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ZORA

by

GENEVIEVE ANNA TYRRELL
B.S. Towson University 2006

A thesis submitted in partial fulfillment of the requirements
for the degree of Master in Fine Arts
in the Department of English
in the College of Arts and Humanities
at the University of Central Florida
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Major Professor: Lisa Roney

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ABSTRACT

This mixed-media memoir uses a variety of forms from short epigrammatic essays to straightforward stories and graphic narratives to explore the author's coming-of-age experiences augmented by chronic illness. Trying to succeed in the film industry, romance, and family situations, the young female narrator navigates the often unexpected or disappointing consequences of having an autonomic nervous system disorder. Relationships between conflicting identities emerge—between healthy versus sick self, projected/envisioned versus actual self, and tough versus vulnerable self—as the narrator journeys toward a more complete and accepting self-understanding.

This is dedicated to all those with Dysautonomia, those who suffer with “unseen” or “invisible” illnesses, and to the people that work very hard in the film industry every day, pushing their bodies, minds, and spirits to the limit.

ACKNOWLEDGMENTS

To my parents: Julie Anne and Joseph Vincent Tyrrell, thank you for your wisdom, patience, spiritual support, financial help, and openness to allowing me to be creative and artistic.

I'd like to thank the researchers and doctors, including Dr. Harvey Mudd and Dr. James Finkelstein, that have not only helped me out along the way health wise, but have also accepted me for the odd patient and human being that I am.

Also, I'd like to thank my creative writing friends within the MFA program for helping me through the writing process of this thesis, including but not limited to: Sherard Harrington, Jen Karr, Jonas Mueller, Ashley Inguanta, April Urban, Patrick Anderson, and Tamra Martin.

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PROLOGUE: ZORA

Under the influence of a gene theory, in which disease arises from features of our genetic make-up, we are better or worse organisms, attacked from within, in a kind of horrible betrayal.

—Judy Z. Segal, *Health and the Rhetoric of Medicine*

Never tell a child you have a soul. Teach him, you are a soul; you have a body.

—George MacDonald, *The British Friend*

In 2003 I studied film at Towson University and prepared to make my escape to Hollywood via a national student exchange program to a college in Los Angeles. During the spring semester I took an introduction to scriptwriting class with the chair of the film department. For my final project I decided to do what a lot of budding writers do—write nonfiction masked as fiction. Looking back on it now I'm sure my mini-script was a dead give-away of diary fodder. I wonder if my professor, despite his thick exterior, actually felt sorry for the young woman who had recently been fired from her job and feared her dad's mortality on a regular basis.

The character of Zora originated from that script, born from my insecurities about writing creative nonfiction, along with my love of Zora Neale Hurston, and the underdog winner, Zora, a contestant on a reality TV show series in its first (and only) season, *Joe Millionaire*. Joe was a construction worker under the guise of millionaire, a persona constructed by the TV show. Women fought for his love on the show, having no idea about his lacking bank account. In the midst of women with dollar signs in their eyes stood Zora, a thirty-something care-giver to the elderly and a substitute teacher—kind and empathetic, but a force to be reckoned with—she never undermined her ethics, unlike the other women who were willing to do anything to get a

millionaire. And one night, as I sat on the edge of my couch absorbing the unfolding melodrama on *Joe Millionaire*, it suddenly dawned on me, “That’s it! Zora! That’s the perfect name for my character!” Funny how these things come about.

So I wrote about myself for scriptwriting class, but replaced my name with Zora—only she was way cooler than me. And wrongs were righted in her world. Bosses who fired their young female employees for not accepting interoffice sexual relations had their fancy cars smashed into by drag queens speeding down the road, too busy yelling out the lyrics to *Like a Virgin* to notice the speed limit. Yes, Zora’s world was much fairer than mine. Zora dealt with my problems and insecurities, kicking some ass along the way.

So, naturally, the character of Zora came with me to Hollywood. I kept working on the script I had originally started in that introductory scriptwriting class as something I hoped to one day produce. Something strange happened though: Zora became my muse. I shared secrets with Zora, the woman I wanted to be and really always had been deep down inside. I took notes everywhere I went, documenting my adventures and hardships, jotting down dialogue, describing encounters. A scripto-manifesto. Zora would play it all out in the script I constantly worked on.

When my health failed me, I turned inward. I hated myself while loving Zora separately. Who I wanted to be and who I actually had become were two identities that drifted farther away from each other with every passing day. Zora charged onward, healthy, strong, the film girl extraordinaire, the bad-ass girl on set lifting heavy gear and running errands for directors, while I lay in bed feeling sick.

One day, as I described my latest installment of Zora to my mother on the phone, Mom asked, “So will Zora have your health problem?”

“What?” I gasped. She couldn’t have actually said what I thought she said.

“You know, will she have what you have and then you can write about—”

“*Hell no*. I would never—I could never do that to her—How could you expect me to do that to Zora? Jesus, Mom.”

I had fallen in love with the character I created and essentially the persona I had created. I wanted to protect her at all costs. I couldn't make her sick like me because it would be like giving my own child a disease on purpose. Truth be told I didn't see what I had as permanent either. Somehow Zora and I would persevere. The times that tried my body served as mere temporary road blocks that strong people could overcome. I just had to be strong. Like Zora. So for the first couple of years in Hollywood there would be no sick Zora.

But life has a way of taking paths we least expect. Eventually it became impossible to even imagine Zora as healthy because I no longer knew anything close to healthy. How could I write what I didn't know? And I needed her. I needed her to fight this battle for me too. I needed her there with me in the doctors' offices holding my hand while I waited cold under tie-in-the-back hospital gowns. I began to consider the possibility of writing Zora as a sick character, a crushing blow for me initially. Even after I accepted her as ill, I couldn't bear the thought of putting my real name as the author of such a script. What if people found out I was sick? What if they thought I was too weak to work? What if word got around? *Oh God*. The film industry didn't exactly welcome illness with open arms.

By November of 2007, Zora needed more than a script length project. As my asshole boss screamed at me in the background, I jotted down notes for the “Nano-Wrimo Challenge” a friend dared me to partake in. I didn't ever enter anything for the contest, but it got me thinking about the potential of writing a novel first and then maybe afterward a script. Zora really did deserve a full length book. Her life was too complex for a mere ninety-minute script. Within a

year, my uncle gave me *My Movie Business*, a memoir by John Irving, the writer of both the novel and screenplay of *Cider House Rules*. Creative nonfiction appealed to me. I valued how Irving managed to make early gynecology interesting in his memoir—fascinating and engaging even—and then take his personal knowledge of gynecology to the big screen in *Cider House Rules*. It seemed mind-blowing to me how artfully Irving could weave the scientific with the human condition. I wanted in.

In 2008 I decided to own up to me. All of me. For better or worse. I decided to embark on a memoir about what it's like being a young woman in the film industry while dealing with an autonomic nervous system disorder, tracing the steps of how I got there along the way. This me could talk about family mental illness, a biological father who left, what it's like being adopted by my grandfather, and how as a patient I sometimes feel like a zoo animal on display. This me could spew biochemistry with gusto wearing nothing but a buttless hospital gown.

I respected that the average person doesn't know how to write a book without formally learning the skillset necessary, so I applied to graduate school for creative writing, and started the fall semester of 2010. My first semester of my Master of Fine Arts, I signed up for a Ph.D. level course in medical humanities, which is how I became introduced to Jerome Groopman's *How Doctors Think* and Judy Z. Segal's *Writing and the Rhetoric of Medicine*. These opened up a meta-cognitive element to my creative writing. I studied myself as a patient, and how that could potentially influence why I thought the things I did about myself, why I felt compelled to write about the topics I chose, and why I felt such a sense of brokenness of identity taking place within myself.

What I hadn't anticipated was just how much more of my journey I would have to live in the midst of writing this memoir. I thought I already had a story to tell, and, yes, I certainly did, but as a memoirist, you keep living even while writing about the life you already lived.

I thought I had already gone to the darkest places I'd ever go, but half way through my M.F.A., around December 2011, I found out otherwise. Then I didn't think I could come back from that dark place. The pain I felt—physically and spiritually—overwhelmed me. Frankly, there wasn't enough typing in the world that could express it. That Christmas, I felt an overwhelming sense of loss. I didn't logically think I'd find good health under the Christmas tree, and yet after unwrapping all my presents, I felt such a sense of sadness that all I really wanted was good health but no one had given it to me.

By then it became clear to me that Zora was much more than a character or muse. She really represented my soul. I had spent many years separating my soul from my illness, from my body, from the life I really lived, in order to survive, in order to have hope, in order to get through each day, each doctor's visit, each let down. As I had developed into more of a whole person through writing my memoir, Zora—my soul—finally faced my illness. Zora finally took on my illness and all its consequences. I was whole and fractured all at once. It was too much to bear.

At that point I turned to God with questions, to my doctor for anti-depressants, and I sought to investigate what more I could add to my life in order to get through my sense of loss. Around this time I looked up David Mack's work that had moved me many years prior, back when I was still a teenager. His heroine through many of his graphic narratives is code-named Kabuki, and her journey of identity crisis has resonated with what I've gone through. To my surprise his latest book in the series, *Kabuki: The Alchemy*, served as her personal struggle to

confront her persona, to confront becoming a whole person and fulfilling her dreams, albeit never in ways she had anticipated before. She turned to her childhood love of visual art to complete her healing, making her own graphic narrative to inspire others.

Visual art had been my childhood love, and the film industry I had gone into had been an extension of that. Yet, during my career ups and downs, and my illness, I had stopped creating visual art altogether. After reading *Kabuki: The Alchemy*, I realized that my journey couldn't be effectively expressed through a chronological narrative or even through writing alone. I decided it would be told best by mixing genres and incorporating visual art as well. And strangely, in turn, this change of artistic process created new discoveries about myself and a sense of peace from the dark place I had gone. Between writing short stories, essays, and poems, I began making visual art on a regular basis and even took a couple of classes to brush up on my skills. I felt myself and Zora become one, whole, finally with some sense of peace regarding this unity. She—I—We can bear taking on the consequences of my illness better with writing and visual art. We are one without separate goals or plans. We dream as one in the here and now. More so than ever before she is simultaneously my own spirit and muse, creating, manifesting, divulging.

Does this book signify the end of a journey? No.

This is my story thus far—dual identities of the girl I am and the girl I wanted to be—and perhaps the woman I've become.

(Note to reader: Some names have been changed to protect the guilty.)

FOR SOME

For some it's a way out of some place they don't want to be.
For some it's running to the chaos they know best.
For some it's trying to be a part of something larger than life.
For some it's to say, "I was there."
For some it's a longing to tap into a Camelot of sorts, a Classic Hollywood, the days of Marilyn Monroe.
For some it's because they need to be validated as a successful Somebody in two-story font size lettering.
For some they got to watch the teary-eyed Oscars speeches on TV one too many times as a kid.
For some they did it on a dare.
For some their parents pushed them into it.
For some they needed dough for rent or food and there was this guy who knew another guy who said he had a job opening.
For some it's actually about the art form.
For some, Manipulation is an art form.
Some thought it was the only way they could be creative and still make a decent living because there aren't exactly Fine Arts firms hiring.
Some thought they'd see the world.
Some are born entertainers and it's their "calling."
Some realized they need to supplement their theatre paycheck with film and TV.
Some found out that being an electrician in Hollywood isn't limited to wiring houses.
Some had a friend back home who said, "Dude, let's go!" and so they said, "Okay, bro!"
Some just need an audience.
Some need a family.
Some had a father who was a stunt man.
Some need an impossible challenge but can't cut it in the Olympics.
Some thought if they didn't go, they'd regret it for the rest of their lives.
For others it's purely business and they just happened to have grown up in the area. They know nothing else.

I'd say it was at least eleven of these reasons for me.
Twelve if I'm being honest.
Thirteen if I'm feeling confident.
Fourteen if you can show me a good time.

LOS ANGELES 101

The 101 will scare you the first time you drive on it through Los Angeles. I'd say it scared me worse than the first time I drove up the 83 through Baltimore. At least the 83 only had two or three lanes at any given point. There weren't five lanes across like some sections of the 101, six at a couple of the exit-ways. But it's the winding nature of so many lanes, while lanes disappear and new lanes emerge to make way for upcoming exits and on-ramps, that makes it so scary. Don't forget the pot-holes. Just when you get the hang of turning the car at that speed with several lanes of cars across, you will hit a big bump in the road that will send you a bit off course, maybe even temporarily losing control of the car. That's only when it's moving though. When the traffic is congested, which it often is, your life comes to a bumper to bumper halt. You can't exit even if you want to. Then, every quarter of a mile, going around downtown, you'll end up under an overpass, bumper to bumper. At times like these I always remembered my Dad's many structural engineer lectures during road trips where he pointed out how unsound every structure would be in relation to an earthquake or fire. Earthquake resistant structures were his specialty after all. That's the other thing: The 101 is one of those few highways in the states where you can expect that maybe, just maybe, the ground will give out below you during your day or something will most definitely come crashing down on you. Hell, maybe you'll even be so lucky to be stuck behind a landscaping truck, rusted out, with tree limbs stacked twice as high as the truck should hold. The further up the 101 you go, you can almost count on having some sort of traffic jam due to smoke from wildfires clogging your vision in August and September, though any time of year it can happen.

The first time I drove the 101, it scared the living piss out of me, but I was determined to master it like the 83. I felt if I persevered, if I was devoted, if I paid attention just long enough, I

could know the 101 like the back of my hand. I could steer the wheel with my eyes closed. I could get to where I wanted to be.

Funny, I didn't notice the 101 when I was fourteen, back when my parents took me on a cross-country trip that landed us in Santa Monica for a couple of days. While waiting at a bus stop in Santa Monica, an old lady complimented me on my one long, thin braid adorning the side of my bob haircut. She didn't give me that look like I was a trouble-maker with a funky hair cut. The kind of look I had gotten quite a bit back home, even though we were only an hour from the city of Washington D.C. to our west and forty-five minutes from Baltimore to our north.

I made up my mind at that moment that I wanted to live in Los Angeles at some point in my life. I put it on my mental "list of places to live" I had started accumulating at age ten (the first place being Orlando because of Disney World, palm trees, and warm weather of course). I saw Los Angeles as a place where I could be me and that was okay. I saw it as a place that wouldn't stifle me.

APOPTOSIS

Act I – Training

Mom wove peanut butter and jelly sandwiches from fabric and stockings. Silk-screened traffic-jammed ants onto T-shirts. Knew how much Phenobarbital to give our Labrador when lightning and thunder threatened to bring on epileptic seizures. The early morning when Mom found Grannie confused in the shower, Mom reassured her, “Oh you’re not late for work, Grannie. Don’t you remember? Today’s Arbor Day. You have off work, honey,” guiding her blind footsteps back to bed. You were in awe of Mom’s skillset, until the day she zipped through a red light with your passenger door still open. She said to keep you from “being abducted by serial killers.” You understood then that the responsibility had become yours to do the problem solving.

Act II - Evolution

You evolve into an 8am pencil skirt and red Mary Janes rushing across the sidewalk along Sunset Blvd. Every single type of flavored creamer, hazelnut, mint, mocha, vanilla, strawberry, is holding your day together. You never know what flavor the producer might want to try today. Stockpiling possible solutions is necessity.

Office phone rings. The producer screams *What The Fuck* on the other end of the line. But this has been anticipated. You find the words, the tone of voice, and the plan to ease his fears. You are tempted to tell him it’s Arbor Day but instead say, “I’ve got it all under control. No worries.”

This is how you develop, like a third breast for your second puberty. You tell yourself you don’t give up. You are a fix-it person. You are seer of all possible solutions.

ACT IV – *Encyclopedia Girl Speak*

You try to explain, really you do, when people ask, “What is the name of your illness?”

The diagnoses sound like science fiction calamities:

NCS and POTS are forms of Dysautonomia. NCS is Neurocardiogenic syncope which is also called vasovagal syncope, and syncope means “to faint,” but then this also can overlap with POTS which stands for Postural Orthostatic Tachycardia Syndrome, and of course most “syndromes” are simply a list of symptomology that include everything but the kitchen sink, with no known cause or cure. There’s quite a bit of overlap with the symptoms of Chronic Fatigue Syndrome actually, though many patients have also been diagnosed with Fibromyalgia.

You try.

Somewhere—usually around the fourth syllable of “Neurocardiogenic”—people’s eyes glaze over. The ones that have a little more gumption hold on until the word “Postural.” You resolve to simplify your answer: *It’s called Dysautonomia, and that means the Autonomic Nervous System is out of whack or broken.* But then you have to define the Autonomic Nervous System for most people, saying it’s everything the body takes care of without consciously thinking about it—breathing, heart rate, blood pressure, temperature, and gastrointestinal tract.

For years you only tell the ones you trust with this information. You fear telling the wrong person in the film industry. Who wants to hire a production assistant who might spontaneously black out? Can you hold up this sham much longer? You tell yourself that this is temporary, that you can fix yourself, even if your doctors can’t.

Your mantra: *For every problem there is a solution.*

Act V – *Inner Monologue*

I wanted panoramic. I wanted cinemagraphic. I wanted camera angles. I wanted lights. I wanted action. I wanted painted scenes. I wanted costumes. I wanted gear. Wires. Tape. Audio. Microphones. I wanted wind machines. This life was meant to be directed. I wanted shouting out orders. I wanted megaphones. What doesn't kill you makes you stronger. What doesn't kill you makes you stronger. What doesn't kill you makes you stronger. *You wanna make this rough? You wanna show me how much you can throw at me? Well bring it on.* Gimme Your Herpes High Definition. Gimme Your Fainting Gaffers. Your Deafest Audio Men. Your Gimpiest Runner. Your Blindest Production Assistants. I'll complete this film if it's the last thing I do. I'll complete this film if it's the last thing I—

I need to know: Where does my soul go when I black out? The pain in my head, the cold concrete floor mashed into my face soaked in a puddle of my own drool, the fuzzy nature of the world—a small opening of light at first—like I've just entered a portal to someone else's life—the immediate surroundings of just a couple of inches in focus at first and then slowly the rest of the world becomes clearer—and then speeds up in fast motion as the mumble of voices I cannot quite discern other than the tone—the syllable—the sound at the end of each mumble is raised as if asking me a question, and then the individual words come, they spill out all over my brain like photographic developing fluid turned on its side chugging out in rapid glug-glugs—MA'AM? MA'AM? CAN YOU TELL ME YOUR NAME AND NUMBER?—and I wonder how I got there and where I am, but before any of that process of becoming human occurs—before I am fully re-animated—Where was my soul? Did it leave and then re-enter my body? When I passed out, falling out of that chair, did I keep falling? Did I fall into space, into the universe wide-open, slipping through the earth in a 1/16000th camera shot speed, going through molten

rock and eventually China, did my soul fall some place so far that my own body became a foreign residence? Will it ever be the same again?



Act VI – *Underneath*

It wouldn't matter you know, even if you became healthy now, because there's a change taking place—PRI-OR-I-TIES—Fixing other people's flavored-creamer emergencies surfaces on the other end of your twenties as futile, as petty, as not the kind of life you want to live. Focus shifts from queen of fixing outside chaos (because that's what you do so well), to healer of inside chaos (for your own physical survival).

The new you is bleary-eyed ready. Unhinged. Armored.

Don't analyze tit and ass size to know who'd make a good production assistant. Don't critique hairdos as verification of who can manage production finances. Am I cute enough for you? Because I die in secret. Am I good fuck material? Because I pray I can make it through to

lunch time. Hey baby, hey baby, you know my eyes are up here, right? They're bloodshot from searching the web late at night—to read up on the methylation cycle, the endocrine system, the mechanism of nitric oxide on the arteries near the heart.

Enough. It wouldn't matter you know, even if you became healthy now. You realize you love film as an art form, not the celebrity, not the paychecks, not the kiss-asses. You realize the division within yourself. You realize you love film so much you must leave the film industry.

Act VII – Whole

You have divided into two, only to come back as one whole. No longer do you pretend to be healthy when you are not. For a time you are revitalized. You are reborn. Your new career affords empathy. Your new friends bring you food when you're too sick to leave home. Your new city isn't so material-obsessed. But that doesn't stop the pain deep in your limbs that keeps you up at night or the mind-numbing fatigue that makes you forget simple words like “spoon,” “book,” “cereal,” or complete thoughts vanishing mid-sentence. It doesn't stop the trips to the bathroom where you can barely walk a few steps because of sore, stiff legs, tender feet that feel as if tissue paper is the only protection between floor and body tissue, dizziness that sends you careening a knee or forearm into a doorway, or the shortness of breath from standing back up after sitting on the toilet to take a piss.

Act VIII – If This is Peace, I'll Eat My Hat

Researchers find there's a genetic mutation causing low Choline levels in multiple areas of your body. They say that among other problems, this weakens the immune system. But then you knew that already. You read about the lab mice. You know the outcomes. For now

Shingles deform your skin as you sit on the floor trying to figure out how you arrived here, at this place of consequence, the permanence of genetics which have no cure. Sledgehammers pulverize all two hundred and six bones. Meat grinders work your muscles. You cannot imagine childbirth is worse and then you cannot imagine that you will ever bear a child.

You conjure up a fetus starving for Choline in your belly, a tiny translucent chest heaving up and down, glowing red like E.T., heart failing deprived of its vital nutrient, because your mind takes you there, because you're morbid, because you have lost something human. Or perhaps this is what human is at its core.

Silence.

You uncross your legs from Indian style. You roll to your side for better leverage, hoisting yourself up off the floor, and step toward the bathroom, taking off shirt first, then pajama bottoms, then pride. The soul takes a long, hard look at your naked reflection, weighing the situation, calculating your numbers. *So this is how it is.*

Shiver. Turn knob. Hot water rushing out. Stopper in drain. Bathtub filling up. Shiver. Dip. Burn. Plunge.

Breathe.

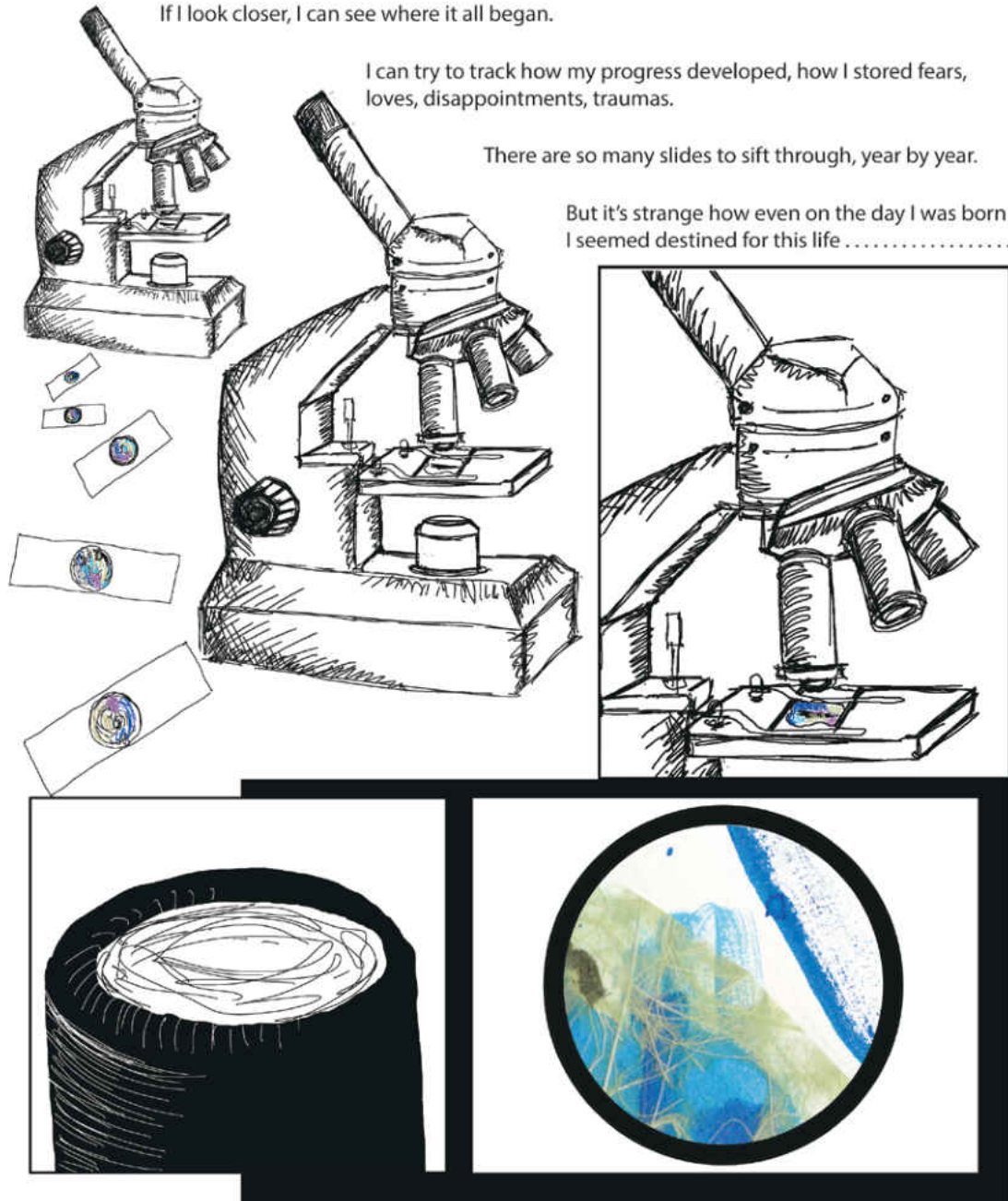
The words, "I quit," fall out of your mouth. For the first time in your life you recognize them for what they are and you are relieved. The phrase spills out of you again and again, more audible than the last time. You find yourself shouting. *"Do you hear me? I quit."* You splash

the bathtub water. The neighbors upstairs stop moving, waiting to eavesdrop your next installment. *“I don’t have to suffer anymore.”*

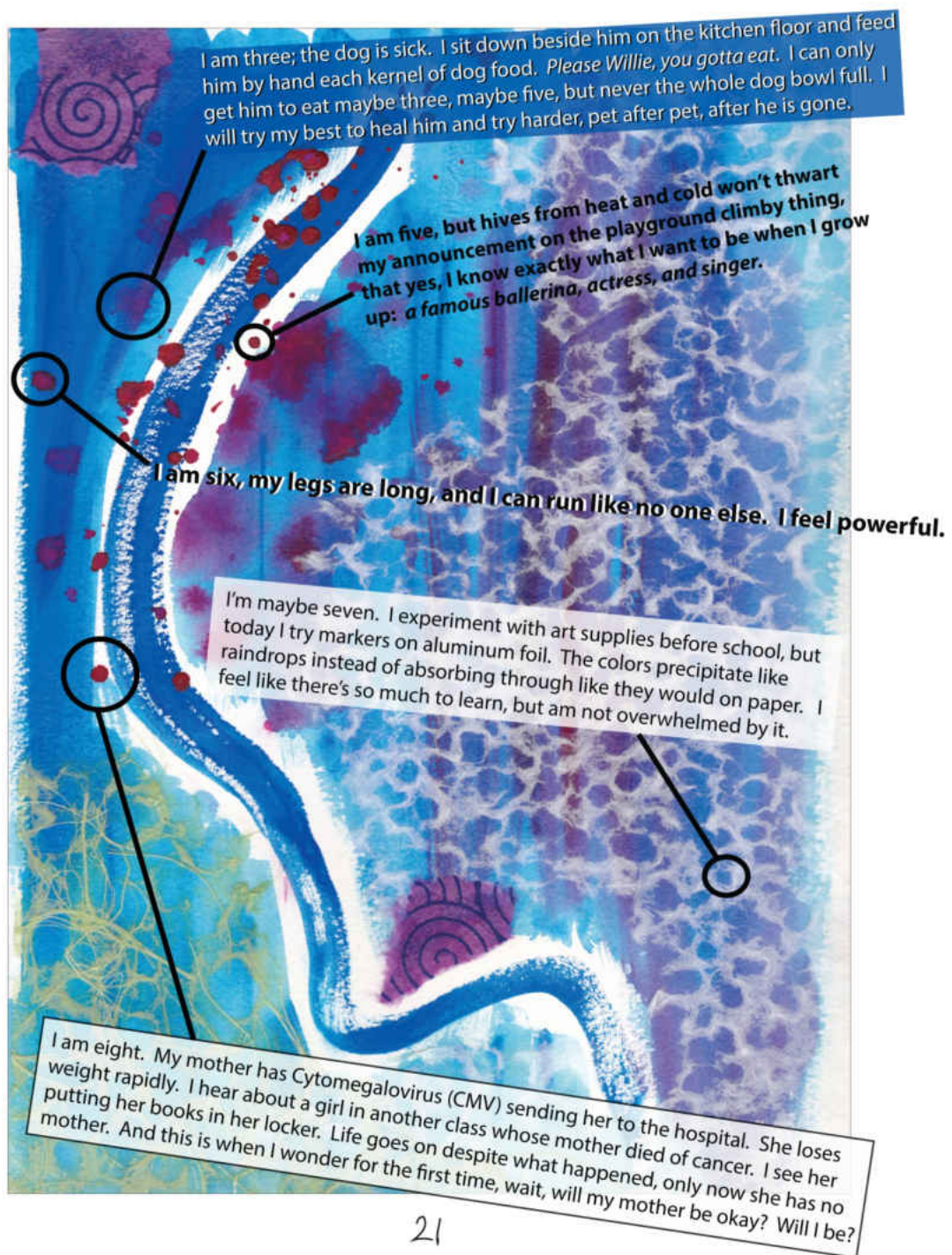
You imagine your soul free of this body. You imagine a thousand different deaths creating a release. You are seer of all possible solutions. For the first time in weeks you feel a smile cross your face. For the first time in years you’ve fixed something.

TIMELINE OF SELF-ESTEEM AS DEMONSTRATED THROUGH HEALTH & ART

TIMELINE OF SELF-ESTEEM AS DEMONSTRATED THROUGH HEALTH & ART









I am eight. Our gym teacher told us that overweight, lazy, unhealthy kids have too high of a heart rate. She teaches us to calculate ours by showing us how to push on the arteries in our necks or pressing on our wrists. I figure mine out while gasping for breath, and realize I'm not in the norm. I lie and say that I am. The gym teacher eyes me like she knows I'm lying and asks me again. All the other kids turn to look at me, so I lie again. I tell no one about how my heart pounds in my chest and from now on I feel compelled to lose weight.

I am nine. My new anti-histamines and my own hormones help me pack on the pounds. I hide my body as much as I can. I feel fat. I feel ugly. I don't even bother calculating my heart rate anymore.

I am ten and April, the pudgy red head in my class, says I'm a liar, that I couldn't possibly have drawn Eleanor Roosevelt that well. I take this in stride. I know I'm that good, and April can kiss my butt.

Eight, nine, and ten. My parents raise me on old time movies. At ten I watch Hitchcock's *Rear Window* back to back, over and over, studying the storyline, dialogue, clothing, cinematography, acting, directing, lighting, even the soundtrack. I want to be a part of it all, and I study, feeling confident one day I will be.

I am eleven and the hives come on with a vengeance one day after playing soccer in gym class outside. I feel light headed. I feel like a freak, but in some ways I don't mind feeling this way. Different is interesting, unique.



I'm ten or eleven. We are coming home from a beautiful day out. We see my yellow Labrador, Sassy, convulsing in the backyard, trying to stand up, and then falling back down. I can't get back there fast enough, but Mom keeps me away. I'm scared of what I'll see. I'm scared she's eaten something poisonous. *Is she going to die?*

I can't get rid the image of her standing up and collapsing like a broken doll over and over. It feels like an assault on my dog, and when I find out that it's "epilepsy," and then what epilepsy is, I am disturbed by something inwardly assaulting her. This horrible thing that happens to her seems like only something that a bad man could do to an innocent. I can't reconcile her own happy-go-lucky, tail-wagging, ball-fetching body waging war against itself.

And then something even stranger happens: My mother comes to me one day, sits me down for "a talk," and asks me if I would like to give Sassy up for another, new Labrador without epilepsy. I yell, "No," and then interrogate my mother: "How could you even ask me that?" She says that she promised me a healthy dog, and she didn't think I'd want to give Sassy up, but she just wanted to make sure. I cry. I tell her it's not even a question that should be asked. This is the first time I realize that people make decisions based on health. People can choose to abandon you if you're not well enough.

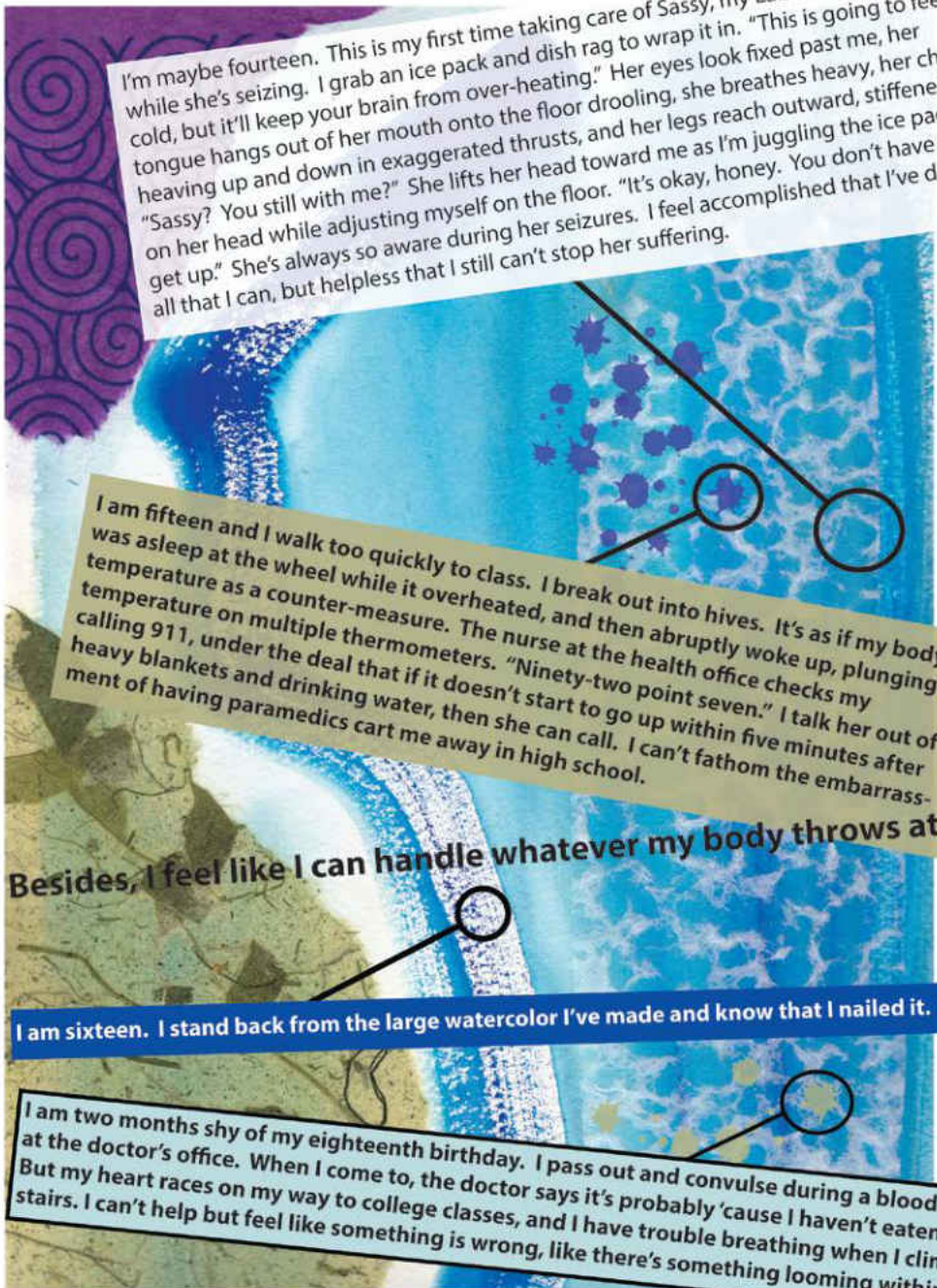


I am eleven and hives start to close my throat, suffocating me, and I go blind for a few minutes, until Dad brings me ice water which somehow stops the attack. Now I have to carry around an Epi-pen in a purse during the school day. I feel like I must be the only girl in school packin' a needle.

