newly bandaged hand and wave. “Who are you waving at your mom?”

“I don’t know?”

Candace looks over her shoulder and sees the three nurses staring back at me. She coolly glides back in her stool—never turning her body toward them—stands and snatches the curtain closed. I watch as their silhouettes turn to face each other in astonishment. One of the nurses verbalizes her disdain. “Ah, ah did she just . . .” She pauses for a moment before motioning to the other nurses. “Come on, let’s go.”

Candace continues on unfazed as Mom laughs silently. “Nina you may want to take some ibuprofen for your pain later on.”

“Okay I will, but not on an empty stomach. I just want to eat first.”

“By all means, go somewhere and eat until your heart’s content. Dr. Vincent will be here shortly to talk to you. After that, you’re free to go.” Careful to avoid the bandaged area she reaches down and shakes my hand. “It was a pleasure working with you today, Nina.”

“It was a pleasure meeting and working with you Candace. Hopefully I won’t be in the hospital again anytime soon, but if I am I hope, I get you.”

She beams with pride. “Thank you Nina. That means a lot.” She reaches across the bed and shakes Mom’s hand next. “It was a pleasure meeting you too, Regina. You raised a wonderful young woman.”

“Oh, thank you. It was a pleasure meeting you as well. You really have a mothering spirit.”

"Well, I have two girls of my own. I just treated her the way I would want my girls to be treated. Ladies, I'm going to head on out. Enjoy what's left of the day and get something good to eat."

"We will, ahem, thanks again Candace." I watch as she leaves the room. "What do you have the taste for Mom?"

"I'll leave that up to you. I'm not the one who just had an endoscopy."

"What about seafood? I could really use some flounder."

"Flounder sounds great. Do you have a place in mind?"

"I have a couple in mind."

"Alright, well you let me know when you narrow it down. Are you thirsty Sweetie Girl?"

"Yes ma'am."

"Here, have some water." I watch as Mom pours water from the small pink pitcher into the white Styrofoam cup. She unwraps the straw and bends it before dropping it into the water. "Wait one second." Mom places the cup on my tray table and presses the button to elevate my head. "There we go." She holds the cup close and guides the straw in between my lips. "How's that?"

I breathe in between sips. "Good, Mom I don't feel good."

"Well you just had a procedure done."

"I know, but it shouldn't make my head hurt and I feel really disoriented."

"It's probably just the anesthesia."

"Knock, knock!" Dr. Vincent walks in stands at my bedside. "How are you doing, Miss Hayes?"

"I don't feel so great and remember you can call me Nina."

"Before I say anything, I am required to ask if I have your permission to discuss this in front of your mother. Are you okay with that?"

“Yes.”

“Okay, well I have a theory about why you’re feeling so bad. Has anyone ever administered Demerol to you before?”

“No.”

“Well I would advise you to never use Demerol again. It appears you have a severe Demerol allergy.”

Shocked Mom questions the notion. “Really, what lead you to believe this?”

“Just as I was about to insert the tube into your mouth, you broke out in huge welts all over your body and your blood pressure started to drop. I’ve never seen anything like it. I intravenously gave you Benadryl and waited for a few minutes. The welts disappeared and your blood pressure went back to normal range.”

“That’s probably why I’m still so tired and disoriented. And my head, it feels like I was hit in the head with a hammer.”

“Yes, those symptoms could very well be the result of your allergic reaction. As far as the results of the endoscopy are concerned, I must inform you I saw some erosion in your esophagus. I took some biopsies and when the results come in I’ll be able to better assess what’s going on.”

Mom chimes in. “Question Dr. Vincent.”

“Yes.”

“What could be the cause of this erosion?”

“It could be a number of things. The main thing we want to be certain of is that it’s not cancerous. I highly doubt it is. It’s more than likely from acid reflux or the excessive vomiting she reported.”

“Mm” Mom’s face sinks as she takes everything into account. “And how long will it take the results of the biopsies to come back?”

"Two to three weeks."

"Did you hear that Gianina?"

"Yes ma'am."

"So I better receive an update about this in two to three weeks or I'm going to come down here and maul your head."

"Huh, yes ma'am."

Dr. Vincent leans back and laughs. "I think mama bear means business."

"Well, Nina do you have any questions?"

"No, I just want to say thank you. You acted really quickly and caught my allergic reaction. I'm beyond thankful."

"You're welcome Nina. I added this allergy to your file for future reference okay."

"Okay."

"Well, if you don't have any other questions, I'll leave you to get dressed and get out of here. It was a pleasure meeting both of you. Have a wonderful day." He waves at both of us before turning to leave.

"Bye" Mom and I reply in unison.

"Alright Sweetie Girl, I'm getting hungry too now. Are you ready to get dressed?"

"Yes ma'am."

The first endoscopy results. "Have a seat Nina. How are you today?" Dr. Vincent rocks back and forth in his chair smiling with his fingertips touching in a pyramid position.

"I'm fine, on pins and needles of course."

He leans forward, opens my file, and flips through several pages before stopping on one.

"Well according to the lab results, there are no signs of cancer."

"Whew, that's a relief."

"I'm sure it is."

“What about the cause of all this, do you have any idea what the root cause of the erosion was?”

“I’m inclined to believe you have GERD.”

“GERD, what’s GERD?”

“It stands for gastroesophageal reflux disease. It’s just a fancy term for acid reflux.”

“Oh, and what about the vomiting and stomach pain?”

“Well that is more than likely related to the GERD.”

“So how do I get it to stop?”

He closes the file and scoots in closer to his desk. “Do you drink coffee?”

“Lots.”

“I figured you would say that. Most people in your line of work do. About how many cups do you drink a day?”

“About five or six.”

“Whoa, five or six!” He places his hand over his mouth, using his thumb and index finger to stroke his facial hair. “I know it may be a stretch, but would you consider cutting your coffee intake in half?”

“Wow, that’s a tall order Dr. Vincent. I get to work at 3:15 every morning and after my shift ends at 9:00 I have to be right back no later than 2:00.”

He pauses for a moment before responding. “I know it seems like I’m asking a lot, but consider the damage it’s doing to your body. Even though the erosion is not cancerous it’s certainly not healthy. Over time, you could do permanent damage to your esophagus.”

Deflated, I sit back in my chair. “Then I’ll figure something out. Maybe I’ll double up on my vitamins.”

“Another thing that may help is to avoid drinking before bed. Do you drink before laying down?”

"I have a cup of Sleepy Time tea almost every night. I don't sleep well without it."

He offers an empathetic nod. "As a doctor I can certainly relate to sleep depravity and erratic sleep patterns. So I'm not saying don't drink the tea. I'm simply advising you to drink it two hours or more before you lay down."

"That makes sense. Is there anything else I can do to fix this?"

"Based on what I've seen and what we've discussed, you should be fine if you follow those simple rules. Now if the vomiting and GERD do not stop you can always come back and see me." He stands and leans across the desk to shake my hand. "Take care Nina."

"Thanks, you too Dr. Vincent."

Granny's passing. It has been nearly two years since I overcame my fatty liver. Dr. Sharma was so impressed with how disciplined I am. I lost 15 pounds and brought my BMI down to 23%. The ultrasound showed a very healthy, lean liver. After everything I went through, I will never allow myself to be in such a predicament again.

I grab a small duffel bag and begin stuffing it with the usual items for my weekend trips: travel toothbrush, comb and brush, and pajamas etc. If I pack now, I can leave straight from my afternoon shift tomorrow.

As I tightly roll my nightgown, I begin reflecting on my last trip home only two weeks ago. Granny was so weak and tired. Her appearance is a mere shadow of her once full, brown frame. Her already deep set eyes recessed further hiding in between her cheekbones and brow line, revealing traces of life and defiant twinkle. Her shoulder blades and collar bone push through her thin, delicate skin. Even Granny's once naturally, straight hair has a pronounced curl pattern—possibly brought on by the chemo. This was a blessing in Granny's eyes. She always wanted me to curl her hair. I can hear her calling me now. "Toot!"

"Yes ma'am!"

"Would you please come and curl Granny's hair?"

I would walk into the bathroom shaking my head as I entered. “I don’t get it Granny. People pay tons of money to get their hair straight like yours and all you want to do is curl it.”

“People who have curly hair want straight hair and vice versa. My mom always taught me everyone wants what they don’t have. It’s just the way of life.”

I wonder how things will be when I get home tonight. Will she let me help her or will she turn me away and ask for Mom instead? Granny has always tried to shield me from her pain—never allowing me to change her urostomy bag or help dress her. All of this changed two weeks ago. For the first time, Granny allowed me to help bathe her. Predisposed to her usual refusal, when Mom announced she was going to run a bath for Granny I didn’t even offer to help. Instead, she asked me. I did my best to choke back tears with every “ouch” and “ow” she released from her lips as Mom and I helped lower her into the bathtub. Every inch of her body was tender and fragile. Her bones ached and her stomach burned. I have never seen Granny in so much pain. This weekend I don’t care if she tries to turn me away or not. I am going to dig in my heels and do whatever needs to be done.

I walk into my closet, pulling jeans and shirts from the top shelf. A loud buzzing noise continuously resonates in the background. It is then when I realize I forgot to turn the volume back up on my cellphone. I rush out of my bedroom and into the living room to find my phone scooting across the dinner table from the force of the vibration. My Aunt Monica’s name shines brightly through the window of the flip cover. I quickly answer it before it goes to voicemail.

“What’s going on girl? Let me guess, you’re coming home this weekend too.”

“Hi Gigi, how are you doing baby?” Her tone is somber and uncertain.

“What’s wrong? Is Granny’s red blood cell count low again? You know what? She needs some red meat. I’ll pick up some steaks tonight and throw them in the cooler before I come home or better yet, I’ll make a roast. I can . . .”

She interrupts my excited rant. “Have you talked to your mom yet?”

“No, why?”

Monica pauses for a moment before responding. “Granny passed away last night.” A sharp pain strikes my gut and I gasp for air. “Gianina, are you okay?”

“Yeah, what, what happened?”

“We lost her last night at home. I want you to know your mom was a soldier. She performed CPR and brought her back twice while your Uncle Tim called 911. She was alive when the ambulance got there, but she died on the way to the hospital. Your mom and Tim were following the ambulance when they turned the lights and siren off.” Vivid pictures of Mom and Uncle Tim frantically trying to save Granny flood my mind. The way they must have screamed when the ambulance turned off its lights and sirens ring in my ears. They must be traumatized. “Gianina, are you there?”

The lump in my throat impairs my speech. “Mm, hmm.”

“Listen, I know it’s hard baby. The only reason I’m not breaking down right now is because I already did last night and this morning. Right now I just need you to sit tight and wait for Kim, Kyndall, and I to swing by and pick you up tomorrow. We’re going to leave around 9:00 when all this Atlanta traffic eases up. That should put us there around 1:00. Will you be ready by then?”

I curl my lips inward as the tears flow. “Mm, hmm.”

“Listen, I love you baby. I need to start packing so we can get out of here on time tomorrow.”

I swallow hard engorging the lump in my throat and squeeze out a few words. “Love you too.” My knees buckle as I close the phone. I reach for the wall to brace myself, but land hard on my knees. I hug myself and rock back and forth on the carpet. Foreign, guttural sounds stored deep within my soul since birth emanate. My tears meld into the mucous flowing from

my nose and mouth slowly dripping onto the carpet. I will never see Granny in this lifetime again.

Return of the weight loss and accusations. Over-modulated voices and static permeate the backside of the newsroom as I rush back to my seat with my coffee. It has been a month since Granny's passing. Between the vomiting and diarrhea I've been experiencing the last few days, coffee and eggs seem to be the only things I can keep down these days. Not to mention I had Marshall breathing down my neck about when I was coming back to the station. You would think he never experienced a loss in his life. He's probably one of those people who put his parents away in a retirement home and only visits on Christmas. As I get nearer to my seat, the new camera guy stops me. "Hi Nina, I heard about your grandma and I want you to know, I'm sorry for your loss."

It has been a month and I still cannot talk about Granny without tearing up. "Thanks Michael." I look away and scurry toward my seat.

"Morning Nina." I look over my shoulder and see Caroline. Caroline is one of the prettiest news anchors in the viewing area. Her desk is always covered in roses and cards from her male viewers. Her bright blue eyes are fixed and genuinely concerned.

"Morning Caroline."

"How are you doing—I mean considering what you're dealing with?" Still teary eyed, I simply shrug my shoulders in response. She nods her head in acceptance of my silence. "I know you're having a hard time. I'm just worried about you. You have lost quite a bit of weight."

I sniff and swallow hard to maintain my composure. "It's not on purpose."

"Well you look great. Just try not to go too far with it."

"Thanks, I'll try." I feel her watching me as I make my way to my desk.

Todd's eyes are next, slowly following me as I ease my aching body down in my chair. "You feeling alright Nina?"

I turn and face him with a half grin. "I'm here." He grimaces and returns to his work. I expected everyone to be sympathetic about Granny's death, but something is off here.

I close the door behind me and gingerly remove my high heels from my aching feet. "Whew, one shift down one to go." I remove my coat and hang it in the closet by the foyer. Before I remove my makeup and clothes, I just need to sit down for a while. I flop down on the couch and sigh, dropping my purse on the floor by my feet. No sooner than I find a comfortable position, my phone rings. I dig through my purse, pull out my phone, and look at the name. It's Kirk my supervisor from the main office. As much as I need to rest, I have to take this. "Hi Kirk."

"Nina! How's it going girl?"

"It's going, how are you Kirk?"

"I'm great, just great." Clearly something is up. The question is, how long is he going to carry this out before he gets to the point. "You know my wife and I were watching you on tv the other day?"

Almost there, this may go quicker than I thought. "Oh yeah? Is there something I need to work on? You know I don't mind a little constructive criticism."

"Actually we were wondering if you could offer us a little advice."

"Advice, advice on what?"

"We were wondering what kind of diet you were on. We noticed you lost a lot of weight."

I know exactly where this is going. My God I can't believe I am back here again. "Kirk."

"Yeah."

"Did Marshall put you up to this?"

A brief pause precedes his response. "I wouldn't say he put me up to it. He just said he was concerned about your weight and I should see what he was talking about for myself. So, I

sat down and watched you with Brenda and we were astonished. How much have you lost, like 30 pounds?”

“I don’t know. The only time I weigh myself is when I go to the doctor and it’s been a while since my last physical.”

“Are you eating Nina?”

How did I know this was going to be the next question? “Yes Kirk, I’m eating. The problem is keeping the food on my stomach and before this goes any further, I do not have an eating disorder.”

“Oh, I never said that.”

“I know you didn’t Kirk, but I’m sure Marshall thinks so. It’s quite simple. Some people get stressed out, they eat and gain a ton of weight. I get stressed out, I drop weight.”

“It makes sense. I bet you’re still having a hard time getting over your grandma.”

“You have no idea Kirk. I cannot even begin to describe the pain I have inside of me right now. I want to thank you and Brenda for contacting me. I can tell both of you are genuinely concerned and even in his own judgmental, convoluted way I guess Marshall has a heart too.”

“You’re welcome and for the record, this conversation never took place. You catch my drift?”

“Ha, before it even blew.” We both chuckle. “Bye Kirk.”

“Bye Nina. Take care of yourself.”

“Thanks, you do the same.”

Responses of others (layer two)

At this point I was even more overwhelmed by the stress of my symptoms than I was in Chapter 4. The responses in this chapter not only came from my family and friends, but also

from physicians, coworkers, and superiors. The responses were an amalgam of fear, concern, sympathy, shock, dismissal, and judgement.

Fear and concern were the main responses from family members and friends who were privy to my initial symptoms. Many of them experienced the fear of the unknown along with me as I tirelessly sought a correct diagnosis. Mom and Granny in particular feared for my life and were concerned about my experiencing so many troubling symptoms alone. There was also a degree of shock exhibited by Mom, Granny, and Saida who were surprised to find out how much I was hiding about my illness and the progression of my symptoms. Two of the physicians I sought for help, Drs. Adams and Sharma were genuinely concerned for my health. Although neither of them was able to correctly diagnose me, they both worked diligently to aid me in any way possible.

My coworkers and superiors often responded sympathetically, offering physical assistance and private counsel to discuss my horrible ordeal. Contrarily, some were more judgmental than sympathetic, often drawing stereotypical conclusions about my weight loss.

Drs. Mathews, Roberts, and Greer responded with judgement and dismissal. Drs. Mathews and Greer in particular both appeared to label me as a depressed, hypochondriac whose symptoms were psychosomatic in nature. This resulted in a complete dismissal of any of my claims concerning symptoms and a blatant attempt to overrule any attempt I made to participate in bettering my health. Dr. Roberts on the other hand misjudged me as an unobservant, uninformed patient who would simply accept any and all medical advice without question. This effort to dismiss based upon judgement was steeped in an observable level of defensiveness in the interest of maintaining the conventional power dynamic of the all-knowing physician over the ignorant patient.

Comparing my experience to the literature (layer three)

As seen in Chapter 4, I continued down the same path of denial hiding my heightened symptoms from those closest to me (Bury, 1982). As my illness progressed I not only attempted to hide it from my family and friends, but I also my colleagues and a potential suitor. My concern was not only how my illness would affect those around me, but also how it would affect my relationship with those around me (Bury, 1982). I knew if my family found out they would be fearful, hurt, and become overprotective. I was equally concerned about the demise of my work relationships with colleagues and superiors who would possibly deem me weak and incapable of doing my job. Conversely my fear of becoming a burden on Tito and developing a relationship built upon codependency drove me to fully acknowledge my symptoms and how it could potentially affect the rest of my life. Moreover, I continued to view my symptoms “as a nuisance”, but not for the initial reasoning of attributing it to say an “exertion in decorating at home” (Bury. 1982, p. 170). My symptoms were nuisances that interfered with my daily rituals, responsibilities, and impeded my progress. If a numb limb meant I had to come up with money that I did not have for hospital care or cause me to miss work, it could wait until tomorrow.

Day-to-day stress is a reoccurring factor in this chapter as well. The stress of working a split shift, being recognized and judged by viewers in public, and most of all being misdiagnosed and mistreated by some of the physicians I sought advice from more than likely triggered and exacerbated my symptoms (Theoharides, 2002; Theoharides et al., 2009). Unlike in Chapter 4, I gained an audience for my so called jerking fits. Actually being watched by family members and colleagues while experiencing a flare up of this magnitude may have intensified my symptoms as they were presenting.

As noted in Chapter 4, diet may have a profound effect on mastocytosis. High histamine foods such as tomatoes, most citrus fruits in general, some shellfish, gluten, wheat, red wine, and beer may have caused several of my flare ups (Böhn et al., 2013; Fukunaga et al., 2012).

During this portion in my life, I was consuming a primarily plant-based diet hoping to improve my health. Many of the foods I consumed regularly were spinach, tomatoes, lemons, oranges, whole grain cereal, whole wheat bread, and pasta—all of which were high in histamine.

Although I did not suffer with angioedema as I did in the fourth chapter, my bout with what appeared to be chorea became more aggressive and frequent. There was also a marked progression from “diffusely migratory tingling/numbness paresthesias” to full on seizure like movements (Afrin, 2013, p. 2). Another possible explanation could be what are known as simple partial seizures. According to Dr. Mathews, what I was experiencing could not have possibly been a seizure, because I was fully conscious. According to the Epilepsy Foundation (2015) this is incorrect. In fact, there are seizures known as simple partial seizures in which people “are fully awake, alert and able to interact throughout the seizure” such “seizures are brief lasting less than 2 minutes” (seventh heading, first paragraph).

My experience of floating from physician to physician may be due in part to what Elstein and Schwarz (2002) referred to as the medical diagnostic process or clinical diagnostic reasoning. This approach is widely utilized by physicians to investigate and then determine the cause of a patient’s illness and is reliant upon one or more hypotheses. When examining my relationship with Dr. Mathews, his early hypotheses were quite clear; he was convinced I had either MS or Parkinson’s disease and scheduled testing seeking to prove his hypotheses. When his hypotheses did not pan out, no effort was made to develop new hypotheses and further investigate my claims. Instead, I was presumably depressed and thusly the assumed root cause of my symptoms and complications. Elstein and Schwarz (2002) provided research which questions this *tried and true* method by pointing out “diagnostic accuracy does not depend as much on strategy as on mastery of content” (p. 730). Dr. Mathews seemed to possess a masterful level of the content knowledge in respect to neurological functionality. His inability to strategize, nonetheless, left me misdiagnosed and suffering from the side effects of

superfluous, prescription medication. I will further elaborate on the medical diagnostic process in both the subsequent chapter and Chapters 8 and 9.

Chapter 6

A Correct Diagnosis

The events in this chapter took place in Durham, North Carolina followed by a move to Tampa, Florida. My time in Durham, was after I left the journalism industry and moved back home with my mother while pursuing my Master's degree in adult education. Nearly two years after completing my Master's, I moved to Tampa to attend the University of South Florida (USF) and pursue my doctorate. The layered accounts provided in this chapter describe the most salient events that occurred once I received a correct diagnosis and the reactions from my family and several physicians. Each account will divulge pertinent information comparable to the literature regarding mastocytosis, research from a patient's perspective, diagnosing mastocytosis, the diagnostic process in general, reoccurring heightened symptoms, and complications. Unlike Chapters 4 and 5 which offered insight into my work life, platonic and familial relationships, along with my relationship with myself, this chapter provides a glimpse into my newly reestablished academic relationship, and my collaborative relationships with several physicians.

The remainder of this chapter is organized identically to Chapters 4 and 5 which both consisted of three layers in accordance with Ronai's (1995) layered accounts. The subsequent chapter will present the findings from bloodwork and biopsies which accumulated over the course of this chapter's events.

First Partial Diagnosis

A feeling of weakness creeps through my limbs as I squeeze the hot water from my washcloth to rinse the excess soap from my skin. The urge to get out of the tub is

overwhelming. Something is wrong, inexplicably wrong. Slowly I brace myself on the wall of the tub and push myself to standing. I rest my hand against the cool tile and begin lifting my heavy legs—one at a time—out of the water and unsteadily plant my feet on the rug. The familiar itchy, burning sensation that often follows a hot bath radiates from my skin. I reach down and scratch one of my raised and inflamed freckles, which burns hotter than usual. The air is hot and stifling. It's too hot in here. Maybe if I get a whiff of cool air, I will feel better. I snatch my towel down from the rack and wrap myself in it before opening the bathroom door. The cool air grazes my exposed skin, but has no effect on my strained breathing. My vision blurs as I step into the hallway. "Uhh! Okay, okay pull it together."

"What's wrong Tootie?"

Shit, she heard me. "Uh I'm uh, I'm fine." My breathing becomes more difficult as I continue to guide myself down the hallway with both hands on the wall.

"Girl, you sound like you're out of brea Gianina what's wrong!? Why are you walking like that?"

"I don't know, I just need to lie down for a minute."

"Here let me help you." She wraps her arms around me, pulling me away from the wall and placing my weight on her. "Ooh, you're burning up! You think you might have the flu or something?"

"No."

We reach my room. She lays me on the bed. "What's wrong with your skin!? Your covered in splotches!" Mom holds my arm out and examines it closely. They're like perfect red circles. Do they hurt?"

"They itch, burn, and ache but it happens every time I take a bath. It's ok."

My breathy response incites her protective nature. “No, it’s not ok. This could be some kind of virus or maybe even skin cancer. You have to get checked out! I just don’t understand. You’ve already had chicken pox and you had shingles when you were only seven.”

“Mom, it’s fine.”

She ignores me and continues to try and make sense of what she is seeing. “Tomorrow you’re going to make an appointment with a dermatologist.”

I slap my hands across my face, covering my eyes. I can’t believe we are back to this again. She knows how I feel about doctors. “Mom I’m unemployed, my health insurance won’t even cover my EpiPens to keep me from going into anaphylactic shock and you want me to see a specialist tomorrow?” My eyes water as a hugging sensation firmly grips my ribcage and the walls of my throat begin to rub together. “I just cough don’t want another cough . . . stack of bills only to be scoffed at again. I’m not c-crazy cough, cough and I’m not depressed cough . . . cough . . . cough!” I gasp for air as the walls of my throat begin rubbing together.

Instinctively, Mom springs into action grabbing my purse and emptying its contents on the bed next to me. “Gianina do you need your EpiPen or your Alavert?!”

“Cough, cough Alavert.” Mom quickly removes the pill from its case and puts it in my mouth. It instantly dissolves into a pasty, minty liquid on my tongue running into the crevices of my mouth and down toward my throat. Within seconds, I can breathe freely. One long deep gasp fills my deprived lungs and I lie back on the bed.

“You have two choices, Gianina Hayes! Either I’m going to drive you to emergency tonight or you’re going to a dermatologist tomorrow!”

“I can’t afford it!”

“Don’t worry about how much it costs. I’ll pay for it!”

“Fine, fine I’ll go and when they tell me it’s all in my head then what? I have been dealing with this for over five years—people thinking I’m crazy, misdiagnosing me, and I’m just

supposed to keep running back. Don't you get it? No one believes me! If I keep doing this, I'm going to end up in a psych ward."

"Well, have you asked God to help you find out what's wrong?"

My eyes buck in disbelief. Is she really asking me this right now? "Have I asked God to help me figure out what's wrong?" My voice breaks from the intense emotion. "I ask Him every day to show me what's wrong. He doesn't listen to me anymore."

"But sweetie you know God loves you."

"God loves me? If He does, then why won't He help me!?" My body trembles as I sob uncontrollably. "Why won't He help me!? I'm tired Mommy! I'm tired. I'm tired. I'm so tired."

Mom cradles me in her arms and rocks from side to side. "I don't know sweetie, but we can't give up. I believe you. I know you're not making it up. I've seen it with my own eyes. Just go for me please. Can you do that?"

Too tired and frustrated to protest I simply concur. "Okay."

I look down at my feet dangling over the edge of the exam table. I wonder what kind of cynic I will encounter today. Will it be the *don't ask me any questions type because I have a ton of patients waiting after you* or will it be the *I was concerned about your condition until I requested your medical records and realized you were on Effexor so now I don't believe anything you say* type? Either way I just want to get it over with so I can go back to living my life the only way I know how—ignoring and masking my pain.

A light knock at the door interrupts my thoughts. "Come in."

From behind the door steps an attractive, dark-haired man who appears to be in his late 30s to early 40s. His green eyes sparkle through his glasses as he approaches me with his hand outstretched. "Hi, I'm Dr. Glenn."

"Hi Dr. Glenn, I'm Gianina."

"Ah, so that's how you pronounce it. Good thing you said it before I did."

I smile as he peruses through my patient information. "You can call me Nina."

"Nina, alright that's easy enough. So where are you from Nina?"

"Here."

"Here, you're from Durham."

"Yes, I am."

"I'm shocked. You don't seem to have a southern accent. I've been here for a few years and I can usually tell when I'm talking to a North Carolinian."

"Well, my family is military. I guess they moved around too much to pick up a distinctive accent from anywhere. So, there really wasn't an accent of any kind to latch onto in my home."

"Military huh? I'm a military man myself. What branch and which family members are enlisted?"

