

Wigging Out

by

Jeanette Moffa

A Thesis Submitted to the Faculty of
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Master of Fine Arts

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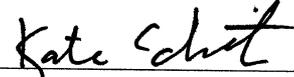
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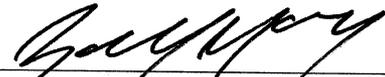
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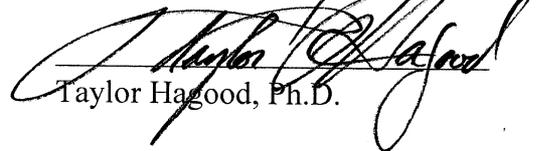


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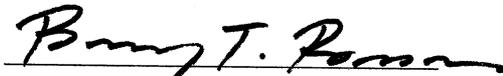
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Abstract

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Wiggling Out, a memoir, chronicles my first chemotherapy treatment which began in 2008 for the autoimmune disease Lupus. The primary focus is on how identity is affected by disability. Each symptom of my disease and side effect from my medications prompted a reevaluation of my identity as I felt a change both in myself and in the way others perceived me. In order to maintain a sense of control, I tried several techniques to pass and cover my disabled status, including the use of prosthetic hair pieces. Ultimately, the use of prosthetics made accepting my situation more difficult as it encouraged holding onto a former identity rather than creating a new one. It was not until I stopped using prosthetics as a form of denial and instead adopted them as part of a new identity that I was finally able to achieve the confidence necessary to fight for my life.

Wigging Out

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Preface

In elementary school, my parents would fight over who would take me to the pediatrician. They knew that as soon as the car approached the large, beige building where Dr. Gill's office was, the screams would begin. My younger brother, like most kids, only got upset over his shots when he saw the needle. But just at seeing the building, I would break out in a cold sweat and panic, sometimes frantically trying to open the moving car door to escape. Nearly every time, there would be a parking lot meltdown as I, making sure to be more than arm's reach away, would beg my case, tears pouring down my plump cheeks as I fought for what I felt was my safety. Often my fear was mixed with hurt and betrayal because my parents had bribed me with ice cream or other treats to get me there in the first place, treats that I then realized would only be delivered after my injections. Worst of all, I felt alone, sad that some stranger was going to hurt me and not even my parents would care. What can I say? I had a flair for the dramatics.

Some might call chemotherapy my karma, or at the very least, bad luck. During a one month round of chemo, I would have one needle penetrate my skin for a monthly blood test, one for my midpoint titer, one for a quick CBC before an infusion, one for the infusion, one to put me in menopause, and usually one or two others at the various doctors I saw. Often the phlebotomist would stand over me with her needle, watching me squeeze my eyes shut, turning my head away from the extended arm that was shaking as

it squeezed the soft ball in my palm, and ask if I was okay. I would nod, ashamed of my obvious weakness, and feel my whole body tense as the needle poked through my skin.

My illness was the one thing everyone wanted me to write about and the one thing I never wanted to put on paper. If I had learned anything at the infusion centers, it was that there was nothing significant about my story. I was one of many people in one of many infusion centers taking two of many different chemotherapy drugs for one of many different illnesses. I was, and am, embarrassed to admit that the only reason it was such a big event in my life is because I was the girl who cried over shots in a pediatrician's parking lot. Because I was a coward. And becoming fearless when I was out of other options, I figured, did not make for a good story.

So by the time I began to read my first disability memoir, Stephen Kuusisto's *Planet of the Blind*, I had high expectations. Despite all reason, I expected him to somehow "beat" his blindness, or, at the very least, make something fantastic come of it. Perhaps it is because "disability has been used throughout history as a crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight," that I was disappointed when Kuusisto's blindness failed in the end to be any more than just an impairment (Mitchell and Snyder 49). But along with disappointment came frustration. A third of the way through the book, when Stephen visits the Prado museum in Madrid, he writes, "I cannot see the famous paintings of Velazquez and Goya because they are hanging behind ropes that prohibit the vandals from drawing too close. Since I can't draw near, I see oceans of mud in vast gilded frames instead of the ceremonial world of court or the sprawl of lusty peasants"

(Kuussisto 67). Having been to the Prado museum myself just a few months prior to reading the memoir, I became infuriated at Kuussisto's lack of determination. *If you wanted to see the Prado so badly, why would you just wander around feeling sorry for yourself?* I couldn't understand why he didn't ask for assistance of some sort, or set an appointment up early in the morning with a guide when the least amount of visitors were there. At the very least he could have approached a security officer and asked to get a better view because of his blindness.

As it would turn out, the frustration I felt in reading Kuussisto's memoir would motivate me to begin writing about my own illness. I remembered so many of my own Prado moments, where, like Stephen, I denied my identity and suffered for it. When I had crippling arthritis, for example, I refused to accept that I needed a wheelchair and instead forced myself to hobble around, causing horrible pain and permanent joint damage. Nearly every occasion that I went out with friends, I would make myself stay awake hours after exhaustion had settled in or pretend I was having a good time when inside I was so nauseated I could barely think. But my worst "Prado moment," I realized, was an entire seven month period when I went through chemo and chose to wear wigs. By wearing hair prosthetics, I both denied my identity to myself and others and filled the void that was left with moments of passing as someone I wasn't. Because "culturally generated and perpetuated standards of 'beauty,' 'independence,' 'fitness,' 'competence,' and 'normalcy' exclude and disable many human bodies," I felt that passing as someone meeting those standards would prevent me from true disablement (Garland-Thompson 7). But ultimately, wearing the wigs and passing as healthy further disabled me. People I was

around, going off the false cues I gave, assumed I was healthy and expected me to perform at a particular level. Furthermore, by denying my identity I also denied myself the ability to ask for accommodations, like Kuussisto in the Prado. As I started brainstorming for this piece, I knew I wanted to create the same frustration in my readers that Kuussisto had in me. Why didn't she just say she wasn't feeling well and go home? I wanted them to ask. Why didn't she stick up for herself?

When I asked myself those questions, the answer was always the same: I was scared. I was scared of what my life would be like if I gave up on whatever normalcy was still in it. I knew that once I was out of the chemo closet, life as I knew it would be over. Even today, over three years since my last treatment, I cannot go to the dentist without Maria, the woman at the reception desk, telling me with exaggerated enthusiasm that I look *so* great. And how am I *feeling*? She asks. It doesn't matter that Maria is a kind and wonderful woman, or how good her intentions are. Her comments remind me that regardless of how healthy I get, I will always be disabled in her eyes. Admitting to my illness while it was at its worst would have been the same as giving up on ever being normal again, something I couldn't do. So I chose to take advantage of "the duality of every prosthesis, its search for a way between emulating the human and superseding the human" (Wills 26). If I could supersede the very natural and human state of disablement, while at the same time emulating the "norm," I could avoid a lifetime of awkward conversations with the many Marias of my life.

But while the fear of being othered was part of my own insecurity, the actual stigmatization was a societal norm, which I found more frustrating than any of my or

Kuussisto's behaviors. The stigmas unfairly justified a lack of accommodations in various environments. Generalizations, which would never, in modern day, allow for the exclusion of people based on race, ethnicity or gender, are widely accepted for the disabled. Kuussisto, if given the opportunity, could have enjoyed the paintings at the Prado. But because "blind people can't see anything," no accommodations were even in place, even if he had asked, for someone with a visual impairment. The image of the vomiting chemo patient seen in movies often gave people I was around the impression that if I was out of the house, I was fine. But other stigmas, such as those about disabled people being "on disability" and having no way to generate incomes on their own, perhaps are behind the poor accommodations provided in stores and restaurants. The deeper I looked into my frustration with myself and my own behaviors, the more frustrated I became with society's treatment of the disabled. As I began writing my memoir, I wanted the reader to be frustrated not only with me, but also with the various environments I brought them to. After asking, "why didn't she speak up?" I wanted the reader to then ask "why did she feel like she couldn't?" and "would it have mattered if she did?" Most of all, I wanted the reader to reflect on their own treatment of the disabled and determine whether or not they were contributing to their exclusion and discomfort by actions that are unfortunately common and accepted practice.

But I realized that using my own, unique experience with one particular disability in an attempt to comment on the treatment of all disabled people was problematic. As Simi Linton argues, "[t]he term *disability*...is an arbitrary designation, used erratically both by professionals who lay claim to naming such phenomena and by confused

citizens” (10). By commenting on the treatment of all disabled people, I was generalizing their experiences in the same disabling way that I criticized societal norms for doing. Fortunately (for the memoir, not myself), Lupus manifests itself in a variety of different ways. I spent a good portion of that time of my life nauseated, but I also experienced months as a cripple and even had psychological side effects from my medications. In short, my experience with Lupus included a variety of different disabilities, giving me what I felt was a diverse enough background to focus the memoir on my own experiences and allow the reader to consider the larger consequences without my direction. I decided to choose stories that showed different types of disablement and the ways in which I tried to pass as healthy in environments where I felt there was no place or accommodations for a girl like me.

Now the question was how to tell the story. From the very beginning I knew I wanted the story to be funny. I wanted people to laugh at the absurdity of not only myself and my experiences but also the ridiculous ways that society tries to ignore or exclude the disabled and the extent to which disabled people sometimes go to hide their identity. People thought Michael Jackson, who also had Lupus, was outrageous for changing his skin color and covering his black identity, yet as a balding chemo patient I felt pressured to cover my head with a wig. Both acts, whatever their motivation, are the same type of covering. If people were going to laugh at Michael Jackson, I wanted them to laugh at me for the same reasons. But getting readers to side with an unconventional view, especially towards something as personal as prosthetics, was extremely difficult. I’ve had many people throughout the writing process shake their heads and say “you can’t just argue

against prosthetics. They help people function who otherwise couldn't. If you lost an arm, wouldn't you want something to help you tie your shoes?" But my argument is not directly against the use of prosthetics, but rather against the need for prostheses, against socially constructed environments where prostheses are required for disabled people to function and be included. The solution, I also argue, is to refuse the prosthetics and make the world reconcile with our bodily differences. At the end of the day, people need to do what they can to get by. But if a person in a wheelchair cannot reach a door handle and instead sits in front of it, blocking the entrance day after day until someone lets him in, eventually the door will be changed. The disabled community is so afraid of inconveniencing others that they allow themselves to be further disabled and sacrifice their quality of life to unnecessary extents. To get these points across, I looked to Cupcake Brown, author of *Piece of Cake*, a memoir about her life dealing drugs, prostituting, and fighting with addiction. What I found most shocking about Brown's story was that after just a few chapters, I was sympathizing with her. Even when she was committing crimes, I was on her side. If she could make me love her even while saying "I felt like shit. I smelled like shit. And I was sure I looked like shit. So I gladly welcomed complete, utter, drunken unconsciousness," then I knew there had to be a way for a person three years over her last chemo treatment to ask those suffering now to throw out their wigs and laugh while doing it (Brown 187).

But soon I realized there is a big difference between laughing at the obscene things Cupcake Brown did while under the influence and laughing at a scared, bald girl getting embarrassed. I would be lying if I pretended I was as confident as Brown. Her

memoir is startlingly unapologetic, with her anger directed at the world, whereas I was full of regret and anger towards myself. While she, at one point, runs towards death, declaring “I had made up my mind about how I would die,” I would have sold my soul to live and, in many moments, lost all of my dignity trying to (Brown 327). More than that, none of the things that happened to me were funny while they happened. I can look back and laugh at myself, but that’s only because laughing at the absurdity of it helps me write things off rather than be owned, or “traumatized” by them. The reality is that nothing about chemo is funny. If I tried to get humor across in the language, it would jolt the reader out of the moment and create an overall very different account of what actually occurred. But then I was right back at square one, not knowing how to approach the memoir and afraid that anything serious would be such a downer that no one would be able to, let alone want to, read the whole thing.

On my first draft, I decided to block the reader out of my mind along with all my grand hopes of getting across a larger message so that I could focus solely on remembering and detailing the events. I never created a specific method to cut down my list of stories to several that would work together, but I found that the ones which were most easy to remember were good representations of my overall experience. What I didn’t anticipate was the great clash between how I perceived those events presently and how I experienced them then. From a medical standpoint, at the time the events occurred I was totally unaware of how my body responded to Lupus. I could not distinguish different types of pain or nausea let alone determine their origin or triggers. My whole life I had known only “sick” and “not sick,” “in pain” and “not in pain.” So when doctors

asked me, on a scale from 1-100, how did I feel my health was? Or, on a scale from 1-10, how severe is my pain? Or, from green happy face to red sad face, how bad are you feeling? I never knew how to answer because I had not yet learned my own range. Every moment I thought I'd reached 10, or 100, or red sad face, I would be proven wrong soon after, discovering something more severe than I had imagined previously. Ultimately we never know the full range, though I know a lot more about my own now than I did back then. Determining both my level of pain and the scale on which I determined it in that particular moment proved impossible.

To make matters even more complicated, I soon discovered that pain was the first thing that had been erased from my memory. I remember, for example, that I had swollen with forty pounds of water to the point that my skin began to stretch and tear. I remember that I felt agony at certain moments. But I don't remember what that feels like. Sometimes I will look at my feet and the thin scars down their sides, barely visible these years and a good tan later, and try to remember the pain, try to recreate it in my mind, only to draw a blank. Life is only what you remember and how you experienced it, so if I can't remember any of my pain then it's almost as if it never happened. I can't write about the pain from my perspective now, because presently I don't know what the pain was like and even if I did, it would be on a scale much different from the one I knew back then. But I also can't write about the pain from my perspective before, because I simply can't remember it. Perhaps it is all for the best, because the vast majority of the time I feel as though what I went through wasn't all that bad. I claim the pain to have been only a 6.5 on the 1-10 scale. I say the deep depression and times where I thought about

committing suicide were just a part of normal teenage angst from someone who is, as my dad says sarcastically when he feels I am recounting a story with different details than he remembers, a “creative writer.” The more I’ve told myself those things, the more I’ve believed them and the more time has passed where any memories that would contradict them are forgotten. Ultimately, I’ve reconciled my story to fit my feelings toward Lupus now: I would rather be hated than pitied because you can’t be both a tough bitch and a victim. Save for the occasional night in bed, when I am choked with panic and flashbacks and fear that a creaky joint in my knee, slightly worse than hours earlier, is the first sign that everything is starting over again, my reconciliation works very well. It’s motivated me to finish both my undergraduate and my graduate degrees early, to travel, to learn the foreign language I always wanted to, to do today what I could do tomorrow, to do whatever it takes to accomplish my goals. And most importantly it has left me appreciative of things I had always taken for granted, something that has made me happier than I believe I ever would have been if I hadn’t gotten Lupus. But all of these things, while great for moving forward and coping, proved terrible for memoir writing.

I’ve heard said that it’s best to wait five years before writing about an event in your life so you have some time to understand the events better and gain perspective. But with my difficulty remembering things, I often wonder if the best memoir would have been the one that compiled the hundreds of journal entries I made during those years. I can’t say for sure, because I don’t remember what they said and I deleted them all after one day deciding they were too pathetic and whiny to be remembered. But perhaps they would have given me some insight into when exactly I felt that my “physical difference

count[ed], under what conditions, and in what ways, and for what reasons” (McDermott and Varenne 328). I could gather from the amount of effort I put into passing that I must have felt I was disabled when I began chemo, but it is difficult to remember if it was because I had started the infamous chemotherapy, or because I bought a wig, or wore it, or finally, *needed* it? So while writing, I decided to make the loss of control gradual. Even from early in the memoir, when I shopped for the wig, the woman working in the store gradually took control and eventually chose the wig I would end up purchasing. By the end of the piece, I was so desperately grabbing at straws, trying to pass in a community I would never belong to, that everything fell apart as I made myself more and more uncomfortable in hopes of maintaining that false identity. In the end, having no control over my body also led to having no control over my life. I wasn’t sure if that was something particular to me, an American teenage girl, or if it was something that all disabled people struggled with. I developed a fear of writing myself as a superficial character, the type of woman who shops at the supermarket with full makeup and heels on, someone obsessed with appearances. My feelings were more complicated than that. The woman who shops at the supermarket with full makeup and heels has control over her appearance and her identity. Even if she is an emotional wreck, she can portray herself as someone who is well put together. She can control how other people receive and respond to her. Also, from the moment she swipes on the lipstick, she is creating what is, no doubt, a familiar image: both the woman she wants to be and the woman she’s come to identify herself as. As the image in my mirror became increasingly less recognizable, I lost all of that control and familiarity. My response to that, as I began to

realize, did not entirely reflect on myself and whatever possible superficiality I would be perceived as having but also the pressures I felt to maintain specific types of control. As Michael Oliver argues, “[t]he personal response of individuals to their disabilities cannot be understood merely as a reaction to trauma or tragedy but have to be located within a framework which takes into account of both history and ideology” (60). What or who made me feel that I needed control? And how could I have been expected to control the uncontrollable?

After my second draft, I realized my memoir had become dominated by the theme of control, mostly of identity but sometimes of environment. In the process, I feared that my underlying desires of making a larger comment on the treatment of the disabled community, and calling chemo patients to “burn the wigs,” was lost. But after reading Elena Gorokhova’s *A Mountain of Crumbs*, I realized it wasn’t necessary or even right to force my opinions on the reader. Rather, it was better to present the events of my life that led me to my conclusions and allow the reader to make their own conclusions. I was particularly struck by how she described her family member. Whereas I was more inclined in my second draft to give my blunt opinion on people I encountered, she gives us carefully ordered facts that ultimately lead the reader to the same conclusion she had without feeling forced into it. For example, Aunt Muza’s father is described as “a factory owner and a man of strict morals, [who] banned [Muza] from studying at the conservatory, where she’d won a scholarship, because no decent woman, in his view should appear onstage” (Gorokhova 133). I would have added a sentence saying “an asshole who prevented a talented woman from following her dream.” But from the way

she revealed the facts, the reader was already led to that or a similar conclusion without having it shoved down their throat. But most significant was the subtle commentary on Russia, which is what Gorokhova, throughout her book, is really getting at. Muza's father, owning a very iconic Soviet factory, where he takes on the role of leader to the proletariat laborers he employs with only "strict morals" and none of the corruption often associated with those in positions of power in Russia at that time. He was not only an average Russian, but the Russian every man hoped to be. So it wasn't just Muza's father, but the ideal Russian man who was preventing women from fulfilling their goals and potential which ultimately was not a very Russian thing to do. In my own writing, I had to allow readers the freedom to come to conclusions their own way and accept the fact that they may not come to the same ones I have. It is certainly possible someone reading Gorokhova's memoir could reason that Muza's father was an upstanding man who was just following the norms of his time, maybe even preventing Muza from an unstable and possibly inappropriate future. It is also possible for that same reader to draw no connections between Muza's father and Russia itself. It was hard for me to let go of the reader and stop trying to control their reactions and interpretations. Just like during my treatment, when I was determined to have control over myself and how people responded to me, I was also determined as a writer to have control over how people responded to my story.

