

VOICES

a literary journal

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VOICES

letter from the editors

One of the wonderful parts about organizing each issue of Voices is the opportunity to thoroughly read the submissions and to gain insight into the thoughts of each author. As we have grown over the past few years, we have received more submissions from patients and healthcare providers outside of the Duke network. In this issue, we feature several of these pieces.

Jacob Goeder's analysis of funding for childhood cancer begins this issue with a clear review of the numerous impediments to achieving adequate funding for childhood cancer research. As a survivor of leukemia, Jacob is well-aware of the life-altering and societal benefits that research funding can make possible. Leryiah Arant echoes a similar sentiment as her mother undergoes novel clinical trial treatment for glioblastoma multiforme. In her role as a patient's daughter, she portrays her journey in a way that elicits incredible emotion each moment the prognosis changes. It reminds us of the responsibility with which healthcare providers must act when discussing their patients' states of health.

Sabran Masoud's essay also reminds us that charts and diagnoses don't always accurately describe the lives behind the medical jargon. We, as healthcare workers, are often inspired and humbled by the patients we treat, as Dr. Jooste and Dr. Bohannon so intricately demonstrate with their descriptions of patients through poetry. In our daily professional lives, it is important to remember the humanity that exists in each and every one of us. Elisabeth Abeson recounts this through her own struggles with rheumatoid arthritis. Karishma Sriram brings this to life on an individual level with her series, Humans of Duke Med, as she interviews individuals throughout the Duke Med community.

As always, we hope you enjoy this issue as much as we have putting it together, and we would love to have your piece in our next issue. If you would like to join the editorial team, we are always looking for new ideas and ways to improve. Please submit your pieces, interest, and any other thoughts to dukemedvoices@gmail.com.

Your co-Editors-in-Chief,
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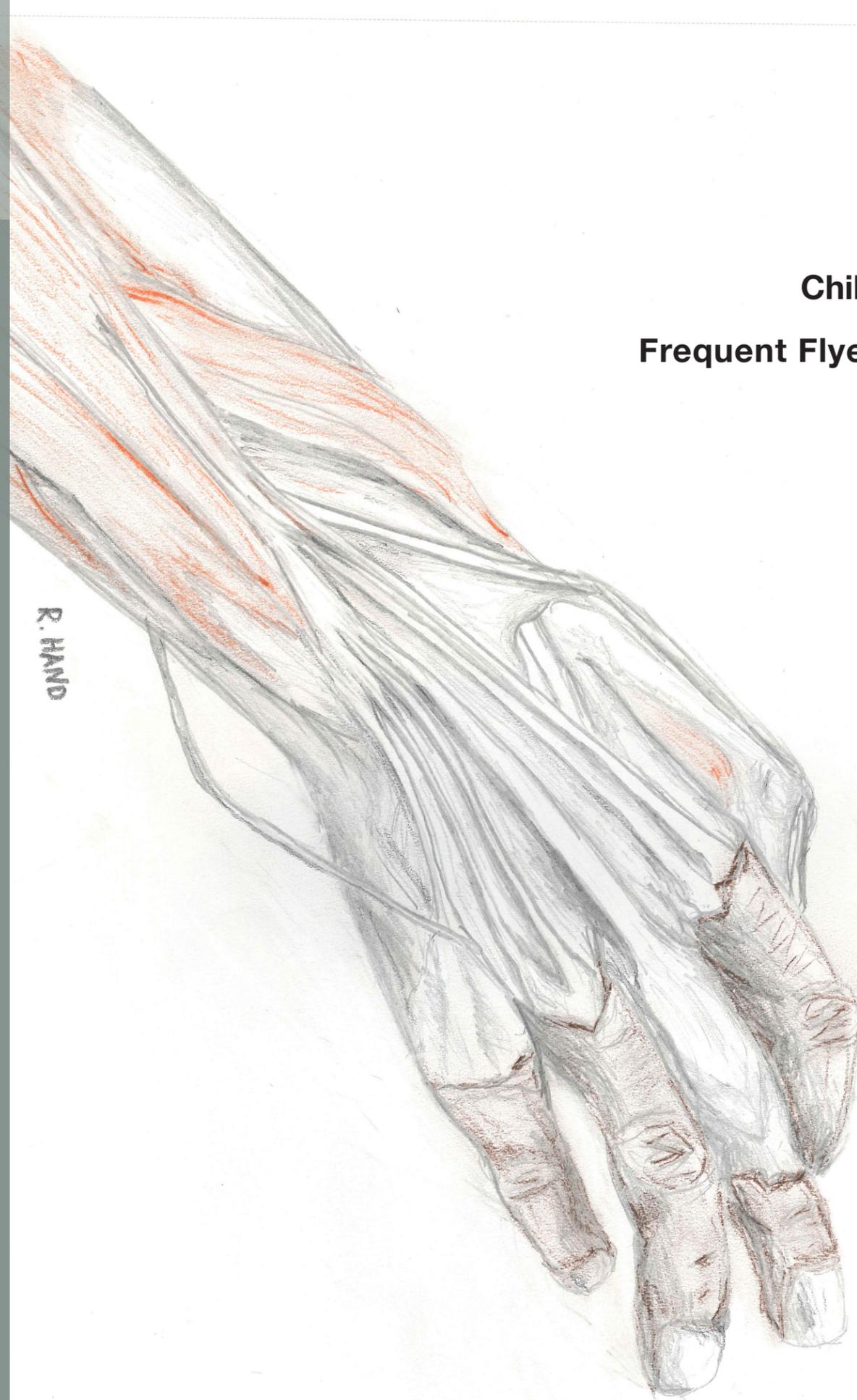