Wow, this guy is lot like Dr. Adams was. He actually seems to care. "My grandfather, father, and uncle were all marines. My dad and uncle are retired and my grandfather passed away back in o-two. What about you? What branch are you in?"

"Uh oh, are you ready for this?" I cock my head to the side with a half-smile anticipating his response. "I'm a Navy man. So after today's visit you make sure you tell your dad only Navy men can save lives."

"Ha, ha I'll be sure to tell him."

"I just got back from my third tour." He reaches into his pocket and pulls out his wallet. "Here are some pics of the wife and kids. No matter what happens. I make sure I come home to them." He flips through each picture describing each event in detail. "Oh, now here's a fun one. This was bath time. When the three of them get anywhere near water, watch out!"

"Well, their dad is a Navy man."

He laughs loudly. "Good point, don't share that with your dad and uncle."

"You have a beautiful family, Dr. Glenn."

"Thanks Nina. What about you, any kids?"

"No, I'm not ready yet. Maybe after I finish this degree I'll consider it, but at the moment I haven't even met anyone I want to have kids with."

"I understand, you seem rather career driven. If you don't mind my asking what do you do?" Shocked by his continuous inquiry, I snap my head back. He notices and quickly recants. "I'm sorry is this too personal?"

I purse my lips before answering. "No, no it's just . . . most doctors aren't this chatty or friendly for that matter. They don't seem to care about my personal life. They just want to get in and out like a pit crew."

He touches his finger to his lip and looks down with concern. "Well I'm sorry about your experiences, but we do things a little differently around here Nina."

I smile and nod my head. "It's quite clear, Dr. Glenn."

He stands still for a few seconds contemplating our exchange before turning to revisit my chart. "Let's get to the reason why you're here shall we? It says here you're concerned about some spots on your skin. Is that correct?"

"Yes."

"Hmm, do you mind if I take a look?"

"Sure."

He puts down my chart and walks over to me. "Are they in any particular area?"

"Um, just everywhere."

I grin as he starts with my right arm, turning it and examining each spot. "Yeah, you're not kidding. You have quite a few of these."

"What do you think they are?"

"In my opinion, I would say you have adult freckles."

“Adult freckles? I don’t know, I have some family members who look a lot more like you than they do me—if you know what I mean—and they noticed that their freckles fade and return, but mine don’t.” Oh no, what was I thinking. I actually questioned his expert opinion. I brace myself for a sarcastic rebuttal.

“Ah, but here’s the thing about adult freckles Nina, they don’t fade. Once you get them, you’re stuck with them. Now if you had these in your early childhood there’s a possibility you could have grown out of them. Some people have them all their lives. Did you have freckles as a child?”

I can’t believe it. He’s not defensive or snarky. “No, not even one.”

“Interesting.”

“So, none of the spots look like melanoma or anything to you, right?”

“Oh goodness no, don’t worry yourself about that. Besides, the head dermatologist Dr. Branson will be here in a moment to take a look at you.”

“You mean I’m going to see another doctor.”

“Oh yes, we double check around here Nina.” He grabs my chart from the countertop.

Reluctantly I pose a question. “Is she as cordial as you?”

He turns to face me before walking toward the door. “Even more so.” He smiles before walking out the door. “I’ll be back in a moment with Dr. Branson. Just sit tight for a few.”

“I’ll be right here.” He closes the door behind him and I begin staring at the stages of melanoma posted on the wall. Adult freckles huh? Wait until I tell Mom these perfect red circles she was so worried about are just much ado about nothing. I may never find out what’s wrong with me, but at least I know it’s not cancer. The door swings open and in walks Dr. Glenn along with a pretty young woman with short dark hair. Even her baggy lab coat compliments her lean physique. As she gets closer I notice a few tiny freckles on her cheeks adorning her flawless skin.

She extends her hand for a shake. "Hi, I'm Dr. Branson."

"Hi Dr. Branson, I'm Nina."

She smiles heartily as Dr. Glenn stands against the wall. "Nice to meet you Nina, so what brings you here today?"

"I was concerned about some spots on my skin."

"I know Dr. Glenn already took a look at you, but do you mind if I take a look?"

"No, not at all."

Unlike Dr. Glenn, she examines my legs first. She squints and leans forward quickly grabbing my arm flipping it over and running her fingertips across my spots. "Do they itch?"

"Not right now, but sometimes they itch and burn."

She begins shaking her head. "I can't believe this. Can I scratch one?"

"Yee-ah sure, go for it." Either these are the strangest adult freckles she has ever seen or something is seriously wrong.

She scratches a spot on my arm and within seconds it reddens and rises. She looks up at me in amazement. "I don't think these are adult freckles."

Dr. Glenn pulls away from the wall. "What do you mean they're not adult freckles?"

"Come here for a sec Dr. Glenn." He speeds over hastily. "See where I scratched one of her spots here? Freckles don't do that."

He leans in and raises his glasses higher on the bridge of his nose. "No, they certainly don't."

The suspense is killing me. Why won't she just say what it is? "What is it? It's not cancer is it?"

"No, it's not cancer, but if it is what I think it is then you're like a chupacabra. I've only seen this twice in my career." I frown at her curious smile. "I'm sorry Nina, I promise I'm not excited about this. It's just that it's so rare."

"What is it?"

"I don't want to say just yet. We need to run a few tests first."

"Well can you at least tell me what you think it is?" The confused Dr. Glenn turns toward Dr. Branson just as anxious for an answer as I am."

"I think, well, it's possible that what I'm looking at here is mastocytosis."

"I've never even heard of that?"

"Don't worry, most doctors haven't either."

Dr. Glenn frowns with his index finger and thumb spread across his upper lip. "Myself included."

"So what kind of tests do you need to run?"

"The first thing we need is a skin biopsy."

"Okay, I'll schedule one on my way out."

"No, right now."

"You mean right here, right now?"

"Yes, unless you're in a rush."

In all my years of doctor's visits I have never known a doctor to push for something same day other than an ultrasound or an allergy test. Having her cut me when we just met seems a bit sudden. There must be something she's not telling me. "No today is fine. Might as well get it over with right? Do I need a ride or something?"

"Oh no, nothing like that I'm just going to use a local anesthetic and make a tiny incision. It'll be small, but it will require stitches. Is that okay?"

I take in a deep breath. "If this is the only way to confirm or deny, it doesn't leave me much of choice then does it? Sure, let's do it, but can cut in an area that no one can see please? I'm already covered in spots. I don't want to add scars to the roster."

She smiles warmly. "I can do that. It's not a problem at all Nina. How about your upper thigh area?"

I look down at my thighs and grimace. "As long as it's high enough for me to wear this skirt and not be seen."

She nods her head in agreement. "Deal." She pulls out one of the drawers under the exam table and pulls out a cloth robe. "So what I'd like for you to do is take off your clothes and put this robe on. You can keep your undergarments on if you like, and we're going to come back and begin the biopsy."

"Alright, seems straight forward enough." As soon as the door closes behind them I jump down from the exam table, shake the robe loose from its folds and stretch it open. "I came here for answers and I guess I'm getting them." I quietly undress myself, wondering what this disease is and how I got it. Is it contagious? Do I need to keep my distance from Mom until I get better? If this is the case, I should probably have her come in for testing too. Even if this is what she says it is, this masto whatever, it still doesn't explain why I could barely breathe the other night or my jerking fits and insomnia. Even if I do not get to the root of the problem at least I will know a little more about myself. I neatly fold my clothes and place them on the seat of the chair to my left. Quickly, I slip on the robe and get back onto the exam table. No sooner than I plant my rear on the table, there is a knock at the door. "Come in!"

Dr. Branson pokes her head in first smiling. "Hey are you ready for us?"

I cannot help but, smile back. "Yes, I'm ready."

Dr. Glenn timidly pokes his head in next. "I'm going to assist if you don't mind."

"Oh not at all." I smile at him as he wheels in a tray with several items. I begin my usual ritual of scanning the tray to make certain there are no harmful items on it. Let's see alcohol wipes, a scalpel, a syringe, thread and some sort of sewing needle—oh that must be for the stitches, some gauze, a clear container, and what appears to be some sort of antiseptic. Hold

on are those latex gloves in those packs? A nervous tremor builds in my gut. “Wait, before we start, those gloves in the packs are they latex?”

“No, these are latex free. See for yourself.” Dr. Branson grabs one of the packs and hands it to me.

I take the pack and look it over quickly. “Powder free, latex free, nitrile, sterile gloves wow I’m really impressed. You have no idea how many times I have to remind people.”

She responds with her back to me as she washes her hands. “Well we can’t have you going in to anaphylaxis from a simple procedure now can we?”

I quickly concur. “Nah, I really didn’t plan properly for my death today.” Dr. Glenn laughs as he waits his turn to wash his hands.

While drying her hands Dr. Branson explains the procedure. “Okay, so I know this looks like a lot of stuff, but trust me this will be quick and painless. First, I’m going to inject you with a local anesthetic. Wait, we didn’t discuss those. You’re not allergic to any local anesthetics are you?”

“No, not that I am aware of.”

“Whew, good so I’m going to inject the anesthetic with the syringe and then I’m going to make a very small circular incision with a scalpel around one of your spots. I will completely remove the piece of skin and place it in the container to be sent for testing. Then, I will close the incision with stitches, put a little antiseptic on top and cover it with a bandage. Do you have any questions?”

“Yes, never in my life have I had stitches before. How do I take care of the biopsied area and how long should I wait to have the stitches out?”

“Good questions.” Dr. Glenn looks up while he unwraps his gloves.

Dr. Branson walks toward the tray to begin unwrapping her gloves as well. “Yes that is a good question. First of all, do your best to keep it dry for the first 24 hours. After that you can

get it wet to clean it. For instance, you can clean it with soap and water. This is a good way to keep it from drying out too much. Even though you're cleaning, be extra careful not to get your bandage soaked. After you clean it, you need to pat it dry with a clean paper towel. Then, apply a topical ointment."

"You mean like Neosporin?"

"Neosporin is okay, but I would suggest applying Aquaphor twice daily. If you don't have some already, buy a box of large, latex free band aids. As far as suture removal is concerned, I'll schedule you to come back in three weeks and have them removed. Um, that's basically the process. Anymore questions?"

"Yes one more, how long will it take to get the results of my biopsy?"

"We should hear something back from the lab in about two weeks."

I nod my head as I take it all in. "I guess that's it. I can't think of any more questions."

"Are you ready?"

"Yeah, let's get it over with."

"Alright, you said your upper thigh area didn't you?"

"Yes."

"How about you show me specifically where you will be comfortable with me making the incision."

I pull the right side of the robe up point to an area slightly higher than midway between my thigh and hip. "Riiight here."

"Perfect." Dr. Branson takes a marker and draws a circle around one of the spots on my skin. "Dr. Glenn will you hand me the syringe please?"

"Absolutely Dr. Branson."

“Okay Nina, this is just the anesthetic. It may burn a little at first, but once it stops it will numb you completely. So, I’m counting on you to let me know when the area is completely numb and then I will make the incision.”

“I can do that.”

She wipes the area clean with a towelette. “Alright, light stick and a little burn.” The needle penetrates my skin. A mild burning sensation courses through the small area as she slowly pushes the plunger. “Now, we wait. You should be numb in about a minute or so.”

“Okay.” I begin racking my brain, trying to think of any other questions I may have. “So Dr. Branson”

“Yes.”

“I remember you said this disease you’re testing me for is quite rare. How rare are we talking?”

“Like I said, I’ve only seen this twice in my career before I met you today. Not to mention, this is not commonly seen in people of color.”

“Not commonly seen in people of color?”

“No, in fact you’re the first . . . well before I make any assumptions, what is your ethnic background?”

“Well I self-identify as Black, but further down the line I was told there are traces of Native American and White. Do you think it may be genetic?”

“It’s quite possible.” She gently pokes my thigh. “Are you numb yet?”

“Mm, not quite I can still feel you poking me.”

“Alright, we’ll wait a little longer.”

Out of questions, I begin considering the implications of the information I just received. What if I am one those people whose bloodwork reads completely different from how they self-

identify? Henry Louis Gates Jr. was shocked to find out despite having two Black parents his DNA revealed he is roughly 50% White. What if I am not as Black as I think I am?

Dr. Branson pokes at my thigh again. "Numb yet?"

"I can't feel a thing."

"Perfect, Dr. Glenn would you hand me the Betadine please?"

"Here you go."

She drops her head and sighs. "Wait, I forgot to ask you if you're allergic to Betadine."

Concerned and confused I answer candidly. "I'm not even sure what Betadine is."

"I'm sorry, it's iodine."

"Oh iodine, I haven't used it since I was a kid, but I never had problems with it before."

"Okay good." She rubs the cold, rust colored substance over my skin. "Scalpel." She holds out her empty hand. I look down and watch closely as she slices into my flesh, tracing the drawn circle. "Dr. Glenn, please open the receptacle for the specimen." As he prepares the container she turns the scalpel sideways and cuts across, completely removing my skin. I stare at the bloody hole in my leg wondering what it will look like when it heals. She closes the receptacle, stands up, and steps back. "Alright Dr. Glenn, I'll let you stitch her up."

He beams at the notion. "Gladly." He quickly gets the needle and begins threading it.

"Nina, how are you feeling?"

"Numb."

"Good, that's what I like to hear. How's it coming Dr. Glenn?"

"Almost ready Dr. Branson." He takes her seat and scoots in close to my thigh. The needle pierces my skin with ease like thin fabric as Dr. Branson watches closely over his shoulder. I watch in amazement as my skin buckles and closes with the first two stitches.

Dr. Branson swiftly interjects. "Whoa! That's going to leave a scar. We have to cut it and start over." Cut it and start over, I hope I stay numb for this. "Nina are you still numb?"

“Yes.”

“Good, Dr. Glenn do you mind?”

He blushes from embarrassment and quickly stands aside. “Um, no please.”

She grabs a pair of scissors and severs the two stitches. She slides the needle through the initial hole and creates a new one slightly below the second one he made. “See how skin is flat and even? This will prevent a hypertrophic scar from forming. She continues sewing while explaining until her last stitch. I feel a stiff tug as she carefully knots the wiry thread. “Dr. Glenn, will you cut this for me please?” He grabs the scissors and cuts the thread. “We’re all done Nina.” She removes her iodine stained gloves and tosses them in the trash. “Dr. Glenn, please bandage her up. Nina I’m going to leave your paperwork with instructions on how to care for your incision. By the way, when the feeling returns don’t take aspirin or acetaminophen. Take some form of ibuprofen like Advil or Motrin. Aspirin and acetaminophen will increase blood flow and that’s the last thing you need after an incision. Any questions?”

I think for a moment before shaking my head no. “No, I think that does it.”

She smiles and walks toward me with her hand extended. “It was a pleasure meeting you and I sincerely hope your results are negative.”

I shake her hand and smile back. “Thanks Dr. Branson.”

Dr. Glenn firmly presses the bandage against my skin. “All set.” He removes his gloves, disposes of them, and walks back to shake my hand next. “And might I say it was a pleasure for me as well. You weren’t in the least bit squeamish.”

Dr. Branson chimes in. “I know most patients shut their eyes and tell me to tap them when it’s over. You looked right at it. You’re really brave.”

“Oh, thanks. I wouldn’t call it bravery so much as it is curiosity. It was an absolute pleasure meeting and working with both of you. Both of you are patient and open to questions. I really appreciate it.

“Take care Nina.” Dr. Glenn pushes the tray toward the door as he and Dr. Branson make their exits. This will make for an interesting story when I get home tonight.

The results of the skin biopsy. More than two weeks have passed and I have yet to hear anything regarding my results. What on earth is taking so long? I went online to Ask Jeeves and looked up urticaria pigmentosa. Luckily Dr. Branson wrote it down on my paperwork or I would not have had a clue how to spell it. Everything I read seemed to trivialize it as a rash resulting from an allergic reaction. Maybe I came into contact with latex somehow, but wait, it wouldn’t spread all over my skin like this. It could be my soap or my lotion. I take the cordless phone off the charger and begin dialing. If they won’t give me answers, I’ll call and get them myself. The automated system answers and I select four to speak with a nurse. “Duke dermatology.”

“Hi how are you?”

“I’m fine what can I do for you?”

“I had some biopsies done a little over two weeks ago and I haven’t heard back about my results yet. Would you check on them for me please?”

“Absolutely, what’s your last name?”

“Hayes, H-A-Y-E-S.”

“And your first name.”

“Gianina, and it’s spelled G-I-A-N-I-N-A.”

“Alright, and your date of birth please.”

“April ninth, 1979.”

Her keystrokes echo through the phone as she types away. “Okay, let’s see if we can pull you up.” She pauses for a moment. “Miss Hayes . . .”

“Yes, do you mind if I place you on hold?”

“Not at all.”

“Okay.” I hear a loud beep followed by elevator music. I’m sure the results are negative. Even if the results are positive it’s just a rash. The music trails on for what seems like forever. I make myself comfortable on my bed as I wait. Involuntarily I begin humming along to the unknown tune. “Come on, come on.” I shuffle my feet across the comforter and stare at the ceiling.

“Miss Hayes.”

“Yes.”

“It says here you results were in four days ago. You were supposed to receive a call from Dr. Glenn.”

“A call from Dr. Glenn, since when did doctors start calling with results? Usually nurses call to relay results.”

“You’re right that’s very uncommon, but that’s what it says here. This is rather strange Miss Hayes. Hold for just a moment and I’m going to check on things. Before I go, are you sure you haven’t received a call from Dr. Glenn? He may have left you a message.”

“I’m quite sure. I check my messages daily.”

I hear the paper rustling as she reads through her notes and sighs “Alright, please hold.” I roll over and reach for the remote control. If I’m going to be on hold all day at least I can find a way to keep myself occupied. I can’t believe a rash merits this much attention. I push the guide button and begin scrolling through numerous shows. “Miss Hayes.”

I sit straight up and quickly hit the mute button. “Yes.”

“Ok Miss Hayes, I spoke with Dr. Branson and I’m sorry to inform you that your test results were positive for urticaria pigmentosa. She said she’s very sorry. She thought you were already informed. We need to schedule an immediate follow up. How soon can you come in?”

Confused, I pause momentarily. “Sorry I just don’t understand why I didn’t get my results. I mean what if I hadn’t called you?”

"I know, I'm just as shocked as you. No one likes waiting for test results, especially when you get bad news like this."

"Thanks for your concern. Well, I get my stitches out Friday at 2:00 could I have my follow up then as well."

"Let's see. You're in luck I can squeeze you in at 3:15. After you get your stitches out, you can come right upstairs for your follow up."

"That's perfect."

"Okay, I got you down for this Friday at 3:15 with Dr. Branson. Is there anything else I can do for you?"

"No, thanks you have been very helpful."

"Oh you're welcome and again, I'm sorry about your diagnosis."

I hit the end button on the phone. Why is she so sorry? It's just a rash. I have definitely had worse. I had pityriasis rosea when I was 23 and shingles at the age of seven. I'll probably take some antibiotics or something and be fine in a few weeks.

I lightly rub the palm of my hand back and forth against my thigh through my gray trousers as I wait for Dr. Branson. I can't believe the nurse had to cut me again just to get the stitches out. Apparently I healed much more rapidly than expected. I actually had a layer of skin which grew overtop the stitches. The nurse said I should have come in sooner, but how would I have known. The only stitches I ever had were in my mouth after having my wisdom teeth removed and they were the type that dissolved.

The door opens and in walks Dr. Branson. "Hi Nina."

I stand and greet her. "Hi Dr. Branson, how are you?"

"I think the question is how are you?"

"I'm fine."

She blinks several times while sifting through my paperwork. "I'm sorry to hear about your stitches. It didn't hurt too bad did it?"

"No, it's not that bad. I guess no one expected me to heal so quickly."

She cocks her head to the side and looks at me. "How soon had your skin grown over the stitches?"

I look up as I recall. "Um, maybe a day or two shy of two weeks."

"That's definitely above average, but expected given your condition."

"Expected given my condition?"

She squints her eyes as she plops down in the chair at the desk. "Sooo, we need to talk. First let me apologize for the late response regarding your diagnosis."

"No need to apologize, I was just a bit confused by it all."

"As you may already know, Dr. Glenn was supposed to contact you with the results, but . . ."

"But what, he was too busy?"

She lets out a deep sigh. "He just didn't have the heart to tell you that you were positive. He thinks you're a really nice person and it bothers him that this is happening to you."

"Wow, that's so nice but, this is really not that serious. I mean you said it yourself. It's not cancer. So it's what, just a skin disease right? I can take some antibiotics or something and clear it up."

"I wish it were that simple."

"Okay, so it's a little more difficult to get rid of. How do we cure it?"

She rolls her lips inward and crosses her arms. "We don't, it's incurable."

My optimism kicks into to gear as I shake my head in utter denial. "Okay, okay I get it. I can uh . . . I can take medication for the rest of my life. I mean my grandfather did. He was diabetic. That's not so bad right? It's not like I'm going to die or something."

She swallows hard with a disquieted expression on her face. “In some cases it can cause death.” Her response sends a swarm of nervous butterflies through my stomach--ultimately deafening me. I watch her lips closely as she speaks, but only silence fills my ears. Many years ago I dreamt of my own death. My family encircled me, as I lay in a hospital bed, holding hands, and praying as I took my last breath. Is this what claimed my life in the dream? No not yet, not now. I’m only 30, I’m childless, and I don’t even have a will. Focus Gianina, focus. Listen to what she’s saying. Her voice smoothly segues into my thoughts. “. . . to investigate and find out how far it has progressed. Death is a possibility, but this is not a death sentence. Some people live with it for a really long time and it becomes nothing more than an annoyance. We are going to run some more tests and get you treatment.”

Her last statement raises my awareness. “More tests, I thought I already tested positive.”

“In order for us to determine how far this has progressed, we need to run a myriad of tests.”

“What, like blood tests?”

“For starters yes, but you also need a bone marrow biopsy and based on your medical history you will probably need to see a gastroenterologist as well.”

“My medical history?”

“Yes, you indicated that you had an endoscopy about three years ago.”

“Yes I did, but what does an endoscopy have to do with urticaria pigmentosa?”

“I guess you didn’t hear me a little earlier.”

Embarrassed I sink into the back of the chair. “I’m sorry. I kind of blanked out on you when I heard death. This is a lot to swallow. I’m sorry. I interrupted you.”

“It’s alright. I know this is a lot to take in. What I said earlier is urticaria pigmentosa falls under the umbrella of mastocytosis. What we need to do is determine whether or not it is

systemic and the fact that you had an endoscopy raises some concerns for me. Why did you have the endoscopy?"

"I had a lot of issues with acid reflux and vomiting, but he said it was because I drank too much coffee."

She places her hands on the keyboard and begins typing. "What about diarrhea?"

"Yes, I get it quite frequently these days."

"Hmm, any muscle or joint pain?"

"All of the time, especially in the morning. Dr. Branson . . ."

"Yes."

"Before you ask any more questions, I have one for you."

"Shoot." She swivels in her chair to face me.

"A few years back I had these weird jerking fits. I would twitch and shake, kind of like I was having a seizure except I was lucid. Could this be related?"

"It's quite possible yes."

"Wait a minute, you believe me? You don't think I'm crazy?"

"Of course, I've seen this disease do some strange things. If it can affect the body systemically, there's no telling what it can do."

I straighten my posture and clear my throat to choke back the tears. "Ahem, I'm so sorry I'm so emotional right now. It's just, I've been going in circles with doctors for years about this and no one believed me. They thought everything was psychosomatic. I don't have time to make this stuff up and even if I did have time why would I? I know I'm not a doctor, but I'm not stupid either. I know my body; I've been living in it for 30 years. You know one doctor actually put me on antidepressants? He had the nerve to lie and tell me they were sleeping pills, sleeping pills! Sorry, I just get so angry every time I think about it. I don't know what's worse, the fact that I believed his lies or the fact that I stopped believing myself. Over time, I just

stopped trusting myself. All of those aches, pains, and stomach problems I told you about—I pretended not to feel them. I actually started telling myself they were all in my head. I mean if all of these experts are saying the same thing about me they must be right. Maybe I really am crazy.” She looks down for a moment as I pause. “I guess what I’m trying to say is thank you. Thanks for not thinking I’m crazy or trying to put me on unnecessary medication. It’s been a long, rough ride. You have no idea what it’s been like for me.”

She looks away momentarily and shakes her head before returning her gaze to me. “I’m sorry you went through so much. I can’t cure you but we can work together to help you feel better.” A feeling of relief takes over me as the heavy weight from my shoulders is lifted. After all these years I finally have some validation. It’s not all in my head! My symptoms are real and for once I can do something other than just ignoring them. Dr. Branson pulls a pen from her lab coat pocket and begins writing. “Today I’m going to send you to the lab for bloodwork. I’m also referring you to a hematologist, a gastroenterologist, and I really think you should see a neurologist for those jerking fits you told me about. I am not certain what the gastroenterologist and neurologist will decide to do, but the hematologist will need to perform a bone marrow biopsy to determine whether or not you’re systemic.”

“A bone marrow biopsy? That sounds painful.”

She furls her brows and sighs sympathetically. “It’s not comfortable, but it’s the only way we will know whether or not you are systemic.” I pause before nodding my head. “Okay, until then, here’s some information on mastocytosis. It will tell you some things to avoid and symptoms to look out for. Any questions?”

“No, I just want to thank you again.”

“You’re welcome. I’m glad I could help.”

“Dr. Branson.”

“Yes.”

"I'm hope you don't find this inappropriate, but would it be alright if I hug you?"

"Sure, why not."

I wrap my arms around her and whisper "thank you" before letting go.

The second neurologist. Mom places her hand on top of mine, squeezing tightly to keep to keep my nervously shaking knee under it still. "This is a new doctor. He could actually be nice Gianina."

I look down at the floor for a moment and then at her. "The last neurologist was nice, and he lied right through his smiling teeth. All I know is that I'm not taking any pills, Mom. I don't care what he says."

In walks a tall, grey haired, white, man wearing glasses. I completely forgot the door to the exam room was open. Who cares if he heard me? Maybe he will think twice before he tries to push some bogus pills me. "Hello there, I am Dr. Hodson." His crisp English accent annunciates each syllable with care.

"Hello, I'm Gianina and this is my mother Regina."

"Nice to meet you both." He nods and smiles before placing his clipboard on top of the counter and washing his hands. He shakes his hands before reaching for a napkin to dry them. "So, explain to me exactly why you are here."

"Well, I was informed about a week ago that I have mastocytosis—urticaria pigmentosa to be precise, but I have had trouble with some strange jerking fits."

"Hmm, jerking fits you say, and how would you describe these uh, jerking fits you speak of?" His doubtful tone and phrasing evoke memories from my previous encounter with Dr. Mathews.

Remember Gianina, this is a different doctor. "Well, I can't control my limbs. It's like they have a mind of their own. My legs and arms swing wildly and sometimes my chest writhes up and down."

“Don’t forget to tell him about your fingers curling.” Mom softly interjects.

“Fingers curling? Mum I take it you have witnessed these uh jerking fits of hers.”

Sensing his condescending tone as well, Mom’s neck jerks back and she adjusts herself in her seat. “Yes, I have. Sometimes I have to put bottles of nail polish in her hands to keep her from cutting her palms with her fingernails. I’ve even seen her get stuck in certain positions where her muscles contract so hard she cries and as soon as it’s over, she falls asleep. It’s like it just drains her. Is that pretty accurate Gianina?”