Ultimately, I had to take a page out of my own book. The harder I tried to control my identity and appearance, the less control over it I had during chemotherapy. And I eventually realized that the harder I tried to call the disabled community to arms and

make them come to the same conclusions about my situation that I had, the less likely they would. In letting go, I saw my story open up and my project morph into something larger than I'd anticipated. It is as much about a young woman navigating a new and unfamiliar world as it is about the illness and its treatment, and looking back, I don't know why I thought it had to be one or the other. Without constantly focusing on and returning to disability, I think my story could potentially appeal to not only the disabled community but also to those interested in coming of age stories.

Recently I was sitting in the graduate student teacher office, looking up my Florida Atlantic University ID that I can never remember for the thousandth time since I started there two years ago. The office was almost completely empty as I began filling out the form I'd brought with me. To my right was my memoir, the last paper I would ever write for graduate school. One of the new teachers came lurking from some corner of the office and said "hi" as she approached, expecting, I knew very well, a conversation. Graduate students, for all their complaining, have more free time on their hands than any group of people I've ever encountered. It wasn't long before she asked about the thesis she saw on the desk next to me. I always dreaded that question, just a few casual words that forced me to expose the most difficult part of my life. There was no way around an awkward response.

I said it quickly and gave a positive spin to it all in the end before trying to change the subject.

"Oh my God. Wasn't that, like, *traumatic*?" She responded as she moved closer, clearly not interested in changing the subject. If there is another thing I've learned about

graduate students, it's that they love their trauma and wear it on their sleeve. Although, there's not much I can say having written a thesis about chemo to exclude myself from that, I didn't feel defined by it. If I was going to define myself by one thing, it would be my travels across both the world and the US, or maybe the education I feel so honored and lucky to have gotten. Not chemo. It was the worst part of my life, but clearly not the thing I remember best. It is something that makes me unique, a badge I can wear with pride, a scar I can point to when convincing others of what a badass I am.

I told her no, it wasn't traumatic. It has changed who I am in the same way all experiences mold us into who we are. It was something to juxtapose to all the great things in my life to make them seem even greater. It was necessary in order for me to appreciate things the way I do.

Chemo was not my "shots" of college. I may have been equally scared of both and possibly even acted the same way. There were definitely times in college I threw a temper tantrum in my apartment worse than anything I ever did in Dr. Gill's parking lot. I had the same feelings of loneliness and betrayal. And as embarrassing as it is, both times I was a coward. But whereas I look back at that doctor's office and cringe, and still, yes, even today, tense up in extreme anxiety over a simple blood draw, I don't look back on the whole experience of chemo and think of it as "traumatic," which is proof enough to me that I'm no longer a coward, owned by fear.

"Are you just *saying* that, or do you really feel that way?" The grad student dug into me with her eyes, determined to get a good story out of me. If I admitted my trauma, she could admit her trauma, and then we could talk for hours about it. I looked over at my

thesis. Some people live their whole lives in fear. I was so lucky to be no longer afraid.

“Yes, I really do feel that way.” I left the room to turn in my form for graduation.

Whatever adventure came next, good or bad, I knew I was ready.

I.

In the corner of the emergency room, a boy roughly six years old sat a few seats away from me with his parents. His mother's back was arched over his hand, blocking it from view, while his father could only remain in his seat for fifteen seconds at a time before standing up to examine the hand from a new angle and then shaking his head as he paced around them. Every now and then he would go up to the person doing check-ins, an office worker disguised as a nurse in dark blue scrubs, who would answer at first his questions and then his demands with long and empty responses so the man would feel confident that he'd been given an answer up until the moment he sat down again and tried to relay the lack of information to his wife. He made his complaints abruptly and loudly as the hours went by, looking up and down the rows around him in hopes of a response from the other people waiting, for some sense of camaraderie in the emergency room against the institution's failure to provide adequate medical care. But no one acknowledged him. Most of the people in the waiting room were in pain, not the screaming type, but the nagging and mind numbing type, and the exhaustion it led to left them apathetic to the man's call to arms.

During those days, my trips to the hospital were never because something *happened*. I was never the one who tried to fry a frozen turkey on Thanksgiving or climb a precariously balanced ladder to clean out clogged gutters. In fact, I couldn't remember the last time I had climbed a ladder. I was the type of person who, every time I chopped

an onion, or used a knife at all, would focus with the most severe attention to avoid any dismemberment. And I had never, not once, chased a ball into the street as a child. No, I was not in the emergency room because of an accident, because something *happened*, but rather because what had been *happening* for the last year was, once again, reaching levels of intolerability. It didn't matter that my threshold for intolerability had been improving considerably since the last summer, when everything began. My trips to emergency rooms across the state of Florida were still becoming more frequent. And so it was on an afternoon when nothing particular had happened that I sat in an ER forty-five minutes from my parents' house and four and a half hours from my apartment, waiting with a bright pink and green backpack on my lap counting the people sitting around me and trying to determine where I was in line and which cases, after triage, would be placed before me. Most cases would be placed before me because nurses had no idea what to do with a Lupus patient who was swollen with forty pounds of water weight pulling down and sinking her into herself, a girl being buried alive by her own flesh as she slipped deeper into the swollen mass taking residence under the surface of her skin. But the nurses did know that whatever was wrong with me would take longer than stitches or a broken arm, so I waited indefinitely with no expectations of speedy service.

It wasn't long before the man stood up and demanded his panicked wife and stoic son go to another hospital. The mother flung her purse over one arm and was only halfway through collecting her son's belongings, toys and snacks, distractions to keep him calm, before the father began ushering the boy towards the exit. When he turned to see if his mom was following, I saw a thin metal wire sticking right through the kid's

index finger. With a limp wrist, he pointed his finger ahead and away from his body as he slowly walked forward into the empty space his father dramatically cleared ahead of him so as to avoid getting the wire snagged on something else. The ER was getting busy, as five o'clock had already hit and doctor's offices were closed. The mother knocked someone with the oversized bag carrying her son's things as she raced to catch up. Her apology was sincere but unheard by the victim, who spun around with a dumbfounded look on his face, as she chased after her family outside the automatic glass doors.

I tried not to look at the clock or my phone. It was never better to keep track of time in the hospital. Whenever I did, frustration would begin to brew inside me before dissipating into my exhaustion and leaving me even more drained. Instead, I let my chin fall to my chest and my eyes stare deep into the baby blue of the fuzzy slippers my feet were crammed into. I had always loved those slippers, especially in the winter when they would keep my cold toes from losing feeling on the icy tiles of my apartment floor. But now, after collecting the various germs of the ER deep in the roots of the faux fur, they would surely have to be thrown out and replaced. They were beginning to look ragged anyway, I thought with a sigh. They hadn't been made for outdoors, which is exactly where I'd been wearing them for the last month since my feet had become so swollen they couldn't fit in any other shoes. The area where the top of my foot curved into my shin was now just a wrinkle in the larger plush mass enveloping both. I reached over and poked it. My swollen stomach pressed tightly against the backpack in my lap, almost preventing me from being able to reach that far. From the second my finger touched the thin and stretched skin, it burned in pain, but I continued to dig into the wrinkle until I

found its base and could measure its depth. When I pulled it out and examined my foot again, I saw that the knuckles on my other fingers had made deep, red indentations on my shin just from being rested on it.

I reevaluated the one and a half minutes I had spent in triage several hours prior. From the moment I was alone with the nurse in a private room, I had emphasized that I was *Stage IV* Lupus Nephritis and that this swelling was because my kidneys weren't working properly. The nurse typed it indifferently into an old computer angled towards her, clueless and uninterested in what Lupus was, as I tried desperately to improve my chances of moving up the triage list by adding that Stage IV was the worst stage of active Lupus kidney disease. She had taken my temperature next, noting it hovered just above 99 degrees, before strapping on the blood pressure cuff to my arm and pumping it. I was grateful that it was the afternoon. By the end of the day, the swelling in my body was always pulled by gravity into my torso and lower extremities, leaving my arms tender but without swelling so as she pumped away to get a good reading on my blood pressure, I didn't experience much discomfort. After a few moments, she raised an eyebrow, cracking what had looked like a permanently bored expression on her face, and for the first time looked straight in my eyes. My blood pressure was 185/157, which was, she informed me, alarmingly high. The blood pressure didn't concern me, though. It had been like that for over a month and didn't seem to affect me. At least, I didn't notice it over the pain from the swelling. The doctors had given me three different medicines for it, but I always found excuses not to add any more pills to my daily mouthful. Taking advantage of her attention, I had changed the topic back to my kidneys and the swelling in hopes

that maybe with the high BP she would take me seriously. I even added that my kidneys might fail any moment, which, for all I knew, might have been possible.

It was in that moment I had blown any chance I had, I realized from my seat in the waiting room. Triage was like an interview process, and I had failed. In the short amount of time that it took a nurse to take my vitals, he or she had to be convinced of the severity of my condition. If not, I'd be passed over by other patients all day. I always felt hurt when that happened, when nurses decided my case wasn't all that bad. I'd look around the waiting room. Most of those people were fine yesterday and many of them were fine a few hours before they arrived at the hospital. I had been sick for a whole year straight, for the last 5% of my entire life. It seemed like an eternity. It didn't feel fair that I had to wait any longer. I looked back at my feet, unrecognizable blobs. If someone had chopped them off and put them on a display, I wondered if anyone would even recognize they were feet, let alone human feet. I had never seen anything like them. I'd never even heard of anything like it from all the people I'd encountered in my life. But I supposed doctors and nurses became numb to deformities and alarming symptoms after a while. Nothing surprised them. Or maybe they thought it wasn't as bad as it looked. Maybe I just looked fat and pregnant and they thought I felt the same way a fat, pregnant woman would. But I'd never heard someone complain about their fat hurting, that it hurt them to touch their cankles or beer bellies. My problem must have been that it was worse than it looked to someone who didn't know how I was before. My best bet would have been to play up the blood pressure, to say I felt chest pains, the golden ticket to the top of triage. It wouldn't even have been a total lie. All the pressure from the swelling did actually give

me some discomfort in my chest. But then I thought of the kid with the wire in his finger and felt like a jerk. I started to get frustrated with myself and the world, but once again it melted into exhaustion.

A frail woman with thin hair had been switching seats periodically since I'd arrived, each time trying to engage the people around her in conversation. She wore an oversized, faded t-shirt with skin tight jeans that hugged her knobby knees, stick thighs and flat ass. She cautiously avoided the people who looked sketchier than her, the homeless people and some of the patients who appeared to be there for psychiatric reasons. When she came across someone vomiting, she'd cringe and point while yelling out words of what she felt were encouragement. If she realized the person she sat down next to didn't speak fluent English, she'd start spewing insults under her breath as she'd get up to move. Her goal was to find someone to listen to her story, and not just the story about how she came to be wearing a sling on her left arm, but the story of her entire life with each and every injustice that had occurred in it. Luckily for her, the emergency room was full of people too tired to shoo her away, so she had found entertainment since before I had arrived and would probably find more throughout the evening as new people came in. I felt a little bit of comfort in the fact that she would forever sit at the bottom of the triage list until eventually she became bored and left. It was glaringly obvious from the way she spoke about her pain that she was a junkie, waiting around in hopes of getting a few pills of Oxy, or at the very least, Vicodin, to last her for a few days.

As she started getting closer to me, I leaned my head back on the chair and closed my eyes, resting my hands on my large, swollen belly. Her voice was scratchy from a

lifetime of cigarettes as she began rambling to a person a few seats down from me. He was exactly the target she was looking for, someone naïve to her obvious drug problem and too polite to ask her to leave. He paid attention closely to what she said, because if she had to repeat herself, she got much louder, her voice turning to a shriek that made everyone uncomfortable. To each question he would nod or shake his head with a one or two word answer. He didn't want to get any of the questions wrong. With his worn in jeans, black t-shirt, and tanned neck he looked like some sort of outdoor laborer, maybe something to do with construction. I could tell he was about ten years older than me, somewhere in his late 20's, and good looking in that Southern sort of way. Probably a hard worker with calloused hands and a church boy on Sunday mornings.

From behind my closed eyes, I tried to imagine the tips of his ears turning red and the woman got deeper into her life story and expected greater responses from him. But with nothing visual to distract my mind, it became overwhelmed with my pain. Both feet throbbed with the large, jello-like mass of fluid flopping around on top of them, waiting to pop my toes off and pour out in what I could only assume would be rivers down the aisles of the waiting room. I vaguely heard the man get up, making polite excuses, and walk away towards the bathroom. It took a few moments for the woman to decided to try to engage me next, but by then the pain was all I could think about. It was all I could taste and hear and feel. I wanted to get up and walk around, but I knew the second all my weight was put on my feet I'd be much worse off. The woman tried four times to get my attention. I wanted to open my eyes, to flood my mind with all the things going on around me and push the pain back into the corner of my brain. But I still waited until she gave up

trying to get my attention and moved on to someone else.

When I opened my eyes the pain didn't subside. I needed to walk around to get my body moving. The swelling was pooling in my hips and my feet more than usual from all the hours of sitting. But the thought of putting and pressure on my feet made me cringe. Instead I sat there, indecisive. Eventually my parents arrived, their overwhelming presence intruding upon my meditations of pain. What did they say? What did Doctor Watters say? How many people are in front of you? Did they do any tests yet? Having them stand in front of me like that made me sad. Their presence reminded me that I was not just a blob trying to maintain homeostasis on a such a level that it prevented my explosion. I was Jeanette Moffa, who had sung "God Help the Outcasts" dressed up as Esmeralda from *The Hunchback of Notre Dame* in the fourth grade talent show, who worked at a TCBY scooping ice cream and rolling pretzel dough in the summer before my senior year, who once had dreams of a big future. People had once said I looked like my dad though no one would have said that then as he stood there over me.

I didn't have answers to their questions and it made my mom aggravated, which put me on edge. After all those hours, I had stopped minding the waiting room. No one had been bothering me and all I had to focus on was my pain and trying to control it. But soon after my parents and their questions entered, I was called back into an examination room. I stood up slowly, allowing the pain to escalate at a gradual level rather than all at once. But even after I'd been standing straight on my feet for a few moments, the pain continued to escalate. I tried to shift my weight back and forth while I waddled to give each foot some sort of momentary relief. The nurse offered me a wheelchair, but I

declined it. Pain was somehow less terrifying than giving in to immobility. I moved slowly and unsteadily across the ER towards the large double doors that opened into the trauma ward. The nurse waited for me approach before nodding to someone I didn't bother turning to see and the doors buzzed open. Immediately the nurse took off down the hallway as if she was oblivious to the fact that my family and I were walking at a turtle's pace. At the end of each corridor she would wait, annoyed, for us to catch up before dancing down the next one, gracefully side stepping and dodging the obstacles of the crowded hallway. My mom took my bag from me so I could concentrate on walking. She felt weird walking so slowly next to me, so she eventually left to catch up to the nurse to see what was going on next. My dad continued to patiently walk with me, making predictions as to what the plan would be now to get me better.

Inside the room, I could think of nothing but getting to the gurney before I collapsed. When I sat on the bed, my stomach and thighs tensed from the pressure of each other and the bed, which was digging into my puffy thighs. I let my back fall on the paper sheet and my head on the small pillow, my bloated stomach wobbled back and forth for a moment before settling its weight on my core. A doctor came in and spoke with my parents, but my exhaustion was beginning to make me delirious. It took all my effort to keep my eyes open, and soon I couldn't even do that. I heard my mom tell the doctors incorrect information which she believed to be true. She urged the ER doctor to reevaluate my diagnosis because, as she always would say, "*none of this makes any sense.*" On another day, hearing her question my diagnosis after so many doctors had assured me I had Lupus would infuriate me. I was a year past questioning my diagnosis,

but my mom's denial prevented her from letting it go. My dad stood there, interjecting occasionally, as my mom recounted my life's medical history.

“When she was nine years old, she had a false positive for TB and the doctor made me give her isoniazid for six months even when I told him it was making her sick. I had stopped giving it to her but the pediatrician said if I didn't put her back on it he'd report me to Child and Family Services so I had no choice. Now all this information is out about how it can cause Lupus...” she went on, getting increasingly passionate and angry. I never knew what she hoped to get out of this recitation. Perhaps all she wanted was for someone to tell her she was right and my pediatrician was wrong. Or that it wasn't her fault for giving me the medicine. But none of those things mattered at that moment. The doctor was young, thirty-something, and patiently tried to redirect the conversation back to what was wrong with me currently without offending my mom. But when my dad eventually bowed out of the conversation to make a phone call, the doctor knew he'd had no chance of getting the information he needed without being direct.

My dad phoned his best friend since childhood, my Uncle Ken, an eye surgeon in Pittsburgh, who, for the past year, had put together what information he could to be the best Lupus doctor he could be for my dad. “Pregnant. She looks nine months pregnant. Her stomach is huge!” My dad yelled into the phone. From behind closed eyes, I frowned. Just because we were all thinking the same thing, it didn't mean anyone had to say it out loud. I busied myself with unfolding the thin blanket that I'd found on the gurney. Trying to move as little as possible, I shook it out over my body in hopes of covering my feet. With all the swelling, my circulation wasn't that great and combined

with the cold air conditioning my toes were freezing. Meanwhile, the doctor tried to cut my mom off and get the examination back on track. I rolled onto my side so I could face the wall and avoid the bright fluorescents. At some point, my dad left to get a stronger signal and everything got a lot quieter in the room.

When I was in high school, I used to have a terrible time falling asleep. Every night, I would anxiously toss and turn, unable to escape the day's events that played over and over in my mind. Sometimes when I was especially upset over what happened that day, I would remember the events so vividly that I would actually begin saying my lines out loud without even realizing I was doing it. Often I was disappointed in how my day had gone. Like most high school students, I had my fair share of bullying and usually felt like I didn't have any friends. I would most sincerely regret the moments I was bullied and didn't stand up for myself, and on days when it was particularly bad I would lie in bed imagining alternative versions where I came out on top. I would obsessively go over all the possible outcomes until I found one that was best and then I would *promise* myself that next time I would be the person I wanted to be. Many sleepless nights were spent on AIM instant messenger trying to be that person. I would change my font and the color I typed it. I would use the mix of Hispanic and black vernacular that was accepted as cool. I'd say things I'd always been too shy to say in real life. And then, sometime in the middle of the night, long after my family had gone to bed and turned off their lights, I'd fall asleep hopeful that the next day things would be better. The next day I would make everything right.

I'd had no problem falling asleep in a while. I tried not to relive the day's events.