I am twelve and a skinny, blonde girl makes fun of me for having asthma from paint fumes in Tech Ed. I have to leave my creative project behind. I stand outside the classroom, door shut, with my inhaler. She comes to the window and fake coughs, laughing in between, taunting me in a baby voice: *Aww, poor baby can't breathe, boo hoo, waaaaa, I want my mommy.* One of her friends eggs her on with laughter, and the other friend, a girl I thought liked me, stands there looking confused as to what to do, frozen in one spot, not stopping the torment. I feel isolated.

I am twelve and my art teacher praises my current art project, early before school, as I've done so many times this semester. Doesn't matter how weird my body is. In this art room I rule.

I am thirteen and taken to a hives specialist. I am hopeful about this visit, anticipating that maybe, just maybe he will have the answer so that I don't have to sit out of gym class anymore. But then he makes my mother leave the room, he sits me down next to his desk, and I immediately sense that something is wrong. It's just a vibe at first. Then he says I must have tried cigarettes, alcohol, and drugs at some point. How else could I have my symptoms? I insist I have not. Finally, he sighs, shakes his head, and says, "Well, I can't help you then if you can't even tell me the truth." I am struck by how I can tell the truth and yet be so alone. Somehow I thought that the truth made everything better; that the truth would reveal answers. I decide then that exercise, temperature, and stress-induced hives are just oddities I'm going to have for the rest of my life, and to never have hope again that I'll get rid of them.



I'm maybe fourteen. This is my first time taking care of Sassy, my Labrador, by myself while she's seizing. I grab an ice pack and dish rag to wrap it in. "This is going to feel cold, but it'll keep your brain from over-heating." Her eyes look fixed past me, her tongue hangs out of her mouth onto the floor drooling, she breathes heavy, her chest heaving up and down in exaggerated thrusts, and her legs reach outward, stiffened. "Sassy? You still with me?" She lifts her head toward me as I'm juggling the ice pack on her head while adjusting myself on the floor. "It's okay, honey. You don't have to get up." She's always so aware during her seizures. I feel accomplished that I've done all that I can, but helpless that I still can't stop her suffering.

I am fifteen and I walk too quickly to class. I break out into hives. It's as if my body was asleep at the wheel while it overheated, and then abruptly woke up, plunging my temperature as a counter-measure. The nurse at the health office checks my temperature on multiple thermometers. "Ninety-two point seven." I talk her out of calling 911, under the deal that if it doesn't start to go up within five minutes after heavy blankets and drinking water, then she can call. I can't fathom the embarrassment of having paramedics cart me away in high school.

Besides, I feel like I can handle whatever my body throws at me.

I am sixteen. I stand back from the large watercolor I've made and know that I nailed it. Proud.

I am two months shy of my eighteenth birthday. I pass out and convulse during a blood draw at the doctor's office. When I come to, the doctor says it's probably 'cause I haven't eaten yet. But my heart races on my way to college classes, and I have trouble breathing when I climb stairs. I can't help but feel like something is wrong, like there's something looming within me.

GIVE ME A REASON

Us five or six. Lemon juice sunlight squeezing through, onto ice cube morning. Not far from Towson University. Maryland. Fog. There is this voice inside me and it's screaming I can't carry all that film equipment up one flight of stairs let alone that many. Black metal steps. Endless steps. Stairway to Hell. So many steps. *Who had the bright idea to shoot at this particular apartment anyway?* And the others—My undergraduate film crew. My group. My assigned people. My troupe de film—they don't know what I'm going through. I mean they know a little, but they don't really know. So I pick up what I can in one hand and slink. Slinking's good. Slink away. Steal away. Into the fog. Into this lemon juice sunlight that does nothing to warm up my freezing cold hands. It's a fuck you over the horizon. Somewhere, on the other side of this planet, it's summer, and it's warm, so warm you can sit on your porch in a sleeveless top and shorts, and this, this peeking through of light is a reminder. Bottle Blonde rolls her eyes still in view of mine. I pretend I don't notice and turn away. She whispers *She's so fucking lazy* to the other girl.

WAIT she calls out to me. I stop and breathe. It's coming. I know it's coming.

She walks up, lunges a camera box into my empty hand, and says:

HERE. TAKE THIS.

How were they supposed to know? A couple were about my age, Bottle Blonde was about twenty-five, another was thirty something. At what age does empathy kick in? Must you have illness to truly understand? Or did I simply not afford myself empathy? Was I just too good of an actress? Was it my fault? Did I come across cocky and then pretend too well that I wasn't that sick? If so, why was I compelled to do that? When every doctor kept telling me I was "fine" did I desperately play the part of "fine"? Is this the beginning of separation between

my real self and the self I really wished I could be? Did I ever let the other students see me after walking up the big hills on campus? Or did I hide, gasping for air, until I looked presentable? Did I tell them about the heart palpitations? Or did I just work hard at looking hot in my combat boots? Why didn't I just speak up?

I suppose I feared what they'd say. They were waiting for me to pick the argument so they could tell me everything they'd been thinking about me for the past month or so. They had had discussions about me. You know it when people give each other that look of, *See, this is exactly what I was talking about earlier.* I wasn't willing to play into that though. *To Hell With Them* I told myself. Maybe they were thinking, *How is she going to cut it in Hollywood being this sick?* It was a legitimate question. I clung onto the belief that illness wasn't going to make a push-over out of me. I wasn't just going to give up my dreams because my body couldn't get with the program.

The last night of our undergraduate film shoot there are no endless black metal steps, but I never make it there. I am incapacitated, hospital bound, picked up by some paramedic—I can't tell whether male or female until he or she—he—rests his balls, for what seems like an inordinate amount of time, on my bare feet at the end of the gurney, waiting to find out which curtained room to dump me in. Oh Balls. Balls on my toes nestled like two baby chicks keeping warm, and I am too drugged with Adenosine to slow my heart rate down, to say a sarcastic retort about balls resting on my toes.

“None of this is funny.”

—Uncle Joe

Let me back up: After Bottle Blonde lunged the camera box at me, I got up the stairs with all that film equipment. I did. Black metal steps. Stairway to Hell and all that. I made it. Felt like the fattest, oldest woman alive about to belt out, “Holy cow, I thought I was gonna have me a coronary!” But I didn’t say that. Tried to hold back my gasping for air—ashamed. *If I’m this weak now, how will I make it in Hollywood next year?* I played my part as art director, prop master, wardrobe department, and continuity director for our little group. Got rose petals for the floor (it was supposed to be romantic) and business clothes and shoes for the actress (whose character was clueless about romance or her boyfriend’s advances) and my Polaroid camera and notebook to keep up with scene changes. You wear whatever hats you have to when grouped together for school film assignments.

Once in the apartment, setting up equipment, I couldn’t breathe. Figured it was Asthma. Chalked it off to the Bronchitis I was still getting over. I lay down on the couch while they all went out to McDonald’s for breakfast. I asked if they could pick me up an Egg McMuffin sandwich. I’ve never understood blatant eye rollers without adjoining commentary.

Do they realize I’m here, you know, in this room, with them?

Cowards. Just say it.

Say it loud and clear to my face without the passive aggressive eye roll.

You think I’m a lazy pre-madonna bitch who can’t pull her own weight.

Just say it.

After the shoot, I managed to make myself even more of a pain in the ass. I couldn’t drive myself home at 9am, I was so delirious from lack of sleep. The others carried on with nicotine, caffeine, and this thing called relatively good health (I say “relatively” due to their

caffeine and nicotine addictions of course). Two things I couldn't have and one I could never seem to master. So Bottle Blonde drove me home, glancing at me sideways, as I drifted in and out of consciousness on the ride back to my apartment. The world felt like a blurry place—the cars, the trees, people on the side walk, the strange dashboard ornaments of Bottle Blonde's car—what were they? Hulu girl? Jesus? Beads dangling from the rear view mirror? It didn't matter. If I actually focused my energy on any one thing for too long, a sensory overload flooded my brain until it overflowed into my nerves and blood vessels down to my stomach—churning. I closed my eyes and thought about my bed, soft comforter, a happy, warm dog to cuddle up with. I thought about how after ten hours of sleep I would find good health

Gesundheit!

Good health.

It's waiting for me somewhere, wrapped up in warm blankets and soft pillows.

It has to be. Oh mother Mary let me weep at your statues in cathedrals to bring about this thing called good health. It must be waiting for me lost in a meadow somewhere, in a garden, or like some school child in the wrong wing of the Science museum during the fieldtrip.

It must be.

Scene Change.

You want me to tell you how I grew up in the ghetto and I starved every night, while running from gangs? Fat chance. I mean I could tell you that if it makes you more sympathetic to my story. No, I was a shy, spoiled, middle-class only-child, a loner. At that point in life I hung out with only my best-friend-since-kindergarten, Patrick, and my on-again off-again

boyfriend, Matthew, who lived almost two hours away. Patrick rolled his eyes every time I told people we met that we've been friends since kindergarten, but I knew he secretly enjoyed it. I hadn't learned how to ask for help from anyone but my parents, my boyfriend, and sometimes Patrick. I was about as socially capable as a six-foot-high fence, though at parties—what parties I don't know—well, Patrick had a Super bowl party and some end of the school year party or was it Christmas?—I could sometimes fake “outgoing.”

I digress.

So after Bottle Blonde drove me home, I slept for many hours, awaking with a growling stomach, limbs weak and shaky, while my brain struggled for clear thoughts. I called my parents, saying I needed help getting my car back. I remember feeling confused as to what I was doing and how to get what I needed. All I could process was that I had to get my car back, that I had to eat something, and that I was in no shape to figure out either.

My parents drove up to Towson to buy me food (*how was I entirely out of food? Is that symptomatic of being twenty-one?*) and retrieved my car from some grocery store parking lot where all the film crew had originally met up before the shoot. My mother said, “How can you be entirely out of food,” until she saw me in person and then I suspect I looked like a shell of a human being. Yes, that over-used image, in all my gray glory, translucent skin, dark circles under my eyes, coughing—*a shell, I tell you*. A shell of her former, perfect, five-year-old daughter that could do no wrong and look as healthy as a fresh picked peach. I sat on the squishy couch in the living room, and she handed me a Lunchables packet with pre-sliced mini-servings of ham, cheese, and crackers, including mustard packet, like I was still five-years-old. I laughed. Both parents looked tired. Dad bundled up his coat tighter and said he'd be out in the

car. Mom scolded me one more time for not having food in the apartment and said she had to go. I argued as she gathered up her coat and bag, that I worked hard, I played hard when I got the rare chance, I had sporadic sleep, and I was usually too broke and/or tired most of the time to make home cooked meals. I reasoned that everyone else my age lived that way, so why shouldn't I be able to?

“So what you're saying is it was all your fault?
Getting sick had nothing to do with your genetic issues?”

—Uncle Joe

“Well, I guess what I'm saying is I could've taken better care of myself. I wasn't willing to live differently than everyone around me. I mean, everyone at that age lives that way, right? Besides, I didn't know at the time I had genetic issues.”

—Me

Was my roommate, Kristen, already home, asleep after a long shift waitressing? I can't remember. Perhaps. But to my best recollection, the events continued to unfold as described below, and in my blurry mind it felt unreal. It felt like the movie I should have been making.

EXIT PARENTS FROM APARTMENT.

ARRIVE ROOMMATE, KRISTEN, HOME FROM WORK.

GEN, OUR HEROINE, GULPS DOWN “LUNCHABLES” FOOD, AND THEN RETURNS TO HER BED.

My relationship with my roommate is strained by her boyfriend, DJ Spice, abruptly moving in with us while I had been away for two weeks during the summer before. All I know is he gets

blow jobs from strange girls at the turn table each weekend but doesn't deem that as "cheating," snorts some occasional cocaine, is way too white to be spinning Hip-Hop professionally, sometimes slaps Kristen, isn't exactly friendly with her puppy, and to top it off uses all of my items in the bathroom—shampoo, body wash, lotion, tooth paste, tooth brush. (The cigarette smoke taste on the brush gives it away.)

Is there no God?

I lie there on my bed. I'm drifting in that perfect full stomach sleepy state with fluffy comforter. My breathing slows, wavers, grows shallow, then deeper, much deeper, breathe in, but wait, I can't breathe out. I can't breathe out. *Oh God, I can't breathe out. What is this? Is this asthma? But asthma I can't breathe in, not out. This is like earlier during the film shoot, at the apartment with too many black metal steps.* I fumble for my inhaler anyway. I breathe out, press the inhaler, breathe in—ackk—cough, cough, cough. Have you ever choked on your coughs? Like when you've swallowed the wrong way "real bad?" Like when you've had the wind knocked out of you?

PICTURE'S UP.

PICTURE'S UP.

PICTURE'S UP.

ROLLING.

ROLLING.

ROLLING.

I'm on the floor. Wood-patterned linoleum under part of me, and my leopard-patterned rug under the other part of me. It's the area closest to my bedroom door, yet open enough for lying down, and I can't help but remember—after I've already heaved my body to the floor—that this is the same area Kristen's pitbull puppy, Girlfriend, always chooses to poop if Kristen is too exhausted to walk her in the morning—the dog knowing I'd never scold her for not being able to hold it in and it's our little secret. Right now I think Kristen has whisked Girlfriend away into her bedroom, keeping Girlfriend locked in there while the current havoc unfolds, but I can't be sure. Right now, trying to breath and wondering who will help me breathe, consumes me.

Kristen is on the phone with 911 like the calm, collected news reporter she's been training to be, when the door opens and guess who. DJ Spice. He drops his groceries and is by my side. I'm actually glad to see the asshole. In his spare time outside of spinning Hip-Hop and getting blow jobs from eighteen-year-olds who will give anything to get with a DJ, he has kept up with his CPR certification, because deep down he really misses being a paramedic.

DJ SPICE SUPPORTS GEN'S WEIGHT, LIFTING HER TORSO AND HEAD OFF THE GROUND, CRADLING HER.

DJ SPICE

Tell me how you feel right now.

GEN

I feel like I could pass out, throw up, and shit myself all at the same time.

DJ SPICE

(Laughs)

Okay then. Well. Let's try the inhaler again.

DJ SPICE HELPS GEN WITH INHALER TO NO AVAIL. GEN GOES INTO ANOTHER GAGGING-COUGHING FIT. DJ SPICE HITS GEN'S BACK TO AID IN BREATHING OUT. DJ SPICE THEN ASSISTS GEN IN LYING BACK DOWN ON THE FLOOR.

ENTER PARAMEDICS AND POLICE OFFICER.

POLICE OFFICER SNOOPS AROUND APARTMENT LIKE HE SUSPECTS DRUG USE IS INVOLVED. PARAMEDICS GO THROUGH USUAL PROCESS OF HOOKING THEIR PATIENT UP TO AN IV AND HEART MONITOR MACHINE, WHILE ASKING QUESTIONS RELATED TO AGE, MEDICINES PRESCRIBED, AND SYMPTOMOLOGY. KRISTEN AND DJ SPICE RESPOND TO THE MAJORITY. GEN'S HEART RATE CONTINUES TO RISE. AT 146 BEATS PER MINUTE, THE PARAMEDICS ADMINISTER A SHOT INTO HER IV. NO CHANGE IN PATIENT STATUS. THE TWO PARAMEDICS AND DJ SPICE GIVE EACH OTHER A LOOK.

When Death is near you'll know it with a sixth sense. It's primal really. Like when pets know they're going to die so they hide. There's nothing mumbo-jumbo or hocus-pocus about it. My hypothesis is: *Unless it's a freak accident or a murder you don't see coming that kills you, you'll have the time to sense Death loitering nearby.* Have you ever had your eyes shut and someone else tip-toed into the room but you still sensed someone else was in the room with you? Or have you ever been out in public and you feel you're being watched, only to finally figure out that *Aha! Yes! That creepy guy across the food court is coveting your Cinnabon roll with every bite you take?* There is a presence there, waiting, watching, planning. Death is the hunter and

you are the hunted. Only, you have a choice. You have some say in this matter. So when Death is close by, it is then that you have a decision you must make: Accept Death as an option or consciously state you are “not ready to go yet.” Oh, you might not necessarily get your way, but think of it as a job interview for staying alive. *Tell me, how much do you really want this job?*

Sell it, girl. Tell them you want it badly.

You have less of a chance if you seem unenthusiastic.

Fight for what you want.

PARAMEDICS ADMINISTER ANOTHER SHOT INTO GEN’S IV.

I thought that the paramedics would put me on a gurney to then take me down the stairway and into the ambulance at the curbside. Most paramedics I’ve had in my lifetime have had common sense and worked well with people. This is the point in which I’m all too aware now of the paramedic whose sex I cannot discern. My mind goes to weird places during serious events. *I may be dying, but I wonder if that’s a man or a woman.* Perhaps it’s a coping mechanism to let my mind drift. Perhaps, because I’m an artist and a writer, I instinctively pick up on the details of a situation. Either way, this paramedic orchestrates a two-person under-the-arm-pits-and-knees delivery method of me, which is about as awkward and painful as if I gave birth to myself down a flight of stairs.

Winding,

winding,

winding,

down,

down,

down.

Flicker, FLASH. Car lights, car lights, so bright and dim. This is the truck that takes you to the place that takes you somewhere not human. I am swimming into sleep. Don't you know? It's a beautiful evening for banana fish. The shots of medicine are finally kicking in. Second one must've done the trick. JOLT. Jerk. At least Death has left. I escape in my truck. Funny. All these lights and sirens just for a short trip. We only drove around the block in order to reach the hospital. That's where balls rest on my toes. Who accidentally pulls a patient on a gurney too close to their private parts and then just stays that way while waiting to hear from a nurse where to dump the patient? Who doesn't step back? Who is that person? I am ready to drift far, far, far down into sleep. Into dreams of banana fish and Billie Holiday.

EXIT PARAMEDICS.

ENTER NURSES.

Someone is rubbing my shoulders. *MA'AM. WAKE UP.* Nurses. Med Student. The med student is frozen in that place of wondering whether this is what she really wants to do with the rest of her life. For now, it's her job to watch, learn, and hold my right hand while the nurse rips out the IV in my left, but—*Oooowwww. That hurts. What the fuck did you do?* Blood everywhere. So much blood. On the sheets. On the floor. On my hand. Who knew that much blood could be pumping through one vein in the top of my hand? This little curtained room is

packed with people and everyone falls silent. *What the hell happened? Why won't anyone say something?* Silence is scary. Silence is being alone.

My brain slips the disk in the audio-video feed:

The Time Machine—1960—Rod Taylor as H.G. Wells—Yvette Mimieux as Weena.

Fast forward to scene where people of the future bask in the sun near the water while a girl starts drowning and shouting for help but no one responds.

They fall silent. They are ready to let her drown.

I am her.

I am a disease. I am the Plague. I am not worthwhile. I am the ever lasting image of what Med Student doesn't want to do with her life. I cry like a little girl. I sob like I scraped my knee. I am toxic. I am difficult. I am the problem patient. Oh the pain. Who knew so much pain could come from my tiny hand? I thought my hand was a flower. I thought she felt pain like a lady. I thought she'd fall back onto a fainting couch before she'd ever let on that kind of pain. *Please hold my other hand while they put the new IV in*, I say like I need my Mommy and Med Student is the substitute. I grab her hand before she can say no. Her hand is limp in mine and her eyes dead like fish. As fast as the IV is slipped in, Med Student rips her hand away from me, wipes it on herself like a junk-yard dog has just licked it, and then disappears for good.

Her disgust at having to partake in a simple hand gesture of kindness makes me angry.

I want to call out to her.

HEY.

HEY YOU.

WHERE HAVE YOU BEEN ALL MY LIFE?

I just need a lil' something. Just a slow dance. Maybe a kiss.

Haven't we met some place before?

I'm a sexy patient.

I'll make you happy.

I'll slur my words for you real good.

I look HAWT in buttless gowns.

ALL NURSES EXIT.

ENTER GEN'S MOTHER WHO COMFORTS GEN.

ENTER GRAY-HAIRED DOCTOR.

Mom is now here to my left and the doctor is to my right. He questions me about my potential drug use. He will not take my response, "No, I don't do any of that," as an answer. I'm asked over again, as though to see if I'll finally cave, if I'll slip up. Mom pipes up that I've been having trouble with symptoms for years, that I've been to several specialists already. The doctor excuses himself and asks Mom to come with him.

I found out later from Mom that the doctor didn't seem to believe me or her that I wasn't using drugs. That's when it clicked for me: my treatment by the other medical and emergency staff up until that point had been under the presumption I was some silly, stupid college girl who took drugs. I hadn't been worthy enough to hand hold, to gently take out the IV, to get an explanation or apology after ripping the IV out caused immense pain and blood to spill everywhere, to take me out of my apartment on a gurney instead of leaving me bruised. I was a suspect. It's why the police officer started snooping around my bedroom. I suppose all too often they see young girls doing stupid things. I understand their suspicions, though I'm not sure how ethical it is to treat even an overdose patient as less than human. What I don't understand is the guilty-until-proven-innocent approach.

Too many times I've gotten the reaction that I am too young to be as sick as I am, leaving me not only alienated among my peers, but among those who are supposed to be treating me.

To his credit, the doctor ended up apologizing to me after getting my blood and urine samples back. He said something like, "I'm sorry for putting you through the barrage of questioning. Too often I see young people taking drugs." Then he listened to how I had seen specialists, how they all said I was "fine," how I struggled to walk around campus, how I tried so hard to keep up with people healthier than me to no avail.

I took the first draft of this story to my uncle Joe, a journalist and film reviewer, for his feedback. Granted, it was still a grammatical and poetic train-wreck then, but I was surprised by his reactions:

"See, your nearly dying is the story.

It's the most important part of this chapter.

Why bash the med student?

You don't know her. You can't judge her."

"You're the one who's not empathetic.

You offer the med student no empathy."

"There's no likeable characters.

Hell, there aren't even characters.

Just props. And you blame everyone

when it's clearly all your fault."

"Your almost dying is the most important part!

There's your opening scene.

That's your chapter.

That's the beginning of the book."

—Uncle Joe

After his comments, I felt that pull within me—the one I had felt back as a film undergrad—a tearing between trying to be normal, yet justifying how I could be so far from normal. Between pretending so much to be fine that maybe I had fooled others, but the discomfort that I hadn't been offered kindness or empathy for not actually being fine. The covering up versus seeking validation of my illness. With uncle Joe's comments, I also felt a

revitalization of conflict between validation of my illness as potentially life-threatening (and thus seemingly worthy of empathy), versus validation of my illness as draining the quality of life from little, everyday tasks, like walking up a flight of stairs (and thus seemingly frivolous).

When I was younger, I kept the turmoil of my illness and the conflicts it cultivated within me under wraps. I told myself I would be successful in Hollywood, perhaps a youthful long-shot dream, but a sincere one at that. I told myself that everything was temporary. My illness. The frustration, anxiety, and depression I felt. The unkind words or actions of others. I told myself that career success would even out everything in the end. Wrongs would eventually be righted. Healing would take place.

So in the meantime, while I waited for my ship to come in, I opted to use my mother's mentality of "kill them with kindness," when my undergraduate film project with *Bottle Blonde* and the others came to a close. During the editing process I continued to ignore their eye rolls and sideways glances. I ignored comments about how it was "no trouble at all" not to have me at the final shoot night because my job was "so easy." Yes, I participated in the decision-making regarding where to cut the film as though nothing were wrong.

Then, in front of perhaps two hundred students and teachers, my group and I debuted our final project to the film department, garnering such respect for our work that our professor invited us down to the front of the auditorium to discuss our success at achieving such a well-made film. She wanted us to each give our perspective about how other students might be able to create the same caliber film. One by one my group pointed out the level of cinematographic mastery, the careful decisions in our editing process, the actors, the script, and then it was my turn.

“Honestly, it was my group, all of us together, working together. We were great at communicating our ideas and respecting each other. And on a personal note, I’ve been dealing with an unexplained heart condition, I got sick during production, but these guys were so incredibly understanding, thoughtful, and kind. Really, it takes a team to make a good film.”

I didn’t look at them much while I expressed my thoughts, but I could feel each one uncomfortably shrinking beside me. After the film debut, I never saw them again.

INGREDIENTS

It was never kept a secret from me that my mother had fallen in love with Michael, a man from Austria who fancied himself a chef, and that he left her when she was pregnant with me. Her mother died a few weeks before I was born. And so my mother moved back in with her father, my “Pop Pop,” who legally adopted me to become the father figure I didn’t have. I do not remember the point in time in which I found this information out. The knowing is older than my memory.

At three and four years old, I feel like my mother’s relationship with my biological father and my creation is some sort of very complicated story that I don’t entirely understand but it sounds like some sort of fairytale or nursery rhyme, like the old woman living in a shoe. I don’t understand why an old woman would live in a shoe with a bunch of children or how they could even fit into a shoe, and I don’t understand why we can’t just go see my biological father or how his relationship with my mother could be so broken. I figure it is grown up stuff that I am too little to “get” and that someday I will finally “get it.”

My mother still seems comfortable showing me a picture of Michael. Almost as if she holds out hope that one day he will return for us, for her. He is an elusive ghost. A mystery man. He lives in Pennsylvania and we live in Maryland. I assume one day he will call and we will make the road trip to meet him. In the meantime my mother keeps his picture.

I ask my mother how the story ends and she doesn’t know what I mean. I say, “What happens next?” But she doesn’t know how the rest of the story goes, and that bothers me. I decide I will school myself in this strange fairy tale or nursery rhyme about an Austrian man

until I can make sense of it and fix it so it ends the way it should. Because really, it feels unfinished. The story is incomplete.

Somewhere in Canada a researcher and her team are multiplying my skin cells. I submitted myself to the process: Iodine smeared on my pale forearm skin, needle injection to provide local anesthetic, and scalpel to cut into multiple layers of skin, extracting a piece of me. The tiny scar serves as a reminder. Now they analyze my Choline-transporter. They make lab mice based on my DNA mutation.

In Tennessee, North Carolina, and Maryland researchers test my many regular blood samples, precisely calculating amino acid and lipid levels. In a very small sector of the biochemistry research world I'm sort of a big deal in all my mutated glory. The fact that I can actually discuss the biochemistry with the researchers makes me an extra special patient, though spouting the information gets me nowhere at social gatherings.

My specimens must be shipped to specialized labs and so I go to a local lab or doctor's office to get my blood drawn and processed, and then normally I'm the one buying dry ice at the grocery store to personally ship the tubes of blood across country. It's a complicated system marked by bureaucracy, leaving the burden of blood delivery on the research patient.

People sometimes ask me what the autonomic nervous system does and how mine is screwed up. My answer is to think of the autonomic nervous system as everything that automatically happens in the body, ie., breathing, heart rate, blood pressure, body temperature regulation (thermoregulation), and everything gastrointestinal. Now imagine none of those bodily functions work properly, and that is my situation. This is called, "Dysautonomia."

It is questionable what caused my Dysautonomia. There is no known definitive cause for most patients, but some genetic abnormalities in my DNA may play a part in the severity of my symptoms. These problems are thought to be the result of inheriting one gene from my mother and one gene from my biological father. As much as my mother would like to deny Michael as a part of me, the fact of the matter is they equally created me.

Sometimes when I go to the grocery store on a dry ice/blood draw errand I think to myself: *I wonder what Michael is doing right now. Maybe he's going to the grocery store to buy bread and milk.* When I reach for the dry ice I envision Michael reaching for frozen peas. In an alternate universe I'm the one reaching for peas and he's the one reaching for dry ice.

My mother told me long ago that when she was pregnant Michael left canned goods and a package of meat on her doorstep. I try to imagine the day and time when he decided it would be a good idea to go to the grocery store to pick up food to leave on a doorstep. Maybe he didn't go to the store. Maybe he had the goods on hand. I wonder what his intentions were and what exact items he left. Canned green beans? Carrots? Chicken soup? Leg of lamb? Left over ground beef? Filet Mignon?

If I were to finally meet my biological father I imagine it would be like an on-the-spot journalistic ambush; a Dateline Chris Hansen impromptu interview with cameras finally catching my father in the middle of daily errands, forcing him to face the reality of the situation. He'd try to block the cameras with his hand and shout, "I have no comment!" Then rush back into his car or a building as an escape, dropping his groceries along the way.

There is no love lost for Michael as far as I know. He will not even acknowledge me as his own daughter.

I am almost thirty now. I look for helpful books on raising adopted children for my cousin Cissy, who is an adoptive parent, only to stumble upon books I buy for myself. The titles are cheesy. They are the self-help books written by therapists, psychologists, doctors. “Searching for Self” sounds like an act of a broken person, a person missing something, someone needier than I consider myself. But turning the pages of *Being Adopted: The Lifelong Search for Self*, a book detailing stories and quotes from adoptees, one quote stops my skimming:

“I feel like a cereal box with no ingredients,” says Jamie, who is twenty-four. “Even my furniture has a tag that says what it’s made of. And written on the tag is, ‘Do not remove.’ ”

I go through periods of time wondering: What goes through a man’s mind when his ex-lover places the phone call from the hospital to let him know that his daughter has been born and he hangs up the phone? How can a man not go see his newborn? And then, when the papers are sent to him to sign, to give up his legal rights as a parent, how can he pretend like he never got those papers? Was it a last little glimmer of hope that he actually did indeed acknowledge me and couldn’t bear the thought of actually putting pen to paper to sign me away? Or was it such sheer thoughtlessness that he would disown me to the point he wouldn’t even acknowledge there were any rights to be signed away in the first place?

After a period of time went by, and the documents had been posted in the local court house, by default his legal rights were dismissed, and my grandfather took the legal steps to adopt me. My biological father never signed me away. But he didn’t acknowledge me either.

I search the web and buy more books. I search for some sort of scientific explanation. My obsession leads me to a quote by one of the few authors I can track down who investigates how birth fathers feel about having a child put up for adoption:

[In one study a] large majority of the men...had experiences of both the pregnancy and adoption. A large majority (83%) did not see or touch the baby but a majority (60%) said they would have liked more contact with the baby. In the weeks and months immediately after the birth and adoption, many reported thinking about the child frequently. The adoption experience was described as “a period of crisis, emotionally disturbing, marked by feelings of confusion and ambivalence. Only one or two felt no strong feelings.

(from *Birth Fathers and Their Adoption Experiences*, Gary Clapton, 11)

Michael acknowledged and took care of the daughter he had before me and the three children he fathered after me. I try to imagine him having a period of crisis, but then stop myself.

Those mornings of innocence, my mother nods okay to my request to view the photograph of Michael. She is groggy with sleep, slipping on her glasses, getting up from her bed, reaching for a top drawer in the dark antique bureau that had been her grandmother's. She smiles when placing the photograph in my tiny hands. I stand there with her and study the artifact. He is with his other daughter, Alexi, my older half-sister. They are smiling. They hold up presents for the camera, one is a black and white kitten, as if he had just celebrated Alexi's birthday with her or something.

Now that I am older I still wonder what the celebration happened to be. Was the picture just all for show? Was he really that loving father, showering his daughter with gifts? Or was he making up for something he couldn't be? When I was three these things did not cross my mind. I studied their faces. I tried to find the similarities in my face with theirs. My biological father has dimples like me when he smiled. Every outing strangers commented on my dimples and how I was such a pretty little girl because of them. I was proud of them. They made me unique.

My nieces, Zoë and Mia, are eight years old and adopted from China. Technically they are my third cousins, but when my second cousin Cissy asked me, "Would you rather be called Cousin Gen or Aunt Gen," I took the latter. I wanted to be an aunt. I was already a cousin. I told her my chances were quite slim I'd ever actually be called "aunt" by anyone, even though the odds were in my favor having four half-siblings. Siblings who feel too awkward responding to my emails. Siblings I have never met in person.

My nieces and Cissy live at my parents' house in Maryland along the Magothy River, and so I've interacted with them quite a lot over the years, during visits to see my parents. I've spent many days either at the mercy of or basking in a child's curiosity. Zoe and Mia's questions are always a spontaneous act; they ask me out of the blue when we are cleaning up leaves in the yard or they catch me writing in my journal or we are dipping our feet into the Magothy River at the end of the dock.

"Did you know your grandmother?" Mia asks.

"No, unfortunately she died before I was born. I knew my great-grandmother but she was senile by the time I knew her."

Mia looks perplexed and says, “Wait. Don’t you have another grandmother? What about your other grandmother? You know, your bi-ah-bi-ah-bi-logic—”

“My biological father’s mom? That other grandmother?”

“Yes,” Mia sighs with relief that I’ve finished her thought.

What about my other grandmother? is something I have asked myself many times.

“I never met her either. I’ve heard she wanted to meet me but my biological father wouldn’t let her. That is all I know about her, other than she grew up in Germany or Austria.”

They ponder these answers to their questions with puzzled looks. I wonder if they long to know more about their grandmothers like I long to know more about mine. I *know* they long to know more. My nieces are searching for answers to a riddle called Family. I have at least half my cereal box ingredients, but they have none.

