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# From Prison Zooms To Hospital Rooms: Unmasking the Positives Of Remote Education

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**FROM PRISON ZOOMS TO HOSPITAL ROOMS:  
UNMASKING THE POSITIVES OF REMOTE EDUCATION**

by

**MOLLY CHAO YESELSON**

**SUBMITTED TO SCRIPPS COLLEGE IN PARTIAL FULFILLMENT  
OF THE DEGREE OF BACHELOR OF ARTS**

**PROFESSOR KIMBERLY DRAKE  
PROFESSOR JENNIFER GROSCUP**

**APRIL 28<sup>TH</sup>, 2023**

**Abstract**

*From Prison Zooms to Hospital Rooms: Unmasking the Positives of Remote Education* is the culmination of a seven-year battle for my life and my education. Remote and hybrid education are perpetually identified as the cause of pandemic-era learning deficits. My project seeks to challenge such rhetoric by detailing the positive educational experience I, a student with a disability, along with my incarcerated peers, have had thanks to distance learning. I argue that as the world shifts from a pandemic to an endemic approach to COVID-19, higher education must keep its virtual doors open to nontraditional students.

“We cannot keep teaching people who are sick that they need to be healthy before they can live their lives.”

- Claire Wineland  
Activist, speaker, philanthropist, author, and  
Cystic Fibrosis patient<sup>1</sup>

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<sup>1</sup> Claire's Place Foundation, "*We Cannot Keep Teaching...*", outdoor vinyl sticker (4-inch x 4.6-inch rectangle), accessed April 28, 2023, <https://store.claresplacefoundation.org/we-cannot-keep-teaching-4-x-4-6-vinyl-sticker-pack-of-two/>.

“COVID is your friend, Molly,” said Liz, my palliative care doctor.<sup>2</sup>

It was March 13, 2020. A mere two days earlier, the World Health Organization (WHO) declared COVID-19 a global pandemic. I was perched on the edge of an exam table in the Center for Cancer and Blood Disorders Clinic at Children’s National Hospital (CNH) in Washington, DC. While I had been wearing the cheerful pediatric “Mickey Mouse and Friends” surgical face mask for years, this was the first time that everyone else in the room was masked up as well. It was evident that COVID was disrupting more and more of what remained of “everyday life.” While most people were annoyed, saddened, or in some cases, enraged by school closures, Liz saw this shift as an opportunity for me to finally resume my education. My mom and I exchanged nervous but excited glances. For the past two-and-a-half years, I’d been unable to attend college due to a conglomeration of rare, chronic, and even life-threatening health problems. While I was frequently encouraged to transfer to Georgetown University—exactly one mile from my house and where my mom is on the faculty—I remained adamant about returning to *my* college, a school that happens to be 2,635 miles from home. A school that had also never offered online courses nor planned to do so—that is, until 2020 rolled up with a lethal virus in tow.

In the three years since that appointment with Liz, I’ve often felt isolated when conversations and news stories about the pandemic’s impact on daily life have inevitably turned into trash-talking virtual school. That’s not to say online school is easy, nor is it ideal. I do believe, however, if one is determined enough to make remote learning work, it’s possible to

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<sup>2</sup> Palliative care is not the same thing as hospice. Palliative care is for patients with serious health conditions who need more support to manage symptoms, coordinate care across multiple specialties, and achieve the best quality of life they can despite their illness. Concurrent/curative treatments are still offered. Patients with life expectancies less than six months can be transitioned from palliative to hospice care.

have engaging and meaningful interactions with professors and classmates. In fact, the students who understand the value of “Zoom University” just as much, if not more than me, are even more nontraditional than I am. That’s because they’re in prison.

Like me (and other students with disabilities), the incarcerated students in Pitzer College’s Inside-Out Pathway-to-BA have had to fight for their education. All of us have had to prove our worthiness to get an education over and over. We’re accustomed to having both literal and metaphorical barriers popping up unremittingly. Speaking from within this distinct group, I would say our perspective has shifted and we see challenges as things to work through, rather than avoid altogether. We’ve adapted to make the best out of terrible circumstances. We’ve “befriended” COVID because it’s forced the rest of the world to rethink pedagogical approaches and has heightened awareness of the inaccessibility and inequities in traditional educational models. My experience and that of my classmates at the California Rehabilitation Center (CRC) demonstrate that with the proper pedagogical training, IT support, and student engagement, a rich and challenging liberal arts education can be obtained via remote and hybrid models.<sup>3</sup>

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COVID-19 was (and is) a global, tragic, and life-altering event. As of April 12, 2023, the WHO has recorded 762,791,152 cases worldwide. (In reality, that number is likely much higher due to underreporting of cases diagnosed via at-home rapid antigen tests.) Of that staggering number, 6,897,025 people around the globe have lost their lives to the virus.<sup>4</sup> Despite the fact

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<sup>3</sup> The most explicit discussion about Inside-Out appears towards the end of this project because I first use my own journey to and through college to contextualize and highlight the origins of the personal connections I’ve formed with my incarcerated peers.

<sup>4</sup> World Health Organization, "WHO Coronavirus (COVID-19) Dashboard," World Health Organization, accessed April 16, 2023, <https://covid19.who.int>.

that the United States comprises just 4% of the world's population,<sup>5</sup> the US is home to 13% of the world's COVID cases and a staggering 16% of the world's deaths from COVID.<sup>6</sup> Thus, it's vital that I acknowledge my "friend[ship]" with COVID was born out of a traumatic period in human history.

A plethora of research has demonstrated—and will likely continue to demonstrate—the particularly negative impact of COVID on the lives of youth around the globe. From increased rates of poverty, food and housing insecurity, psychological distress, child abuse, suicide attempts, and domestic violence to decreased availability of mental health services and routine medical and dental checkups, and most notably (and most relevant to my argument) to the learning deficits caused by remote and hybrid instruction, it's evident COVID has imprinted its spikey mark on all aspects of everyday life.<sup>7</sup>

I have heard various professors gripe about the increasingly obvious learning deficits amongst their college students whose high school (and soon-to-be middle *and* high school) experiences were disrupted by remote and hybrid learning. Students matriculating to college in the fall of 2020 and beyond will have missed out on learning content that professors expect their students to have already mastered. Many students won't come equipped with basic study skills since exams given virtually—that is, if they were given at all—were officially (or quite often unofficially) open-note/open-book. Additionally, many students will be starting college lacking crucial time management skills. Learning how to balance coursework, socialization, self-care, and physical/mental health has always been challenging for first years. Now throw a bunch of

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<sup>5</sup> United States Census Bureau, *U.S. and World Population Clock*, accessed February 11, 2023, <https://www.census.gov/popclock/>.

<sup>6</sup> World Health Organization, "WHO Coronavirus," World Health Organization.

<sup>7</sup> Charles Oberg et al., "The Impact of COVID-19 on Children's Lives in the United States: Amplified Inequities and a Just Path to Recovery," *Current Problems in Pediatric and Adolescent Health Care* 52, no. 7 (July 2022): accessed February 11, 2023, <https://doi.org/10.1016/j.cppeds.2022.101181>.

18-year-olds who academically and socially function more on the level of 16-year-olds (their last “normal” year), and it’s understandable that many students are struggling to meet the demands of college-level work.<sup>8</sup>

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Georgetown had always been my dream school. I practically grew up on campus. I knew all the “tea” about the English Department. Before attending any event like the annual Christmas party, my mom would have to drill me on all the things I would need to pretend I *didn’t* know. From divorces to sketchy paths to tenure, I was a fount of knowledge that she needed to (politely) zip it. As I got older, however, I began to realize how much I didn’t want to go to Georgetown. Not because it isn’t a “good” school, but as they say in the “college admissions industry,” “It wasn’t the right fit.” I’m not making that judgement solely based on my experience running up and down the halls of the English Department in New North and taking trips to the supply closet. (What can I say? I love school supplies, especially when it’s *free*.) I actually took two classes at Georgetown during my gap year.

As my mom and I walked down the hill to “The Hilltop” during that year—I’d argue that’s a misnomer as our house is, in fact, up a steep hill from Georgetown—she teasingly said, “Well, Molly. You got it. You got exactly what you wanted since you were a little kid. You wanted to go to Georgetown and walk down to classes with me.” I rolled my eyes. While you might think my mom is just as crazy as me for encouraging me NOT to go to Georgetown, where she has taught so long that I qualify for completely free tuition, she had her reasons. She and my dad wanted me to have an adventure. More than that, they wanted me to be truly happy. My

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<sup>8</sup> Eliza Fawcett, “The Pandemic Generation Goes to College. It Has Not Been Easy.,” *The New York Times* (New York), November 1, 2022, accessed February 13, 2023, <https://www.nytimes.com/2022/11/01/us/covid-college-students.html>.



mom, in particular, suspected that Georgetown would not be my “happy place” and my stint taking classes there confirmed that. After class, I would return to her office exasperated.

“I don’t get it. I’m one of like three people who participate in a class of 30 or so. It’s also just blatantly obvious how few people actually do the readings.”

“I know. Sometimes it’s like that. What can I tell you?”

“No one seems interested in actually working together. Also, the class is just too big.”

“Well, this is why you’re applying to Scripps.”

Scripps College in sunny Claremont, California was the first college I ever formally toured. This meant every campus tour after that was in comparison to Scripps. From its wide assortment of courses and extracurriculars to its small class sizes in both STEM and humanities classes, to the benefits of being a member of the prestigious Claremont Colleges consortium, to the stunning campus in a Mediterranean climate, and to the genuinely welcoming students I encountered during my visit, I could easily picture myself at Scripps. My mom could as well. Of course, I toured about a dozen other colleges over the following six months, but none lived up to the extraordinarily high bar set by Scripps. My conviction that Scripps was the “right fit” was so strong that I applied via the College’s Early Decision I cycle.