I smile at Mom as a symbol of thanks for standing up for me. “Yes ma’am, you said it all.”

“Hmm, why don’t you hop up here on the table and let me have a look at you.”

“Should I change into a robe first?”

He smirks and pats the seat of the table. “That will not be necessary. Just take off your shoes please.” I unlace my shoes and slide them under my chair before walking over to the table and taking my seat. He pulls a light pen out of his lab coat pocket and shines it into my eyes. “Follow the light please.” I dart my eyes from corner to corner following the pen. “So did your previous physician have any theories about what these jerking fits are?”

“Yes, at first he thought it was MS or Parkinson’s, but the tests he ran were negative.”

He nonchalantly turns the pen off and places it back in his pocket. “And his conclusion?”

I sigh deeply in preparation of the judgement. “He didn’t believe me.”

“Did not believe you, what does that mean?” His tone borders on barking.

“It means exactly what it sounds like.” A look of surprise wipes his face in response to my rebuttal. Check your tone Gianina. Don’t let him take you there with him. “He did not believe me and he assumed my symptoms were psychosomatic. So instead of investigating further, he prescribed antidepressants.”

“Hmm, were you depressed? Hold your right arm out in front of you please and resist against me as I press down.”

I know this arrogant son of a . . . did he really just ask me if was I depressed in passing? Respond calmly, but firmly Gianina. I hold my arm out as I position my head to make direct eye contact with him. “No, I was not depressed.”

Still looking deep into his eyes, I wait for his response as he presses down on my arm. “Your left arm please.” Defeated I look over at Mom and shrug my free shoulder. She sits perfectly erect at the edge of her seat, heels raised with her hands on her knees as if ready to pounce. Maybe I will never find out what these jerking fits are, but at least I know what’s wrong with my skin. For the next five minutes, I indulge him in the rigmarole typical of a skeptic. Maybe the gastroenterologist and hematologist will be more investigative and hopefully friendlier.

The second and third gastroenterologists. I reach down into my purse and pull out my vibrating phone. “Hi Mom.”

She responds in a low whispering tone. “Hi Sweetie Girl, I’m in a meeting. I stepped away to find out how your appointment went?”

“Oh, I haven’t met the doctor yet. I’m waiting for him to arrive now.”

“I sure hope he’s nicer than that son of a gun you had to deal with last Monday. You might as well of been unconscious while he was examining you. He didn’t give a damn about anything you had to say.”

“I know, it’s a good thing he met me at a point when I ran out of steam. A few years ago I would have told him where to go and how fast to get there.”

“I almost did, but you know what?”

“What?”

“God can handle him far better than either of us can and if that’s how he deals with his patients, he’s going to reap what he has sewn. Believe me when I tell you, you will find someone who will and can help you. It just hasn’t happened yet. Cheer up Tootie Fruity!”

A light knock at the door interrupts our conversation. “Hey Mom, that’s the doctor.”

“Oh okay, I’ll let you go. Call me and tell me how it went.”

“Come in!” The door creaks open and in walks a young, blonde man about average height. “Okay, I will. Gotta go, love you.”

“Love you too.”

I quickly put my phone away and stand to shake the doctor’s hand. God, please let him be nice. I’m not in the mood for another cynic. “Hi I’m Gianina, but you can call me Nina.”

He grips my hand firmly and locks his gaze. “Nina” he looks down at my file. “That’s much easier to pronounce. I definitely would have gotten your full name wrong if I tried to pronounce it on my own.” He continues to shake my hand, awkwardly gazing at me. “Hi I’m Dr. Lawrence.”

“Nice to meet you Dr. Lawrence.” I gently pull my hand away.

He snaps back into reality. “Goodness I was staring, wasn’t I? I hope I didn’t make you feel uncomfortable. It’s just, well you don’t look sick. I’ve never met a masto patient, but I’ve seen pictures and they certainly don’t look like you.”

Unsure of whether I am responding to a professional or social compliment, I answer timidly. “Um, thank you?”

“You’re welcome.” He continues to stare intently, smiling as he washes his hands vigorously. “So do you have any spots?”

“Yes I do. They’re right here.” I roll up my sleeve to reveal the affected area.

He walks over while drying his hands. “You certainly do. They look pretty calm right now. Do they ever raise up or burn and itch?”

“Yes they do, especially after a hot bath.”

“Interesting and if you scratch it?”

“They rise when they’re scratched as well.”

“Wow, and you’ve been walking around with this for how long?”

“A little over five years now.”

“Wow that must have been tough!”

“It certainly wasn’t easy. I’ll tell you that.”

He anxiously looks at the door. “Sorry, we’re waiting on one more person. Dr. Walters should be here shortly.” He pulls the stool from underneath the desk, sits on it, and wheels in closely in front of me. “I hope this doesn’t offend you, but I’ve never seen this before. To be honest, I’m still learning about it. Would you mind terribly if I scratched one of your spots?”

Elated by his enthusiasm, I promptly hold my arm out. “Go for it.”

Gently holding my forearm, he rotates and inspects it—literally looking for just the right spot. He pauses for a moment. “Hmm, how about this one?” His receding fingernails never make contact with my skin, leaving the burden on his fingertips to rub across the spot vigorously to no avail. “It doesn’t seeeeeem to react.”

“Here, let me.” I wiggle my fingers in front of him, flashing my lengthy nails before scratching the small red spot. Immediately, I feel an itchy tingle as the spot begins to redden and rise like dough.

“Would you look at that?” He squeezes my arm tightly pulling it closer to his face for a better look. “Does it hurt?”

“It’s just itching and tingling a bit.”

Unfazed by the knock at the door, he continues to rub and observe the spot. “Come in!” In walks a tall, swarthy young man. His ambiguous facial features make it nearly impossible to determine whether his swarthiness is the result of a tan or his genetic makeup. His presence

carries an observable coldness which reeks of self-importance. Dr. Lawrence scoots back in his chair presenting my arm to his colleague. "Come here, take a look at this!" As he leans his tall lanky frame over Dr. Lawrence, I get a closer look at his immaculately groomed facial hair gracing his nonexistent pores. Perhaps his cold demeanor is a product of arrogance due to his physical attractiveness.

He squints his eyes, cocking his head to the side before responding. "Interesting, but what is it?"

"It's called Darier's sign" he announces excitedly. "This is the patient I told you I was researching last night. She has mastocytosis."

"Oh yeah, you told me about this." He takes a deep, bothered breath, stands up straight and rests against the wall.

Sensing his disinterest, Dr. Lawrence lets go of my arm and quickly changes directions. "Uh, maybe we should get her on the table and take a look at her abdomen." He looks back at his unresponsive colleague who is standing idly with his hands in lab coat pockets. "Okay." He blinks feverishly and smirks before returning his attention to me. "So Nina, you don't need to put on a robe or anything. All you have to do is pull your shirt up to your ribcage and pull your pants down to your hips. You can leave your undergarments on. Are you comfortable with that?"

"Sure, but I would be much more comfortable if I knew who the other person in the room was." I shift my gaze to his colleague. "Hello."

He looks me up and down, like a king who has been disgraced by an uppity peasant who dared speak to him. "Dr. Walters."

I feel my left eyebrow rising involuntarily as I stand with my right hand extended. "Dr. Lawrence told me your name earlier. I just thought a formal introduction would be more appropriate. I'm Gianina, but you can call me Nina."

He gives me a brief, limp handshake before returning his hand to his lab coat pocket and turning his head to speak to Dr. Lawrence. "We should get started."

"Wow, nice to meet you Nina. Nice to meet you too Dr. Walters. See that's what usually follows a friendly introduction." We trade glares as I snicker before hopping up on the exam table and exposing my abdomen.

Clearly uncomfortable with our micro aggressive exchange, Dr. Lawrence clears his throat. "Ahem, let's get started shall we?" He glides his fingers across my sternum. "You certainly have a lot more spots on your belly than you do on your arms. Has it always been like this?"

"No, the spots started showing up on my arms when I was about 18 or 19, but I don't really recall when they started spreading. I just dismissed them as freckles."

Attempting to get him involved, Dr. Lawrence calls for Dr. Walters. "Dr. Walters, come take a look at this please."

He puts away his pager and slowly walks over, standing next to Dr. Lawrence. "Hmm, is there any tenderness?"

"I don't know. I haven't started pressing yet. Nina, I'm going to press on your belly and I need you to tell me if you feel any pain or discomfort okay."

"Will do." I tilt my chin forward and place the palm of my hand under the base of my head, gently pulling it up for a better view.

He begins at my sternum, pressing his fingertips down in a deep circular motion. "Any tenderness Nina?"

"No."

"Has this area ever been tender in the past?"

I look up and quickly recall having being prescribed hyoscyamine in the past for upper gastric pain. "Actually yes, I have had a few episodes with a heavy, dull pain that radiates from

front to back in that region. I was prescribed hyoscyamine for it in the past, but no one was really sure what caused it.

"Hmm heavy, dull, and you could feel it from front to back, did anyone think to check your liver?"

"Yes, my primary care physician determined that I had fatty liver."

"Really, do you mind if I press on your liver a bit?"

"Not at all." I sneak a peek at Dr. Walters who now seems somewhat interested watching over the shoulder of Dr. Lawrence.

"How about that, does that hurt Nina?"

"No not at all." As he makes his way down passed my belly button a mild soreness causes me to flinch.

"Uh oh, looks like a hit a sore spot. How would you describe the pain?"

"I would say its minor. It's probably more uncomfortable than it is painful."

As he continues the examination, moving further down the discomfort increases. "There goes that face again. What are you feeling right now?"

"It's a little worse than earlier, but not unbearable."

He pauses before pressing again. "It feels a little swollen in this region. Dr. Walters, what do you think?" Dr. Lawrence steps aside and makes room for Dr. Walters.

Dr. Walters steps in and presses on the area. His words are abrupt and his tone harsh. "It's a little swollen."

"So what are your thoughts? Should we investigate further?"

Perturbed, he scowls at Dr. Lawrence. "I mean it's not like it's severe or anything. She said herself it was minor."

Denied the privilege of receiving any further interaction, Dr. Lawrence turns to me. "Nina have you ever had pain in this region before?"

“Yes I have, but it is close to my cycle. Maybe that’s why.” I roll my body up halfway and lean back on my elbows. “I don’t know what you’re feeling today down there while you’re pressing on my stomach. All I know is I had diarrhea and vomiting off and on for years now. Sometimes the pain and swelling are so bad, I can’t leave the house. I took the hyoscyamine like I was told, but it still came back periodically. I’ve had fatty liver and high enzymes in my liver, but no traces of hepatitis. Now Dr. Branson seems to think this could be related to the mastocytosis. So my question is, what can we do to stop all of these stomach problems I’m having? I mean, I’ve had an endoscopy before and all it showed was GERD. Do I need another one? I don’t know. I just feel like maybe they were missing something, but you could be the ones to find it. Can you help me?”

Dr. Lawrence looks over at Dr. Walters. “What do you think Dr. Walters?”

His scowling transitions into a stone face. “We can prescribe some more hyoscyamine for now. Based on what I felt, there’s no need for another endoscopy. What are your thoughts?” The familiar feeling of heat creeps through my body and explodes in my head. I need to get out of here fast.

“Alright.” I plant my feet on the table, lift my pelvis, and snatch my pants back up to my waistline, quickly zipping them before fumbling with the button. I watch as Dr. Walters’ mouth drops open as I sit up straight and pull my shirt down. I adjust my sleeves and collar while he stammers over his words.

“Do you uh, would uh like um, want the prescription for the hysocytamine?”

I hop down from the table and grab my purse before turning to face him. “Oh, I think we’re done here. Dr. Lawrence, it was a pleasure meeting you [emphasis].” I shake his hand and nod approvingly. You really know how to listen and address the needs of your patients.” I walk over to Dr. Walters next and extend my hand, waiting for what seems like an eternity for him to offer his for a shake. Upon contact, I give him a painfully firm hand shake. “And Dr.

Walters” I stare fearlessly into his eyes, “it’s been interesting.” I hold my left hand out. “I’ll take that prescription now.” He abruptly ends the hand shake, snatching his hand back and shaking away the soreness. He then pulls a pen from his pocket, to illegibly scribble down the scrip and places it in my hand. “And when the pain keeps coming back, I’ll keep coming back and nagging you until you give me something that actually works.” “Good day sir.” I shrug my shoulders, donning a superficial grin before walking out.

The bone marrow biopsy. “So what did you say this doctor’s name was again?” Mom places her book on her lap.

“It’s Dr. Kartal.”

“Is he nice?”

“Yes ma’am, he’s nice.”

“Gianina, look at me.”

I look up from twiddling my thumbs. “I’m not really scared of the pain if that’s what you’re referring to. Honestly, I don’t think anything could hurt worse than the spinal tap I had a few years ago. I guess I’m more afraid of what he might find.”

“What do you mean what he might find? If he sees something, you may have to take medication for it and that’s okay. Listen, I know you don’t like taking pills Gianina, but there are some things that herbs and vitamins cannot heal.”

I look down at my hands again realizing I can no longer protect her from the truth. “It’s not really that simple. I, I didn’t want you to worry. So I left a few things out.”

She rears back in her seat with a questioning look. “What did you leave out?”

“Depending on the biopsy results, I may have to have chemo.”

“Chemo! You never said anything about chemo!”

“I know and this is why. Look at how you’re reacting.”

She picks her book up and begins reading again. "Well that's not going to happen." I guess after taking care of both Granny and Poppie until their deaths, the thought of another loss sends Mom into a defensively, optimistic state. I follow her in my mind, defensively pleading with God as if He were unaware of all of the things I have not done. Chemo can cause infertility. How can I start chemo when I have never had children? I've never been married. Who's going to want to marry a bald, bony woman? I can deal with it later God, just not right now.

"Hello there." In walks Dr. Kartal a deep, caramel-colored man. His curly, jet black hair graces the jawline of his clean shaven face. The endangered hairs lining his forehead form a neatly coiffed, sparse pack nearly reaching the crown of his head. His warm, brown eyes look out over his pronounced nose surveying Mom and I. "Ah, I see you brought Mommy with you today."

"Yes I did."

"How are you Mommy? I'm Dr. Kartal."

Mom leans down and drops her book in her purse smiling. "I'm fine Dr. Kartal, how are you?"

"Oh I'm fantastic. And how are you Miss Hayes?"

"I'm fine Dr. Kartal."

"That's good to hear, good to hear." He places my file down on the counter and takes a seat on the stool in front of us. "So do you have any questions today Miss Hayes?"

"Please call me Nina."

He smiles coyly leaning his head to the side. "I'm sorry Nina."

"No problem Dr. Kartal. I have two questions actually. First I was wondering what kind of pain killers I can take after the procedure. I noticed the paperwork I was given suggested I take ibuprofen which I am advised to avoid because of the mastocytosis. The paperwork also

states I should avoid acetaminophen due to its tendency to increase blood flow. I really don't know of anything else I can take. What do you recommend?"

He leans back looking up toward the ceiling. "Whew! That's a tough one, hmm." He turns and grabs my file hurriedly flipping through it. "Good observation by the way. I completely forgot about that. Those are standard rules for the average patient." He looks up from the file disappointedly shaking his head. "How would you describe your threshold of pain?"

"Pretty high."

"Good because from what I'm seeing, you're going to have to grit and bear it. Are you okay with that?"

I shrug my shoulders as I grimace. "Well I really don't have a choice at this point. I'll mangle. I always do."

He places my file back on the counter. "And what's your other question?"

"Well I do have quite a few allergies, some of which are to anesthesia. I was wondering what kind of anesthetic you are going to use today."

"Now, this part I did consider, ha, ha." He laughs and slaps his knee. "You caught me with my pants down about the ibuprofen, but not this time. Given your condition, I'm opting to use local anesthetics only."

"You mean I'm going to be conscious?"

"Yes, I need you awake in case you feel an allergic reaction coming on. I also prefer for the patient to be awake so they can tell me if I am hurting them. Trust me; I have done this before, even on patients who do not have mastocytosis. The pain will be minimal. If anything you will experience more pressure and discomfort."

I slap both hands down on my thighs. "Let's get started."

"Mommy, do you plan on staying? You're more than welcome, but I do not recommend it. It can be rather distressing to watch."

Mom grabs her belongings and stands up. “No thank you. Give me a kiss Sweetie Girl.” I turn my head giving her access to my cheek. “I’ll be waiting for you out in the lobby okay.”

“Okay.” Part of me wanted her stay, but after what happened with my spinal tap, I can’t blame her. Not to mention, watching Granny die in front of her and reviving her twice before the ambulance came. She has seen more than her fair share of trauma. “I’ll see you soon.”

She stands still for a moment, second guessing her decision. “Are you sure you’re going to be okay?”

Putting on my bravest face, I smile at her. “I’ll be fine. Now get out of here so we can get started. I’m hungry.” She shoots me a half grin before walking out.

“Don’t worry Mommy! I’ll take good care of her” Dr. Kartal announces proudly. She turns and waves at him before walking down the hall. He turns and faces me. “Nina, I am going to get my equipment. What I need for you to do is pull your shirt up to your ribcage and pull your pants and underwear to the base of your buttocks. Then I need you to lay flat on your stomach. I’ll be right back.”

“Don’t forget the latex-free gloves, Dr. Kartal.”

He smiles and points his finger straight up in the air, as if to recite a famous quote. “Everything here is latex free Nina. You’re in good hands.”

I smile back at him. “Sorry, I’m so used to issuing the warning.” I wait for him to close the door behind him and begin rolling up my shirt and tucking it under my bra. Immediately I feel the chill of the cold room triggering goose bumps on my stomach. I unbutton and unzip my pants, digging my thumbs down past the waist of my jeans and under the elastic of my panties—wiggling them down simultaneously. The chill spreads further. “I need a blanket.” I lean over, opening the drawers searching for something to keep me warm until Dr. Kartal returns. Flipping through layers of printed robes, I reach the bottom of the pile where a thin, white, and crookedly folded blanket lay. I slide the blanket out, careful not to disrupt the neatly

folded robes above it. I push the drawer closed and hop up onto the exam table. Taking two corners of the blanket, I shake it loose and drape it over myself before rolling onto my stomach. The blanket offers only mild protection from the cold—still allowing a good portion the cool air to seep through the transparent weaving. Lying in wait, I breathe deeply in anticipation of the pain. No matter how many times a doctor told something would be painless, it was always painful. Maybe Dr. Kartal is right for a change. Either way I would rather be prepared than caught off guard.

A loud knock at the door startles me. “Come in!” The door creaks open followed by the sound of squeaky wheels. I look over my shoulder and see Dr. Kartal pushing a cart with a nurse.

“You know you’ve been to the Dr.’s office far too many times when you know where to find the blankets on your own haha!” The nurse covers her mouth and giggles.

“What can I say? It’s freezing in here Dr. Kartal. Is there anything you can do about the temperature?”

“Unfortunately no, the thermostat in this building is universal with the exception of the operating rooms. We still have some prep to do. So bundle up until then.” I roll onto my side and curl myself into a ball. “Nina this is nurse Jacobs. She will be observing today.”

She keeps one hand at her side and waves shyly with the other. Her voice barely above a whisper, just reaches my ears “Hi Nina.”

I wave back. “Hi nurse Jacobs.” I glance at the cart, surveying the many items that will be used. A large needle with a blue handle, quite similar to the one used for my spinal tap lays next to a smaller needle also with a blue handle. Flashbacks of my spinal tap begin pouring into my head. I quickly look away and rub my temples. This is different Gianina. He has latex free gloves and he knows what he’s looking for.

“Are you alright Nina?” Dr. Kartal asks concernedly.

“Yes, I’m just hungry.”

“I remember you saying that. Don’t worry, we’re about to start in just a moment. Nurse Jacobs, would you mind washing your hands for me and then taking one of these sheets and draping it over Nina?”

“Sure” she whispers before walking over to the sink.

“I know you’re cold Nina, but I’m going to have to steal this blanket from you.”

“It’s fine. I’m ready.” I pull myself into a tighter ball, rubbing my arms.

“Okay Nina, I need you to lay on your back and nurse Jacobs is going to drape one of these paper sheets over you.” I uncurl my body, once again exposing myself to the chilly air and roll on to my stomach. A light breeze glides across my back as she shakes the paper sheet loose before gently laying it across my lower back. I hear the water rushing at the sink again as Dr. Kartal washes his hands next. “Before we begin Nina, I would like to debrief you on the procedure. I know in addition to the consent form you signed there was information explaining the procedure, but I would just like to go over it with you again for good measure. The first thing I will do is numb the area. First I’ll numb your skin and then your bone. So that’s two injections before we start. I am relying on you to tell me when you are numb. Then I will make a small incision. Next I will begin the procedure. The first part of it will be me taking what is called the aspirate. After I get the aspirate, I will take a sample of the actual bone marrow. After that, I’ll put pressure on the area to stop the bleeding and dress your wound. Do you have any questions?”

“Yes, how often do I have to change the bandage?”

“You will probably have to change it in about four to five hours after the procedure. After that you shouldn’t bleed a whole lot. If you do, come back immediately. Also let me know if you have pain that continues to increase over the weekend. The pain should lessen, not become more intense. Any other questions?”

"No, not that I can think of."

"Okay let's begin." He positions the paper sheet over me and presses through what feels like a hole in the sheet.

"Is that supposed to be there or did it rip?"

"Ha ha, no it's supposed to be there." He positions the sheet just so before swabbing the area with alcohol. "I will take the biopsy through this opening."

"Oh okay."

"Alright, this will sting a little bit." A light prick followed by a burning sensation spreads under my skin. He gently rubs the area. "I'll give it a few seconds to work." The seconds fly by before he gently taps the area. "Can you feel that Nina?"

"Yes."

"It should have taken effect by now. Okay, let's wait a little longer." I lay on my stomach contemplating yet another painful procedure. This is supposed to be quote unquote routine. According to the pamphlet and post procedure instructions, I could go back to work tomorrow if I want to. I'm starting to think it is standard procedure to bullshit patients into thinking the pain will be minimal so we will not avoid having certain procedures done. "How about this? Can you feel this?"

I feel a fuzzy, tingling sensation, similar to how it feels when one of my limbs falls asleep. "I think it's working. I'm not completely numb, but it feels kind of tingly."

"That's good, that means it's working. Now I need to numb the bone."

"You can do that?"

"Oh yes. That's what the second needle is for. You will feel some discomfort though. Get ready, just a little pressure here."

A painless presence penetrates my skin which is rudely interrupted by a deep dull pain. "Mmm."

"I know I know I'm sorry. I just need to numb the bone before we can continue." He rhythmically moves the needle up and down like a sewing machine, repeatedly striking my hip bone. I close my eyes and exhale until he stops. "How are you doing Nina?"

"I'm fine."

"I must tell you, you're handling this really well so far."

"Oh, thank you. You make it easy."

"Okay, I'm going to make just a tiny incision—you won't even feel it. Then I'm going to insert the needle and take the aspirate."

I close my eyes bracing myself for the incision. "Let me know when you start."

"I've already made the incision."

"Already? I really didn't feel it."

"Yep, this time you're going to feel a little more pressure than before." I focus my attention on the wall searching for some small, unique inclusion to focus on and take my mind off the procedure. A thinly smudged black line, shaped like the number seven lying on its side beckons to from the off white wall. "You may want to find a focal point on the wall or something."

I chuckle "I'm way ahead of you Dr. Kartal."

"Ha, that's good to hear Nina, good to hear. Okay, a little pressure."

A heavy, dull, yet somewhat tolerable pain permeates my lower back. I hold my breath and my tongue, staring intently at the mark on the wall. The pressure intensifies. Vibrating sensations travel in both directions, down my thigh and up my spine. I stretch my neck and peer over my shoulder to find him bearing down on my back, twisting the needle. I quickly return my gaze to the seven on the wall and begin mouthing the Twenty-hhird Psalm. "The Lord is my shepherd. I shall not want (Psalm 23:1, KJV). . . ." Suddenly, the twisting stops and the pressure of his weight is lifted.

"I am going to take the aspirate now."

Breathe Gianina, just breathe. You can't freak out on the table with a needle stuck in your bone. "Okay." Don't look back. Just look at the seven. A sharp pain joined by vigorous suctioning surges through my bone. My jaw stiffens as I continue to stare intently at the seven. Where was I? Where was I? I quickly pick up where I left off. ". . . He maketh me to lie down in green pastures. He leadeth me beside the still waters. He restoreth (Psalm 23:2-3, KJV) . . ."

"Nina did you say something?"

I must have been whispering more than I was mouthing. "No, no I didn't say anything."

"I'm almost done with the aspirate. Are you hanging in there for me?"

"I'm here." Another sharp, suctioning pain travels through my bone. "Cough, cough ahem!" I choke on the reservoir of saliva building in the corners of my mouth.

"Just one more." I hold my breath in anticipation, tightly clenching my teeth. My body trembles as the agony arrives and departs. Eyes closed, I exhale and slowly relax my muscles. "How are you Nina?"

"Ha ha! About as well as I can be while you're drilling into my bone."

"Hey, as long as you're not screaming or crying, I guess I'm not so terrible at this. Well I'm done with the aspirate, and most patients say it's the worst part. The next part is getting the actual bone marrow."

"I'm ready when you are, Dr. Kartal."

"You're going to feel some pressure—deep breathe Nina."

I inhale deeply as his body weight presses down firmly on my lower back. A grinding sound echoes in my head. Oh my God, is that my bone I'm hearing? Vivid pictures of my bone falling away like sawdust as the drill penetrates deeper sends me into panic mode. My heartbeat quickens and breathing becomes unsteady. Pull it together Gianina! Don't think about it. Just look at the seven. My body involuntarily rocks from side to side from the force of

him twisting the needle in deeper. I grab the corners of the cushion on the exam table to steady myself—squeezing tightly until my fingers turn white. Another dull, aching pain permeates my bone. “Ow.” I reveal my pain in a low whisper in an effort to keep calm.

“What was that?”

“Sorry, you told me to tell you if you hurt me and that hurts.”

He pauses for a moment. “Oh, I’m sorry. I know I’m drilling hard, but you seem to have a really dense cortex. It’s taking a lot more elbow grease than I imagined to get the biopsy. I can try to be gentler, but it may take longer to get the biopsy. Is that okay?” Either I can endure intense pain for a brief while or endure less pain for a longer period of time. I shake my head indecisively. “I have to know soon Nina before the anesthetics wear off.”

Shit, okay you can do this Gianina. Just let him hurry up and finish. “Nina?”

“Just uh, just go ahead. The sooner you pull that thing out of me the better.” He immediately returns to drilling. I stare off into the void imagining it standing up straight and dancing across the wall. Suddenly the drilling stops. Several clicking and sliding sounds continue in the background. “Did you get it?”

“Yes, I’m going to remove the needle now. This takes a little while.” My body returns to its earlier side to side rocking motion, but much softer this time. “I have to wiggle it a bit before I can get it out.”