The girls are outside with friends in the summer heat and I take some time to search for new apartments online, utilizing the street view aspect of Google-Maps, peeking at houses as if I stood in the driveway. This is my sure fire method of avoiding ghetto areas. *If there’s bars on the first floor, it’s somewhat sketchy but perhaps doable. If there’s bars on both the first and second floors, it’s too rough to live in.*

My nieces come dancing into my peripheral view, still full of energy after playing outside. They continue with their many questions, the resounding one being, “Whatcha doin’?” They find it “cool” that they could view a street hundreds of miles away with me. I soon realize this online tool can be used for other things, like exploring China. I tell the girls to ask their mother the names of their Chinese cities. Cissy asks why the girls need to know this. It’s not a curiosity, but a fear I sense. She gives us the information we need with hesitation as if we three are about to steal something from her.

When we find no Google Map street views available we sigh and groan together, but then there are photographs of certain street corners, monuments, temples. I click on the pictures one by one, as Mia and Zoë coo, “Oooooooooo, pretty!”

They ask again and again, “So this is the city I am from?” “So this building is actually in the city I’m from?” “That’s a temple in *my* city?” I relish their excitement. Every few minutes, they run back upstairs to their mother, declaring their latest discoveries, telling of the treasures they’ve just seen.

At thirty, I bring up Michael to Dad in the car on our way to Target. I tell him how my mother has said my curiosities would only prove hurtful to him. He says that’s all nonsense, that “it’s only natural you would be curious.” Even though I knew he would probably feel this way it is a weight lifted to hear him say the words.

I am admitted into a research hospital facility where I hope to gain more answers about my genetics and health. It’s disappointing when I don’t, but then, before I leave, they take skin from my mother, who volunteers. They swab her arm with iodine, cut into multiple layers of skin, and extract a small piece of her for testing. We are forever bonded by this ritual and the scars on our arms.

The research hospital agrees to test to a certain extent. They won’t do a full DNA analysis because they deem it too expensive without both parents’ DNA to compare. It dawns on me that I cannot even be acknowledged as whole by the research world because I don’t have two biological parents to get DNA from. It’s a hard dose to swallow. A man I never met, who left when I was born, controls how fast, if at all, I get more information about how to fix myself.

Information about my biological father and his family tree have come in sporadic pieces over time from multiple sources. I've shaped and then had to reshape in my mind who my father is, what my half-siblings must be like, and how things became so messed up in the first place. It's detective work. I talk with one witness, only for another witness to refute the previous witness' statement, or to add on their own little details, but then each witness may change her story over time as well. At first I found out information solely through my mother, who was more receptive to giving it when I was younger. Then my mother stopped giving me information. Then when she did give information it had a negative spin, and maybe some shocking new information to add on. Every now and then I might hear a tidbit of information from my Aunt Joanne. Eventually, my cousin Cissy would grant me access to information, though I could never tell when she was being reliable or not, and I normally had to keep it a secret from my mother that I had received more information.

With each witness came their own anecdotal feelings towards the situation. My mother would emphasize how "these people"—my biological father and his family—were "evil." My cousin would swing between emphasizing how my mother made the situation much worse than it had to have been, to stating outright to me, "Well, if you had been a boy, Michael would have wanted you."

Seeking out information went beyond trying to connect with a family member; I wanted to reach out to my other half of DNA only because I was trying to get the story straight, or a fuller picture. My frustration grew for a need to weed out misinformation just to know the truth. Eventually, I spent most of my information-seeking days not asking anyone, and instead tracking down information online.

My nieces weave stories about their "Chinese mommies."

"My Chinese mommy has horses."

"My Chinese mommy has unicorns."

Cissy asks me, "Why do they need to have Chinese mommies? They have me. They do know I'm their mommy, right?"

Mia had been neglected so much in the orphanage that her head had a flat side at the time of adoption. Cissy found ligature marks on Zoë, who had been tied to her orphanage crib so often that we developed ways to hide her new crib bars with blankets. "This one is a bad one. We will understand if you want another," the orphanage women said to Cissy as they handed Zoë to her. My cousin says that Zoë was the only Chinese toddler being adopted that day that did not cry when she was handed over, that she reached for Cissy, anxious to get away.

Though my nieces have always been included into our family as blood relatives would be, they are the only Asian faces currently among our pale white family members. They inherently understand their difference. And they long to understand a strange land called China and what it means to be Chinese. Like them I long to understand my German-Austrian heritage.

I tell my cousin, "This has nothing to do with one mommy being better over the other. And it has nothing to do with you."

At about the age of four, I stop asking to see my biological father's picture. My mother buries it deep inside her bureau drawer, closing the chapter on what might have been. We—my mother, Pop-Pop, and me—move to a new town, I start school and make new friends, we get a new dog. There is so much life going on around me it isn't that I purposely decide to stop asking

to see Michael's picture; I'm a kid doing kid things. I move on from the photograph. I need more than it can offer me.

My mother's sister marries a man who had a daughter from a previous marriage. So I begin playing with my new older cousin, Courtney. I hear her call her father the word "Dad." This is a strange and new term to me. I sit in the bathroom listening to her babbling to her father in between brushing her teeth and fixing her hair, Dad this, Daddy that. I hear it as a foreign language. My mother has always called her father "Pop Pop" around me. And that's what I know him as. I put the pieces together that perhaps I should be calling him Dad instead.

One weekend outing in Annapolis, as I skip along the sidewalk, I ask my mother if it is okay to call Pop Pop "Dad" instead.

"Well, why don't you ask him yourself?" she says.

This is my first interview. *I'd like to fill the position of daughter please.* I feel too shy. Mom and I are dawdling behind Pop Pop and I beg her to ask for me.

"Just ask him yourself. Hey, Pop Pop, she wants to ask you something," she calls out like a bratty older sister.

"Well?" He looks confused.

Tiny words come out of me. I can barely hear them.

"What is she saying?"

"She wants to know—"

"Can I call you Dad?" I speak up.

He smiles, takes a moment to think, and says, "Well, yeah, I guess I don't see a problem with that. Sure." I am thrilled and at the same time I feel very sad all of a sudden. I am usurping his title of Pop Pop. I am gaining a dad but losing a grandfather. I skip along self-

consciously trying on Dad for size, interchanging it with the title Pop Pop. I ease him into his new title, but I am also easing myself into the new name-calling situation, like training wheels for my bike.

“It’s a beautiful day, isn’t it, Dad? Dad-Daddy-Pop-Pop-Poppy.Um, Pop Pop, what do you think we’ll have for dinner, Dad?..... I think I’ll still call you Pop Pop sometimes though. Is it okay if I call you both Pop Pop and Dad?”

As a teenager I become curious about the photograph of my biological father again. I encounter more instances where friends inquire, “Do you have a picture of him?” But my mother deflects my attempts to see the photo again.

“First of all, Pop Pop is your *real dad*. He adopted you. Michael is just a sperm donor. He’s your *biological father* but he’s not your real dad. Frankly, I think you must be very ungrateful for the life you have. You must not appreciate all your dad has done for you. He’d be very hurt by all this.” Comments like these are made over dishing out McDonald’s food to each other in the car, after the drive thru. As a child and teenager my biological family conversations with my mother happened as spontaneously as the ones I have had in recent years with my nieces. There’s never really a right time or place to bring up the subject. And all too often, the questions have been built over weeks of hesitance and anxiety, only to abruptly surface in everyday life.

By the time I am seventeen, there is always an excuse for why my mother can’t look for the photograph of my biological father now, tonight, tomorrow, or next week, and by the time I am in college, she finally says I should just forget about her ever finding the picture. This is sometimes followed by guilt trips that I am going to send Dad to an early grave and usually her

too. Now my longing to see the picture has become a crime against her. How and when this change took place had gone over my head during all my years of just going about daily routines of homework, chatting gossip with girlfriends, getting boyfriends, going through breakups, listening to rock music, going to movies and concerts—all the normal things that go on when you're growing up. When I wasn't looking, when I hadn't been paying attention, my mother had a pain and paranoia growing inside her that I couldn't understand, and frankly, sometimes I still have trouble understanding. And when neither of us were looking or paying attention, I had a curiosity building within me that was shaping a longing I couldn't shake.

Dad comes into Mom's room and asks to know what all the yelling is about. I feel like I just got into an argument with my mother about birth control or something else incredibly private between mother and daughter—and now my dad has just walked in. There is an awkward pause. Dad's face scrunches up, his eye brows lift, and our silence makes him expect something absolutely dreadful will come out of our mouths. Who murmurs out any words first is unclear, my mother or me. But the scene plays out something along the lines of me mumbling, embarrassed, looking at the floor with tears in my eyes and my nose starting to run, while I stand in the doorway of my mother's bedroom—standing close to my dad who has just arrived on the scene. My mother holds steadfast in her room. This is her frontline of a battle she will not allow herself to lose.

“Mom won't give me the picture of Michael,” I say softly with sniffles.

“Who's Michael?” Dad asks.

My response of, “My biological father” overlaps with Mom's reply, “Her biological father.”

“Oh,” my Dad says with a sigh and then a crooked smile. “That Michael.” His sideways glances tell me he wishes he had kept watching TV and minded his own business.

“Yes, *that* Michael,” I say with growing conviction. “Mom has a picture of him, but she won’t let me see it. I know she has it, but she refuses to give it to me. She keeps stalling. But I know she has it,” I tattle.

My mother tries to argue she simply couldn’t find it, but I cut her off with, “Oh please! You’re stalling! That’s all this is!” and I storm off to my room.

Usually Dad is passive in arguments between my mother and me. He’ll say things like, “Now girls, let’s not argue,” putting us at the level of two young sisters, or he’ll quietly whisper to me that I should just go along with whatever my mother wants or says so there’s “no upset,” no matter how impossible she might be. He likes to avoid conflict at all costs. But in this altercation, one of his other traits overrides his natural passivity. Dad is a logical man. He’s a retired civil engineer who thinks in numbers, statistics, measurements, not an artist like my mother. To him he can’t see any logical reason why I shouldn’t be allowed to have the one photograph of my biological father.

In my bedroom, I can’t hear the whole conversation between him and my mother. Most of it is muffled behind closed doors. But the one sentence from him that I hear is the honest question, “Why won’t you just let her have the picture, Julie?”

I know I finally received the photograph. I cannot remember who handed it to me or the exact words said. But it was extremely awkward. I felt like I had done something terribly wrong. My Dad, again, wanted there to be no conflict, so now that I had picture in hand I shouldn’t discuss the topic anymore with my mother. My mother, again, played the part of

victim as if my probing for the truth was persecuting her. The house went quiet and the sun set. I sat on my bed in a state of shock, joy, and sadness staring at the photograph.

I had forgotten my sister Alexi was in the picture. “*How could I forget something so important?*” I said to myself. I gently touched her hair, my finger running over the matte early-eighties texture of the photograph. I was mad at myself for forgetting. Over the years, all I had stored in my mind’s eye was a hazy image of a big smile; no sister, and for that matter I had forgotten the kitten and the presents too. But I knew he had a big smile in the picture. And he was balding. That was all I had remembered from being a little girl. As I studied the picture, a flood of memories rushed back of standing in my mother’s bedroom as a little girl. And when I again saw the dimples and the arched eyebrows on his face I saw myself. It was evidence of me. I had done something naughty digging for the truth. I was a bad kid. I was a bad person. But it was my buried treasure I had reclaimed. I grinned with pride. I laughed. It was his grin on my face.

Zoë and Mia sometimes say they are afraid of not being loved forever, of not being good enough to keep. Sometimes they tell my mother or me in secret, uncertain of how to address their concerns with their mother. I can’t help but wonder if the question they’re really turning around in their minds—whether they can fully put the concepts and words together yet or not—is the same one I know I have thought: *If a biological parent can so “easily” give up a child, how hard could it be for an adoptive parent?*

There is a day when I am misbehaving in some regard like little kids do. I can vividly recall my mother and I continue the argument after we get into our dark blue station wagon and

then, as we turn the corner off our street, she solemnly states to me, “You know I just don’t know about you, Jenny. I can’t handle the stress. If you’re going to act badly, if this is how it’s going to be, I dunno, I think I’m going to have to put you up for adoption. I’m going to have to send you someplace else. Because I just can’t deal with this.”

I begin to cry, pressing my body against the door of the station wagon, burying my face into my arms. The more I cry, the more my mother reiterates this is exactly the type of behavior she would send me away for. Whether my mother intends for it to be or not, the message is clear: *Children who are too much trouble are sent away.*

“Pop Pop wouldn’t let you give me away,” I dare in spite of my fear he will not keep me.

“Well, I don’t know about that,” she says, sighing like she is actually giving this some serious thought. “He might want you, but it’s an awful big responsibility. He’s busy with work and he’s had his children already.”

She never does follow through with her threat, but I feel uneasy about my family unit, about its stability. My fear that I will be too much trouble for my grandfather-turned-dad never goes away but grows stronger the older I become. Even though he is indeed my biological grandfather, he certainly isn’t my biological *father*. In my mind what he is doing as an adoptive parent is extra credit work. It isn’t necessary. No one is forcing him. That means it will be easy for him to leave or send me away. I fear he can revoke being “Dad” anytime he wants.

I’ve retained an accumulation of stories from my mother, and from my cousin, Cissy, who originally worked with Michael at a restaurant and later introduced him to my mother, and these are bits and pieces I’ve put together about this time period:

Michael is a married man when my mother begins dating him. Mom is twenty-seven at the time, but very naïve. Michael tells her he was divorced from a woman named Evelyn. He is actually only separated. He tells her Evelyn is a crazy mess and a drug addict. In truth she “looks like Zsa Zsa Gabor” and she meets with my mother after I am born. Evelyn takes one look at me and in her thick Yugoslavian accent says, “Oh yah, dat’s Michael’s baby!” Even then as an infant there is no denying that I am his.

No one ever prepares you for your mother losing her mind. In kindergarten we were given coloring books depicting all “the strangers” you should never talk to or walk away with, and what sorts of lures they might use to abduct us, whoever they were. I remember one scene with a nice man holding a dog leash saying he needed help finding his puppy, lingering around a playground swing-set. These were real problems. And we were trained thoroughly.

But there is no coloring book for this. And anyway, the coloring-book responses from cartoon children cagey enough not to get abducted usually were, “I don’t talk to strangers. I’m getting my mommy.” Mommy will save the day. Mommy will know what to do.

I’d like to say it is my mother that trained me. She always had a penchant of dealing with the impossible in creative ways, but even in this situation I feel terribly unprepared and alone.

It starts out as a petty fight, like when I was seven, in the passenger seat of my parents’ dark blue station wagon—only now I’m sixteen. Mom never could regulate her temperature properly, and neither could I. On this early evening she is cranking up the heat in the car as she bickers with me over what seems like everything I do and say. I open the window just a crack. The sky is spitting rain outside, and this escalates our arguing into atomic levels. This window serves more as a feeble attempt at power for her, and a symbol of freedom for me. She reaches

across my body at stop lights, closing the manual window back up, yelling at me while driving as I re-open it—not to keep this battle going with her, but because I feel like I am choking. I feel like I am suffocating. *All that pressure on my chest.* I envision breaking the window open just to feel some cool air on my face. I think: *This is what a panic attack must be.* She yells about how disobedient I am, so much trouble I am, and a lot that just blurs together, as I feel like less and less oxygen is available. I say I feel sick. She says I'm dramatic. She grabs tightly at the steering wheel, shaking it as if she were choking my own neck, while we drive over the Route 50 Severn River bridge at fifty-five miles per hour in the drizzling rain. I beg her to calm down while driving. I plead. Now all I want is to breathe. I reason to myself that I need to get out of the car at the next stop.

In Annapolis, the sun has not set yet, the rain still spits—for a moment there's even bright light peeking through the clouds—and people are all on their way home during rush hour. The streets are packed bumper to bumper. We stop in a lane next to a left turn lane. This seems to be my only chance. I decide I will get out to walk to a local 7-Eleven and call Dad who is away on business in Chicago. I unlock my door and open it, about to take off my seatbelt, when my mother screams like someone is killing her. Just as the last few cars go through the left turn lane beside us, and that lane's stop light goes red, she zips her car over into the left turn lane, while my door is swaying open. She turns left, through the intersection of now on-coming traffic, right through the red light. Cars have to screech to a halt in the middle of intersection not to crash right into my door. Their horns blare. They barely miss us, and she pulls us into the parking lot of a business that's been closed for at least a year.

My eyes are wide open. Mom is sobbing now while screaming about how if I get out of the car “serial killers” will abduct me, how unsafe it is outside the car, and then the rest is so

incoherent from the tears and mucus coming out her nose and choking her throat that I can't make out all that she says. Her screaming becomes guttural. She slams her hands on the steering wheel, over and over. I am in awe. *I have to get out.* I keep trying to get out of the car, but she lurches the car forward every time, lifting her foot off the break and slamming it back down, jerking my body so that the seat belt locks to impact restraint mode each time. I try the emergency break. She had always taught me how it could come in handy and now I am using it because of her.

The sky belts out rain.

All I know is sound in this moment. Soon, the sounds from my mother fade behind my heightened awareness of these large, loud, splattering rain drops. They wash the windshield clean. The sky is so dark now. I hear a horn beep.

I turn to see my mother still hysterical, but I hear nothing from her, and she hasn't heard the horn from the car parked on the other side of her door. It is a stranger in an SUV. He waves to me, and motions a combo of hand gestures and mouthing words that ask: *Do you need my help? Do you need me to call 911?*

The rain pours harder; I didn't think it was possible. This is monsoon rain. I want to stand it in and have it pour all over me—I don't know whether as a way to wake me from this scene or because it just feels right—like it would be an honest act—something unabashed and soulful, something relieving, something sane—but there's no leaving this car right now.

I have a decision to make. It feels like a year goes by before I make the decision. I go through my life, assessing what I have and might end up with if I choose unwisely. I think about handcuffs, family court, social workers, doctors' visits. I think about the good school I go to, with friends, projects I'm working on, and how changing schools could affect getting into a good

college. I think about dogs, Sassy and Jeanie, my cats, Spud and Cleo—all older animals, some with health problems. I think about what might happen to them. If I'm sent away and mom is too ill, then no one will take care of the pets. *Will they be given away? Will they put them to sleep?* I think about the beautiful room I have. All the material things I have at my fingertips. I think about who I might live with. Cousin Cissy is never around. Uncle Joe is a busy journalist. Neither will want me. Aunt Joanne has three children of her own and is married to a man with manic depression—a man who flips out just as bad as this. I'd probably end up there. *Out of the frying pan and into the fire.* Because you see: Why should my grandfather-turned-Dad come back from his business trip in Chicago, see a woman arrested by the police or in a mental institution, and think that I could or should still live with him? He doesn't want to raise a teenager by himself. *He's had his children.* I'm a burden. He'll think he has to take care of my mother first, and that I'd be better off with someone else. He won't send Mom for help; he'll send me away. The courts will deem his home unfit with her there. Maybe I could get emancipated at my age? But what money do I have? I can't even drive yet. How long would getting emancipated even take? And in the meantime what happens? He'll say it wasn't meant to be anyway. He'll say technically he's my grandfather and nothing more. And off I'll go to my aunt's home, having lost everything, to share a crammed bedroom with a cousin, listening to my aunt's husband yell throughout the house.

I turn back to the stranger who now gestures, *Well???* I wave him off. He is incredulous, throwing his hands up in disgust. *Stupid drama queens,* I know he must be thinking. He drives off in a hurry and I look longingly at the last glimpse of the back of his car, as the sounds of my mother sobbing and babbling about serial killers comes back into my sensory perception.

I receive an email from a researcher with an attachment showing my mother's biochemistry testing done on her as part of routine analysis of my own biochemistry problems. Results show she has half the normal level of S-adenosylmethionine, also known as Adomet and SAM-e. The researcher says it's probably inconsequential, but for me it all makes so much sense now. I've read about other patients and how mood is changed by SAM-e. I know how it's a precursor to neurotransmitters like Serotonin and Dopamine. I accept my mother for the first time in a long while, and then I think: Am I less of a person if I needed to see biochemistry proof of why she might act strangely in order to forgive her? Would I have ever forgiven her had I not see this blip reading in her blood levels? And despite the fact we—myself—researchers—anyone—cannot seem to fix me beyond my own genetic “ingredients,” has my whole health journey been actually worth the sense of peace I now have with my mother—now that I know her own genetic flaws? I suppose it has. I can't imagine if I had been healthy that I would have found the patience or time to better understand her or ever forgive her for some of the pain she unnecessarily caused in the past.

At twenty-two, while getting ready to move from the east coast to Hollywood, I make up my mind it is time to call my biological father. It seems like it would be easy. If it was anyone else I would be on her case to contact her biological father. But now that it is me, I stall at the edge afraid to take a leap of faith.

For a long time I just hold onto his work number, something I managed to obtain through my cousin Cissy, but of course sworn to secrecy not to divulge to my mother. He owns a German-Austrian cuisine restaurant with an Inn attached. I could call him at that number. I

could look up the restaurant and inn online. I could read the menu and look at all the photographs. Wiener Schnitzel. Filet Mignon. Escargots de Vienne. Austrian Cheese Strudel. I read the blurbs about how the gazebo is a lovely area for a wedding reception. I read the establishment's reviews. Every time I see a bad comment, I think, "Aha! See? He's not doing well without me," but every time I see an award or accomplishments I feel a strange tension between being proud of him and feeling bad that he is doing alright moving on without me.

Finally, one night I decide I have to do it right then. I pull my car over and dial the number. I sit in the dark listening to the dial tone. Someone picks up. I ask to speak with Michael. The man answering asks, "Junior or Senior?" My heart skips a beat.

"Senior," I reply.

"I'm sorry, he's not in at the moment. Can I take a message?"

"No, that's okay, thanks." I hang up. I sit in a daze for a moment while the hazard lights on my car blink, making a soft clanking sound inside the car.

"So I have a little brother. And his name is Michael too. ..Good to know."

Many months go by before I try again. It is the day I am leaving to drive across country to move to Hollywood. *It's now or never*, I think to myself. I reason I would become rich and famous in Los Angeles, and when that time happened I didn't want family coming out of the woodwork asking for money. Immaturity? Arrogance? Spirited? I'm not sure what drives me, but I know I want my father to acknowledge me as a nobody. So I figure *This is his last chance*.

In my aunt's house, the last stopping point before my journey to Los Angeles, I sneak out of the living room and into my cousin Samantha's incredibly messy bedroom, somewhat abandoned since she left for college. It has turned into part college-student-crash-pad, part guest-bedroom, part family storage room, and part cats' hiding-nook. I close the door to muffle

the sounds of cartoons my little cousins watch, and to hide my secretive act. I sit on the bed, still in my pajamas and sweaty from the humid summer heat. I look around, feeling as if there should be some sort of ceremonial outfit I should be wearing instead for such an important occasion. The rotating fan sends a breeze across my face. Everything seems so highly ordinary. I take a deep breath and pray it will be all okay. I dial the number.

“Who may I ask is calling,” the voice on the other end of the line question.

“His daughter, Genevieve,” I say.

“Hold on just a moment.”

My heart pounds in my chest and palpitates. I think it’s going to burst. Suddenly a man with a thick Austrian accent speaks: “Hallo? Who is this?”

What does one say? What is the standard protocol of introduction in this sort of situation? I didn’t know. Being a blunt person I cut to the chase: “This is your daughter Genevieve.”

There was a long pause.

“*Vaht?*”

“Your daughter, Genevieve. Remember me? April 4th, 1981?”

There was an even longer pause. *He’s probably been anticipating this moment all these years, but I bet he didn’t expect it would be today,* I think to myself.

“*Vaaahht?*”

“Look, I don’t need a relationship with you. I have a dad. But like it would be nice to talk with my sister, Alexi, ya know? Something like that?”

“I don’t know vaht you’re talking about,” he says sternly. After all these years, he still denies I’m his.

I sense the tide changing and I feel a shift inside myself towards anger—and yet so much fear.

“Oh, really? Well, maybe I’ll just have to show up on your doorstep then.” Then I hang up on him before he can hang up on me. I can’t have him reject me again. I can’t have him not show up at my birth and then hang up the phone on me as an adult. So I hang up first.

I imagined months afterward, every time the doorbell rang at his house, even the pizza delivery guy, Michael would dive under a table or behind the couch in the living room, afraid it was me.

During my moving around Los Angeles in my first year there, the photograph of Michael with Alexi was lost. Gone. For good. The one photograph I had, gone. I had taken it out so many times just to stare at it that I must have left it in a desk drawer in the second apartment I lived in. I was devastated. It was the only thing I had of him. I had taken such good care of that photograph that I put it in a safe place to be forgotten.

I kept hoping I would find it again among my belongings but never did. Finally, after several weeks of being pent up in my Los Angeles apartment, often too sick with Dysautonomia symptoms to leave, I went onto Myspace looking for Alexi and the half-brother, Michael, I knew I had. I couldn’t find Alexi. But I found Michael. He was a sweet kid, but young, just started college. I was twenty-four, and there before me was more evidence of me. That smirk, those eyes. I saw myself in my half-brother. His picture consoled me for the time being. Somehow his picture made me exist even more.

At twenty-six-years-old I have accumulated enough information to know that my biological father had a second wife, Gertie, with whom he had three children: Priscilla, Michael, and Danielle. Alexi grew up with her mother, Evelyn. I reach out to all his children at some point, via Facebook with the younger three, via private email to Alexi, who now is a biochemistry researcher, ironically. My brother, Michael, admits to me that he felt rather awkward and strange from my first email. We talk maybe three times via Facebook over the course of several years, but then I hear nothing when I try to get in touch again. I still don't know if my messaging him was how he found out about me in the first place. Had I been a dark secret that only Alexi was aware of from her childhood?

At twenty-nine, I reach out to Alexi stating that I'm available if she'd ever like contact, and then suddenly Michael and I are no longer Facebook friends. I have to wonder what happened. As for the two other girls, they never respond to my messages. In fact all children eventually go hidden on Facebook, difficult to find via a random search. It's made it so that I not only want to find out the truth about this other biological half of me, but I want them to know the truth about me. Just what exactly has been said about *me*? And why don't they care about the truth as much as I do?

I don't think my mother has ever tried to be mean or cruel regarding my family tree. In some ways she was just thoughtless about the process of having a daughter who is—not intentionally cruel. I call myself “half-adopted,” but she often would prefer to think of me as not adopted. Her reasoning has been that because she didn't adopt me, and because I'm related to my grandfather, I should somehow be content that I have one of my two biological parents and that should suffice. In other moments I think my mother has just been struggling with her own

fears and insecurities. That she was abandoned too, her heart broken, and that I might ever connect with the man that broke her heart, even in the slightest way, would somehow mean I love her less.

And if I choose to partially define myself by my German-Austrian roots, and she chooses to define herself in large part by me, that will mean she will be in direct conflict with her tumultuous past that she'd rather forget. The unfortunate result is that until very recently my mother has not accepted me for who I am, from a cultural perspective. My German-Austrian heritage has been a dark blot. She has always been accepting of me as a person with a chronic illness—with an Autonomic Nervous System disorder—but overhearing me practicing German for my foreign language class was like catching me in the act of doing something dirty.

I longed for her to accept me for who I am as the daughter of an Austrian man the way she accepted me for who I am as someone disabled at times. I felt shameful for wanting to know more information about my biological father, his family, and my German-Austrian heritage. After all, they made no attempt to no know more about me, despite me extending the invitation, so am I pathetic for wanting to know about them?

I have heard my grandmother, my biological father's mother, wanted to meet me. She had interest in me. My mother has never changed her story on that piece of information so I assume it to be true. I don't even know my grandmother's name. I try German-Austrian names on for size. *Oh, thank you so much for the cookies, Grandma Helga. Oh, dieser ist guter Apfelstrudel, Großmutter Olga, danke!* The story goes that when I was born, Michael apparently told her if she went to see me he would not allow her to see her other granddaughter, my older half-sister Alexi. And so she relented to his demands. I don't know if she relented easily or if it was a huge argument. I wasn't there though so I cannot really judge her. She loved her

granddaughter Alexi, who was five years old at the time. The thought of losing her was too much to risk by meeting me. This is perhaps the only thing I am angry at my father for. *If he didn't want a relationship with me, well then, fine and good riddance, but why did he have to keep my grandmother from having a relationship with me?*

St. Patrick's Day is our day. We have a whole national day of celebrating being Irish and I feel proud to be a part of that. Weeks leading up to St Patrick's day my parents play Irish folk music in the house and car. They give me an *Erin Go Braugh!* pin. *Ireland Forever*. I wear it proudly to grade school and announce to all that I am Irish. Barrettes with streaming ribbons of orange, white, and green—the colors of the Ireland's flag—decorate my hair. Year after year, Dad walks in the Baltimore St. Patty's Day Parade with the Ancient Order of Hibernians, an Irish Catholic brotherhood.

Though this day is the ultimate day for corned beef and cabbage with boiled potatoes, we actually eat the stuff during the rest of the year too. Anytime I turn my nose up at boiled potatoes, Mom says, "But you're Irish! We eat boiled potatoes." Eventually, I have retorts like, "We have a choice now. We don't *have to* eat potatoes anymore," or "Well, I'm also *Austrian*." Sometimes I ask for sauerkraut in place of boiled cabbage.

I become well-versed in our Irish relatives and their accomplishments. One great-great grandfather invented the S-pipe seen under kitchen and bathroom sinks. Another relative had a shipping yard in North Carolina and after Abraham Lincoln took ships from the yard to use for the Civil War, our family was never compensated. Some family members changed the spellings of their last names to sound more French so they could get more work since Irish discrimination

was prevalent at the time. My parents are proud of our Irish relatives' struggles, triumphs, hardships, and ingenuity.

With the Irish pride I gain, I also gain more longing. The more of my Irish roots I learn about the more I realize what I am missing out on from my German-Austrian side. In the midst of an all-Irish clan, I am the Austrian imposter craving sauerkraut in lieu of boiled cabbage with mustard. Certainly there is more to be had than just sauerkraut. There is a whole other language to be learned.

At twenty-nine, I'm watching a video of my biological father making lobster salad on the internet. He is cordial. He is well-versed in the amounts of butter, the pepper, the timing of baking the lobster, the delicate ways in which to position the vegetables with the lobster. This is a video some cooking site interviewed him for, and right now, right here, he is in my bedroom looking straight at me, with the most ridiculous white baseball cap on, and a face that looks like an older James Lipton. He's grown a beard. He has glasses now. He's an artist with a canvas to prepare.

I become enthralled with the ingredients.

Two fat lobster tails, beautiful greens, sliced beets (*ick, I hate those but I could pretend to like them if necessary*), cherry tomatoes, black pepper (*I'm not a huge fan of pepper*), and he sprinkles in nuts I'm allergic to. I wonder if I ever met him would he cook for me? Would he forget my allergy to pecans? Would I have to lovingly remind him? Would I try to sift through the lobster salad, de-nutting the entrée on the sly so as not to offend? Would he feel like I'm less his if I'm allergic to nuts that he's not allergic to?

I ask my mother during a phone call if she has any more information about my grandmother, like what her name was, and I lament that I wish I could have met her.

My mother blurts out, “Oh whatever. She was interested in you all of five minutes. And as soon as the next grandkid came along she dropped you so fast.”

“Why would you take that away from me?” Tears stream down my face, as I try my damndest not to cry.

“What are you talking about?”

“Why would you take away the one person who wanted to see me, take that away from me? You would take away the one shred of caring or interest bestowed? What kind of a mother are you? My grandmother wanted to see me, did she not?”

“Yes, but—Where the hell is this coming from? Look, they were horrible people. I hate them and you should too. They’re evil. God, I don’t know where this—”

“I feel sorry for you, Mother. I reached a sense of peace with it all. And you want to take that away from me.”

“Peace?”

“Yes, peace. Whether you like it or not I’m a part of that side of my biological tree and they’re a part of me. There are people in our—your— family we don’t talk to or like, but that doesn’t make the entire family all bad. And let’s say Michael’s family are all ‘evil.’ I won’t live my life in hatred towards them. I will not waste the energy.”

After that talk, I figure there will always be a half of me cut off from her.

I’ve been asked many times throughout life the key question every adoptee encounters and though it may vary in exact words and sentence structure, sometimes containing awkward

pauses, it is usually along the lines of: *Is there really any sort of link that ties biological family members together or are we simply the product of learned behaviors and traditions from the people who raised us?* I grappled with this question through high school and as an undergrad.

My niece, Zoë, does not like red meat or spicy foods but she loves fish. Mia, on the other hand, loves red meat and spicy foods. She's also quite flamboyant in dress, loving colorful clothes and anything sparkly. The people of the area that Zoë is from in China eat predominantly fish and very little to no red meat and spicy foods. Mia's town has a long cultural heritage of dressing in bright colors with shimmering threads woven in, and eating predominantly red meat and spicy foods.

I love sauerkraut and always have.

These are perhaps silly examples or even coincidences. But there is something in my mother's words hinting on the verge of complete annoyance, "Oh, you're so much like Michael," that makes me step back and say to myself, *Just what exactly does that mean?* And the first time I saw photographs of my half-brother, immediately I saw the same facial expression I've given in so many of my own photographs. That "I'm up to no good" smirk stared back at me, coy like my ancestry. It was then that I knew in my heart there is always a tiny bit of everyone that ascends biologically.

To acknowledge I may have relatives who were German soldiers—Nazis—would probably make most Americans feel uneasy to say the least. Our culture views every single one of them with absolute disdain, and for obvious reasons. But when I feel like I'm coming to that side of the boat—that life where everything is viewed black and white without gray—I think back on a German exchange student friend in high school who told me her grandfather had to

join with the Nazis: “He didn’t agree with them, but they told him they’d kill his entire family if he didn’t do his part. So what else could he do?”

With my health problems it’s hard to reconcile people purposely setting out to kill people with physical “defects.” Perhaps the idea is more daunting for me than healthy people. But for me to pretend these things did not happen and pretend these issues do not exist, to pretend I do not have a whole other half to me, is a huge mistake. For people who are not adopted (and even for some who are adopted) there seems to be this idea to “leave well enough alone.” For me I see the truth reinstating my existence (or perhaps establishing my existence in the first place), no matter how bad the facts.

My cousin Cissy tells me that Michael’s father was in the Luftwaffe during WWII. The German Air Force. My Dad, my adoptive dad, my “Pop-Pop” was in the airforce, but on the side of the United States. He missed combat by two weeks. The war ended right before he was about to be sent overseas. From what my cousin remembers of a conversation with Michael several decades ago, Michael’s father had not been so fortunate. She recalls that Michael’s father didn’t make it out alive during his stint with the Luftwaffe. I think back to conversations between my Dad and me regarding airplanes he flew in training. He talks about different airplane models like a captain of a ship, full of pride and authority. I can never remember the names, but he remembers every make, model, and color like it was yesterday. Sometimes I ask him to tell me the story again, even though I know it now by heart.