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One night in November of 2016, I was up late in pretty severe full-body pain. I don’t remember when I first read something online that referred to such a state as “painsomnia,” but that’s exactly what was going on. Having submitted my Early Decision I application a couple of weeks earlier, I found myself searching Scripps College in quotation marks on Google. I hate the cold, in part because my chronic pain gets significantly worse in the winter months. The year-round sunny and (generally) warm weather catapulted Scripps to the top of my college list.

Looking at pretty pictures of Elm Tree Lawn and reading about the exciting things Scripps students were doing was a good mental escape. I could easily envision myself doing homework under a palm tree. Page after page on Google, I read articles, watched videos, and looked at images. By the time I was on something absurd like the 15<sup>th</sup> page of Google, an article from Dysautonomia International popped up. I was baffled. Why on earth would “Scripps College” have a hit from an organization devoted to the very condition that was causing the “painsomnia” that led me down the Google rabbit hole in the first place?

I clicked on the link and realized I had read this very article entitled “POTS in College: Choosing a School that is Right for You” when it had been first published a year earlier. The surprises just kept coming. It turned out one of the young women interviewed in the article was a Scripps alum. Her name is Maddy Ruvolo and when asked about her decision to go to a school 3,000 miles from home, she said:

My doctor advised me that a temperate climate would improve my health, and after experiencing increased pain during cold East Coast winters and humidity-induced headaches during the summers, college in California sounded really good.<sup>9</sup>

I was, of course, shocked as this sounded SO similar to my own story. I looked at Maddy’s biography at the end of the article and saw not only was she a 2014 Scripps alumna, but she was actually sitting on the Board of Trustees as the Recent Graduate Trustee. A quick search on Facebook revealed that we have a mutual friend—whose last name is coincidentally “Friend”—and I asked him to introduce us. He told me Maddy was also from the DC area. A few days later,

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<sup>9</sup> "POTS in College: Choosing a School that is Right for You," *The Dysautonomia Dispatch* (blog), entry posted December 1, 2015, accessed December 17, 2021, <https://dysautonomiainternational.org/blog/wordpress/pots-in-college-choosing-a-school-that-is-right-for-you/>.

Maddy and I met over Skype and had a great chat about Scripps, her work creating the 5C Student Disability Resource Center (SDRC), and what she'd been doing since graduation.

Talking to Maddy really eased my nerves about whether or not I'd be accepted to Scripps. Frankly, I hoped that the Admissions Office would see the numerous parallels between Maddy and me. I figured, "Well, they love Maddy. She succeeded in college even though she, too, did not have a normal high school path due to her health." After my admissions decision popped up with a cheesy gif of green confetti and ribbons, Maddy informed me that she'd emailed Scripps' Director of Admissions, Laura Stratton, and put in a good word for me. That's not to say Maddy was *the* reason I was accepted, but it certainly didn't hurt. She also said to me, "Whatever you do. Take a class with Kim Drake. She's also got a cute dog!" That's probably one of the single best pieces of advice I have received in my entire life.

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The condition that Maddy and I share is called POTS, which stands for Postural Orthostatic Tachycardia Syndrome. The first word is "postural" because it refers to the difficulties POTS patients have with changes in posture. Orthostatic means "Associated with the erect posture; manifested or occurring while a person is standing up, or in the act of standing up."<sup>10</sup> Tachycardia is a high heart rate. (For adolescents and adults, tachycardia is a heart rate greater than 100 beats per minute.) Thus, the name of the condition explains exactly what it is: a person standing up and having their heart rate inappropriately increase.

POTS is a type of dysautonomia, hence the article featuring Maddy being published on Dysautonomia International's blog. Dysautonomia is exactly what it sounds like; it's

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<sup>10</sup> 'orthostatic, adj.," in *Oxford English Dictionary*, accessed December 17, 2021, <https://www-oed-com.ccl.idm.oclc.org/view/Entry/132871?redirectedFrom=orthostatic>.

DYSfunction of the autonomic nervous system. The autonomic nervous system controls numerous bodily functions, including blinking, sweating, breathing, heart rate, blood pressure, and digestion. When there's a disruption to the autonomic nervous system, things go haywire and POTS patients can suffer from a myriad of symptoms, including tachycardia, hypotension (low blood pressure), heart palpitations, exercise intolerance, GI problems, fatigue, headaches/migraines, lightheadedness/dizziness, syncope (fainting), "brain fog" (difficulty focusing and remembering information), tremors, chest pain, shortness of breath, blood pooling in legs, and chronic joint and/or muscle pain.<sup>11</sup> The reason POTS patients are symptomatic is that the blood vessels in the legs struggle to push blood back up to the rest of the body upon standing. The heart rate increases in a last-ditch effort to get the blood circulating to the vital organs, including the brain.

The diagnostic criteria for POTS are actually quite simple. On the other hand, the test necessary to make the diagnosis is pretty uncomfortable. It's called a tilt table test. The provider straps the patient down onto what looks like an ordinary exam table. Instead, the tilt table allows the provider to raise the head of the bed until the patient is essentially standing upright against a board. If a patient's heart rate increases by at least 40 beats per minute in adolescents or at least 30 beats per minute in adults and does not go down after 10 or 30 minutes—depending on a particular hospital's protocol—the diagnosis of POTS is confirmed.<sup>12</sup> The rationale behind strapping patients onto the table is that if they do pass out, it's done in a controlled setting where the patient is not at risk of injuring themselves and the provider can quickly return them to a

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<sup>11</sup> Dysautonomia International, "Postural Orthostatic Tachycardia Syndrome," Dysautonomia International, last modified 2019, accessed February 5, 2023, <http://www.dysautonomiainternational.org/page.php?ID=30>.

<sup>12</sup> Dysautonomia International, "Postural Orthostatic," Dysautonomia International.

supine position. While fainting is a common symptom of POTS, it's not necessary for the diagnosis.

The tilt table test is reminiscent of the so-called “rest cure” invented by American neurologist Silas Weir Mitchell in the late 1800s for the treatment of female hysteria. The “treatment” involved six to eight weeks of complete isolation, bed rest, massage, and electrotherapy (now known as electroconvulsive therapy or ETC). Women were prohibited from doing anything but lying in bed. Mitchell thought his patients were suffering from mental illness as a result of “too much mental activity and not enough attention to domestic affairs.”<sup>13</sup> While undergoing a tilt table test, the patient is required not to talk unless asked to respond to a question from one of the people conducting the test. The mental stimulation could inadvertently throw off test results.

Despite the fact that Dysautonomia International estimates between one and three million Americans have POTS, the condition hasn't received much attention or dedicated funding for research.<sup>14</sup> I can't help but think this is partly due to the fact that POTS overwhelmingly affects adolescent and young adult females. The female-to-male ratio of POTS patients is 6:1.<sup>15</sup> One theory swirling around the medical community is that there is some sort of autoimmune component and autoimmune conditions are more common in females. As a result of the sex disparity, some medical providers can be dismissive of the condition. POTS is also much more common in white people. In fact, I often get told I'm the only or one of the very few Asian patients a provider has seen with my combination of health conditions. The only theory I've

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<sup>13</sup> Mütter Edu Staff, "Victorian Mental Health and Women, Part Two: Eating Disorder Treatments," *Education Blog*, entry posted August 27, 2021, accessed April 28, 2023, <https://collegeofphysicians.org/programs/education-blog/victorian-mental-health-and-women-part-two-eating-disorder-treatments>.

<sup>14</sup> Dysautonomia International, "Postural Orthostatic," Dysautonomia International.

<sup>15</sup> Deobrat Mallick et al., "COVID-19 Induced Postural Orthostatic Tachycardia Syndrome (POTS): A Review," *Cureus*, March 31, 2023, accessed April 28, 2023, <https://doi.org/10.7759/cureus.36955>.

heard about the racial imbalance of POTS patients is that African American and Latinx cultures frequently use a lot of sodium in dishes, so it may be that patients are unknowingly self-treating themselves. My POTS doctor also theorized that there might be an element of racial bias resulting in fewer patients being referred to him for tilt-table testing (i.e., primary care and other specialists may prematurely exclude POTS from the differential in BIPOC patients with hypertension because they don't realize you can have POTS and hypertension.)

Interestingly, a surprising number of individuals are developing COVID-19 Induced POTS. As a result of the influx of cases, the wider American healthcare system has begun to recognize POTS as a real and potentially debilitating chronic health problem as opposed to modern-day hysteria.<sup>16</sup> In fact, it was only in October 2022 that POTS received its own ICD-10 diagnostic code: G90.A.<sup>17</sup> It's important to explicitly note that even though POTS is not rare nor is it life-threatening, it can still be debilitating. Treatment is limited. In addition to staying hydrated and eating a lot of salt, other interventions like physical therapy, medications like vasoconstrictors and beta-blockers, and integrative medicine practices like acupuncture, biofeedback, meditation, and cognitive behavioral therapy are frequently part of the treatment plan. If all else fails or symptomatic improvement is insufficient, IV fluids—most commonly normal saline, which is literally salt water—can be an effective therapy. Due to the need for repeated vascular access, however, IV fluids can result in numerous complications, including infection and thrombosis. Given the heightened attention to COVID-19 Induced POTS, the hope is that the research being conducted around the world will lead to new and more targeted therapies.