“It’s fine, we’re almost done anyway.” My gurgling stomach reminds me I have neglected it for too long. In just a few minutes, I can get off of this table and go eat with Mom. The pressure on my back lessens and faint grinding sound plays in my head. The sound fades out leading to more clicking and clanking sounds. “Is it over?” My question is met with silence. “Dr. Kartal is it over?”

“Nina I have a little bad news.”

Foreboding butterflies stir in my gut. “Bad news, how is that possible? I thought it took weeks to get the results.”

“No, no nothing like that. It’s just, well nurse Jacobs showed me the marrow. It’s not enough.”

“Not enough, do you mean we have to do this all over again?”

“No, not all over again, we have enough aspirate. We just don’t have enough marrow. Can you handle another biopsy?”

“I really don’t have much of a choice right now do I? Let’s do it.”

“You’re such a good sport Nina. Again, I’m very sorry Nina. I will move as quickly as possible.”

The pressure and rocking return almost immediately. I do my best to lead my mind far away to a safe haven, but the sound of my bone grinding holds me at bay. Panic begins to sink in again as flashbacks of my spinal tap taunt me as I struggle to center myself. I recall one verse from the Twenty-third Psalm and replay it over and over in my head.

Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me; thy rod and thy staff they comfort me. Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me; thy rod and thy staff they comfort me. Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art with me; thy rod and thy staff they comfort me. Yea, though I walk through the valley of the shadow of death, I will fear no evil: for thou art (Psalm 23:4, KJV)

The drilling stops and the gentle wiggling returns. “You’re done already?”

“Yes, I told you I’d be quick.” I peer over my shoulder at Dr. Kartal once again. His brow bone is thick with beads of perspiration. Two strands of his hair lie sprawled out like rivers on a map across his cheek. “You should be happy to have such a thick cortex. It’s a good thing.”

“Yeah, says the man on the other end of the needle.”

“I know I know it’s much easier to make that statement from my perspective right?”

“Did you even have to ask?” I continue to face the wall as he dresses my wound.

“Keep in mind Nina, if there is excess bleeding or pain that lasts more than a few days becomes more intense, it is important that you let me know. Oh, and don’t wet the area tonight. Keep it dry for now. Do you have any more questions?”

“No I’m just ready to eat.”

“Well you’re in luck. You’re all bandaged up right and ready to go.”

“Whoo hoo!” I slide down from the exam table and plant my feet on the floor. The impact sends a fuzzy feeling up my right thigh into my lower back. I wiggle my pants up before zipping and buttoning them. Thank God I wore low rise jeans. I pull my shirt down and adjust it before shaking his hand. “Thank you Dr. Kartal.”

“Oh wow this is new. Most people aren’t in a handshaking mood after a bone marrow biopsy.”

“Well I’m not most people. I just want to get to the bottom of this thing so we can figure out what we’re dealing with.”

I quickly turn to face nurse Jacobs. “Nurse Jacobs, it was a pleasure meeting you as well.” She nods her head in silence and nods as we shake hands. “Well, I’m out of here.” I grab my purse from the chair and walk toward the door. My leg drags awkwardly as I fight the fuzzy resistance. “Oh wait do I need any paperwork or anything when I sign out Dr. Kartal?”

“No, not yet you will be contacted when the results are in. You’re free to go.” He smiles and waves. “Take care Nina.”

“You too Dr. Kartal.” I walk down the hallway attempting to adjust my steps before reaching the lobby. Mom doesn’t need to see me walking like this. I pause at the door, close my eyes tightly, and shake my head as the sound of my bones grinding rings in my ears. “It’s over now. Just block it out. Just block it out.” I picture Mom sitting in the lobby waiting for me and the corners of my mouth begin to curl as I twist the knob and walk into the lobby. There is Mom, sitting directly across from the door smiling just as I pictured her and right next to her is

my Uncle Tim. They both stand to their feet. My smile becomes increasingly more genuine as I walk toward them.

Uncle Tim leans in toward Mom muttering under his breathe. "She's not walking right."

"Mm hmm, she's hurting." I walk into Mom's outstretched arms, grinning at Uncle Tim as I rest my cheek against her shoulder.

He greets me in his usual way. "Hey Pippi!"

"Hey Uncle Pippi!"

He shakes his index finger at me. "You can't call me your name." I always loved Pippi Longstocking as a child. I read all of the Pippi books and even watched the movies. Uncle Tim added this nickname to the roster. When I was about seven years old, he saw me in the morning and said my pigtails were sticking straight out, just like Pippi. And just like Roastie, Gigi, Tootie Fruitie, and all the rest of my nicknames it stuck.

Mom politely pushes me back to get a good look at my face. "Are you alright?"

"Yes ma'am."

I lean over and hug Uncle Tim as Mom smirks sarcastically. "Liar."

He wraps his arms around me squeezing tightly. My lips involuntarily release a groan.

"Ugh!"

"Oh I'm sorry Pippi! Are you okay? Did I squeeze too hard?"

I rub my palm against my lower back. "It's not your fault. I think the anesthesia is starting to wear off. I know you both want to know what happened back there, but can we please just go get something to eat."

Mom pauses briefly before nodding. "Let's get you out of here Sweetie Girl."

The cumulative results. "Hi Nina." Dr. Branson struts in smiling.

"Hi Dr. Branson."

She takes a seat across from in front of the computer. "How are you feeling today?"

“Eh, so, so, I stayed up until about 2:45 last night and when I finally did fall asleep I had a night sweat.”

Her perfectly erect posture curves as she slumps out of sympathy. “Oh no, I’m sorry to hear that.”

“Hey, I’m graduating in a couple of months. So, that trumps everything.”

She perks up immediately from the good news. “This is your Master’s right?”

“Yes, I’m so excited.”

“That’s great news! Do you think you’re going to go back for your doctorate?”

“Huh, not in this lifetime.”

She grins and shakes her head as she flips through my charts. “I don’t know how you can stomach all of that writing. It would drive me crazy.”

“It’s no worse than all the reading and memorization you medical students have to do. There are way too many human body parts for me to remember. My patients would leave botched.”

We both laugh as she settles on a page and pulls it from the folder. “Soooo, I have your bone marrow biopsy results here and looks like they were unremarkable. There were some scattered cells, but in his notes it appears there’s nothing to be concerned about. Considering that in combination with your low tryptase levels I am inclined to believe you are cutaneous.” She looks up from the paper, puzzled. “Oh come on, that’s at least worth a round of applause. This is good news. Aren’t you happy?”

“I am, but something isn’t right. Did you look at some of his other findings in the report?”

“Wait, you can understand the bone marrow biopsy?”

“Not without some help of course. I looked up some of the terminology and interpretation online and I asked Dr. Kartal to explain the rest.”

“Don’t get me wrong. I’m not doubting your intelligence. It’s just awesome to see a patient get this involved.”

Flattered and shocked by her compliment, I blink repeatedly as I respond. “Wow thanks.”

“You’re welcome. I took us totally off track. Let’s get back to this concern you have.”

“Oh yeah, I was concerned about my iron levels and the description of my blood cells.” She reopens the folder and begins flipping through the results. “Under iron it says there was none seen and none stored. Then he reiterates stating that I was completely absent of storage iron. Then”

“Wait, wait let me catch up to you.” She pauses skimming over a page. “Okay, I see it here. Hmm, that is rather disturbing.” She looks up at me concernedly. “What did he say about it?”

“He didn’t seem bothered. He said it was normal for a young menstruating woman; especially one who bleeds as heavy as I do, and if you remember, the bloodwork you ran for me showed that my red blood cell count was slightly below normal.”

She cocks her head back stunned. “That’s right I remember that. It was such a mild deficit. I didn’t expect it to run this deep. Did you want me to look into starting you on some iron pills?”

“No, it’s probably my fault. I used to take prenatal vitamins to keep my iron up and stopped a few months ago. I’ll pick some up on the way home and start on them again tomorrow.”

“And what were you saying about your blood cells? Oh wait, I see it right here. Wow it says they are abnormally shaped with a slightly off center nucleus. And he wasn’t bothered by any of this?”

“Not at all, he said the main focus should be on the fact that he only saw scattered cells and not dense aggregates of mast cells like you found in my skin.”

“Mm.” She continues reading and nodding her head slowly. She lets go of the sheet of paper and continues rummaging through my folder with furled brows. “Did you ever hear back from Dr. Hodson? I don’t seem to have anything in here from him or Dr. Walters or uh, Dr. Lawrence for that matter.”

“That’s probably because they didn’t run any tests.”

The papers fall from her hands as she looks up stunned. “I’m sorry, could you repeat that?”

“They didn’t run any tests.”

Her frustration is clear in her blank stare. “Okay, so what did they do?”

“Dr. Hodson asked me some questions and had me walk back and forth across the room and Dr. Walters and Dr. Lawrence did pretty much the same. They asked me some questions, pressed on my stomach, and sent me on my way.”

“That’s it?”

“That’s it.”

She crosses her arms and breathes heavily through her nose. “I am so disappointed. I was really curious about these strange jerking fits you told me about and I was really hoping Dr. Lawrence and Dr. Walters would have done a more thorough workup on you. Wow.” She shakes her head and faces the computer screen. “Nina I would like to see you in three months just to follow up and make sure you’re okay.” She turns in her chair to face me. “And I am so sorry that I don’t have more information for you. I just can’t get over the fact that they didn’t run a single test.”

I shrug my shoulders nonchalantly. “Don’t worry, I’m used to it. At least you, Dr. Thomas, and Dr. Kartal did your jobs.” She flashes a half smile and looks down before bidding me adieu. Hopefully I won’t have any more night sweats this week.

Second Partial Diagnosis

After moving to Florida to pursue my doctorate, I strategically built a new medical team at the Carol and Frank Morsani Center. I found the most highly rated primary care physician and then strategized with her find the best dermatologist, hematologist, immunologist, and gastroenterologist in the facility. Although I took my medication as directed and followed a strict low histamine diet, my symptoms continued to worsen. I began experiencing frequent night sweats, severe bone and joint pain, rashes, hair loss, abdominal pain, bloating, tachycardia, and tinnitus. Despite my complaints, my allergist/immunologist and dermatologist both seemed to focus on my low tryptase levels.

More night sweats and stomach upset. I awaken abruptly, panting as a baking heat builds inside. I snatch the covers back and dangle one of my legs over the edge of the bed, but not even the cool air provides relief. Frantically I fan myself, but still no relief. My fingers make a light splashing noise as I rest my hand on my chest. Alarmed, I look down and see my fingers resting in a puddle of sweat. Tracks of the cool sweat roll down my belly and into the folds of my pajamas as I sit up in bed. “Not today, not during the conference” I whisper. My hands glide across the wet sheets. Instinctively, I begin tugging at the fitted sheet before reminding myself I am in a hotel and thankfully I do not have to do the laundry. The bright red numbers on the alarm clock read 5:05 A.M. There is no point in going back to sleep. My pajamas and the sheets are soaked and I have to be up an hour anyway. I slip out of bed and tiptoe past my roommate who appears to still be asleep. “Ow!” I bang my foot on the leg of the desk on my way to the bathroom. I grimace silently, limping to the bathroom as I watch Tara roll over in bed. The cold bathroom tile soothes my foot and slowly spreads through my limbs cooling my

body. I stand still momentarily before flipping the light switch. “Seriously?” I lean across the countertop toward the mirror and run my fingers along my moist, curly hairline—a sharp contrast from the rest of my straightened hair. I never even considered packing shampoo. The conference is only two days long and I just straightened my hair yesterday. Maybe I can use the hotel brand. I pick up the tiny bottle, carefully reading each ingredient. Around the second line, I notice the usual suspects sodium lauryl sulfate, citrus limon peel extract, and citrus limon peel oil. The last time I used a shampoo with sodium lauryl sulfate alone my scalp was cracking and bleeding the next morning. Between the sodium lauryl sulfate and the high amount of citrus in this shampoo, I could go into anaphylactic shock by breakfast. Salty sweaty hair is certainly not my forte, but I cannot chance it, not here. I snatch a hand towel from the rack, shake it loose from its folds, section off my hair, and pat and squeeze my roots dry. There may not be enough time to wash my hair, but at least I can straighten it before breakfast. My frizzy roots transition from wet to slightly. I grab my brown butterfly clip off the counter and secure my hair into a tight chignon and plug in my flat iron. I tug at the collar of my pajamas and watch as the fabric slowly separates from my skin as if it were being unglued. Careful to avoid rewetting my hair I open the collar wide, pull the cold, wet shirt over my head, and place it on top of the toilet. I then separate the soaked elastic band of my pants away from my waist and step out them. I catch a glimpse of my plump, loose belly in the mirror. How did I get so fat? I have never had a gut like this before. I breathe heavily through my nose in disgust before grabbing a large towel and wrapping it around my head and continue the drying process. “It’s just one weekend Gianina. You can make it through.”

Severe stomach pain. I smile as Dr. Lester provides the answer to one of the homework problems. This is third one I have gotten right so far. Cara leans back as Lisa leans across her desk whispering as she gazes at me overtop her glasses. “Nina did you get that one right?”

"Yes I did."

She shakes her head looking down at her paper. "Can I see yours?"

"Sure." I pass my paper to Cara who passes it along to Lisa.

"How did you get this? I don't understand how I got this wrong?"

"I can't take all of the credit for my work. I belong to a study group."

"A study group, I don't have time for that. I'm married with two kids and I home school them."

I lean in closer and whisper more softly. "It's not like that. We don't meet in person. We compare notes online and catch each other's mistakes. If it wasn't for Tara, I would have gotten that one wrong too. She showed me where I had the wrong degree of freedom. It threw the whole thing off. I can add you to our list serve if you like."

She clasps her hands in a praying position. "Could you?"

I smile warmly. "Of course."

"Me too please" Cara beams.

"No problem, I'll add both of you right now." I click on my email tab and begin constructing an email to my current group members welcoming Lisa and Cara into the group when suddenly a sharp pain shoots through my sternum and down into my gut. My body involuntarily jerks into an erect position. Determined to push through, I continue typing the email and press send. "There, all done."

"Thanks" Cara and Lisa respond in unison.

"You're welcome. Hey did I get number four right? You still have my paper."

"Ooh, I'm sorry!" Lisa covers her mouth in embarrassment as the stares of the students in the row in front of us inform her that she has breached the acceptable volume level. She sinks back into her chair as she slides my paper across the desk to Cara. "My bad guys."

I laugh as I take my paper back from Cara. Another sharp pain shoots through me—this time extending to my rectum. I close my eyes and clench my fists tightly waiting for it to dissipate, but it lingers. A hot stirring sensation grips my gut as tiny beads of sweat form on my forehead.

Cara taps my shoulder. “Nina are you alright?”

I put on my calm, everything is okay mask before responding. “Yeah, I’m fine. Why?”

“Because you’re shaking.”

I look down in shock at my trembling hands. I was so focused on maintaining the stoicism on my face that I completely neglected my body language. Unable to maintain the charade, I reveal a shred of truth. “It’s just a little pain and it’s hot in here. Are either of you hot?” I take off my sweater and fan myself with both hands.

Lisa chimes in. “Hot? Nina it’s freezing in here.”

A dull, aching pain grows in my liver as the hot stirring sensation intensifies. My stomach begins to bubble. This feeling is all too familiar. I have to get to the bathroom fast. I use the back of my hand to wipe the sweat from my forehead before grabbing my purse and standing. “Would you excuse me for a moment?” I silently bolt out of the room and speed walk to the bathroom, all the while maintaining my unfazed expression. Thankfully, the bathroom appears to be empty. I have an hour before Dr. Lester releases the class for a break. Hopefully no one will come in before then. The generously portioned lunch I had at Olive Garden gradually creeps into my chest and hot poker like shooting pains attack my rectum. I run into the first stall, slam the door shut and lock it. Confusedly I pace back and forth in the confined space, unsure as to whether I should face or turn my back to the toilet. My lunch, now in my throat, stalls momentarily before taunting my gag reflex. The decision has been made. I hold my hair back, lean over the toilet, and open my mouth heaving heavily. I attempt to maintain a safe distance from the splashing toilet water, but the uncontrollable heaving only draws me

closer. Suddenly, everything stops. I catch my breath during the brief intermission before the dry heaving finale. My eyes and nose water from the forceful thrusting motion. Brief, mild hyperventilation follows.

Finally, my body stills. I reach down and tear off a long piece of thin, one-ply tissue and fold it several times before wiping my eyes, nose, and mouth. Weakened and disgusted I look down at my mess which is significantly smaller than I expected. Only a handful of vomit stares back at me. With all of the heaving, I would have expected at least three times the amount. The bubbling and stirring along with the searing rectal pain return. “God not diarrhea too.” I face the wall of the stall and place both palms on it defensively as I clench my cheeks and thighs together tightly. It’s one thing to regurgitate in a public bathroom, but I’ll be damned before I let myself become known as the smelly woman. I grunt and sweat as I clench deeper and tighter. Displeased with my resistance, my stomach releases a roaring, gurgling noise which continues for what seems like eternity before finally ceasing. Sluggishly, I push away from the wall and pull another long sheet of toilet paper to wipe the sweat from my brow. I raise my arms, allowing air to circulate under my moist armpits. A quick glance under each armpit reveals two large stains. I know who won’t be raising her hand tonight. “Come on come on, pull it together and get back to class.” I murmur encouragingly to myself before flushing the toilet and leaving the stall. A thorough inspection of myself in the mirror prompts me to freshen up my makeup. I gently wipe away the smudged mascara with my fourth finger and peel the excess pieces of rolled up toilet paper balls off of my face before powdering the shiny spots on my forehead and cheeks.

A young woman walks in behind me and heads straight for the stall I was in. “Ewe! Uh, uh!” Her face contorts into an expression of extreme displeasure. The smell of my vomit must still be lingering. I wait until she finds a suitable stall before beginning the mouth swish of

shame and exiting. No one can convince me that I am still cutaneous. It is clear to me now; I am going to have to badger my physicians until someone listens.

Severe unexplained back pain. I awaken overheated and soaked, from yet another night sweat. I take a deep breath and stare at the ceiling. The lights from the parking lot pouring in through the blinds form long skewed patterns stretching across the ceiling and down the walls. It's only 5:02 am. That gives me plenty of time to get clean before I leave for work at 8:45. I begin rolling up into a sitting position when a piercing pinch in my spine stops me halfway. "Yelp!" I let out a high pitched squeal and flop back down on the bed. "What the hell was that?" My second attempt draws tears. "Oh my God! What's wrong with me?" Determined to get out of bed, I lay flat again and roll on to my right side, pull my knees into my chest, straighten my legs and carefully roll out of bed onto my feet. While attempting to stand up straight, the agonizing pinch stops my body at a 45 degree angle. I slide my feet along the carpet and press my palm into the wall, bracing myself until I am fully erect. "Uhhhh! " I quickly get my voice under control remembering that my roommates are still asleep. Just a moment ago I was just planning my day around how fast I can get cleaned and dressed after my night sweat. Now I don't even know if I can bathe and wash my hair on my own. "Tylenol, Tylenol." Sciatica plagues me with each movement as I push away from the wall and slide my feet along the carpet toward my desk. I unzip my purse and wiggle my hands in and blindly feel around for the bottle. My fingertips brush across the sharp edges of my keys as I make my way down to the bottom. "Got it." I pull the bottle out and place it on my desk next to the unfinished bottle of water from yesterday. Two of these should do the trick. I untwist the cap from the water bottle and place it on the desk. My fingers lose their grip and slide across the pill bottle as I fumble with the cap, twisting it until the two triangles align. I shake two pills out into my hand and toss them into the back of my mouth. I take a large swallow and allow the room temperature water to carry the pills down.

Like clockwork yesterday's coffee and water turn flips in my bladder. I shuffle my feet all the way into the bathroom, turn on the light. I stare for a moment in anticipation of the pain to come from trying to sit down on the toilet. At least the countertop is close enough for me to hold on to. I slide my feet across the bathroom floor, careful to avoid tripping over the rugs. I turn my back to the toilet, lift my gown, and secure it in between my teeth. Holding on to the countertop tightly, I lower myself down. The fabric from my gown muffles my otherwise loud grunts as the piercing pain continues to stab at my spine. Unable to maintain my balance, my feet slide from under me and I collapse on the toilet. The shock from the impact sends my pain to a new high. I scream through the moist fabric stuffed in mouth as the tears flow profusely. How did this happen? I didn't lift anything heavy and I have not worked out in weeks. I wipe, and place one palm on the countertop and the other on the toilet seat to steady myself as I slowly push myself to standing.

My mind becomes inundated with the endless responsibilities I have yet to fulfill for the week as I make my way to the sink. The last thing I need right now is to hear my boss's mouth in response to me calling in sick. This woman works me 30 plus hours a week and had the nerve to say to me along with her team of graduate assistants (GAs) "Who do you think you are keeping score of every hour I work you? You should be thankful for the opportunity to learn." I have never called in sick before, but I remember how she treated me when I asked to leave an hour early to prepare for a midterm. She stared intently at me, coolly said "Okay," and rolled her eyes before swiveling in her chair to face her computer. I thought everything was fine until she was conveniently busy every time I needed her signature on my timesheet for the next month and a half. None of the other GAs had trouble getting her signature, just me. All of this came from the same person who once said "Never be afraid to let me know if you need some extra time for your homework or a test or something. Remember, academics come first." I wonder what the punishment will be this time. My presentation in Dr. Gene's class is only three days

away. I can barely stand up straight as is. How am I going to stand in front of the class like this? I scrub my hands harshly under the warm water thinking about my paper for Dr. Lester's class. My partner ditched me and left me with all of the work. We started out as a trio, but Lisa dropped the course. She said she needed more time with her family and she should not have taken this class along with two other heavy courses. I knew I was doomed the moment she told me she leaving. Without her there is no buffer between Kevin and I, which means all of the work falls on me. He promised it would not happen again after his low level of involvement in our last project, but in true Kevin fashion, he was unavailable unless it was to explain why he could not meet to work on the paper. I am a huge proponent of second chances, but this time I shot myself in the foot. So far I am 12 pages in and he has not even added a coma to this paper. I turn the water off and look at myself in the mirror, mentally laying out my plan of action. The first thing I have to do is call in to work. Whatever the consequences are, I will just have to deal with them. Oh my God, I took Tylenol on an empty stomach. There's no way I can cook like this. I remember the granola bar I dropped in my book bag last night to have for a snack today in case I could not fit lunch in. I'll eat that and go back to bed. I am sure the pain will be gone by the time I wake up. It has to be.

The smell of burnt coffee from the maker at the foot of my bed invades my nose, rudely awakening me. Startled I look at my clock. It is 10:00. I must have slept through my alarm. "Uhhh! I can't believe I overslept." The adrenaline rush coursing through my veins is thwarted by the severe pain in my back. "Ahhhh!" I scream out in agony as I lift my head and shoulders off the pillow. That does it. I have to go to the doctor. I lay flat, reach for my cell phone, and dial the doctor's office.

"Carol and Frank Morsani Center, this is Keisha. How may I direct your call?"

"Um yes, I would like an appointment with Dr. Korrapati."

"Okay, and your date of birth?"

"Yes 0-4-0-9-1979."

"And your first and last name?"

"Hayes."

"One moment please."

"Is that Gee-aunna?"

"Close enough."

"Ha, ha I tried. Well she has an opening Friday."

"I can't wait until Friday. I have to come in today."

"Oh, you need a same day appointment. Hmm, let me check her schedule." The clicks from her computer keys aggravate my already aching head. "Do you mind if I place you on a brief hold?"

"Not at all."

"Okay, one moment Miss Hayes." I begin praying silently, begging God to please give find an opening for me today. There is far too much at stake for me to spend the next couple of days in bed. "Miss Hayes?"

"Yes."

"You're in luck Dr. Korrapati had a cancellation at 12:30. Is that doable for you?"

"Yes, thank you. I'll take anything at this point."

"Okay let me put you down for 12:30." Her fingers tap away at the keyboard. "And the reason for today's visit?"

"I am experiencing excruciating back pain."

"Yeah, I can hear it in your voice." She continues to attack her keyboard filling in all the required information. "Okay I have you in the system for 12:30 today with Dr. Korrapati for severe back pain. Is there anything else I can do for you Miss Hayes?"

“No, thanks for all your help Keisha.”

“Oh you’re welcome Miss Hayes. I hope you feel better.”

“Thanks me too.” I hang up and wipe my left hand over my face. Is two and a half hours going to be enough? “God, please give me the strength to get over there.”

Eyes closed I lean against the wall of the exam room, utterly exhausted from the amount of energy I exerted to get here. The physical pain is equally matched with the embarrassment from being the object of pity of each passerby. The valet driver teared up when he had to reach into my car and physically pull me out because I was in too much pain to get out of my seat. It took me over an hour and 40 minutes just to get dressed and I could not even get out of my car. I need answers today and I am not backing down until I get them. There is a light knock at the door. “Come in” I murmur weakly.

Dr. Korrapati peeks around the door smiling brightly. Her smile quickly morphs into concern as she looks me up and down. “Why are you standing Nina?”

I finally open my eyes and respond. “Because I’m afraid that if I sit down, I won’t be able to get back up.”

She walks over and gently places her hand on my shoulder like a concerned friend. “How did this happen?”

“I don’t know. I woke up like this.”

She looks down at her chart. “Your blood pressure is quite high. That is to be expected with the amount of pain you are in. I noticed here that you have a low grade fever as well. Any coughing or sneezing lately Nina?”

“I have a fever?”

“Yes, you don’t remember me telling you, you had a slight fever?” I look up and see Trisha, the nurse who took my vitals before Dr. Korrapati walked in. I was so out of it I did not see her standing there.

“No, I guess I wasn’t paying attention.”

Dr. Korrapati looks into my eyes sympathetically. “It is certainly understandable given your circumstances.” She walks around and stands behind me. “Hmm, I wonder if maybe you have a pinched nerve. I need to take a closer look at you. Do you think you can lay on the exam table for me?”

I take a deep breath and nod my head. “Yeah.” I slide my feet along the floor making little squeaks as the rubber soles on my shoes catch the tile.

Dr. Korrapati waits for me at the exam table. “Are you unable to take actual steps Nina?”

“I tried, but when I lift my feet too high it hurts my back.”

“Hmm, I do not like the sound of that. Come, come I will help you up.”

I pause in front of the exam table, anticipating the initial pain from stepping up onto the foot rest. I press my palm into the cushion bearing down on the table and lift my left foot.

“Ahhh!” My foot flops onto the floor before even reaching the halfway mark.

“Goodness Nina, you must be in tremendous pain. Rest for a moment and try again.”

Resting would be the right thing to do, but there is far too much work to be done and no one to help. My innate tenacity and stubbornness kick in. “No, no I got it.” I raise my leg and plant my foot firmly on the foot rest. “Ahhh!” I feel myself rocking back as I lose my balance. My awkward fall is broken midair by Trisha.

“I gotcha, I gotcha.” She grunts as she positions me back to an upright position.

Dr. Korrapati stands aghast with her mouth open, collecting herself before responding.

“Nina I am so sorry. I did not realize it was this bad. Please do not try to lift your other foot. Let me do it for you.”

Too embarrassed to argue I simply say “okay.”

“You can lean back on me. I gotcha.” Trisha tightens her grip around my waist with her reassuring words.