Dad tells me he made the mistake one time of not wearing his seat belt during a barrel-roll maneuver, “which would have been just fine if I had had my cockpit closed,” he laughs as he recalls the tale. “Never made that mistake again.”

“What did you do?” I say.

“Held on for dear life,” and he mimics how he spread out his arms and legs to grip the cabin of his plane. When I heard that my German-Austrian grandfather had been in the Luftwaffe I wondered if he would have had similar stories. I wonder if Michael maybe missed out on hearing them.

Evelyn is Michael’s ex-wife. She tells my mother the story of what would be her last straw with Michael. Evelyn and Michael take their daughter Alexi on a family holiday to Europe. When Evelyn isn’t around Michael steals her passport and kidnaps Alexi back to the States. There is no quick way to correct the problem; there is no internet; there are no cell phones. Evelyn stays trapped in Europe for months trying to get back to America. In the meantime, Michael tells four-year-old Alexi that her mother does not love her anymore, that she is a “drug addict,” and to just forget about her. By the time Evelyn gets back to the States, Alexi is thoroughly confused and traumatized.

This is the third-hand story I have been told. I don’t know how much of this story is true, but I don’t doubt my biological father is capable of this behavior. I simply keep the open mind that, as my great-grandmother Genevieve used to say: “There’s always three sides to every story. Your side, my side, and what really happened.”

I am given bits of information from my cousin Cissy and my mother about my German-Austrian grandmother—my biological father’s mother—the one who wanted to see me— that suggest she was not only disturbed, but abusive with her children and other grandchildren. Mom says one time she even told Michael some of what she saw firsthand and he immediately got on

the phone to his mother, cursing her out in German. I try to put the pieces together and realize perhaps he did right by me by not letting his mother in my life. I'm not sure. I don't know one way or the other, but a part of me is curious as to what burdens he himself bears.

My parents come to live with me in Florida for a few months while I'm attending graduate school.

At first, the days I study my German, it feels like I am doing my dirty deed of reciting the language of the enemy, while my mother watches TV in the other room. One night, after studying Austria for a German class test, I cry myself to sleep like a child. Having stared at the map of Austria, learning the names of the rivers and cities, provokes something primal within me. It's the not knowing which river or mountain my family had lived near or which city they grew up in that tears me a part. Having dealt with my genetic issues and Dysautonomia for many years now, this map of Austria feels like one more mystery about myself I cannot explain or get more information about.

A few weeks into my parents' stay a transformation takes place with my mother. I'm not sure how or why it takes place. Every once in a while my mother pops into my bedroom saying things like, "*Ghost Hunters* is on. They're at a German castle!"

"I hate *Ghost Hunters-Europe*."

"But I thought you liked stuff about Germany."

"Yeah, but I don't like that show. Besides, I'm doing my homework."

"Whatever. Just thought you'd be interested." She'd leave the room and a smile would come across my face.

Then one day mom plans a mother-daughter outing. She takes me to a German restaurant in Sanford. She grabs little round drink placemats, the ones with names of German beers plastered across, and has me take some home in my purse. We swap German cuisine, discussing the flavors of the potato salad and sauerkraut.

After I come back from a academic trip, I find a big German-English dictionary on my desk. I pick up the book and smile.

“Did you get this for me?” I ask her.

“Yes,” she beams.

I do not want my nieces to feel ashamed for wondering about China. I do not want them to feel like they are doing wrong by their adoptive family by asking about their biological roots. And I do not want them to ever fear that they are not good enough, that they will be sent away, returned because they are too much trouble. I want them to be able to investigate their identities in this world, just like any other kid would. Navigate their existence.

When my nieces and I Google-Map China we are at once sisters in our curiosities. They ask me to show them what town my biological father and grandmother were from. I look down and say, “That’s the thing. I don’t know.” I turn my head back to the global maps. “I can show you a map of Austria and Germany. Here, look. See? Hundreds and hundreds of miles across. But I don’t know what town. I don’t know where to even start. I wish I knew.” They sense my longing. They say, “Oh,” with commiserating sadness, as they put their arms around me, sitting in front of the glaring computer screen. After a moment of hug between the three of us, as I stare blindly at Austria and Germany, Zoë tries to break the tension. “Well, *that sucks*,” she says with laughter.

I smile. “Yes, it sure as hell *does*,” I reply. We all laugh.

“Let’s go back to China,” I say. “I want to see your towns more.”

They are delighted. They are like new home owners *proud* to show me their bedrooms, living rooms, bathrooms, re-admiring the couches they just bought, their new flat screen TVs.

Michael is a part of me, for better or worse. For the most part I don’t equate his actions with my self-worth. To say having a parent abandon you does not impact your self-worth whatsoever is naïve. But I can accept the complexity of the situation and refuse to criminalize my father. While researching my own health problems I have examined myself on a cellular level. It’s made me realize how complicated we truly all are and sometimes we are not so beautiful.

Would I have wanted to know about him had he have been a serial killer or rapist? I’m not sure, but perhaps the not knowing is worse than anything I could ever find out. The sense of longing I feel is much more about needing to know information. I do not think Michael could have been a better parent, but just having names and places and stories has been something to fill the longing. All of it provides documentation of my existence and the cereal box ingredients to print on my soul.

I think my mother is at more peace with my longing to know information but even if my mother would prefer I think of my father as evil, even his entire family and ancestry as evil, I cannot go there. Though I can reconcile I am my own person—that who he is does not wholly define me—to deny my entire family back many generations is disturbing to me.

I’m no longer interested in denying parts of myself. I’m working on exploring all aspects of myself in order to become a whole person. I’m not sure if the story I heard at three-years-old

will ever be “fixed” or have an “ending” in the Hollywood film sense, but I’m currently finding fulfillment in finding my own story. Sometimes now I think of it this way: Perhaps the story with Michael was a mini-series cut short due to lack of funding or studio backing, or maybe the writers couldn’t agree, or maybe the actors didn’t get along with the director, but I have control over writing my own story in response to the many things I have no control over. There’s a limitlessness to it because it’s all mine. My ingredients have taken on a form all their own.

AUTONOMIC

It's September 2003. I'm twenty-two and I've only been in Los Angeles for a couple of weeks. I'm riding around in my Honda Civic figuring out where everything is. Because that's what I do at twenty-two. I get myself lost on purpose to learn from my mistakes.

Maybe it comes on suddenly. Maybe it happens with each breath over the course of thirty minutes and I'm just not paying attention to my body until it gets unbearable. I decide I will go to the hospital in Beverly Hills. They have to have excellent doctors there. *It's fucking Beverly Hills.*

I can't tell you how many times it's come out trite or overly poetic or too clinical or like the whiny diary of a patient.

~~My chest hurts like a motherfucker and I'm scared shitless.~~

No.

~~I'm choking. A day out turns into a day inward. My heart throbs with the weight of a sledgehammer on my sternum and coronary arteries. To know pain is to live pain is to feel it throbbing inside of you. And still there is no oxygen getting through.~~

No.

~~The arteries are probably constricting, causing localized high blood pressure in the chest area, which in turn creates angina, while the rest of my body drops in blood pressure. No matter the cause though, the heart obviously beats with increased speed and effort to get oxygenated blood to the brain. As less oxygenated blood reaches the brain, decision making and other cognitive functions become impaired.~~

No.

Imagine you're suffocating despite the air you're breathing in, and your heart is an engine trying so hard to do its job, pumping harder and harder, faster and faster, but getting this body nowhere. Something is breaking down somewhere, and as it does, you feel light headed, your vision starts to blur, your hands start to shake, your muscles ache, and figuring out where you are now and where you're going is downright rocket science.

I pull the car over and get out my laminated map of Los Angeles. Not everyone in 2003 has a GPS device. Besides, I like the feel of a bigger picture in my hands.

The bigger picture reads I'm getting too ill to drive. Maybe I already am.

I should call 911. I'd hate myself if I careened my car into someone.

Don't be a melodramatic cunt and call 911 in the heart of Beverly Hills. You can make it the next few blocks if you just slap yourself and make it happen. You want to direct scenes, not be one.

SLAP

I am there and the hospital emergency sign reads in blurred red. I don't know how I made it on this gurney, but they're hooking all kinds of stuff up to me. I am a big extension cord outlet getting ready for Christmas. They are worker bees. They are beavers building a dam. They are bayou men sand-bagging the levee. They are placing plastic tubes for oxygen in my nostrils. Sticking round electrodes on my chest, under my breasts, on my neck. Ignoring the beeping monitors. Saying my color is gray. Asking me questions. Taking blood from me. Hooking up an IV bag above me. Lowering my head, and raising my feet. I am a diabolical military maneuver. I am the Easter ham. I feel like this is two years earlier and the firemen at

the scene of a car accident say, “We’re probably going to have to cut her out,” and I think to myself, “Isn’t that a bit drastic, guys,” having not realized my car is totaled.

They are telling me I must be kept overnight for observation and more testing.

There is no memory between the ER first floor and the single bed room they put me in upstairs. This is that space in time that rainy afternoons occupy, the kind that wipe you out with the rhythm of the droplets on the window pane. The kind where the sun has called it a day, hours early, maybe never getting up in the first place. You know those people who run in the rain, no matter how soaked they get? Yeah, this is not that. This is body in hibernation. There is no fighting this programmed period of rest to recover from the attack hours before.

Then migraine sets in. I want to reach into my skull and carve out my brain with my bare hands. When the nurse asks if I’d like some medication, I accept the offer. The pain melts from my skull in a slow wave, lulling my neurons to a dopey calm. And then hunger sets in. I realize I haven’t eaten in maybe six or nine hours. Time has been lost to me.

Someone brings me food and I think to myself, “This is the best sandwich I’ve ever tasted in my entire life.” As the sandwich fills my stomach, completing the dopey calm, I feel my throat closing. This is something I’ve felt before, years earlier. I know I’m in trouble. I know this is an allergic reaction. I push the nurse-call red button over and over again, hoping I don’t pass out before I get to express my situation. They’ll think the drugs put me to sleep. They won’t realize I’m silently suffocating until it’s too late. I must get help. And the drug is taking a hold of me as I slur my words to the nurse. *Don’t make me explain to you how I know what anaphylaxis feels like.* Time. Time is not something I have. She offers me pill or shot of Benadryl. Having been poked and prodded so much that day already I stupidly opt for the pill.

She gives me a pill and leaves me. She does not stay with me. I wonder now, who leaves someone going into anaphylactic shock? Who does this? Did she not believe me? Why was I okay with her going away? Was I sick of being attended to and watched over by that hour? Was I dumb with medication? Was I too weary of asking her to stay?

I feel my stomach churn and in a spontaneous retching motion I heave all the contents of my stomach onto the hospital room floor. I gasp for air. My throat is still closing. I squint, scanning the floor. I see the pink Benadryl pill still whole lying among the splatter of partly digested food. It looks so pitiful. Sad little pink pill.

I reach for the red button. Push. Push. Push. Puuuuuuusssssssshhhhhh the red button.

They are annoyed to see my light flashing again. They answer, “Yes?” in that tone that says *What the fuck now?*

“I need help. MythroatisclosingandIthrewup.”

“I’ll call the janitor to clean up.”

“I need nurse. Nurrrrssssssee. Throatclosing.”

The nurse comes in and argues with me that she cannot give me “more” Benadryl. She is young and trying to follow protocol. I groan my slurred words and manage to force her to look at the pink pill on the floor. I demand she give me a shot of Benadryl before my throat closes entirely. *Don’t make me explain to you how I know what anaphylaxis feels like.* Time. Time is not something I have.

The janitor woman comes in and mops up my vomit. It seems larger to me now. It seems like it has grown alien-movie style. It is definitely several feet across. I score a ten in the projectile vomiting category of the Olympics. I feel so sorry for the janitor lady. I feel I have harmed her in some way. No one has cleaned up my vomit before this except my mother. Have

I harmed my mother too? At least strangers shouldn't have to see my vomit. Yes, I have harmed this woman. She will be scarred for life. There will be a pain-in-the-ass patient barfed story to tell her husband tonight. Or maybe she will use this to tell her kids how hard she works to give them a better life. She looks like a good person. She doesn't deserve this. I tell her over and over, "I'm sorry."

The nurse administers the shot of Benadryl and I am out like a light within two minutes.

People introduced themselves to me loudly to wake me up like my parents used to speak to me when I was a kid and it was 7 a.m. and we were on a road trip somewhere in some hotel. GOOD MORNING. TIME TO GET UP, HONEY. Only now it wasn't, "You need to go to the bathroom and then eat breakfast so we can get on the road," it was, "You need to sit up so I can take your vitals." Usually having nurses rigorously shake me and call me "honey" was enough to irritate me awake. I was nobody's honey. It wasn't even agreeable when my mother used to say it.

After three days hospitalized, a battery of tests, and nurses waking me at all hours of the night and day, my leg and arm pit hair had grown out past acceptable length to me, my own stench offended me, and they still didn't know what was wrong with me. I decided I had to get the hell out of there. I was ready to climb the walls on day four. I talked the cardiologist into letting me leave. I insisted I felt well enough to go home. I promised him I'd make an appointment to see him in his office instead. He was a sweet man and I lied to his face. Maybe a part of me did think I might make a doctor's appointment and go visit him, but I think deep down I knew I'd never go back to see him. The symptoms experienced the day I had checked myself into the hospital ran the gamut of previous episodes in the past couple of years. I had been

around the cardiologist block already. No one could help me. And eventually, I figured, this cardiologist wouldn't be able to figure out what was wrong with me either. I figured sooner or later he'd tell me I was over emotional or needed more exercise. I couldn't again go through being told, "Everything seems fine. Your blood work looks good." I settled into the fact that maybe I was just going to feel like shit for the rest of my life and have moments where I couldn't breathe and my heart felt like it was going to explode, without any answers. I needed to learn to live with it and get used to it.

When I got back to my apartment, I couldn't rub off the medical tape sticky residues still left over on my skin after blood draws and IVs fast enough. Bruised like a junky. Shaving my legs and armpits in the shower never felt so satisfying. I contoured my bikini line and the stubble along my pixie haircut. On a Thursday I had left the hospital and that Saturday I donned my fourteen hole black army boots, put on my mask of make-up, and teased my short hair to go to the Goth club. Each boot lace threaded through each hole, every swipe of eye shadow across my lids, the glossing over of red lipstick, and each garment of clothing I put on my body got me that much further away from my hospital self.

I went to the Goth club to dance, to take away any reminder of Hospital Gen, to free myself in rhythmic movement, far, far away from zombified in bed. Yet, most of my pretend-everything-is-fine evening was spent sitting on my ass, absorbing the bass beats and new wave sounds from a nearby speaker, wasting time in an old church pew that had been fashioned into a Goth seating arrangement.

I played the game of sitting down for as long as I could get away with it, before some skuzzy dude would realize I was there by my lonesome and try to strike up conversation with

me. Too exhausted for small talk by my hospital stay, I had left me with no patience for strangers. I spotted a guy walking my way, mid-thirties, weather-worn face, light eyes, with a black knit cap on, probably concealing a receding hairline I figured. I looked away from him and kept thinking the same phrase over and over again: *Please don't sit down next to me.* It seemed the more times I thought it, the faster I thought it, the closer he crept near me. He then sat down right next to me. *Okay, so maybe if I wait the appropriate amount of time it won't be totally obvious and offensive when I get up and walk away.....shit, I've already been to the bathroom and back three times avoiding weirdoes... I'm too tired for this.....Huh...Maybe I was wrong. Maybe he's not going to talk to me after all.*

“Have I seen you here before?” He leaned over and asked.

Fuck. He's talking to me.

He told me his name was Chris. To break up his practiced smooth-talking routine I interrupted with, “Short for Christopher or Christian?” He said short for Christian. He was there to pick up some potential actresses to cast in a vampire flick he was pulling together. He said he was a filmmaker. *Yeah, you and everybody else here in Hollywood, buddy.* I could tell he sensed my skepticism. I told him I was a filmmaker too. He offered to help me find legitimate production work I think partly to hit on me, and partly so that I would take him seriously as a filmmaker. I figured it was a long shot that it was something worthwhile. He said it was a TV show in its first season of production. *Black Hills Creek.* I'd never heard of it, but I told him I loved film so much I'd be the janitor if that's what would get me on the set. I thought back on the janitor woman cleaning up my vomit in the hospital. I loved film that much. Yes, I would have cleaned up someone else's bodily fluids if that's what it would take.

NO ONE LIVES HERE

I am waiting, you know. Waiting. For the next note. For the next beat. Something other than dead air. To connect the dots. This melody we live. Something other than, “You’re just fine.” Something other than normal results. Something that acknowledges the walls falling down inside my body. Something that attaches itself to the intuitive pangs that signal WARNING. WARNING. ABANDON SHIP. It’s always there, this hope, this longing, to know whatever it is I need to know. But I don’t hold my breath. I’m not expecting a savior. There are no angels here.

*How
can someone
be so broken
but still hit off
the charts as
exceptionally
normal?*

My mother has begged this doctor to save me. We met her just yesterday. I didn’t want to. Mom said *What’s the worst that can happen?* And all I could think was: *Nothing. Absolutely nothing. And that’s too much to bear.* She’s nice enough, but then half of them are nice at first. And nice is up there with not-a-mass-murderer. Nice is smiles with a handshake. Nice is pretending to listen. They seem harmless. They think it’ll be easy. They’re sure they’ll have answers. And when they don’t, well baby, they don’t know you anymore;

You vanish into dead air.

I told her she wouldn’t find anything. I told her it’s always that way. She says stop drinking liquids the night before. Not a drop of water she says. I laugh. Okay, that just might do it. I need water like oxygen I say.

So here I am now

on a gurney.

In the middle. In Between. No room.

Just curtains divide this area. Cubicles of poor health.
--

An Older Nurse brings a Young, Dark-Haired Nurse to me. Would it be okay she says. To have this nurse-in-training put the IV in she says. I laugh. Okay I say. *But my veins are hard to get to. They're tiny* I say. I'm all for learning and teaching. And why not me? Why not me?

She can't get a vein to save her life, but I don't blame her. *This is just what happens* I say. But then she's sweating. She wants to make a good impression. So she digs around for a vein and I yelp in pain. I can't help it. But still, I'm not mad. Just defeated. And then it starts. The Black Out. *Oh God* I say. *I'm starting to, Oh God.* Just when I might show that I'm not normal, I'm gonna blow it by flunking before there's any monitors hooked up to me to show I've flunked. *Figures* I think. *I always fail before failing.* Young, Dark-Haired Nurse is frozen as Older Nurse gently pushes her out of the way. The needle is taken out.

The Doctor rushes in.

Lower her head and raise her feet!

All

me. around
scramble

ABORT MISSION. ABORT. ABORT.

Let's get her stable before we try again Doctor says.

Young, Dark-Haired Nurse vanishes into dead air.
Older Nurse takes the wheel, but

Doctor steps forward, raising her stethoscope to my chest, plugging her ears with the listening ends of the device.

Time

is suspended by my heart. beat.

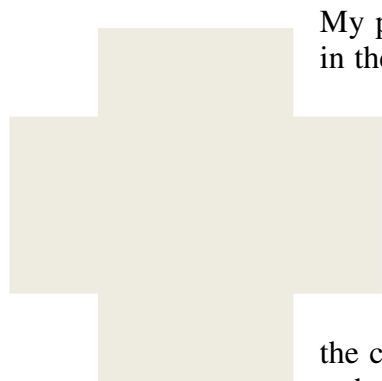
Silence happens. Breathing happens. I can only guess what Doctor hears as she listens to the music of my chest. For what seems like eternity. For what seems like one of those awkward moments when someone hugs you too long and you're not sure what you're supposed to do, what your job is. But then the blood rushes back into my brain. Older Nurse wraps a blood pressure

cuff around my arm. <Pump><Pump><Pump><Pump><Pump>
Silence. Listen. Acknowledge. Hissssssssssss. Doctor pulls away
and unplugs her ears. It's X number over X Older Nurse says.
Doctor sighs. Okay, we'll wait five more minutes she says . . .

Then laughter. *You can't black out before we've started my dear*
Doctor says. I'm trying I say. I see Young, Dark-Haired Nurse,
brisk steps, quick glance at me, frowning brows, frigid mouth, pass
by the foot of my gurney. I'm in the doghouse with her. I have
embarrassed her. I have shamed her. I will never see her again.

Well, you weren't kiddin' when you said it's difficult gettin' a vein
with you, Older Nurse says. But now I'm properly hooked up.
Science experiment will commence. I am rolled away to a private
room.

This must be where they generate android people. This must be
where Frankenstein was created. This must be designed with the
mindset to keep the Electro-Shock Therapy feel indicative to the
patient's experience. *But then how else could anyone even*
construct it? Furry, pink wall padding? Happy faces on the floor
tiles? Streamers from the ceiling? Hot purple monitors? I
suppose . . . that would just piss me off. This is the kind of shit
you think of. No, this is a sterile life. This is how it should be
done. It's just, it's just, it's just I'm on a flat, stainless steel table,
and now they're tightly, TIGHTLY, strapping me to the table, at
the chest, stomach, knees, ankles, with these big, thick, black,
Velcro strips tying me down. *This better be worth my while.* And
it's cold in Android Land. It's machinery cold. It's Dr.
Blumenthal stethoscope cold.



My pediatrician used to joke that he put his stethoscope
in the refrigerator just before coming in to check me out.
He'd pat my tummy and always, always ask me if
cookies were in there. *Chocolate chip?* He'd say.
Sugar cookie? Milanos? When I was smaller I'd
giggle up a storm, telling him how silly he was.
When I got older I'd say *Chocolate chip.* When I
got even older I'd say *I wish.* And I remember I
never, never worked up the nerve to tell him that
the cuff of his coat sleeve always tickled me relentlessly
as he felt my abdomen. I was too shy to say.

I'm cold I say in Android Land. Let me get you a blanket Older
Nurse says. And a pillow. She adjusts my positioning one last

time, maneuvering my feet *just so* along the metal stand at the foot of this stainless steel table.

“

When we raise you upright, that's what you'll be standing on. The straps will keep you from falling should something happen. We'll keep you lying here for thirty minutes before we start. That will make sure you've been at supine position and peaceful before, well, you know . . .

You just rest now and I'll get ready she says.

I let out a long sigh and stare at the sponge hole ceiling tiles. When is Life not sponge hole ceiling tiles? I close my eyes, and hear her subtle movements around me, plugging in equipment, turning dials, pushing buttons, beeping monitors, printing out paper.

Sorry dear.

I crack my eyes open.
~~I crack my eyes open.~~

Have you ever had electrodes hooked up to you?

Yes I say.

Ah, then you know what I need from you she says.

Yes I say.

She loosens the chest strap, pulling down my hospital gown to reveal my chest. She wipes me down with a couple of alcohol wipes. I wriggle my arms out of the strap and raise them above my head, turning my head left, then right, as she places gel stickers on my neck, chest, under breasts. *I guess we should have done this first* she says. *Ah, well.* It's okay I say. It's early in the morning.

I'm strapped back in. And now the waiting commences. I look down at the straps on my body. *If I were one of those panic attack people I'd be flipping my shit right about now* I think. I see my heart beat squiggles on the machine and I whisper a little prayer to God, Jesus, Joseph, Mary, St. Anthony, St. Genevieve, St. Bernadette, St. Jude, and St. Rita that this test will find something. I need all the help I can get.

Doctor and Older Nurse come back in and we are ready to begin. Doctor crosses her arms and stares at me, but not at me, at my body, even through my body, as if this is the showdown she has anticipated and she will conquer my body's mystery right now, right here, today. A print out is made of my current heart rate and

blood pressure. I feel like it should come out of my mouth. I am hooked to machines and surely, certainly the cash register-like receipt should be spilling out of my gaping mouth.

██████████ MEDICAL CENTER
ANNAPOLIS, MARYLAND 21401

Patient: TYRRELL, GENEVIEVE A
MR#: ██████████
Date of Admission: 06/17/2004
Date of Procedure: 06/17/2004
Physician: ████████████████████
Room Number:

PROCEDURE NOTE

TILT TABLE TEST

REASON FOR THE TEST

A 23-year-old Caucasian female with three recent episodes of syncope. The tests is being done to rule out a neurocardiogenic etiology.

FINDINGS

Following informed consent, the patient was brought to the cardiac catheterization and was monitored in the supine position on the tilt table for approximately 10 minutes. The patient had a blood pressure of approximately 112/68 with a heart rate of 81 beats per minute. The patient was then tilted to 70 degrees. The heart rate immediately increased to 126 beats per minute and the patient complained of being sick. After approximately six minutes, the patient's heart rate peaked at 147 beats per minute. She complained of nausea, difficulty breathing and overall poor feelings, quite similar to her feelings prior to her recent syncopal episodes. The patient's heart rate suddenly decreased from 147 to 72 and the patient passed out. The patient was returned to the supine position and given IV fluids. She immediately regained consciousness.

CONCLUSION

Positive tilt table test for vasovagal syncope.

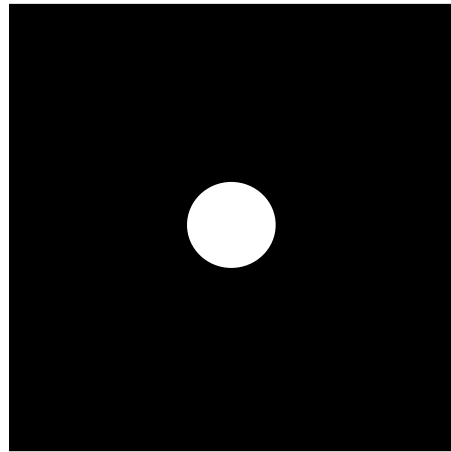
This document is a testament to my existence, even parts of myself I wanted to stamp out, forget, deny. This document says I was here and that event did happen to me. It is a story told about me, and when I read it to myself out loud, I fully realize the separation of self—between body and spirit—that has taken place. When I read this document out loud there is no beautifying the details. I am flawed. And I have experienced a trauma, that I know I suffered in isolation and in silence for so long. When I read this document out loud to myself it is a song of my history and of my fellow patients who go through what I go through. It is a simultaneous declaration of thriving and illness.

What they don't say is how it felt to be raised up—how it felt like being raised from the dead out of a coffin, but then I felt like I was going to die. What they don't mention is how Older Nurse found just the right way to re-squish the pillow behind my head and neck after it started to fall. What they don't tell you is how Doctor's eyes opened wide as saucers when it seemed like my heart rate would never stop climbing. There isn't a reference to Older Nurse coming close by me asking over and over how I felt and to just let her know anything, anything at all, as if to keep me awake. There is a nicely rephrased version of what I really stated which was: *I feel like I'm gonna vomit, pass out, and shit myself all at the same time*, something I had said to a paramedic during another incident a couple years earlier. There's only a mention of three previous episodes, which leaves out what I've gone through day to day. And there isn't a detailed account of the chaos that ensued when my heart rate crashed from 147 to 72 in a matter of seconds.

The room is going dark, oh God, I'm blacking out.

Put her down, put her down right now, I've seen enough.

They say I passed out. I did but I didn't which is so typical for a patient like me. The room went tunnel vision I recall. The room went black all around my periphery and began to close in on the very center, and then that center began to flicker, as I gasped for air like underwater, like drowning, strapped down. I don't think I lost complete consciousness. There's no mention how Older Nurse panicked and accidentally began to tilt the table up to ninety degrees, instead of down to one-hundred and eighty. How Doctor held her breath for a moment, her heart skipping a beat, and then yelled at Older Nurse only to apologize later. How Older Nurse said *I got it, it's okay, she's going down, I'm so sorry. It's okay honey. We'll have you down flat soon*. Maybe it was down "soon" but it felt like eternity as I heard the gears grinding, a hum of electricity bringing the Bride of Frankenstein back down to supine position.



And then there was light.

Doctor is by my left side now, devastated for me. She says *How could no one give you a tilt table test before? Why didn't they do that?* I dunno I say. *You have vasovagal syncope.* Older Nurse and Doctor unstrap me, ripping at the Velcro. Doctor takes my hand. *Well, there is no doubt in my mind what is wrong.* Oh thank God I say. Thank you for diagnosing me, thank you so much I say, relieved. I tell her to find a woman with short hair and glasses in the lobby waiting for me, probably reading magazines. I tell her she likes People Magazine, but will read Marie Claire sometimes too. I tell her to ask for a woman named Julie. I say *Please explain everything to her for me.*

I think this day is the end to a long journey, but it is only the beginning.

ONLY YOU: AN ODE TO BOY

I'm not going to fuckin' Irvine for a fuckin' arbitration on a fuckin' chicken coup, screams the old bat in the wheelchair: this is the image that goes through my mind as Adam lays out his story to me over the phone. I always feel compelled to grab a pen and piece of paper the moment I hear anything resembling words of wisdom—"So I said, 'Her lawyer is where? Irvine? Man, fuck that. I'm not' "— choice phrases I should definitely know not to say, make sure to always say, or store in my memory bank for when I'm old, gray, and senile, usually catatonic in my wheelchair, when I'm at my prime for blurting out revelations.

"I mean, whatdya gonna do," is Adam's life philosophy. It's not a question, rather it's a conclusion that completes the rationale for fixing any of life's quandaries. He can sum up anything with this phrase. It puts the little things in perspective and in fact makes everything a little thing by default.

"She wouldn't even eat fish. Fish, for christsake. I'm sorry, but Vegetarianism is an eating disorder. I had to dump her. I mean, whatdya gonna do."

After our phone conversations, I fantasize about using this line.

I had to murder him and throw his body in the river. My boss was an asshole. I mean, whatdya gonna do.

I used my left over explosives to blow open the bank vault. I had to get money somehow. I was broke. I mean, whatdya gonna do.

Adam tells me his soon-to-be ex-wife doesn't want the chickens, but she's suing him for the chicken coup.

Rick was a gun-toting magician turned Special FX make-up artist. A former cop with a healthy marijuana plant on his front porch, he was anti-establishment, yet if you needed martial law he was your go-to guy. Rick missed his father as if he had died just last week and not two years earlier. He missed his old German Shepherd like a brother who had passed away in battle. He loathed his ex-wife for changing her mind about wanting children. Cooking me dinner, sketching out tattoo designs, and shooting at the firing range seemed to take him to a peaceful place, but cross him and an explosive Italian temper came out. It didn't take much really. Sometimes he'd pick the fights. Gun laws. Women being difficult. The environment. The film industry fucking him over.

The man I fell for had created a rose for me out of a napkin on our first date. I could tell it was probably a date night trick he had done a million times before, but I longed for the human contact he could offer. I felt like a woman around Rick.

As the lights of the club came on, signaling closing time, I stood in front of Jeff with my hand on my hip and said, "Wait just a minute here. Do you not have a card to give me with your number because the last one you have already has another woman's name and number written on it?" Jeff turned bright red. He thought he had flipped the card back into the shuffle fast enough for me not to see, and he certainly didn't think I'd actually call him on it.

The night I met Jeff, I watched him hit on every woman in the club. Even caught him checking me out while another woman wrote down her number for him. *I wonder when he'll get around to me.* On the dance floor. He introduced himself with a formal handshake and shouting in my ear over the din. I told him I liked dancing by myself. I dreaded being danced up on, the sleazy way most guys thought was an appropriate come on. As if I want some stranger's

junk rubbed up against me and his sweat dripping on my chest. But Jeff allowed me my space and soon I found myself wondering if I could fall for a bald man.

The first time I met John, we ate lunch in a western-themed restaurant on Sunset Blvd. Both John and Jeff looked out of place—two New Wave enthusiasts amidst a backdrop of wood paneling and neon Broncos. John asked how Jeff and I had met, and Jeff nearly choked on his sandwich when I blurted out my answer. John laughed and said, “I like this one.”

Eventually, I gave John his nickname “Johnny.” Our flirtation developed the more Jeff and I didn’t get along. One night I drove Johnny home after the club. And it would have been too long of a drive home for me after such a long drive to his place. Shit, there’s so many good excuses why I was there. Being twenty-three was the best one.

Matthew was the only one who touched my body and noticed its changes, voicing concern when he ran his fingers through my hair and noticed how much it had thinned in a year. I had to tell the others when I was sick. Some just didn’t notice because they didn’t care, some were too self-involved to notice, and others didn’t want to notice because health problems scared them. And maybe, just maybe, I had become good at hiding it.

Baby, do you think if we stopped comparing each other to past lovers that maybe that’s what love is? Sometimes I wonder. When we’re just enough for each other to not have to always measure up?

They were always much older than me. Five years isn't much, unless you're seventeen and he's twenty-two. But then they were seven years older, nine, twelve, even fifteen. Rick was forty and I was twenty-five when we dated. He said I had "daddy issues."

In the dim light, Chris lifts my blouse over my head. We lie down and on cue I draw closer to the heat of his body. I feel his facial stubble graze across the curve of my jaw. He whispers to me in between kissing my neck and running his hands down my body, slipping his fingers along my bra:

"What do you like to call stuff? ... Pussy? ... Vagina? Cunt? ... Cock? ... Penis? ... Dick? ... You can call me Daddy if you want."

I can't stop the laughter from bursting out of me. "You're not my daddy."

At seventeen, I emailed Matthew an itemized list of everything he did wrong on our first date, but said I was giving him another chance. Years later Matthew told me, "I just looked at the computer screen and said, 'Nooooooooo, I don't want another chance!' and yet I just kept coming back for more hell."

Eric said to our mutual friend one night, "I can't be bothered by a girl who I'd have to help with her homework."

I turned the car right back around when I heard this, and found myself on his porch, knocking down the door. I'm not sure what bothered me more: That my age had suddenly become a problem or that I knew I had never asked or needed his help with my homework.

Chris told me Jeff must be gay because his apartment's carpet is white. The prop master at work confirmed this theory. White carpets and gay men that is. I bounced between Chris and Jeff when one would tell me he didn't want a serious relationship. Chris was fun until he kept comparing me to his last girlfriend, Rena.

"You know, Rena and I didn't go through this bullshit until at least a year into the relationship," he'd say to emphasize a point. And: "You're pretty mature—*for twenty-two*," as his way of letting me down gently.

Patrick is my best friend since kindergarten and finds it ridiculous I must tell the world this detail, on a regular basis. He is the one that said to me, as I sat in a wheelchair at the airport crying on the phone to him, "Look, it's just temporary and it's just a wheelchair. It's simply a mode of transportation. No different than a car or bus."