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<sup>16</sup> Mallick et al., "COVID-19 Induced."

<sup>17</sup> Lauren Stiles and Jeffery R. Boris to Providers, n.d., accessed April 28, 2023, <https://www.dysautonomiainternational.org/pdf/ICDProviderLetter.pdf>.

My POTS was pretty severe. Without a doubt, the worst symptom for me was brain fog because I suddenly struggled to read or do schoolwork. I went from being a straight-A student at Georgetown Day School (GDS) to just seeing words and numbers on a page that were devoid of meaning. Things were so bad I essentially missed my entire junior year of high school. Thankfully, medication, physical therapy, hydration, and increased salt did help me. I improved enough to return to a full class load but opted to take a gap year to continue stabilizing my health before matriculating to Scripps in Fall 2017.



Image 1: My parents and I were featured on Scripps' Facebook page for Move-In Day.

Scripps' motto is "Incipit Vita Nova," which translates to "Here begins new life." It truly felt like I was getting a reset after such a rocky path through high school. Unfortunately, I was yanked out of my "new life" by my rapidly deteriorating health just six weeks into my first semester. At first, it felt like a frustrating reminder of a struggle my parents and I thought we had

under control thanks to medication and physical therapy. But as I continued to get progressively more malnourished and dangerously dehydrated, it became evident I needed more specialized care. My “new life” at Scripps was starting to feel familiar and not in the way I wanted. What I had thought was going to be a one or two-night stint at Children's Hospital Los Angeles (CHLA) turned into a full month of testing, experimentation, and a panoply of medications.



Image 2: Blondie, one of the approximately 125 CHLA therapy dogs, came dressed as a spider for Halloween and kept me company while I was on bed rest for invasive GI testing.

While the admission was, of course, stressful, the support I got from friends across the 5Cs, professors, and Scripps’ administration was unparalleled. Danny Shapiro, the previous rabbi for Hillel—an organization that helps build Jewish communities on college campuses around the globe—ferried my friends to and from Claremont on numerous occasions, so they could visit me. (He was also the person who drove me to the ER initially and hauled three little red wagons worth of books, games, and other stuff I acquired during my month at CHLA back to campus upon discharge.) The wonderful dean in charge of accommodations, Julie Loppacher—who has



also since left Scripps—brought me clean clothes and textbooks. Professors emailed and called me to check in and assured me that we would figure out how to get me caught up. Even former Dean of Students, Charlotte Johnson, whom I'd never met or spoken to, called me and offered to have In-N-Out sent to me. I politely declined the offer and explained that I was admitted because my GI tract was failing. The next day, my nurse walked in and said I had a card and that I could also go see a plant that Dean Johnson sent at the hospital's front desk. CHLA has a ban on all forms of live vegetation, so Dean Johnson's sweet gesture was also discarded. But it was a true "It's the thought that matters" type of situation. My parents were floored by the support the College provided, not only me, but them. Julie would often call my parents after visiting me just to let them know I was doing okay. When my mom recounted the extent of Scripps' support, she would always say something along the lines of "Molly is truly not a number at Scripps. She'd only been a student on campus for six weeks, but the College bent over backward to help her."

Despite the love from Scripps, the team at CHLA determined that it would be best for me to return to my "old life" temporarily. I needed a surgical feeding tube inserted into my abdomen as the feeding tube dangling from my nose was rife with complications. CHLA felt it would be safest for me to have the surgery back in DC at Children's National with the team who had treated me for years. Julie arranged for me to leave my belongings in my dorm since the plan was for me to return for the spring semester. While it was, of course, disappointing not to be able to finish the fall semester, I was already focused on the next semester and proceeded to register for courses the same day I returned home. Because I was medically stable enough to fly commercially, I was sent in a cab from CHLA to LAX, put on a red-eye back to DC, where my parents picked me up, and was driven straight to Children's National Hospital to be directly admitted. I didn't even get the opportunity to stop at home and say hi to our dog because we

couldn't risk my bed assignment being given away to another patient. After I settled into my room on the GI floor and met the residents and attendings assigned to my case, they immediately put the kibosh on my return to Scripps for Spring 2018.

It's not uncommon in academic medical centers for "the plan" to change an absurd number of times in a matter of moments. Whether it be something small like the infectious disease team ordering another blood test or something major like being an emergent OR case, I've learned to adopt the catchphrase "I'll believe it when I see it." As a result of spending so many of my formative years in and out of hospitals, I've become jaded. I'm not jaded in all aspects of life, but tempered expectations are a survival mechanism in hospital world—a survival mechanism also employed by many of my incarcerated peers. It's much harder to be disappointed or surprised when things don't go as anticipated when you come to expect everything to be botched. For my inside peers, being jaded helps them cope with a wide variety of things that accompany incarceration, such as not getting released from prison when they're supposed to.

Although I wouldn't "believe it until I [saw]" a feeding tube sticking out of my abdomen, I still sobbed when the hospitalist<sup>18</sup> reaffirmed that not only was I going to be stuck with a nasal tube indefinitely and not be allowed to return to Scripps for Spring 2018, but also that CNH wanted to transfer me to one of two programs: the feeding disorders program at Kennedy Krieger Institute (KKI), a pediatric rehab hospital connected with Johns Hopkins Hospital in Baltimore, MD or Cumberland Hospital for Children and Adolescents in the middle of nowhere Virginia. The latter is a deceptive name, given that a quick Google search reveals it is not a typical free-

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<sup>18</sup> A hospitalist is like a primary care provider, but for inpatients. Their job is to think overall about the treatment plan and coordinate communication amongst the various specialists. They have the power to make your stay hell or decent. There is no such thing as a good hospitalization.

standing children's hospital, but instead a locked psychiatric hospital with a unit for (I kid you not) *medically non-compliant* kids who need someone to force them to take their medications and do their treatments. I did not want to go to either institution, but despite being 19,<sup>19</sup> I didn't really have a choice to not go somewhere. The last thing I needed was for them to have any sliver of "proof" that I was medically non-compliant. Given that Cumberland was a locked psych hospital and further from DC, I opted for what seemed like the lesser of two evils, KKI. My parents were told that KKI had experience weaning patients' tube feeds and that they would be able to get me eating and drinking 100% by mouth. While my parents didn't love the idea of me having to be in the hospital again, they felt it was a worthy trade-off. They kept saying, "You'll be able to go back and eat whatever you want of that delicious Scripps food without getting sick." I was skeptical that any program could magically cure me and having done the Mayo Clinic's Pediatric Pain Rehabilitation Center six months earlier, insurance was skeptical as well.

Much to my dismay, our insurance plan did end up covering my admission to KKI. What was initially estimated to be a four-week admission ended up being 10 full weeks of being held hostage at KKI. It's honestly a miracle that I didn't develop medical PTSD as a result of my time there. The feeding therapists immediately questioned why and how they were expected to get me off the tube feeds. Unlike the rest of the patients there, I was not under the age of nine; I wasn't on the autism spectrum, nor did I have problems eating certain colors and textures. I had a broken digestive system and they could see that. Yet, the hospitalist and behavioral psychologist

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<sup>19</sup> In case you are wondering why I went to a children's hospital at 19, it's because the age cutoff varies amongst hospitals, departments, individual doctors, and whether one needs inpatient or outpatient care. KKI will admit up to age 21, while Cumberland admits *through* age 21. In general, Children's National admits until one's 22<sup>nd</sup> birthday and its outpatient cutoffs vary widely. Some providers like my geneticist will see me for life. It's not uncommon with rare conditions to have a combination of pediatric and adult providers, since it can be difficult to find adult providers with training and/or experience managing diseases that typically originate in infancy, childhood, and adolescence.

kept insisting if I stuck with the program, I'd be fixed. So, three times a day for an hour, I sat in a tiny square room at a preschool-height table and was forced to eat bites of lukewarm hospital food. Despite this being a *pediatric* hospital, it looked and was run like solitary confinement in a prison. Some of the rooms had padded floors and walls as the little kids with autism would frequently have violent outbursts when given foods they didn't consider "safe." Other rooms had one-way mirrors, so parents could watch the feeding therapists working with their children. All of the rooms were windowless and had a deadbolt at the top of the door—as opposed to the normal position by the doorknob—to prevent the kids from running away. Every single bite was recorded and coded by a behavior data specialist so that they could have an objective measure of improvement. The problem was I wasn't getting better—at all. In fact, I had gotten objectively worse.

I also had another problem on the other side of the country. Scripps had over-enrolled the class entering in Fall 2017 and Residential Life now desperately needed my room to be emptied out for use by another student. We asked a couple of friends from the LA area if they would do us the enormous favor of packing up my room and putting my items into a storage pod. They agreed and we set a time. So, I sat trapped at KKI directing my friends as to what items should go where over FaceTime. I'm not going to lie. It's kind of weird having people (even people you trust) going through all your stuff. It's one thing for people to dig through your belongings when you're either dead or otherwise occupied. It's another to just watch people going through your stuff while you can't touch anything yourself. Having this odd experience really helps me empathize with my incarcerated classmates who are subjected to this kind of search at a moment's notice. For me, it was awkward but necessary. My items were handled with care by friends who mailed me the things that I needed from my room. Not only is this level of care and

respect not shown towards my incarcerated peers, but destruction or seizure of property is common even if the item in question is perfectly acceptable. For example, one of my classmates had his copy of our class' coursepack shredded by a corrections officer (CO) for no reason other than the fact he could. My classmate never got a new packet and had to borrow others' coursepacks for the rest of the semester.