It was easier to roll with the punches. Unconcerned with what sort of misinformation or extraneous crap my mom was subjecting the doctor to, I feel asleep in the gurney despite the bright lights and pain. It may or may not have been a while before I was woken by a nurse who came in to draw some blood. After examining the crook in my left arm and seeing no veins, she let out a sigh of annoyance. She tapped my arm a few times, switched to my right to see if I had any visible veins on that side, and then switched back before diving in with a needle and hoping for the best. The pinch was a relief, a pain that distracted me from the normal, unceasing pain of my lower extremities.

When it was finally time to be admitted, a wheelchair was already waiting at the door of my room. It was hospital policy, not that I was going to fight it at that point anyway. I watched the white linoleum flooring run beneath my immobile feet as someone in scrubs wheeled me through the hallways with my parents following behind. In the elevator the noise of the ER finally stopped, leaving us all in a heavy silence that grew thicker at each floor until the doors finally opened to a silent hallway several floors up. The hushed voices of nurses at their station were silent to our ears even as we got within a few feet of them. I was brought into a single room where the bed faced the door. The bed was larger than the gurney downstairs and to its left was an uncomfortable looking green chair. Behind half closed blinds, a window exposing the night made me wonder how many hours had passed since I'd first arrived at the hospital. Again, as I sat on the bed, I felt tension in my stomach as if my skin was about to rip, but I was so exhausted the pain didn't faze me. My parents left with promises of returning in the morning and before the door even closed behind them, I'd fallen asleep.

It was sometime in the early hours of the morning that I met Amir. I was awoken by the bright florescent lights that were abruptly turned on above my closed eyes as he made his way into my room with a cart.

“Hello. I am Amir and I will be your nurse today.” I blinked several times trying to adjust to the light, but I refrained from moving in hopes that if I stayed very still I wouldn’t feel my body. Amir was a Middle Eastern, male nurse, which was unusual enough that I curiously watched as he took my blood pressure and temperature. His fingers were long and thin and his nails were clean and trimmed short. Amir was very cautious and precise as he touched me, carefully undoing the Velcro on the blood pressure cuff rather than jerking it off in one rough yank. His fingers were so light that as they grazed the surface of my skin it tickled. When it was time to draw my blood, I reluctantly gave him my veinless arm. Holding it by the forearm, he stared intently at the inside of my elbow for a long moment before gently pressing down twice to feel the vein. I was worried he wouldn’t be able to find it, that he would hesitate if he did, and that the end result would be a massive bruise. But in a swift second, the needle was in and I barely even felt the pinch. We both watched my crimson blood flow through the clear tube in silence, the only noise being his quick and graceful swapping of vials, all nine of them.

Amir did not examine my swollen body. In fact, he gave no sign of having noticed it. I felt relieved, almost like I was getting away with something. I knew it was impossible to escape my health, but in those moments when people didn’t notice any of the things wrong with me, I’d feel like I almost had. I’d always looked to others to tell me

how bad my condition was, doctors, nurses, my parents, the internet. So when someone else treated me as if I was perfectly normal, it almost cancelled out one of the people who had told me otherwise.

“I am sorry to wake you up so early,” Amir said with a louder voice than I’d anticipated him having after his gentle and delicate movements.

“Oh, it’s okay. I’ll probably fall back asleep as soon as you leave.”

“I wish I could do that as well.”

“I’d switch places with you in a second.” His face frowned in sympathy, so I tried to lighten the mood. “Whoever gets the swelling gets the naps. The two come together.”

“And whoever doesn’t have the swelling has to work. Nobody wins.”

“Life sucks for everyone,” I laughed.

“It’s not all bad.”

“I guess. I mean, I could actually be pregnant.” A quiet laugh came out from between the lips of Amir’s smile as he cleaned up the materials he’d set on my bed and put them back in the small white bin he’d come in with.

“They’ll be back in to wake you up around seven for breakfast.”

“What time is it now?”

“Five-thirty.”

I never got to sleep more than a couple hours at a time in hospitals, but I also never had to go more than a couple hours without getting to sleep. My parents and doctors came in that morning and decided on Lasix, a diuretic to make me pee out all the fluid that my skin was stretching to hold. At first it was every five minutes that I’d have

to get up and use the bathroom, but it soon slowed to every half forty-five minutes or so. Hyper aware of the IV catheter in the crook of my arm, I refused to bend or use that arm at all during the process, which made things difficult in the billowing hospital gown I had on. By that afternoon, I felt lighter, but my feet looked exactly the same. So when the final doctor of the day came in, he gave the go ahead to take some more of the medicine.

Amir came in sometime after with an injection for my IV. His twelve hour shift was almost over and he looked exhausted.

“Why do they make you work such long shifts?”

“I have no idea, but at least I don’t have to work through the night.”

“I can’t imagine the nights are fun. But at least most patients are sleeping, right?”

“Patients never sleep. We don’t let them, remember?”

“Oh, shit!” I yelled out, startled. “I feel...my heart.”

“What do you mean?”

“The medicine. It’s weird. But my heart is warmer than the rest of my body and I can feel it...Jeez! It’s a lot bigger than I thought. I swear it’s like I’m touching it, or it’s touching me. This didn’t happen last time.”

“You had the pill form last time. This one is a little different. But does it hurt?”

“No.”

“I think you’re fine.” The large lump in my chest slowly began losing the warmth that had seemingly jolted it to life. I hadn’t even thought about any organ besides my kidneys in months. But to feel the power of my heart, not just the thump of my blood pumping but the violent and rhythmic, mechanical movement of my heart, made me feel

strong for the first time in a while. It made me feel alive.

“So where are you from? I mean, originally?” I didn’t usually ask hospital staff personal questions.

“Pakistan. I moved here when I was 17.”

“Do you like it here?” Amir stopped jotting things down on the clipboard he was holding and looked at me for a moment as if he was deciding whether or not to let this conversation go further. I felt my face start to blush. Maybe I’d pushed things too far.

“It’s...I like it but I miss my home sometimes. It depends on the day.”

“What about today?”

“Today I like it.” We were both quiet for a moment. “Well, I’ll be back in the morning. I think Melissa will be your nurse tonight.”

“Okay. Well, thanks.” He nodded on the way out.

That night was my first chance to really worry about what came next. The swelling was going down, so my mind wasn’t fogged with and numbed by pain like it was earlier. But the swelling was just a symptom of my kidney disease, and, like many symptoms, it was easy to treat. Fixing my kidneys was going to be a whole lot more complicated. Somewhere inside of me I knew that life as I’d known it was going to radically change the next day. I was scared of what it would take to get better, scared of never getting better, of feeling worse. But I was also somewhat scared that I would get better. I knew how to be sick, how to be in pain, and how to be exhausted. But in the short year I’d been sick I’d forgotten how to do anything else. I’d forgotten how to have friends and make conversations with them. I’d forgotten how to spend my free time and

have a life. Learning how to do those things all over again seemed so overwhelming that as much as I knew I wanted to get better and didn't want to spend another second of my life feeling sick, I was also scared. I didn't know what else I could spend my days thinking and caring about. Or if I would ever again be able to care about some of the trivial things normal people have the luxury to care about. The things *I* had cared about before everything was put into a life or death perspective.

Whatever way it went, I felt scared of what was ahead. I had been trying to ignore the doctors since I'd arrived at the hospital. They were always so dramatic about things. For six months they had been discussing chemotherapy, but I always just took that as a threat. If I didn't take my medicine, I'd need chemo. If I didn't slow down and take care of myself, I'd need chemo. But the threats so far had proven empty and I had, for the most part, tried to be healthy. Sure, there were those rare occasions when, in a fit of fury, I would drive to a gas station, buy a pack of cigarettes, and slowly smoke through them as an act of defiance, as a big "fuck you" to my doctors, my Lupus, and myself. But I'd somehow always convinced myself that the medication was working even as my condition deteriorated. I had done that with Prednisone, Imuran, Methotrexate, and Cellcept. I couldn't allow myself to accept that the drugs that had made me violently ill for months on end just simply hadn't worked. I couldn't believe that all that suffering was for nothing.

I knew from the way the doctors talked about it that there was no turning back from chemo. Agreeing to it meant that my case wasn't going to turn around, that it wasn't just going to burn out on its own without a serious chemical rape. Agreeing to it meant I

wasn't okay, that I actually might die unless radical measures were taken. But, relieved of my swelling, there were no extraneous things to distract myself, my family, and my doctors from the issue at hand: my kidneys were going to fail unless something happened fast. Terrified of getting worse, scared of the treatments, and worried about the difficulty of starting over if I got better, there was so much fear surrounding me that it had, almost, pushed me over the edge into fearlessness. If whatever way you turn there's a nightmare, all you can do is say "fuck it" and charge forward blindly, hoping for the best. I was almost at that point, but not knowing what I'd be getting myself into kept me from the blind charging. I didn't know how bad the chemo would make me feel. I'd been sick from medicine from a year. How much worse could nausea get? What memories and scars would I carry the rest of my life? What moments would I never be able to forget?

I remembered a day seven months earlier, when the only doctor I was seeing treated me with large quantities of narcotics, 128 pills a month of Darvocet. My mom had come up to college to visit and was stopped three cars back at a traffic light on the way to pick me up when I began crossing the street in front of her. I was nearly crippled, hobbling so slowly and painfully across the road that the light changed when I was only halfway through. I looked up at the green light to my left and the many cars to my right and kept hobbling across. No one honked. I didn't even realize my mom was in the line of cars, but when she picked me up she looked horrified. At 18 years old, I was rail thin, my joints constantly throbbing and my muscles always aching, and I was losing a ton of my hair. Back at my apartment, I planned to do what I always did after my miserable days at college: stand in my shower until the hot water ran out. The heat of the water and

the steam in the bathroom would ease the pain in my joints and muscles, my main source of Lupus pain back before it moved on to my kidneys. But my mom insisted on making some food first, even when I told her I wasn't hungry. She sat me down at a table with macaroni and cheese and grape juice as if I'd just gotten home from the third grade rather than my freshman year the University of Florida. Despite my ever present nausea and pain, I ate the food until she was satisfied and then, as quickly as I could, got undressed and into the shower while she cleaned up and turned on the news. It was difficult to get into my oversized shower, but on a previous visit she had installed a handle for me to use to get into the high tub. The hot water began to ease my pain, and the shower radio playing pop music distracted my mind from the day's struggles.

My memory sharpened as I remembered what happened next. Suddenly, I'd curled over and began violently throwing up in the shower. Purple stained macaroni, from the grape juice, poured out of me and immediately clogged the drain of the shower. At first, I couldn't stop heaving to turn the water off so the tub began to fill up to my ankles with the macaroni. But when I finally could breathe in between heaves, I began screaming to my mom. The vomiting was so terrible and exhausting to my already weak body that I felt myself getting close to blacking out. I managed to shut the water off and hold onto the edge of the tub, shivering so badly that I almost slipped in my own puke. With everything I had, I screamed for her. I was too weak to move and the colder my wet body got the more I shivered and the more pain my arthritis caused. She didn't hear me. My mom never had good hearing. But right before my legs and arms gave out and I was forced to lay down in my own purple macaroni vomit and wait, she came in to see why I

was screaming. When she saw the mess, she was furious. Why hadn't I gotten out and thrown up in the toilet like a normal person? Why hadn't I started to clean it all up? As she helped me out of the tub, she looked repulsed by me. My feet had macaroni pieces on them and my tears and snot had run together and dripped off my jawline. I looked back the shower, my last safe place ruined.

The event had by no means been the worst of the past year. But for some reason it had stuck with me. Perhaps it's because I really was on the verge of collapsing into my own puke, of completely losing my dignity to rest and recover in my own purple vomit. Every time I flashed back to that moment, watching myself shivering and screaming, the cold seizing my joints and grinding them, my heart would start racing. I was scared of her, of myself, of the girl in the bathtub. It was in moments like that when I saw myself break into two people, the one I knew and the one that scared me. If both of them were me then I wasn't who I thought I was. Would chemo create more moments like that which would further divide and separate me from who I was, from who I thought I was, until I was so unrecognizable that I became lost forever? Would I be trapped in the body of that desperate and scary monster from the bathtub?

By the time the night nurse, Melissa, came to check on me, I was extremely restless. Part of me wanted to run, as fast and as far as I could away from what was coming tomorrow. But the other part of me was afraid to leave. As she introduced herself, Melissa stared at my feet. I could tell she would have really gotten off on seeing how bad they were earlier.

I'd had met nurses like Melissa before. She seemed like the type who had gone

through a six month course to get her certification in hopes of getting job at the hospital and meeting a doctor in three. From the looks of it, that hadn't worked out so well. But even if I was wrong about her past, it was obvious that she hated her job. After giving me my medicine, she condescendingly watched to make sure I swallowed the pills, as if I was going to hoard the medicine under my mattress and trade it for crack later. I passively aggressively took one pill at a time, making sure to take an excruciatingly long time to swallow each one as she waited impatiently.

At some point in the night, I'd bent my arm too much and blew the thin vein in my arm that the catheter had been in. Melissa was so slow in coming to my room that I eventually just pulled the catheter out myself before any more fluid was pumped in my arm. She wasn't happy about that when she came in and saw the blood running onto the sheets, and neither was I. I'd done a bad job of pulling it out and already had a large bruise forming. After roughly putting a new catheter in my hand, she left the room in a huff. Alone, I started to feel uncomfortably hot and my lower back and ass began to ache from being in the same position for so long.

I regretted coming to the hospital. I wanted to go back home to my soft bed where I could watch Michael Phelps and a million other athletes compete in the summer Olympics. The sheets were so warm from my body heat that I couldn't stand it. I tried to kick them off but they were tucked in too tightly around the bed. I knew I wasn't any better for all the poking and prodding and time wasting that had gone on since I'd arrived. I tried to take a deep breath to calm down, but I felt increasingly suffocated by my body, my life and the hospital room.

A month before I was diagnosed with Lupus, I had gone on a three week study abroad trip in Mexico. It was shortly before my 18th birthday and a present from my parents for graduating high school with enough dual enrollment credits to start college as a junior. We were all hung-over, the ten or so of us that had hiked two miles through the rainforest to see a massive waterfall. Dripping in sweat, we'd jumped in the river farther downstream to rinse off. While everyone laughed and splashed around, a current pulled me up and over a ledge and rolled me down twenty feet of rocks. We didn't realize there was a smaller waterfall because it couldn't be seen from where we'd gone in. I scratched and clawed at the rocks the whole way down, trying to get any one of my extremities hooked or snagged on something before I fell any farther. But the current was so strong that eventually I had to let go, hold my head, and pray I didn't get knocked unconscious. When I hit the water, the roar of the current disappeared. I was deep underwater and disoriented with no air in my lungs. And then the small bubbles from beneath me, created by my fall, began to move through the turquoise water. I followed them to the surface, breaking the silence and gasping for air only to realize the current was pulling me still farther to who knew what other drops were downstream. I swam fiercely to the side of the bank and began wildly throwing my arms up towards the thin branches from the plants that hung over the river. When I finally got out of the water, I was pretty banged up and bleeding all over, but I felt powerful and alive in a way I never had since. A year later, things hadn't changed. I was still suffocating, if not from my life than from the fluid that never failed to return.

I wondered then in my bed why I had survived. I wondered how it was possible

that every part of my body had been banged up except for my head. I wondered what I would have said, standing on the bank of the river, a wild Amazon, if someone had shown me a picture of myself on this night in the hospital, swollen and defeated, just one summer later. I could tell I was starting to get too far into my own head, so I decided to focus my attention on the TV. It was the first time I'd turned it on since I'd arrived, and I hoped that maybe the Olympics would be on. Sure enough, they were, but here in the hospital the noise after hours or quiet aggravated me until finally I shut the TV off and threw the clicker down the bed, accidentally hitting my right foot. Fuck me. I counted to forty-five until the pain began to subside.

Around 9pm my parents came with a bag of food from McDonald's. Because of my kidney problems, I had been put on a low sodium free diet, allowing me only the worst options on the hospital food menus. My mom felt guilty passing the bag over to me, but at the same time she felt bad for me. In two minutes, I ate more salt than a normal person was probably supposed to eat in three days. Melissa came in at one point, saw me with several French fries halfway in my mouth, and gave me a dirty look before walking out. Small victories.

"I think they're going to want to start Cytoxan tomorrow," my dad said gently after I'd finished eating. I guess he wasn't sure if I knew that it was all happening that fast. "The doctors here think it's a good idea and a few weeks ago we even got that second opinion in Charleston. Everybody seems to be on board. I wish we had more time to think about it all, but it doesn't look like we have that option anymore."

"What are we going to do about my eggs?" I looked over at my mom. She was

always skeptical of doctors, convinced that her extensive time spent on WebMD made her better qualified to make decisions about my health than anyone. Her greatest qualm with me undergoing Cytoxan, the chemo drug they wanted me take, was the risk of losing my fertility by destroying all of my eggs. Personally, I felt detached from the whole thing. I didn't believe I was ever going to date again, let alone get married and have kids. It wasn't like I had the best genes to pass on to the next generation anyway. I really just wanted whatever instant gratification I could get. I'd take anything that made me feel better now. But my mom felt that preserving my fertility was as important as preserving my life and, surprisingly, the doctors came up with something that might help: menopause. By giving me injections for prostate cancer, I could be put into a chemically induced menopause which, as the doctors described it, would "hopefully preserve my eggs." Other doctors suggested having my eggs removed and stored, but noted that there were better chances of success if the eggs were fertilized. So far Lupus had left my vagina alone, and I wanted to keep it that way. Plus, removing my eggs with a needle and freezing them sounded like something out of a science fiction movie. Once my dad had said, "maybe you should just leave it in God's hands." He must not have known what to say, because I gave him a weird look and my mom yelled at him for being an idiot. Ultimately, we'd made no decision and we were running out of time.

"I just don't think you should do any of this. I think if you just come home and rest..."

"Dad, what do you think?"

"I think the egg freezing thing is just too out there. And the doctors all seem to

recommend this menopause thing. You'll just get, you know, hot all the time. Like your mom."

"I am not hot all the time! And it's more complicated than that, Joe. It's not just getting hot." My mom was suddenly furious, but we all knew it had nothing to do with the comment about her being in menopause.

"All right. Whatever," I knew it was like all the other discussions we'd had. The doctors would tell us what I needed to do and my family and I pretended those things were options to be discussed. I didn't have options, and I was just finally beginning to realize that.