In our first big fight, a shouting match outside at night that I'm sure the neighbors heard every word of, I stood there all of seventeen-years-old while Matthew, at twenty-two, gave this argument all his effort. Then something incredible happened. Matthew stopped and said, "*You* have feelings? Don't you realize I have feelings too?"

Until then it had never occurred to me that he had his own feelings, and that they were valid. I simply hadn't been raised by my mother to think that was possible.

Adam and I find that the condom is broken and we agree to get the Morning After Pill first thing tomorrow. I lie there stoic in the dark. *This is not what happens to me*, I think to myself. *This doesn't happen to me. Stupid. Stupid. Stupid.* Adam sits up on one elbow,

watching my face, waiting for me to react. Finally, the weight of my thoughts flow out of me as one long, heavy exhale. He shifts his weight to embrace me. “It’ll be okay. Don’t worry,” he says.

The next day, Adam and I drive to a clinic at the Spanish ghetto end of Melrose Avenue, three blocks from Paramount Studios. As we sit in the office, I stare at the puke color walls, peeling paint, the chairs starting to spill out their foam entrails from another decade. People sit as if something has *happened* to them. As if aliens have abducted them the night before. I probably look the same. Adam leans towards me, cupping his hand around my ear, and whispers, “I bet that guy over there has the clap!” He gets a smile out of me and is pleased with himself.

When the nurse called my name I no longer felt present. The doctor seemed somber and weather-worn to me; a rebel soldier in a post-apocalyptic world. His questions were short and terse as if extraneous time could put our lives in jeopardy. Perhaps other people’s lives. My needs may have seemed frivolous, perhaps over conscientious. He looked at me with raised eyebrows and said, “Well, *I suppose* we can give you the morning after pill.”

As Adam and I walked out of the clinic, Adam patted me on the back and said, “Good Job. I’m proud of you. You handled that well.” I realized then that he had never considered me a grown up. That was the first time he wanted to spend the day with me after a night.

Eric sat tired, with hair disheveled and sweat dripping from his brow, across the table from Matthew and me at a cafe. Eric poured out his heart to us, how he’d been roommates with some girl he was crazy about, only to wake up that day, venture into the kitchen and see her much older wrinkly-assed, badly tattooed tweaker boyfriend standing naked in the kitchen, fridge

open, drinking straight from a carton of milk. Eric realized in that moment that things didn't bode well for a blossoming relationship with his roommate crush object (and he realized he needed to live someplace else.) I wondered just how many much more subtle hints have gone over his head, while he wistfully found inspiration in his recent muse. I found it amusing because I could easily see myself in the same position.

It hadn't occurred to me how harshly I had spoken to Matthew, until Chris did to me all the time.

Michael was soft-spoken and gentle. We didn't date, but after a couple of photoshoots, he got me to undress for the next one. He saw softness, curves, woman, canvas where I couldn't. I felt like a piece of art to Michael, not meat.

Jeff's body was sculpted out of marble. In the moonlight, his sweat-glistening pecs, abs, biceps, triceps—just the fact I could discern every single one to name it—made me praise the Lord. He always left me bruised, either by gripping my limbs with such force or biting me. I found addiction in our rough Saturday nights after the club. I needed more and more to feel human.

The steroids made me gain weight rapidly. I could feel Rick's wandering eye follow women with flat abdominal muscles, strong thighs, tight buttocks, lean arms. He used to be a personal trainer, and wanted a girl who could go hiking with him. We tried once. My body wasn't strong enough and I knew I had failed a test of sorts.

Adam says he doesn't mind the weight I gained, says when he first knew me I was too skinny, says he likes having more ass to grab and smack. He says "it's sorta kinky" being with a girl who has some jiggle. I take this as the compliment I know he means it to be.

Oh, honey, you tell yourself you know me, but you don't.

Another one I knew from a film industry internship; he was my supervisor and I looked up to him as a big brother who always had my back. But I came to the party only to realize I was it. First, he got me stoned. I thought we were friends unwinding from a long week, until I saw his face change. He turned into a stranger as I figured out I could barely move, and then he said to me, "Let me make you another drink." It hit me—I knew—I just knew—so I made the decision that I'd rather have a bad memory than a traumatic one. I stopped saying no, slurring my words. I touched where I was supposed to touch. I rubbed what I was supposed to rub. *I'll make the best out of a bad situation*, I told myself. *This will feel good for me too*, I told myself. *I'm in control*.

I'm not sure if at the start he knew just how far gone I was. I'll give him that last bit of goodwill maybe. But then, yes, then he still kept taking my clothes off even after he realized I couldn't tell appendages apart from one another. *It was a bad mistake I just won't make again*, I told myself the next day. A year later, I ran into former co-workers at a reunion event. He must've blabbered about his not-so-chivalrous conquest of me, because those boys couldn't look me in the eye. I had never seen boys look sideways and at their shoes so prolifically.

Adam and I had one of those game-changing arguments. The kind I'm never quite sure how I ended up in the midst of fighting but all the elements are in play that we will never come back from this: 4am, he's had a lot to drink, I'm feeling hurt, I ignore him like a brat, I pout like a child, he tells me to leave, I refuse and say this has just gotten out of hand, I say I'm too exhausted to drive, in fact I could fall asleep right now, he screams to get out, I say let's just start over, I say we're both just overly tired, but then oh crap, he's throwing my bag out the front door onto the side walk, and holy shit, now he's yanking his jacket off my body and pushing me out the front door.

Henrik and I fought over vegetables. He regularly instructed me on how to get myself healthy, stating I simply needed to put good vibes out into the universe and the rest would happen, and eat lots of vegetables to "change DNA."

Chris' Bassett hound, Zoey, plopped a crusty thong in my hand. I didn't know what it was until I looked closely. *What the hell?* With glee in her eye and a tail that gave away her excitement she waved around the object to provoke me into playing tug of war. Then it dawned on me: Zoey had been digging for treasure in what used to be Rena's side of the closet.

The crusty thong belonged to Rena.

My options were clear: A) Play tug of war, B) Throw it away, or C) Display it off the top point of Chris' head board. Crusty side out.

I left a note on his desk:

"Zoey found treasure while digging in your closet. I left it hanging off your bed. Good times."

On my birthday Jeff spends most of the concert smoking cigarettes with his ex-girlfriend Jennifer on the outside balcony of The Fonda Theatre. Later that night he slips and says, “Ohhh Jenny” in between thrusts. He hesitates in fear for a second, but then keeps going. He thinks he got off easy. My name is Gen, short for Genevieve, but I know he’s never once called me *Jenny*.

I don’t say a word because it’s my birthday and I want to get off. He owes me that much.

I told my phlebotomist, who swears she’s dumped her exboyfriend for the last time, that I got in trouble with Henrik when he broke into my private email account and found that Adam had typed: *Hey babe, wanna fuck?* Didn’t matter that I had emailed back: NO.

Usually their brokenness attracted me. I didn’t want to change them, but I loved dressing their wounds. I could never heal myself.

Chris’ body felt hollow and lanky against my back. He traced his fingers up and down the curves of my body. I took his hand in mine and kissed it.

“Chris, I’m worried about you. You need to lay off the meth.”

“What? What are you talking about? I don’t do meth,” he said as good as all his lies in the past. If I didn’t already know he was using, I would have bought this lie too. It disturbed me how lying had become so natural for him.

“Oh, c’mon, Chris. Don’t even go there. You forget I already know.”

“Oh . . . Yeah. . . Well, don’t worry.”

“Easier said than done, babe.”

“I’m not sure what you want me to say,” he said and pulled his hand away.

“Now don’t be like that. I’m not mad. I’m not judging you. I just care about you. ...You’re so talented and intelligent. I hate seeing you so sick. I worry.” I turned around to face him. “Ya know?”

“I know,” he said defeated. He admitted he had started all his drug use to keep up with production work schedules on the sets. Still, over and over we’d continue to partake in a sort of dance: He’d pretend and hide like he didn’t have a drug addiction, while I’d pretend and hide like I didn’t have a chronic illness.

My body feels like I fight with ninjas in my sleep. Henrik often massaged the blood back into my painful limbs, working life back into my wrists, palms, fingertips. Henrik didn’t have enough pain to keep me.

My mother was jealous of the first few. She’d say anything to get them to leave. But Matthew didn’t leave after my mother pulled him aside in the backyard, telling him that I wasn’t emotionally and mentally stable enough to be in a serious relationship. Not even after she lied to my father that Matthew had hit me. Not even after she told Matthew to break up with me.

I escaped the chaos at home to be with you. Sunlight through cyan, magenta, yellow plastic sheeting, your make-shift curtains, scraps from printing ads at work. Perhaps it was just the way your sweat mixed with your cologne that intoxicated me. Perhaps I wouldn’t have felt a thing otherwise. It would be easy to say it was cheap infatuation. But I know I liked myself for the first time in years. Maybe ever. If you were here you’d say it was nothing. You’d say I’m

being silly, maybe even call me crazy. You'd say it was over a decade ago. You'd say *just the one that got away, that's all*.

You'd say if you had to do it over, you wouldn't.

I had just gotten the hang of how to shut the bedroom door without making a loud creak. I had just memorized where the bathroom light switch was in the dark. I had just gotten the hang of feeling all the colors, all the notes. I could save face and never mention any of this again. I could pretend that it meant nothing to me. But why? Felt like paint, cool, then warm, and full of color, pouring out of me. You took advantage, and then could never look me in the eye again.

Much love in ways I cannot express, you said. You always found hyperbole an art form.

You were twenty-eight. I was nineteen. Your addiction with breaking beautiful things, to make what is light into dark, ended our friendship. I was so young— I didn't know how to react.

Steve said it tasted like poison and shoved the pink-colored drink in my face as he wrapped his arm around my shoulders and fell into me laughing.

“Oh my God, I think that's my ex-girlfriend over there—Shit—it is. Fuck. Hide me,” Steve whisper-yelled into my ear, spinning me around into a velvet corner lounge chair. “That's the voodoo priestess one, you know? She can cast spells on people.”

“In other words she's a crazy bitch.”

“Yes! I swear she's caused car accidents and the flu.”

The incident regarding the microwave prompted me to end things with Henrik.

“*This* is why you are sick all the time,” he shouted at me. “You are destroying vital nutrients with the microwaves!”

As he continued telling me how I had brought illness upon myself, I watched the digits on the microwave count down, knowing full well as soon as the timer was done, I would leave the apartment and our relationship would be over. He would call. He would beg. Weeks afterward I would use him one last time, and then never speak to him again.

I never dated Steve yet we spilled the beans about everything to each other on Saturdays at the club. The night an ambulance rushed me from the club to the ER, he realized he didn’t know enough about me to fill out the medical forms. He wandered into my room looking lost.

“Jesus, I don’t even know your birthday.”

“I’m an Aries. April 4th.”

“Really? Me too! April 9th.”

Steve and I began the process of meeting each other all over again.

Jeff told me how much he loved me one night. Just fell short of asking me to marry him. It didn’t dawn on me for a few years that maybe it was just the weed talking.

Rick just didn’t get it. In simple terms, I needed to be touched, and not by a doctor or nurse with latex gloves, but to be caressed. “Preemies” that are encased in incubators with wires hooked up to their little bodies need to be touched. They heal faster and they learn to connect on a human level. Is it that much different for an adult who has been hooked up to machines over and over again, having more doctor appointments than dates?

I bought them flowers and little surprise presents, sometimes instead of buying myself food and gasoline. Other times I made them gifts. Two I wrote love songs for and sang to them with my guitar. Eric immediately cleared his bedroom wall to make space for the large, framed cartoon of him I had created. I gave Jeff a hand puppet of a duck that looked similar to a Jim Henson Fraggle: bright colors, a tuft of frizzy hair on top with googly eyes. If Jeff were to press together the mouth, it let out a quack; if he did it fast enough the quacks had tones that connected to form melodies, one being “Mary Had a Little Lamb.” Even as Jeff yelled at me the next morning for making him late, the googly-eyed duck peeked out of his work bag on his hip.

The arrogant ones amused me. Something about the ones who thought they could insult me and then have me, intrigued me.

Chris had the rugged look working for him, unshaven, cowboy hat, jeans, and when he was healthier, some muscle to his arms. His blue eyes flickered in the sunlight on the western set we worked together on in a canyon north of Los Angeles. His passion for film fed mine.

Jeff couldn't walk past a reflective surface without checking himself out and preening. I'd tap into his O.C.D. issues by wearing two different socks on purpose, just a shade or two different from the other.

Adam sang the entire song of “Rebel Rebel” from David Bowie on my voicemail, guitar included, as a way to woo me back.

The one who had gotten me stoned “friended” me on Facebook three years after. My first reaction was, “No way in fucking hell,” until I found myself thinking about all his possible film industry connections, how even if his reference wasn’t helpful in the future, at least accepting his friend request would keep me in his circle of networking. It took me two or three days to make the decision whether to accept or not.

Eric’s email read, “My very last harsh, and unthoughtful words to you have weighed both heavily on that day, and figured on my interactions with others to this day. There are no true remonstrations that I could give to bandage such unthoughtfulness, and to that, I am truly sorry, as it is not the person you had known me for, nor the person I had wanted to present myself as, or to become. If there is such a thing as a true apology to another human, I mean to give such to you.”

I joked he must’ve had a lot of practice over the years apologizing to have come up with such an eloquent apology. From his non-response I realize that he didn’t find my comment funny, so then I felt like a girl all over again.

Chris is three thousand miles away on his way to a date. We text each other nude body part pictures for a good time.

I’m so hard.

I’m so wet.

My friend tells me this doesn’t count as getting laid. I say, “This one bit of phone sex is all I’ve got from the past three years and you wanna take it away from me? It totally counts.”

Every now and then, Adam still calls me in the wee hours of the morning from the West Coast, often with a characteristically inappropriate joke. He is the random factor in my life, someone whose artistic judgment I trust, who calls me out of nowhere with stories about assholes at work, and then gives me pep talks, saying I can prevail no matter what happens in my life, and *by the way, giving blow jobs should help too, har, har, har.*

After we both belt out raucous laughter, he tells me with confidence, “No, but seriously, you can accomplish this. You’re intelligent and talented.”

Rick IM’s me at night that he looks back on our time together with a smile. He is married now, with a toddler son and a baby girl suffering from the trauma of encephalitis. He tells me he has become “the wife.” I tell him he is the word machismo so there’s no way that could be right. But he is out of work, living with his mother-in-law in Texas, and doing wee hour feedings to a severely brain damaged and developmentally delayed six-month-old, and I wonder if anything I say—even though I believe it like doctrine that he is one of the manliest men I know—I wonder if he believes it when I say he is machismo. Part of me thinks he knows me well enough to realize I won’t tell someone something unless I truly mean it. But part of me also knows how stubborn he is. Part of me knows that we both judge ourselves harshly no matter how much anyone might discourage us from doing so. We have our own standards and goals in mind, and nothing, not even illness can sway that. I think I’ve come to more peace than he has though. Or perhaps I’m just kidding myself that I have. But when I hear how restless he sounds I feel like I’m hearing some of my former self speaking. Former. And I wonder just how

much I have come to truly accept, versus become complacent—which is simply stillness without true peace.

I'm watching that real life forensics show again. Darlene gets killed now at 3a.m. by a chainsaw like she did at 11p.m. when I really should have gone to bed in the first place. A month ago you said the new house was working out great. You said, "So I dunno, I guess I should get married again." I laughed. I told you people get married because they love each other and want to spend the rest of their lives with each other. Not because it seems like what you're supposed to. You knew I was right, but we both knew you'd still pop the question. Now your Facebook page says you're married.

An oral surgeon in the hospital providing free dental care during my stay made me laugh before, during, and after extracting my decayed tooth. I thought to myself: *Now this is a man I could love.* I've never seen him since.

Somehow Matthew and I drifted apart. Even years later, every time I came back into town, we spent time together, but then one day we just stopped speaking. I'm not sure that it was intentional. I think he couldn't look past my flaws from over a decade ago, and I couldn't look past his flaw of holding the past against me. He let go of my hand and I didn't try to find him.

Last year you were in the middle of figuring out if you wanted a divorce from your first marriage, so you came to see me in Nola to fully experience the Super Bowl in Saints' country. Well, after the game, everybody just about lost their minds in Nola. I'd say if ever there was a

moment to use the term blissed-out, well, it was one of those times. I've never high-fived and low-fived with so many strangers, or any strangers really, in my entire life. Traffic crept through the jam-packed French Quarter streets, as drivers and passengers alike reached out through pickup truck windows to anyone walking along the side walk to slap them five. WHO. WHO. WHO DAT SAY THEY GONNA BEAT DEM SAINTS? WHO. It had been our pre-game war song. It had been our we-dare-you-to-try-to-beat-us-you-other-team-I-can't-even-remember-the-name-of threat. Now it was our gloating victory hymn.

“I have a confession to tell you,” I said in that Bourbon Street diner. “I mean it’s silly. How many years has it been?” You chowed down on your burger while I sifted through my oily grits debating whether I wanted to put my stomach through all that grease.

“Anyway, on our first date, well, um, I really had no intention of having sex with you, it’s just, we were kissing and then I got up to do something real quick and then *bam!*—just like that—in a few seconds you were already laying there with your pants off. I just didn’t have the heart to tell you no.”

A BRIEF EMERGENCY ROOM INTERLUDE



ICE CREAM

Piece by piece. My cells retreat. Lost my production gig. Reality TV show job. Makeover series. Makeover. If anyone needs a makeover. I need a makeover. A do over. I'm so sorry I tell them. It came on so quickly I say. There's just no way I say. I can't do the shoot this week I say. They sigh. They ask me for an alternate. A replacement. A recommendation. Someone to take my position. I'm now on their shit list. Of lazy assholes. Flaky bitches. Screw ups. For a week I wake and sleep and dream in a blur. My pillow. And pillows for my pillow. With my tissues. Thermometer. Water bottles. Anti-virals. Anti-biotics. Anti-Mucous. Blood pressure cuff. Ricola. Vitamins. Nasal Spray. Dirty dishes. TV remote control.

And now I
stand in the kitchen.

Cookie dough chocolate swirl dream in cardboard cup. Mom says give half to Dad. *Half to Dad* I repeat. My cousin watches the scene play out. I'm a scene again. Like in the hospital before. *C'mon*, Mom says. Give some to Dad she says. *Share* she says. Didn't they teach you in kindergarten she says. I'm already sharing. Half of myself. All of myself. To illness. Disease. Disruption. Disorder. Destruction. Inside. Organs. Systems. Cells. Capillaries. Nerves. My nerves get on my nerves. She says give him just a little. What's wrong with you she says. This is mine I say. Mine. I fumble. Spoon. I push into the solid block. Ice cream won't budge. I tremor. I always tremor. But today I tremor more. What kind of a daughter are you that you can't share some ice cream with your father. Frozen Yogurt I say. *Part of why I picked it was for the bacterium* I say. Bacterium. I realize I sound like a fucking biologist. *You know, because of the Anti-biotics* I say. Have to combat the diarrhea I say. *Whatever* she says. So I try again. And Puuuusssshhhh. We argue. I push. My hand. Keeps slipping on cardboard cup condensation. And I push the spoon in. And we argue. I push. And she pushes me to my edge.

A big chunk.

Flies.

Into the Air.

Onto the floor.

My cousin leans back. Applauds.

A slow, LOUD, deliberate, cupped clap.
Well that was smart she says.

Mom says *Oops!* like I'm in kindergarten.

And neither one have noticed how hard I tremor.

The spoon. The ice cream—Frozen Yogurt. The wet cardboard cup.
The pressure building. Neither one knows the day I can hold my hands
steady. The day I can make myself all my meals without being Miss
Dropsy. Miss Mishap. Miss Spills. Miss Burn Myself on the Stove.
The day I'm none of those.

Just once.

So there I am in the kitchen.
For few seconds all I can get out is silence.

Well, I say. I guess Dad certainly isn't getting any ice cream now.
But I could scream.
Over ice cream. Staring at my career on the kitchen floor.

HARDWIRED

During my Goth girlie days, I learned a rather ethereal dance movement with my hand and arm. It involved a curling and twisting of the hand and fingers way above the head, very Indian or even Middle Eastern belly dancer in nature, twisted down to waist level, then a graceful thrusting straight outward gesture ending with the palm up much like a Victorian invite to dance. I had done it maybe a million times on countless Saturday nights and an occasional Thursday or Friday. A gesture programmed into the deepest parts of my brain, remapped over and over each time I danced.

What did dancing offer me? What did the Goth clubs offer me? A chance to let my soul free after a stressful week, in a place where no matter what might happen I'd be accepted.

I've always had health issues. I was always the kid out sick for two weeks at a time. I even got "heat hives"—or "cholinergic urticaria"—from exercising during gym class. In fact my first few years of dancing at Goth clubs in Baltimore were riddled with nights of lobster red rashes all over my arms, chest, neck. I had to take breaks to recover from overheating, downing glasses of ice water. I remember one night I wore a spaghetti-strap dress and a man flirting with me took a closer look in the dim light, seeing the rash all over me. I felt exposed, waiting for him to abruptly walk away, but he stayed there by my side and talked to me about it. I can recall the kindness I felt, not the words said. After that the sense that I'd be okay at the Goth clubs. All of us had been deemed freaks, weirdoes, or out-casts at some point in our lives. Here was the only place where I could escape my problems—my body—to a pulsating, primal rhythm, that felt so human, so real, but if I got sick, I'd still be accepted. The goth club was where I felt the least conflict of self.

I suppose it was no surprise, given my life long health history, that new symptoms cropped up. By the end of my freshman year of college lightheadedness, dizziness, shortness of breath, and fatigue conflicted with simple tasks like walking up a flight of stairs to class. Five years in, those symptoms seemed likely to ruin my career dreams to work in the in film industry. Shame is what I felt. Shame that I couldn't "cut it." Shame that I couldn't find the physical strength and mental resilience to be well enough to function. I was and am a woman of my word. If I say I'll do something—in this case be successful in the film industry—I fully intend to do it. To retreat is failure. To give up is weakness. Illness threatened the chance to let me be all that I had dreamed of being.

CONCLUSION

Positive tilt table test for vasovagal syncope.

RECOMMENDATIONS

The patient to be started on beta-blockers.

After my tilt table test in 2004, being diagnosed with vasovagal syncope, I was put on a beta blocker, which was meant to slow down a fast heart rate. The thinking is that if the heart can be slowed down, then all else will follow: normal blood pressure, easier breathing, no lightheadedness or dizziness. My cardiologist at the time made it sound like I'd take this little pill for the rest of my life and everything would be fine. I'd lead a normal life. I think even she believed that. I had every reason to believe her. I had seen different specialists for five years trying to get diagnosed properly, and she was the first one that diagnosed me—within twenty-four hours of meeting me at that. I felt grateful for a quick fix to my health problems. The beta-blocker seemed like my saving grace. In fact, I thought I'd be able to be my fullest potential as soon as I had the health to fulfill my career goals.

In truth, taking beta blockers was an issue from the start, but my doctor kept telling me either we needed to adjust the dose, change the type of beta blocker, or that my body needed time

to get used to new medication. It was a messed up trade off: My lesser symptoms day to day, hour to hour, weren't as bad, but my worse symptoms became more intense when I actually did have them—worse meaning the potential for full loss of consciousness. I had trouble working the remainder of my internship at Miramax, particularly in the mornings. Either extra exertion in the morning (like a crazy craving run for the producer where three different stores or restaurants had to be walked to in order to have the ultimate breakfast), or being a half an hour late with my next beta blocker dosage, could make me so lightheaded I'd have to sit or lie down on the floor, something that became increasingly difficult to get away with in secret.

Still, my doctor convinced me it was possibly the natural progression of my illness and just adjusting to the medication. I seemed sicker trying to come off the beta blockers, so it was easy to convince me that I simply needed a higher dose of beta blockers, not to go off them entirely. With the high stress schedule I had I didn't have time to take weeks weening off the medication anyway. After all, I craved a simple treatment to my situation. I wasn't in my illness for the long haul. I wanted someone else to fix me, so I could continue in the fast-paced, high-stress film industry. I liken it to a stretched-thin executive downing a Redbull to keep up a long day. Instead, I'd pop a pill to slow my heart.

But my health deteriorated. While on my beta blockers I blacked out at Long Beach airport trying to catch a flight home for the holidays, after the previous attempt to travel to the airport in which an ambulance had to be called to my apartment before I lost consciousness. My parents decided that it would be best to just keep me in Maryland for a much longer stay than I had intended. They were right, of course, and I didn't have the financial security to keep living in Los Angeles at that time. I was just too stubborn to see so. Upon being back in Maryland, my beta blocker dose was adjusted yet again.

It is night time now, I'm staying at my parents' house in Maryland, and I take my beta-blocker, having also taken my anti-anxiety medication not long before. The latter I've taken for years without a problem. Both combined are not supposed to be a problem. I lie down, under the metal frame sculpture erected over my bed years earlier—something I had built with a boyfriend out of metal pipes, wire, glass beads, and colored plexi-glass shards to create something of beauty to fall asleep to and wake up to. I begin to fall asleep. I feel heavy with the weight of sleep. I am breathing harder, deeper, only now I'm suffocating. I sit up in darkness feeling nauseated, dizzy, and panicky. Something doesn't feel right. I am fight or flight when I should be calming down for rest. My heart is pounding faster and faster. And then without volition, *my hand moves*.

First the fingers, they coil and twist. My eyes widen. Whose hand is this? It cannot be my hand, and yet I know this movement all too well. It doesn't take long before it wants to dance violently. My hand is on a Saturday night stint at the Goth club while I am here, present, at home. Who is this woman creeping out of my body? Who is in charge now?

In the late hours of the night, I phone a friend in desperation to talk me through Hand Gone Wild. I am ready to go into a full blown panic attack. He calms me down, though I'm not sure he entirely believes me or is awake enough himself to understand what is going on. He talks to me about how Lithium messed him up years ago and this is why he stays away from medication. I focus on his words, his stories, the sound of his voice. My body's movements lessen, I lie down again, cradling the phone to my ear, and soon we say our goodbyes. I drift back towards sleep.

Then the arm becomes more involved. I am startled again by a dancer. I fight my right arm and hand from rising upward above my head and then thrusting out to gesture—to gesture to whom?— myself?—to dance.

I yell for my mother. I never yelled for her like this in the middle of night when I was a child, but as a young adult dancing against her will, it seems appropriate. I say, “You must hold me down. I am exhausted at this point. I can’t dance anymore. Please, I can’t dance anymore.”

At first she must repeat herself several times to process the information: “Wait, so you don’t have any control over this?”

“This is a dance move I do at the club. For whatever reason—the medication I took—made this movement what my brain picked to relive right here, right now.”

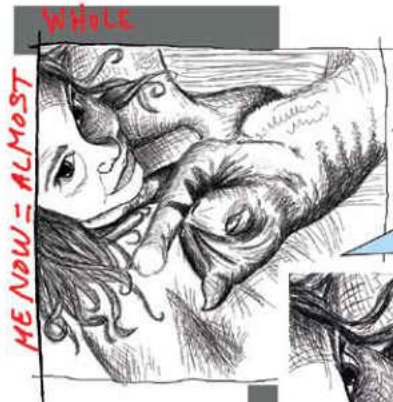
“Shouldn’t we call 911?”

I tell her I’m too exhausted to go to the hospital and I don’t want to be there. I tell her what I need is sleep and I’ll never sleep in an ER. She understands.

“So what should I do?” she asks.

“Hold me down until I can sleep,” I ask my mother, a woman I haven’t always been able to trust not to use any means to control me for her own motivations. Now I need—am more than willing—to have her physically detain me.

She sits on my bed and fights my arm and hand like they are psych ward patients out of control, until I can sleep. As the sun begins to rise, soft blue light peaks through my curtain. My arm and hand fight her less and less, until I am ready to pass out from exhaustion, rather than from a sudden change in heart rate or blood pressure. I mumble to Mom that I’m falling asleep, as I close my eyes to my last glimpses of that morning’s soft, blue light.



I see it now.

It would have been hard not to feel a division taking place within myself if I didn't feel like I had control over my body.

A separation of true spirit from physical, autonomic self seems only natural to take place, where I longed to connect with the ...

PAST ME =
DIVIDED PARTS =
3



spirit self -- my true essence and muse-- and be her full potential while I fought the physical disabilities that felt like failing my own spirit.



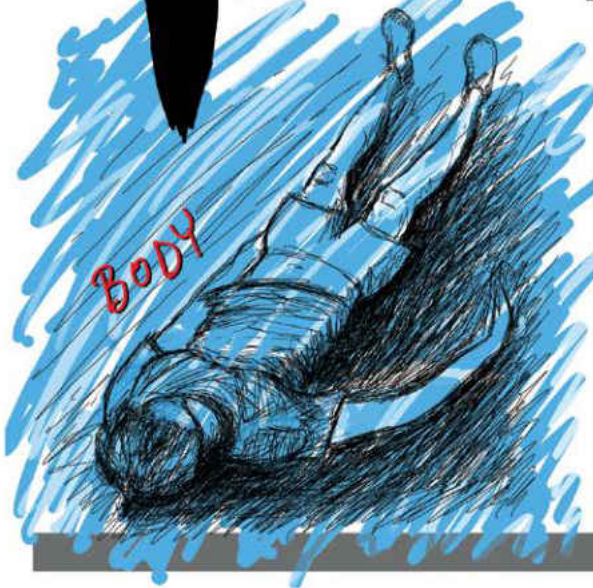
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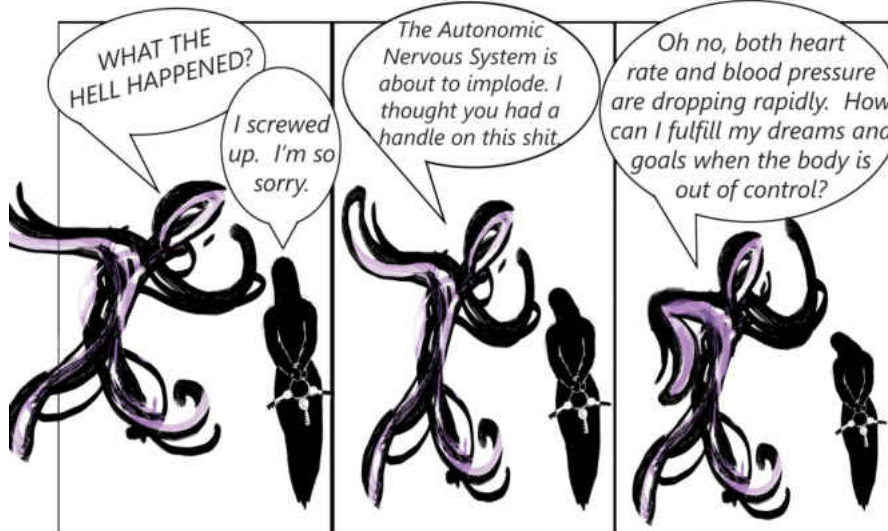
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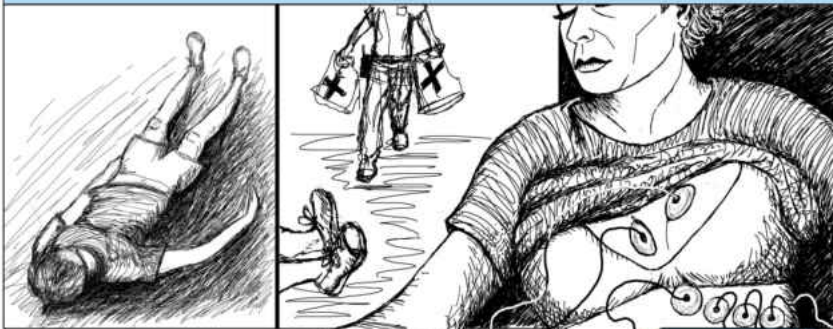
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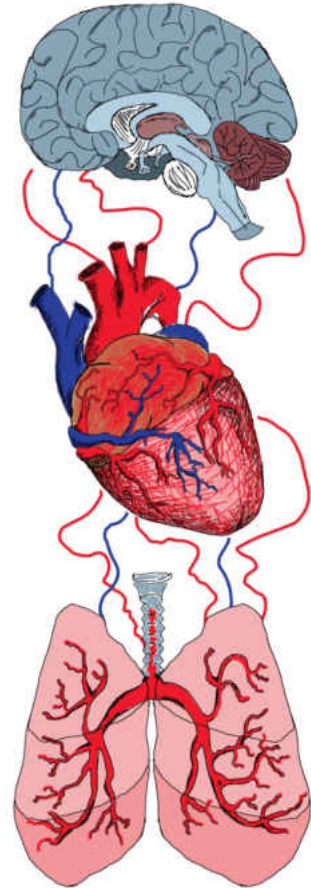
I developed the sense that my identity was becoming more of a noticeably disappointing gate-keeper to a loud, dysfunctional vessel, rather than the beautiful manifestation of my soul contained within a quiet, working body.



And the more dysfunctional that vessel became,



Autonomic Nervous System = Control ≠ No Control



In June 2005, after six months of trying to get well at my parents' house, I am already in the process of trying to lessen the dosage of my beta blocker. I have grown weary of the side effects and my goal is to either lower the dose for good or go off of it altogether. So far it's been working out okay. But today, the day I plan to start my road trip back to Los Angeles, between the heavy lifting, packing, and then fighting with my mother over something stupid, I suddenly feel like I am having a heart attack:

I sit on my bed, collecting my breath, feeling my left arm going numb, except for pins and needles sensations, and a deep crushing pain going through the front of my chest to my back. My cousin walks in to determine a solution to an argument with my mother (we can still hear Mom shouting in the background), then stops mid-sentence with, "Oh shit, are you okay?"

"No. Something is very wrong."

"What do I do?"

"Help me get on the floor in the hallway." I say the hallway because I'm already preparing myself for the possibility that paramedics may have to come, and I'm allowing easy access of my body next to the front door foyer. I reach out for my cousin, she takes part of my weight, and we stumble forward, until somehow we manage to situate my body onto the wood floor.

It's hard to feel any sensation but the pain in my chest and higher consciousness that *this is not good*. It's a moment in time when all is drowned out. Maybe I hear snippets of sound every now and then, but for the most part I am the closest I've ever been with myself. It is a meeting of selves, between the essence of my spirit—the woman I've grown increasingly further from—and the gatekeeper to a dysfunctional vessel of a body—the woman I'm becoming more

and more every day. We are in a vast space of quiet where I reason with her that this will be taken care of. To just *hold on*. She's disappointed in me, maybe even angry. Like a film executive whose assistant fucked up something important.