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After a month of experimenting and only causing more problems like severe dehydration and nearly perforating my bowel by running my tube feeds at an extremely dangerous rate, Kennedy Krieger finally admitted they had no clue what they were doing with me. (I knew from my first night trapped at KKI that a place even remotely qualified to wean, let alone just run tube feeds, would not have overdosed me on formula to the point of projectile vomiting and would not have then proceeded to underdose me for the following three nights despite my numerous attempts to alert the team.) The KKI team agreed to stop wasting both the feeding therapists' and my time. I was off the hook for my thrice daily stint in solitary confinement—er, I mean feeding therapy sessions. That said, they had no alternative plan to get me home. They were still convinced there was something that could be done to “fix” me.

Our good family friend had told my mom, if we ever needed help with getting in with a specialist at Hopkins, she could help us. One of this woman's close friends is an executive assistant for Michael Bloomberg at Bloomberg Philanthropies. As of May 2021, Bloomberg has donated an astounding \$3.55 billion to his alma mater, Johns Hopkins—more money than any philanthropist has ever given to an institution of higher education in the US.<sup>20</sup> His presence is

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<sup>20</sup> Susan Adams, "Bloomberg Adds To \$3 Billion In Johns Hopkins Gifts: \$150 Million To Boost Doctoral Student Diversity," *Forbes*, May 12, 2021, accessed April 21, 2023,

everywhere at Hopkins. From the state-of-the-art pediatric inpatient tower named The Charlotte R. Bloomberg Children's Center (after his mother) to having the University change the name of one of the graduate schools to be the Johns Hopkins Bloomberg School of Public Health, the place is practically a shrine to Bloomberg's generosity. So, when Bloomberg (or, more accurately, his "people") call Hopkins, the impossible becomes possible almost instantaneously. And I needed the impossible. ASAP. Within a matter of days, my chart had been handed to Dr. Jay Pasricha. A prized possession of Hopkins, whom they just lost to the Mayo Clinic's Arizona campus in Fall 2022, Dr. Pasricha founded the sub-speciality of neurogastroenterology.

Neurogastroenterology focuses on the brain-gut axis; in other words, it examines the relationship between the nervous system and the digestive system. Dr. Pasricha's theory is that if he can correct a problem in the nervous system, he can improve his patients' motility disorders. Motility disorders such as gastroparesis (delayed stomach emptying), chronic intestinal pseudo-obstruction (the small bowel acting as if there is a mechanical bowel obstruction when none exists), and colonic inertia (delayed transit of waste throughout the large bowel, a.k.a. the colon) are notoriously difficult to treat. There's a wide spectrum of severity. Some patients can control symptoms with simple diet changes or medications. More severe patients may require surgical options like gastric pacemakers (literally a pacemaker for the stomach, rather than the heart), or pyloroplasty (where the pylorus is opened up to help food empty from the stomach into the small bowel faster), and/or nutritional support from tube feeds. For those who cannot tolerate tube feeds, they may be placed on total parenteral nutrition (TPN), which is IV nutrition that bypasses the GI tract entirely. TPN comes with extraordinary risks like sepsis from the central line (a

permanent IV needed to infuse TPN) and possibly developing liver failure from the lipids (IV fats). At the most extreme end, for patients who cannot tolerate TPN, develop liver failure, have recurrent sepsis, and/or develop blood clots that cause them to lose precious vascular access needed for their central line to function, multivisceral transplant (some combination of abdominal organs including the liver), modified multivisceral transplant (some combination of organs except the liver), and isolated small bowel transplants may be an option. The point is the stakes are very high and life-threatening by the time one gets referred to Dr. Pasricha. Because he is so focused on his numerous research endeavors, Dr. Pasricha only had one half-day a week of clinic. So as powerful as Bloomberg is, it was ultimately up to Dr. Pasricha as to whether or not he would take me on as a patient. He could easily have said no. In fact, he's at that level of doctor fame where he didn't even need to say no. He could simply ignore the request.

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As I sat in Kennedy Krieger's playroom about to crush my recreational therapist at yet another board game, we got a call from the nurses' station saying I needed to come back to the floor immediately. None of my friends nor my parents had texted to say they were coming to visit, so I was a bit confused as to who it could be. I unplugged my IV pole and headed right up to find one of Dr. Pasricha's fellows (a doctor who has completed residency but works under an attending to specialize in a specific area) waiting for me. She explained she was there to get an overview of my history that she would then summarize for Dr. Pasricha. We talked for over an hour and the next day she and Dr. Pasricha left the gorgeous Bloomberg-funded mecca that is Hopkins and walked through the sketchy underground tunnel to KKI, also known as "Hopkins' Ugly Step-Child."

Dr. Pasricha entered my room and the first thing he said was, “Come here. Let me give you a therapeutic Dr. Pasricha hug. Anyone who gets to the point of seeing me has been through a LOT.” While I’d received hugs from other providers, it was never a first appointment type thing—let alone the first interaction. I was both shocked and relieved. FINALLY. Someone believed I had severe GI problems and not a feeding disorder like the three-year-old patient down the hall who had autism and got 100% of his calories from 30 strips of bacon every day. FINALLY. Someone had a plan that seemed like it was worth a shot. Part of my shock was the fact that this doctor, who was spoken about and treated as if he was the Wizard (as in the *Wizard of Oz*), was seemingly down to earth. Despite his numerous patents and NIH-funded research, he could explain things in a less jargon-laden fashion, although he did tend to mumble in a stereotypical scientific genius fashion.

Dr. Pasricha pulled up a rickety old chair (like all of KKI’s furniture) and exclaimed that not only had he never been to KKI, he’d never even heard of the place despite being just a creepy tunnel away from the Temple of Bloomberg. Dr. Pasricha explained that he was going to order a boatload of tests—some new, some I’d done before. From 30-plus tubes of blood work to more extensive motility testing, to a skin biopsy, to GI biopsies, he left no stone unturned. He explained that I definitely did not have a feeding disorder and, instead, I had a constellation of problems that he referred to as JAG-A. ‘J’ for joint hypermobility, which I have as a result of a connective tissue disorder called hypermobile Ehlers-Danlos Syndrome (hEDS or formerly EDS Type III). The first ‘A’ for autonomic dysfunction, which I have had since I was diagnosed with POTS in high school. ‘G’ for gastrointestinal dysmotility, which CHLA had diagnosed. No one knows why he threw the hyphen in there, but the final ‘A’ stands for autoimmunity. While I’d previously been tested for autoimmune conditions, I was never formally diagnosed. Some of the



testing Dr. Pasricha ordered indicated that I have some sort of autoimmune issue, albeit ill-defined. My GI testing also revealed that my motility had objectively gotten worse than it was just three months earlier when I had been tested at CHLA.

The results of the extensive workup qualified me for Dr. Pasricha's trial examining the efficacy of IVIG as a treatment for autoimmune gastrointestinal dysmotility (AGID). IVIG, which stands for intravenous immunoglobulin, is a type of medication made up of healthy antibodies from donors. It's extraordinarily expensive at about \$40,000 a month out-of-pocket. While its use for the treatment of certain autoimmune conditions like Common Variable Immunodeficiency (CVID) and Juvenile Dermatomyositis (JDM) is well-established, its use for AGID is still quite experimental. When I participated in Dr. Pasricha's trial in 2018, the only other study that had used IVIG for AGID patients had been completed on 23 subjects at the Mayo Clinic between 2006 and 2014.<sup>21</sup> My pediatrician was thrilled when I reported that Dr. Pasricha was going to give me four cycles of high-dose IVIG. She had recently read Susannah Cahalan's *New York Times* best-selling autobiography, *Brain on Fire: My Month of Madness*, and said to me, "This is your Dr. Najjar. I've always felt like we were missing \*something\* and I think this is that missing piece to the medical puzzle that is you." For the first time, we had hope that we were actually going to treat the underlying disease rather than just throwing medications at me and hoping that they might do something.

Unfortunately, IVIG is known for causing a myriad of unpleasant symptoms as the body adjusts to foreign antibodies. That said, the potential benefits of IVIG far outweighed the potential side effects—or so we thought. While Susannah Cahalan's life was saved by IVIG, I

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<sup>21</sup> E. P. Flanagan et al., "Immunotherapy Trial as Diagnostic Test in Evaluating Patients with Presumed Autoimmune Gastrointestinal Dysmotility," *Neurogastroenterology & Motility* 26, no. 9 (July 20, 2014): 1, accessed April 21, 2023, <https://doi.org/10.1111%2Fnm.12391>.

nearly lost my life to IVIG. Although I tolerated the first two rounds relatively well, rounds three and four were disastrous. From less concerning symptoms like severe headaches and nausea to aseptic meningitis (meningitis without a bacterial cause), hemolytic anemia (in which the body destroys red blood cells), and liver failure, with each passing infusion, I became less and less of a fan of what was supposed to be my miracle cure. My liver enzymes became so dangerously high that I began going through the process of being listed for a liver transplant as a status 1A which is reserved for patients with “acute (sudden and severe onset) liver failure and are not likely to live more than a few days without a transplant.”<sup>22</sup>

Except, it wasn't Dr. Pasricha helping my parents and me navigate the terrifying reality of being critically ill. No, it was Dr. Sukanya Subramanian, a small bowel transplant and motility specialist at MedStar Georgetown University Hospital. The unfortunate reality of Dr. Pasricha being so researched-focused is that he does not actually manage his patients. He thinks of himself as a “consultant,” which seems contradictory to our initial interaction and therapeutic hug. Because Dr. Subramanian was not involved in my foray into IVIG, she repeatedly called Dr. Pasricha's assistant in an effort to speak to him about my dire situation. She was told he was unreachable because he was in India visiting family, but she insisted that there must be a way to get ahold of him. Eventually, her persistence paid off and he returned her call. Not only was Dr. Pasricha not in India, he was actually in Colorado at a ski resort because he'd stuck around after attending a conference. I was flabbergasted. Here I was sicker than I'd been in my entire life and

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<sup>22</sup> Health Resources and Services Administration and U.S. Department of Health & Human Services, "Questions and answers about liver allocation," Organ Procurement & Transplantation Network, accessed April 26, 2023, <https://optn.transplant.hrsa.gov/patients/by-organ/liver/questions-and-answers-about-liver-allocation/#:~:text=Status%201A%20patients%20have%20acute,1B%20at%20any%20one%20time.>

he was having his assistant LIE to another medical professional who had inadvertently been tasked with cleaning up his mess.