I relax my body and release control. Dr. Korrapati looks up at me cradling my ankle.

“On the count of three—one, two, three.” Ten seconds and countless whimpers later, I am lying on my back wiping my tear soaked face. “Nina, can you tell me where it hurts?”

“Yes, it’s my mid back.”

“Hmm, and you say it hurts when you raise your legs.”

“Yes, I can only take baby steps.”

“Nina I would like to try something while I have you on your back.” She hovers her hand about five inches or so above my right foot. “I would like you to try your best to raise your foot to my hand.

I shake my head in protest. “I don’t think you understand. I can’t, I’m in too much pain.”

“I know, but I just need you to try please. This will give me an idea of your range of motion right now.”

I exhale deeply and look up at the ceiling. “Okay.” As I struggle to lift my strained, shaky leg the sensation of nails being hammered into my mid back radiates all the way down to the soles of my feet. I release a strangled shriek as my leg slams down on the table like lead. I reach around to try and comfort my back, but the damage has been done.

Dr. Korrapati rushes from the foot of the table to my side. “Nina I’m sorry. I won’t ask you to raise the other leg. Are you okay?”

I bite down on my lip allowing my breathing to return to its normal pace before responding. “Mm hmm.”

“My goodness I have never seen you in such pain.” She looks down for a moment before making her next request. “Nina I know this is hard for you, but I would like to take a look at your back. Don’t worry, you don’t have to move. Trisha and I will turn you on your side.”

Everything inside me wants to get up and run, but I cannot. I’m stuck here inside this body until someone can help me. “Okay.”

Trisha stands on my right, directly across from Dr. Korrapati. “Trisha if you gently push her toward me I will guide her onto her side.”

“Okay Dr. Korrapati” Trisha looks down at me. “I’m going to try and do this quickly so I don’t hurt you okay Nina.”

“Okay.”

“On the count of three Trisha one, two, three.” The hammering pain strikes my spine. My strangled shrieks graduate to profuse bawling. “You’re on your side now Nina.” I wipe my eyes and look up at Dr. Korrapati who is now crying with me. She dries her tears with the sleeve of her lab coat. Her face sinks into a disappointed expression as she tenderly brushes my tear-moistened hair back from my forehead locking me into her apologetic gaze. “Are you still with me?” I nod silently. “I am so very sorry Nina. I am going to take a look at your back now.” I nod again and listen as her light footsteps end behind me. She slides my shirt up and begins pressing along the base of my neck. “Let me know when it hurts Nina.” Her fingertips continue on reaching my upper back causing minor discomfort. The hammering pain returns on cue as soon as her fingers reach my mid back.

“Oww!”

She pulls her hands away quickly. "Okay, okay. Nina, I don't want to do too much with you today. I'm afraid I will do more damage than good." I hear her footsteps coming around the table to face me again.

I wait until she is in view before speaking. "What do you think it is?"

"I am not sure. Your discs seem to be aligned properly. My guess is a small fracture. I have been researching your condition and I read about osteoporosis associated with mastocytosis. Have you heard about this Nina?"

"Yes, but if that is the case it would mean I am systemic, like have been saying all along. Dr. Korrapati, you are the only one who believes me. Not even my dermatologist and immunologist have shown as much interest as you and you never even heard of mastocytosis until you met me. Please, you have to refer me to someone else."

She looks down as she thinks. "I can send you to Dr. Sanders, she is a great gastroenterologist and Dr. Ajam is an excellent hematologist. How does that sound?"

"Sounds good." A weak smile follows my confirmation.

"For right now, we have to do something about this pain. I am going to prescribe Vicodin to dull the pain and I would also like schedule a DXA scan."

"What is a DXA scan?"

"It's a dual-energy x-ray absorptiometry. It's like an x-ray, but it measures bone loss. I also want you to have general x-rays on your back and feet. I remember you complaining about your feet a lot in the past. We might as well get them looked at too. Do you have any questions?"

"No, I just want to pick up my meds and end this pain."

She nods empathetically. "I understand. Do you know how to get to x-rays?"

I shake my head. "No, I've never been."

“Okay when you leave here, you will take the elevator to the first floor. It will be on your right near the side entrance.”

“Oh I know where it is, thanks.”

“Are you ready for us to help you down?”

“Woo, give me a minute if you don’t mind.”

“Sure take your time.”

I mentally prepare myself for my slothful trek through the building. The faster I can get through this, the sooner I can get pain relief. Braced for the pain, I stretch both arms out toward Trisha and Dr. Korrapati. “I’m ready.”

Normal or abnormal lab results. I scroll through the long list of emails on my phone, prioritizing which ones should be read and responded to first. It makes no sense for me to be here. The nurse already called me with the results from my endoscopy and colonoscopy. Perhaps it is just the policy of the Carol and Frank Morsani Center to have an in-person follow up. Besides, I leave for Sweden in two days. I could be at home packing.

While most people would have been relieved about receiving negative results on a simultaneous endoscopy and colonoscopy, I was left perturbed and desperate—perturbed by still coming up empty after spending the last three years trying to prove that I am systemic and desperate to find a cure for this abhorrently, persistent nothing I was told I was experiencing. I did everything humanly possible to prove that further investigation was necessary. I even requested all of the doctors review my medical records from my previous physicians in North Carolina and compare notes concerning my symptoms, but nothing seemed to bring my point across. Dr. Edwards, my immunologist/allergist words of discouragement play in my head. “I’ve checked your tryptase levels twice this year and they have never risen above 5.5. Your bone marrow biopsy revealed only scattered cells. Let’s not forget your x-rays were unremarkable and your DXA scan revealed very strong bones. I know you seem to think there is more going

on, but the tests don't lie. You're simply not systemic." Never mind the fact that I have three lesions on my face that flake and peel until they are raw. I am still having frequent night sweats, bone and joint pain, worsened diarrhea and vomiting, heart palpitations, hair loss, my red blood cell and platelet counts are low, and my liver enzymes read similar to those of an alcoholic. Maybe it's something different altogether like a thyroid issue or something. I give up.

It almost feels like the grueling procedures [endoscopy and colonoscopy] were all in vain. Dr. Sanders took five biopsies and even inserted a Bravo Implant to gauge what was going on and none of her efforts yielded anything new. Now I have to pay this huge bill for nothing. At least I found a gastroenterologist who cared enough to look.

Dr. Sanders walks in through the open door and knocks on the metal frame. "Hi Nina." Small sections of her thick raven hair cascade along her hairline, framing her face as they feather back into her butterfly clip. Her dark features and complexion remind me of my mother's a deep, rich, chestnut hue, and her eyes are always engaged and concerned.

I quickly save the draft of my email and slide my phone into my purse. "Hi Dr. Sanders."

Although polite, her usual warm smile is absent. "How are you feeling Nina?"

"Today is a good day. The last two days were really rough though. I was nauseous and had a splitting headache, but that's nothing new. Oh before I forget. I have seen some improvement since I eliminated gluten and wheat from my diet. Maybe there's something to it."

She takes a seat across from me. "Well just because your celiac disease panel was negative, doesn't mean you are digesting wheat and gluten well. You very well may have an intolerance. If you're comfortable with it, continue on with this diet and see if there are any long term benefits. Anything else you want to ask me?"

"No, not that I can think of."

She takes a deep breath and rests her hands in her lap atop the manila folder. "So, how are you handling your diagnosis? Have you come to terms with it?"

I wave my palm indicating my nonchalant attitude toward the predictable routine. “Oh, I’m quite used to taking tests that come back with negative results. I have already accepted the fact that I may never find out the root cause of my pain. I mean I’m clearly not systemic. So, it has to be something else right?”

Her jawline tightens as she stares at me confusedly. “What are you talking about? We haven’t even gone over your test results yet.”

“Oh no wonder you called me in for a follow up. You didn’t know that I already received my results. Yeah, I got a phone call and they told me everything was fine”.

Her face crumples as she leans forward in her chair. “Who told you that”?

“The nurse did. She called she said everything was fine. Was she not supposed to do that? Oh no, I didn’t get her in trouble did I?”

She wipes her hands across her face looking up at the ceiling and then back at me. “Nina I’m so sorry, but you have been misinformed. The nurse must have called before the second round of testing was complete. The lab forgot to run the CD117 stains on your biopsies I requested. The results of those just came in a few days ago. She only had half of the results.”

“So wait, what are you saying? You found something?”

“Unfortunately, yes. I’m so sorry but, your entire digestive tract is populated with mast cells. There were so many in your colon we could not count them. Based on the biopsies, my estimation of the number of mast cells in your digestive tract would be somewhere in the millions.” Her words strike like a nuclear bomb shattering everything in its path—my dreams and aspirations obliterated in seconds. Deafened by the impact, I watch as her lips move silently. Visions of Mom and Dad tearfully accepting my posthumously awarded Doctorate of Philosophy (PhD) flood my mind. I adjust myself in my chair shifting repeatedly until the sound returns. “. . . not just your stomach, but each one of the five areas that I biopsied. I can’t imagine how much pain you must be in. This explains a lot.”

Still recovering, I sit firmly on fidgety hands silently containing the battle brewing inside of me. “Let me get this straight. You’re saying that there are millions of mast cells in my stomach? Do you think this could be the cause of my jerking fits?”

“It’s quite possible.”

I swallow hard bracing myself for the impact. “So does that mean, I have to start chemo?”

“I am not sure, but right now I would say no. To be sure, I would like you to make an appointment with Dr. Parker (hematologist) so he can check your tryptase levels again. I would say that you are systemic based on your pathology report, but he may disagree. If we all work together I am sure we can figure out how to help you. I do have one suggestion.”

“Sure, anything what do you suggest?”

“I know you have expressed disinterest in the past, but I think now is a good time to for you to start taking the Cromolyn.”

I sink down in my seat. “Anything, but that Dr. Sanders. You know how I feel about prescription medication.”

“Nina, your internal organs are under duress. I really think this could help.”

I let out a deep sigh and rest my chin in my hands. “Let’s make a deal. I’ve been following a strict low histamine diet for three years now and I just started eating gluten free last week. Why don’t we give it a little time to see how affects me. If there are no noticeable benefits, I will try the Cromolyn.” I look at her expectantly as she shakes her head.

She responds reluctantly, slamming the manila folder closed. “Deal. Do you have any more questions Nina?”

“Yes, is it possible for me to have a copy of my lab results? I would like to keep them for my records.”

“Absolutely, I’ll print them for you right now. I’ll be right back.” After she leaves, I stand looking down at the floor, allowing a fraction of optimism to penetrate the fortress of doubt in my mind. She didn’t say I needed chemo. She said she wasn’t sure and the need for medication is still debatable. The gluten-free and wheat-free diet just might work. Who am I kidding? I have been begging for someone to examine my intestines for three years now. There’s no telling how far gone I am at this point. “Here you are Nina.” She hands me the thick stapled sheets.

I smile and firmly shake her hand. “Thank you Dr. Sanders. If you would have relied on just my tryptase levels and bone marrow biopsy results, we would have never discovered this. I can’t begin to tell you how much it meant to me for you to take the time to investigate my complaints. They have been falling on deaf ears for quite some time.”

She searches my face for a more common and perhaps more human response to the news. Only Mom and Granny had the ability to see beyond the veil of my poker face. She hands my paperwork to me. “You’re welcome. I would like to see you again in three months and please reconsider trying the Cromolyn.”

Equally relieved and afraid, I walk away carrying the heavy load of new information. How will I tell Mom? When will I tell her? Should I tell her at all? “I’ll take that from you ma’am.” The clerk at the checkout desk takes my paperwork. “It looks like Dr. Sanders wants to see you again in three months for a follow up.”

“Okay.” I scroll through my calendar looking for holes in my tight schedule maneuvering through meetings, homework assignments, and study groups. We negotiate until something finally fits and he hands me an appointment card. “Take care.”

“You too.”

My interaction with the clerk granted a brief intermission from the drama that is now my reality. The weight of this new, unwelcomed knowledge bears down on my very soul, getting heavier and heavier as I walk to my car. It’s too much to handle by myself. I have to tell Mom.

I stop on the breezeway and pull my phone from my purse. Three deep breaths clear the knot forming in my throat. My heart beat quickens with each ring. “Hey Tootie Fruitie.” The sound of her voice floods my eyes. “Hello . . . Gianina.”

I snivel before answering. “I’m here.”

“What’s wrong?”

The urgency in her voice makes me reconsider my foolish decision. Why did I have to do this? I should have just kept it to myself and waited. “I just need to breath.” I exhale before sharing the news. “Whew, my test results came back and my entire digestive tract is populated with mast cells.”

Mom pauses for a second. “What? No, that can’t be right. I thought you got your results weeks ago. They must have you confused with another patient.”

My voice quivers as I attempt to explain. “No, they didn’t mix me up with another patient. The nurse called me before the lab work was complete.”

“Wait, I don’t understand what you’re saying.”

I take another deep, choppy breath holding my snivels at bay. “I’m trying to tell you that it spread. It’s not just on my skin anymore. It’s in my organs now too. She wants me to start taking medication and I may need chemo.”

“Okay, well let’s not jump to conclusions. It’ll be alright.” Okay, jump to conclusions, is she serious right now?

My voice raises half an octave. “Mom, did you hear what I said?”

“Yes, but where’s your faith Gianina? You know how to pray and you know no matter what happens we will all be there for you. If you have to take a leave of absence from school and come home to do your chemo, then we will do that.”

Angered by her dispassionate response I climb into my car and slam the door shut. “I feel like you just don’t get it. I could die and you’re sitting here asking me about my faith.”

“No I get it. I don’t think you get it. You’re crying and stressed out knowing full well how stress affects your mast cells. Unless you want to be up all night regurgitating with diarrhea and night sweats, I suggest you pull it together.” Her intentions are clear now. She’s not being indifferent. She’s being practical. “Have you eaten?”

“No ma’am, I didn’t have time. I was washing clothes to pack for Sweden.”

“Here’s what you need to do, take the card we share and go get yourself a good breakfast. Sit down, have some coffee and relax. Think about the fun you’re going to have on your trip. Now after you’re done eating, I want you to get some takeout to hold you for the next couple of days. You don’t need to waste time cooking. Just heat your food up in the microwave when you’re ready. And listen, I don’t want to hear anything about you paying for your food on your own. I am paying for this and I don’t want to hear another word about it. Do I make myself clear?”

“Yes ma’am.”

“Alright, now go and get your breakfast and call me later tonight when you’re done packing.”

“Yes ma’am, I love you.”

“I love you too Tootie Fruitie.”

“Bye Mom.”

“Bye Sweetie Girl.”

I look down at my phone and realize I have missed a text message from Dr. Walton. She’s already in Sweden and asking me to clarify the list of foods I cannot eat. It looks like I am going to have to add gluten and wheat to the list after all.

Responses of others (layer two). Rather than the usual blend of fear and concern demonstrated by my family and friends with respect to my illness, the overall response was more of an aggressive call to action. The concern and fear were still present, but manifested

more in the form of tough love. Mom established her position at the forefront of the tough love movement when she threatened to physically take me to emergency if I was unwilling to seek medical attention and when she calmly reminded me to keep calm after receiving the results from my gastroenterologist. Distance may have also played a key role in how my family and friends responded. Considering my proximity to my family members and friends, they were not physically in front of me to gauge how well or poorly I was feeling which made it much easier to maintain a façade. Although I made new friends after moving to Tampa, I did not allow any of them to get close enough to me to see what I endure on a daily basis.

Here the return of the genuinely concerned physician is duly noted. Just like two of the previous physicians—Drs. Adams and Sharma—Dr. Branson did not dismiss my symptoms based on the lab results. Just as the two previous physicians, she referred me to several other specialists including a hematologist, gastroenterologist, and neurologist. Disparate from Drs. Adams and Sharma, Dr. Branson's advantage was being fully informed about mastocytosis which resulted in a speedy diagnosis. Out of the specialists she referred me to, only the hematologist put forth an effort to thoroughly investigate my claims. Dr. Hodson [second neurologist] was overtly cynical and eagerly dismissive, while Dr. Lawrence exhibited signs of genuine concern and an inquisitive nature which seemed to be stifled by the opinions of Dr. Walters. The same level of genuine concern and inquisitiveness was exhibited by Dr. Korrapati who seemed more concerned with my wellbeing than with what the literature stated about my lab results. She was determined to alleviate my pain. Her decision to refer me to a gastroenterologist catapulted me into a greater understanding and somewhat clearer perspective of my diagnosis and prognosis which indicated that tryptase levels and bone marrow biopsies do not always tell the full story.

Comparing my experience to the literature (layer three). Despite the positive result of my skin biopsy, my normal tryptase levels were indicative of a cutaneous classification. This

is backed by Sperr et al., (2002) who assert tryptase levels for those not suffering from mastocytosis are less than five, and abnormal tryptase levels for sufferers of mastocytosis over 20 suggest systemic mastocytosis. The results of the bloodwork performed by Dr. Branson revealed my tryptase levels were 4.4. This was within the normal range and definitely not indicative of systemic mastocytosis. The results of the bone marrow biopsy that only yielded scattered cells reconfirmed the initial cutaneous classification. The definition of mastocytosis provided by Hartman et al. (2001) implicates “the skin” as “the organ most frequently involved”, but also makes mention of how “mast cells also accumulate in the bone marrow, gastrointestinal tract, lymph nodes, spleen, and liver” (p. 143). Not to be discounted are the various publications such as Akin and Metcalfe’s (2004) *Systemic Mastocytosis, Evaluation of the WHO criteria for the Classification of Patients with Mastocytosis* by Sánchez-Muñoz et al. (2011), and *Gastrointestinal Involvement and Manifestations in systemic mastocytosis* by Sokol et al. (2010)—all of which concur with Behdad and Owens’ (2013) definition of SM which states it “is characterized by clonal MC [Mast Cell] accumulation in bone marrow and other extracutaneous organs such as liver, spleen, lymph nodes, and the gastrointestinal (GI) tract” (p. 1220). Although there does not appear to be any research establishing a correlation between back pain, fever, and SM, I would be remiss not point out the similarities between my severe unexplained back pain account and the symptoms of the patient involved in Hein and Hansen’s (2005) study; he was diagnosed with SM only months before his death after exhibiting “nearly daily afternoon low grade fevers (100.0°-102.0° F) and his “symptoms were accompanied by low back pain aggravated by movement and a subjective sense of weakness” (p. 95). It is plausible that some of the physicians who were novices in regards to their knowledge of mastocytosis sought literature that did not cover gastrointestinal involvement. It is equally probable that some, more seasoned physicians sought only to satisfy the WHO criteria, which do not recommend gastrointestinal biopsies.

Both Drs. Korrapati and Sanders seemed to adopt the decision-making paradigm of clinical diagnostic reasoning process. Consider Dr. Sanders' approach to performing my biopsies; she did not simply concur with my then diagnosis, but rather deemed the "diagnosis as opinion revision with imperfect information" (Elstein & Schwarz, 2002, pp. 731-732). The imperfect information refers to what Elstein and Schwarz refer to as clinical evidence or in this case drawn conclusion of cutaneous mastocytosis based solely upon my bone marrow biopsy and tryptase levels. According to Elstein and Schwarz (2002), her resolve to update the opinions of her colleagues with her own imperfect information stemmed from Bayes's theorem which posits both a pre-test and post-test probability. "The pretest probability is either the known prevalence of the disease or the clinician's subjective impression of the probability of disease before new information is acquired" (p. 730). Conversely "the post-test probability," which is "the probability of disease given new information, is a function of two variables, pretest probability and the strength of the evidence, measured by a" preponderance of evidence ratio (p. 730). Similarly, Dr. Korrapati who knew nothing of mastocytosis until I shared articles with her and presented my own account, also took a unique Bayesian stance by measuring her "subjective impression of the probability of" me being systemic prior to Dr. Sanders acquiring new information against the new information which she relied on Dr. Sanders to acquire. The decision making paradigm exhibited by Drs. Korrapati and Sanders sets them apart from physicians like Dr. Edwards—who ascribed more to categorization and pattern recognition—due to it [decision making paradigm] being more amenable to reformation prior to receiving the results of blood tests or biopsies—a stark contrast from the problem solving paradigm (Elstein & Schwarz, 2002).

Seemingly, I was not alone in my quest for more knowledge about and control of my physical health. Eighty percent of internet patrons have sought health related information online, many of which expressed a substantial impact on their perceptions and actions (Pew

Internet and American Life Report, 2011). Rather than learning for the sake of learning like the general self-directed adult learner (Knowles, 1975), I was learning for quality of life. This is in agreement with Guglielmino (2008) who noted that self-directed learning may transpire in various contexts as a response to individual necessity and may be performed either collectively or individually. Given that there is such little scholarship regarding mastocytosis, I thought it beneficial that I and my doctors conduct as much research as possible.

Chapter 7

Cross Comparison of Literature to Findings

In Chapters 4 through 6, I provided narratives describing several blood tests and biopsies. During the period when the bloodwork and biopsies were taken, I collected some of the lab reports. In this chapter I compare the results, diagnoses, and prognoses given to me by physicians to datasets from literature concerning bloodwork and biopsies of patients with mastocytosis. First, I compare the results of the pathology report from my gastrointestinal biopsies to what the literature states about biopsy results concerning mastocytosis. Second, I compare my mean serum tryptase levels to the mean serum tryptase levels of participants in a study conducted by Sperr et al. (2002). I then compare the results of the biopsy on my duodenum to the mean results of patients with SM, CM, and both from study conducted by Seigert et al. (2004); the comparison results are then converted to z scores and represented on a bell curve. Finally, the narrative portions of my autoethnography were coded revealing emerging themes, which were then noted and analyzed via a method utilized by Holt (2003) known as recreated dialogue.

Comparing Lab Results

According to Valent and associates (2001), the existence of aggregates of mast cells totaling 15 or greater in at least one extracutaneous (any area other than the skin) organ is indicative of systemic mastocytosis. My pathology report reveals the results of my gastrointestinal biopsies performed by Dr. Sanders (see Appendix C). This includes five biopsies taken from my duodenal, stomach, ileum, right colon, and left colon. According to the results, each biopsy taken yielded a minimum of 30 mast cells per High Powered Field (HPF)

(see Appendix C) in each specimen. This was twice the minimum criteria for systemic involvement (“Me and my Mast Cells”, 2013; Siegert et al., 2004; Sperr et al., 2002). Table 5 depicts my biopsies alongside the minimum criteria for systemic involvement. According to Dr. Sanders my right colon was so immensely infiltrated with mast cells that the lab technicians were unable to count the number of mast cells (see Appendix C and Table 5). As a result, I was diagnosed with mastocytic enterocolitis .

When comparing my tryptase level from my first drawing to those of the study participants, my results were still below the minimum criteria for systemic mastocytosis which is greater than or equal to 20 (Sperr et al., 2002). In comparison to the mean tryptase levels of 6 patients with cutaneous mastocytosis and 56 patients with systemic mastocytosis in the research conducted by Wilson et al. (2011), my results were lesser than both the systemic and cutaneous study participants. Table 6 offers a comparison of my first tryptase level drawing to the mean tryptase levels of participants in the Wilson et al. (2011) study. Although it appeared my biopsies denote systemic classification, because the two theories are incongruent, my diagnosis appears inconclusive. It was clear I had mastocytosis, yet unclear whether the form of mastocytosis I had was cutaneous or systemic.

After bringing this enigma to the attention of my gastroenterologist, she was not only pleasant, but open to considering the implications of the conflicting evidence. She redirected me back to my hematologist. Both agreed that despite my low tryptase levels and clean bone marrow biopsy, I met the criteria for systemic mastocytosis. This caused me to wonder why testing a patient’s tryptase levels is considered the *go to* method for categorizing a mastocytosis patient as either cutaneous or systemic. If there is clearly another method with the capability of distinguishing these two forms of mastocytosis, why not recommend it regularly? If testing tryptase levels is the best method, why did my tryptase levels indicate normality, yet my biopsies revealed otherwise?

Table 5

Comparison of Pathology Report to Normal and Systemic MC/HPF

Specimen	My MC/HPF	Normal Cells/HPF	Systemic Cells/HPF
Duodenal	30	<15	≥15
Stomach	30	<15	≥15
Ileum	40	<15	≥15
Right Colon	Innumerable	<15	≥15
Left Colon	40	<15	≥15

Note. Aggregates of mast cells classified as systemic are in bold. MC/HPF = Mast Cells per High Powered Field.

Table 6

Comparing My Tryptase Levels to Patients with CM and SM From a Study Conducted by Wilson et al. (2011).

Source	<i>n</i>	Means Serum Tryptase Levels	<i>SD</i>
My Results	1	4.4 (Derived from first tryptase drawing)	Not Applicable
Study Participants with CM	6	6	Not included in study
Study Participants with SM	54	42	Not included in study

Note. * See Appendix D. Serum tryptase levels ≥ 20 are considered indicative of SM (Sperr et al., 2002). CM stands for Cutaneous Mastocytosis and SM stands for Systemic Mastocytosis.

According to Dr. Saaba (personal communication, July 2012), tryptase levels can fluctuate and therefore are not the most reliable method. Consequently, it should be noted the term systemic applies to many degrees of manifestation; this means I am systemic because the disease is evident in my gastrointestinal tract, but individuals who have a tryptase level of 20 or greater and evidence of larger aggregates of mast cells in their bone marrow are simply more systemic than me (Dr. Saaba, personal communication, July 2012). Thus, a myriad of tests should be run before making a definitive diagnosis (Dr. Saaba, personal communication, July 2012). He also called to my attention that the disease may potentially progress and, therefore, periodic

testing of my tryptase levels is essential to early detection in an effort to identify an onset of mast cell leukemia (Dr. Saaba, personal communication, July 2012). This scenario alludes to the conflated use of classification schemata mentioned in Chapter 2.

Table 7 compares my lab results from the biopsy of my duodenum taken by Dr. Sanders to the mean results of participants from a study conducted by Seigert et al. (2004).

Interestingly, those with UP had a greater mean of MC/HPF than I and study participants who were diagnosed with systemic mastocytosis. This further supports Drs. Sanders and Saaba's stance on what it means to be systemic.

Table 7

Comparison of the MC/HPF in My Duodenum Biopsy to Mean MC/HPF Duodenum Biopsies of Patients with CM/UP and SM in Seigert et al. (2004) Study.

Location of Biopsy	My MC/HPF	MC/HPF of Study Participants with SM		MC/HPF of Study Participants with UP		MC/HPF of Study Participants with SM and Skin Involvement	
		Mean	SD	Mean	SD	Mean	SD
Duodenum	30	31.6	12.3	45	14.1	33.6	12.7

Note. MC/HPF stands for mast cells per high powered field. The Seigert et al. (2004) study examined biopsies not only from the duodenum, but also from the gastric corpus and the gastric antrum, both of which are portions of the stomach. Due to Dr. Sanders' report not disclosing what specific region of my stomach she biopsied, I opted to only make comparisons between biopsies of my duodenum and those taken from the patients in the study. In this study $N = 152$ and for patients whose duodenum was biopsied only, $n = 25$. I do not have a mean score or standard deviation because this procedure requires full sedation and therefore was only performed once.