I think I make the decision to have 911 called but I cannot be sure. It's always a painful choice to call. It's never easy. Calling 911 is admitting you have no control over a situation. Everyone in film production is in a sense their own 911 rescuer, and if they can't be, then they have no business working there. It's an aspect of the film industry I had been fond of. It felt like a superhuman trait: to be able to handle anything that might come up. There was a level of competence needed to fix an emergency which garnered respect. I enjoyed taking care of other people's emergencies—not being my own. I enjoyed having others count on me.

Now I couldn't even count on myself.

I hear my little nieces in the background asking about what is going on, and then it goes back into quiet and slow motion. It is just me here on a cold, wood floor, staring at the plastered ceiling, gasping for air, thinking over and over: *I just have to get back to Hollywood. Please help me.*

Fuzzy, white spots start appearing in my view, moving in size from small to large, like the effect from a camera flash bulb. Now there are two paramedics by my side, young men, very personable, asking me my name, how I'm doing. They might as well have come from a space ship because I am not all there. All the energy I have left is focused on staying awake. I don't trust losing consciousness. Death feels too close for comfort.

I hear one paramedic whisper to the other: "Shit, her heart rate is fifteen beats per minute."

"Fifteen? Are you sure?"

“Yeah.” They both turn to me.

“Hey darling, is this usual for you? Fifteen beats per minute?”

I can’t help but laugh. This is an all time low for me in more ways than one. “No,” I say.

“Her blood pressure is dropping.” The number is something ridiculous like sixty over forty. It’s not healthy. Healthy is one-hundred and fourteen over seventy-seven. I have it memorized as a goal I learned in ninth grade honors biology.

“We need to get her out of here, *now*.” I sense the urgency in his voice. “Hey Gen? How the hell are you still awake I want to know? You shouldn’t be conscious.”

“It’s taking everything I have. I’m holding on as best as I can.” *I’m afraid I’ll never wake up if I pass out.*

I had met a man, named Jeff, at the main Los Angeles goth club, “Bar Sinister,” a Saturday night hosted by Boardner’s Bar off Hollywood Blvd. He watched me for a time, as I demonstrated my goth moves I allowed myself to get lost in—that all too familiar hand and arm gesture—until he finally introduced himself with a handshake and a smile. It didn’t take long before Jeff and I started dating. Through most of our relationship I was undiagnosed, and even when I had been diagnosed he didn’t always understand what was wrong. But in the winter of 2004, after my first black out in a public place, Jeff was panicked and wanted to see me right away. I spoke to my mother on the phone in the hospital and asked her to call him for me. For whatever reason—maybe I felt he was the closest person in my life at that time in Los Angeles—despite our relationship ups and downs, he was the main person I wanted to know. So my mother told him that I had just been rushed to the ER after I passed out the Bourgeoisie Pig Café—the night I couldn’t remember what my own name was until the ambulance was already

pulling away. That night, Jeff gave me a silky-soft plush toy white-tiger-striped cat with big, ice blue eyes that he named for me, “Snickers,” which seemed stupid at first—the name, not the toy—but it grew on me. After that, I found myself on many nights of the week falling asleep while holding onto Snickers. Eventually, I couldn’t sleep without him. I’m not sure I can simply summarize Snickers adequately. Why do children cling to a stuffed animal? Sentimental value? To keep the monsters away? Comfort? Sometimes I think in my isolation of being ill, I needed something—anything—to keep myself from going entirely mad. Snickers was a token of love given to me by someone I cared about, and no matter how alone I was, it was like having that love nearby. I think about the volleyball in *Castaway*, where the character, played by Tom Hanks, talks to his volleyball, “Wilson,” regularly on a desolate island. Hanks even weeps when he loses his precious Wilson. Snickers meant that much to me. We were in this mess together.

If you asked me today to tell you event by event in chronological order of all that happened between June 2005 to January 2006, it would come out like a jumbled mess. I lived in a blur. There were several episodes during this period of time, while my beta blocker was adjusted again and again. I moved back to Los Angeles. I did. It’s funny when I think about it now because it seems like such a crazy choice. It seems reckless even. I reasoned that if I stuck with a beta blocker—at yet a different dose or a different kind—and I stabilized for a period of time, that all would go back to normalcy, whatever that was; at least that’s what I convinced my mother. I reasoned I just had a rough patch of bad health I had to push through. Frankly, I see now that I had not accepted my illness at all, and in turn I was denying myself a real existence.

I was hardwired to pursue my goals no matter what, no matter how illogical, no matter what the cost. I know I *thought* I could accomplish almost anything if I just put my mind to it.

Where did I get that from? Did I grow up in a generation that thinks that they are capable of just about anything if they put their minds to it? Was it because I was raised that way? Or was it some sort of innate personality trait distinctive to me—the kind of trait that so many people in the film industry have?

With my return to Los Angeles, I assumed I would again participate in the Goth club scene as well. I thought I would win back Jeff's heart. I would strut my stuff and work my moves on the dance floor. My first night back I hadn't even danced yet. As I walked down a flight of black, metal steps to find Jeff in the packed club, I wondered if I'd find him with another woman. I wondered if I could ever get him back or what I would say when I saw him. At the end of the stairs stood a platform next to the bar, with one of the club's paid dancers, topless for the exception of black electrical tape X's over her nipples, twisting her bare stomach, and gyrating her hips, as men reached up to put money in her garter belt. There wasn't an ounce of cellulite on her, and her moves were flawless. I wondered what it would be like to have a flawless body, inside and out. At some point making my way down the stairs to Jeff, I blacked out, but my last memory beforehand is of the dancer.

Jeff didn't even know I was there that night, as the paramedics attended to me outside on the sidewalk where friends had laid me down on a jacket. As I heard the sirens and loud speakers yelling, "Pull over," to traffic deadlocked on Hollywood Blvd, I opened my eyes to the dirty city, being blinded by emergency vehicle lights sweeping across the buildings, and at that moment I realized that the one place I had found sacred, had now been tainted by my illness in a way that seemed unforgivable. And no matter how much I could get over this spiritual loss of a

sanctuary, it still didn't change the fact that I was declining to the point where I could rarely leave my apartment, let alone go out dancing.

I'm in my apartment in Studio City and right now Snickers is all that I have of any soulful value. Right now I am cradling myself, shivering in my red fleece coat and blue jeans, on a mattress that's resting on a carpeted studio apartment floor. A mattress I've stripped of all covers and sheets. I sit up, wrapping my arms around my legs, rocking, rocking, rocking back and forth, always rocking. Heart pounding, running a marathon without a runner.

This is an island I sit on. There is no saving land around me for miles. And now, you and me—You—the person I was and wish I could be right now—and Me—an empty vessel seemingly—have a decision to make. When there are no bugs but it feels like they're all over. When muscles twitch and spasm in my back, arms, legs, and even my right eye ball pulses, no matter how hard I squeeze that eyelid tight. When I feel unclear. When it's obvious that my new beta blocker dose triggered all this but it will take hours for it to get through my body. When I haven't slept since—shit—who can remember when? Who knows what day it even is now? How long has this even been going on? All we know is right now it's morning and this is an island with lots of bugs that like crawling on skin. Should we jump off the apartment balcony to end this? Should we jump in front of a Los Angeles city bus to make it stop? I would do anything to make this stop right now.

This is isolation. This must be those dark times people talk about. This is the separation of self that takes place when a medication doesn't do what it's supposed to. This is the division that evolves when illness leaves little room for You.

Where have You gone? Are you watching, waiting, to go to Heaven? Should I lead us there by a bottle full of pills? Are you deep within me where I can't find You, just holding on, hoping I do too? I'm trying to rock us to sleep. I'm trying to make it okay as best I can. I bury my face in my knees, rocking, always rocking.

My stomach churns and I feel like I can't breathe. I look up. "Let's get fresh air, yes, fresh air cures anything," I say aloud. "Snickers? You're coming with us." I grab Snickers lying nearby, my back pack, and a bottle of water. There is a mission now, though Lord knows the outcome. I open the apartment door to blinding, early morning sunlight. I immediately raise my arm and hand up to block out the light from my view, like a cave prisoner just set free. I scramble for the keys. "We have to try to get through this. Lock the door." I lock the door and get to the top of the metal stairs of the apartment complex. I close my eyes. "Please God don't let me black out on the way down." I open my eyes and grip the hand rail tightly, leaning backwards in case I lose consciousness, I can fall back instead of forward down the stairs.

I get to ground level and rush out of the apartment complex to the busy street sidewalk. I'm a twenty-four-year-old clutching a stuffed animal, my back pack, and a water bottle in a jumbled heap, with my fleece coat still on. Instinctually, I turn right, towards the suburbia community of Studio City. "We will walk these blocks until we're okay," I whisper. First the walk has urgency, as if there's some sort of goal, and then the body overheats, so I take off the coat and keep walking, coat hanging off me, sometimes dragging. "We will get through this." I walk until I can find some semblance of You, when I realize that Snickers is no longer with us.

We are frantic now. Snickers is all there is. We search block after block until they blur into a maze. And then the tears start to fall. I am sitting on a curb in front of someone's Spanish style ranch house and nicely cut hedges, with my head in my hands.

I'm not sure where You were, whether You were inside me crying too, whether You sat down next to me wrapping your arms around me, whether You did a little of both. But Snickers was never found and that felt like the worst cruelty, right then and there. You must have felt it too. You must have broken into pieces and it's all because I let you down. I lost Snickers—for both of us.

Separation of self had become complete for me by winter of 2005. I led dual lives not only continually, but now *consciously*.

I know what happened. My body taunted me with involuntary dance moves, cut off the relationship I had developed from the goth club, made it so that I blacked out there, and then my strange saving grace in this world—Snickers—I lost because I was tripping my brains out along a suburban street to realize I had dropped him. For me back then, all I had left was my drive to do well in the film industry. Everything else had fallen away. And so I wanted to get over this illness even more than ever.

Besides, giving into illness seemed like letting someone else win.

If I could go back in time I would give myself the love I needed. I would have taken away the isolation. I would have accepted myself as a whole person. I didn't need a place to go to, to be accepted, or a thing, or a person to accept me so much as I needed myself to accept me.

T.M.I.

For several years in Los Angeles, I temped in different administrative departments of the film industry, but when I move to New Orleans, I temp for a real estate office—or maybe it is insurance—working for people who voice interest in how a temp ended up a temp and what my real goal in life is. Besides being temporary in life that is. I state that I am writing a memoir about being a young woman in the film industry while dealing with an autonomic nervous system disorder.

This leads each inquirer to draw a little closer and ask me to tell him or her more.

And then most people confess. When people know that I'm telling all about my illness, they start spilling the beans to me about an illness they've had or one that a close family member or friend has. This one woman at the New Orleans office looks around herself to make sure we're alone every tenth syllable as she confesses to me right there in the lobby at the front desk that actually she has Lupus and nobody in this office knows, and THANK GOD she's not the typical Lupus patient: She doesn't get the rash on her face, she gets it on her chest which makes it easy to hide and look, see, she'd never actually wear a top this covering-up—you know—with the heat and all—*but look, see, I'm starting to flare up again on my chest, but nobody knows, and THANK GOD*, she says.

It is then that I realize it extends further than the film industry. This pretending and hiding and covering up at work like it's the darkest secret, like we all should be ashamed, like we should all live in fear we're too much of an insurance liability to stay hired, to stay human.

She seems grateful to me for telling all in my book. In fact her on-the-spot confession to me is exactly that—breathless and relieved, maybe even a tear or two welling up. She has not shared this with anyone but I am temporarily here yet intending to permanently tell everyone—

the whole world—on paper—that I am flawed, broken, even at times infectious, a complete liability.

I understand the woman with Lupus. She's tried to play the part of a healthy person for her colleagues, probably for many years now, and it's never felt quite right or natural for her, because it's not the truth. The truth is she's sick and it's still a stigma to be sick. When I didn't have confidence, when I was still in hiding, when I was still afraid about losing a job over illness, I too developed various roles for dealing with what information I divulged to others. I was a chameleon of sorts. I had a rehearsed role for just about any occasion, some more honest than others, some entirely a lie. Who I portrayed was based on who you were.

The Industry Employee

If you were a film contact, I would play it like World War III was not happening inside my body. I would force a huge smile and crack a joke. I'd ask, "Is there anything I can do *for you?*"

If we happened to be working on-set, you might ask, "Where'd you go?" and I'd say, "Oh, just picking something up for one of the actors," and then smile. I wouldn't tell you about how I had hunched over in an abandoned area—whether in the bathroom or behind some set wall—praying to God I can get through the next three hours.

If we were attending a schmoozing event, I'd order ice water in a clunky glass that looks like it might contain Vodka, and I'd hold it with both hands so you can't tell I have tremor. Sometimes I'm stuck with the plastic cup which gives away the water.

"Oh, I have to drive a lot right afterward. Don't want to drink too much. Already had a rum and coke earlier," I'd say.

The Good Patient

If you were the average doctor I'd try to roll my symptoms out for you as best I could chronological style, dictating a series of events, like I'm telling a mechanic about the weird sounds my car has been making. It would be simple and to the point, but I'd hold back a good bit of information because chances are I'd only overwhelm you. Either you wouldn't want to see me again—you'd be like one doctor who had his assistant call to say my next appointment had been canceled—"He feels your situation is too complicated"—or my knowledge about my health problem, about biochemistry, about research I've read (and understand) would threaten your ego. So I'd have to play a little dumb.

I'd try to keep my emotions in check as best I can, no matter how I feel in my buttlless gown. No teary-eyes. No wavering voice. No lengthy diatribes. You would feverishly write down notes in your pad of paper and let out, "Hmmm," and I would try to avoid that equating: *More Exercise, A Dose of Prozac, With a Positivity Chaser should do the trick.* There'd be no upsetting outburst of expressing my genuine isolation, just solid eye-to-eye contact. Perhaps I'd allow my head in my hands with an emphasis on how these incidents have ruined my quality of life—yes, *quality of life* is a very good phrase, because it's true and it sounds like a legitimate assessment value— yes, and I'd go on about how my symptoms make life difficult to function and work at my job. We live in a monetary world. *I'm having trouble being that upstanding, hard-working, go-getting, positive-outlook citizen that doctors admire as patients—that the world admires.*

The Normal Stranger

If you were a regular Joe or Jane not in the film industry, I'd have to size you up within a few seconds of conversation. I might test the waters, if asked what it is I do. (This question

always killed me in the past. *What is it I do? Well, let's see. There have been long periods of time where I was too sick to work so I spent hours online researching my health problem to find a cause and treatment, or to commiserating and educating fellow patients. Sounds sexy, right?*)

I mention a little bit about my health problem. Some I can tell by their eyes glancing around for an exit, for an escape, at just the mention of “autonomic” which sounds like an complicated-person sob story to them. With those people, I know that either illness scares them or that they place blame on the ill for not being positive enough to overcome. So I shut up and change the subject to what a friend is working on, the weather, or a celebrity story I have up my sleeve.

But with the average Joes or Janes that keep direct eye contact with me, I would then go through a second phase of sizing them up, wondering how much they can handle. I would say, “You don't really want to know” or “It's a long story,” but there have been those people who have surprised me, leaning in, and they've really wanted to know. They've been on the edge of their seats and I stop myself half way through yet again and say, “Are you sure you want me to go on?” and they say yes, that it is “fascinating” —not that what happened to me was good, but nonetheless, it's fascinating—and I am in awe of this reaction no matter how many times it's happened.

The Comrade in Arms

With fellow patients it's like swapping war stories. Many times we're just venting. Many times we don't even hear each other I suspect. We feel each other's pain. We bear the burden for each other when it's too rough for us on our own. There is comfort to hear someone say, “You're not alone,” and you know that they actually have a very real sense of what you go through.

The Fellow Geek

And then there is some friend of a friend I first met in middle school, who does biopsies on patients who wait with bated breaths to know their fates. She dissects their tumor tissue into a million little slices and I always see in my mind the shredded skin slices that day I went on an Honors Geek Program fieldtrip to Johns Hopkins when I was ten or eleven. With her, the friend of a friend, well, with her I can talk right out of a science text book, and it's so freeing.

The Happy-Go-Lucky Friend

If we're friends and you ask me how I'm doing, well then it really depends on what friend you are to a degree. I've usually tested your limits and know what you can and can't handle, but I can promise you that I will always try to work extra harder to put on a smile or crack a joke for you. I don't want to lose you. I don't want to bum you out. I don't want to overwhelm you with problems you feel lost how to fix. There are days when I'll slip up in my Happy-Go-Lucky-Friend role, I'll tell you how things are rotten, and then the guilt takes over when I'm alone, that I've said too much. If that happens, then I'll either make a point of pretending to be well for a week or two, or I may go so far as to apologize for being a burden.

At times, I've felt like I should be getting paid for each role. I've felt like saying, "Tell me, baby, what do you want me to be? I'll be anything you want. Just tell me." I realize that everyone—whether healthy or sick—is a different identity to each person in his/ her life. Everyone means something different to us. I get that. What I guess I find so disturbing is how contrived some of my roles developed—how severely they could contradict my spirit—and how sometimes I still have to play them when I just want to say, "Look, let's just cut the crap, shall we?"

RITUAL

It starts with a diagram. Susan, fellow patient, shows me the way—via IMs, emails, phone calls—in which CFS patients are connected to this thing called the Methylation Cycle. I learn biochemistry online, in between periods of crisis my boss goes through. This time my boss needs me to set up a phone conference with Berlin, but the time difference with Los Angeles is difficult. When we start our days, Berlin will have left their offices two hours ago. But they are willing to compromise. They will stay an hour late if we come in an hour early. My boss says there's no way he'll do it for them. Says he can't come in an hour early. Says his dog, Apple, has to be taken to doggy daycare at a certain time. I say I'll take her. Apple is a black lab mix, a rescue, I met once via a sloppy kiss and tail-wag. My boss won her at a wine festival auction while drunk on Apple martinis (I say to my cubicle neighbor *How does one get drunk on martinis at a wine fest?* We come to the agreement: *Anything's possible with him*), and my boss woke the next morning to a pile of dog shit on the floor and confused as to how he had a dog, and so began his love affair with Apple. But he doesn't trust me to take her to doggy daycare.

So he argues with Berlin. And I argue with him. *It's not unreasonable to compromise.* In between smoothing things over with Berlin I learn of the methylation cycle. I learn how our bodies need it for DNA replication. To rid toxins. To do the most basic, fundamental tasks in our bodies. The idea, Susan says, is that there are parts in this cycle—

genetic mutations—*SNPs*—not working for CFS patients—at least that’s what some scientist she’s talked to reasons—and that maybe it’s the same for *our kind* too. Rich Van Konynenburg is his name. So I read his PowerPoint presentation online.

I study the amino acids and vitamins in this cycle until I know them by heart and what other cycles they connect to. *For instance, did you know that SAM-e—or S-Adenosylmethionine—escorts histamine out of the body? Or how B6 leads to the creation of a vital anti-oxidant, Glutathione?* Sometimes I hear myself spewing out these sorts of details to my cubicle neighbor. Then, I come to Homocysteine. I read about how it blocks nitric oxide needed to open the coronary arteries to allow for oxygenated blood to flow freely. I think about my chest pain when walking, how my heart beats fast and hard, how it feels like I can’t breathe. Chest pain the doctors call “angina,” only they never know why I have it.

I am determined to get well. This thought is punctuated by every difficult breath while on an errand, while walking across the studio lot, past the sound stages, past the Star Wagons, past the men building sets, hauling lumber, chords, lights, even trees. They all call to me. Even the lumber says, *Get better and then you can work on-set with me.* I have a hypothesis that too much Homocysteine flows through my body, and that’s why I have chest pain. Maybe it’s even part of why I have Dysautonomia. My cardiologist finally calls me back, and I argue *It’s*

only a little blood work. What's the harm? It's not like I'm asking for surgery. And hey, when it turns out fine you will have proven me wrong.

He laughs and says okay, that he'll order the test. But when it comes back abnormal he won't talk to me. I'm on the phone with his receptionist, she cups her hand over the receiver, but I still overhear him tell her to get rid of me, to tell me he's not there. I thought he'd at least refer me to someone else. *I've been her* I think. *I've been the puzzled assistant whose boss blows off someone with questions, someone who needs guidance.* I imagine my old internship, the scripts piling up, the lost dreams piling up—and the acquisitions director saying, *Why do you talk with them? Why give them any hope? Just tell them I'm in a meeting and eventually they'll take a hint.*

I experiment on myself, left to my own devices. One day I count all the different vitamins and amino acids I take. Clunky pills, white horse pills, tiny pink pills, orange tablets, clear yellow softgels, white gelcaps. The total is twenty-two. Most I pop at home on my lunch break from the studio. I try Folic Acid for two months to combat the Homocysteine, get a new blood test, and still it hasn't gone down. So I hunt for contact info on research papers. I email leading researchers of Homocysteine. I explain my situation. And Dr. Finkelstein says he and his colleague, Dr. Mudd, are willing to help. I didn't have to beg. I didn't have to argue. They just want to help to be nice. *How is this possible?* On the phone Dr. Finkelstein sounds like Ed Wynn, and while he speaks and often pokes fun

at himself, I imagine Ed Wynn playing Dick Van Dyke's uncle Albert in *Mary Poppins*, laughing so hard he's floated himself to the ceiling. Dr. Mudd seems only tolerant of me at first. I like to say *Dr. Mudd doesn't suffer fools*. But then he calls. Says my first shipment of blood samples in dry ice is lost in Tennessee. Several hours and phone calls later, I track the package down. He says, *I don't know how you found it, but good for you, Gen*. I say, *I'm in the film industry. This is sort of my thing. Fixing bizarre problems*. Dr. Mudd realizes I'm no fool.

There will be many more blood draws, and changing up vitamin regimens, until it's discovered I'm the first documented case of a Betaine deficiency in the entire world. Dr. Mudd says, *It may sound strange, but I've waited my entire life for this, for you, Gen*, and I begin calculating just how old he is, how long it took him through medical school, through his biochemistry PhD, how many years he must have pondered over the hypothesis that somewhere out there, there must be a Betaine deficient patient.

For periods of time new discoveries are made with new hopes—though held in check—never released into a full blossom of hope—that this plan or that treatment will be what helps me. First it seems like taking Betaine is the solution, but without a clear explanation my SAM-e heightens to liver failure levels. *Cross that treatment off the list*. Then it's found I have a Betaine deficiency because I'm the first documented case in the entire world of a SLA44A1 Choline transporter problem. *The*

transporters are like cars having trouble driving enough Choline in and out of my cells, so I'm deficient in Choline, and a Choline deficiency leads to a Betaine deficiency, which leads to abnormally high Homocysteine, I tell friends whose faces look like they're still putting together the first half of the sentence, let alone understanding the whole thing. I feel like there must be a zoo for my kind of weird.

Meanwhile I find research which states that mice deprived of Choline have orthostatic intolerance. *Go figure: Light-headed mice; what will they think up next?* The pieces feel like they're coming together, like a scavenger hunt, one by one, clues opening up to other clues, but Dr. Mudd says, *Sometimes the answers only lead us to more questions.* He says, *This science is so new,* and I know it's a reminder that we may not find out the answers to my body in this lifetime.

Finding information, c o n n e c t i n g information, studying it all becomes my daily ritual. I am torn between building a life for the future and what feels like back-tracking to my childhood, my birth, my DNA, my family tree for answers that could help me better hypothesize a future. I'm losing myself in illness. And always, always it seems like the phone rings. There's another meeting to set up. There's another expense report to do. There's one more battle with Berlin to smooth over.

YOU COULD PROSPER

When the credits started to roll at the end of the film, as we waited for the mass of people to pour out of the theatre ahead of us, I looked up at the screen and saw right at the top, my high school friend, Caitlin's, name. I knew she had gotten into the film industry but now, here, in bright white lettering the evidence of her success slowly drifted high above me until it no longer showed itself on the screen. On one hand I felt happy for her; on the other hand she was living my dream. Not even being around my best friend, Patrick, that evening could seem to make that nagging feeling of being a "failure" entirely go away.

Caitlin and I had lost touch after high school, but a couple of years ago I got back in touch with her online, while in the process of reassessing my life, because somehow grasping at the past Me might help me fix the current Me? I grew unhappy in the film industry, and eventually I understood it as full blown disillusionment, the kind of thing I heard about, read about, but never imagined myself feeling. Over the years of chasing the dream I thought I wanted so badly—and at one point I know I truly did want it badly—my Autonomic Nervous System disorder increasingly made any aspect of involvement in the film industry physically difficult. But that's not the reason I finally left it behind, because Heaven knows I'm stubborn. No, the sicker I got, the less I took life for granted. The "little things" in life meant so much more to me, and I had less patience for pettiness, frivolities, materialism, manipulation, sexism and back-stabbing—all aspects of the film industry that I had grown severely allergic to, whether or not the sting is truly all that much worse than any other industry.

Names are important in the Industry.

They have the power to make or break a film or TV show.

They have the power to make or break a career.

“Look, let me be honest with you. I’ll lay it all out for you and tell you like it is. If you don’t have Russell Crowe on board with your script anymore, then no one is going to pick it up,” I said to the Nobody filmmaker on the line who kept trying to get a phone call back from the Acquisitions Director I worked for. He wouldn’t take a hint that my boss was never going to return his daily phone calls. I had witnessed this sad dilemma play out several times. I felt for the guy; I really did. But someone had to tell him the truth. Somebody had to tell one of these guys how it truly is.

The guy tried to make his case to me: “But—But Russell’s not available for two more years! I don’t want to wait that long to make my film! His film schedule is booked *for the next two years*. He was on board, but I’d have to wait. I just can’t wait two years to make this fi—”

“Wait the two years,” I interrupted. “Seriously, it will probably take you much longer to make your film without a big name like Russell Crowe. I mean you’ll be lucky if you get it made in five years without Crowe. You can tear your hair out scrounging around for money to produce it on your own without him, and then no one will probably see it anyway because you won’t be able to finance a big marketing campaign like a big studio can. That’s just the way it is. You’re better off with Russell on board and without him a major studio is not going to back your script. That’s the bottom line. You need a big name like Russell Crowe. And if he’s willing to be on board with your film two years from now—take what you can get.”

If you stepped into a time machine and traveled back to the five minutes after I first met J.C. Lyons on the set of *Black Hills Creek*, you might find the words, “I’m so lucky” rolling out of my mouth, as fast as how credits roll when a movie is formatted for TV, rushing over the

screen high on coke or meth-amphetamine, squeezing in just in time for commercials and the next movie. I had a dream of someday being a great film director like Alfred Hitchcock, and J.C. Lyons actually met Hitchcock. Hell, Lyons knew everyone.

My new friend and colleague, Chris, took me over to a white-haired man in a dark gray suit, out in the drizzling rain shaking hands with the crew setting up a scene. Chris leaned over to me and whispered that the man was a famous producer, had worked with all the greats, dated Marilyn Monroe even. We walked over in the mud and Chris introduced me to J.C. Lyons, who shook my hand and greeted me with a smile. Lyons handed me his card, told me to be in touch, and went on his way. Chris whispered to me, “See that? Hold on to it. That card is important.”

But after calling Lyons I found that the eighty-five-year-old producer and then consultant for *Black Hills Creek* turned out to be a very dirty old man, dropping in hints and innuendo about hot young women and how beautiful I looked on-set. I turned bright red, my face hot against the phone, and hardly heard any of it. But the part of the conversation that has stuck with me all these years had to do with his star. J.C. Lyons wanted to know if I had seen his name on the Walk of Fame.

“Oh, why, yes Mr. Lyons,” I said in my twenty-two-year-old polite voice which always sounded more like a child’s voice to me no matter how hard I tried for it not to.

“Oh, please, call me ‘J.C.’.So, tell me somethin’, darlin’: Did ya stomp on me?”

“Excuse me?”

“Did ya stomp on me?”

“What?”

“My star. Did ya stomp on it?”

“Ohhhh stomp on *your star*.”

Caught off guard by the question, I just answered honestly. “Oh, no, I mean, actually I usually walk around the stars out of respect. I never step on them and I certainly don’t stomp on them. I dunno, it’s kind of like when I don’t want to step all over someone’s grave out of respect,” I admitted.

He seemed utterly disappointed. “Oh that’s no good.”

I laughed, but then felt unsure if I had said something wrong. I realized I just mentioned “grave” to a very old man.

“You need to go down there and stomp on me,” he said with complete enthusiasm, as though it would be an experience everyone should do at least once in their lifetime. *What a funny, strange old man.*

Lyons then stated that to have a sexy woman stomping all over his star would make him very happy, particularly if I wore a hot dress. *Maybe he just talks dirty like one of the guys. In person he’d be the professional man I met on Black Hills Creek.*

I set out to devise a plan to get myself noticed as worthy enough to be invited to the lot where Lyons worked, Supreme Pictures Studios, which seemed like a reasonably safe environment. I figured Lyons still worked there five days a week and he knew everyone in the Industry. *I’d be a fool not to try to make good contacts through him.*

So with a disposable camera, on a cold, windy evening as the sun set over the city, I dodged the tourists on Hollywood Blvd, making my way down to Lyons’ star to take some angled pictures of my long legs leading down to my platform heels planted on his star. I then played around with one of the images in Photoshop until every curve of my legs, heels, his star, his name was contoured and then I inverted some of the colors. The final product looked like a sexy neon sign photograph. I printed it out and wrote with black magic marker in the white

margins I left around the picture, “Dear J.C., I stomped on your star just for you. Sincerely, Genevieve.” Then I framed it and shipped it as a Christmas present.

Lyons took notice and invited me to meet with him on the Supreme Pictures Studios lot where he’d show me around. He said he found my gift idea creative and sweet. I thought I had gotten my big break.

Around the same time J.C. Lyons decided to set up an appointment to meet with me on the Supreme Pictures Studios lot, my body became increasingly symptomatic.

Prior to my move to Los Angeles, I had struggled with strange symptoms that grew worse during my first year there. My heart beat too fast and too hard, pounding in my chest like it would burst into my throat. It tried pumping oxygenated blood as fast as it could, but I often found myself breathless even while walking. Elevators were my new friends. Light-headedness and dizziness would ensue, my body would tremble, and I used what little energy I had to keep from throwing up. Prior to Los Angeles I had seen a couple of doctors who couldn’t help me despite trying their best, and also some who rudely told me it was all in my head (one added, “Maybe you’re just one of those people susceptible to fainting,” as if there happened to be some populous of over-emotional people he had in mind that just randomly blacked out over nothing). Others passed me along to yet another specialist because they didn’t want to deal with whatever it was that I had; I started to feel like either an unwanted child or a cheap whore being passed from stranger to stranger. Despite needing to seek emergency medical treatment for a particularly bad episode of shortness of breath in my first couple of weeks living in Los Angeles—or perhaps *because* of that episode—I resolved myself to the fact that I would never

know my diagnosis and instead, I would just have to trudge through it somehow. I guess I felt like if I didn't make it a big deal, it wouldn't actually be that big of a deal.

One day in February of 2004, I was proven wrong. I drove to the Bourgeois Pig Café to set up shop to work on my homework for some classes I took at Cal-State-LA. I bought a big banana milkshake as my usual treat. I felt physically exhausted—a sensation as if weights were hanging all over my body and that all too familiar feeling of breathlessness, only now I felt it even sitting down. I ignored my body and turned on my laptop to start a film essay just the same. A woman walked into the cafe with a beautiful Husky. I stood up to pet the Husky and then sat back down.

I woke up on the floor.

All those symptoms I thought I'd have to learn to live with finally caught up with me.

For a few seconds I thought I had fallen asleep on the floor out of my sheer exhaustion and I started to feel embarrassed. As I slowly came to, I realized I had drool coming out of my mouth, while some man asked me my name and number. Funny enough, I thought he was hitting on me, until I found out much later that he was a doctor that happened to be at the café that night. Apparently, I replied to his question with: "It's NONE OF YOUR BUSINESS." Stunned, he looked at the surfer dude café employee dialing 911, who shrugged and replied to the doctor, "Dude, she just woke up. Maybe she just wants to be left alone, man."

When the paramedics came, I couldn't remember my name when they asked me.

There's nothing worse than not being able to remember your own name. It's like you don't even exist to your own self.

Somehow I did remember I was inside the Bourgeois Pig Café. The paramedics chuckled, and I couldn't help but smirk at the situation. I couldn't remember my own name but I

could remember that obscure café name. Still, as they started to cart me away, fear began to take over.

“Oh my God. I can’t remember my name. Why can’t I remember? Why can’t I remember my own name?” They sensed the distress in my voice I’m sure.

“It’s okay, just relax. It will come to you. Don’t worry about that right now.”

But I couldn’t relax and instead I thought really hard until I made my brain hurt. Finally, in the ambulance I blurted out, “Genevieve Anna Tyrrell! That’s my name! That’s who I am! Oh thank God.”

When I got to the hospital the medical staff told me I had passed out and had experienced some sort of seizure-like episode. My cousin’s partner, Dana, came to get me out of the hospital. For me, I felt a bit awkward, since my fifth cousin, Ann—my only relative in the Los Angeles area— and I had been somewhat estranged for months. Ann had feared my health problems were of my own making, which left me feeling isolated, but after my black out in the café I was glad to see Dana just the same. Dana just looked tired but concerned. And later on Ann would apologize for our previous misunderstanding.

While Dana and I sat there waiting for test results, a doctor walked in, looking the spitting image of Saddam Hussein wearing a white medical jacket. He wore a name tag that read, “Dr. Seuss.”

I started laughing. I thought: *Of Course I get Dr. Seuss. Of course.*

“That’s not your *real* name is it?” I asked. He said yes it was with a tone of voice that signified, *Take me seriously, Goddamnit.* I laughed some more, but he clearly had no sense of humor.

Dr. Seuss, my favorite childhood author of all time, told me that he figured I was either concealing the possibility of being knocked up or having a drug problem. The presumption was my health problem must be my fault if he couldn't find out what was wrong. When I told him about the symptoms I had experienced and how no, I wasn't pregnant or an addict, he accused me of lying. He continued with, "I cannot help you if you're going to withhold information from me. Young women tend to pass out when they're pregnant. And not to offend, but a lot of drugs can cause your symptoms as well." Even his tone of voice sounded condescending and accusatory despite trying "not to offend." It wasn't as if he stated pregnancy and drugs just needed to be routinely ruled out. It was as if he firmly believed I was lying to him and he couldn't conceptualize the possibility that I could have a serious illness at such a young age. And I couldn't help but flash back to being eleven years old at the hives specialist's office—the one who told me he couldn't help me concerning my chronic hives if I was going to lie to him about drug use. So in front of Dr. Seuss, I felt a primal wave surging through me—a need to protect the little girl inside me.