It was often those days that I'd want to check out in the middle of conversations with my parents. We only had one thing to talk about: Lupus. And if we didn't talk about Lupus there would be nothing left. We wouldn't talk about my life because I didn't have one and we certainly didn't talk about my plans anymore. I didn't talk about my next trip. I was always talking about my next trip whether it was a weekend away or a long vacation abroad before I got sick. I loved to travel. But it had been a while now since I'd made any plans like that. We couldn't even discuss anything going on in the world either. None of the news seemed relevant because our worlds had stopped. Even when we were in good moods we talked about Lupus. I'd talk about how, before the swelling, I was the thinnest I'd ever been and about the size zero jeans I couldn't wait to fit into again. We would evaluate my doctors' personalities and rank them by compassion, intelligence, and access to cutting edge research. Very often we'd have the same conversation and repeat the same stories.

And normally it was all somewhat tolerable. But the closer I got to taking Cytoxan the less we could even pretend that things were okay. We didn't have anything left to talk about, and as the conversation veered off to the dog and trying to remember who had let her outside last, I starting wanting them to leave. Nothing they could say would make anything better and I was tired of dragging a heavy horse carcass around with me everywhere I went just so we could beat it whenever we opened our mouths. There was nothing left to be said and I didn't feel like talking about the dog. But the moment they were gone, I wanted them to come back. The loneliness was overwhelming and the silence of the hospital started to give me the creeps. I thought I could hear all the bodies around me breathing, each and every person trying to keep their body functioning despite whatever ailment was trying to take over. How many people would win that fight? How many people would stop breathing that night? I cried because I couldn't scream. And then I cried because it was pathetic that I was crying. And then I fell asleep.

I woke up to the bright fluorescent lights above my head feeling, for the first time in a while, well rested. I appreciated the silence and the darkness outside the window. The sheets didn't feel suffocating anymore. Rather, they were comfortable and warm, protecting me from the cold air conditioning that must have filled my room while I was sleeping. I felt Amir's cold fingers on my arm as he delicately put my blood pressure cuff on.

"Another day," he sighed.

"Eh, they all run together."

"I suppose you're right. My son doesn't sleep through the night yet, so my wife

and I don't sleep at night. It makes it seem like the days never end."

"Kids. Are they all they're cracked up to be?"

"It's not a good time to ask me at 5:30 in the morning when I am just starting a 12 hour shift after no sleep."

"Ha."

"But without kids, what is there?"

"What happened to your IV?"

"Oh, long story. I mean, it's not really a long story. My vein blew and I ripped it out."

"If you're going to take it out yourself, you have to do it right. Always push down. Otherwise you end up with...that."

"I'll keep that in mind next time." We were quiet for a moment while he did his routine check up on me. I felt comfortable in the silence, comfortable enough to say, "I think today's gonna be the big day. I think today they're gonna start chemo. What do you know about all that?"

"About what?"

"About chemo?"

"I know they have really strong anti-nausea medications now and they give them before you even get the chemo."

"So it's not that bad," I looked away from Amir. I was really trying to convince myself. "I mean, this is doable. I can do this. I mean, people do this all the time."

"All the time," Amir collected his things and headed to the door. "All the time,"

he reassured me on the way out.

The next time I was woken up, it was daylight and Doctor Watters stood in the room with my parents. It felt weird seeing him outside of his office. He looked all professional in his white coat and intimidating standing over me. I'd always talked to him face to face in his office before. But wearing a hospital gown in bed with my greasy hair made me feel embarrassed, like I'd shown up underdressed to a business meeting. Doctor Watters paced around the room reading my latest blood work as we watched in silence. I remembered the first time I'd seen him, six months after I was diagnosed and left untreated by the doctor who had prescribed me pain killers. My were throbbing and my muscles aching as I sat hunched over on an examining table, only able to think about my breathing and dread the journey it would be for me to get from where I was to the car. His first words to me were, "You are very, very, very, very, very sick." And from that moment on he was my favorite doctor, the only one to acknowledge that something seriously fucked up was going on with my body after all those months of people brushing it off as nothing. I trusted him with my whole heart. I knew he wouldn't lead me somewhere I couldn't handle and he'd stop me from deteriorating into nothing. When he finally looked up at me, I was already staring at him in anticipation.

"As you know, you're very, very sick." I laughed. "I know they decided up at the University of Florida that Cytosan was the best choice and then in Charleston the best Lupus doctors in the world said the same. So I think that's the next step. Now, did you talk to another doctor about the fertility issue?"

"I think I'm going to do the Lupron injections."

“Okay. Well, ideally we would have done that a few weeks ago to get a head start, but we’ll have to do it today before you start the Cytosan.”

“All right,” was the only answer I could give. My dad just nodded along. We knew my situation had been heading down this road for a while. It was just that we’d expected more time to prepare for it, to talk about it, to pretend it was just a possibly and not the only option. But coming to hospital had expedited the whole thing. It exposed my swollen body to the doctors and allowed the hospital the freedom to read the truths that were tattooed on my blood. Now there was no more time, no chance for me to go home and relax and hope that maybe the next day it would go away.

I don’t know why I thought Dr. Watters would be there as they set up the treatment. There was nothing he could do for me and a million things he had to do that day. But as I watched him walk out of the door, leaving me to face my fate alone, I felt uneasy.

It took about an hour for Amir to come in with a plastic bag full of clear liquid. I expected something more...green. With a skull and cross bones.

“Is that...it?” I asked. I wanted to touch it. The bag. Maybe even smell it.

“No. This is just anti-nausea. I’ve got to give you the Lupron injection in your hip, too.”

“Oh, okay.” I felt weird exposing my hip to Amir. We were friends and friends didn’t pull aside their hospital gown to expose themselves to each other. My body relaxed as he carefully gave me the injection and then lifted my hand by my fingers to examine the catheter in my hand.

“Your hand doesn’t look so good.”

“It doesn’t feel good either. I think Melissa screwed up the IV.”

“Let me try a flush.” Amir pulled out a syringe from the pocket of his scrubs and attempted to push the water through the catheter.

“Ouch,” I said nonchalantly.

“Vein is blown.” I watched the water in my hand swell up my blown vein and then slowly disappear somewhere into my hand.

“My veins are really crappy from the medicine I’ve been taking.”

“I’ve noticed.” He carefully lifted each of my arms and examined them. “I’m going to have to put one in your wrist.”

“My wrist?!” I’d never had one in my wrist before. “No. There’s gotta be another spot.”

“Nope, you’re all out of other spots.” Looking at my wrist, I started to panic. There were so many bones. I imagined the needle slipping in between all the small joints and getting crunched by them into a million splintered pieces. And I couldn’t see a vein at all, but I knew it was under thicker skin than in the other spots IVs were normally put in.

Like my mom with the menopause, I wasn’t really worried about the wrist. It was an IV catheter, no big deal, in a spot I hadn’t had one before. But it was going to be the catheter the chemo was put through. It had to be right.

“I think my other arm is good.” I nodded repeatedly, trying to seem confident.

“Trust me, I’m good at this.” I looked carefully around Amir. His half smile was confident and the air around him seemed calm. It was contagious.

“Okay...” The moment my permission was given he tied a blue string of rubber tightly around my forearm and I almost immediately began losing circulation in my hand. Then he squeezed my wrist with more force than I’d seen him do anything and in half a second had the catheter in. When it was over with he’d done such a good job that I didn’t even feel the thin plastic tube hanging inside my vein. Knowing the chemo would go through there made me feel better about it.

When he left the room, I watched the anti-nausea drip from the IV bag. It was so crazy to me that a bag of clear liquid could change a person. I suppose vodka should have been proof enough. But this small bag of fluid was going to prevent me from getting sick, or at least, prevent me from getting too sick. It made me wonder how much control we really have over ourselves, if we’re that easily altered by things. I was only myself if nothing touched me and it was impossible to live life, even if I was healthy, with nothing ever touching me or affecting me in some way. What percentage of our lives, I wondered, do we actually spend in a pure state of ourselves? Probably not much, and yet we still identify with that idea of who we are.

I’d never been able to prepare myself for medication before, though, so I definitely wasn’t complaining about the drug making me some alternate version of myself. Every morning I usually shoveled a handful of pills into my mouth and then waited first twenty minutes for the overwhelming feeling of nausea to come over me and then two or three hours for it to smolder down to a tolerable level. Looking up at the clear fluid, I felt confident that I could take whatever came next.

What came next was a larger bag of liquid.

“No worries, this is just prednisone. It’s just like the steroids you take every day but in a liquid form.”

“Why do I have to take that?”

“A lot of patients get this along with their chemo. It won’t make you sick.” I had been taking prednisone on and off for a year and I didn’t handle it very well. It affected my mind, which no one felt was significant enough to stop treating me with it. The steroids made me incredibly anxious all of the time and extremely emotional. Whatever I was feeling, there were no degrees to it. When I was frustrated, I was enraged. And when I was disappointed, I was devastated. I often felt suicidal from the medication, but I was usually too angry in those moments to get collected enough to go through with it or so sad that the feeling would shift to indifference. I had tried before to discuss it, despite my shame, with a few of my doctors. But the results were more prescriptions and the suggestion that I see a psychologist.

And whenever someone suggested I see a psychologist, I’d be furious. Italian families don’t believe in psychologists. It was a “first world problem,” in my opinion, to pay someone to sit and listen to me complain about my life. If you had enough money to pay someone to do that, you were better off than most people in the world, and if the only person that would listen to your crap is someone you’re paying, than you’d be better off spending your time repairing whatever bridges you burned or work to build new ones with different people. That was how I saw it. My mom saw any suggestion of seeing a psychologist as offensive, as an accusation of insanity and a sign of weakness, an inability to deal with your own problems. We both felt that going to a psychologist meant

an acknowledgement of a loss of control over ourselves. Clearly I'd lost control over my body, and I'd be damned if I lost control over my mind.

My first semester of college, while grossly anxious and neurotic from just starting on the steroids (Prednisone) that no one had told me had cognitive side effects, I went to the school clinic over a cold and was interrogated about my Lupus. The doctor suggested I see a psychologist, and, because it was the first time anyone had ever suggested that, I figured I'd give it a try. I didn't realize until I got there that I'd been sent for a possible eating disorder. I was so incredibly insulted that all my problems were reduced to me being too OCD about my vanity that I swore I would never go back. To expose the whole system for its bullshit, I faked my way through fifteen minutes, despite my anxiousness from the meds, and convinced the psychologist that I was perfectly stable. She wrote back to the original doctor saying I was dealing with my health issues very well. I knew from that day forward, I'd dealt with whatever I classified as a "mental issue" alone.

I tried to develop techniques to calm myself down and convince myself that it was just the medicine making me feel a certain way, but in the back of my mind I knew I had very little control over how I'd feel. My struggle was like Marvel's Hulk. Once I started to feel an emotion take hold, I couldn't stop it from escalating to the point that it consumed me. But the worst part of the medicine was the withdrawals whenever my doses were changed, which was often. If they were lowered, I'd absolutely lose my mind until my body stabilized with the new dosage. I stared at the bag of liquid crazy, knowing whatever came next wasn't going to be good and when the day came to lower the dosage it'd be a nightmare.

“How many milligrams is that?” I had been taking 64 milligrams a day for the last few weeks and I was seriously struggling with that. I knew the IV would be more.

“It’s 1000. A gram,” Amir said as he plugged the clear tubing into my wrist and I watched what looked like water flow into my body. All I could do was lie back and wait for it to happen, for the radical shift in my personality that I’d never be able to control.

But whatever transformation I was waiting for, I didn’t see it happen. Instead, I fell asleep. My bloated body, not only swollen from my kidneys not working properly but also from all the liquid being pumped into my veins, weighed me down into the bed and pressed on my eyes and mind to sleep.

I was awoken with a loud bang as a nurse I’d never seen before swung open the door to my room and rolled in a cart. Amir came in behind her with a stack of blue papers. Ignoring me, Amir gave the other nurse half the stack and then began unfolding the sheets he had until I could tell they were paper clothes. The two nurses wore paper pants, shirts, shoes and hats before putting on their masks and approaching. Standing over me, the two nurses made me extremely nervous. I felt my skin get hot and my heart race. The silence was making me squirm.

“What is your name?” The nurse I didn’t recognize asked. I looked over to Amir. Did I really need to introduce myself?

“Jeanette.” She continued to stare. “Moffa. Jeanette Moffa.”

“Name!” she ordered Amir.

“Jeanette Moffa,” Amir read off the IV bag he held in his gloved hands. The nurse grabbed my wrist and read the bracelet with my information on it that I’d been wearing

since I was admitted. I looked over at Amir, but he never once looked up from the bag in his hands.

“Jeanette Moffa,” she reaffirmed. “Date of birth?” she ordered. Put on the spot, I forgot for a second before answering.

“Uh, 7-7-89.”

“7-7-89,” Amir read off the IV bag. Why wasn’t he looking at me? Was he tired from not sleeping last night?

“7-7-89,” the nurse read off my wristband. Dropping the bracelet she’d been holding my wrist up by, the nurse walked to the front of the bed and began reading a pamphlet to Amir and he began hooking up the relatively small bag of Cytoxan to my IV. His hands were just as gentle as before, but he didn’t look at me while he did any of it. Even his face was farther away, like I smelled bad, and his arm was more extended to keep a greater separation between us as if I was dirty. His relaxed personality was gone and replaced with a stone cold stranger. I wanted to ask him a question about something unrelated, like his family, or hell, even the weather. But I was too scared to. I felt my heart racing and the words “lethal injection” flashed through my mind. Was this what people on death row felt like? Did no one look at them, or want to touch them? Did they feel this dirty? This less human?

I broke into a cold sweat as I watched the liquid, clear like all the others, fall down the tubing and disappear into my wrist, as if my wrist had all the storage room in the world for all the liquids they wanted to put in there. I felt the instinct to rip the tube out before the poison entered it, but I was frozen in fear. Just as abruptly as they came in,

Amir and the other nurse disappeared and I was left waiting to feel something happen.

I expected a burn, or to feel my heart on fire like I had with the Lasix. I expected to feel so nauseated in every part of my body that I wanted to vomit out of my pores and my veins rather than my mouth. I couldn't calm down and I struggled to breathe in my panic. The waiting continued until it exhausted me, leaving me completely drained.

I wouldn't allow myself to fall back asleep until it was over. Amir came in to get the bag and asked how I was doing. His tone was still different, as if I was someone else, maybe a child, or maybe a dog. I said I was fine and looked away, refusing to glance up as he left the room. I woke up a little later when my parents came in. I felt pretty well rested, but they were shocked when I asked for something to eat. I was hungry, but not just hungry. I was *starving*. And after what felt like a long nap, I wasn't tired at all. In fact, I was more energetic than I'd been since I could remember.

My parents found all of this extremely alarming. They encouraged me not to eat too much, expecting every bite I ate to be thrown up shortly after. They wanted me to rest more, but all I wanted to do was get out of my bed and pace around the small hospital room. I was itching to get out of there and suddenly very irritated by the fact that I hadn't showered since I'd arrive two days earlier. I was angry at Amir, for what I didn't exactly know. Perhaps for scaring the shit out of me. For wearing those paper clothes as if I was contagious. For being one of *them*.

The last time Amir came in, I stared at him from the moment he entered to the moment he left. He still wasn't looking at me. I wanted to scream at him, to demand he look at me and acknowledge me. I wanted, so badly, for him to talk about the weather,

about any of the many generic things people discuss in small talk. I didn't understand how the chemo had changed all that. It was like it had taken away my person status, that the drug had made me an untouchable, a mutant, or even contagious both in a physical and karmic way. I wanted to tell Amir that I was the same person I was before. The identity I'd been so confused about, that felt so fractured by past experiences –I'd take it. That was me! I visualized myself calling after him as he left, tears streaming down my cheeks, yelling out "I'm the same! I'm the same person!" But the person I saw doing the yelling was same girl covered in purple macaroni vomit, another splinter, another scary version of myself. Another step away from who I thought I was and towards who I was scared to become. As Amir walked out of the door, I gripped onto both railings of my bed, refusing to take that step, refusing to move even an inch away from where I'd been before the treatment.

II.

That summer my mom began renovations on our house. It started when my dad asked his friend if he could hire out one of his workers for a few days to fix a leak in the roof. But from the moment Claudio stepped foot in the house, my mom had bigger plans for him. First she wanted to fix up my brother and my side of the house. She wanted the walls repainted, the old popcorn ceiling scraped off and repainted, wooden floors in the rooms and new fixtures in each of our bathrooms. She also wanted to close off my brother's bathroom to the hallway that connected our rooms and create a new door so that the entrance was through his bedroom. And that was just phase one.

I'd spent a lot of time that summer hearing Claudio banging away in my brother's room, where he started. My brother, meanwhile, had moved all his things in the living room and chose to spend most of his time out with friends to avoid the mess. I was glad I didn't have to hear his late night video games, but the incessant banging was already starting to get to me before I'd even gone to the hospital. Stuck like a bloated frog in my bed, I'd turn the volume on the TV to its maximum level so I could hear the announcers reading the names of the Olympic competitors. I liked to hear all the different names. Shericka, Hasna, Yuliya.

But since my return from the hospital, I had barely gotten to watch any of the Olympics. Everyday my mom demanded that I come with her to run some sort of errands

whether we were going to the market for groceries, or Target for hand soap, or Costco for paper towels. My least favorite would be when we went to a hardware store like Home Depot or Lowes, where she'd carry around some obscure sort of object that needed replacing and go up and down every aisle searching for it. My mom always had to go up every single aisle in the stores we went to. A few years later, after she stopped bringing me along with her, I'd start doing the same thing. And now today I can't buy a new tube of toothpaste without spending two hours in a store going to every department from children's toys to lawn care. But those days, like the many before it and many more to come, I felt terrible.

The energy I'd felt after my chemo had remained, but it was only in my head. Mentally, I felt like I could run all day, but physically my body dragged. It made me very bored watching my body move at such a slow pace and I was extremely bored with the errands we ran. It didn't take me long to realize that only a small percentage of them were necessary and most of them were altogether made up. I often would stand uncomfortably, trying to equally balance my weight between both swollen feet and watch as she unloaded her cart onto the conveyor belt in the check-out line with random things she insisted she needed. Many times she would throw a pair of shorts or a shirt into the cart without even trying it on, just so she could make me come back the next day with her to return it.

I don't know why I allowed myself to be bossed around, especially when I, myself, am bossy. It might have been because in the back of my head, I knew she was right, even if that was clouded by a deep resentment of what I saw as her tough love.

There were no excuses I could make for staying at home when she got it in her head that I was going with her on a particular errand. Even on the days when my swelling was especially bad, when the Lasix diuretic pills they'd given me at the hospital didn't seem to work, and the added water weight exhausted my whole body and prevented me from fitting into any of my clothes, she would find a way to make me go even if it meant spending more time finding clothes to fit me than the whole errand itself would have taken. It didn't bother my mom that the only things that would fit me were large muumuu dresses from the back of her closet that she'd only ever used as beach cover ups. Almost all of them had large, Hawaiian floral print in bright tropical colors. I would complain. In fact, I would pitch a fit. But my mom has never given up on anything in her life and there was no winning against her determination.