Data Analysis

Figure 4 depicts my utilization of the data from Table 7, I converted my results to a z score ($-.047 \sigma$) in reference to the study participants with systemic mastocytosis and skin involvement who had a mean result of 33.6 and a standard deviation of 12.7, only 51.99%

yielded a number of MC/HPF larger than 30. Due to my exhibition of both SM and skin involvement, I thought it best to compare my results to this group of individuals. Given what the literature states about mastocytosis classification, I expected a larger number of study participants to yield a number of MC/HPF greater than 30. Considering only a little more than half of the study participants surpassed the number of MC/HPF in my biopsy may indicate the need for further research into sampling soft tissue as opposed to just bone marrow, and tryptase levels.

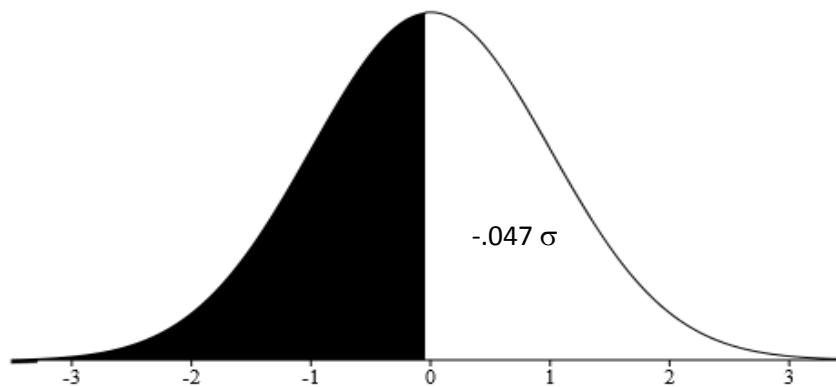


Figure 4. Where my biopsy falls on a normal distribution. This is an illustration of where my duodenum biopsy falls on a normal distribution in reference to other patients with systemic mastocytosis and skin involvement from a study conducted by Seigert et al. (2004). The portion that is not shaded represents the 51.99% of systemic mastocytosis patients who had a number of mast cells per high powered field greater than 30 in their duodenum biopsies.

Recreated dialogue. From my relationships and discussions with 15 physicians from two states (Florida and North Carolina) and six different practices whose specialties encompass primary care, allergy/immunology, neurology, gastroenterology, and hematology, what could be described as an organic form of triangulation occurred. Three themes emerged from my open coding process (see Tables 2, 3, and 4) regarding the approaches of the physicians I interacted with while assuming the role of patient; these themes are Problem Solving Conclusive (PSC),

Problem Solving Absolutism (PSA), and Decision Making Democratic (DMD); these three themes follow closely with the research of Elstein and Schwarz (2002). Finally, two distinct themes which I refer to as phases emerged while analyzing the diagnostic process. These two phases are the pre-test and post-test phases (see Tables 2, 3, and 4). Though the three emerging themes are in line with Elstein and Schwarz, the two phases (pre-test and post-test) are not to be confused with Elstein and Schwarz's (2002) pre-test post-test probability, which is a part of the decision-making paradigm, but rather as terminology to note my relationships before and after medical diagnostic testing (i.e., bloodwork, biopsies) were performed. Hence, the term phase follows both pre-test and post-test. Within these two phases, I recreated a dialogue from the comments made during the diagnostic process with each physician. This was undertaken in an effort to represent the relationships existent between the physicians and I.

From the data properties, assigned pseudonyms, and demonstrative narratives in my open-coding process, I constructed three physicians to embody the three themes which emerged from the physicians' approaches in both the post-test and pre-test phases (see Table 3). Each physician is symbolic of an amalgam of multiple types of physicians including primary care physicians, neurologists, immunologists, gastroenterologists, and gynecologists. *Dr. York* is demonstrative of the Problem Solving Conclusive theme in which physicians believed that if test results did not validate their hypotheses about physical illness, the only conclusion was depression or anxiety. *Dr. Castle* is representative of the Problem Solving Absolutism approach where physicians who believed if test results did not validate their hypotheses about theorized illnesses, the only conclusion was I was healthy. *Dr. Sanford* illustrates the Decision Making Democratic approach of physicians who conducted general tests to holistically assess my overall health before forming a hypothesis; in the event the test results were inconclusive, *Dr. Sanford* either misdiagnosed me or referred me to a more qualified specialist. As close to the actual discussion as possible, exact quotes from both me and each physician were fashioned

into a narrative discourse. The line breaks signify the end of one dialogue and the start of a new one within the same phase.

The first two pseudonyms, Drs. York and Castle, seem to reflect a Foucault like mentality which posits his termed medical gaze as less than objective:

The clinic—constantly praised for its empiricism, the modesty of its attention, and the care with which it silently lets things surface to the observing gaze without disturbing them with discourse—owes its real importance to the fact that it is a reorganization in depth, not only of medical discourse, but of the very possibility of a discourse about disease. (Foucault, 1973, p. xxi)

In the above statement, Foucault (1973) calls attention to the misperception of medicine being absent of ulterior motives and judgement. In fact it is Foucault's perspective that the so-called objective, observations of the human body made by physicians are not interpretations of what the body is telling them, but are rather interpretations influenced by the physician's medical training. In this frame of reference, the body does not speak for itself per say; it (the body) instead speaks to ears and eyes clouded with preconceived notions that only hear and see what is deemed familiar and consequently applicable. This is much like holding steadfast to a stereotype of a certain ethnic group under the guise that it does not in any way sway how you make meaning of what an individual from that particular group says to you. This unvarying way of viewing the body, renders patients like me undiagnosed for extensive periods and often fatigued by the bureaucratic diagnostic process.

Recreating dialogue 1: the pre-test phase. The setting of each discussion below is an examination room to conduct what is commonly referred to in the medical community as a consultation . The purpose of the dialogue below is to exemplify a discussion that transpired between me and my physicians during the consultation concerning my prognosis prior to blood tests, urinalysis etcetera.

Dr. York: "Well, based on your symptoms I would say you have Parkinson's, MS, or perhaps epilepsy. We'll run some tests for all three."

Me: "Oh no, what makes you think I have Parkinson's or MS?"

Dr. York: "What you are describing sounds a lot like Parkinson's or MS. We need to run some tests to rule them out and I'll see you in a few weeks to discuss the results."

Me: "Sure, see you in a few weeks." He's a doctor. He knows what he's doing. Who am I to question his opinion?

Me: "What exactly do you think I have? I'm nervous and scared and no one seems to be able to help me."

Dr. Castle: "What you're describing, I have seen it before. Every time, it's MS, Parkinson's, or epilepsy."

Me: "I agree that MS, Parkinson's, and epilepsy are the main candidates, but does that mean that they are the only candidates? I was tested for all three and the results were negative. I have read about several diseases that mimic others and as a result patients were either misdiagnosed or undiagnosed. I am asking this because the neurologist that I saw recently suggested that my birth control pills could have caused some of my symptoms. Could it be that we are looking for the wrong thing and that this could be something completely unfamiliar?"

Dr. Castle: "I don't want to pooh-pooh on your little theory, but birth control pills don't cause what you are describing. I've been doing this for a long time and I'm pretty sure I know what we're looking at here. Ok? Trust me, I'm a professional."

Me: "Pooh-pooh on my theory? Are you related to Dr. House?"

Dr. Castle: "Excuse me?"

Me: "I'm sorry; I thought bedside manner might be hereditary."

Dr. Castle: "Miss Hayes, do you want my help or don't you?"

Me: "Yes, your help . . . not your cynicism. And we can start by you speaking to me like an adult. I may not be a medical professional, but this is my body that you're running tests on and I think I deserve some input on what happens to it."

Dr. Castle: [Eyes wide] "Fine, but you need to let me do my job. I'd like to run the tests again just in case you had a false negative. Sometimes minute things don't show up in tests. Maybe it'll be more apparent now."

Me: "Fair enough."

Dr. Sanford: "I read your patient information form. You recently started breaking out in hives in addition to everything else you've endured. You're having a rough time aren't you?"

Me: "I appreciate your concern. Yes I'm having a hard time and I am really frustrated. I feel like I'm running out of options. Before we begin any testing, please understand that I have already been tested for MS, Parkinson's, and epilepsy. The results are always negative. Could we please check for something else? My bills are piling up and they're all from the same tests over and over."

Dr. Sanford: "I am sorry that all of this is happening to you. Let's start with a look at your overall health. We can begin with a complete blood count and run some tests to check your blood sugar levels, cholesterol, you name it. When we get those results then we can move toward more specific testing."

Me: "I'm willing to try anything as long as we're not being redundant and we figure out what's going on here."

Recreating dialogue 2: The post-test phase. The setting of Dialogue 2 is also an examination room. Each of the three discussions concerns recommendations from physicians York, Castle, and Sanford based on the results of the tests that each physician authorized. Once more Dr. York represents the Problem Solving Conclusive perspective, Dr. Castle is representative of the Problem Solving Absolutism perspective, and finally Dr. Sanford embodies the Decision Making Democratic perspective.

Dr. York: "Alright your results are in and everything looks great. I am, however, a bit concerned about your state of being."

Me: "My state of being? I'm not sure I follow."

Dr. York: "News is a very stressful line of work Miss Hayes and stress can trigger all sorts of responses in the body. I think if you slept more you could function better."

Me: "Okay, but will it help with all of the other symptoms I'm having like the jerking fits, diarrhea, and regurgitation. I just want to get back to my normal lifestyle."

Dr. York: "Once you take these sleeping pills everything will fall back into place. Trust me, I know what I'm talking about here."

Me: "Thank you, sometimes I go for days without sleeping." I hate taking pills, but he is right. I need to sleep.

Dr. Castle: "So, we have your test results and everything came back clean. You're good to go."

Me: "What do you mean good to go? I feel horrible."

Dr. Castle: "I mean you're healthy. There are no MS, no Parkinson's, and no signs of epilepsy. Everything's fine."

Me: "So what are all of these symptoms I'm having?"

Dr. Castle: "I don't know but, they're certainly not MS, Parkinson's, or epilepsy."

Me: "I know, this is the third time I've been tested for all three. Do you remember me stating that in our initial conversation?"

Dr. Castle: "What do you want me to say? The tests don't lie!"

Me: "Really? Because I clearly recall someone saying that my previous tests could have yielded false negatives. You certainly look familiar. Wait a minute. Was that you?"

Dr. Castle: "I know what I said!"

Me: "So are your tests superior to the previous tests?"

Dr. Castle: "Look, you're fine!"

Me: "Then what do you suggest I do about my symptoms? I'm at my wits end here."

Dr. Castle: [Smugly] "I don't have any suggestions for you, because there's nothing wrong with you."

Me: "Then prescribe something for this nothing and help me!"

Dr. Castle: "I think you're beyond help."

Me: "And you think you're beyond reproach?"

Dr. Sanford: "Well your blood sugar is fine, but your blood pressure is pretty high. It may be because you're under duress with all that's going on. So I ran further testing and I found a few red flags. Your folic acid is so low that it's immeasurable, your iron level is borderline anemic, your liver enzymes are extremely high and the ultrasound we did showed that you have a fatty liver. Based on your breakouts, I also think that you might have allergies of some sort in addition to your latex allergy. I'm still not so sure about what's causing these so called jerking fits."

Me: "Alright, so what does that mean? Where do we go from here?"

Dr. Sanford: "Hmm, I don't know what this is, but I don't like it. I'm really concerned about this upper gastric pain you complained about near your pancreas. If you plan on having children one day, we need to really get your folic acid in gear. First, I am going to prescribe some Hyoscyamine for your stomach pain. Then I'm going to refer you to a gastroenterologist. Maybe he can tell us more about what's happening with your liver."

Me: "Thank you so much. You have no idea how rude some of the other doctors have been to me. I'll be honest; there were a few moments when I allowed myself to sink to that level. I'm just tired and I want to feel better. You're the first person who doesn't think that I'm depressed or crazy. Even if we don't find out what's wrong with me, it just feels good to know that you believe me."

Dr. Sanford: "Oh you're welcome Nina. In the meantime, I would like you to review these pamphlets on fatty liver and high liver enzymes. Nina, do you have internet access?"

Me: "Yes I do."

Dr. Sanford: "Good, because I also have some information I printed out for you about dieting for fatty liver. There are do's and don'ts for eating and the links at the bottom of the last page will take you to sites with recipes. There are also three refills on your prescription. You don't have to take it every day, just as needed. Good luck!"

When analyzing Phases 1 and 2 of the recreated dialogue, there is a clear distinction between the perspectives of Doctors York and Castle in contrast to the perspective of Dr. Sanford. Drs. York and Castle seemed to value a very systematic approach or as Elstein and Schwarz (2002) noted a problem solving paradigm. This approach only allowed room for

familiar theories with utter disregard for the possibility of new theories. Such familiar theories were often based upon classic cases of disease. This typecast me in the role of the rule rather than the exception to it. Once the rule was broken by negative test results, I was faced with accusations of mental instability or dismissal. This approach ultimately led me back to square one countless times.

Dr. Sanford's approach, on the other hand, was reminiscent of qualitative academic research. Unlike Drs. York and Castle, Dr. Sanford did not commence with a theory and seek to validate it with quantifiable evidence. Instead, Dr. Sanford began with a broad approach and as evidence emerged, the tactics narrowed in scope. Moreover, my sanity was not called into question nor was my unexplained illness dismissed as idiopathic. Dr. Sanford admittedly expressed unfamiliarity with my condition rather than absolute faith in a presumably infallible theory, and readily referred me to a specialist.

Due to her being the only physician who knew what mastocytosis was prior to my diagnosis, Dr. Branson did not fit into any of the emergent themes. Consequently, she was not represented in the recreated dialogue.

Overarching theme. Upon the continuation of my coding process which moved from open, to axial, and finally selective an overarching theme of self-directedness emerged from my experiences noted in Chapters 4 through 6 (see Table 4). I did not include any inquiries into self-direction or self-directed learning into my research questions, but my strategizing and behavioral patterns during my journey toward a correct diagnosis are indicative of self-directed learning. For example, once I realized Dr. Mathews prescribed an antidepressant without my consent, I ended my relationship with him. I repeated this pattern with Drs. Roberts, and Greer. Even with physicians who were extremely kind and willing to help, I still sought other physicians until a diagnosis was reached. In the case of Dr. Korrapati, for instance, I encouraged her—against the advisement of her peers—to refer me to another specialist. I realized the limitations

her fellow physicians placed upon her and presented an opportunity for her to seek an alternative opinion.

My strategizing and behavioral patterns are nearly identical to those of King (2014) who noted, “my travels through urgent and confounding situations were propelled by healthcare processes that failed” (p. 5). In fact King’s (2014) cyclical model in Figure 5 accurately depicts the period in which I floated from physician to physician. According to King (2014), the cycle depicted in the figure was initiated when she as “the patient recognized the limitations of the physician” (p. 10). Specifically, each physician “provided inappropriate treatment, presented inaccurate diagnoses, failed to provide any or sufficient answers to her questions, provided inaccurate responses to her questions, Ignored or trivialized the symptoms she shared, or Intimidates the patient” (pp. 10 -11)



Figure 5. Discovering empowered healthcare choices model. This model depicts the cyclical nature of King's (2014) relationships with several physicians as she maneuvered through the healthcare system. This model illustrates six stages in her process which progress clockwise. Each stage is marked by her response to the conditions or conflicts presented in her healthcare. From *A Journey with Chronic Pain: Self-directed Learning as Survival* by K . P. King, 2014, *New Horizons in Adult Education & Human Resource Development*, 26(2), pp. 5-18. Copyright 2014 by John Wiley & Sons. Reprinted with permission.

Chapter 8

Discussion

The autoethnographic research design utilized for this study served to juxtapose my experience with mastocytosis beside pertinent literature, data, and abstract analysis via a form of autoethnography known as layered accounts (Ellis et al., 2011). Not only did I seek a better understanding of my own experience, but I sought to build awareness and provide a better understanding of mastocytosis for those who are unaware of the existence of this disease. Furthermore, I sought to address the current cultural ties as well as create new cultural ties with those who have been diagnosed with mastocytosis, their caretakers, and the physicians who treat them. In this chapter I answer all of my research questions and discuss observations I made while conducting the study. In pursuit of fulfilling the purpose of this study, the following research questions were utilized as a guide:

- 1) How do I—as patient with mastocytosis—describe and perceive my journey toward a correct diagnosis?
- 2) How is mastocytosis defined by multiple academic and medical literature sources versus my personal experience?
- 3) How do multiple academic and medical literature sources delineate the general diagnostic process and how does this differ from my experience?
- 4) What parallels exist between the facilitator-learner relationship, demonstrative of adult education, and the physician-patient relationship?
- 5) Which adult education principals and philosophies did I utilize while working with physicians to establish a correct diagnosis?

- 6) Among those utilized, which adult education principals and philosophies were most salient in arriving at a correct diagnosis?

Research Question One

The first part of research question one—regarding my description of my journey toward a correct diagnosis—was answered in Chapters 4 through 6. By presenting my experiences starting from the emergence of my symptoms to finally receiving a correct diagnosis, I accurately described my journey toward a correct diagnosis. I immersed myself into each recollected event as if it were happening in the present. To summarize the second part of research question one that inquired about my perception of my journey toward a correct diagnosis in a few words, I would say I perceive it as blind, discouraging, and isolating.

I use the term blind in three different contexts. The first context comes from the third of three definitions offered by *Merriam-Webster's Dictionary* (2015) to describe the passive behavior I exhibited early on during my journey by “accepting the actions or decisions of someone or something without any questions or criticism” (*Merriam-Webster's Dictionary*, 2015). It was my blindness which gave Dr. Mathews (first neurologist) the opportunity to prescribe a superfluous medication which further complicated my already arduous journey. Being blind to the fact all medical professionals are not honest and some may actually violate my trust in a rather furtive way was inconceivable at the time. As a result, I blindly trusted him without so much as reading the side effects of the medication. Blind is also an accurate term to describe the doctors who were “unable to notice or judge something” (2015). My symptoms which resulted from mastocytosis were in plain view, but the proclivity to stick to the traditional diagnostic process and seek classic case illnesses left several physicians blind to what I was truly afflicted with. The second gastroenterologist I visited chose to simply press on my belly based on his observation of my not looking sick. Even the physicians who were genuinely interested in determining the underlying cause of my symptoms were equally blind from lack of

awareness; as mentioned in the review of literature mastocytosis is an orphan disease, which is rare and difficult to diagnose (*Medicine Net Online Dictionary*, 2012; Schieppati et al., 2008; Zhang et al., 2011). In a way I was also blind to my ability to become knowledgeable about medical terminology and my own body; I assumed my lack of expertise placed me in a permanent position of ignorance. Many of those who interacted with me daily may be described as blind as well. Although it was obvious something was wrong, I was able to maintain a certain level of discretion regarding the specifics of the trauma I was enduring. Only those closest to me such as family members and my best friend Saida were able to see through my charade.

The disheartening part of my experience was the result of years of frustration from being unable to reach a diagnosis. The fatigue from floating from physician to physician left me feeling hopeless; at one point I gave up, refusing to visit another physician only to hear the same thing again. The agendas of some of the physicians such as Drs. Matthews, Greer, and Roberts, and Abbot who were insistent upon making me out to be a hypochondriac if their theories concerning my diagnosis did not pan out were quite disheartening as well. Even more so disheartening was attempting to maintain normality in my everyday life believing things may never change for the better. The fear of spending the rest of my life coping instead of living—avoiding opportunities to travel abroad, never being involved in a romantic relationship, and never having a family of my own—dragged me to a dark place of despair.

Constantly living under the threat of being in public places when I was stricken with chorea persuaded me to isolate myself; being in public places where viewers of the news stations I worked for posed an even greater threat. Many nights when I could have gone out with my friends or on dates, I opted to stay at home where I was safe. Even when interacting with others who have witnessed one of my chorea episodes or any other symptoms, I felt a need to protect them from the truth. In some instances the isolation was emotional; although physically present, I often told Mom, Granny, and several others I was okay when I was in pain.

I emotionally isolated myself from Tito and any other man who showed interest in me. Upon deeper introspection, I also exercised an internal isolation of sorts by isolating my intuitive self from my practical self. After years of repeatedly being told I am not ill, it is just stress, or psychosomatic I no longer accepted my intuition as a guiding force, but as an unreliable source which needed to be diminished. Even when my symptoms were in a heightened state, I ignored my body and looked to a contrived sense of knowing based upon misdiagnoses and cynicism from some (not all) of the medical professionals who treated me.

Research Question Two

This research question which inquired how multiple academic and medical literature sources defined mastocytosis versus my personal experience was answered partially in Chapters 2, 4, 5, and 6. The review of literature provided in Chapter 2 contrasted and compared four different definitions of mastocytosis and Chapters 4 through 6 divulged my personal experience. Chapter 2 not only provided multiple definitions of mastocytosis, but also revealed inconsistencies in how mastocytosis is defined. Duly noted among the inconsistencies is the absence of the descriptor myeloproliferative in all but one of the definitions. Again, the Mastocytosis Society of Canada (2011) was the only source to describe mastocytosis in this way; the term myeloproliferative implicates the disease in having adverse effects on “blood cells—platelets, white blood cells, and red blood cells” that cause these particular blood cells “to grow abnormally in the bone marrow” regardless of whether or not it presents in its cutaneous or systemic form (“University of Maryland Medical Center”, 2015). Only two sources, the Mastocytosis Society of Canada (2011) and Horny et al. (2008) make mention of the involvement of stem cells in mastocytosis. Subtle differences in definitions such as those mentioned may become a hindrance to reaching a correct diagnosis, classification, and a somewhat accurate prognosis. For instance, if doctors who are unfamiliar with mastocytosis were to research it, they may adopt a definition which does not fully describe it. Multiple,

inconsistent definitions of mastocytosis are not a new occurrence. As noted in Chapter 2, disparities in definitions of mastocytosis date back as far as 1877.

Perhaps there are some in the medical community who would consider one definition of mastocytosis to be the most reliable of those presented in Chapter 2. My personal experience, on the other hand, presented more of an amalgam of definitions as opposed to one or the other. Likewise, other aspects of the disease that are not mentioned in any of the definitions such as chorea should not go unmentioned. When compared to my personal experience, the definitions offered in the literature leave much to be desired in the interest of developing a more detailed and inclusive definition of mastocytosis. If I were to translate my personal experience into a definition, I would define mastocytosis as an orphan disease marked by an abnormal increase in mast cells (good immune cells) with myeloproliferative, neoplastic, and stem cell implications. Mastocytosis may present singularly or sometimes in both forms which are cutaneous (relegated to the skin) or systemic (internal). Due to the high degree of variability in regards to clinical manifestations, organ systems involved, and links to hematologic diseases, blood, bone marrow, and internal organs should be thoroughly analyzed; failure to do so often renders sufferers misdiagnosed, undiagnosed, or dismissed as having psychosomatic symptoms. This may in turn lead to the neglect of necessary care and possibly implementing superfluous care for several years.

With respect to symptoms, the literature provides a lengthy number of symptoms which sufferers of mastocytosis incur which include: weight loss, syncope or fainting, pain, vomiting, fatigue, malaise, headache, bone pain, hair loss, tinnitus, skin lesions or sores, tachycardia, skin rash, numbness and tingling in face and extremities, spots, anesthesia difficulties, redness, anemia, hives, anaphylaxis, uterine pain, difficult periods, pain in the kidneys, spleen pain, bladder pain, pain in the liver, unexplained weakness, temperature (hot/cold) sensitivity, eyes tearing/dry, itching, and eye pain (The Mastocytosis Society, 2011; The Mastocytosis Society of

Canada, 2011). My experience with symptoms encompasses all of those listed in the literature as well as a more aggressive form of chorea which includes not just numbness and tingling of the face and extremities, but also spastic involuntary movements, which may have also been simple, partial seizures. According to the literature an individual with SM should exhibit at least 10% bone marrow accumulation and serum tryptase levels should be at 20 ng/mL or greater (McNeil & Katelaris, 2011; Metcalfe, 1991; Sánchez-Muñoz et al., 2011). My first serum tryptase drawing was 4.4 ng/mL and I only had 2% involvement in my bone marrow. Biopsies performed on my internal organs—not considered mandatory for classification purposes—revealed aggregates of mast cells of 30 or more in each HPF. According to the Mastocytosis Society of Canada (2011), the difficulty associated with diagnosing and classifying mastocytosis may leave sufferers of mastocytosis seeking a correct diagnosis for 10 years or more. Depending on whether I consider the nearly four and a half years I spent floating from physician to physician or the possibility of my having mastocytosis in childhood and going into a 20-year remission, my experience can be either consistent or inconsistent with the literature.

Research Question Three

Chapter 2 along with Chapters 5 and 6 address how multiple academic and medical literature sources delineate the general diagnostic process and how what the literature states differs from my experience. In my quest to find both academic and medical literature delineating the general diagnostic process, my search for medical literature returned partially empty. By medical literature, I am referring to the more accessible and trusted literature from sources such as Web MD and Mayo Clinic. Wikipedia did offer a definition along with a medical algorithm; the algorithm was unfortunately not general, but specific to diagnosing obesity. There were links which led to further information on Bayes's Theorem, but the information given was not written in laymen's terms. This absence of an easily accessible and general explanation of the diagnostic process is problematic for individuals searching for answers about their illnesses, the

healthcare process, and the diagnostic process. With the number of illnesses in existence, it is rather disturbing to think patients seeking answers as to why their physicians diagnosed them with depression or psychosomatic issues would only be able to locate an algorithm addressing how obesity is diagnosed.

Many of the less widely accessible and more recently published academic journals address the diagnostic process from a theoretical and practice perspective, focusing more on the steps of the process or on how to diagnose a specific illness. Some of the older literature such as Elstein and Schwarz's (2002) *Clinical Problem Solving and Diagnostic Decision Making: Selective Review of the Cognitive Literature* and Charlin, Tardif, and Boshuizen's (2000) *Scripts and Medical Diagnostic Knowledge: Theory and Applications for Clinical Reasoning Instruction and Research* provided perspectives which addressed theory and practice, as well as discussed the cognitive psychological aspects of the general diagnostic process. The latter perspective (cognitive psychological) was more appealing to me because it allows the reader to better comprehend why physicians make the decision they do. This in turn provides more information for implications for practice. Whereas Charlin et al. (2000) analyzed the diagnostic process from a cognitive psychological aspect, proposed the utilization of scripts which "are networks of knowledge adapted to goals of clinical tasks" (p. 182), and released a more recent publication on scripts in 2007. Only Elstein and Schwarz (2002) incorporated the commonly utilized Bayes's Theorem into the diagnostic process; ergo I relied primarily upon Elstein and Schwarz's research.

