

gene
edit
me
please

Elaine
Katz

GENE EDIT ME, PLEASE

Elaine Miriam Katz

GENE EDIT ME, PLEASE

A Creative Memoir-Based
Thesis



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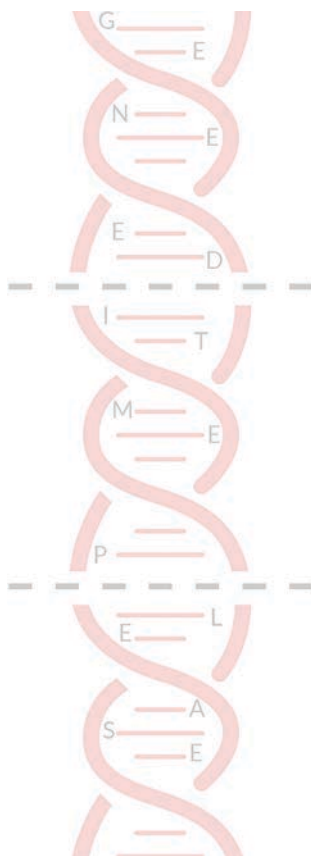
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In submitting this thesis to the Department of Organismic & Evolutionary Biology in partial fulfillment of the requirements for the degree with honors of Bachelor of Arts, I affirm my awareness of the standards of the Harvard College Honor Code.

Name: Elaine Katz

Signature:

Dedication

To Kate Vieni for teaching my sixteen-year-old feet how to walk and to Dr. Marin Jerome for reinstating my faith in my body at age 26. Without Kate as a teenager and Dr. Jerome as an adult, my legs would have succumbed to immobility well before they could carry me into the narrative I am proud to call my own.

To Rebecca Alexander for bearing the burden of illness with me and for demonstrating that disease can pave the way for an uncertain but exceptional life. Without Rebecca, my thesis would have been laced with defeat, rather than with triumph. It is precisely because of our bond that I am no longer a prisoner of my own history and that I have the audacity to move forward with purpose.

To Dr. Andrew Berry and Dr. Elena Kramer for their continuous support, time, and commitment to my academic career and to my personal circumstances. They are the reason that I was granted the opportunity to tell my story as my senior thesis through the lens of science, psychology, and creative nonfiction.

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Endorsements

An extraordinary tale extraordinarily well told. This story of Elly Katz's struggle with genetic disease (and, all too often, with the medical establishment) is simultaneously inspiring, tragic, and informative. The book's two strands—memoir and science—are masterfully interwoven: The scientific complexities brilliantly unpacked as an integral, organic part of Katz's story. Written with verve and wry humor, the book engenders in equal part tears and smiles, sometimes both on the same page, but it remains throughout upliftingly positive. It succeeds superbly in personalizing its message—that rare diseases are too frequently overlooked by doctors—and will have a far-reaching impact.

Andrew Berry

Lecturer on Organismic and Evolutionary Biology

Assistant Head Tutor of Integrative Biology at Harvard.

I have advised over a dozen senior theses in my career at Harvard but this is easily the one of which I am the most proud, both of the student's accomplishment and the work itself. Elly poured her heart and soul into this work and it shines through on every page. It is a unique work that synthesizes personal memoir, human genetics, molecular medicine, and biohacking, all seen through the lens of her life. The work blends two distinct perspectives. First, there is a comprehensive coverage of relevant

scientific literature that helps us put the author's genetic diagnosis in scientific context and, second, what I would call the "bio-hacking" component provides deep insight into how patients with rare diseases have to be their own best advocates and literally experiment on themselves. The perspective on modern medicine is particularly compelling and should be read by anyone who actually has the power to address these issues.

Elena Kramer

Professor of Organismic and Evolutionary Biology at Harvard

Director of Graduate Programs in the Natural Sciences

This is a story of exceptional resilience, on physical, mental, and spiritual levels.

If you want to understand what it's like to live as a gifted young woman with a rare and debilitating genetic disease, then this is the book for you.

Beautifully written, Katz interweaves the science of her rare disease with descriptions of daily life as a Harvard undergraduate and the many challenges she faces.

Her resourcefulness is remarkable—in overcoming roadblocks to her academic career and in creating cherished interludes of "regular" social life that other college students take for granted. Throughout, she is a detailed observer of her life, showing vulnerability and humor.

("It's a good day since I only had to relocate my shoulder joint and not my hip joint too.")