On one such day when I was forced to wear the muumuu dress, my mom dropped me off at the front doors of Target while she parked and I wandered inside to get an electric wheelchair. I called days when I needed a wheelchair to get through a store "one of those days," and hated every single one of them. After the first few, I'd realized how poorly accommodated handicap people were in most businesses. Many stores only had two electric wheelchairs, and at most they had five. The older the electric chair was, the less time it held a charge. There ideally would be an employee at the front of the store to assist in getting one of the chairs and then, upon its return, make sure they were plugged in to keep charging, but most of the time that wasn't the case. Instead, that day I had to find an employee and ask if he could drag one out for me.

"None of them are really charged," the guy shrugged underneath his red t-shirt

and name tag. “But that one over there is probably the best,” he added encouragingly. He dramatically dragged the heavy chair out in a wide circle, waited for me in a my fuzzy slippers and floral print house dress to sit before turning the machine on and then disappearing. By that time, my mom had arrived and as we started up the first aisle, women’s clothes, I started to feel better looking around at all the different designs and bright summer colors. On a three foot advertisement, a gorgeous, thin model flashed a carefree smile behind her as she ran through sand wearing a tiny yellow bikini. Her long blonde hair grazed her tan shoulders as it blew in the ocean breeze. She was perfect.

I was so happy for her. When someone gets that lucky, when all the good things in the world align in them, it’s a win for humanity as a whole, a triumph over evil. I wanted a friend like her, someone who was beautiful and fun and lived only the very best parts of life. She could come over and tell me all about the friends and guys in her life as I’d listen carefully to the gossip and give her the best advice I could. She would say something funny and smile that big smile from the advertisement as I doubled over laughing. She’d invite me to parties and barbeques and the movies and the beach. She’d always take my side against the world and maybe even, with her amazing luck, force fate in my favor once in a while and help me beat my disease.

The cart slowed dramatically. I fidgeted with the buttons, then the handle, and finally the lever for speed, but it slowed even more, going so slow I was barely moving, until it stopped. I looked behind me at the entrance of the store. It was probably fifty or sixty steps away. I felt like I’d swam too far out in the ocean and didn’t know if I’d be able to make it back.

“Mom?” She didn’t notice my call and kept strolling ahead while looking off in the opposite direction at the clothes. “Mom...Mom!” I was so tired of her bad hearing. There were people around me and I didn’t want them to realize my wheelchair battery had died. I pretended to fidget with a sweater than hung on the rack next to me, but she continued to get farther and farther away. “MOM!!!” I finally yelled. She turned around as if she thought she’d heard just the faintest whisper. Now people looked directly at me and my face flushed.

“What’s the matter?”

“It won’t move.”

“Try it again.” I pressed the button to turn it on and the lights actually flashed, but when I pressed the accelerator, it inched forward slower than a snail and then shut off again about two centimeters later.

“This is ridiculous.”

“I can’t drag this thing. It’s too heavy.”

“What do we do?” Neither of us was sure.

“Abandon ship?” I suggested. We both started laughing for a moment before I tried to quickly removed myself from the chair and leave it behind, like a shopper at the grocery store deciding last minute they shouldn’t eat that quart of ice cream in their cart and leaving it instead on a shelf in the isle they’re in. But I clumsy and slow, and when I did get out of the cart, my feet’s puffiness immediately began affecting my balance so it was all I could to do stand there and wait while my mom disappeared to get another wheelchair.

Five minutes later, I watched the same Target employee from before dragging a second wheelchair down the center of the aisle towards me with a disgruntled look on his face while my mom followed behind. I was embarrassed as he watched me awkwardly get into the new cart. I could tell he thought I was just obese, another fat American too lazy to walk around. Not a girl that didn't feel well. A thing.

When the cart turned on, he took the other and dragged it quickly behind him. It made a loud noise as the locked tires squeaked across the linoleum. I was so embarrassed. Only a few shoppers had witnessed the wheelchair exchange, but I looked up at the cameras all over the ceiling and imagined several security guards pointing at a black and white screen and laughing.

I'd gone roughly another twenty feet further when the second wheelchair shut off. *Are you kidding me?* I thought. Pissed off, I stood up and left the wheelchair where it was in the middle of an aisle and decided to just endure the pain and hobble along behind my mom. My anger took the edge off the pain, but not for long. By the time I made it to very heart of the store, it was so intolerable I couldn't take another step.

"This is crazy. Let me go get someone again," my mom looked around the intersection of aisles we were in. We both saw the guy stocking shelves at the same moment. I was about to yell "no" to my mom, but she'd already gotten his attention before I could even open my mouth. The guy was hot in that scruffy, laid back, I-play-guitar-but-don't-sing-in-my-band sort of way. He seemed shy but nice as my mom told him about the carts. Not told, yelled. My mom yelled about the wheelchairs to this scared and seriously cute guy while I stared at my blue fluffy shoes, bright and new after I'd had

to throw the old pair out, and felt my face light on fire in embarrassment.

The guy had no idea about the wheelchairs. It was painfully obvious from the moment my mom had said the word. He stuttered and apologized for not knowing but offered that someone at the front of the store could probably help.

“She can’t walk to the front. That’s why she needs the wheelchair!” My mom was fed up, and I would have been too if I wasn’t so mortified. “Wait here! I’ll find one myself!” My mom disappeared, storming up to the front of the store and leaving me to stand alone with the guy. He wasn’t sure if she’d told him to wait there or if it was directed at me, so he just kind of lingered a few feet away and stared at his own feet.

“So far I’ve had two carts and they’ve died on me. I had to just abandon one in the middle of the store,” I said, trying to laugh about it.

“I’m sorry,” the guy said professionally. “There are others at the front.” He looked at me but never really in my eyes. I wanted to tell him he didn’t have to wait, but it seemed too awful to acknowledge that he was just standing around because he didn’t know if I could be left alone or not and he wasn’t willing to risk my mom’s fury to find out.

It took almost ten minutes for my mom to come back, and when she did she had a cart with an attachment in the front for small children that was in the shape of a red plastic car and had two stools inside for toddlers to sit on.

“They don’t have any wheelchairs,” she announced. I looked at the cart, and then back at the guy and then desperately at my mom. *You’ve got to be kidding me*, I pleaded.

“You know that’s for kids, right? I won’t fit in there.” I hoped she would say this

was *her* cart and someone else was bringing me a new wheelchair.

“Oh, sure you will.” The guy stood there watching as I crawled through the small opening and sat my large ass across both stools in the cart. I don’t know why I didn’t stick up for myself and refuse to get in there. Maybe it was sheer exhaustion. My legs were too long to fit inside, so my fluffy shoes hung out and dragged on the floor. If I’d known how uncomfortable it was going to be, or how ridiculous I would look with my feet sticking out, I might have fought harder. Or maybe I would have just killed myself before she got back. But once I was inside, I knew I was never going to get out without some serious help. At that moment, a group of girls my age walked by loudly talking and laughing about something they’d done together recently. The guy that had been standing with me looked over to check them out.

“This will work,” my mom said determinedly as she gave the guy a look and began walking away.

“If I don’t lose forty pounds of this water weight tomorrow, I’m going to the hospital! I’m tired of being so swollen!” I yelled out, hoping the guy would hear. I felt like I had to explain myself and prove that this was just today and not my whole life. The guy looked up, saw I was staring right at him, and laughed. It wasn’t malicious. But it hurt none the less. I don’t know what I expected or even would have wanted. Was it for him to agree? Be furious at my doctors? Sympathize with my disease by telling me about his grandma’s kidney problems? There was no right response but a million wrong ones. And I felt stupid for opening my mouth in the first place.

My mom had plans of continuing our shopping trip up and down the aisles. When

we ran into the girls again, they noticed me this time and ceased all conversation to stare. After that, I demanded we leave. My mom walked me near the front of the store and then, in a deserted aisle, helped me get out. If someone were to have looked up the sleeve of either side of my muumuu dress as I awkwardly climbed out of the cart, they could have easily seen my breasts. I definitely wasn't wearing a bra. But no one was looking and no one would have wanted to anyway.

I did not leave the house for days, even when my mom began to bring Claudio into my room to talk about what would be done in there. At first he would nod to me in my bed with a wave and "hello", but then when he started having to come in without my mom, he felt too awkward to even acknowledge me. Instead he just kept his head down and took whatever measurement he needed as quickly as possible. He knew me as Cathy's very sick daughter, and above all else he didn't want to be there when I croaked.

Soon enough the construction moved to my room, and my mom, with the help of my dad, brother and Claudio, began moving everything from it out into the living room. Luckily, about half of my belongings were still in my apartment four and half hours away. But with all the furniture moving it still took a little while to get everything out of the room and organized into a rectangle around my bed the far corner of the living room. I was furious about the whole thing. All I wanted was to hide in my room forever, and that was being taken away from me. Even as the stuff began to tower up over the bed on all sides, I could still be easily seen sleeping in there by anyone that walked by. I had no privacy.

But it was my bed after all, so I continued to spend most of my days there in what

I'd decided to name my "nest." My mom had been hoping I'd hate it so much I'd want to spend more of my time outside the house, but every time she suggested I go with her somewhere I either ignored or exploded in anger at her. When my dad would come home from work he'd say it wasn't good for me to lie in bed all day but remind me that all of this was "temporary," as if that would make me feel better enough that I'd become motivated to get out of bed.

It was the steroids that really prevented me from getting out of the depression I'd started feeling. My mind would relive the last year over and over, sometimes getting so lost in it all I'd forget that it was in the past. Perhaps that was why I could never get over the things that happened, never put them behind me. Instead, they just piled up, one sorrow after another until the list was so high that I couldn't see over it into the future. When I looked in the mirror, all I saw was the list.

Until I saw something else. One of the side effects of the steroids was called "moon face," or, as I called it, "chipmunk cheeks." For whatever reason, prednisone redistributed fat in the body from its typical locations and moved it to the cheek area of the face. The movement quickly began changing my appearance and would continue to do so until I was unrecognizable. Whatever few features I had found attractive and healthy looking in myself were disappearing and replaced with abnormalities like massively large cheeks and marshmallow feet. I didn't want to go out and be looked at like I had in Target. I didn't want to be an "it."

So I came up with my own errand. The day of our neighbor's funeral, I decided to buy a wig from a kiosk I'd once seen in a mall by my house. It was the only place I had

ever seen wigs that weren't from a costume store or glued to the plastic scalp of a manikin. I figured a wig would give me a healthier look and the long, thick hair would hide my cheeks. I was determined to show up at the funeral, where most of my neighbors would be whispering about whether or not I was next to croak, looking the most alive I possibly could.

“Do you really need one?” My mom had asked me as we rode the escalator up from the parking garage at the Galleria Mall. Buying a wig seemed so *cancery*.

“Yes.” I sounded sure, but the truth was I didn't know if I really did. The doctors, in their usual manner of speaking, had given me the impression that I might or might not lose some or all of my hair. It was a brutally hot, South Florida summer and the mall was somewhat crowded with bored and broke teenagers and lethargic old people looking to stay cool and entertained until early bird specials began. Everyone was moving incredibly slow and listlessly, except my mom.

“I'm pretty sure that place moved a long time ago,” she announced from where she'd stopped about 20 feet ahead of me. She had no idea, no idea about the place or wigs or the whole chemotherapy thing and whether or not buying a wig would mean my hair, for sure, would fall out. I saw the store. It was just a few kiosks down from where my mom was standing and she would have seen it if she'd bothered to look. A foam head with gorgeous blonde hair was staring down at me from the top of a display case. The kiosk in front of it was an Auntie Ann's. It was still three hours until the early bird specials began and the distinct buttery smell of hand rolled pretzels was hard to resist. A long line extended out from the cash register, leaving a few people at the end close

enough to the wigs to touch them.

“It’s right across from the swimsuit store! See it?” I pointed. She did not look where I was pointing.

“No,” she immediately responded. Then she looked. “Oh, I guess it is still there.” We walked side by side past a kiosk selling dog clothes, and then the pretzels before approaching the blonde wig. The kiosk was a lot larger than I had remembered and nearly three times the size of any other around. A square of glass cases modeled wigs and hair extensions on foam heads, marking off a center area where customers, two at a time, could sit and try on different hair pieces with the assistance of an enthusiastic woman wearing tight clothes, heels, perfect makeup and long, red acrylic nails.

My mom and I split up and she made her way around the cases, looking at long and short wigs ranging from black to bleached blonde. I remained where I was and examined the blonde one. It was the sort of blonde that would blend in perfectly with the sands that were about a mile east of us, light and pale without the bottled bleach look. Highlights and layers gave it an authenticity. It looked real even on the foam head. I knew that one would look good on. I wanted to reach out and touch it. Did it feel like hair? The woman with red nails was suddenly standing next to me.

“I can help you?” She loudly announced her presence in a thick Hispanic accent, her voice piercing through the white noise of the mall and causing me to instantaneously jerk my arm down and back to my side.

“I…” I couldn’t determine what sort of look she was giving me, but I was convinced she was either mad I tried to touch the wig or wondering what a nineteen year

old was doing at her kiosk that clearly, from the photographs of models placed intermittently between the wigs, was geared for middle aged and older women. “My hair is falling out?” I asked and immediately blushed. I hadn’t meant to *ask*. The woman cocked her head to the side, threw her manicured hands to her waist, and lost eye contact with me to look at my hair, which was in a ponytail at the back of my head.

I waited for her to tell me that her kiosk was not for playing dress up. Instead she said, “so, you want wig?”

“Yes.”

“You like that one?” She nodded towards the blonde wig that I had already forgotten about. I looked up at it, the highlights looked natural blending in almost unnoticeably with the rest of the hair.

“Yes.”

“You try on. Come here.” She left the wig, perfectly tousled, on the foam head above us, not giving it a second look as she motioned for me to come inside the space blocked off by the cases and towards one of the rotating chairs in the middle. “Sit there. I find it.”

I sat in the chair and looked out over the shorter cases at my mom. She was intensely contemplating something she saw in the case, a deep wrinkle running across her forehead. I tried to call her, but of course she didn’t hear me. Or was she ignoring me? I never could tell. Either way I gave up on the third try, slid my butt back from the edge of the chair and rested my purse on my thighs, wrapping and unwrapping the shoulder strap around my index finger.

I avoided looking in the mirror as my reflection avoided my eyes. I wanted to get a wig, but I didn't want to admit to myself, to the girl in the mirror, that I needed one. Instead, I looked to my right and watched the woman open a drawer hidden behind one of the tall display cases and flip through an unorganized pile of plastic bags, each containing a neatly folded hair piece. There it was. She flipped the bag over in her hands, looking for something but not finding it, and then shrugged before unclipping the plastic bag and carefully pulling out the wig. Gently shaking it out, she and I both realized the wig was not the same as the one I'd seen on the foam head. Instead of long and layered, that wig would have barely grazed my shoulder and was all the same length except for its short bangs.

I didn't like the idea of a short wig. Most of life I had long hair, sometimes *too* long for the hot summer months, and my mom had always agreed I should keep it that way. But pictures proved that I was almost completely bald until I was three years old. My brother's baby pictures show a kid with a head full of thick Italian hair. But on my head, there isn't more than peach fuzz for years. Then, according to my mom, at around four years old, when my hair finally began to grow out, I snuck into my closet with a pair of scissors and cut off a large chunk of the long awaited locks. Since then, my long hair had been sacred.

"E-ver-y time she do this. E-ver-y time," the woman shook her head towards me. Could I believe it? She seemed to be asking with her eyes. I shrugged and, unsatisfied with my response, she turned her attention back to the wig and spent a full minute carefully folding it in such a way that not a single hair was out of place before gently

slipping it back inside its packaging. As soon as the clip on the bag was snapped closed, she aggressively yanked open the drawer under the one she had been fishing through and threw the wig inside with great force about millisecond before she slammed the drawer closed after it. Suddenly back to her good mood, she began searching again in the first drawer for another blonde one

“What are you doing in there?” My mom’s elbows were on the counter of one of the shorter display cases as she leaned over inquisitively.

“Trying on a wig.” There was an awkward pause as she looked around and saw no wig. “She’s finding one for me.” I pointed to the woman’s ass, which was all that could be seen of her from the angle was bent in as she searched through the drawer.

“Oh. Did you see the ones over there?” They’ve got some really cute, short ones.” She pointed to the case under her elbows. Short ones? I couldn’t believe she was giving up on the long hair she’d spent so long growing out on me as a kid. But then again, wigs didn’t have to get grown out.

“I don’t really want a short one,” I suddenly felt stupid for only looking at one wig. The kiosk must have had fifty. Turning my head, I was surrounded on all sides by hidden drawers in the backs of the display case. From where I was sitting, the only wigs I could see were on the tops of the cases. The one nearby was gray and extremely short. I imagined myself with the gray wig on and wondered if I would get more or fewer stares with it on than I already did wearing fluffy slippers outside.

“You don’t want a long one. It’ll get all knotted.” I hadn’t thought of that. But couldn’t I just brush it out? “Come look at…” Next to me the woman triumphantly shook

out the right blonde wig. The long layers bounced weightlessly. “Oh wow, Jeanette. That one *is* nice.” I couldn’t wait to try it on.

“That your mom? Come inside. We going to try on the wig.” My mom walked between two displays and stood by my side, looking in the mirror. Her face was making me uneasy.

“You know,” she grimaced, “that blonde might be too light for you. It might wash you out.”

“I already have blonde hair,” I said in an irritated voice.

“Not since you were twelve,” she laughed. I looked at my hair in the mirror. My hair was much darker than when I was a kid, but it was still a golden, honey color. At least what was left of it after the year of being sick and going through months of mild hair loss.

“First I need put your hair in this.” The woman carefully pulled out a lumpy piece of black netting and held it in front of my face. Then, with gentle fingers, she carefully tugged out my hairband and ran her fingers through my hair. It felt good to have someone comb my hair for me. She gave me goosebumps every time one of her red fingernails grazed the back of my neck. “No too much hair here. Why you no have hair?” I tried to think of a response that would require five words or less.

“Oh, you know...wait, does my hair have to be up in that?” My hair had been put in a do-rag. The tight elastic wrapped around my head cut the circulation off in my brain. People were looking. Were people looking? Everyone must have been looking. In the mirror, a small tuft of my hair stuck straight up through a hole in the netting at the top of

my head like Alfalfa.

“I fix. I fix. You have to wear so he wig no slide off.” Digging her red nails underneath the band across my forehead, she pushed the elastic up until it was exactly covering my hairline. I got goosebumps again when she ran a finger under the back side of the netting to make sure there weren’t any loose hairs dangling out of the bottom.