I later found out Dr. Pasricha was willing to lie about other things as well. After failing IVIG, Dr. Pasricha introduced my parents and me to one of his colleagues Dr. Glenn Treisman, a psychopharmacologist who uncannily looks and acts like the pediatric psychiatrist Dr. Iggy Frome on NBC's *New Amsterdam*. Dr. Treisman is the head of Hopkins' inpatient Pain Treatment Program. Not only was I unwilling to endure yet another pain program, this one was and still is housed with the geriatric psychiatry unit at Hopkins. Yep. Literally "crazy old people." And because of its location, the program billed insurance via a patient's mental health rather than medical benefits. (Typically, mental health benefits are less generous than medical benefits, which is just a holdover from the belief that mental health problems are somehow less real than physical health problems.) Its home in the geriatric psych unit also meant the Pain Treatment Program had all the rules of a typical psych ward, like no contraband, restricted movement, and limited access to technology. It was going to be even more carceral than KKI. At least at KKI, I could call and text my parents whenever; I could have whatever items I wanted and I had unlimited access to crafts and board games.

Dr. Pasricha announced that he knew what I had. I braced myself.

"I think you have ARFID."

And there it was. ARFID stands for avoidant restrictive food intake disorder. It's a type of feeding disorder. It's the feeding disorder that KKI treated me as if I had. It's the diagnosis Dr. Pasricha had explicitly said I did not have just a few months earlier. I straight out rejected his new proclamation.

“I’m not anxious about eating. It’s impossible to have ARFID when you don’t get anxious about the food. My GI tract doesn’t work. The repeat testing you did showed that my gut got even worse after the IVIG trial.”

He conceded and then said, “Well, in order to admit you, we’d need to come up with a psychiatric diagnosis to get insurance to cover it.” This is what’s called **insurance fraud**. Not only is it insurance fraud, but it’s also damaging. If he threw into my medical records a diagnosis of schizophrenia, it would come back to haunt me for the rest of my life. Getting doctors to take you seriously is already difficult enough as a young female. Give them a psychiatric diagnosis like that and you can kiss medical treatment goodbye. There was also no plan. I was going to just be a guinea pig indefinitely. Once again, my parents were encouraging me to go along with his plan. They thought we had no other options. The déjà vu was overwhelming; this was how I ended up at KKI. But it was Dr. Subramanian who convinced my parents that admitting me to Hopkins was unequivocally a terrible idea. In retrospect, my parents realize how damaging it would have been for me to have a fake mental health diagnosis slapped onto my chart.

We’ve since discovered that there’s nothing we could have done to prevent my health from falling off a (metaphorical) cliff. I have some sort of mitochondrial dysfunction that has not been described in medical literature. That could change as access to genetic testing becomes more common and it’s possible someone else will have the same mutation(s) and presentation as me. If/when that happens, the mutation(s) would no longer be classified as variants of unknown significance or benign and instead be considered pathogenic. But for now—as my dad often teases—I’m “a special snowflake.”

The most basic scientific definition of that mitochondria is that they are the powerhouse of the cell. Dr. Richard Boles, a pediatric geneticist who specializes in mito, explained to my

parents and me that the average person is like a healthy cell phone battery. That “battery” can charge to 100% and depletes at an appropriate rate. People with mitochondrial dysfunction have defective cell phone batteries. For me specifically, the test results showed that the max I can charge to is 70%. The battery also gets depleted faster than it should. As a result, when I get sick or even just overexert myself by going about my day, I can have what’s called a “mito crash.” Not only do my various organ systems start going haywire, but I take an incredibly long time to get back to my baseline. Dr. Boles is hoping to find more targeted treatments based on my specific genetic mutations. So, even though we don’t have all the answers, it’s been both comforting and validating to know that all my rare and seemingly unrelated health conditions are actually explained by mitochondrial dysfunction. I finally have my “unifying diagnosis.”

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As I hopped off the exam table at CNH in March of 2020, Liz handed me two pieces of paper: a refill on my pain medication and a note clearing me to “return” to Scripps. It seemed funny to me to need formal clearance to sit at my computer and do school. I’d actually done some classes online during my senior year of high school, so I knew what I was getting myself into to some degree. But just like in-person education, all online education is not created equal.

A newly released systemic review and meta-analysis in *Nature Human Behavior* on education during the pandemic supports the anecdotes about learning deficits swirling amongst educators. The study estimates that students lost out on approximately 35% of the learning completed in a typical school year. While the learning deficits did not get *worse* throughout the pandemic, they have not been rectified. The study notes that socioeconomic status played a significant role in the amount of “learning loss” that occurred. Sadly, but also unsurprisingly, lower-income students had significantly more learning loss than their peers with more financial

privilege. Another key finding was that math skills were hit harder than reading skills. The researchers hypothesize this achievement gap was, in part, a result of parents being more capable of helping kids with language arts than with STEM. They explain STEM requires far more specialized knowledge in order for parents or other adults to assist with assignments. Individual tutoring and small group instruction, along with increasing opportunities for learning during the summer, were proposed as possible mediators to get students back on track. Unfortunately, the lack of funding and chronic staffing shortages in schools across America drastically reduce the availability of extra academic support many students so desperately need to catch up and keep up.<sup>23</sup>

Most of the formal research about learning deficits has been focused on K-12, but a 2021 study in the journal *CBE—Life Sciences Education* found that disabled undergraduates frequently had difficulty receiving accommodations and/or having them implemented correctly during virtual learning. The researchers observed that many students were left to fend for themselves as disability resource centers were overwhelmed and unsure of how to provide accommodations from a distance. The study found that, in general, remote STEM courses presented extra challenges for disabled students because of a lack of access to reduced-distraction testing environments (I would argue that students were taking tests in *extra* distracting testing environments as many were living at home with a cacophony of bickering siblings and barking dogs), lack of note-taking services, lack of access to tutoring and on-campus resources like drop-in hours for homework help, snafus with extended time on exams, reduced

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<sup>23</sup> Eden David, "COVID-19 may have impacted our children's learning progress in school: Where do we go from here?," ABC News, accessed February 13, 2023, <https://abcnews.go.com/Health/covid-19-impacted-childrens-learning-progress-school/story?id=96763525>.

access to course materials and information, and inaccessible video lectures (i.e., lack of captions and/or ability to ask for clarification on the spot).<sup>24</sup>

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During my blissful first six weeks of college in 2017, I had been enrolled in Professor Mary Hatcher-Skeers' general chemistry class—colloquially referred to by its course code, Chem 14. Like many first years, I was (and still am) interested in going to medical school. While the course was challenging and unbelievably time-consuming, I was doing well. Because so many first years take chemistry, I made friends both in my section and in other sections. We would do homework together and scratch our heads at pre-lab quizzes on Sakai (a primitive version of Canvas).

None of that was true when I re-enrolled in Mary's class virtually in Fall 2020. I have the unique perspective of being enrolled in the exact same course with the exact same professor and having a wildly different experience—not for the better. In an effort to try to make virtual classes more interactive, the W.M. Keck Science Department<sup>25</sup> decided to make its classes “flipped.” This meant lectures were pre-recorded videos (paying attention to lectures on Zoom was hard enough, but pre-recorded Zoom lectures were unbearable) and class time was instead spent in breakout rooms doing practice problems. The whole class would reconvene at the end of the period and as long as just one person in a breakout room could provide the correct answer to the assigned problems, nothing ensured that all members of a breakout room understood the basic concepts and could solve the problems themselves. Like the authors of the study in *CBE—Life*

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<sup>24</sup> Logan E. Gin et al., "COVID-19 and Undergraduates with Disabilities: Challenges Resulting from the Rapid Transition to Online Course Delivery for Students with Disabilities in Undergraduate STEM at Large-Enrollment Institutions," *CBE—Life Sciences Education* 20, no. 3 (September 2021): accessed February 13, 2023, <https://doi.org/10.1187/cbe.21-02-0028>.

<sup>25</sup> The joint science department shared by Scripps, Pitzer, and Claremont McKenna. Although, the latter is leaving the department to form its science department.

*Sciences Education* observed, this arrangement didn't work, given that those of us with extra time as an accommodation would not get that much needed extra time in the breakout rooms to solve problems. Instead, I would often get left behind as the initials—er, I mean classmates—in my breakout room would plow ahead through problem sets and then just spoil the answers so that they could be done sooner and could revert to watching TikToks or whatever it is that initials do. I found myself keenly aware of the stark difference between my understanding of the concepts when I had taken Mary's class in-person just three years earlier versus that trying to teach myself from YouTube videos.