Her disease is all-consuming, yet she forges strong connections with friends, professors, lab mates, and clinicians with abundant support from family and mentors.

This extraordinary book is perfect for anyone with a rare disease, for their loved ones, friends, doctors, and nurses, and for all those advocating for more research on rare diseases.

Maryellen Ruvolo

Research Professor of Human Evolutionary Biology

Harvard University

Foreword

Metta Scan by Elly Katz

Feet—those motivated and unstoppable soles forever forging onwards—good morning to you. May you be peaceful. May you be happy. May you be liberated from the shackles of pain. May you forever remain undaunted by life. May you trail forward, despite the tide that seems to pull you back to the darkness from whence you came. May you carry my spirit through the earth.

Legs—those muscular pillars of support that somehow bear the gravitational brunt of all that lies upstream—hello from your inattentive, distracted inhabitant.

May you be free from spasms. May you courageously move me into experience. May you delight at the momentum life affords. May you forever gaze ahead at that which is always unknown.

May you never give up, give in, nor succumb to defeat. May you continue to staunchly rebuild me as life demands. May you be content.

Pelvis—that parabolic bowl that steers the ship of my being—I will never forget you.

May you refine the art of alignment. May you find tranquility in equilibrium. May you smile contagiously and grant me the pleasure of singing at life. May you savor the movement of the moment. May nothing preclude you from directing me into phenomena.

Ribs—that accordion encircling me into myself—I acknowledge you silently at each inhale. May you expand and contract with ease. May you learn that you are independent from shoulder blades and pelvis—that you can move autonomously. May you have the audacity to respire throughout the day and night. May you permit me to breathe into you as I please. May you find solace in the overlooked and infinitely interesting task of gas exchange.

Neck—general headquarters of my peripheral nervous system—I wish we were less acquainted with each other, that you occupied less of my time to sustain yourself and carry my cranium.

May you become stronger each day. May you become the resilient highway of my nervous system and demand less attention. May you carry my most prized possession, this thing I call self—that tangle of neurons above—with ease. May you be happy. May your pain dissolve into the atmosphere. May you be free from persistent distress.

Cerebrum—that essence I call self—I am awed by you, by your constant adaptability to the shifting conditions of the body, by your capacity to change and render me someone different in each moment.

May you continue to shape me into myself. May you continue to refine your ability to be present, to land upon each moment gently. May you take me everywhere. May you lead me into whoever I am meant to be.

Comprehensive being—that totality that forever outshines and baffles the sum of its parts. Thank you for today. For being here. For enabling me to complete this sentence, to type this poem. Thank you for every moment you give.

Artist's statement

When I arrived at Harvard seven years ago, I presumed that I, despite my lengthy medical history, would fit the mold of an average student. However, as my body presented one roadblock after another to my completing Harvard on my own terms,—joint dislocations, gastrointestinal dysmotility, a spontaneous cerebrospinal fluid leak, cervical instability, temporomandibular joint dysfunction—it became clear that my physiology was uniquely mercurial. As a freshman, I was finally diagnosed with Ehlers-Danlos syndrome (EDS), a debilitating and incurable disorder that renders connective tissue throughout the body friable.

As a science student at Harvard researching polyglutamine and musculoskeletal diseases, I futilely tried to outrun EDS' hold on me, to carve out a realm of experience outside of its domain. I soon learned, against my will, that I could no longer retreat from the systemic symptoms that defined my life; instead, I went on the offensive and transformed my physically circumscribed world into a research laboratory designed to fight EDS.

For most, the defining feature of 2020 was, of course, the COVID-19 pandemic. In my case, however, that year is synonymous with the inability to talk, walk, sit, or do anything. Now, as my recovery progresses with the help of regenerative medicine and I gradually develop musculoskeletal strength, I am finally confronting my disease head-on through this thesis. While I am not currently well enough to return to laboratory work, crafting the following

research-backed account of my illness has transformed me from someone who can only suffer its symptoms into someone who can actively combat them.