Again, Elstein and Schwarz's (2002) research is in concordance with Bayes's Theorem and offered two paradigms for the diagnostic process with the intent of describing and analyzing "psychological processes employed in identifying and solving diagnostic problems" (p. 729). Although one paradigm appears to be favored above the other, the authors point out that neither is infallible. Elstein and Schwarz (2002) discussed these two paradigms in great detail positing

the problem solving paradigm as a method exacted “by generating a limited number of hypotheses early in the diagnostic process and using them to guide subsequent collection of data” (p. 729). Each of the generated hypotheses may “be used to predict what additional findings ought to be present if it were true, and the diagnostic process is a guided search for these findings” (p. 729). There is, nonetheless, a notable disparity between experienced and novice physicians who prefer this approach. The experienced physician is said to formulate higher quality hypotheses and form their hypotheses much sooner, allowing for more rapidly developed diagnostic plans. Equally, the novice physician is noted as often getting stuck in the data collection phase, which in turn stunts their consideration of possibilities as well as the ability to quickly design a plan of action. Elstein and Schwarz (2002) continued by emphasizing the heavy reliance of this approach upon “pattern recognition or categorisation” (p. 730). What is more, the data collection process—no matter how thorough—does not insure that certain findings will not be ignored, misunderstood, or misinterpreted. For this reason, Elstein and Schwarz (2002) emphasized the stark contrast between accuracy and thoroughness.

The decision making paradigm is reliant upon the frequently mentioned (in this dissertation) Bayes’s theorem which suggests the use of a pre-test, post-test probability approach to the diagnostic process. “The pretest probability is” defined as “either the known prevalence of the disease or the clinician’s subjective impression of the probability of disease before new information is acquired” and “the post-test probability” is defined as “the probability of disease given new information” which “is a function of two variables, pretest probability and the strength of the evidence, measured by a ‘likelihood ratio’” (Elstein & Schwarz, p. 730). This paradigm does not view a diagnosis as a definitive declaration, but rather a “means of updating opinion with imperfect information (the clinical evidence)” (p. 730). As stated this method seems more effective especially when diagnosing rare illnesses, but it falls short in that “Bayes’s theorem tells us how we should reason, but it does not claim to describe how opinions are

revised” (p. 730). Furthermore, errors have been noted in the probability estimation with respect to availability and representativeness. Elstein and Schwarz (2002) discussed the power of availability by indicating the media attention given to certain diseases and injuries which gives the impression that the publicized illness or injury occurs more often than it actually does; this occurrence is thought to have a clinically psychological effect due to its “overemphasis of rare conditions, because unusual cases are more memorable than routine problems (p. 730). Representativeness in this context concerns the estimation of “the probability of disease by judging how similar a case is to a diagnostic category or prototype” (p. 730). The concern is comparing cases to other similar categories or prototypes may initiate an “overestimation of probability either by causing confusion of post-test probability with test sensitivity or by leading to neglect of base rates and implicitly considering all hypotheses” as being “equally” plausible (p. 730). The incorrectness of representativeness in this context is deemed rightfully so based on the hypothetical instance that a physician may compare a case to two diseases which equally manifest similar symptoms to the case and because one of the diseases is more common than the other the case will presumably be labeled as the more common disease. This type of probable decision making is indicative of conjunction fallacy which is marked by “incorrectly concluding that the probability of a joint event (such as the combination of findings to form a typical clinical picture) is greater than the probability of any one of these events alone” (p. 731).

The two paradigms discussed by Elstein and Schwarz (2002) practically mirror my personal experiences divulged in Chapters 5 and 6. Some of the physicians I encountered—namely Drs. Mathews, Greer, and Vincent—all seemed to rely upon the problem solving paradigm when attempting to diagnose me. Each physician approached my case with rather inflexible hypotheses based upon pattern recognition/categorization. Take Dr. Mathews for instance who—reliant upon visual cues—incorrectly hypothesized I was a sufferer of either MS

or Parkinson's and tested me accordingly. This "failure to generate the correct hypothesis" caused him to order superfluous testing, and ultimately misinterpret the findings leading him to conclude my symptoms were psychosomatic (Elstein & Schwarz, 2002, p. 731). Similar measures were taken by Dr. Greer. Though he did not voice his initial hypotheses about my case, his approach was to conduct tests based on the patterns he was given via my personal accounts which I verbalized in his office. It is likely Dr. Greer's lack of knowledge about mastocytosis placed him at a disadvantage rendering him unable to observe the obvious visual cues like my having UP. He, like Dr. Mathews, misinterpreted the findings and misperceived the fact that my results did not fall into a familiar category; consequently, I was again labeled as a hypochondriac with psychosomatic symptoms. Interestingly, the notion to develop new hypotheses and test them never occurred to Drs. Mathews and Greer. Albeit my encounter with Dr. Vincent was far more pleasant than my encounters with Drs. Mathews and Greer, his approach was indicative of the problem solving paradigm. Based on the patterns of fatty liver, upset stomach, and late night vomiting, he conducted the endoscopy in search of evidence of GERD. Dissimilar from Drs. Mathews and Greer, he did not attempt to psychoanalyze me. This may be due in part to my test results being congruent with his hypothesis.

The actions of Drs. Adams, Sharma, Glenn, Branson, Korrapatti, and Sanders seemed to follow the decision making paradigm. Dr. Adams, who had no clue about what was going on with me, performed a physical test and ordered x-rays—both of which yielded results inconsistent with his diagnosis of a pinched nerve—did not conclude I was a healthy hypochondriac, but rather revised his own opinion and sought a second one from another physician. The same methods were carried out by Dr. Sharma whose diagnosis in this case was not ultimately correct (i.e., diagnosing mastocytosis), but she was able to accurately diagnose my fatty liver. Even with a correct diagnosis (in this context), she still viewed her own opinion as imperfect and hence open to updates and revisions. Drs. Glenn and Branson

seemed to function in a working relationship that fostered the decision making paradigm and relied on each other to consider and possibly update each other's opinions. For example, Dr. Glenn did display some errors in his diagnosis which could be attributed to availability and representativeness; whereas Dr. Branson had the advantage of previously witnessing the disease first hand and was able to revise Dr. Glenn's opinion with a partially correct diagnosis; I use the terms partially correct because it was not yet determined that my internal organs were affected. Drs. Korrapati and Sanders similarly followed the decision making paradigm even in light of opposition from the opinions of other physicians who refused to pursue any further testing which could revise their opinions. Dr. Korrapati sought yet another opinion which imminently led to a diagnostic breakthrough. Likewise, Dr. Sanders could have easily considered the opinions of her colleagues and dismissed my symptoms as idiopathic. In my case, she sought out errors in the initial probability estimation and began to estimate the probability of my being systemic based on a never before conducted (on me) line of testing. Dr. Lawrence exhibited an eagerness to participate in this paradigm, but seemed to fall prey to a presumable group dynamic which did not allow for the revision of a colleague's opinion.

The approaches of Drs. Hodson and Walters were difficult to analyze. Perhaps if either one of them had actually performed any further testing such as an MRI or bloodwork to rule out other possibilities, there would be evidence of the problem solving or decision making paradigms. Due to their rigid techniques of hypothesizing, this could not be determined. In my experience in academia, the systematic and meticulous problem solving method is ideal for quantitative research, but when dealing with the human body and mastocytosis, which both exhibit a high degree of variability, thoroughness may often overshadow accuracy.

Research Question Four

Much of Chapter 2 was dedicated to answering research question four. Chapter 7 also answers this question by presenting recreated dialogue which depicted the existing parallels

between the facilitator-learner relationship, demonstrative of adult education, and the physician-patient relationship.

My relationship with Dr. York depicted in both the pre-test and post-test phases of the recreated dialogue is indicative of the transmission perspective in adult education and the traditional perspective of the physician- patient relationship where the physician is the Subject Matter Expert (SME) and the patient acquires the knowledge that the physician renders (Bodenheimer et al., 2002; Boldt, 1998). Unlike the traditional physician-patient relationship, the transmission perspective is proposed as an approach to increasing the effectiveness of learning by instituting tests and exercises repetitiously—wherein the traditional physician-patient relationship allows physicians to maintain a position of power by concealing rather than sharing knowledge with patients (Bodenheimer et al., 2002; Boldt, 2002). Dr. York did not give me much to consider in the pre-test phase other than the fact that my fate was in his hands. During the post-test phase, he was careful to conceal knowledge even in regards to the medication he prescribed. My passive behavior may have further perpetuated the existing power dynamic giving Dr. York the impression I was one of those idle, uninformed beings who brought nothing “to the table besides their illness” (Bodenheimer et al., 2002, p. 2470).

Though his approach was harsher than Dr. York’s, my relationship with Dr. Castle depicted in the pre-test and post-test phases of the recreated dialogue is also indicative of both the transmission perspective in adult education and the traditional perspective of the patient physician relationship. Not only did Dr. Castle appear to view me as idle and uninformed with no knowledge to offer, he actively reminded me of my place, furthering his dominant position as the SME in the power dynamic. In addition to concealing knowledge, he did not offer any information or literature nor did he refer me to another physician.

The relationship between Dr. Sanford and I in both phases most closely parallels the developmental perspective. This perspective poses a stark contrast from the transmission

perspective by pushing learners to the forefront while content lays waiting in the background—creating a learner-centered environment (Arsenau & Rodenburg, 1998). Dr. Sanford who acted as the facilitator charged herself with the task of turning me into an SME rather than maintaining her position as facilitator and SME (Arsenau & Rodenburg, 1998). This is in agreement with the developmental perspective, a post conventional view for teaching in the exam room known as self-management education is also noted in her approach (Bodenheimer et al., 2002). Equally antithetical to the transmission perspective, self-management education understates conventional physician-patient learning relationships by providing “patients with problem-solving skills to enhance their lives” and ultimately promotes role expansion (Bodenheimer et al., 2002, p. 2470). Self-management education is also comparable to self-directed learning which affords learners the autonomy to engage, navigate, and evaluate their own learning process (Merriam et al., 2007). Dr. Sanford did not attempt to conceal information from me. In fact she gave me pamphlets and websites which would empower me to take control of my health.

Research Question Five

Based on my experiences as relayed in Chapters 4 through 6, I utilized three identifiable principles of adult education and three identifiable philosophies of adult education. The three principles utilized were involvement, experience, and problem centered (Knowles, 1970).

Three principles. The three principles of adult education I identified are a part of Knowles’ (1970) principles of adult education which include:

- (1) Adults need to be involved in the planning and evaluation of their instruction
- (2) Experience (including mistakes) provides the basis for the learning activities
- (3) Adults are most interested in learning subjects that have immediate relevance and impact to their job or personal life. (p. 43)

The first principle covers the importance of adults’ involvement *in the planning and evaluation of their instruction* and is reflected in my constant struggle to find physicians who were amenable to my inquisitive nature and longing for the implementation of collaborative care as proposed by Bodenheimer et al. (2002). When revisiting my journey toward a correct

diagnosis, examples of this principle reoccurred on multiple occasions with different doctors. Those who welcomed my involvement tended to adopt an exploratory approach, and leaned more toward reasoning within the decision making paradigm. Examples of doctors who implemented this principle were Drs. Adams (first to witness symptoms), Sharma (diagnosed fatty liver), Branson (diagnosed cutaneous mastocytosis), Kartal (performed bone marrow biopsy), Sanders (possibly diagnosed systemic mastocytosis), and Korrapati (encouraged further testing and referral). The inverse was seen with Dr. Roberts (gynecologist) for instance, who seemed to perceive my inquisitiveness as officiousness and met any and all queries about the birth control pills with hostility. Even the second opinion I was offered from a neurologist seemed to threaten the power dynamic between us.

The second principle emphasizes the importance of experience—even in reference to mistakes made—as a basis for learning activities (Knowles, 1970). The field of adult education values experience and considers learners to be a rich information source (Knowles, 1970). The duration of time while floating from physician to physician over the span of several years exemplifies a substantial amount of experience laden with observable mistakes on both my and some of the physicians' parts. For example, my mistake of not reading the prescription information on the Effexor to find out what the drug was for, the side effects, and withdrawal symptoms resulted in a personal *teachable moment*. The teachable moment resulted in what I now adopt as a routine learning activity in which I not only read the prescription information handed to me by the pharmacist, but I also voraciously read articles which discuss the medicine in great detail. I also visit blogs to read how the patients who are actually on the medication feel while taking it. This principle is also in accordance with collaborative care which credits the knowledge patients bring to the table and equates it with the knowledge of the physician (Bodenheimer et al., 2002). In collaborative care, patients are equally valued as highly

informative resources who are experts about their own lives (Bodenheimer et al., 2002; Knowles, 1970).

The third principle establishes the high priority among adult learners of learning about things which have a great impact on their work and personal life (Knowles, 1970). Mastocytosis heavily impacted both my work and personal life. The symptoms, complications, and treatment often compromised my punctuality at work as well as my ability to perform competently on the job. My social life was equally impacted. In an attempt to hide my symptoms and complications I forced myself into isolation avoiding romantic relationships and keeping those closest to me only partially informed. Given such extenuating circumstances, I made a point to increase my health literacy to a level where I could effectively communicate with physicians, even when they resented it.

Three philosophies. The recreated dialogue also revealed three identifiable philosophies of adult education: liberal, behaviorist, and humanistic as discussed in Zinn's (2004) table. It should be duly noted these philosophies are based upon the roles assumed by the physician and patient which are mirrored as teacher and learner roles demonstrative of the adult education philosophies.

The liberal philosophy was reflected through my relationship with Dr. York who established himself as the expert who transmitted knowledge in an authoritative manner by directing the process of learning as he saw fit and not essentially in a manner which would best be received by me the learner (Zinn, 2004). Though I exhibited the tendencies listed in the table by Zinn of being someone who "seeks knowledge, conceptual, and theoretical understanding" (p. 72) my efforts were stifled by Dr. York's resistance toward sharing knowledge or utilizing his position of power to direct me toward credible knowledge sources I could seek on my own. Despite his apparent intentions to make me "literate"—regarding my condition—"in the broadest sense" (p. 72) this was not without an element of duplicitousness; by focusing on the broader

issues of my not sleeping and the strange symptoms he conveniently left out necessary intricacies such as my unwittingly taking antidepressants.

The behavioral/behaviorist philosophy was exhibited via my relationship with Dr. Castle. As the teacher, Dr. Castle not only attempted to manage, but to also control, predict, and direct “learning outcomes” in an effort to elicit “desired behavior”—which in this case was unquestioning obedience (p. 72). I, as the learner, sought an active role in the learning process, consulting with Saida about her experience with the same form of birth control I was on and why it was prescribed for her as well as considering Dr. Mathews’ advice about the birth control pills. I did, nonetheless, allow the “strong environmental influence” (p. 72) of harsh sarcasm and cynicism to draw me into a heated exchange of unpleasanties. His obvious hostility and resistance expressed toward my asking questions was done so under the guise of bringing about “behavioral change” to “ensure compliance with standards and societal expectations” (p. 72). Specifically, my disobedience (not taking the pill) would ultimately result in infertility.

My relationship was with Dr. Sanford was demonstrative of the humanistic philosophy. Dr. Sanford presented herself less as a teacher and more as a facilitator willing to guide me through the learning process (Zinn, 2004). She offered me a partnership by promoting, but not directing the learning process. This in turn fostered my self-directed and highly motivated nature toward learning, allowing me to take “responsibility for learning” (p. 73) and my self-development. She not only provided me with standard pamphlets, but also with literature she printed. She also encouraged me to seek other sources.

Research Question Six

My experiences in Chapters 4 through 6 along with the recreated dialogue in Chapter 7 provide answers to the research question concerning which adult education philosophies and principles were most salient in my arriving at a correct diagnosis. The most salient principle that assisted me in arriving at a correct diagnosis was the first of three listed, which states “adults

need to be involved in the planning and evaluation of their instruction” (Knowles, 1970, p. 43). I finally arrived at the realization that I not only could be involved in the planning and evaluation of the instructions I received from physicians, but it was my right to do so. As I continued on in my journey toward a correct diagnosis, I learned to seek physicians who elicited my involvement and avoid those who resisted it.

The most salient philosophy I utilized to assist me in arriving to a correct diagnosis was humanistic. Take Dr. Adams for instance. He was the first physician I sought during my early onslaught of symptoms. Despite his obliviousness to what was happening to me, he never attempted to control the learning outcome, nor did he present himself as the sole SME. He instead assessed the situation in accordance with his knowledge base and determined a second opinion was in order. This was a far cry from Dr. Mathews whose liberal approach led him to identify himself as the sole SME and arrive at the decision that no other opinions were necessary. This is in line with a statement made by Dr. Nguyen. “We [physicians] are not in the business of not knowing. Some of us would much rather pretend to know what we’re looking at [physical presentation of symptoms] than to honestly say ‘I don’t know’” (H. Nguyen, personal communication, January 2014). On the topic of why so many physicians were unable to correctly diagnose me, his response was “so many of us are looking for a horse, when really we should be searching for the zebra” (H. Nguyen, personal communication, January 2014). His perspective is reflective of the decision making paradigm offered by Elstein and Schwarz (2002).

Observations

Though there was no effort on my part to collect data, analyze, or discuss the influence of sex and gender roles among physicians, observably all of the female physicians fell into the humanistic philosophy. In reference to the physician-patient relationship, I experienced great difficulty contacting some of the physicians with whom I was no longer a patient. There seemed

to be an impenetrable barrier of sorts, which did not allow my countless emails and phone calls to reach some of them. The only successful attempts were with Drs. Douglas, Saaba, and Nguyen. Perhaps the success with reaching Dr. Douglas was due to my mother maintaining contact with his daughter who completed her PhD and appealed to her father to speak with me and help me with my dissertation. Not only was Dr. Douglas available, he was willing, interested, and actually remembered me from 33 years ago. The information from these three physicians was received either prior or subsequent to my receiving a correct diagnosis, which did not allow for them to be incorporated into the narrative portion of this dissertation. Their absences (Drs. Douglas, Saaba, and Nguyen) from the narratives allowed me to incorporate their opinions without posing the risk of linking them with an assigned pseudonym and ergo exposing them in the text. It is quite possible that the communication barrier I experienced was necessary to maintain a healthy work-life balance between physicians and patients. Other than obstetricians, I am not aware of any physicians who allow patients to contact them personally during treatment and, in my case, after treatment as well. I am quite certain there would be even richer data to present if I were able to reach some of the physicians who previously treated and attempted to diagnose me.

Chapter 9

Summary, Conclusions, Implications, and Recommendations

The purpose of this study was to investigate mastocytosis from the perspective of an individual diagnosed with the disease. The autoethnographic research design juxtaposed my experience with mastocytosis beside pertinent literature, data, and abstract analysis via a form of autoethnography known as layered accounts in an effort to investigate mastocytosis my perspective due to my being diagnosed with the disease. This chapter includes a summation of Chapters 1 through 8. It also introduces conclusions and implications as well as recommendations for future research.

Summary

This study provided a glimpse into my journey toward a correct diagnosis. This glimpse offered background information which introduced the reader into my life with mastocytosis along with multiple sources of literature about mastocytosis juxtaposed with my personal experiences with the illness. The introduction and extensive review of literature described autoethnography and its many forms, mastocytosis symptoms, complications, various definitions, and conflated usage of classification schemata. The review of literature also discussed the importance of health literacy, the medical diagnostic process, and the existent parallels between the physician-patient relationship and the facilitator-learner relationship in adult education. Autoethnographic layered accounts were then utilized to divulge my personal experiences as I floated from physician to physician in search of a correct diagnosis. Emerging themes were then analyzed, coded, and presented in the form of recreated dialogue alongside test results from biopsies and bloodwork which were compared to datasets from previous studies. The results were a myriad

of stark contrasts between what the literature states my experience as an individual with mastocytosis should be versus what actually occurred which implied a need for increased health literacy among physicians and patients alike as well as further inquiry into the high degree of variability associated with the presentation of symptoms and complications with mastocytosis.

Conclusions

Several conclusions arose from this study regarding what I learned about mastocytosis, the diagnostic process, myself, and my role as a patient in the physician-patient relationship. My conclusions provide a path for me, which leads me closer to clarity and closure.

Concerning mastocytosis, I learned a low level of health literacy among patients with mastocytosis paired with a low level of awareness regarding the existence of mastocytosis among physicians may lead to patients experiencing prolonged suffering while waiting for a correct diagnosis, as well as superfluous medications and treatments.

When patients afflicted with mastocytosis are unable to effectively articulate what is happening to their bodies, accurately comprehend the terminology utilized by the physician, or fail to understand the necessity and usage of a prescribed medication patients may essentially provide the means to develop a parent-child relationship with the physician. I know now when assuming the role of patient, being passive concerning my knowledge base about my body is absolutely unacceptable; I owe it to myself to be active and vocal about my needs and concerns. Equally, physicians who are oblivious to the existence of mastocytosis who exhibits a proclivity to the problem solving paradigm of the diagnostic process may view their own ignorance in accordance with that of the patient's as grounds for utter disregard of the symptoms that are plaguing the patient and may ultimately misdiagnose the patient with idiopathic symptoms.

Attempting to define and understand mastocytosis is a rather confounding endeavor. With so many different definitions of mastocytosis in existence, even physicians can find

themselves in a state of confusion and only a partial understanding of the disease. For this reason, it is my responsibility to increase my health literacy and learn as much about mastocytosis as possible.

I now understand the diagnostic process to be a process that often involves more than one physician from more than one practice, as opposed to a process that is guided by one physician. This means, while assuming the patient role, it is up to me to find a physician who I am comfortable with. If I am not comfortable with the results, I can simply seek a second opinion. I do not need another parent or a dictator. What I need is a partner who is willing to collaborate with me in my efforts to improve my health. The physicians who took the Decision Making Democratic approach—as portrayed by Dr. Sanford in the recreated dialogue—were the most helpful in my journey toward a correct diagnosis. They filled the role of partner by acknowledging and welcoming my need to be a part of the preparation and assessment of my instruction (in this case the diagnostic process), relying on mine as well as their own experiences (even our mistakes) as a means to provide a foundation for our learning, acknowledging my interest in learning about my health due to its high impact on my personal and professional life, and promoting rather than directing the learning process which allowed me to be accountable for my own learning (Knowles, 1970; Zinn, 2004). More importantly, I realize it is not a privilege to collaborate with a physician regarding my health. It is my right to do so. My questions and concerns should not be ignored nor trivialized, but rather heard and addressed.

Implications for Practice

All things considered concerning the physician-patient relationship, physicians and patients alike can benefit from this research. Specifically, physicians who are unfamiliar with mastocytosis and patients who are desperately seeking a diagnosis or classification of mastocytosis may read this, reflect on similar experiences, and analyze their approaches.

Hopefully the research provided in this study will encourage physicians and patients alike to view themselves as lifelong learners rather than assuming the roles associated with the traditional power dynamic. Although far more advanced and experienced in the learning process in reference to the human body, physicians are learners nonetheless. Equally, patients should not discredit themselves as codependent beings waiting to be enlightened by their physicians, but as capable and diligent learners who are willing to participate in the learning process.

When considering medical procedures, my arduous journey toward a correct diagnosis may serve as an exemplary recommendation to add gastrointestinal biopsies to the current repertoire of assessing serum tryptase levels along with skin and bone marrow biopsies. As my experience points out, the current methods for determining mastocytosis classification overlook gastrointestinal involvement. Revisiting the case study discussed in the introduction about a patient who suffered from systemic mastocytosis may illustrate how excerpts from my experience combined with the literature from this study could have been practically applied to the individual who suffered from mastocytosis in Hein and Hansen's (2005) case study. Bodenheimer et al. (2002) noted "if physicians view themselves as experts whose job it is to get patients to behave in ways that reflect their expertise, both will continue to be frustrated" (p. 2470). Bodenheimer et al. (2002) continue by stating "once physicians recognize patients as experts on their own lives, they can add their medical expertise to what patients know about themselves to create a plan that will help patients achieve their goals" (Bodenheimer et al., 2002, p. 2470). In this instance, Hein and Hansen (2005) could have utilized the recommendations of Bodenheimer et al. (2002) by equating the importance of the knowledge the patient provided with their own expertise. This is not only in accordance with Johnson and Pratt's (1998) apprenticeship perspective, but also concurrent with Knowles' (1970) first principle of adult learning which expressed the importance of adults being involved in how their

instruction is planned and evaluated, and the humanistic perspective which posits facilitators should act more as partners with learners during the learning process. From this combined expertise of Bodenheimer et al. (2002) and Hein and Hansen (2005), a new approach to treatment which involved different medication than the patient received could have been devised.

Though Hein and Hansen (2005) did not appear to put the recommendations of Bodenheimer et al. (2002), Johnson and Pratt (1998), or Knowles (1970) into practice, they should be commended for not only diagnosing the patient with mastocytosis so expediently, but also with taking a liver biopsy in addition to determining serum tryptase levels and bone marrow involvement as well as considering the implications of the results of the liver biopsy in reference to mastocytosis. The steps taken in Hein and Hansen's (2005) case were indicative of Elstein and Schwarz's (2002) decision making approach which provided the opportunity for opinion revision and may have, in turn, allowed them to diagnose mastocytosis within a brief period of time wherein several prior physicians were unable to do so.

My encounter with the first neurologist Dr. Mathews, revealed a physician who was unable to correctly diagnose me and resultantly prescribed antidepressants for me—an individual who was not clinically depressed. It is possible that Dr. Mathews' lack of awareness about the existence of mastocytosis and my low health literacy during that time equally contributed to my incorrect diagnosis. In addition, Dr. Mathews' tendency to base the diagnostic process solely on an early hypothesis about what he observed rather than exercising decision making may have been equally responsible for my incorrect diagnosis (Bodenheimer et al., 2002; Elstein & Schwarz, 2002). If Dr. Mathews approached my case utilizing the decision making paradigm along with a humanistic philosophy, an apprenticeship teaching perspective, and provided the opportunity for me to be involved in my own evaluation—by at least letting me know he thought I was depressed—conceivably the outcome could have been different. Instead

of holding fast to his initial hypotheses, he could have conducted more rounds of testing based on new and different hypotheses to challenge and possibly revise his initial opinions. Moreover, he could have sought council from other physicians or simply accepted the fact he had no plausible explanation for what was happening to me. More importantly, I was completely left out of the process. At the very least, he could have asked me if I felt I was depressed and if not, referred me to a psychiatrist to evaluate me. I am far from blameless in this scenario.

Once again, my passive, trusting nature (at the time) combined with my low health literacy provided the opportunity for Dr. Mathews to take complete control of the learning relationship and exact more of a transmission teaching perspective, liberal philosophy, and an utter omission of all adult learning principles. This hypothetical scenario is yet another indication of the necessity of equal participation from physicians and patients during the diagnostic process as is warranted by facilitators and learners during the learning process; it also emphasizes the importance of both parties—regardless of role—viewing themselves as lifelong learners.

Recommendations for Future Research

As stated by Ellis and Bochner (2000), autoethnography is a style of research and writing that exhibits multiple layers of consciousness and ties personal experiences to cultural ones (Ellis & Bochner, 2000). Writing this autoethnography required me as the researcher to “retrospectively and selectively write about epiphanies that stem from, or are made possible by, being part of a culture and/or by possessing a particular cultural identity” (Ellis et al., 2011, p. 4). In this case I divulged my experience as being part of the culture of individuals diagnosed with mastocytosis as well as the culture that Kole and Faurison (2009) emphasized which often neglects the voices of the patients with ODs, in favor of epidemiology. I conducted research to particularize and analyze the culture of individuals diagnosed with mastocytosis, whose voices often go unheard, via my own experiences and provided implications for further investigation.