Although I managed to hobble through Chem 14, I was forced to drop out midway through the spring semester's Chem 15. While the study from *CBE—Life Sciences Education* notes the failures of disability resource centers in terms of implementing accommodations virtually, they are not solely to blame. STEM courses are often structured in a way that makes catching up nearly impossible. STEM classes are inherently cumulative and missing just one class is incredibly stressful since the material is being presented so quickly. Unlike the structure of humanities-based courses, in STEM, you can't skip an assignment and go back and finish any previous homework you missed. Everything needs to be completed in its intended order for the material to make sense. Additionally, because of concerns about test security, Keck issued a department-wide ban on makeup exams. While I understand their worries, I had little to no choice about dropping Chem 15 after missing the first exam (extremely low hemoglobin leading me to sleep nearly 20 hours a day) and the second exam (I was admitted at MedStar Georgetown University Hospital as a result of surgical complications).

When my parents and I found ourselves meeting with Acting Dean of the Faculty (and Keck Biology Professor) Gretchen Edwalds-Gilbert about my need to remain remote during the



2021-2022 school year, she said something along the lines of it being impossible to offer STEM courses and labs remotely for me because it was not a “reasonable accommodation” under the Americans with Disabilities Act (ADA). Having suffered through cutting up a Lucky Charms box in pursuit of creating a spectrophotometer, a device that measures colored light absorption, I was in no mood to argue with her about the global issue of inaccessibility in STEM. Additionally, because I hope to go to medical school, I recognized that I needed to truly learn the content rather than just squeak by. I decided to put STEM on the back burner for now<sup>26</sup> and declared my major in Writing and Rhetoric.

That said, my parents, my advisor and Chair of the Writing and Rhetoric Department, Professor Kimberly Drake, and I felt Scripps was being unreasonable when they initially refused to allow me to continue virtually in any of my courses during the 2021-2022 school year. The crux of our argument was that allowing me to remain remote for *certain* classes was a “reasonable accommodation” because we were not asking the college to be entirely remote. What we *were* asking for was for me to be allowed to remain a full-time student and enroll in courses with professors who had previously agreed to go above and beyond and teach hybrid or via independent study. So, after several meetings and emails were met with resistance and apologies, we brought out the big guns. We planted the possibility of suing the College for violating the ADA by refusing to provide any accommodation for me to continue remotely longer due to my risk of developing severe COVID. As soon as Scripps’ lawyer got wind of a possible ADA lawsuit, it was as if a switch flipped. Suddenly I was completely cleared to continue virtually. Funny how that happens.

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<sup>26</sup> I intend to enroll in Scripps’ Postbaccalaureate Premedical Program beginning May 2024 in order to get the prerequisites required to apply for medical school.

One of the reasons my parents and I found it particularly baffling that we had to threaten legal action for me to be granted remote classes as an accommodation was because Scripps had spent an ungodly amount of money preparing for this exact circumstance. Three traditional classrooms and nine of the outdoor classrooms at Scripps were outfitted with fancy Zoom Carts. At about 30K a pop, these things are high quality with a ceiling-mounted microphone and a display monitor/camera in both the front and back of the room, so professors and in-person students can see and hear their virtual classmates from any spot in the room. While the technology wasn't perfect, it was good enough that I truly felt like part of the class despite being on the other side of the country. I was able to participate in both whole-class and small-group discussions. Seeing as I was on two screens that made my head about 3 feet tall, it was also impossible for anyone to "forget" that I was in the class. People joked that whenever I talked in class (which is often), the surround sound made it like I was this booming voice of God.



Image 3: My view of the classroom via the Zoom Cart in the back of the room.

While technology like Zoom facilitates remote and hybrid learning, it doesn't automatically make for an enriching educational experience. Additionally, humanities courses are not inherently better suited for remote learning. A perfect example of how *not* to teach a humanities course online was exhibited by a Pitzer neuroscience professor during the summer of 2020. For three hours, three times a week for six weeks, the professor would do a PowerPoint lecture to an entire screen of black squares with initials. This situation was not a sign that all the students were uninterested; rather, the professor specifically *requested* everyone turn off their mics and cameras for the entire duration of the class. Frankly, I found it bizarre to actively discourage participation. The passivity within that class serves as a stark contrast to my Inside-Out courses—all of which have been remote or hybrid—throughout college.

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The Inside-Out Prison Exchange Program was founded at Temple University in 1997. The program describes its philosophy as being “grounded in the belief that our society is strengthened when higher education/learning is made widely accessible and, at the same time, when it allows participants to encounter each other as equals, often across profound social barriers.”<sup>27</sup> “Inside students” are incarcerated, while “outside students” are “traditional” college students who attend a college or university in the general vicinity of the prison and have classes *inside* the prison along with their incarcerated peers. Inside-Out exists to give incarcerated students a more typical classroom experience where they can actively participate in discussions, ask the professor questions in real-time, and form connections with classmates. As much as

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<sup>27</sup> Inside-Out Prison Exchange Program, "About Us," Inside-Out Prison Exchange Program, accessed April 3, 2023, <https://www.insideoutcenter.org/about-inside-out.html>.

possible, the goal of Inside-Out classes is to give inside and outside students the exact same educational experience. Same curriculum. Same assignments. Same expectations.

The Inside-Out pedagogy breaks away from the correspondence model that dominates prison education across the country. In the correspondence model, students are given the materials to learn the content and then submit assignments to a teacher via snail mail (or occasionally via a stripped-down version of Canvas).<sup>28</sup> There is no discussion whatsoever nor opportunities to create a community of scholars in the correspondence model. Additionally, teaching oneself is hard and in prison getting anything done takes ten times longer than in the “regular” world. Not only does it take a very long time for inside students to have their questions forwarded to the teacher, but a timely response—or any kind of response—is not guaranteed. Additionally, items get lost or destroyed with some regularity in prisons. Although my inside peers can’t use the classic “My dog ate my homework” excuse, they can use—and I have seen them use—the “The corrections officer shredded my coursepack” excuse, unfortunately, with justification.

Back in 2014, the Claremont Colleges began offering a handful of Inside-Out courses at the California Rehabilitation Center (CRC), a medium-security men’s prison in Norco, California.<sup>29</sup> Thanks to a \$1.1 million grant from the Andrew W. Mellon Foundation, the Justice Education Initiative (JEI) at the Claremont Colleges was founded in 2018 “[t]o confront mass incarceration as a defining social problem of the contemporary era.”<sup>30</sup> Each week, professors and

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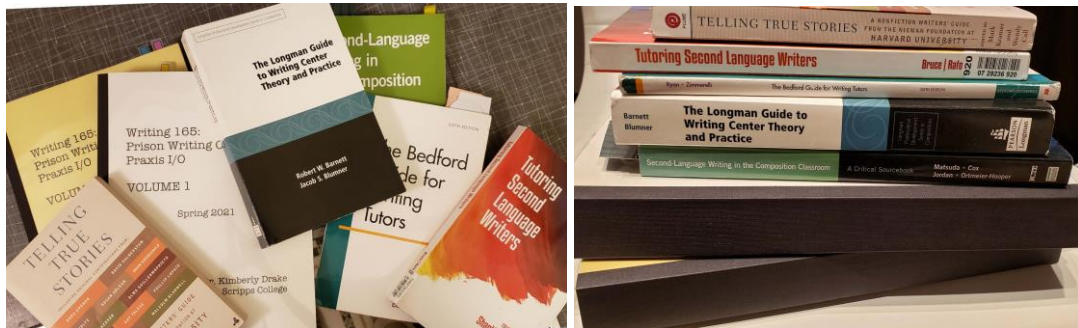
<sup>28</sup> It’s as dull as it sounds. Having done some online courses this way, I can attest to the fact that it makes you feel like you’re just doing busy work.

<sup>29</sup> Dickson, “Academic Spotlight,” *Office of Communications* (blog).

<sup>30</sup> Justice Education at the Claremont Colleges, “Our Mission,” Justice Education at the Claremont Colleges, accessed April 27, 2023, <https://colleges.claremont.edu/justice-education/our-story/aboutus/>.

students from the 5Cs piled into buses and made the 45-minute trek out to CRC for class. That all came to a screeching halt when the world went into lockdown due to COVID-19.

Unlike most prison education programs that switched to a correspondence model during the pandemic, JEI was determined to continue to give inside students equal access to classes. In particular, the lead dean and faculty liaison for JEI, Nigel Boyle, was adamant about coming up with a solution since Spring 2021 was the first semester of the Pitzer Inside-Out Pathway-to-BA program. While other prison education programs, such as the Bard Prison Initiative—part of Bard College in Upstate, New York—offer bachelor’s degrees to incarcerated persons, the Pitzer program is the first BA program that is based on the Inside-Out model. But, unlike us outside students, it was far more complicated for inside students to pivot to remote learning given their lack of access to both technology and the internet. By some miracle, JEI was able to convince the California Department of Corrections (CDCR) to allow the program to install Zoom Carts in two of CRC’s classrooms for Spring 2021. Inside students were also given laptops—albeit primitive and highly restricted ones. For example, PDFs are blocked on their laptops because CDCR doesn’t seem to understand that scans of books fall under the fair use exception for educational purposes. The ban on PDFs resulted in a 1200-page two-volume coursepack for Kim’s Writing 165: Prison Writing Center Praxis in Spring 2021.



Images 4 and 5: The two-volume 1200-page coursepack and other required texts for Writing 165: Prison Writing Center Praxis.