"Oh really?" I said. I could feel the sarcasm and attitude bubbling up from some deep place of frustration and anger. My sharp tongue suddenly had more energy than I had had all week. "First off, I'm on birth control pills, and I wish I had been laid in the last two fucking weeks since my period, but alas I haven't gotten any, Dr. Seuss. So unless this is the second coming of Christ, I'm not sure how the fuck I'd be pregnant. As far as the so-called drug problem? Take my piss. See what I care. Go ahead! Fucking take it!"

I could feel Dana's presence wilt in the chair next to my bed. I had forgotten she was even there. Dr. Seuss took me up on my pissing offer, and later walked back in with the worst

forlorn look of being proven wrong, only to tell me he had found nothing, except low electrolyte levels. Apparently I wasn't a drug addict or pregnant. What a revelation.

When I pulled through the gates of Supreme Pictures Studios the first thought that came to mind: *Heaven*. The second thought: *And to think, only a few weeks ago you blacked out in a café*. Note to self: *Don't black out on the Supreme Pictures Studios lot*.

The man at the entrance booth asked to see my driver's license, he saw that my name was on the list to see J.C. Lyons, and I got my visitor's pass and name tag. The man in the booth smiled at me. He recognized the excitement in my eyes. This was the film industry and even men in booths respected it and stood in awe of it. For many people there is a shared enthusiasm, particularly for Old Hollywood, and this studio itself is truly is the essence of Old Hollywood, from the walls and gates, to the studio's vintage sign, down to the sets that still stand on the lot, used over the span of many decades of filmmaking, and of course the many 1930s and '40s buildings in their full historic glory overseeing the lot like wise old men or gods even. It's hard not to feel the presence of history; some people have their civil war reenactments at old battle fields, but for me, just walking around a studio lot makes me feel like I've gone back in time and am part of something larger than life. The world is changed on a studio lot. Images that will shape people's dreams and even nightmares are formed there; social commentary is created there—a medium of social change that is so utterly American—Film. It's hard for me not to feel all this as I pass through the spaces of a studio lot even to this day. But that day, the day I went to see J.C. Lyons, was the first time I'd ever been on a studio lot and I was a starry-eyed twenty-two-year-old.

When I got up to his office I thought that there'd be no way he could act inappropriate in his office; surely someone would be able to see him. I hadn't anticipated that he would have the entire floor to himself, his assistant at the far end of a hallway, and his office inside another office. We walked through one door, closed it behind us, and then walked through another door and closed that behind us. I was alone with him. Completely alone.

The walls of his main office were covered from top to bottom, from frame to frame, with photographs of Lyons with other big stars, usually starlets on the red carpet. Doris Day, Marilyn Monroe, Joan Crawford were the ones that caught my eye, but there were other pictures with Bob Hope, Bing Crosby, and former presidents. Lyons had been an attractive man back in his day and appeared quite confident. One of his many claims to famous associations, besides Marilyn, was his close friendship with Ronald Reagan. In full view among all the photos of stars and presidents sat the "I stomped on your star just for you" picture I had created for him, mounted on a table, signed with the black marker I had used like a starlet would when she autographs her photos. My name among royalty, I felt honored to be a part of the shrine of Hollywood legends. It gave me a sense of hope that maybe I was getting somewhere.

I began showing J.C. Lyons some photographs of family and myself, along with my little art portfolio, just for conversation sake. Before I knew it J.C. Lyons began name-dropping and pointing out photographs on his wall, which, to be honest I did find thoroughly interesting. Before I knew it he wrapped his arms around me and was trying to stick his tongue down my throat. It happened so quickly I was in a state of shock. At first I couldn't get him off me and I couldn't think of a way to release his grip. For an eighty-five-year old man he seemed as strong as a man a third his age. I decided to pull the old trick of pointing behind Lyons, yelling, "Look!

It's Elvis!" And the man fell for it, slightly releasing his grip, so I jumped back. Truth be told, I wasn't a liar, I really was pointing at a picture of Elvis on J.C. Lyons' wall.

All of this happened at such a fast pace, that the next thing I can recall is J.C. Lyons telling me that we could have sex on his desk. *Is this happening—for real?* I tried the polite route first of saying that wouldn't be a good idea and somehow we got into a discussion about how even though he was eighty-five he could still show me a good time. I figured at that point that I had to take the direct route with Lyons in order to get his attention.

"Look, though I'm flattered—I wouldn't care if you were twenty-five years old, the richest man in the world, and famous—the way you just came onto me just now was completely classless. There's no way I'd ever have sex with you on your desk. I'm just not that kind of girl."

"Fine! Then I'm completely turned off now!" J.C. Lyons yelled.

"Good, that's sorta the point," I mumbled. Fear swept across me. He was obviously angry. *Did I just piss off one of the big names in Hollywood? Am I now getting kicked out of his office?* Uncertainty tugged at my stomach and, for a moment, my awkward attempts to correct the situation clouded the room. I tried to find the "right" next words to say in such a situation, stumbling through "I don't mean to offend" and "I hope we can get past this" statements. My head started spinning; I can't remember what I said versus what I thought. Then out of nowhere, Lyons said he'd like to show me a film. *Whew.*

So he sat me down on his chocolate leather couch and popped a documentary about himself into a TV, narrated by none other than Ronald Reagan—from the oval office no less. *Have I just entered the Twilight Zone?* Quite pleased with himself, I could tell he thought that showing me a documentary about himself would seal the deal. *How narcissistic can this get?*

Afterward, Lyons tried to make out with me on his couch, pulling the old arm-around-the-shoulder move.

I blurted out, “Gosh, it’s gotten so late and I have things I need to get done.” His mood changed again. He had given it a good solid try, but resigned himself that I wasn’t going to put out. So, since the work day was drawing to a close, he asked me to walk down with him to his brand new Thunderbird that Ford had simply “given” him. I obliged, still hopeful not to piss off such an influential man. When we entered the elevator, the interior of it had a grip bar at about waist level. Lyons grabbed it behind himself and looked over at me with lust.

“So I guess you’re not an elevator kind of girl, huh?” Lyons asked with a sly grin and smooth, deep voice. *Apparently I hadn’t seen his last try yet!*

“Nope,” I answered with nervous laughter.

At his new car, a silver remake of the classic Thunderbird, Lyons hugged me one last time, pulling back just enough to look deep into my eyes and say, “Oh sweetheart, the things I *could* have done for you.” To this day that statement still haunts me as simultaneously laughable and a crushing blow.

J.C. Lyons drove off and I could roam free for a bit around Supreme Pictures Studios. I walked through the spaces of the studio lot and took in the history, lonely, confused, and yet still excited by the Industry, making my way down an empty New York City street set, praying to God and all the Hollywood ghosts that I hadn’t just made a terrible mistake.

Never in my wildest dreams did I think the name “Genevieve Tyrrell” would already be taken in Hollywood, but there is a successful costume designer by the same name, same spelling. On my business cards I included my middle name to make the distinction between us:

“Genevieve Anna Tyrrell.” *Now I sound like one of those pretentious people who use three names everywhere they go.*

At first I found the situation amusing and I liked being associated with a successful person. I even “friended” Genevieve on Facebook. Her real name was Gennifer, but she liked her grandmother’s name so much she changed it years ago. To a degree it annoyed me that my name had been stolen so to speak, but I resigned myself to thinking perhaps it had been a good twist of fate that we shared our name. Perhaps Genevieve would pass along my Production Assistant (“PA”) resume to her contacts in the Industry and help me get production work. Yet, she didn’t seem eager to help and I’m not certain if she did ever pass along my resume. She almost seemed put-off that I had asked her.

As time wore on, it became daunting being confused with the other Genevieve. I was listed under the movie database IMDB as “Genevieve Tyrrell II”. I had never thought of myself as second to someone else—not that I thought I was better than everyone else—rather, up until then I thought of myself as unique. The twist of fate would be that random people emailed me, asking to be on my “team,” asking me—asking *her*—to give them a chance. “Attached is my resume” they’d say. Many times they groveled. Some of the emails I received were from people whose approach to correspondence seemed rather green and inappropriate. One woman started out an email to me: “I’m sending you an updated version of my résumé for your review and putting this out into the universe. I want to work on a major motion picture!”

The times I gave advice to newbies looking to break into the Industry, my comments were often either ignored or blown off. After all I wasn’t Genevieve Tyrrell, the successful costume designer, so what did I know? My frustration led me to create the policy that I either do

not reply at all to emails not addressed to me—the Genevieve who is not a costume designer—or I just state that they have the wrong Genevieve and leave it at that.

Perhaps the worst outcome of the identity confusion was having family and friends confuse me for the other Genevieve. My little niece, Mia, exclaimed during the credits of *Race to Witch Mountain*, “Look! It’s Aunt Jenny! She’s famous!” Her mother had to tell her, no, that wasn’t the correct Genevieve. Her reply was that of disappointment and, “Oh.”

When I was finally diagnosed with “vasovagal syncope,” I finally had a *name* for my health problem. The doctor told me my heart rate would skyrocket and my blood pressure would crash, though the opposite reaction could happen as well. Everything my body was supposed to be taking care of on its own to regulate itself was dysfunctional.

At first it felt so satisfying to have a name to my health problem. There was a sense of validation that it hadn’t all been in my head. My cardiologist at the time assured me this condition would be simple to regulate now that we knew what I had. I would start a new medication and go about my film career like I had planned.

But it wasn’t that simple. Over the next year I deteriorated to the point that I could barely take care of myself. I spent a lot of my time in bed. Sometimes I didn’t leave my apartment for a week at a time. Most of my energy consisted of sitting on my apartment floor with my laptop, applying for film studio internships and assistant positions online, even though I didn’t think I’d be well enough to fulfill them should I get the chance. At one point I couldn’t even drive my car for fear that I might black out. My immune system weakened; infections ran rampant, particularly in my respiratory system and urinary tract. I spent quite a bit of time in the hospital,

for near black-out episodes and even a serious bladder infection. This rapid transformation into such absolute illness on a daily basis took its toll on my spirit.

I didn't realize at the time that the other name for "vasovagal syncope" is "Neurocardiogenic syncope." I didn't even realize what I had was a form of "Dysautonomia," which is a fancy name for saying "dysfunction of the autonomic nervous system." So when I sought out other patients online it was difficult to find any support groups for vasovagal syncope, which is considered a bodily response that can happen even to healthy people. Sometimes military men suffer from it after standing for too long in one position and they black out. Really, a vasovagal syncopal episode can feasibly happen to anybody given the right circumstances. So imagine how I felt when I sought out similar patients and couldn't find any online support groups. For a while I stopped trying to find others like me. I didn't know I wasn't looking for the *right name* of the medical problem. These days you can find support groups under a search of "vasovagal syncope," but what a difference a few years makes. At the time, if I had typed in "Dysautonomia" or "Neurocardiogenic Syncope" I wouldn't have been alone. It would be another two years after my diagnosis when I realized this.

Instead, I sunk deeper and deeper into a sense of isolation and loneliness. When my prescriptions contributed to hallucinations of bugs crawling all over me, well, then I just wanted to die. My friend was the addict downstairs who was getting evicted from her apartment. My other interaction with the outside world was my friend's cats, but from time to time J.C. Lyons called me.

Lyons would tell me old Hollywood and funny sex stories that made me laugh. I never let onto Lyons just how sick I was and so our conversations never had to do with illness. Instead, I lived vicariously through him. He told me that about a half century ago, while walking

down the street with Marilyn Monroe one day, she caught a glimpse of her butt in the reflection of a department store window. She stopped and frowned.

“What’s wrong?” Lyons asked her.

“Just look at my ass. It’s *huge*. I’ll never be a big star with an ass like that,” she said.

Lyons told me, “Really, it’s funny, because I always thought her ass was one of her best assets. But can you imagine that? She said she’d ‘never be a big star.’” Lyons chuckled.

One of my favorite sex stories of his regarded a visit to a couple’s house for drinks. When the husband left the room to mix drinks, the wife got all up on Lyons, unbuttoning her blouse, and blowing cigarette smoke in his face. He thought it was so hot. And then the husband walked in, yelling, “Susan!” Lyons thought he was in for it, but the husband finished with, “Susan, I thought you quit smoking!” Lyons proceeded with the threesome sex scene he had with them.

He was indeed a strange, dirty old man, but his storytelling was my saving grace during that time sick in my apartment. Eventually, I figured out how to deal with my health problem better, was put on different medication, and slowly regained some of my strength, but Lyons helped keep my spirit alive though during a rough patch.

When I landed a short term internship on the set of *You Don’t Mess With the Zohan*, starring Adam Sandler, it was after being the best saleswoman of myself ever. They really didn’t want me. Interns are considered a “liability” on-set, and if you’re new to anywhere in Hollywood, you have to prove yourself worthy. I stood there with the 3rd and 2nd Assistant Directors (ADs) trying to state I was a perfect match for their set. They had told me “No” in several polite round-about ways already, but just then I thought about J.C. Lyons. I thought

about how he had always persevered in the film industry no matter what. *What would J.C. Lyons do? J.C. Lyons wouldn't take 'No' for an answer*, I thought to myself.

I repositioned my stance, and said to the 2nd AD, “Look, how ‘bout this: Don’t say ‘No’ just yet. Think about it first. I’ll stop by at lunch time with my resume, and you can look it over and if you like what you see, then at the end of the day I’ll check back in with you. You can make up your mind then.” He smiled and agreed.

On my resume I included that I had been a finalist for the Directors Guild Association (DGA) Trainee Program. It is a prestigious apprenticeship program, which about thousand people apply to each year, and yet I had made it through to the final round of contestants just a couple of months earlier. With a notation like that on my resume, a name like the DGA, the 2nd AD was impressed. He decided to let me intern on the set.

I couldn’t wait to get on the phone with Lyons to tell him how he had inspired me to persevere. I thought he’d be so proud of me. I thought we’d discuss our common dream: Film. There’d be laughter and wisdom shared. It would be the perfect ending to a life-changing day.

When Lyons called me back it was about 9pm. Before I could really get into the story of my day, he was already coming onto me. So I pushed on, ignoring his advances, but still, he didn’t care. He wasn’t proud and he didn’t care that I had been inspired by him. He didn’t care about me as a human being; he just wanted a phone call screw. I suddenly felt very alone and angry.

“FINE. If it will shut you up.”

I gave him phone sex.

Don’t ask me the details. I burned them out of my memory years ago. And really the salacious details aren’t important. What is significant is that I had gone to a dark place I never

thought I'd ever go. I felt dirty and cheap, and what's worse is I had done it to myself. For a long moment after we got off the phone I just sat there in a daze. A state of shock. *Did that just really happen?*

Then I started talking to myself.

“What the fuck have I become? Who the hell am I? Why did I just do that?”

I curled up in a ball on my bed and watched the TV. I laid down the groundwork in my mind of how I would stamp out any memory of what had just happened. *Just pretend it didn't happen. Never speak of it. It didn't happen. No one can know.* I had worked so hard to be taken seriously in the Industry and thought of as “one of the guys,” and as a woman, as a feminist, I had failed myself. I had failed my morals, my character, my decency. My father would be so disappointed in me. That has always been a sort of mantra or rule in my head: *If Dad would be very disappointed, whatever it is, don't do it.* I had broken the rule.

While the TV screen flickered the eleven o'clock news I tried to find sleep.

The phone rang again.

It was J.C. Lyons, again. *So much for stamping out bad memories.*

His voice sounded all hot and bothered—deep and rough—like he was working himself up to do something dirty again. “Hi, darling. I enjoyed spending time with you so much I just couldn't help myself.” Lyons always did have a way of feeling our phone conversations were in-person escapades. He had the vivid imagination of a filmmaker. “I thought maybe we could---”

“What?” I snapped. “Have phone sex again?”

“Well, yes, I—”

“Are you fucking kidding me? It's eleven o'clock at night. I have to get up for work at six a.m.”

“Oh...Sorry, I...” If J.C. Lyons could appreciate anything it was having to go to work on the studio lot. Strange code of civility and decency that man had. Needing sleep to go do hard work for the film industry was the only okay excuse for not giving him more phone sex.

“Geez. Lay off the Viagra, will ya? Christ.” I hung up. I was pissed and he didn’t call back that night. I didn’t talk to J.C. Lyons again for another year and half after that, despite all his phone messages.

For a long stretch of time, I could only land temp work assisting in the many offices of Goldberg Studios Entertainment, and truth be told I wasn’t really healthy enough for on-set production anyway.

During a few months I assisted Tom Schroeder, Chief Financial Officer of Goldberg Studios Entertainment, Television and Film. One day, while Tom was in a meeting with a couple of his bosses, the CEO, John Devins, called. I sent an email and cell text message to Tom, both reading: DEVINS CALLED. It was important that I get the message across loud and clear, because when the Big Cheese called, there usually wasn’t a good excuse not to get back to him right away.

Tom chewed me out in a response email that it was inappropriate and improper that I did not use Devin’s first name in a message. Even though the messages were only sent to Tom himself, I shouldn’t have stated “Devins Called,” but instead “John Devins Called.” It was the first and only time Tom actually got upset with me about something. It seemed so unimportant and petty. Something inside me snapped. I IM-ed my friend Jean, who had worked in the Industry much longer than me, asking if perhaps I was missing something. Perhaps my boss was

just overreacting? But Jean didn't think my boss had overreacted at all and instead said, "Well, that's just the way the film industry is. If you can't handle it, maybe it's not for you."

It wasn't that I "couldn't handle it" I replied. It was that in the whole scheme of things, how petty and frivolous was it to reprimand me for such a non-event? I was happy just being able to sit at my desk without blacking out. I had bigger problems, bigger fish to fry, and having people fret over the "stupidest shit," as I put it to Jean, got to me on a level it never had prior to being so incredibly ill. My blood began to boil. *These people should be grateful they can walk, that they can drive, that they can do their jobs. They should be grateful for the little things in life.*

No more, I thought. *No more office politics bullshit*. I began to make plans to move to Louisiana. Film production was booming there due to tax credit incentives for film studios. I connected on-set production with the prior sense of fulfillment I had on the set of *Black Hills Creek*. After all, I had wanted to be a director and in office work could only afford me the opportunity to become a producer, something I had no desire to become. I reasoned that if I was doing something I really loved, headed on a career path I enjoyed, then I could also deal with my health problems better; that on-set production would bring me so much joy and a sense of fulfillment I wouldn't notice my body feeling like Hell as much. Part of that was because I viewed on-set production as a whole other animal from in-office Industry work. On-set there can be a sense of family unlike the office, and anyone who loves production will tell you that it's exciting to be on a set. There's that larger than life feeling, similar to how I always felt going onto a studio lot.

Louisiana offered me an artistic city to live in that might have less pettiness all around and it offered me the chance to do on-set production, which I was struggling to find in Los

Angeles due to the tanking economy and because my film production connections were minimal. Louisiana offered a place in the industry in which originally Los Angeles-based and New York-based production managers were desperate just to find someone who really understood the ins and outs of the Industry. The truth was I had a greater chance of getting on-set production work in the state of fried chicken, swamps, Cajuns, and jazz. The news media was coining the name “Bayouwood.” *Yes, I’ll be happier doing on-set production in Bayouwood.*

I took J.C. Lyons’ call not realizing it was him calling. When I answered I hardly had the time to tell him I couldn’t speak anyway.

Lyons jumped right in: “Remember that woman I told you about that couldn’t cum unless she called her husband while we were having sex?”

“Yeah, uh, really how could I forget that?” I laughed.

“Okay, well, I found out the darnedest thing. Get this: the entire time he was in on it!”

“What? *Really?*” I laughed harder.

“Yeah, apparently she’d call her husband and he’d get off on the fact that she was fucking another man. How about that, huh? I never knew. All these years! I can’t believe I never knew.”

I ended up asking Lyons what he had been up to, who he’d been hanging out with, and what was the latest.

“Well, do you know who Phyllis Diller is?” he asked.

“Of course,” I replied.

“Well, I just got off the phone with her before calling you. She said, ‘J.C. I’m in a terrible way; I’m out shopping and I can’t seem to find a forty-two long.’ So I said, ‘Forty-two

long' pant size? I don't think that sounds like the right size for you, Phyllis.' And she says, 'Not forty-two long pant size—BRA size honey!'"

We both burst into more laughter.

I went for almost another year not talking with him, still disturbed by our phone sex encounter, despite him calling me on Valentine's Day and again that spring as a thank you for the birthday card I had sent him. (I usually start my cards with something along the lines of: "I can't believe you're still alive, you dirty old man!") A few days before that Christmas my cousin asked me how J.C. Lyons was doing and I decided to give him a call to check up on him.

J.C. Lyons was happy to hear from me and even seemed lonely. I asked him what he was going to do for Christmas and if he was going to see family, but he kept changing the conversation back onto me. Realizing holidays and family must be a touchy subject that made him sad, and that he might very well be alone on Christmas, I switched the subject to a lighter mood.

"Gosh it's been such a long time. I can't believe you still remember me, sweetheart!" I said with a spirited tone of voice.

"Of course, I remember who you are. I got your name tattooed right here on me, darlin'," J.C. Lyons said without missing a beat.

Doctors tacked onto my diagnosis the name, "Postural Orthostatic Tachycardia Syndrome" or "POTS," which was just a more all-encompassing name for the symptoms that couldn't be explained due to Neurocardiogenic Syncope. POTS is just another form of Dysautonomia. I gave the diagnosis an eye roll. Now I knew that it didn't matter what diagnosis name was stamped me; no name would fix me. A name for a diagnosis doesn't mean there's a

cure for it. The only thing this new name gave me was further legitimacy of my symptomology to doctors I encountered, and even then it didn't always have that effect. Big names in the medical field don't always get the same respect as big names in the film industry.

With my new diagnosis name in tow, I moved to New Orleans, also known as "Nola," "N'awlins," and "The Big Easy," to try once again to make it in the industry.

I felt lighter, freer living in Nola. Something about simply walking around the French Quarter and listening to jazz and blues put me at ease. It was such a different atmosphere than Los Angeles. After living through Hurricane Katrina, everything else was just small stuff to the people of Nola, and they didn't sweat the small stuff. Their days were on a different time—N'awlin's Time—slow, easy-like, in a way that could appreciate small joys.

A couple of weeks after I moved there I got a call asking if I could be a Production Assistant for a few days on the set of *Starship Battle* in Shreveport, Louisiana.

"Shreveport is like five hours north from me," I said to the lead PA who was obviously not from around there. At first I turned the job down but then worked out a deal with my mother to borrow some money for hotel stays for which I'd pay her back later. I'd essentially spend my entire paycheck paying my mother back for a few nights at a hotel after driving five hours up to Shreveport, but the contacts I could make would be invaluable. After all, in a couple of months *Starship Battle* was going to continue shooting closer to New Orleans, which meant there was the opportunity to prove myself worthy enough to work on the set location closer to home.

The first day I had on-set took place at the air force base just outside of Shreveport. I spent most of my day wrangling extras, which at the base, consisted mainly of Air Force guys and Marines. In our downtime, waiting to be corralled to wherever, we stood around on the air

strip in the hot sun and talked. They really only cared about one big name on the set, Michelle Rodriguez, because, as they said, “She’s hot.”

They also happened to be curious about what I had done in the film industry, but I found myself equally curious about what they had done as servicemen. One of the boys, Anthony, told me he couldn’t wait to go to war. He felt frustrated about “missing all the excitement.” Anthony was only nineteen and hadn’t been deployed yet. I told him that war was more than excitement.

“Yeah, yeah, that’s what all the guys who have been over there tell me,” he said, his smile beaming from ear to ear. His enthusiasm reminded me of how I felt before I went to Hollywood, but the major difference was he was putting his life on the line. And no sooner did I think this, when I realized—though not for noble causes—I could potentially put my own life in jeopardy continuing on-set work that wreaked havoc on my autonomic nervous system—straining my heart, depriving my brain of oxygenated blood, opening myself up to greater potential for cracking my skull open from a fall or surrendering to another seizure-like episode. What was my job worth? Certainly not freedom of a nation or to restore order and peace. Did it even fulfill me? Help me feel whole? Or like I was making a difference? I dismissed these questions and told myself: *Filmmaking is the love of my life.*

Another Marine, who had been deployed already once or twice, seemed like he was missing a part of himself. He appeared separate from the group; a loner amongst the crowd in his demeanor. He kept his eyes lowered most of the time and never smiled. But the military and war had become his life—*he couldn’t envision doing anything else.*

At one point he tried to pick a fight with one of the other Marines, but the guys broke it up before it became anything.

“Is he okay?” I asked one of the guys.

“The war messed him up,” he shrugged. A sentence said and then quickly the subject was changed.

When it came time for a helicopter scene, the boys took great pride in telling me that that was not how a helicopter is supposed to be flown.

“Look at ‘em tryin’ to make it all dramatic and shit,” they’d say and then go back to picking apart how all the lead actors’ military costumes were “all wrong” and not up to code. I laughed and for a moment it felt like being back on *Black Hills Creek* again, back when I had to suit up extras with their props—satchels, rifles, even plates of food for some scenes—while they teased me about being green, about my age, and the food getting cold as we waited for the director to call, “Action!”

When the scene changed again, I had to give up my boys—my temporary family—who jumped into trucks “to fight aliens.” I was placed with a very pregnant five-foot-one, twenty-one-year-old, red-headed Air Force gal, named Alex, and we were assigned to keep military traffic from interfering with the scene. At first we just stood with one another in silence, looking at anything but each other. Eventually we got to talking. When I found that she was expecting her second child, was living with the love her life, that she had come a long way from being orphaned, and that she had already witnessed people blowing themselves up in the Middle East—something that brought her to the verge of tears while she described it—I realized my life was missing something deeper, more meaningful. I took assessment of my own life, finding that a good portion of it was lonely and that my duties often seemed frivolous.

The two days of shooting I did next were not on the base, but instead in downtown historic Shreveport area. When they stuck me next to a gigantic smoke machine chugging out disgusting clouds of whatever that stuff was for about nine hours, I reached the point where I

seriously considered getting out of the film industry. My superiors didn't even bother to give me a mask of any sort even, though I was stationed right next to the machine in order to stop traffic, and I could only get away from it when I walked two blocks, which I wasn't allowed to do.

I had already been caught sneaking sitting down by the time my supervisor reassigned me to a new station. Usually getting caught entails dirty looks from your colleagues and bosses, and then not getting hired again for the next day to work. No matter how dead your area is, even if there is no traffic and you are far away from the actual scene being shot, as a PA it is absolute blasphemy to sit down at any point during the entire twelve to fifteen hour day except at lunch time or to use the bathroom. With a health problem where my autonomic nervous system has trouble regulating my blood pressure and heart rate, it is crucial that I be able to sit down sometimes. Of course I couldn't tell anyone I had a health problem; I'd be a liability.

It became very clear to me: I had finally gotten to work on a set again and it felt like Hell. *Be careful what you wish for; you just might get it.* The suffering I was putting my body through wasn't worth any of it.

Even though I had been scheduled to work a couple more days, they decided to replace me with a twenty-two-year-old blonde girl who giggled a lot. I took one look at her and knew why. Her big smile beamed brightly, her sloppy ponytail made her look naturally sporty, her tight tank top and jeans showed off her tiny waist, perky breasts, and even some cleavage. At one point I had been her, but after my weight gain from health problems and medications, I was far from her. I felt caught between being annoyed I obviously wasn't fuckable anymore or just repulsed that some girl was getting hired due to her fuckability. *Is it actually better to be her?* I wondered. She hadn't been a PA before, so I had more work experience than her; I was definitely more qualified for the position. I watched my young self play out in front of me. I

wondered if she realized the decision she had made, not just of signing up for a job, but everything that would come along with it. I couldn't tell if she was naïve or completely in control and fully aware of her sexuality. *Could I have in fact used my sexuality better? Does she play this game better than me?* I had gotten to the point where I even questioned my decision not to sleep with J.C. Lyons. *Could I have effectively slept my way to the top?* I almost got to the point of envying her, when I heard another PA tell me at lunch time that the 2nd AD had slept with the last young girl he had hired. It was assumed he would sleep with this one too. Suddenly, I felt sorry for her and I questioned just how in control she was. I wondered if she'd get fired even if she did sleep with the 2nd AD.

When they told me I wouldn't be needed on the set anymore, I felt simultaneously relieved and disgusted. My last moments with the crew, consisted of filling out time cards, while the guys greedily ogled the new girl like she was gazelle ready to be pounced on and slaughtered in the Serengeti. I signed my forms as quickly as possible and got the hell out of there.

"Thank fucking God that is over," I said to myself in my car.

During my long drive back to Nola and the next two weeks sitting in my apartment, I wrestled with my disillusionment. *How could what I love make me feel so badly—emotionally and physically? Do I not love it anymore? Who am I if I'm not in the film industry? How did I fail so miserably at my goals? Am I "giving up" if I leave the Industry? Does that signify "defeat"?* The answers to those questions eluded me, but at the end of two weeks in deep thought while battling bronchitis and a sinus infection from my experience on-set with the smoke machine, I decided something had to give and something had to change.

I thought about what I love to do and what I can physically handle, along with what kind of career might have a wide range of possibilities and could make me feel fulfilled. I thought

about all the old childhood dreams I toyed with from ages eight through nineteen. Filmmaker hadn't been my only one. Visual Artist. Paleontologist. English Teacher. Cardiologist. Musician. Writer. As Genevieve the Visual Artist I often liked to incorporate words into my art. English teacher could go along with writing. Even during my pursuit as Genevieve the Filmmaker, I had thought about writing scripts.

As a writer I could write about my experiences to help others. Fulfillment.

As a writer I could write in bed if I got sick.

As a writer maybe I might come back to film in some regard.

Writer just made sense.

So I made up my mind I would apply for an MFA in creative writing.

I still couldn't shake that feeling of failure after watching *Hangover 2* and seeing Caitlin's name on the big screen. Even with Patrick there—Patrick—my rock—my person who makes everything okay—I couldn't shake the feeling.

"It's bad enough to constantly be confused with the successful costume designer Genevieve Tyrrell," I said.

Patrick chuckled.

"But now? Now it's like God's just rubbing my nose in my defeat. Caitlin's living *my* dream and I failed."

"But Gen, you're a writer now. I mean, that *is* what you want to do, right?" Patrick asked.

"Yes, but I can't help but feel like I failed. I mean, I know I've been sick. I just couldn't keep up with the film industry. It's difficult when you're competing with healthy people and

then also people on coke and meth. I mean how could I measure up? How could anyone keep those insane hours? But sick? There was no way.” It was as if I was talking myself into what my life had become.

“If you hadn’t been sick, would you still be in the film industry?”

The answer was yes and no. If it had just been the physical aspect of my broken body, that would have been one thing. I might have tried to push on no matter what. But Dysautonomia changed me as human being. I began to see life in a different way. My values had changed. Yet, I still felt like a failure, and though I knew that feeling was perhaps silly and illogical, I couldn’t reconcile my rational mind with this inexplicable inner turmoil that a simple name on a movie screen had caused. After all, I had created my life—my identity—around the Industry. In fact, I had even divided my identity into parts in order to function within the Industry.

“So why do you feel like a failure?” Patrick asked emphatically. I could hear the tone of *Duh, Gen. You’re being silly* ringing in his voice. He’s always had a knack for being my voice of reason.

“Seeing Caitlin’s name on the big screen—she was able to do it. She is living *my* dream. I worked my ass off. I did everything I was supposed to do, Patrick, and I always held onto that notion that if you put your mind to it, you can accomplish *anything*. I did that. I put my mind to it and yet I still couldn’t do it. I really couldn’t be anything I wanted to be after all. Or maybe, I dunno, I suppose I feel like I let myself down. Maybe I didn’t try hard enough?” I grasped for answers. “I can’t help but envy her physical and mental stamina I suppose? It’s wrong. I shouldn’t be jealous of her. It’s really not about her specifically.”

Patrick asked me if I'd like to get into script writing. I laughed. I thought back to all the lousy scripts I had to go through and read, and rejected as an intern.

“You know, I might someday.” I was talking myself through the process, working out the details in my brain, trying to make my confusion turn into something that made sense. “We’ll see. I never seem to know what the future holds. I never would have thought two years ago I would be here in Orlando doing an MFA in creative writing.”

All the mixed feelings of regret, sadness, and confusion left me feeling lost. Even if it's my body that couldn't function, I have faulted myself for that many times. But where does it end? At what point do I let myself off the hook? Dysautonomia? If I were missing limbs? If I was paralyzed from the waist down? What would it take for me to finally feel like it doesn't matter how hard I tried; that my chronic illness made me incompatible with my film industry career choices? Would it even matter if I was healthy? Would I actually still want to be in the film industry? I'm not sure I know the answers to these questions. I know my illness changed my outlook on life so much so that even if I miraculously got healthy overnight I'm not sure I'd even want to go back to film industry, but I guess it's the idea that I don't necessarily have that option that gets to me—the fact that I can't physically handle being on set—and to be honest with myself, I even struggled in the office. How many times did my immune system fail me? How many times did I come down with a terrible virus during my stints as an executive assistant? How many times did I have an Epstein Barr reactivation? Herpes in my nose, fevers at work, sore throats? How many times did I find myself light-headed from sitting in the same position for hours on end taking phone calls, or have to pound on my chest to reset my heart rhythm after a stressful incident with an executive? The truth was I could barely do the office let alone on-set production.

And it's hard not to find fault with myself for that; it's *my* body after all. I should be in control of it, right?

Patrick went to sleep and I stayed up late on my computer, emailing my friends, Jen and Sherard, about my lapse in judgment, my insecurity, my confusion. I decided despite my petty envy—and even because of it—I would announce on my Facebook page “Congratulations” to Caitlin for being towards the top of the credits for *Hang Over 2*. I tagged her name so that she would get notified the message was there.

Jen replied right away to the private email I had sent her: “You went to LA and you gave it everything you had. There are a lot of people who wouldn't even have the guts to try. Do you think it would make you happy at all if you could write movies?”

Sherard wrote: “Even though the practical side of you may be saying this over and over, you still need to hear it from a voice that's not inside your head 24/7. It's not you. It's not your fault. You're going to write the fucking memoir of the quarter-century, only to be surpassed later by its amazingly insightful sequel after you've spent a great deal of time on vacation in the Hinterlands and snuggled at the ankles of the Alps.”

They made me smile. *I should be grateful for the friends I have. I am grateful. I am so very blessed.*

Somehow, my friends could foresee a creative, fulfilling, successful future for me despite my on-going crisis of illness consuming not only my identity but my fate. They had hope when I didn't always have it. When sometimes I needed the chance to allow myself to be weak, vulnerable, and broken. When putting on a positive façade became too much for me, these were the people who could put things in perspective in ways that didn't denounce what I had been through, that didn't blame me for failing my body for not trying hard enough—at times even

celebrating my openness of vulnerability as an accomplishment—but could still see a powerful creative endeavor being born.