Gene Edit Me, Please is my attempt to embed EDS and, by extension, my personal narrative in the language of science. In this effort, I leverage my educational and research background to ground my disease in disciplines including but not limited to psychology, molecular biology, genetics, epigenetics, neuroscience, and evolutionary biology. While scientific explanations are scattered throughout the text, the manuscript begins with an in-depth scientific introduction (Chapter 2) that serves as a framework to understand the nature of my condition and concludes with a detailed discussion of potential EDS causes and therapies (Chapters 23–24). In the intervening chapters, I explore the development of my EDS, starting with my early childhood when I began to experience symptoms that culminated in my diagnosis two decades later. The innocent memories I depict (Chapters 3–4) function as a reference point for the narrative that follows. In addition to exploring EDS through the lens of scientific mechanism, *Gene Edit Me, Please* is about Western medicine's inability to deal with rare "zebra" diseases, how the isolation imposed by EDS's many assaults (beginning during my teenage years) shaped me into who I am becoming, and about my relationships with others and with science itself. At its core, my thesis has become a narrative of adversity and triumph, of getting knocked down and clawing my way back up. I am immensely grateful to have the opportunity to look my disease in the eye—to unpack its scientific underpinnings and, consequently, to make sense of my life. Thank you for taking the time to read my work.

Disclaimer: *What follows is a work of creative nonfiction. I have tried, to the best of my ability, to recreate events, people, and conversations based on my memories of them. Although all the episodes portrayed are true, in some cases, I have altered names of individuals, identifying features and/or institutions to maintain anonymity. All ascribed quotations are my recollections of conversations, not direct quotations. In my recreation of these discussions, I tried to do justice to the essence of what was conveyed, not to reconstruct them verbatim.*

A note to the reader:

This book was written as Elly's college dissertation in the field of Evolutionary Biology, but, as was her way, Elly brought her full and creative intelligence to the material. The result is a deeply personal memoir that tells the story of learning to live with a genetic disease, and that, with the exception of two chapters, will engage and inspire all readers. The two science-heavy chapters are Chapters 2 and 23. For the uninitiated, they might be daunting. For those who choose to do so, those chapters can be lightly-read or skipped altogether, without losing the thread of the narrative.

*Only I can tell myself the next sentence of my story.
I craft adventures out of walks and dance down
Cambridge streets utterly and innocently
credulous of Sia's words: "I am unstoppable."
I am buoyed by my bounce back, by my spirit's
dogged capacity to resuscitate after ricocheting
off the unforgiving walls of existence.
And, yet, I feel defiled by experience, robbed of
something I once called joy.
In making meaning, I am forced to literally redesign
the dictionary, to redefine happiness, wellness,
and so much more.
The world resonates with perspective.
Walks can be journeys, moving can be wellness,
disease can set the stage for an unexpected,
unscripted, yet magnificent life.
My world echoes with the hum of something I call
bliss, which I will define and redefine ad infinitum
forever undaunted.*

1

The peril of spontaneity

I am okay with being out of place, with arms out of sockets that rest on bed pillows, with knee caps that pop in and out as they try to figure out where they belong in this universe, with nerve pain that glides like a practiced figure skater down the midline of my arm, with bruises canvassing my thighs, with life in pieces, with fragments.

For what are we if not broken?

Drip. Drop. Drip. The inaudible and ceaseless internal leak continues. The rupture within and the gap between me and my world widens. Seated in my introductory genetics course, I observe my professor point to the evolutionary diagram in a corner of the classroom. I adjust the glasses on my nose, thinking doing so would somehow rally my internal reservoir of concentration. I remove them from my face and place them on the table before me. Fruitless in my effort to focus, I stand up with my legs encircling an exercise ball, which had recently replaced my classroom chair.

The professor draws a curlicue emerging from a string of DNA on the chalkboard to elucidate the defunct genetic byproducts of a particular chromosomal rearrangement. But the mutation

extended beyond his drawing. Little did I know, it had taken hold of me. My brain struggles to interpret his illustration, to envision the sequence of the two-dimensional genetic code after its contents are shuffled. I feel heavy and lethargic all over as though my cerebrum had been replaced with a bowling ball. The dizzying sense of my own weight encourages me to resume my position on the inflated seat. Notwithstanding my confusion, something within me experiences a kinship with the genetic anomaly being expounded upon; I feel scrambled, my insides garbled like the adenine and cytosine nucleotides on the board.

After a summer research internship at Harvard, I can only classify as a mental high, during which my mind felt unstoppable, I was floored, only two weeks later, by my brain's own waning computational power. I felt like I was running on some basal level, as though I was walking through mud and endeavoring to see clearly through a thick and impenetrable fog. A switch within dimmed and, by the conclusion of the first week of the term, was flipped off, rendering me lost en route to class buildings I had frequented for the past three years and unable to hold my head upright against the unforgiving tug of gravity.