“Now like this.” She grabbed the gorgeous blonde wig right in front of the center and stuck it directly in the middle of my forehead. Then, slowly, she stretched it to cover my scalp, once again running a finger along the back of my neck to make sure no stray hairs had escaped the netting.

Even before I was able to get a good look at myself in the mirror, my mom said, “Way too light. It’s way too light for your skin.” She was right. It looked horrible. The light color immediately washed out my face. Every imperfection looked worse, as if the blonde in the wig was not a sandy color but a highlighter yellow, illuminating my situation by juxtaposing healthy looking hair to an unhealthy face. A fact that didn’t seem that unhealthy before the wig was on. At least, I didn’t think I looked that sick.

“Color no good. Too light. I fix.” In one swift movement, she ripped the wig off my head and went back to her drawer. I pulled the netting off, defeated.

“Why don’t you try one of the shorter ones?” My mom asked again. “Come look.” I imagined six different versions of the Grandma, gray wig I’d seen earlier.

“No, I think I’m gonna try on that one.” I pointed to the first long one I could see, a black one just below shoulder length with a bit of a wave near the bottom.

“The black one?”

“Well, yea. The other one was too light.” She looked unconvinced. I sounded unconvinced. We both turned to look at the black one. Its perfect wave curled around the neck of the foam head.

“Will you just try on the short one? It’s a neutral brown. You don’t want something to stick out. It’s better if it doesn’t draw attention.” Walking back through the display cases, my mom headed over towards a case to get the wig and prove her point.

“Here you go. This the right one.” Right in front of my face, the woman dropped two feet of mahogany hair connected at the top with what appeared to be dark brown roots. “Looks real. Look! Roots!”

“I don’t know about that color.” The red undertones to the brown hair gave it an exotic look that I knew would be worse than the blonde. At least I’d had blonde hair before.

“Trust me. This one perfect.” She threw her hand to her hip and stared intently at me. She wasn’t going to give in.

“Okay, I’ll try it after the black one.” I gave a half smile. She shook her head and without a word brought the black one over.

“Why you take the net out? No touch the net.” This time she combed her fingers through my hair roughly, snagging one or two on a loose knot and yanking my head back towards her. I leaned forward and then backward as she adjusted the hairline and tucked stray hairs, once again, into the netting. It was hard to avoid my reflection in the mirror. I was two feet away from it and the mirror was so large I couldn’t look around it without moving my head, which was in the fierce grip of the woman’s hands. Taking in my

appearance, I could tell I didn't look well. Puffy blue bags under my eyes sagged down and disappeared into my swollen cheeks. I sucked on and bit my lips to give my dreary face some color.

"Lean back," the woman ordered. She once again pressed the wig into the center of my forehead, holding it there while she pushed my head forward and stretched the rest of it over my head. Before I could hear anyone else's response, I jerked my head upward to get a good look. Immediately I cringed. My face looked pasty and the blue bags underneath my eyes seemed darker. I saw the woman in the mirror, arms crossed, trying to hold back her own cringe.

"You look like a witch," my mom said with a smirk. It was true. It looked like I'd gotten the wig at a Halloween store. All I needed was a crooked nose and I could pass as a witch even without the costume. I could tell we were all on the verge of laughing, but my mom and the woman helping us were waiting for me to start. I wanted to, but instead I just slipped the wig off, discouraged.

I don't remember what gave me the impression that a wig would give me spectacular hair. Maybe it was because anything seemed better than what I had left at that point. I remembered the girl from the advertisement in Target. The wind carefully lifting her thick, glossy hair and making it dance behind her smiling face. I wanted dancing hair and movement on a body that was stagnant with exhaustion. Gravity was pulling the fluid from the swelling down to my feet, keeping my limp and unhealthy hair hanging lifelessly around my face, and pulling the bags of my eyes down to my nose. I just wanted something to stop the deterioration, even if it was fake. I worried that if I didn't

make it through, this sad body would be the only way people would remember me. I would be buried in this distorted body that wasn't my own. At least the hair would be something I chose, not something that came against my will like an unstoppable force.

"This one gonna be better." Rejuvenated, the woman, having carefully put away the black wig into the drawer from which it came, charged forward with the mahogany wig. I shrugged, entirely indifferent. Her acrylic thumb nail scratched my forehead as she eagerly pressed the wig into it and peeled it back over my scalp. I thought I might be bleeding, so I looked up to check before she had even adjusted the hairline.

I didn't get it, but somehow I looked healthy. I didn't look like I had perfect hair, though the hair was silky and straight. I was not blown away by the highlights or the layers or how it brought out my eyes and looked like it could be a natural hair color for me. But I looked healthy for the first time since I could remember. The hair distracted from my tired eyes, pasty skin and swollen cheeks, but didn't wash me out. It was perfect. I wondered what that meant, that *this* was the wig that looked the best and it was the last color I would have ever dyed my hair. Was this me? The new me? Was there ever going to be any going back?

"That's the one." My mom said matter-of-factly. The woman began combing the wig with a special brush and then carefully tucked some of the hair behind my right ear.

"You like?" she asked but she could clearly see the answer in my face.

"Do you think I'll get used to it?" I asked. I wondered if there would ever be a time where this looked normal to me, if I would ever look in the mirror and think this new look was familiar. I wanted to turn my head to see it from a different angle, but I was

afraid the whole thing would slide up and pop off the top of my head.

“Yes. Very fast. I love mine. Keep it in my car always. So easy: already styled, no flat iron, no blow dry.” Looking carefully, I realized the woman was actually wearing one of the wigs from the store, a very short, trendy red one similar to the ones my mom had been looking at before.

“You’re wearing a wig?!” My mom exclaimed.

“Yes, I am wearing that one right over there.” She proudly pointed to a brown one in the same style over on the top of one of the display cases. I couldn’t believe this woman, who seemed pretty healthy, was wearing a wig in a wig shop and we hadn’t even noticed. I wondered what her real hair was like, if it was an ugly color or had a bad texture to it. I bet people didn’t even recognize her in the wig. She could be whoever she wanted.

“I was looking at that one before. It looks so real on you, though. I didn’t even notice.”

“Nobody ever does,” she smiled. I imagined her being in the CIA, switching wigs to pass as different people so she could fly under the radar and go unnoticed. I wanted to be like that too.

My mom asked a series of questions that I immediately zoned out. *I think this treatment is going to be all right.* I thought. Even if all my hair fell out, it wouldn’t matter with that wig. And maybe I didn’t look all that sick. If the wig made such a difference then maybe it was just my thin hair that made me look so bad in the first place. Maybe the rest of my body only seemed to be such a wreck because it was so different from how

I looked before. But if I stopped comparing myself to how I used to be, I figured that I probably wouldn't feel that bad anymore.

“Can I try that one on?” My mom asking to try on a wig jerked me back into the conversation.

“You want to try one on?” I asked. Why? Her hair was great. Was she thinking about my CIA fantasy as well?

“You two switch,” the woman ordered us before turning around and walking across the enclosed space to a drawer at the far end. My mom shrugged and blushed, as if to say the decision was out of her hands. I stood up, afraid to move my neck in fear that the wig would slide off, and stood to the side as my mom got comfortable in the chair.

Putting my mom's hair into the do-rag proved to be difficult. Her extremely thick, dark hair was too heavy to be contained. By the time the woman got it up, my mom had a massive bun on the top of her head that I figured would definitely show through the small wig.

But sure enough, I was wrong. The wig fit perfectly and the light brown looked great with her tan skin and green eyes. The styled haircut was bold: sharp bangs and a little bit of a poof on top. It looked great, certainly real, and the woman was so excited that someone else looked good in her wig that she was nearly unable to contain herself. But I found my smile fading when I realized something was wrong that I couldn't put a finger on. My mom seemed to feel the same. It looked good on her, just as good as on the woman. But the woman also had acrylic nails, a borderline extreme amount of makeup, and high heels. My mom had never had acrylic nails, rarely wore makeup, and hated high

heels. If someone were to style their hair like the wig, it would take at least an hour. And that specific shade of brown suggested regular coloring and highlighting. It wasn't believable that my mom would waste that much time styling her hair, but it was believe that woman helping us would.

“What do you think?” My mom asked. I could see she was thinking the same thing I was.

“It *does* look nice,” I said in defense of it.

“It does, doesn't it? With, you know, a nice outfit or something. Not for every day.”

“Not for every day. But yea.” She looked back into the mirror a moment and then turned to the woman.

“How much do these cost?”

“Two hundred seventy-five for the long one and one hundred ninety-five for the short.” It hadn't even occurred to me to ask beforehand how expensive they were. I knew at a Halloween store, costume wigs usually went for twenty to thirty dollars, and after all, the black wig did make me look like a witch. But I had no idea wigs could be this expensive and no idea if this was a good price or not for a “real” one. I'd find out later that wigs could go up to three thousand dollars and the ones we got cost just a little more than average. But up until that point, I hadn't looked them up online and I certainly didn't know anyone to ask.

My mom looked back into the mirror and I could tell she didn't like it enough to spend two hundred dollars on it. But suddenly her expression changed to a smile and she

said “well, I just think this looks great. What about you, Jeanette. Do you like yours?”

I looked in the mirror again, and the idea of taking off the wig and going back to looking sick seemed too hard to bear. “Yea. I really like it.”

“Okay, we’ll get them.” The woman spun around to her cash register, where she had additional products that she tried to sell us: wig shampoo, wig conditioner, wig brushes. Not knowing better, we bought all of the things she’d convinced us we needed so that our wigs would last more than a few months. When the bill came out to over five hundred dollars, my mom said, “Well, at least you’ll feel comfortable going back to school and you won’t have to worry about what other people think if you lose your hair.”

“Yea. I think I’ll just wear it in my classes from the beginning so no one notices the change.”

“That’s probably a good idea.”

“Thanks, mom.” I really was grateful she’d gone with me. Going by myself would have been miserable.

“You want me to put the wigs back in bag?” The woman held out two plastic bags. My mom and I looked at each other with our new hair and shrugged.

“No, we’ll just wear them, if that’s okay.” In one swift movement, she nonchalantly tucked the plastic bags into the shopping bag with our shampoos and brushes, tied it off and passed it over.

When we got home, my brother, Michael, and dad were in the kitchen making something to eat. My mom thought it would be funny to surprise them, so while I walked in the kitchen and asked what they thought about my wig, she came around behind them

and tapped my brother's shoulder. Sandwich in hand, he screamed.

"You scared me! Wait, why did you get one?"

"Because I liked it. A lot of people wear them now. It's so much easier than blow drying and ironing and styling your own hair." Michael reached out to touch the wig and my mom bent over to oblige him.

"Weird." He leaned forward and took a massive bite of his sandwich. A piece of turkey dangled from the side of his mouth for a moment until his tongue swung it back up to his teeth.

"So do you like it? Does it look *real*?" I turned to ask my dad. He was rinsing a few dishes in the sink when he looked up to analyze it.

"Yea. It looks really nice. My mom wore those things all the time." My dad's mom had died of cancer when he was fifteen and he'd seen her struggle for many years trying to fight it. "But why is dark on the top?"

"It's supposed to look like roots. Like I dye my hair this reddish color and my dark brown roots are growing in." He looked confused.

"I thought women didn't like roots."

"It makes it look more natural, you know. More *real*."

"Oh, well then it does a great job of doing that. It looks beautiful." Then he noticed my mom. "Oh! Wow, you got one too!" He let out a little laugh. "No wonder it took you guys so long."

"Do you like it?" She asked

"Yea, it looks really pretty."

“Good. I think I’m gonna wear it to the funeral this afternoon.”

“Oh, do you think that’s a good idea?” My dad didn’t seem so sure. I stared at her questioningly too. I looked for Michael’s reaction but he’d left the room with whatever was left of his sandwich.

“Why not? I thought you said it looks good?” The smile on her face began to drop.

“It does. I just didn’t know if it was comfortable.” We know that wasn’t what he was really thinking.

“It is,” my mom responded defiantly.

“Well, we better start getting ready. We’ve got an hour to get there.”

“I didn’t realize the funeral was early?” I asked but what I really wanted to know was ‘do I seriously have to go?’ One of our neighbors had passed away of old age and his grandson had been pretty close to my brother for the last few years. I, on the other hand, barely knew anyone from the family. And to be honest, I hadn’t been a fan of the old man. Until the week before he passed, he’d spend at least a few hours a day doing some sort of real or imagined yard work, always with one eye observing the houses surrounding his. It also conveniently worked out that every argument I had as a teenager with my parents took place in the driveway, and usually during his watch. Whenever this would happen he’d stop his yard work, face our house, and stare. He didn’t like me. And the fact that he watched my bouts of angsty teenage frustration over what my curfew was or why I couldn’t do this or that infuriated me.

“It’s just a lunch sort of thing. It’s actually kind of weird. There’s no service or

anything,” my mom answered. I already knew she was not excited to go. For one, the ‘funeral lunch’ was at the neighborhood country club where the wealthy spent tens of thousands of dollars a year to be a part of. My family wasn’t a part of the country club. Because it’s a neighborhood thing, those who belong are usually regulars and outsiders generally stick out. But the worst part of it would definitely have to be our other neighbors, entitled WASPs always looking to one-up each other while perpetuating their battle schemes in the war of passive aggression

“What do you wear to a funeral luncheon?” A sundress? A black one? Both seemed oddly appropriate. In the middle of summer, the men at the country club would be wearing Tommy Bahama shirts with khakis and the women would be wearing flowery dresses or pastel golf wear. There was no doubt that black suits and dresses at 3pm would seem odd. But then again, someone had died. Would the casket be at the end of the buffet?

We wore black. And by the time we got from the front door to the car we were already sweating profusely from the nearly hundred degree weather. A few beads of sweat trickled down my scalp and behind my ear. The wig was all I could feel, and it felt like it was suffocating my brain. The black netting itched terribly along my hairline. Outside of the mall and the comfort of our home, my mom’s high fashion hair made her look a bit like a peacock and her makeup didn’t do much to help. She was never very good at doing her own makeup and rarely did it in the first place, so her foundation was at least two shades too light and her blush looked slightly clownish. She was certain to be the only one at the event looking cheerful; that was for sure. The haircut was too bold,

especially for a woman who had never had her hair anything but straight and equal length. And the styling was complicated. It was not believable that clownface had blow-dried, ironed, and, using an unnoticeable amount of hair gel, created the masterpiece herself.

“We’re here for the funeral,” my dad half yelled out the window to an indifferent valet, one of the four gorgeous twenty-somethings clearly hired for the entertainment of the many divorced cougars that roamed the country club. The valet nodded, and then, after stretching his arms as far as he could above his head and then rolling his neck from left to right, stood up and slowly made his way down the long entrance to my dad’s car. He did not open the passenger door for my mom but instead stood with hand on his hip, annoyed, as we struggled out of the car in the clothes that were now sticky with sweat.

Once inside, we were directed to a section of the large open restaurant in the back corner. Even at three o’clock, there were still many people getting lunch at the center buffet. Our section of the restaurant was marked off by a smaller, separate buffet, but otherwise there was no real privacy from everyone else. Amongst a sea of pastel, the twenty-five or so people in black made quite a scene, one that many of the other patrons went out of their way to get a good look at.

We were greeted by Vivianna, the daughter of the old man and mother of my brother’s friend. She had heard, as everyone had heard, about my diagnosis, and at seeing me went from a face of devastation to one of immense pity. ‘At least my dad lived a long life,’ she seemed to be thinking. ‘I can’t be that sad when there’s people like this girl that will be lucky to make it to twenty.’ She hugged me for about three seconds past

uncomfortable before moving on to the rest of my family and then directing us to a table where our neighbors from across the street, the Havreys, were already sitting.

“Cathy!” Elena Havrey stood up and exclaimed in front of everyone. “Your hair!” The whole funeral party turned to look at my mother, who was clearly lost for words. Dylan, my brother’s friend, meanwhile approached Michael and my dad jumped in on that conversation immediately. My mom and I stood next to each other not sure what her angle was. The absolute queen of passive aggression and cruelty, Elena had notoriously starved and degraded her average-weight daughter until the girl became bulimic. She had never said a nice thing to anyone, and the perma-frown on her face was so severe that even as she flashed my mother the fakest smile anyone had ever seen, she still looked like she’d smelled something awful. I immediately felt that she must have seen my mom’s wig at the mall. The Galleria was, after all, just a few minutes away from our street.

“Hi, Elena. How are you?” My mom sat down at the table and turned around to hook her purse on the corner of her chair. Maybe ignoring the comment would make it go away.

Not. “I just can’t believe your hair. Wow. Look at all that poof!” She stared directly into what I can only assume were the peacock’s hidden eyes. I couldn’t tell if Elena was just mocking my mom for the hairstyle or trying to get her to confess to wearing a wig. Either way, it was clear she wasn’t going to drop the topic.

“Yea, I’m trying out a new look. How are your girls doing?” Even after a few minutes in the air conditioning, I was still sweating. I wondered if I had soaked through my clothes and the only thing dry was the wig that would inevitably start sliding around

on my wet, real hair.

“And Jeanette, I don’t think I’ve ever seen you with dark hair. It looks fabulous.”

I cringed. She stared back and forth between us, waiting for some sort of response.

Waiting, I worried, for a confession.

“I’ve always wanted to try out short hair, but I’m worried that once I do I’ll just hate it, you know? I’m just not ready to accept that I’m old enough for that.” Elena threw her head back and laughed loudly. No one around us seemed to notice. The family of the deceased was preparing to start whatever sort of ceremony they had planned and everyone else was wrapped up in their discussions. My dad, insisting his way into Michael’s conversation, kept interjecting comments and nodding furiously.

“If everyone could sit down, we’d like to get started,” Vivianna looked deflated. Her body seemed to have shrunken into her already thin frame, leaving her skin sagging on her face and arms. My dad and brother joined us at the table, my dad nodding and my brother waving at Elena and her husband, who made no effort to hide his boredom. In less than a minute, everyone was seated. With great effort, Vivianna cleared her voice and began again. “First, I’d like to thank you all for coming here to celebrate my father’s life. I speak for my whole family when I say we are so grateful to have such good friends around us during our time of mourning.”

I looked at each of their faces, Vivianna, her kids, her husband, her mother. I knew the old man and his wife didn’t speak English. So as Vivianna was speaking, her mother stared off into the crowd with the same intrusive eyes I’d hated her husband for having. She gave everyone roughly two seconds of her time until she landed on my mom.

At that point, she tilted her head slightly and looked at the peacock with bewildered eyes. The look on her face was so strange that a few people from other tables noticed it and followed her gaze back to my mother's hair. Vivianna began to cry quietly, an abrupt end to her very unoriginal speech. But her mother didn't notice, even as others from the family approached Vivianna and held her in a group embrace.