Writing 165 represents the first course in a series working towards establishing a writing center within CRC. While writing centers in prison are rare, the ones that do exist typically rely on outside tutors like volunteer professors or local college and university students. This staffing model creates a dynamic that's antithetical to Inside-Out. It implies that the inside students are less than and need saving by "experts." In contrast, Writing 165 includes both the pedagogy of tutoring writing, along with offering students the chance to practice tutoring, hence the reason the course title includes the word "praxis." One of my inside classmates, Damian,<sup>31</sup> is a perfect example of why a writing center run by and for inside students is not only feasible but desirable.

Damian has been incarcerated almost my entire life.<sup>32</sup> He writes that "[he] was watching TV, and the jail showed the movie *Good Will Hunting*. [He] was overcome with the concept that mathematics could be a gateway to another life for a guy like [him]."<sup>33</sup> Back in 1999, there was no education in prison; but that situation was not going to stop Damian's quest for knowledge. He began requesting that the prison library order him math and physics textbooks and then proceeded to teach himself. Eventually, he was able to start taking college classes and over his 23-ish years of incarceration, Damian earned countless certificates and an astonishing SIX associates degrees in General Studies, Business Administration, and Social and Behavioral Science at Coastline College, along with Math and Science, Liberal Arts, and Business Management at Palo Verde College.<sup>34</sup> While earning his own degrees, Damian also tutored incarcerated men working on GEDs for fun. Tutoring brought him joy.

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<sup>31</sup> Inside-Out runs on a first name basis for the privacy of all involved parties. Damian was recently released from CRC and consented for his real first name and details about his life to be used in this project. Even though Damian is on parole, I have still redacted his last name.

<sup>32</sup> Inside-Out prohibits the discussion of inside students' alleged crimes, which is why I do not cover them at all in this project. The thinking is that such information distracts from not only the course content, but the emphasis on equality between inside and outside students.

<sup>33</sup> Damian [Redacted], "Hullo," e-mail message to author, February 24, 2023.

<sup>34</sup> Damian [Redacted], "Resume for San Diego State Pell Coordinator," last modified February 26, 2023, .docx.

Then in December 2020, Damian was selected to be a member of the inaugural cohort of the Inside-Out Pathway-to-BA. At the program's launch event, Damian said, "My cohort and I have been blessed with the outstanding opportunity to obtain what I thought was impossible—a bachelor's degree behind bars." Unbeknownst to me at the time, I had actually echoed Damian's statement when my parents, Kim, and I were appealing Scripps' ban on remote learning beginning in Fall 2021. I stated, "none of us could have ever imagined a global pandemic would have been my ticket back to Scripps. [B]eing able to continue my education has been such a blessing in this apocalyptic time."<sup>35</sup>

Having done so much schooling while incarcerated, Damian then went on to praise the Inside-Out model in contrast to the correspondence model by explaining, "We can interact with the professors and the students and in doing so, we are given a sense of self-worth and humanity."<sup>36</sup> I could have chosen to feature any number of my inside peers to offer a glimpse into the power of Inside-Out, but Damian and I have a special connection and I think these quotes help exemplify why. Despite our 30-year age gap, Damian and I have found solace in academia. School has been an escape from our respective situations. For three hours a week, it feels like we're transported into some sort of liminal space. A space in which we are classmates—not a prisoner and a patient.

I've done countless classes while attending to my health. From Zooming while stuck at O'Hare International Airport while traveling for a second opinion at the Mayo Clinic to waiting in the ER to head to the operating room, to joining in while getting blood transfusions, and even to being septic, I've shown up with my camera on and ready to learn. I'm not trying to be a

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<sup>35</sup> Molly Yeselson, "Urgent Meeting?," e-mail message to Amy Marcus-Newhall and Gretchen Edwalds-Gilbert, August 25, 2021.

<sup>36</sup> Dickson, "Academic Spotlight," *Office of Communications* (blog).

martyr and there are, of course, times that I've missed class, but my logic is, if Zoom is there, I might as well log in because I'm going to be sick either way. Even though it can be challenging to hear and/or determine who is talking during my Inside-Out classes, as all the inside students are crammed together in Ms. Alana Noyes' (a member of the prison's education staff) classroom within CRC, everyone pays full attention. Inside students don't have the ability to turn the camera off. They want to be fully present. We owe it to one another to be fully present.

Despite returning to Scripps in-person for my senior year, my health conditions require me to be connected to not one but two IV pumps 24 hours a day. As a result, it is logistically impossible for me to actually go inside CRC. Thus, I actually still take my Inside-Out courses via Zoom. Keeping Zoom as an option is beneficial, not just for me. As more and more cohort members get released from CRC while still a few credits short of graduation at Pitzer, they avoid being cut off from all of their classes by finishing up on Zoom. And even though Damian graduated from Pitzer in December 2021 with a bachelor's degree in organizational studies, he still attends Kim's Inside-Out class every single week. Not only does he enjoy doing the readings and discussing them, but joining that class is how he sees his friends. Normally when someone is released from prison, they do not have the ability to check in on their friends "face-to-face." CRC recognizes this as a potential loophole for illicit communication and has been trying to clamp down on the presence of Zoom for Inside-Out classes. They're not alone in this push to return to the days of yore.

COVID is "over" in the minds of most Americans. (That is, if they believed in COVID from the beginning.) From dropping mask mandates in healthcare settings to removing remote and hybrid schooling to forcing employees back into the office and to the impending end of the federal COVID-19 Public Health Emergency on May 11, 2023, it's clear we are no longer in a



state of crisis. That said, for people like me who are at high risk of developing severe COVID, the threat is not gone. I have no clue if there's another variant lurking in the shadows. My Mickey Mouse mask is here to stay. But why is Zoom not here to stay? I've never once said in this project that Zoom is superior. It's filled with annoying glitches. It's frustrating when the sound drops out or when the spotty connection in CRC goes down entirely. But it is better than nothing. For years, I watched my classmates from high school moving on with their lives and gaining independence while my life revolved around appointments, tests, procedures, and an increasing dependence on the American healthcare system (flawed as it may be).

Zoom is why I am just two weeks shy of graduating with a bachelor's degree in Writing and Rhetoric from Scripps College. Zoom is why Damian and all my inside peers have/are on their way to graduating from Pitzer College with degrees in Organizational Studies. Would I have preferred to be on campus for my entire college career? Of course. Would my inside peers prefer to be on campus rather than incarcerated? Obviously. But that's life. It's not perfect. It's messy. It's unpredictable. It's filled with challenges.

Why can't we retain some of those lessons learned the hard way from the pandemic? Given that institutions of higher education, including Pitzer and Scripps, tout their diversity, equity, and inclusion initiatives, doing things like eliminating outdoor classrooms and removing Zoom Carts is blatantly hypocritical. We don't have to remain close friends with COVID, but like any relationship, there's always something that can be learned and carried forward—even if circumstances require that learning to occur remotely.

### Afterword

As I sit by the gorgeous Scripps pool writing the culminating project of my undergraduate education, I can't help but feel nostalgic for the college career I expected to have but was rudely destroyed by my health—or, more accurately, lack thereof. When people find out how I managed to get through college, they tend to question my sanity. Why would I go across the country when I could walk down the street and attend Georgetown for free? (I answered that question in the project itself, so if you skimmed that section, scroll back up.) But the other question is, why did I want to return to Scripps virtually? The truth is that I have no clue if I would have ever “returned” to my dream school had there not been—what I seriously hope is—a once-in-a-lifetime global pandemic. Perhaps, Scripps would have perpetually remained a dream. A green light, if you will. So, as soon as Liz planted the idea of COVID being my friend, I ran with it.

Truth be told, one of the main reasons I enrolled in Kim's Writing 175: Social Action Writing and Rhetoric during the one and only Scripps summer session in 2020 was because I was trying to knock out a GE. I'd actually been in Kim's Core I (Scripps' three-semester interdisciplinary humanities sequence) during my brief stint at Scripps in Fall 2017. I knew she was a great professor, but I never intended to devote my college career to Writing and Rhetoric. The major didn't even exist when I matriculated. But as you read, my plan to major in one of the sciences through Keck flew out the window and for that change of plan, I'm genuinely grateful.

The primary motivation behind my project is to question the narrative of remote learning as a sort of distorted form of education that must be annihilated as soon as possible. While there have been articles here and there about the benefits of remote education, the focus tends to be on K-12 education still. The minuscule existing body of literature about the benefits of remote

education in college tends to be based on generalizations as opposed to following the specific journey of a real-life disabled college student who benefited from remote learning. The August 2021 article “For Some College Students, Remote Learning Is a Game Changer” in *The New York Times* resembles my project the most, but it differs in a key way: the article interviews students with disabilities versus my project in which I, the student with a disability, am writing in the first person.<sup>37</sup> A lot has changed since 2021, so my project covers the benefits of remote learning over a longer period of time. I also have the rare perspective of having attended college, albeit briefly, as a student with a disability long before COVID came into our lives. The other striking and unusual thing about my project is that it draws parallels between my experience and that of my inside peers. While I would have loved to include more perspectives than my own and Damian’s, the scale of this project required me to focus solely on the two of us. Additionally, as I mentioned in the project, all other Inside-Out programs shut down during COVID. Thus, only we outside students at the Claremont Colleges have the ability to speak to the experience of doing Inside-Out remotely.

Having taken a total of 16 Writing and Rhetoric courses, I learned how to write in a wide variety of genres: from place writing to food writing to literary journalism to traditional academic essays to podcasts; I’ve done it all. Although I envision one day expanding this project into a full book, my project, as it now stands, consists of a series of personal essays with some science writing and literary journalism interspersed. I could easily make an argument for the influence of any of those 16 classes, but the three that stand out the most are Kim’s Writing 140:

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<sup>37</sup> Amanda Morris and Emily Anthes, “For Some College Students, Remote Learning Is a Game Changer,” *The New York Times*, August 26, 2021, accessed April 28, 2023, <https://www.nytimes.com/2021/08/23/health/covid-college-disabilities-students.html>.