My characteristic 10pm bedtime trended asymptotically toward 8pm, but my widened sleep window did not help; I awoke enervated and bleary-eyed. Presuming that I, even in the face of the multitude of energy-enhancing supplements I consume daily, had succumbed to the fatigue often associated with my disease, I began ingesting potentially record-breaking quantities of almond butter, avocados, and collagen protein. In doing so and forgoing my usual half-hour of aerobic exercise on an elliptical machine,

I was confident that the exceedingly positive value of my calories in versus out equation would synergize with the extra hours of rest to yield a more stable and energized version of myself. But I was wrong and misread the signs my body was sending.

I cannot recall the last time, at least in the previous half decade, that I have been at such an impasse. My disease has armed me with an arsenal of tricks that probably strike any able-bodied person as preposterous. I can rapidly relocate my shoulders, knee caps, fingers, ankles, hips, and ribs, all of which test their boundaries of stability and dislocate at the slightest provocation. I dare anyone to beat my time of popping a rib or shoulder back into place. I have the jigsaw puzzle of my body down to a science; I know its cryptic physics and how to unify its parts. I have relocated my arm into its socket as many times as my mother has kissed my cheek. As though out of a science fiction film, hives erupt like landmines across my legs and abdomen. My gastrointestinal cavity expands with the force of a helium balloon. I vomit until I am hollowed out and spend nights on my bathroom floor listening to audiobooks about people wrapped neatly into narrative confines, characters who suffer but achieve some climactic sense of wholeness in the story's denouement.

Occasionally, I awake on my right side, evidence that I jostled my right shoulder and hip in the night, which is sufficient grounds for my daily right shoulder and hip dislocations. I may slip on or take off my undershirt in too much haste and dislodge my shoulders. I may step off a curb gawkily and torque my ankle or knee cap out of socket. I may perch myself on a hard surface, and, in five minutes, my hip will emanate from its girdle, sending nerve pain ricocheting down the outer lining of my leg. I may consume

a histamine-releasing food, like honey or banana, and witness my skin become engulfed by orange-sized red patches.

This new setback at the outset of senior year, however, did not fit that causal mold. I propelled myself, fueled by sheer willpower, from my off-campus apartment to class and back again. After four days of a full course load, I began to consider the option that I was dying.

Weakness and fatigue crept into every part of me; I moved down Concord Avenue maladroitley like the animated Gumby. My proprioceptors—responsible for telling me where I was in space—went on strike, and I ambled this way and that, weaving myself through an invisible loom that stretched across the streets. I was utterly unsure of what to do with the alarming heft of my head when I sat and resorted to creating my own type of dance, a pattern of sitting and standing, to get through my classes. Upon arriving home, I sprawled myself on the floor for hours praying to something in Einstein's "out yonder" that this unbearable and so unclassical Elly sentiment would pass. But it did not. I tried to put in words how I felt during my near-hourly phone calls with my mother.

"My scalp feels like it's being yanked backward. I feel like someone slipped me a hefty dose of roofies."

We laugh because I have never been a mile within a situation in which date rape drugs, or even dates, are present. Because, at age twenty-four, my body acts more like a prison than a vehicle for experience. Although I have been at Harvard College, the home of finals clubs, and exclusive social organizations, for just over three years, I have never found my way into anything

resembling a party or a date. I have yet to be kissed. My journey, against my will, diverges from that of most because of my connective tissue that hardly connects. Our laughter holds so much pain and mutual understanding.

"Mom, I can't think. The lights are off inside my brain. I am not sure where I'm heading or why I'm heading there. This headache is nonstop. A reprieve only comes when I lay down."

Typically, after someone concludes a thought, there is a pause on both ends for the speaker to gulp some air and the listener to process what has been uttered. Even over the phone, across wires and distances, my mother knows my thoughts before I speak them. She does not require a quiet interlude. There is something telepathic about the bond we share.

"El, I'm leaving work and coming to you. Stay put."

Within four hours, my mother was at my door and shepherding me into a car bound for the emergency room at Beth Israel Deaconess. This was certainly not our first trip to the ER. I have spent probably as much time in hospital corridors clutching my mother's palm as I have in Harvard College classrooms. In fact, it was only four months ago that we found ourselves in the very same hallway as electrolyte-rich fluid migrated down narrow plastic tubing into my veins. Back then, at the end of April, a headache that only let up upon lying down and a sense of cerebral heft, which seemed to accrue as the day wore on, left me incapable of holding my own head up. By evening, my fists had to become a prop on which I rested my chin so I could scan articles on *NOTCH2NL*, a human-specific gene, in preparation for a paper I was ironically writing on the genetic architecture of the human brain.