The next day I received a thank you message from Caitlin and she said, “Happy Writing!”

Indeed, I am a writer. That’s who I am.

The confusion and envy began to melt away.

A couple days later, after Patrick had made his journey back to Maryland, I decided while I ran errands to stop for Chinese food. I felt like hell that day, and I opened my fortune cookie expecting to get some lame note. Instead it read:

YOU COULD PROSPER IN THE FIELD OF ENTERTAINMENT.

I burst into a fit of laughter.

NEW YEAR'S RESOLUTION: AN OPEN LETTER FROM A PATIENT

I am writing this on New Year's eve, 2012. It's a particularly strange time for patients of Dysautonomia, specifically the forms known as Postural Orthostatic Tachycardia Syndrome (POTS), Neurocardiogenic syncope (NCS), also known as vasovagal syncope. A lot of us don't know our own fates. There are no long term studies we can calculate our lives by, to determine whether this will be a particularly good year or bad, or what new complications may arise, or how long we have to live. We just don't know our outcomes. Our New Year's resolutions revolve more around goals that might seem small to a healthy person or simply remembering to love every minute that we have and get to experience. I think that latter part is key. Just because you're breathing doesn't mean you're actually experiencing Life.

When we hear others say how they'll get in shape and lose thirty pounds this coming year as their resolution, I think it's safe to say a good portion of us now roll our eyes. Some of us used to be those people at one point in time. Well, I know at least I was. But now? Now, we're either Dysautonomia patients who can't gain weight even if we try, or we're Dysautonomia patients who have gained a bunch of weight and are too ill to exercise enough to lose it. There was one January I ate a box full of Entenmann's chocolate devil food cake donuts within forty-eight hours, desperate to gain a couple of pounds on my lanky frame. After a couple years on a steroid medication and then dealing with a body too weak to exercise, I ended up tipping the scale at two hundred pounds. At this point in my health decline, the usual New Year's resolution to lose a few pounds seems petty and futile. I just got a wheelchair to help me get out more when I'm too weak to stand or walk.

My point is we live in unexpected extremes. At some time during our illness we get used to the fact that there will always be unexpected extremes, until one more thing happens that

surprises us. And then? Then it seems almost devastating. There is a momentary lapse of faith in Life, and for some, maybe even God. What causes this devastation is the not knowing. What are our projected outcomes? When something else goes wrong with our health we get to wonder haunting questions like: *Is this just a minor isolated incident or is this the beginning of a major trend? Is this a relapse I'll have for the next month or for the next year? What can I tell my loved ones to expect? Do I quit my job? Do I get a wheelchair now?* It's not like other diseases where there are researched, documented stages of health or decline. It's just one big guessing game. You may fully recover. Or you might die in the next couple of years. Or you may live the next twenty years, just very sickly. Or, like myself, you may have a mix of periods where you're so well you can travel around New York city and other times where you are bedridden and unable to make yourself a meal. Who knows? And really, more importantly, who cares?

In my quest to find some answers when I was initially diagnosed with POTS—after spending many years identifying with my earlier diagnosis of vasovagal syncope and then realizing a lot of doctors interchanged the diagnosis name vasovagal syncope with NCS—I couldn't find much research in the way of specifics for life expectancy or prognoses for POTS, or NCS, other than these illnesses can cause significant fatigue, can be potentially debilitating, and that quality of life can potentially be poor (to which I thought: *Duh.*) What I also found were many symptomology overlaps with Chronic Fatigue Syndrome (CFS or “ME,” short for the older term Myalgic Encephalitis) and Fibromyalgia (FM or “Fibro”). I couldn't find clear distinguishing criteria for what the difference would be between either. For instance, what's the difference between a POTS patient with significant fatigue versus a CFS patient with significant orthostatic intolerance? Both could theoretically flunk the tilt table test, a determining criteria for the symptom of orthostatic intolerance, and both could be too fatigued to leave bed most of

the day. There may even be an NCS patient who experiences significant muscular pain, but then isn't distinguishable from a FM patient who gets light-headed upon standing. Really, for patients at online forums I visited, it boiled down to which specialty the doctor that finally diagnosed them had more knowledge in, what the patients got diagnosed with first, and how the patients themselves viewed their identities. Still others identified with multiple diagnoses, signing each post with "Diagnosed with POTS, NCS, and Fibro," or even simply under their names, "POTS and CFS." I think the ones who say "diagnosed with" are actually—whether consciously or unconsciously—pointing out that it's only a diagnosis, and who can be sure what's really going on when these illnesses don't have found causes? To add even more confusion, there are some patients who would prefer to do away with all the diagnoses names we have thus far because they feel there's too much stigma attached to the names. And then strangely, when I mentioned on one POTS/ NCS/ vasovagal syncope forum that I thought there was too much of an overlap with CFS for us to not consider new treatments out there now for CFS, there was a backlash. Patients didn't either want to be recognized as CFS (whether because of the stigma associated with the name or because they had grown comfortable with identifying themselves as POTS/ NCS/ vasovagal syncope patients), or they said they "didn't really experience fatigue." Thus, either the idea of that name disturbed them, or they had no education that actually CFS patients experience quite a lot of overlapping symptoms with POTS and NCS—even Autonomic Nervous System symptoms—other than potential fatigue.

I found similar issues in the medical field as well. At one point it became clear to me that a lot of doctors I encountered actually thought of "vasovagal syncope" as a silly symptom of fainting at the sight of blood or anything upsetting. In other words, I "got the vapors" and passing out was simply due to an emotional trigger. (Note: The average person, even healthy, can

indeed faint at the sight of blood, and that is also vasovagal syncope. Doctors often had trouble realizing that I on the other hand had an actual Autonomic Nervous System disorder that could provoke the vagus nerve over a bowel movement, lifting heavy objects, outside temperature changes, etc. Getting my blood drawn could also provoke fainting, because my veins were so tiny, that drawing blood could be difficult and quite painful with someone inexperienced and/or if they failed to use a pediatric size needle to access the vein more efficiently—*not* because I had a fear of needles or blood). Once I realized that, I always stated that I had Neurocardiogenic Syncope (NCS), which promoted more of a neurological-cardiology mechanism I had little to no control over via my emotional state of mind wreaking havoc on the vagus nerve. The change in the identification of what I had didn't change my symptomology, but it did lessen some of the blame on me, the patient, as being an over-emotional woman bringing illness onto herself. Yet, over the course of several years, I found that doctors often associated these hard to diagnose illnesses with one very specific symptom, with little knowledge that the patients actually suffered from other symptoms. Usually, doctors thought POTS/ NCS/ vasovagal syncope patients just have a problem blacking out or being lightheaded upon standing, that CFS patients just have debilitating fatigue, and that FM patients only experience chronic pain. Yet patients from all three diagnoses groups can potentially experience, as part of their illness, “brain fog” or cognitive dysfunction that hampers word retrieval skills, problem-solving, memory, and speech; fatigue and physical weakness; immuno-deficiency issues (more likely to get sick with a cold and have trouble recovering, and/ or reactivate with other illnesses like Herpes Simplex or Shingles, and in my case, Epstein-Barr); wear out easily from minor activity; tremor; sleep disturbance; numbness or tingling sensations; bowel or bladder abnormalities, including but not limited to, interstitial cystitis and irritable bowel syndrome; chronic pain—muscular, joint, chest,

or head; heart palpitations; chemical sensitivities to over-the-counter medications or minute doses of medications (more likely to have the adverse reactions listed as “rare,” like severe allergic reaction, etc.); dizziness; even “crinkling” sounds/ sensations in the neck and a greater susceptibility to lightheadedness when the head is craned back, both of which actually may be a sign of Chiari Malformation of the cerebellum, adding yet another diagnosis name to the list.

After a while of investigating what could possibly be the distinguishing factors between diagnoses, to assess even my own identity, treatment options, and prognosis, I found myself saying out loud, “This is all semantics.” Interestingly, I now find myself starting out my sentences with, “I’ve been diagnosed with” or “*I’ve been told that* I have,” instead of simply “I have.” To date I’ve been diagnosed with: POTS, NCS, vasovagal syncope, CFS, FM, and even mild Chiari Malformation (though some doctors disagree on that). Many times, if asked in person, I only mention the POTS, because frankly, I think I sound either too depressing or too consumed with my health status if I list all of them out loud.

This New Year’s eve I’m at the final stages of working on my creative writing thesis, while applying to another graduate program, yet I have no idea what this year holds for me—whether the current decline of health I’m in is a sign my functional life is over—whether I should even bother applying to another graduate program at all. So when I began to see, yet again, Facebook posts from healthier friends about losing weight as a new year resolution, I turned to my Dysautonomia friends to see what they were posting. A couple said they were just grateful they got through another year, others said nothing, but one posed the question: “What should be my New Year’s resolution?” Certainly her options are somewhat limited because none of us know what our bodies will bring this year, other than we can count on at some point being really sick—whether on intermittent days during each month, or for an entire month or many

months we're not sure. For me, though, I can't help wonder: *How many years do I have left at the health status I am at currently?* Certainly, my goals for this new year reflect just how many years I think I have left, yes? Of course anyone, whether healthy or sickly, could meet his or her demise at any point by a freak accident, but generally, as humans in our twenties, thirties, forties, even fifties, we plan as though we have decades to look forward to. Generally, we're either optimistic or in denial. Personally, I consider myself a realist who prefers confronting issues head on, and I like planning ahead. Having been as sick as I've been, my time is extremely precious. I don't take lightly to wasting it.

The closest life expectancy study to POTS I could find was one on CFS within the *Journal of Health Care for Women*. It states that CFS patients are much more likely to die of "heart failure, suicide, and cancer, which accounted for 59.6% of all deaths. The mean age of those who died from cancer and suicide was 47.8 and 39.3 years, respectively, which is considerably younger than those who died from cancer and suicide in the general population" (Jason, et al. 615). The general public, and even the medical community, rarely hears about deaths from CFS, or even POTS. Normally, at the online communities I frequent for both CFS and POTS, deaths are announced via word of mouth. This article points out that we cannot think of CFS as a cause of death itself, but rather that CFS instigates the circumstances for an earlier death:

Most CFS investigators believe that CFS can be a devastating and debilitating illness, but not a fatal one. Despite this common belief, it is conceivable that people with CFS might develop other serious secondary or co-occurring health problems. In populations with poor health, we would expect to find an increased susceptibility to many common

diseases. Clearly, it is important to establish if CFS leads to other illnesses or a shorter life expectancy. (Jason, et al. 618)

Yet this article also notes that there is so little data on such patients that they (the researchers) can't be certain of even their own findings that suggest CFS overwhelmingly relates to an early demise via heart failure, cancer, or suicide. In fact, they can't be sure that the patients were properly diagnosed with CFS in the first place because no one has definitive criteria for diagnosing CFS. They go on to reiterate a point I can't emphasize enough, which is that “[c]learly, a study on causes of death related to a condition that may have been unreliably diagnosed is a serious issue. There are so few published findings in this area, however, that the current study could at minimum serve to stimulate additional, better controlled studies” (623).

POTS and NCS patients are no different. There are no categories for causes, or accurately assessing those causes, let alone data to suggest an understanding of patient life outcome. To me this is a travesty. Patients go usually for several years not being diagnosed, then are relieved to get a diagnosis, only to realize that it's merely an outline of symptomology rather than something that directs the patient to a cause which can be directly treated. (In fact, often getting the diagnosis of a syndrome gets you nowhere with some doctors, such was the case in multiple incidents that have happened to me in emergency room settings. Some doctors often don't believe the diagnosis as anything other than psychosomatic. Thus, the patients aren't allowed access to their true sick role.) Instead, there is the mentality, whether directly stated or not, that the patients should at least be ecstatic they were diagnosed at all, and now they should be happy to accept some lackluster treatment options which target symptoms, not causes, without even an understanding of whether treating those symptoms is in fact worsening the causes in the long term. There is simply no push to find out *why* a patient has POTS or NCS. The mentality

from doctor to doctor is that some research institute should figure it out for them, while the research institutes have little or no interest or funding backing Dysautonomia research, or the funding they have is to reiterate current treatment plans, such as administering beta blockers to lower heart rate (having no clue as to why the heart is beating so hard and fast in the first place other than the autonomic nervous system is “out of whack” or that the patient happens to have low blood volume, though that can’t always be explained either).

Upon further review of more data, I came across an interesting study about how CFS and FM patients are viewed as people, and I have to wonder if this may lead to less concern for better treatments or research in general for related illnesses. Results showed

physician's interpretations of patients in moralising terms. Conditions given the status of illness were regarded, for example, as less serious by the physicians than those with disease status. Scepticism was expressed regarding especially CFS, but also fibromyalgia. Moreover, it is shown how the patients are characterised by the physicians as ambitious, active, illness focused, demanding and medicalising. The patient groups in question do not always gain full access to the sick-role, in part as a consequence of the conditions not being defined as diseases. (711 Asbring and Narvanen)

Of course the CFS and Fibro patients also demonstrated a high level of knowledge about medical information and a greater distrust of doctors (715 Asbring and Narvanen). I can attest to being similar in nature, but that was after several years of being treated like I was either mentally ill, over-emotional, or treated as though I must be on drugs or hiding something, before finally

being recognized as needing help. I invested in my care, researching on my own as to what might help me, because no one else would, not even after I was properly diagnosed.

As I've come to terms with my diagnoses, I've: A) worked hard at trying to uncover the cause(s) and B) tried to justify the sick role for patients like myself—that we deserve care and research, and that the situation is indeed serious enough to warrant such care and research. POTS, NCS, CFS, and Fibro can't be viewed as simply “benign” illnesses. Quality of life, and perhaps duration of life, hangs in the balance. I know I suffer, and I know my fellow online patients suffer, and I also know that every now and then deaths are spoken of—how someone committed suicide because it was all too much, how another patient blacked out home alone and never woke up, how other patients slowly succumbed to organ failure. I feel like saying, *We exist, Goddamnit.*

It took me a long time to justify the sick role even for myself, coping with a sense of betrayal from my own body, but I have been a patient who has pushed and persevered for answers. Yet I've needed extensive financial and physical support from my parents in order to survive. There are days right now where I can hardly function, yet the United States government does not deem POTS or NCS as “disabling,” so trying to obtain meager S.S.I. disability support has itself been impossible. Besides, I don't want to be disabled. I want to be able to survive on my own. I don't want to have days where I'm bedridden. Is that too much to ask?

To date, we know that I have a Choline transporter genetic mutation, only because of the years of medical research I subjected myself to and my own stubborn nature not to let something go. The transporter essentially starves my cells of vital Choline, making me deficient, despite ingesting large quantities. Yet, the research facility that had been seeing me has currently lost interest, not feeling there's much support needed for POTS and NCS. In other words, they find

the genetic mutation itself interesting, and if it were linked to something deemed important, like cancer or Alzheimer's, they might care, but currently, they have no invested interest in its possible connection to my diagnoses of POTS and NCS. After all, these are conditions considered as illnesses that patients can just learn to cope with—sometimes even referred to as illnesses “generally benign” (Sousa, et al. 153)— and if those patients actually can't manage their symptoms, well, they're a statistic easily forgotten. I only have a shred of hope left working with two research doctors on the side, as unaffiliated with a research institution, with their friends in other parts of the research world, out of the goodness of everyone's generosity (which I am very blessed to have). These people, to me, are what science and medicine should be. They see me as a whole person in need, struggling to stay whole.

Fortunately, this past year has garnered much more research in the investigation of POTS than I would have ever found a few years ago. So the trend is a good one. An interest is growing. For the year 2012, I counted on “Pubmed” online medical database approximately twenty-seven research papers published worldwide regarding POTS. Though some were merely regurgitating previous research, others sought to investigate very specific genetic and biochemical causes, and this gives me hope that there are people out there who not only care, but share my passion and scientific curiosity.

What hasn't seemed to change, from my personal experiences and talking with other patients, is a level of interest and awareness down to physician-patient interactions during specialist appointments, primary care visits, and particularly emergency room settings. There is often a disconnection taking place:

- 1.) Between patient and doctor (in regard to respectful communication and rhetorical listening), and/or

2.) Between doctors and research facilities [in which doctors would rather research facilities figure out the cause(s) of illness and best treatment plan for their patients' POTS or NCS, while research facilities would prefer physicians deal with their patients themselves and order necessary tests.] This latter disconnection is often a “catch twenty-two” for patients who, ironically, are usually quite willing to give of themselves to testing, but can't find anyone willing to run further studies beyond the standard tilt table test. There may be some doctors who will refute they aren't “equipped” for more testing, but I'm arguing that even ordering blood labs concerning thyroid levels, adrenal function, autoimmune diseases, and even amino acids can be beneficial, yet aren't always considered, when trying to determine a cause or better treatment plan.

As for patient-doctor communication, I have met some excellent doctors, but there is still an undeniable percentage of doctors with a deficit of empathy regarding what Dysautonomia patients go through. There needs to be a level of respect and appreciation that these patients have already been “through the wringer,” so to speak, that they are well-versed in medical information, and that that shouldn't be viewed as a threat to physicians. Also, in my own personal experience as being a research subject for four years, there is still the general mentality that POTS and NCS aren't that serious, and there's simply a lack of interest to investigate the underlying causes, or that any emphasis should be placed on current prescriptions to treat symptoms (the “stay-the-course” mentality). In my own case, if there are any developments regarding my diagnoses in conjunction with my Choline transporter mutation, they will probably be due to my own stubborn follow-through.

These are, I concede, my own anecdotal views in combination with what other patients have discussed with me, but it seems like change is much needed. What particularly hasn't been

dealt with in the research community are the long-term outcomes of POTS and NCS patients, tracking their lives over the course of many years, through face-to-face interactions, studying not only their orthostatic measurements, but also their quality of life, capability to function in everyday life (such as holding a nine to five job), any overlaps with CFS and Fibro, and if medications they're prescribed have continued to help them or abruptly stopped helping (something I've heard all too often on online forums). Just how well do these patients do over the course of a decade? Two decades? Three? What are their projected outcomes?

So this year, when I think upon my New Year's resolutions, it's still difficult. I'm not sure of what my fate holds. And so, it's a struggle to conceptualize a future with a significant other, a full career, my own place to live without my parents helping me out, devoid of days when I'm too sick to leave my home. I'll be thirty-two years old this April, and while many of my friends my age have already accomplished these dreams or goals, I'm not sure whether those will be a possibility for me. Dare I make a New Year's resolution?

I'll go a step further: I charge us *all* with the resolution to help care for and research Dysautonomia patients. Because we matter. Because we exist. Our suffering should be recognized with a thorough, invested, and compassionate medical research response, which can only be effectively achieved within a larger medical community that recognizes illnesses like POTS, NCS, CFS, and Fibro, without shying away from wanting to know more about such illnesses. Physicians need to be willing to "step outside the box." We are complicated patients, but our complexity should garner scientific curiosity, not fear, resistance, or abandonment.

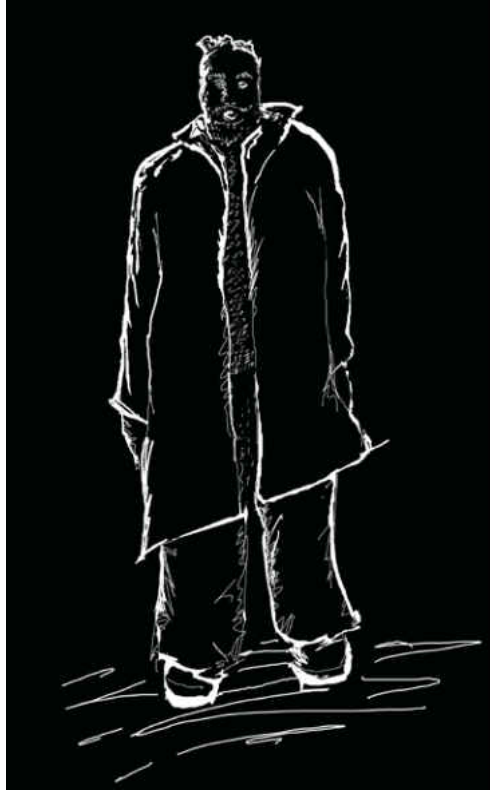
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EPILOGUE: ON HOLLYWOOD BLVD



In the first year I lived in Los Angeles, when I felt lonely and down on my luck, I'd walk Hollywood Blvd at night, going down to Mann's Chinese Theatre and sticking my hands and feet in Marilyn Monroe's prints, along with a slew of other greats. It always recharged me.

One night, just as I fed a parking meter along a side street of the boulevard, a rather large, black, homeless guy with a bad eye and a trench coat approached me asking for change. He must've been six foot two, and his bad eye and trench coat evoked a cliché horror flick character. I stood there for a moment, taking in his vision, along with raspy voice begging for change. Had I never experienced hunger or hardship when I moved to Los Angeles, I might not have given him a second look, but instead I answered, "Well, I don't give out money. But I'm about to go get something to eat at Greco's Pizza. If you wanna come I'll get you something."

"Oh wow, that would be great. Please, yes," he said.

So we walked down the boulevard, introducing ourselves to each other. He told me his name was Michael. At the pizza place, we each ordered a slice and sat together at a table under fluorescent lights next to mirrored walls, discussing life, people, pizza. Even after finishing our pizza, we talked for two hours straight. We swapped our stories. I told him about a car accident I had been in years ago.

I said, “We—some guy I had recently met who wanted to date me but I wasn’t really into him—we were in my car—a gold Saturn, four-door. Came to a stop sign. Cars kept coming, and I grew impatient. Then I see another car coming—one of those big, clunky SUV’s—an older model—like when they were still made out of heavier metal. I see it come ‘round the bend fast, but I think it’s a beautiful sunny day, and surely they’ll see me. So I go for it. I mean they were speeding, but I thought for sure they’d see me and then slow down. Damned if she—the driver—some teenager just got her license—was gunning it for the yellow light at the next intersection beyond the one I was stopped at. She didn’t even see the intersection I was at. She was trying to make a yellow light because, see, there’s no turn on red there and, well, the light is real short. This is Towson, near Baltimore, by the way.”

I am lost in my story. I can see the car vividly in my mind, coming right at me, in slow motion and fast-forward at the same time. Dark blue metal crashing towards me. I grip the steering wheel tightly, bracing myself, saying, “Ohhh fuuuccckkk,” and then—

“BAM! She hit me right in the driver’s side door at about forty-miles-per-hour in a twenty-five-mile-per-hour zone—still accelerating! There were no skid marks later, I heard. She hit my car, and I spun around in the intersection, hitting a parked car. My head hit the frame—you know the one? That bar between the windows of a car—between the front and back windows?”

Michael nodded and said, “Oh yeah, I know what ya mean.”

“Yeah, well I hit my head on it twice. When I came to, everything was real fuzzy. I couldn’t see in focus past about a foot in front of me. I saw that teenage girl flailing her arms in the air, saying, ‘I killed her! Oh God, I killed her!’ ” I raised my arms up in the air, waving them around for effect. Michael laughed.

I continued my story with how the guy in my passenger seat spazzed about not being able to find his glasses, about the physical ordeal of getting hoisted out through the back passenger door of my car, because my side of the car was totaled, how lucky I was, how the door had come in over my left arm, glass everywhere. How I hadn’t managed to break a thing, but had a concussion and chest contusion. I described overhearing the firemen at the scene say to one another that they might have to cut me out of the car, and me—still dazed—had thought they were overreacting, because I had no concept of just how messed up my car was. I tell Michael how the paramedics said if I hadn’t worn my seatbelt I could’ve died.

And then I told Michael about how the car accident changed me. How when I realized, finally, that I could’ve died, I wept on the floor of my bedroom one night, a week later. I wept and promised myself and God I’d try my hardest to do something with my life, to follow my dreams, to never abandon them, to be somebody and not live life with regret. I told Michael how this pushed me to make the leap to move to Hollywood.

After my revelations, Michael shared with me his accident story.

He said, “I used to ride bikes. Motorcycle racin’ for a livin’. That was my thing. How I made my money. I was racin’ this one bike up this big dirt hill and on my way down I lost control of the bike. Went flyin’. Hit my head. You know I ended up in a coma.”

“Really? What happened? How long were you out?” I leaned in, curious.

“Well I was in a coma for ‘bout a month and let me tell ya, I was beat up real bad. Broke almost all my ribs, broke my left leg, screwed up my back, head injury. The doctors told the nurses that I was so bad off that if and when I were to wake up I would be paralyzed. Well, so I started to wake up and guess what? Wakin’ up from a coma ain’t like what you see on TV. No sir. Nothin’ spontaneous and abrupt about it. It was gradual-like. The colors was all messed up too.”

By then Michael had started moving his hands and fingers, as if to paint this picture in front of us. I was mesmerized, having learned at that point not to stare too much at his bad eye, but instead take in his entire personhood.

He said, “Stuff was blurry and colors were weird.” I could see it with the vision of a filmmaker. I imagined opening my eyes in a hospital room, only to a blurry, colorful sensory overload instead of the usual drab cream and white.

He continued with his story just as I got the hang of the sensory overload. “Well, what made it bad was the last thing I had remembered was ridin’ on my bike. I didn’t even remember the crash. One second I’m on my bike and the next second I’m wakin’ up, seein’ this bright light hoverin’ above me, seein’ figures with white coats sneakin’ up round me. I looked down at my chest, and well they had stapled my chest! And all these tubes were coming out of me. Damn it, I thought I had been abducted by aliens! I swear! So I started rippin’ things out of me freakin’ out. Boy did I give them nurses a scare. They was told I’d be paralyzed.”

I laughed so hard. I hadn’t expected that as the outcome. Aliens. Perfectly reasonable, actually.

“Yeah, sincerely, how was I to know, ya know? I mean all I remembered was bein’ on the bike, and then here’s these aliens got me sucked up in their space ship. I thought fo’ sure they was doin’ experiments on me or somethin’!”

It was a legitimate assumption, I wagered.

When storytelling came back to me, I told him about how during my move into Los Angeles, my car had been broken into and my stuff stolen. Some were precious things, like a vintage suitcase my mother had bought me in downtown Annapolis, which contained all of the jewelry I had hand made to date, that I intended to sell to make some money to eat, plus some other art supplies and photos. I also had one thousand dollars worth of CDs stolen as well. With a genuine smile Michael replied, “It’s okay. I was sleepin’ on the street last week and I had this backpack that had all my stuff. Everything I owned in it. While I was sleepin,’ damned if someone didn’t take my bag.”

Everything?”

“Yup. *Everything*. Everything I owned was in that bag. Some sentimental thangs in there too like you was sayin’ bout what you lost.”

“Oh that’s terrible. I’m so sorry to hear that.” I started to feel small.

“Let me tell you somethin’,” Michael continued with good spirits. “It’s just *stuff*. I still got me. Still walkin’ around talkin’. So it’s okay. I can get more stuff. You gonna be okay.”

I was admittedly floored by this statement. I figured if someone with hardly anything could then lose what little he had and still be in good spirits, well, then I could find it in me to get over losing my stuff.

I think back on Michael from time to time, reflecting on the things he said, particularly his statement about only needing himself. On one hand it's something I grapple with because sometimes having just myself isn't enough—not in the materialistic way we discussed—but because sometimes I'm so sick that if I think about having myself as what gets me through the day, well, sometimes it's my own body that's making it rough to get through the day. For a while this was a lot to handle. In time I've grown to think of myself as my soul, my spirit, not my body. George MacDonald stated in the *The British Friend*, “Never tell a child you have a soul. Teach him, you are a soul; you have a body.” This was published in the 1800's with the original intention of being a religious quote to lessen mourning over death, instilling hope for Heaven. For me it lessens a type of death I've felt while alive—a sense of loss over a life I had envisioned for myself, and it instills a sense of hope in the life I currently have, as a chronically ill individual. If I change the nature of how I identify myself—as soul instead of body—then Michael's quote takes on a meaning further than the surface value I took it at years ago. I do have all of me. Albeit, in some ways this soul of mine is a bit weather-worn, battered, perhaps even broken in some spots, but she's all there.

Back in December 2011, I had come to a place where I was accepting Zora and myself as one whole, living in a dysfunctional body, and with that acceptance came the realization that my health—determined by genetic factors no one has control over—might not get better, but in fact, could get very worse. I had come to accept myself as a whole person only to realize the division that had taken place in myself—my build-up of a heroine I called Zora who would eventually overcome anything like the perfect Hollywood ending—against the current status of me, a bit of an anti-hero broken by illness—had in fact kept me from facing acceptance of the gravity of my poor health, and also allowing myself joys in the here and now. My life seemed hinged on the

idea of *I'll have joy when I'm well*. It's seems almost as silly as Thelma Ritter's character in one of my favorite Film Noirs, *Pickup on South Street*, who spends her whole life saving up for a special burial plot in an upscale cemetery, never enjoying her savings with the life she has in her current state.

I'm not an advocate of how the positivity movement has been distorted into a think-yourself-happy-and-well pressure put on us all privately suffering. I value exploring my darkest days. I don't think anyone can grow as a human being without doing that. However, I do feel like I can live my life in the most fulfilling ways I can, so that there is some joy in my life, without denying myself to feel down on some days. I'm no longer interested in denying parts of myself, good or bad. In fact my writing and my visual art allows me the opportunity to do something joyous while exploring darkness, suffering, fear, and loss of hope if I so choose. I'm so looking forward to years ahead of me, embracing wholeness, investigating all my strong points and flaws, my ironies, my good and bad, beautiful in my brokenness, loving intensely, feeling passionately, acting with purpose. But if I don't have many years left, in some ways that's okay. All these years I've been trying to not live my life with regret, while inadvertently doing just that by denying who I am in the present. No more. I'm living in the here and now for the first time in my life, and the weight of regret is lifting off me.

LAYMAN'S GLOSSARY OF TERMS

**Medical terms have collectively been taken from Mayo Clinic database, Phoenix Rising CFS website (co-founded by the late Rich Van Konynenburg, Ph.D.), the Center for Hypotension at New York Medical College, and private correspondence with Harvey Mudd, Ph.D, M.D. Also, private correspondence with Dr. Van Konynenburg was made prior to his death. Any other information is cited specifically.*

**Further information (research papers, medical articles, and diagrams) on any of the medical terms listed below can be accessed at www.imazebra.net at the "Resource Database" section.*

Acetylcholine- important neurotransmitter needed for proper function of the Autonomic Nervous System. Choline is a precursor in the production of Acetylcholine. Also, Alzheimer's decreases the level of Acetylcholine in a patient's brain.

AD – Assistant Director in the film industry.

Autonomic Nervous System- also known as **ANS**. Provides regulation of breathing, HR, BP, gastro-intestinal function, and temperature.

Betaine- Also known as Trimethylglycine or TMG. Betaine is needed to convert Homocysteine into S-Adenosylmethionine (also known as SAM-e and Adomet), in part so that Homocysteine does not build up to excessive levels.

BP- Blood Pressure.

BPM- Beats per minute, for heart rate.

Bradycardia – slowed heart rate. Resting HR below 60 bpm, though trained athletes can have a healthy HR under 60 bpm.

CFS- Also known as **Chronic Fatigue Syndrome**.

Choline- pre-cursor to Acetylcholine. Also needed to create Betaine.

Choline Transporter- transports Choline in and out of the cells.

Collagen- the “glue” that holds your entire body together. Collagen is a form of connective tissue, composed of amino acids Proline, Glycine, Hydroxyproline, and Hydroxylysine. Collagen is found in skin, bones, blood vessels, cartilage, tendons, ligaments, and cornea.

Dysautonomia- disorders characterized by dysfunction of the Autonomic Nervous System.

Includes but is not limited to: POTS, NCS, vasovagal syncope.

FM or Fibro- also known as **Fibromyalgia**. Characteristics include specific points on the body that patients describe as feeling “bruised” when touched, along with wide spread muscular pain. Another symptom that can occur is tingling in the extremities, or, as some patients describe, “creepy-crawly” sensations in the limbs.

Homocysteine- An amino acid, which in higher than normal levels, is associated with cardiovascular disease, stroke, heart attack, and miscarriage. Breaks down collagen. Normal Homocysteine levels measured at most labs: 5 to 15 u/mol. Preferred range: 7 to 10. Above normal range, Homocysteine breaks down collagen throughout the body, including the vascular walls. High Homocysteine is linked to an increase risk of arteriosclerosis, heart attack, ischemic and intracranial stroke, Alzheimer’s, and even miscarriage. For the average patient with elevated Homocysteine the cause is a deficiency in Folic Acid and/or B6 and/or B12, which can be corrected through supplementation and/or change in diet.

HR- Heart Rate. Normal resting heart rate for an adult is 60 to 100 bpm.

Methylation Cycle- needed for DNA replication (turning it “on” and “off”), healthy immune system/ detoxification, and production of the anti-oxidant Glutathione.

Neurocardiogenic Syncope- also known as NCS and **vasovagal syncope**. A form of **Dysautonomia**. Neurocardiogenic syncope is a temporary loss of consciousness associated with a drop in arterial blood pressure, quickly followed by bradycardia (Grubb and McMann 133).

During the syncopal episode seizure-like activity may occur, distinctive from an actual seizure disorder, such as epilepsy (Grubb, et al. 871).

Orthostatic Intolerance – also known as “OI.” symptoms occur upon standing, and can be derived from a lack of blood flow, unstable blood pressure, or hypovolemia (decreased blood volume). Symptoms can include lightheadedness, headache, fatigue, visual disturbance, exercise intolerance, weakness, tremulousness, sweating, palpitations.

PA- also known as Production Assistant for film sets, and as Personal Assistant for celebrities or executives.

POTS- also known as **Postural Orthostatic Tachycardia Syndrome**. Also sometimes called “Postural Tachycardia Syndrome.” Criteria for diagnosis includes 30+ HR upon standing.

POTS is a form of **Dysautonomia**.

S-Adenosylmethionine - also known as SAM-e and Adomet. Part of the methylation cycle.

Screenplay- also known as a script. For a feature length film, desired length no more than 92 pages, while longest epic films not last more than 120 pages. Guideline: one minute on camera per page.

SNP- “Single Nucleotide Polymorphism” – genetic mutation.

Syncope- “faint” or “black out.”

Tachycardia- fast heart rate. Above 100 resting HR. Also an acceleration above 30 bpm upon standing is prevalent in POTS-related tachycardia.

Vasovagal Syncope- also known as **Neurocardiogenic syncope**.

Vagus Nerve- Overstimulation of this nerve is thought to provoke a vasovagal syncopal episode.

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