Creative Nonfiction, Writing 130 Inside-Out: Literary Journalism, and Writing 120: Tech Rhetorics.

Writing 140: Creative Nonfiction was essential to the creation of this project as the course helped me to understand some of the more nuanced differences that exist within the overarching genre of creative nonfiction. In particular, the course clarified the difference between a memoir and a personal essay beyond just a difference in length. Memoirs tend to be more reflective and so the events are in the past. A personal essay can include events that are more recent/currently unfolding. Personal essays tend to be more conversational, which is the primary tone I employ throughout the project. Literary journalism falls under the umbrella of creative nonfiction, so it was actually quite interesting to take Writing 130 after having taken Writing 140. I was able to dig deeper into writing about events from a more objective standpoint while still incorporating more creative elements like dialogue, descriptions of people and places, and quotes from others—all of which I included at points throughout the project.

Writing 120: Tech Rhetorics was my favorite Writing and Rhetoric class, strictly speaking in terms of the course's content. Because I am interested in both the humanities and sciences, Writing 120 allowed me to blend the two. In that class, I was able to practice “translating” medical jargon and distilling the most important information from research studies into pieces that are accessible to a general audience. My thesis is, in fact, aimed at a general audience because I want it to be read widely. After all, one of the aims of the Writing and Rhetoric Major is to help break down the language barriers treasured by academia. Although the current “venue” of this project is something to be read, I am excited to turn it into a more TEDTalk-style format for Scripps' Capstone Day, thanks to honing my “adaptation skills” in Writing 120.

When I began writing this project, it was much more linear. Part of that, I assume, is because my brain is very linear, methodical, and logical. While that type of thinking helps me when it comes to keeping myself alive using IV nutrition and medications, engaging in research—such as the research I’m doing on establishing a writing center in CRC with Kim and Damian as part of my Racial Justice and Equity Fellowship—and serving as the Editor-in-Chief of the 2023 *Scripps College Journal*, it can be dry. Kim pushed me to jump around in time more and include more vignettes. It was uncomfortable at first, but after getting over the initial hump, I realized how much more interesting it made the project. The other challenge Kim threw at me was to show more feelings/emotions. People who know me in real life know I’m extraordinarily sarcastic and tend to use extremely dark humor to downplay the extent of my health problems. Going back to the stress and numerous disappointments throughout my journey does not come naturally to me, so that was undoubtedly the most difficult step in the creation of this project.

There are four books that served as inspiration for my project: *Educated: A Memoir* by Tara Westover, *This is Ear Hustle: Unflinching Stories of Everyday Prison Life* by Nigel Poor and Earlonne Woods, *Just Mercy: A Story of Justice and Redemption* by Bryan Stevenson, and *When Breath Becomes Air* by Paul Kalanithi.

Ironically, *Educated: A Memoir* by Tara Westover helped me realize what this project—in its current form—could not be.<sup>38</sup> The level of gut-wrenching details, along with the memoir’s chronological order, was not going to work. I simply did not have the space to expand small moments, like the one in which Westover realized how out of place she was at Brigham Young University because of her lack of any previous formal education. That said, I hope one day to revisit Westover’s book when I expand this project into a full-length memoir myself.

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<sup>38</sup> Tara Westover, *Educated: A Memoir* (New York: Random House, 2018), digital file.

*This is Ear Hustle*<sup>39</sup> and *Just Mercy*<sup>40</sup> worked in tandem as guides about how to handle talking about incarceration as a non-incarcerated person. The former enables the men at San Quentin State Prison to speak for themselves, as the book is actually based on the hit podcast *Ear Hustle*. The book is essentially a transcript of interviews between the authors and men at San Quentin. *Just Mercy*, on the other hand, is Stevenson's memoir, but he also presents some of the stories of his clients on death row. I made a conscious decision not to speak for Damian and, instead, to use direct quotes from his messages to me à la *This is Ear Hustle*. I also felt that it was necessary to give a bit of background on Damian and, as Stevenson does with his clients in *Just Mercy*, I aimed to ensure the facts of Damian's life were correct by relying on his resume.

At my high school, GDS, there's a tradition during graduation rehearsal in which the Head of School hands each senior a book in lieu of the diploma they will receive a few days later. For the Class of 2016, we were gifted *When Breath Becomes Air*,<sup>41</sup> so it feels very full circle that it is the most influential of the four books that served as inspiration for the culminating project of my college education. Firstly, the book is the shortest and it is unfinished. Obviously, Kalanithi not finishing the work due to his death is not the same as me feeling this project is unfinished because of space constraints and the pressure of a deadline, but the question is, would I ever feel this project is finished? Would Kalanithi have ever felt like his memoir was finished? After all, as far as I can tell from his writing, we both are perfectionists. The second reason why *When Breath Becomes Air* was crucial to the creation of this project is that it blends science and humanities. Both Kalanithi and I break down our conditions and treatments in a way that those

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<sup>39</sup> Nigel Poor and Earlonne Woods, *This Is Ear Hustle: Unflinching Stories of Everyday Prison Life* (New York: Crown, 2021).

<sup>40</sup> Bryan Stevenson, *Just Mercy: A Story of Justice and Redemption* (New York: Random House Publishing Group, 2014).

<sup>41</sup> Paul Kalanithi, Abraham Verghese, and Lucy Kalanithi, *When Breath Becomes Air* (New York: Random House, 2016).

with no medical background can both understand and appreciate the significance of our situations. Finally, Kalanithi's memoir served as a core inspirational work for this project because it affirms the idea of living while you can. The prospect of operating on a person's brain whilst battling terminal lung cancer would seem bizarre to most people, but to Kalanithi, such an act was a way of holding on to his own truest self as a doctor in service to others. While, of course, attending class while septic is somewhat less bizarre, I admit it's still an unusual choice. For both Kalanithi and me, the act of trying to live our lives as "normally" as possible was—and is—essential to mental and spiritual health. Preventing us from spiraling into the pit of utter despair that is common for people dealing with terminal and/or serious rare/chronic diseases.

I opened my project with an epigraph from the late Clarie Wineland. An activist and motivational speaker, Wineland had Cystic Fibrosis (CF). She died at just 21 after having a massive stroke while recovering from a double-lung transplant in 2018. Her words, attitude, and grim sense of humor brought a smile to my face whenever she popped up on my social media feeds. I struggled to choose just one quote as Wineland impeccably articulated the struggles of being a chronically ill young adult. In one of the many speeches she delivered as a disability rights activist, Wineland said, "When you look at me, instead of seeing the poor, happy, sick kid... See someone who has lived an incredibly complex life; an incredibly beautiful life; an incredibly painful life; and has made something from it. And realize that you have that power as well."<sup>42</sup> My hope is that the project you've just read enables you to extend those positive sentiments to my friends at CRC—friends who were brought together by our mutual friend, COVID.

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<sup>42</sup> Claire Wineland, "Claire Wineland gives inspirational talk at Klick MUSE New York," speech presented at Klick MUSE, New York, NY, March 31, 2016, video, YouTube, <https://www.youtube.com/watch?v=kP41Zv3CaSo>.

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My acknowledgments section would be about 100 pages long if I named everyone who has helped me not just with this project itself but with just getting to and through college. That said, I cannot in good conscience publish this project without thanking some folks by name. First, to “The Gang of Nine” for being the absolute best workshopping partners I could’ve asked for. To Danny Shapiro, Rabbi Yossi, and Rochel Matusof for welcoming me with open arms and helping me throughout my chaotic college career. To Julie Loppacher for taming some of that chaos and believing that somehow, someway, I was going to graduate from Scripps. To all my classmates, both inside and out, who checked in on me, helped me out when I missed class, and expanded my world. Of course, Damian needs a special shoutout. To my friends who’ve cheered me on and listened to me rant, especially Michael Oosterhout, Nick Ruggeri, Maddie Flickinger, and Clary Taylor. To my family, both near and far, particularly Evan and Alisha McDonough. You’re the real MVPs. To my vast medical teams across the country and, in particular, Drs. Leah Brasch, Robin Felker, Katherine Gibson, Cindy Xi, Yaser Diab, Sukanya Subramanian, Benny Kerzner, Richard Boles, Daniel Pine, Jeffery Moak, and Liz Bettini, my home health nurses Michelle Atherly and Julia Siporen, my dietician Kelsey Griffin, my physical therapists Maria Arini Lopez and Pili Weinzapfel (plus Scott and Halo Weinzapfel). To Georgetown Day School and all my teachers there who prepared me for college. To all my professors at the 5Cs who accommodated my wild circumstances and unpredictable absences. To the inventors of Zoom and Kevin Mullis. To my parents, Maureen Corrigan and Rich Yeselson, for literally everything, including being willing to make Scripps a reality despite the countless people and cosmic signs insisting it was a terrible idea after the first two failed attempts. To my furry sisters Maddie and Nellie for just being themselves. To Glenn Simshaw and Jen Groscup for their guidance and humor throughout the stressful reality that is Senior Thesis. To Maddy Ruvolo for introducing me to the world’s best advisor. And, of course, endless gratitude to the dogs and the woman who made this all possible, Wicker, Roxie, and Kim Drake.

In loving memory of Arielle Davis (Pitzer ‘18).



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