During this initial stint in the ER, doctors interpreted my cradling of my scalp with my hands, an effort to lure it upward against the sensation of quadrupled gravitational force, as simple dehydration. "Doctors are trained to think horses, not zebras, when they hear hoof beats," my mother would tell me later. But this approach of seeing the majority and forgetting those on the margins does exactly that; it overlooks zebras like me with ease. If doctors are blind to medical zebras, or rarities, who is responsible for sighting them? After a night's worth of Ringer's lactate solution doused my venous network, the attending doctor proudly noted that "I was a dead flower that he had sprang back to life." That might have been the case, but he could not predict that the life he (or the fluid) had bestowed came with an expiration date of about four months.

As my wheelchair rolled through the ER doors in late August for the second time, I felt smothered by fear. I wondered if I would ever again find a way to trust my body after its latest betrayal or if the panic I felt would become a part of who I was for the long term. My mother played up her doctor status the way she always does in these circumstances. She whipped out her Weill Cornell Medical College badge as though it were a weapon and told the attending at the check-in desk that I needed hydration immediately. My mother is, rather rightfully, protective of me, even more so in ERs than in bustling New York City crosswalks.

Patients with my zebra disease have been painfully misunderstood by doctors who, more often than not, are incapable of appreciating the fragility of my condition. Operating under the false premise that my connective tissue is in tip-top shape, physicians jam my shoulders into place with undue force that causes

refractory dislocations and nerve impingement. In addition to her certified doctor decal, my mother is compulsive about her lipstick, which she applies with the diligence of an A+ schoolgirl. I have learned to diagnose my mother's sanity, or lack thereof, by decoding the frequency with which she outlines her mouth with Lancôme. Regularly spaced applications every ten or so minutes indicate that she is even-keeled, but, as the lipstick-free intervals shrink to five minutes and trend toward five seconds, I know that the robust mantle of my mother's emotional stability has begun to fragment, that she will soon lose it and her Lancôme will run dry.

ER doctors strictly follow my mother's orders to the letter. One glance at the red and white plastic pronouncement of her medical credentials and they abide. A female nurse strung one bag, and then six more, of clear liquid onto a pole and drove a small needle into my arm. She proceeded to take my temperature, harness a blood pressure cuff around my bicep, and measure my oxygen saturation using a device I can only describe as a finger hugger. The ER was packed, and I was stationed on a stretcher. My mother sat beside my head and witnessed the electrolytes oozing into me. All suffering demands a witness. My mother is just that and so much more.

Between my diagnosis three years prior and my visit to the ER in August, I became my own experiment. Because my disease lacks a course of treatment or anything close to a therapeutic blueprint, I subjected myself to elimination diets, ultimately landing upon a cyclical ketogenic diet, and prescribed myself supplement cocktails consisting of ingredients including aloe vera, bovine bone marrow, lamb liver, and vitamin C. I spend roughly

15 minutes each morning extracting the closest approximation to a cure for my disease from the insides of fifty-four bottles.

When my head pain developed in April, I substituted gastrointestinal-aggravating Aleve with CBD and arnica pellets, the latter of which I had been ingesting strictly on the hour. As I lay on the stretcher grasping my mother's hand, the hour struck, and the time for ten more of my arnica tablets arrived. My mother surreptitiously placed the cylindrical dispenser in my hand as her eyes darted from one nurse to another. When our eyes met, uncontrollable and unbridled laughter ran out of me and my mother faster than the electrolytes ran into me. Once we began, there was no stopping us. That's what my mother and I excel at: Finding pearls of joy and togetherness in the darkness of illness. If you can find laughter in the ER, you can do almost anything. Beneath the transparent bedsheets, I rotated the movable circle at the tip ten times as ten pellets fell synchronously into my palm. That is the closest I come to rebellion: Furtively taking my own medication in the hospital.

While the liquid resuscitated me to an extent, it was not as magical an elixir as it had been in April. The morning after my overnight hospital stay, I had enough vigor to attend a meeting with my genetics professor, but, by 3 p.m. that day, I felt like roadkill again. My father decided to come to Cambridge for the weekend and aid my mother in my return trip home to New York City on Sunday.

If my mother is my medical middleman who alarms ER doctors into submission, my father is the highway to my innocence. My Dad has this transfixing way of making me erupt into laughter