"You'll have to let me know who does your hair," Elena whispered in line roughly thirty minutes later at the buffet to my mother. I waited for a snap, for my mom to tell her to fuck off or, even better, throw her plate of wild rice and honey glazed chicken in Elena's face. But neither of those things happened. My mom said the name of the woman that had cut our hair for years and then walked away before a follow up question could be hurled out after her.

I was sure everyone knew. The old man's wife could be seen periodically throughout the meal staring at my mom's peacock hair and Elena managed to bring all conversations back to the topic. The whole neighborhood had heard about me, about my diagnosis first and then the start of my chemotherapy. Even if they hadn't seen me in ages, my wig was too perfect, the strands too conditioned and shiny, for anyone to believe it was the hair of someone who had been in and out of hospitals for over a year.

It didn't help my insecurities when Vivianna pulled a chair up between my mom and me and leaned forward, almost until her chin touched her knees, and, reaching one hand out to rest it on my arm and turning her head to face my mom, asked "How is she *feeling?*"

"Well she had her first infusion just over a week ago, but she seems to be doing

really well considering.”

“She looks great. I was so surprised to see her *eating*.” At that exact moment I was shoveling a heaping spoonful of rice into my mouth. Swallowing most of the grains of rice whole, I looked at my near empty plate, smeared with the remnants of what was clearly a large portioned meal. I felt embarrassed first for pigging out and then for being a fraud. It was as if people had been anxiously awaiting my deterioration and I was letting them down by not playing the role of the cancer patient that everyone had become familiar with from the movies. What was I doing wearing the wig anyway? Pretending I was the cancer patient when I wasn’t? What person going through chemo ate like I did? I didn’t realize at the time that the prednisone had completely cancelled out any nausea I would have normally felt and was responsible for my increase in appetite. Was I trying to play that role from the movies, thinking that was who I was supposed to be? Or was I just trying to pass as healthy and miserably failing?

I was in the middle of trying to answer my questions when I heard my mom tell Vivianna about the wig. At the word, I jumped back into the conversation and immediately felt an upsurge of rage towards my mom for exposing me. For, without asking, telling my secret while she kept hers.

“If I didn’t know better, I never would have been able to tell. It’s such a natural look for you.” Vivianna looked at me so encouragingly. She even attempted a smile that faltered halfway and then sunk back into her sad frown. It felt weird to have my neighbor comforting me at her father’s funeral. I felt guilty for stealing the spotlight and even worse for not being comforted by her kindness.

“Thanks.” I could feel my blood boiling up to the surface of my skin as my mom reached out to tuck some of the loose strands behind my ear, slightly jerking the whole wig to the right on accident. All three of us pretended not to notice.

“Well, I’d better get back to everyone,” Vivianna stood up, bent over to kiss us each on the cheek, and then left.

“Why the hell did you tell her I’m wearing a wig?” I went for a whisper but it came out as a growl.

“Everyone already knows about your treatment. They know that’s not your real hair.”

“I haven’t seen these people in months. What do they know?”

“It’s not a big deal. You still have hair underneath there. It’s like an accessory.”

“If that’s what it was like, why didn’t you tell them you were wearing one too?”

“Oh come on. Are you ready to go? I think this thing is about over.” Without another word, she stood up and waved over to my dad and brother, who had once again wandered off. She pointed to her watch as if we had somewhere we needed to be and then turned to Elena. “It was so nice to see you guys. But we’ve got to head out. The dog needs to be let out. You know how demanding these dogs can be.” The dog, like the infant, like the old grandparent, is the easiest out of any situation. It’s the planned “emergency phone call” from the best friend during a first date in case an escape must be made. It was my mom’s go-to exit line.

As we walked out of the country club, I found myself unable to calm down. I was furious at my mom for exposing me. I was furious at Elena for being a bitch. And I was

furious at the old man, for, even in death, getting involved in my business. I tried to tell myself that it was the steroids making me so upset and that none of what happened inside there was a big deal. I tried to take deep breaths and count to ten. I made it to four.

In the car I yanked the wig off my head. The hot air actually felt cool on my sweaty scalp, but I still felt suffocated in my black dress. The two minute car ride home felt like an hour. I bounced my right heel in anticipation of getting back into the cool air conditioning. Even without the wig on, the back of my neck still itched.

Inside, my mom took her peacock off, put it in a drawer, and never wore it again.

III.

“So what are we doing for dinner?” I asked from the barstool where I was sitting, overlooking the kitchen while my mom folded laundry on the island countertop a few feet away. For the last ten minutes I had been sitting there clinking the lids of the six glass jars that were lined up in front of me as I open and closed them. My mom always made sure each was filled with a different snack and changed them up regularly to keep us from getting tired of them. There were usually at least two different kinds of nuts, some sort of cookie, a salty snack like Goldfish, and a candy along with something we’d never tried before. Indiscriminately I had been reaching my chubby fingers into the jars and grabbing handfuls of the stuff without keeping track of how much I was eating. Neither of us noticed.

“I think your dad wanted to go to Old Florida Seafood tonight,” my mom responded without looking up from her laundry.

“Yes!” I said with great enthusiasm. I wasn’t even necessarily excited about going to a place with good food, but rather one with a lot of food. Three weeks after my chemo treatment, the effects of the prednisone were worse than ever. I’d started to get too anxious, with or without the wig, to go out much anymore. The times my mom did succeed in dragging me out, she had to stay right by me the whole time or I’d panic thinking I’d lost her. And with the swelling still fluctuating, I had a great fear that I’d find

myself stuck somewhere with no ability to leave. But perhaps worst of all was how much I was eating. I literally couldn't stop, even when I knew my body was full. It was almost like I'd gotten the munchies, permanently, and no matter how much food I had in my stomach, I still felt like I was starving.

"But you're not going unless you take a shower. You look like a slob," she looked up only to shake her head at me. It was true. Personal hygiene had become a huge drain on my energy and everyone knew I was letting it slide. My hair was greasy and I'd worn the same muumuu dress for almost a week. On the way out of the kitchen my mom reminded me that a postcard from one of my doctors had come in. Dr. Watters had already set up the appointment for my next chemo treatment with Dr. Jahn, a hematologist I'd visited once before. It was less than a week away.

"I can't believe it's been a month. Does it feel like a whole month has passed?"

"It feels like an eternity," my mom said. She looked tired.

In the shower, I stood letting the hot water jab at my swollen stomach and hips before running down my padded thighs and feet in thin rivers. I could feel the weight of the water as it slipped down my legs, burning me as if the round droplets were made of clear and heavy mercury trying to pop the tightly stretched skin. It was the afternoon, when I was usually at my best, so I felt I had no real excuse to refuse my mom's demand. But as I stood there with my arms over my head, scrubbing the foaming and bubbling soap into what little hair I had left, my arms started to tremble under the weight of themselves. I let them drop to my side and stood under the water, closing my eyes and hoping all the soap would run off my scalp without any more use of my hands.

When I started to get dizzy, I knew it was time to get out. I stepped out of my parents' shower (mine was half-way through demolition) and threw a towel over my head and body to start drying off. I could tell that exhaustion was reaching its limits, that soon my brain was going to fall asleep no matter where I was, so, still fairly wet, I wrapped the towel snugly around my body, tiptoed across the empty house to my 'nest' in the living room, and jumped back into bed, shivering until the warm blankets turned the cold water droplets into beads of sweat and then falling immediately into a deep sleep.

When I woke up, I was shivering away. My wet hair, towel, and body had soaked my pillow, sheets and blanket, and the air conditioning had made it quite cold. I got out of bed, annoyed at the cold, wet bed and myself for having a body that just ran out of steam like that, exactly like the electric wheel chairs in Target. One minute I was fine, and then abruptly I would feel everything shutting down with little time react. On the bright side, my batteries still appeared to be rechargeable. Just a short nap would often give me the boost I needed to finish whatever it was that I was doing. Wrapping the towel snugly around myself, I carefully, so as not to slip, walked across the tiled floor, through my parents' room and into their bathroom. I picked up where I left off, cleaning my ears with Q-tips and rubbing my face with astringent when my back started itching like crazy. I stopped what I was doing to scratch it and went back to what I was doing, but it kept itching. It took a moment for me to realize it wasn't something on my back that was itching. I swung the towel off to examine it. Maybe something had gotten on it from the nest. I had, after all, been eating in bed a lot lately.

Naked, with the towel spread out in front of me, I noticed the white cotton was

absolutely covered in hair. I tried to count the strands but there were so many it was impossible. I'd never lost that much hair in before in my life. In fact, I didn't realize I even *had* that much hair to lose. Grabbing a new towel, I wiped off all the strands that were across my back and all over my body. The strands must have come off while I was drying my hair so that when I dried my body, I rubbed them all over myself. My stomach was trying to eat itself as I looked in the mirror, unwilling to look at what I knew I needed to see.

At first, I was grateful to see that I still had hair. With all the hair on the towel, I feared there would be nothing left. But what I still had incredibly thin. My scalp could easily be seen through it. At first, I was afraid to touch it, afraid that more would fall out if I did. But then I angrily grabbed a brush and began ferociously brushing what little hair was left and then examined the bristles afterwards to see if more hair had fallen out. It had.

I felt scared. For some reason, getting through the majority of the month without any hair falling out had convinced me that I was in the clear. That maybe I would be one of the few who kept my hair. I thought maybe I was just stronger than everyone else, that even my hair follicles had refused to give into the treatments. I felt hopeful that I was winning, that I was beating chemo. Looking over at the towel on the floor, I felt so stupid for thinking I would be different.

At the funeral, I'd felt like a fraud for not being sick enough, for not having the same side effects. I didn't know if I should be, if I was *allowed* to be, wearing a wig when my hair hadn't fallen out. I wasn't really one of them, one of those cancer patients

I'd seen and heard about. I didn't even have cancer. But I wasn't really a Lupus patient either. At least, I didn't feel like one. No one I'd heard of with Lupus had gone through chemo. Everyone had a friend of a friend of a cousin who had Lupus, and their stories all sounded different from mine. By not fitting in completely with a Lupus identity and not exactly fitting in with a cancer one either, I thought I might scrape by picking and choosing which of each that I wanted, or maybe trade symptoms. I wouldn't lose my hair, but I'd become a nervous, ravenous wreck with prednisone. I didn't have a tumor, but I had swelling. I wouldn't fit in with any classification, but that wasn't necessarily a bad thing.

But now that my hair had started falling out, I knew I was really in it. Jeanette Moffa was going through chemotherapy. I wasn't saved from anything because I didn't have cancer. I didn't get special treatment from the drugs because my Lupus was different from the other cases I'd heard of. I was getting the authentic experience, I realized, because there was no one way to go through chemo. There was no going back, no false sense of security in my identity confusion. This was gonna be bad and it had just started.

"You're looking too closely at it," my mom insisted as she looked at my hair with a horrified expression on her face. I wanted to believe her. In fact, I wanted to believe her so badly I allowed myself to be convinced for a moment.

"Really?"

"Well, I mean, you're a foot away from the mirror. Step back a few feet." I stepped back a few feet and my vision got blurry. But even so, I could still make out a

dark blonde aura around my head.

“Yea and you can just wear a headband or something and no one will notice. They’ll just think you wore your hair back.” She began shuffling through her cabinets searching for a headband.

“Won’t that just pull more out? I mean, look...” I ran my fingers through my hair and more strands fell out.

“Don’t! Don’t do that!” She swatted my hands away. “Well,” she said confidently, “we’ll just have to wait until it dries. Hair sticks better to the scalp when it’s dry.”

“That’s the most ridiculous thing I’ve ever heard.” But my mom had already disappeared into her closet looking for a headband.

When my dad came home, he said “oh, it does look like you’ve lost a little hair,” as he squinted his eyes to get a better look. “But it doesn’t look all that bad.”

My parents did a great job of acting. Or I did great job of denial. More likely, it was a combination of the two. But I managed to convince myself that while most of my hair was now gone, there was still enough for me to go outside without people thinking something was wrong with me. It just looked like really thin hair. And hey, some people were born like that. I didn’t want to be pretty, just normal. All I wanted was for no one think I was weird.

I would realize years later when I discovered a picture someone had accidentally taken of my back that I actually had a bald spot right at the top back of my head where I had no chance of seeing it in a mirror. Everyone must have known, but no one ever

mentioned a word. In fact, no one even discouraged me from going out in public like that. I guess no one had the heart to tell me, or at the very least figured it would be worse if I'd known.

While everyone got ready for dinner, I sat in my nest staring at the wig. My mom would always say the same thing whenever someone complained about the stockpile of things she kept in the pantry and our garage: It's better to have it and not need it than to need it and not have it. My own version became: It's better to have it and not need it than to need it and have it. Having the wig before was like owning an accessory. I could wear it when I wanted to feel better about myself. But now that I knew I was going to need it, I felt enslaved by it. Just as with my symptoms, I no longer had a choice to pick and choose when I wanted to wear it. It was all or nothing, in or out, and the choice was made before I even realized I had to choose.

I went back into the bathroom and put the thin black netting over my hair. There was so much less than the last time I'd worn the wig that I didn't even need the netting at all. It felt like it was going to slide off without any thick hair to hold itself in place with, so I tore it off and threw it in the trash. I never liked that thing anyway. Then I placed my thumb in the direct front center of the wig, pressed it to my forehead, and stretched it back over my scalp. When I lifted my chin up to look in the mirror, I knew I had a few adjustments to make. First I had to tuck some of my own hairs into the side and I had to adjust the hairline upward a bit.

As soon as I got the wig on right, I felt it itching. I scratched my head by rubbing and shifting the wig, but then after that I had to fix it all over again. I would eventually

learn the ‘poke’ technique and jab myself in the head with my index finger instead of scratching so my hair wouldn’t get messed up. But at the moment I thought I’d never be able to scratch my head out in public. I imagined sitting through a whole dinner like that, unable to do anything about it except endure.

By the time we got to Old Florida Seafood, my stomach was hurting from all the worrying about my hair. Unfortunately, that didn’t start my brain from telling me I was starving. I knew those two sensations, hunger and nausea, should never happen at the same time, and I was certain the result would be bad.

I sat down in the booth next to my dad and across from my brother, who was sitting next to my mom. My dad seemed to be in a good mood. He was glad to be home from work and out with his family. Despite all the crappy things that had been going on, he felt lucky to have all four of us together there for dinner. His positivity was contagious.

The waitress that came around to our table was in her late fifties with blonde hair in tight curls dangling just above her shoulders. She came off as very bubbly with a high pitched voice that always sounded excited about something.

“I’ll have a coke,” I said. It was unusual for me to drink soda but I knew it was my best option to calm my stomach.

“No!” My dad said with an exaggerated look of what appeared to be sheer terror. The woman left her pencil lingering over her order pad and look back up at the two of us. “You want water,” my dad said to me, looking desperate.

“My dad’s personal philosophy on illness was simple: anything can be cured by drinking exorbitant amounts of water, eating well, and taking Vitamin C chewable

tablets. Afraid to somehow tamper with all the medicines I had already been prescribed, he didn't push the Vitamin C on me. As for the eating, he not only enabled and perpetuated, but in fact encouraged my gorging in hopes that I would gain weight, which he equated to healthiness. He saw my eating as a sign that everything was going to be okay, and maybe even better than before. About a month before my swelling had begun, I had been 119 pounds and 5'7. To me, it didn't seem like such a small number. It just felt nice to be thin. But to my Italian dad, I was anorexic. He would often look at me, shake his head, and say 'you look bulimic or something.' It didn't matter how many times I corrected him about what bulimia actually was. So since I'd taken the prednisone and gotten a newfound appetite, he was even starting to wonder if chemo was the best thing to ever happen to me. But on the issue of water, we'd often disagree. All of the fluids from the treatments and the swelling from my kidneys made me feel like I was full of water all the time, even when I didn't drink any. Just the sheer volume of liquid put into my veins seemed to take weeks to flush out, so amidst my feelings of starvation was also an overall sense of bloating. So unlike with the food, I never craved water.

"Uh, no," I gave him a dirty look and turned back to the waitress. "I'll have a *coke*."

"Jeanette, you don't want coke. You need to drink water." Still that open mouthed look of terror was on his face. How could I be killing myself with soda when one simple glass of water would surely cure my Lupus? The waitress dropped her left hip and let her hands fall back to her side. Any pretense of a bubbly personality was gone. She was clearly annoyed.

“No, dad. I’m getting coke.” I looked up at the waitress and nodded. The discussion was over. The waitress rolled her eyes and turned to my dad.

“So, what’ll it be?” she asked him. I felt like a six year old at an ice cream shop asking for the extra-large size cup with six different flavors and whipped cream on top while my mom inevitably ordered me a child-size. And that never even happened in my childhood. I glanced across the table at my brother and mom who just stared at us, not quite sure what was going on.

“Fine.” The waitress left and I bitterly stared after her for a moment before letting loose on my dad.

“My stomach fucking hurts. I wanted a coke because I don’t feel well.”

“Oh. I’m sorry, Jeanette. I was just thinking you need to drink a lot of water to flush out those nasty drugs from your system.” It was and always has been difficult to be angry at my dad. He avoids all types of confrontation.

“Can’t I just have one thing go like it’s supposed to in my life? Like, seriously, can’t I just order a fucking coke without a big fight?” The other thing about my dad is that nothing really gets to him.

“Well, let’s just move on. You’re getting a coke.” But before he could finish I could already feel the pressure behind my eyes that I knew would inevitably result in tears. Tiny droplets seeped out of the inner corners of my eyes as I strained to make them stop. But it was useless. In a few moments, I was full on crying. When the waitress came back and put both the coke and a glass of water in front of me, I couldn’t even keep my crying quiet. I started choking out sobs and felt my nose start running.

I could barely order my food. I tried to start three times but kept crying. The waitress looked appalled. Finally I just had to blurt it out while looking at the table. I couldn't stand

to look at the face of the woman who took away my right to order a drink for myself.

My mom decided she and the rest of the family would pretend nothing was wrong and ignore me until I calmed down with occasional comments of "stop it" and "you're acting ridiculous" hurled my way. It took a full fifteen minutes for me to realize I was overreacting, but that only made it worse. I felt pathetic for having no control over my emotions, or my hair falling out, or even what I ordered to drink. Since when was I a little kid? Since when I was not human?

I tried to boycott dinner, but of course I had no control over my appetite either. The best I could do was wait two minutes after everyone else had started eating to begin with mine. But I couldn't take even one sip of the coke. It sat there, the carbonation pushing the straw to the top of the glass where it rested on the brink of falling out for the entire meal.

As it turned out, I didn't even really need the coke. My stomach settled the moment I started eating. I knew I'd made a big scene, the epic type where I'd humiliated myself and everyone around me. But I'd been embarrassed so often in the past year that it almost didn't matter. I was used to people thinking I was a freak. I almost ripped my wig off so everyone around us could look at my balding head too.