Given the low number of individuals diagnosed with mastocytosis, the reluctance of patients with mastocytosis to openly share their experiences, the little scholarship on mastocytosis, as well as the conflated use of classification schemata and multiple definitions of mastocytosis within the little scholarship that is offered on mastocytosis, future research could involve the sampling of this group for the purpose of obtaining additional information.

There was no attempt on my part to collect data or analyze the culture of the work environment in which each physician worked in or the culture of the institution from which each physician received their medical degrees. This was due in part to my use of autoethnography as a method which relied upon my recollection of past events. This was also due to several of the physicians I encountered being unreachable during the research process. As stated in the observations, gaining an audience with the majority of my physicians with the exceptions of Drs. Douglas, Saaba, and Nguyen was nearly impossible. Considering and analyzing these aspects in future research could provide insight into each physician's approach to the diagnostic process.

In the future, I intend to conduct autoethnographic research divulging what life was like for me post diagnosis. Several months after receiving my diagnosis from Dr. Sanders, I reluctantly conceded to begin taking the prescription medication Cromolyn Sodium Oral. After I began taking this medication, I noticed a reduction in the amount of lesions on my face, lessening of abdominal pain, and significant weight loss—all of which followed a period of side effects. Relaying my experiences on medication may prove beneficial to the mastocytosis community.

I would also like to conduct further research on the series of events that took place during my hospitalization in 2014. Not only were the majority of the doctors clueless about mastocytosis, but those who had some knowledge of my illness disagreed about what led to my

hospitalization. I believe further inquiry may provide insight into little known triggers of mastocytosis complications.

Further investigation of my pathology report, as well as a biopsy of my liver in the future is something I will continue to research. Following my hospitalization, I decided to join The Mastocytosis Society. Upon joining The Mastocytosis Society, I attended countless presentations by physicians and patient advocates over the course of two annual conferences. I have also met and had personal conversations with several physicians and nurses, some who challenged Dr. Sanders' diagnosis based upon the descriptors she utilized to explain the results of each biopsy taken. Both a gastroenterologist as well as a nurse called attention to Dr. Sanders' word usage. For instance, her statement on the pathology report of the biopsy of my ileum which states my biopsy "shows an increase in the number of plasma cells that, at its highest density, reaches 40 mast cells/HPF. These findings are compatible with the clinical diagnosis of mastocytosis." The argument presented by the nurse and gastroenterologist was the absence of the terms *dense aggregates* in her (Dr. Sanders') description of the number of mast cells/HPF. According to them (gastroenterologist and nurse), this could mean I am not necessarily systemic or it may be a simple issue of semantics based on her lack of experience in treating and diagnosing mastocytosis patients, in which case I am indeed systemic. Both agreed I should have my information forwarded to another lab for further review. There was equal concern regarding her usage of the terms mastocytic enterocolitis.

Based upon our conversations, there appeared to be a divide in the medical community about the use of this terminology. This divide in perspectives seemed to be due to the recent emergence of this terminology; apparently, the fact that this terminology is rather novel sheds doubt not only on its usage, but on its actual existence. This suggests the need for further research with physicians and lab technicians familiar with mastocytosis to establish consistency with commonly used terms in reference to mastocytosis and share them with those who are less

familiar. The gastroenterologist also expressed concern about my periodic liver issues and suggested a liver biopsy be performed. He offered to perform the procedure himself, pro bono. Due to the distance I would have to travel to reach his facility and the recovery period following the biopsy, he recommended I have the procedure after I graduate. Further review of my pathology report from Dr. Sanders along with a liver biopsy is grounds for future research with individuals who were diagnosed with mastocytosis in The Mastocytosis Society. More importantly, I was informed by Dr. Metcalfe that the WHO criteria are now under revision. It is not exactly clear what changes will be made, but I was informed there are no efforts being made to stress the importance of gastrointestinal biopsies.

As noted in the observations, I did not make an effort to collect data on, analyze, or discuss how all of the approaches of the female physicians who treated me fell under the humanistic philosophy. Further research on the influence of sex and gender roles among physicians may prove beneficial to better understand the approaches of physicians to the diagnostic process.

Finally, I would like to conduct research incorporating multiple experiences with mastocytosis. This future research would include perspectives from people who suffer from mastocytosis as well as physicians who treat people diagnosed with mastocytosis. Hopefully my membership with the Mastocytosis Society will introduce me to willing study participants.

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Appendices

Appendix A: IRB Approval/Closure of my Study

2/29/2016

Activity Details



Gianina Hayes | My Home | Logoff

[Home](#) [IRB Studies](#) [IACUC](#) [COI](#) [ARC Updates](#)

IRB Studies > From Misdiagnosis to Prognosis

[<< Return to Workspace](#) [< Prev](#) 1 / 5 [Next >](#)

Activity Details (Study that has never been approved is Closed)

Author:	Various Menzel (Research Integrity & Compliance)
Logged For (Study):	From Misdiagnosis to Prognosis
Activity Date:	9/24/2015 9:45 AM

[Activity Form](#) [Property Changes](#) [Documents](#) [Notifications](#)

Close Study - Never Approved Activity

- This activity will close the IRB Study and change the state to Closed - Never Approved.
- Any comments and/or documents entered below will show in the History Log.

Comments:
The Vice Chair, Dr. Kristen Salomon has reviewed this study and has determined: "The activities described in the application consist of autobiography and autoethnography. The protocol does not contain hypotheses that will be tested. There is no structured, systematic analysis. The study information would appear to be descriptive and would not appear to contribute to generalizable knowledge. These activities do not appear to meet the definition of research under USF HRPP policy and are therefore not under USF IRB oversight."

Add Documents:

Name	Description
There are no items to display	

[<< Return to Workspace](#)

Appendix B: Autoethnography Timeline Table

Table B1

Autoethnography Timeline of Events

Event	Approximate Date	Location	Status
Early Signs and Symptoms	February, 2005	New Orleans, Louisiana	Undiagnosed
The Numbness Returns	February, 2005	Greensboro, North Carolina	Undiagnosed
An Audience for my Seizures	March, 2005	Greensboro, North Carolina	Undiagnosed
My First Misdiagnosis	March, 2005	Lexington, North Carolina	Misdiagnosed
The Lab Results	April, 2005	Lexington, North Carolina	Misdiagnosed
Dumping the Pill	April, 2005	Greensboro, North Carolina	Undiagnosed
Side Effects of Effexor (Fissures, Memory Loss, and Accusations)	May - June, 2005	Greensboro, North Carolina	Undiagnosed
The Truth Revealed	June, 2005	Greensboro, North Carolina	Undiagnosed
Withdrawal	June, 2005	Greensboro, North Carolina	Undiagnosed
Anaphylaxis	August, 2005	Charlotte, North Carolina	Undiagnosed
The Allergist	August, 2005	Charlotte, North Carolina	Dismissed/No Diagnosis
Fatty Liver	December, 2005	Charlotte, North Carolina	Undiagnosed
The First Endoscopy	January, 2006	Charlotte, North Carolina	Misdiagnosed

Appendix B Continued

Table B1

Autoethnography Timeline of Events

Event	Approximate Date	Location	Status
The First Endoscopy Results	February, 2006	Charlotte, North Carolina	Misdiagnosed
Granny's Passing	March, 2007	Charlotte, North Carolina	Undiagnosed and Misdiagnosed
Return of the Accusations	April, 2007	Charlotte, North Carolina	Undiagnosed and Misdiagnosed
First Partial Diagnosis,	June, 2009	Durham, North Carolina	Partially Diagnosed
The results of the skin biopsy	July, 2009	Durham, North Carolina	Partially Diagnosed
The second neurologist	July, 2009	Durham, North Carolina	Partially Diagnosed
The second and third gastroenterologists	July, 2009	Durham, North Carolina	Partially Diagnosed
The bone marrow biopsy	September, 2009	Durham, North Carolina	Partially Diagnosed
The cumulative results	September, 2009	Durham, North Carolina	Partially Diagnosed
Night sweats and stomach upset	January, 2012	Tampa, Florida	Partially Diagnosed
Severe unexplained back pain	April, 2012	Tampa, Florida	Partially Diagnosed
Normal or abnormal lab results	May, 2012	Tampa, Florida	Possibly fully diagnosed

Appendix C: My Pathology Report

Patient Name: GLANINA S. HAYES
Date of Birth: Apr 09, 1979
Medical Record: 1919066

PATHOLOGY REPORT

Medical Record Number: 1919066
Received Date: 05/09/12
Procedure Date: 05/09/12

Procedure Type: EGD:colonoscopy
Surgical Pathology #: [REDACTED]
Referred by: [REDACTED]

Clinical History: Age: 33 year Sex: female
History: Abdominal pain; diarrhea
Clinical/Radiological Impression: Suspected GI anastomosis *stain for mast cells*, R/O H.pylori

Specimen:
A. Duodenal biopsies
B. Stomach biopsies
C. Ileum biopsies
D. Right colon biopsies
E. Left colon biopsies

FINAL DIAGNOSES

A. Duodenum, biopsies:

DUODENAL MUCOSA WITH INCREASED NUMBER OF MAST CELLS IN THE LAMINA PROPRIA (see Note).

NOTE: The architecture of the duodenal mucosa is preserved. Immunohistochemistry for CD117, however, shows an increase in the number of plasma cells that, at its highest density, reaches 30 mast cells/HPF. These findings are compatible with the clinical diagnosis of mastocytosis.

Page 1 of 3

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Appendix C Continued

Patient Name: GLANINA S. HAYES
Date of Birth: Apr 09, 1979
Medical Record: 1919066
Encounter Date: May 9 2012 4:23PM

B. Stomach, biopsies:

GASTRIC MUCOSA WITH INCREASED NUMBER OF MAST CELLS IN THE LAMINA PROPRIA (see Note).

NOTE" The architecture of the duodenal mucosa is preserved. Immunohistochemistry for CD117, however, shows an increase in the number of plasma cells that, at its highest density, reaches 30 mast cells/HPF. These findings are compatible with the clinical diagnosis of mastocytosis. Immunohistochemistry for *H. pylori* is NEGATIVE.

C. Ileum, biopsies:

ILEAL MUCOSA WITH INCREASED NUMBER OF MAST CELLS IN THE LAMINA PROPRIA (see Note).

NOTE" The architecture of the duodenal mucosa is preserved. Immunohistochemistry for CD117, however, shows an increase in the number of plasma cells that, at its highest density, reaches 40 mast cells/HPF. These findings are compatible with the clinical diagnosis of mastocytosis.

D. Right colon, biopsies:

MASTOCYTIC ENTEROCOLITIS (see Note).

NOTE" The architecture of the colonic mucosa is distorted by an expansion of the lamina propria due a very prominent infiltration of CD117-positive mast cells. The mast cells are specially numerous under the surface epithelium where mast cells form a dense band to the exclusion of other cellularity. These changes are associated with mucosal edema and focal superficial hemorrhages. Mucosa is preserved. These findings are compatible with the clinical diagnosis of mastocytosis.

E. Left colon, biopsies:

COLONIC MUCOSA WITH INCREASED NUMBER OF MAST CELLS IN THE LAMINA PROPRIA (see Note).

NOTE" The architecture of the duodenal mucosa is preserved. Immunohistochemistry for CD117, however, shows an increase in the number of plasma cells that, at its highest density, reaches 40 mast cells/HPF. These findings are compatible with the clinical diagnosis of mastocytosis.

Gross Description: The specimen is received in formalin fixative in five properly labeled containers.

Page 2 of 3

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Appendix C Continued

Patient Name: GIANINA S. HAYES
Date of Birth: Apr 09, 1979
Medical Record: 1919066
Encounter Date: May 9 2012 4:23PM

Part A is received in a container stating the patient's name, MRN and "Duodenal biopsies". It consists of multiple fragments of pink-tan soft tissue measuring 1.0 x 0.4 x 0.3 cm in aggregate. The specimen is entirely submitted for microscopic examination in cassette A. (mld)

Part B is received in a container stating the patient's name, MRN and "Stomach biopsies". It consists of two fragments of pink-tan soft tissue measuring 0.7 x 0.4 x 0.3 cm in aggregate. The specimen is entirely submitted for microscopic examination in cassette B. (mld)

Part C is received in a container stating the patient's name, MRN and "Ileum biopsy". It consists of multiple fragments of pink-tan soft tissue measuring 0.6 x 0.5 x 0.3 cm in aggregate. The specimen is entirely submitted for microscopic examination in cassette C. (mld)

Part D is received in a container stating the patient's name, MRN and "Right colon biopsies". It consists of multiple fragments of pink-tan soft tissue measuring 1.3 x 0.5 x 0.3 cm in aggregate. The specimen is entirely submitted for microscopic examination in cassette D. (mld)

Part E is received in a container stating the patient's name, MRN and "Left colon biopsies". It consists of multiple fragments of pink-tan soft tissue measuring 1.2 x 0.5 x 0.3 cm in aggregate. The specimen is entirely submitted for microscopic examination in cassette E. (mld)

The grossing of this case was performed at the USF Health Endoscopy and Surgery Center Laboratory (CLIA #10D1087424).

Electronically signed by [REDACTED] M.D. May 20 2012 9:45PM EST Author

cc: [REDACTED]

Appendix C Continued

Colonoscopy Procedure Report

Patient: Glanina S Hayes
Patient ID: MRN-1919066
D.O.B.:

Attending Physician: [REDACTED]
Referring Physician: [REDACTED]
Exam Date: 05/09/2012

Introduction: A 33 year old patient presents for an elective outpatient Colonoscopy.

Indications:

- * Watery diarrhea (787.91) 5-6 time per day.

Assistants: [REDACTED]

Consent: The benefits, risks, and alternatives to the procedure were discussed and informed consent was obtained from the patient.

Preparation: Paused to confirm patient ID and universal precautions. Pulse, pulse oximetry and blood pressure were monitored throughout the procedure. ASA Classification: Class 2 - Patient has mild to moderate systemic disturbance that may or may not be related to the disorder requiring endoscopy.

Medications: GA-TIVA See anesthesia notes.

Rectal Exam: Normal perianal inspection and digital rectal exam.

Procedure: The endoscope was passed with ease through the anus under direct visualization and advanced to the terminal ileum. The scope was withdrawn and the mucosa was carefully examined. The quality of the preparation was adequate. Retroflexion was performed in the rectum.

Findings: The terminal ileum appeared to be normal. Four cold forceps biopsies were taken from the colon. The specimens were collected for pathology. The cecum, ascending colon, transverse colon, descending colon, sigmoid colon, and rectum appeared to be normal. Multiple cold forceps biopsies were taken from the colon. The specimens were collected for pathology.

Unplanned Events: There were no unplanned events.

Summary: Normal terminal ileum. Four biopsies taken. Normal cecum, ascending colon, transverse colon, descending colon, sigmoid colon, and rectum. Multiple biopsies taken to evaluate for microscopic colitis

Recommendations:

- * Colonoscopy recommended in at age 50 years.
- * Follow-up appointment with referring physician as previously scheduled.

Procedure Codes: [45380]Colonoscopy with biopsy



SCANNED

Appendix C Continued

PATIENT: Hayes, Gianina PATIENT ID: MRN-1919066



M.D.

Date: 05/09/2012

SCANNED

Report electronically signed by Dr. [REDACTED], M.D. on 05/09/2012 at 09:56

Appendix C Continued

Esophagogastroduodenoscopy Procedure Report

Patient: Gianina S Hayes
Patient ID: MRN-1919066
D.O.B.:

Attending Physician: [REDACTED]
Referring Physician: [REDACTED]
Exam Date: 05/09/2012

Introduction: A 33 year old patient presents for an elective outpatient Esophagogastroduodenoscopy.

Indications:

- GERD
- Dyspepsia (536.8).
- Diarrhea (787.91).

Assistants: [REDACTED]

Consent: The benefits, risks, and alternatives to the procedure were discussed and informed consent was obtained from the patient.

Preparation: Paused to confirm patient ID and universal precautions. Pulse, pulse oximetry and blood pressure were monitored throughout the procedure. ASA Classification: Class 2 - Patient has mild to moderate systemic disturbance that may or may not be related to the disorder requiring endoscopy.

Medications: GA-TIVA See anesthesia notes.

Procedure: The endoscope was passed with ease through the mouth under direct visualization and advanced to the 2nd portion of the duodenum. The scope was withdrawn and the mucosa was carefully examined.

Findings:

Duodenum: The duodenal bulb, 2nd portion of the duodenum, and major papilla appeared to be normal. Four cold forceps biopsies were taken from the duodenum. The specimens were collected for pathology. Special stains for mast cells to evaluate for GI mastocytosis verified.

Stomach: A diffuse area of possible gastritis was found in the stomach. Four cold forceps biopsies were taken. The specimens were collected for pathology.

GE junction: The GE junction was visualized. The Z-line was observed 40 cm from the entry point. The squamocolumnar junction was visualized. Bravo capsule fired at 34cm, post images adequate latch on to esophagus confirmed.

Unplanned Events: There were no unplanned events.

Summary: Normal duodenal bulb, 2nd portion of the duodenum, and major papilla. Four biopsies taken. Possible gastritis was found in the stomach (535.50). Four biopsies taken. The GE junction was visualized. Z-line visualized. The squamocolumnar junction was visualized. Bravo capsule fired at 34cm, post images adequate latch on to esophagus confirmed.

Recommendations:

- Follow-up on the results of the biopsy specimens.

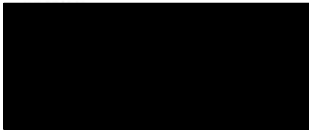
Procedure Codes: [43239]EGD with biopsy 91035: Bravo placement with interpretation



SCANNED

Appendix C Continued

PATIENT: Hayes, Gianina PATIENT ID: MRN-1919066



M.D.

Date: 05/09/2012

SCANNED

Report electronically signed by Dr. [REDACTED] M.D. on 05/09/2012 at 09:40



Appendix D: First Tryptase Drawn

eBrowser · Results for: HAYES, GIANINA (R99476, DOB:4/9/1979) Printed by: ARCASOOI 10/12/2009 1 of 1

Patient: HAYES, GIANINA R99476

Lab Report: Final 07/27/2009 17:08 Ace# OOEL09020020 Acct# 233800

TRYPTASE FRACTIONATION SERUM

Reference

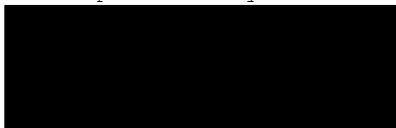
TRYPTASE FRACTIONATION SERUM

TRYPTASE
MATURE TRYPTASE: <1 ng/mL
uniCAP TOTAL TRYPTASE: 4.4 ng/mL

Mature Tryptase: Mature tryptase levels in blood are a measure of mast cell activation. The assay uses a capture mAb that preferentially recognizes mature alpha and beta tryptases. Beta-tryptase is likely to be the predominant if not exclusive form of mature tryptase in vivo. Normal serum or plasma levels are <1 ng/ml. Levels \geq to 1 ng/ml indicate mast cell activation. After insect sting-mediated systemic anaphylaxis, mature tryptase levels peak 30-60 min after the sting and decline with a t_{1/2} of 2 hours. Peak levels correlate to the decline in mean arterial pressure. Levels determined more than 3 to 4 hours after the clinical onset of mast cell-dependent anaphylaxis could be <1 ng/ml. In postmortem sera a mature tryptase level >10 ng/ml increases the likelihood that systemic anaphylaxis was involved in the terminal event. Ratios of total to mature tryptase are typically <10 in systemic anaphylaxis.

Total Tryptase: This assay measures pro and mature forms of both alpha and beta tryptases. Portions of the pro forms are spontaneously released by mast cells at rest, and account for nearly all of the tryptase in non-acute serum. Total tryptase levels in blood reflect the underlying mast cell burden. Normal serum levels of total tryptase average ~5 ng/ml and range from 1 to 15 ng/ml. A baseline level >20 ng/ml, particularly when the ratio of total mature tryptase is >20, is a WHO minor criterion for systemic mastocytosis. Elevated baseline total tryptase levels also can occur in acute myelocytic leukemia, hypereosinophilic syndrome associated with the FIPIL1-PDGRFA fusion mutation, refractory anemias, myelodysplastic syndromes, end stage kidney failure and administration of rSCF. High baseline total tryptase levels may increase the risk for severe anaphylactic reactions to insect stings.

Test performed by:



ORDERING MD:



PERFORMED BY:

EXTERNAL REFERRAL LABORATORY, SEE REPORT FOR COMPLETE ADDRESS

eBrowser · Results for: HAYES, GIANINA (R99476, DOB:4/9/1979) Printed by: ARCASOOI 10/12/2009 1 of 1

Appendix E: Bone Marrow Biopsy

eBrowser Results for: HAYES, GIANINA (R99476, 008:4/9/1979) Printed by: ARCASOOI 10/16/2009 1 of 2

Patient: HAYES, GIANINA R99476

AP Surgical Pathology: Final 10/12/2009 Ace# OOSM09035849 [REDACTED] S M.D.
Surg Path

CLINICAL HISTORY:

Urticaria pigmentosa, rule out systemic mastocytosis. 30-year-old African American female with UP.

GROSS EXAMINATION:

A. "Bone marrow", labeled with patient's name and history number, two bone marrow aspirate smears and one bone marrow touch preparation are received.

B. "___", in AZF. Core biopsies of red-brown tissue 2 x 0.5 cm in aggregate is submitted in toto as block B1.

C. "___", in AZF. A 2 x 1.8 x 0.4 cm aggregate of red-brown clot is submitted in toto as block C1.

F. Received is 3 ml bone marrow aspirate specimen for flow cytometry analysis.

BONE MARROW DIFFERENTIAL COUNT:

500 CELL DIFF	Reference Range		Reference Range		Reference Range
Segs	23 (7-25)	Lymphocytes	19 (3-20)	Plasma cells	7 (0-3.5)
Bands	7 (6-36)	Atypicals	0	RBC Precursors	26 (10-30)
Metas	3 (9-25)	Lymphoblasts	0	Pronormoblasts	1 (0-3)
Myelos	7 (8-15)	Eosinophils	2 (0-4)	M:E Ratio	2/1
Promyelos	2 (1-6)	Basophils	0 (0-1)	Iron	NONE SEEN (Scale 0-4+)
Myeloblasts	1 (0-3.5)	Monocytes	2 (0-2)	Performed By: L.GIVENS	
				10/12/09 17:31	

MICROSCOPIC EXAMINATION:

Bone marrow aspirate: The aspirate smears contain moderately cellular particles. Scattered mast cells are seen. They do not appear atypical. There is a mild increase in plasma cells (3-4%). A few of the plasma cells appear slightly enlarged with a centrally displaced nucleus. M:E ratio is 2:1. Myeloid and erythroid precursors demonstrate complete maturation. Megakaryocytes show normal morphology.

Bone marrow touch preparation: Similar findings are noted.

Prussian blue stained aspirate smear: Stainable iron is absent. No ringed sideroblasts are identified.

Bone marrow core biopsy: Cellularity is estimated at 60%. There is no obvious mast cell infiltrate. Scattered small collections of plasma cells are seen. M:E ratio is 2:1. Myeloid and erythroid precursors demonstrate complete maturation. Megakaryocytes show normal morphology. There is no eosinophilia.

A reticulin stain of the core biopsy shows no significant fibrosis.

Aspirate clot section: Only scant marrow is present. Similar findings are noted.

IMMUNOHISTOCHEMICAL FINDINGS:

CD117 and mast cell tryptase stain scattered round cells (<1%) without any collections of atypical mast cells. CD138 stains 3-4% of cells. Kappa and lambda staining appears polyclonal.

eBrowser Results for: HAYES, GIANINA (R99476, 008:4/9/1979) Printed by: ARCASOOI 10/16/2009 1 of 2

Appendix E Continued

eBrowser Results for: **HAYES, GIANINA (R99476, 008:4/9/1979)** Printed by: **ARCASOOI** 10/16/2009 2 of 2

FLOW CYTOMETRY FINDINGS:

Date Collected: 10/12/09 Container: F
Date Tested: 10/12/09 Sample type: Bone Marrow

===== SAMPLE COMPOSITION =====

	23% Lymphoid	
66% Myeloid		
7% Monocytic	% CD3	% CD19
3% Erythroid	% CD4	% kappa
	% CDS	% lambda

NO PHENOTYPICALLY ABNORMAL CELLS

INTERPRETATION: There is a mixture of lymphoid, erythroid and maturing myeloid cells. No strongly CD117-positive population is detected. The blasts, identified by their CD45 and CD34 staining and side scatter features, are not increased, constituting less than 2% of the nucleated cells. No quantitatively or phenotypically abnormal populations are detected.

Antigens (antibodies) tested: CD7(M-T701), CD10 (W8E7), CD19 (SJ25CI), CD33 (P67.6), CD34 (8G12), CD38 (HB7), CD45 (2D1), CD56 (NCAM16.2), CD71 (L01.1), CD117(95C3), CD123(9F5), HLA-DR (L243) {12 unique total}

This test was developed and its performance characteristics determined by the Clinical Flow Cytometry laboratory. It has not been cleared or approved by the U.S. Food and Drug Administration. The FDA has determined that such clearance or approval is not necessary. This test is used for clinical purposes. It should not be regarded as investigational or for research. This laboratory is certified under the Clinical Laboratory Improvement Amendments of 1988 (CLIA) as qualified to perform high complexity clinical testing.

DIAGNOSIS:

A-C,F. "BONE MARROW" (ASPIRATE SMEAR, TOUCH PREPARATION, CLOT SECTION, CORE BIOPSY, FLOW CYTOMETRIC IMMUNOPHENOTYPING):

NORMOCELLULAR MARROW WITH TRILINEAGE HEMATOPOIESIS.
NO INCREASE IN MAST CELLS.
3-4% POLYCLONAL PLASMA CELLS.
ABSENT STORAGE IRON.

COMMENT: This case was reviewed with [REDACTED] on 10/13/09.

I certify that I personally conducted the diagnostic evaluation of the above specimen(s) and have rendered the above diagnosis(es).

[REDACTED]
Electronically signed: 10/14/09

Performed by: [REDACTED]

Attending MD:
[REDACTED]

Ordering MD:
[REDACTED]

eBrowser Results for: **HAYES, GIANINA (R99476, 008:4/9/1979)** Printed by: **ARCASOOI** 10/16/2009 2 of 2

About the Author

Gianina Shamarr Hayes was born in Marine Corps Air Station (MCAS) Cherry Point, and was raised in Durham, North Carolina. She received both her Bachelor of Arts in Journalism and Mass Communication (Media Management) and her Master of Science in Adult Education (Human Resource Development) from North Carolina A & T State University. After leaving a career in journalism, she began focusing her efforts on adult education, diversity and inclusion, and mastocytosis. She was introduced to diversity and inclusion while completing her practicum at Duke University's Office of Institutional Equity. Gianina, furthered her efforts at the University of South Florida serving as the graduate assistant for the College of Education's Diversity Committee for two years consecutively and co-teaching a diversity module online for Villanova University. This dissertation is her first of many publications to come on mastocytosis. As a member of The Mastocytosis Society, it is her mission to continuously enhance her knowledge about mastocytosis, build awareness about the disease, and convey the importance of a healthy physician-patient learning relationship.