I was still crying when we left the restaurant. I felt people stare at me, though my sobs were quiet. Either way, my face must have been bright red and my cheeks tear

stained because, despite my fast walking and attempts at hiding my face, I knew I wasn't unnoticed by the people waiting outside for a table.

In the car, the rhythm of the drive stopped my tears, almost as if I was being rocked to sleep, but they started right up again when we entered the house. I looked around at my family as they trudged through the living room to their bedrooms to change. They all looked exhausted and fed up. I wanted to stop crying, to get control of whatever my problem was, but I couldn't.

Going back to the mirror in the bathroom, I looked at my pathetic face: my puffy eyes, the ridiculous tears, my hair. What did losing my hair matter if I'd already lost my mind?

The next day was Saturday, so everyone was home while I spent the hours in my nest. No one mentioned the night before. For all I knew they were scared of me. One thing was for certain, though, and it was that I had definitely crossed the crazy line.

But some things were looking up. My swelling had been fluctuating since I'd been in the hospital and started taking higher doses of the diuretic, Lasix. I had good days and bad days with it, but that morning I woke up with the best day yet. My feet were still puffy, but my pinky toe was clearly visible whereas before it was mostly absorbed into the swollen mass. Best of all, I could see my ankle. It was a miracle.

For once the emotion taking over me was joy. I was so happy I started cleaning up a bit in my nest. My things had been laid out all over the place for weeks, so I decided to start setting them in their proper order. I began reading a new book, which always, no matter how many books I read, gives me the feeling of a fresh start.

When I was bored with that I began walking around the house to see what was going on. It felt so much better to walk around with less water weight being carried in my feet and legs. Even my stomach had shrunk down so I only looked about four months pregnant. But my parents were in their bathroom discussing phase two of the renovations and my brother in his room playing video games. I felt bored and restless as the sun began to set, so I started digging in the various drawers of the furniture packed around my bed and found the largest dress I could. Going into my gutted bedroom, I pulled off my nightgown and tried to squeeze into the dress. It was the type of dress that fit snugly under the bust and then fanned out, leaving lots of room for a swollen stomach.

Sure enough, it fit. The fabric was stretching to cover my shoulders and the elastic under my chest was extended as far as it could go, but I was so excited to have it on that I didn't care how uncomfortable it was. Next I tried to fit into a pair of sandals. I tried two different pairs, but it was clear that the only way I was going to get them on was to jam my foot in and subject myself to severe pain, so I eventually just put my slippers back on.

Back in the living room, put on my wig and then I dug through the purse I hadn't used in weeks to find my keys. I wanted to go somewhere. I didn't know where I'd go, but that didn't matter. I wanted to go for a drive that night.

Falling into the low car seat of my silver Jetta, I forgot how hot the black leatherette could become in summer, especially if no one had opened the car doors in several weeks. My thighs burned, but if I continually moved around, the pain wasn't concentrated. After putting sunglasses on, I turned the car on and was slightly surprised at the low roar as it started. It had been so long since anyone had started it that I worried the

battery might have died. The purple glow of my radio came on a moment later, picking up right where it had last stopped mid-song.

I remembered the last time I had driven my car. It was the day before I went to the hospital and, ultimately, began my first chemo treatment. But I didn't want to think about that. I turned up on bass on my car and put on a hip hop cd to get lost in the rhythm and forget about what had been happening to me those last weeks. When the song ended, I was still in the driveway, suddenly nervous about shifting my car into reverse and leaving by myself. My hand gripped the shifter, hesitating while my scalp melted underneath my wig in the heat. I realized the AC was off, so I turned it to its lowest temperature and then convinced myself to take the car out of park.

When I got out on my street, I floored it until I flew over a speed bump I'd forgotten about and scraped the undercarriage. Unfazed, I floored it again. The roads weren't nearly as busy as I'd expected, so I felt a little more comfortable. I switched from the CD I had playing to the radio. Immediately a good song came on, and at a stop light, I rolled my windows down to get some fresh warm, beach air, still present just a mile inland, through my stuffy car. I allowed myself to be absorbed by my car. The steering wheel became my prosthetic arm and the pedals my legs. My vision was enhanced by the mirrors, giving me a better view of everything around me.

On the highway, the six lanes of open road looked like a race track. My engine roared as I quickly accelerated. I kept waiting for my foot to pull back, to slow down, but I just kept going faster, letting my body take over. I was tired of fighting myself. The car hugged the road, keeping me grounded. It was nice to feel grounded.

All my sadness and rage turned into aggression that fueled the car at 90 and then 95 miles an hour. I weaved in and out of cars, suddenly able to judge distances and the size of my car much better than I ever had before. Or maybe I was just lucky. At first, my heart would jump into my throat as I approached a car going significantly slower than me. Would I be able to get in front of the car next to me before I hit that one? Somehow my hands knew. Part of me felt reckless and scared. But an increasingly dominant part of me felt strong and in control.

I ripped off my wig, which was flying all over the place anyway with the wind rushing through my open windows on both sides and whipping through the car. I threw it into the passenger seat and put an old bottle of water on top of it to keep it from getting pulled out the window. I expected to feel free, to forget that I was weak and out of control and get lost inside the power of the machine. To maybe even feel like myself again.

But I didn't. I felt awkward. My thin hair made me feel ugly and ridiculous. When I passed by, were people looking in at me and thinking I was crazy? Did I look old? Or like a junkie? Even when I got away from the other cars, I still felt weird. The confidence and control that I'd felt before was slipping away, so I grabbed the wig, slowed down considerably, and in half a second had it back on my head. It had felt wrong without it.

I opened my visor mirror and adjusted my hairline so that it fit like it had before. I happened to have a brush in my car, so I brushed out the knots and tied the hair around my neck in a hairband that had been stretched around my shifter in case I ever needed one.

For a moment, I stopped staring at the road and looked in the mirror. I was

beautiful, but I wasn't me. Who was the girl in the mirror? The dark hair looked exotic and somehow muted my sunken eyes and pale face. Instead, my green eyes looked explosively bright and I looked *alive*.

I started to swerve, but the stretch of road where I was still didn't have any cars nearby. Paying attention again, I accelerated back to 90 and drove south until I reached Miami-Dade County and then turned around to head back up to Fort Lauderdale. I let my mind go free, moving quickly between rage and sorrow and joy without trying to fight it or control it. One moment I would be crying, the next laughing, and the transitions felt more natural than I expected. It seemed manageable this way. I could feel all of those emotions, even at the same time, without being overwhelmed, without feeling like I was losing my mind.

I got off on a familiar exit, one I hadn't gotten off at since I'd had my high school job at a boat paint warehouse near the port. I followed the bright lights over the massive 17th Street bridge. I looked over to my right to see if the cruise ships were there. I was always amazed at how incredibly large cruise ships were and how they still managed to stay above water. A few of the boats were still in port, but most had already gone out for their weekend cruises. I imaged a sea full of Midwesterners lined up outside the boats earlier that day, wearing their floppy hats and Hawaiian shirts, ready for their tropical adventure cruise. I'd never been on one those ships. As a native Miamian, I would have been embarrassed to admit participating in something so touristy, something that tried to make a commodity of our lifestyle.

The bridge sloped back down to beach level, and I drove along for a while in the

darkness until I hit the main part of Fort Lauderdale beach and A1A turned into a parking lot. I loved this drive. From the day I had gotten my license, I'd regularly made this drive down the beach, looping back and then doing it all over again, for hours, wasting unthinkable amounts of gasoline, throughout my whole junior and senior years of high school. I loved the salty air, the way it made my skin sticky and my car beachy. I never tired of watching people playing football on the sand, or parasailing and jet skiing out in the water. And on the west side of the road the bars, restaurants and shops all spilled out into the wide sidewalk. Greek music, Latin music and hip hop would all blare out of places that used the ocean as their fourth wall, encouraging everyone outside to come in for a quick drink or bite to eat. I liked watching the drunks and the tourists, but I especially loved the locals.

Being in my car, I didn't miss out on any of the fun. It was the best place to be for someone under twenty-one. I got to watch everything going on and feel like I was a part of it. And the street had a party of its own. People in cars driving five miles an hour yelled across to each other. Cars of guys hollered out their windows to get the attention of any girl they passed by. Packs of bikers weaved slowly in and out of each other, showing off their illegal fluorescents without a care in the world. It was a place for me, when I was younger, to learn about cars so I could impress my grease monkey friends. It was where I fell in love with Ferraris and saw some of the most beautiful cars in the world just out for a spin. It was where I'd driven next to the famous rapper Lil' Wayne.

Nothing relaxed me like driving by the beach, and I felt relieved that some things about me would never change. I looked out into the crowds on the sidewalk, at the few

people braving the dark beach and into every car I passed. I was looking for me, me as I remembered myself. And I was certain I'd be able to find that in the face of someone else, someone who came here to drive around the circle over and over again for the same reasons. When I didn't find me, I became sad thinking that girl was gone forever. I'd never be so free and light again. Maybe no one would.

When I got home, I took a shower as quickly as I could. I felt the exhaustion coming on me fast. After I was done, I carefully set the wig into a small, plastic tub that I filled with water and wig shampoo and tousled the strands through my fingers so the soap could get through the thick hair. Then, under the sink, I rinsed the soap out and repeated the process with wig conditioner. When it was done, I squeezed the wig in a towel to absorb as much water as I could. It still remained wet though, as I carefully combed it, trying as best as I could to tug softly so I didn't pull out any of the strands. I remembered not to blow it dry. If I blew it dry, the strands would melt together. In the mirror, I looked at my wet, thin hair, stuck flat to my scalp and neck, and the silk wig in my hand. I knew then I'd have to create a new me. I wasn't ever going to be the cancer patient. I wasn't going to Mandy Moore in *A Walk to Remember*. And I wasn't ever going to be the girl I used to be. I didn't have it all figured out. In fact, I had no idea who I was going to become, who I already was in the process of becoming. But I did know, whoever she was, she'd love making that drive up the beach to clear her mind. And that was somewhere to start.

The day of my second chemo approached quickly. The waiting room was full of people, and after you got through the first one, you were separated into two different

ones, one for a consult and one for treatment. In the treatment waiting room, I looked around at all the people. Some were balding, some weren't. But none of them seemed anxious to be seen by a doctor. Nothing had *happened* to bring them in there and nothing was going to happen at their visit that would fix their ailment. Rather, something had been happening to them for a while, whether it was the sickness itself or the treatment causing side effects. I supposed I wasn't in a rush either. I wasn't going to leave the office any better than when I came, and no particular event had happened to bring me in. The visit was just part of the routine.

I was not concerned with who came in before me and who came in after. Nor was I curious as to who was a patient and who was just there for support. I didn't watch the clock to see how many minutes passed between patients being brought in. Instead I picked up a celebrity gossip magazine that I never read off the coffee table in front of me, skimming through articles and looking at pictures of people I did and did not recognize from the movies and television.

A nurse came over and quietly asked the room for "Jeanette Moffa?" No one looked up or shifted in their seat. "Jeanette *Moe-fa*?" The nurse tried again, pronouncing it a little differently.

"Oh, sorry. That's me." I stood up and tossed the magazine back on the coffee table and picked up the green and pink backpack that was sitting next to me. My dad followed behind as the nurse led me down a corridor to the back of the building, where a line of thirty or so chairs were set up with IV stands next to them. Four TVs played *The Price is Right* about a quarter second behind each other. After the nurse pricked my

finger for a quick blood test and brought over an IV bag to set up next to me, I asked her to wait a second before putting in my catheter. Unzipping the top of my backpack, I reached in, pulled out a hair tie, and carefully wrapped it loosely around my wig just as I'd done in my car. Whatever came next, I was ready for the ride.

Epilogue

“I don’t know what you can really do with this. There’s not much to work with.” I had just had my makeup finished and was being directed over to another part of the stage by a woman wearing all black.

“Sit here,” she instructed and twirled around me in one quick spin so that she stood behind me as I sat looking out over the rooftop. The stage was still being constructed, and I watched as several men with hammers and nails banged away, making it impossible to be heard without screaming.

The woman ran her fingers through my hair, giving me goosebumps. I heard her sigh and then felt her hand drop.

“You know, your hair is amazing. It’s so soft. It’s like baby hair.”

“Thanks,” I smiled. That was unexpected.

“We’ve gotta poof it up a bit. Give it some body.”

“Sure thing,” I had no idea what she meant to do with hair so short it didn’t even reach my jawline.

“Jeanette!” An anxious girl ran up the stage. “Jeanette! We need your help. I know you’re leading the final walk, but we don’t have anyone to be Earth in the beginning. The wind dress was way too small, so we had to put Tricia in it and she was supposed to be wearing the Earth one. You and she are the only girls tall enough to fit in the Earth one!”

“I don’t know if I’ll fit in the Earth one.”

“I think you will. All the dresses are sized like two sizes smaller than they say. What a nightmare! You should be fine though. The Wind was the real problem. I don’t think I could have fit one leg in that dress. Thank God for Tricia...Although, we may need to get you some, you know, padding for the top. It’s a halter dress and the cup sizes are....let me see what I can do. I’ll be right back.”

“I’ll be here.” The hairdresser was definitely doing something to my hair. She’d been spraying hairspray for about a minute straight and I felt her tugging at certain chunks of hair.

“There. I’m finished. What do you think?” The woman held a mirror in front of my face and my mouth fell open. My hair had been sprayed back away from my face and styled in such a way that it looked layered and full. I loved it.

“Wow! I can’t believe you did this with my hair. It’s amazing!”

“That’s what they pay me for. All right, get up. We’re running behind schedule and I’ve got five models left.”

“Ok. And, hey, thanks for this!”

“Yea!” She yelled over her shoulder on the way back to the make-up area to get the next in line. Taking the towel off my shoulders, I stood up and began making my way backstage to the clothes racks. When I got back there, I was attacked with a green dress made of sequin peacock feathers.

“It’s almost a thousand dollars. Please don’t ruin it.” If the woman running the wardrobe had known a thing about me, she never would have trusted me with the dress. I

very carefully put the gown on. It was still a little too long for me and the bust was a disaster. “No one will notice the top. The peacock thing is very distracting and the sequins will catch the light, trust me.”

“Okay...” I took off the dress and watched as they moved it with the rest of the clothes I’d be modeling.

I stayed backstage with the rest of the models as the rooftop began to fill with people waiting for the fashion show. I had one friend coming to see me. One. Everyone that was part of the show knew me as the lead model, the lead model with Lupus in the fashion show raising donations for the Lupus Foundation.

By the time the show was about to start, it was dark outside. The bright lights on the stage seemed to be the only lights around, and like flies everyone was drawn to them. I started to get nervous backstage as I put the peacock dress back on. The music outside was loud and a sea of people were packed out there with a line at the entrance trying to get in.

When the lights dimmed, three other girls and I hurried onstage for the show intro. The lights exploded on, blinding me. All I could hear were the loud cheers from the invisible crowd. Some sort of digital show started with music and then there was a pop as the MC yelled “Earth!” and sparklers exploded somewhere nearby me. I was supposed to spin around and wave. But I froze with my hand sticking up motionless in the air. Wind, fire, and water all spun and waved like pros. But as we turned around to walk back up the runway, everyone cheered loudly as if they hadn’t even noticed me choke.

I changed quickly into my casual fire outfit. Each element had its own casual fashion line. Fire used only the colors red, orange, and yellow. I had on a red dress with a jean jacket, and I felt much more comfortable as the fire girls lined up to go on stage. That was, until, the girl in front of me burst onto the stage and confidently flung her curvy figure around, seductively posing with the male model she was teamed up with. Everyone went wild for them.

“Here goes nothing!” I smiled helplessly at the girls behind me, stepped up the stairs and appeared on the stage with my male partner. He was at least four inches shorter than me and twice as nervous. But we made it all the way down the jagged runway, pausing at each turn and smiling out at a cheering crowd. “That was such a high!” I yelled in the dressing room to the girl next to me as I changed into my final outfit.

“Yea, I had no idea it’d be like that.” The girl watched as I put on a purple shirt over jeans and black heels. “Oh, you’re the girl that’s going to be at the front. I mean, you’re the girl with Lupus.”

“Yep. That’s me.”

“It sounds pretty awful. How are you doing?” She felt uncomfortable asking me, but after three years I’d gotten used to people feeling uncomfortable asking me about Lupus.

“I’m actually great. I’ve been in remission for almost five months now.”

“Wow that’s great.”

“Yea, thanks.”

“Final run, girls!” Someone yelled backstage. Everyone scrambled into place as I

clumsily made my way to the front of the line. From where I was, I could look out and see the digital presentation on Lupus. I didn't feel like I had the kind of Lupus they were talking about. For me, Lupus had been about more than my disease attacking my body and deteriorating my joints and organs. It was about being demolished and rebuilt, over and over again, until the only parts of me that survived were the ones most important to me and the rest was something new that was created to fill in the pieces.

"You're on," a girl with a headset told me as she passed me a lit candle. I stepped out onstage to silence. No music was playing and the crowd was motionless. The only noise came from my heels as I slowly stepped down the runway. A girl whose mom had Lupus followed close behind wearing a white shirt and carrying her own candle. When we made it to the end of the stage we stopped and looked out into the black sea in front of us. As a group, all the other models, wearing white shirts and jeans and carrying the same candles, came up behind us until we were all packed on the stage together. The MC initiated a moment of silence, where everyone closed their eyes and bowed their heads. Wide eyed, I stared straight ahead into the blackness and smiled. A cool breeze blew across the rooftop and through my hair.

I wanted to jump off the stage. In the utter darkness of the crowd, created by the bright spotlights above me, I was certain I would fly.

Works Cited

Brown, Cupcake. *A Piece of Cake*. New York City: Random House Inc, 2007. 1-472.

Print

Garland-Thompson, Rosemary. *Extraordinary Bodies*. 1. New York: Columbia

University Press, 1997. 1-200. Print.

Gorokhov, Elena. *A Mountain of Crumbs*. New York City: Simon & Schuster

Paperbacks, 2009. 1-308. Print.

Kuusisto, Stephen. *Planet of the Blind*. New York City: Bantam DoubleDay Dell

Publishing Group, Inc, 1999. 1-194. Print.

Linton, Simi. *Claiming Disability*. New York: New York University Press, 1998. 1-200.

Print.

McDermott, Ray. "Culture "as" Disability." *Anthropology and Education Quarterly*. 26.3

(1995): 324-348. Print.

Mitchell, David, and Sharon Snyder. *Narrative Prosthesis*. Ann Arbor: The University of

Michigan Press, 2000. Print.

Oliver, Michael. *The Politics of Disablement*. Hampshire: McMillan Press Ltd, 1990. 1-

152. Print.

Wills, David. *Prosthesis*. 1. Stanford: Stanford University Press, 1995. 1-350. Print.