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Childhood Cancer

Childhood cancer is the leading cause of death by disease in children in the United States. Every year, an estimated 15,780 children under 20 years of age in the United States are diagnosed with cancer. Out of these 15,780 children that get cancer, approximately 3,468 will die from the disease. On top of that, 2/3 of the children who survive their cancer will have long lasting chronic conditions from treatment ("Childhood Cancer Facts"). There are dozens of different types of childhood cancers, such as acute lymphoblastic leukemia and neuroblastoma. Despite all of these statistics, childhood cancer is still hugely underfunded. In the United States, the National Institute of Health (NIH) uses less than 4% of its funding for childhood cancer research ("Childhood Cancer Facts and Statistics"). To make matters worse, the White House has proposed a budget cut of a whopping \$1.2 billion to the NIH (Scott). Nearly all of this \$1.2 billion cut will target research grants, which is a strong force in finding better treatments, and eventually a cure, for childhood cancer (Scott). The NIH should not have this budget cut put in place, but instead put more money towards finding better treatments and a cure for childhood cancer. It doesn't take long to find out where most of the money used for childhood cancer research comes from. A quick google search will lead you to many non-profit organizations such as St. Baldricks, Alex's Lemonade Stand, and

Cure Search. The one thing that all of these nonprofit organizations have in common is that it is actually the families of children with cancer that raise the money. They host lemonade stands, shave their heads, and walk in order to raise money in hopes that they can help find a cure. These non-profit organizations then provide grants to pediatric oncologists and teaching hospitals for research. Unfortunately, this is necessary in order to find a cure to childhood cancer, seeing as the NIH only gives less than 4% of their funding to childhood cancer research ("Childhood Cancer Facts and Statistics"). Furthermore, some of the more high profile non-profit cancer organizations give even less money into funding childhood cancer. For example, the American Cancer Society only gives 1% and the Leukemia and Lymphoma Society only gives 2% towards childhood cancer funding ("NCI Funding").

It also doesn't take a lot of research to find out why childhood cancer needs more funding. Let's take, for example, acute lymphoblastic leukemia (ALL), which is the most common type of childhood cancer. The survival rate has dramatically improved over the past few decades for ALL. In the 1960s, the five-year survival rate for ALL was less than 10%, but due to research, treatments started to improve in the 1970s. Because of ongoing research, the five-year survival rate for ALL is now almost 90%. Additionally, even though many

Funding

more children are surviving ALL, the treatments used to cure their cancer can cause serious long term side effects such as secondary cancers, heart and lung problems, learning problems, and bone problems, just to name a few ("Childhood Cancer Facts and Statistics"). Research should also be put into developing treatments that don't hold the risk of many of these toxic side effects. Furthermore, there are still some types of childhood cancer that continue to have low survival rates and some that are terminal at diagnosis. Further research is desperately needed to give the children who are diagnosed with cancer a chance to survive.

Why is there so little funding for childhood cancers compared to that for adult cancers? This is, sadly, because there's more money to be made off adult cancers than childhood cancers. For example, fewer than 10 drugs for use in children with cancer have been developed since 1980. This includes drugs specifically intended for children, as well as ones intended for both children and adults. In comparison, hundreds of new drugs have been developed for cancer in adults ("NCI Funding"). To put the difference in funding into perspective: prostate cancer, which has an average age of diagnosis of 66 years, receives more funding for research from the NIH than all childhood cancers combined ("Childhood Cancer Facts and Statistics"). There are at least 19 types of childhood cancer that all require

different treatments, and therefore should not all be lumped up into one category.

Unfortunately, cancer is seen as a money making business for the pharmaceutical industry. Since childhood cancer is considered rare, and more adults get cancer than children, pharmaceutical companies will research and develop new drugs for adult cancers instead of childhood cancers because there is a bigger profit to be made. However, if you calculate the number of "Person Years Life Lost" (PYLL) in adults vs children who get cancer, children who die from cancer lose an average of 66 years of their lives, compared to the average of 4 years lost from prostate cancer ("NCI Funding"). The pharmaceutical companies, however, only look at number of new cases per year, which at 200,000 for prostate cancer, greatly dwarfs the number of children who get cancer every year in the United States ("NCI Funding").

Because of the huge difference in years of life lost, more priority should be put on funding childhood cancer research. To start, the White House should not go through with the \$1.2 billion funding cut to the NIH. This cut would be detrimental to not only pediatric cancer research, but all cancer research in general. Secondly, the NIH should give a higher priority to childhood cancer research, and not lump all childhood cancers into one funding pot. Each type of childhood cancer should get

its own funding, just like adult cancers. Also, our government could encourage pharmaceutical companies to research and develop new medicines for childhood cancer, possibly by offering tax cuts. All of these changes could potentially remove a large burden off of childhood cancer families, who currently feel the pressure to raise this money on their own since what is allocated now is clearly not enough.

Jacob Goeders is a 16 years old video game master, junior philanthropist, and Leukemia Slayer.



Frequent Flyer: Our Year with a

Before we met Mr. Z, we met his medical record. As part of Duke Med's Hotspotting program, my partner and I were expecting a patient with a high rate of Emergency Department use... just not 7+ ED visits in the last 12 months.

That did little to stop our eyes from glazing over when we reached our patient's "problem list": HTN w/ reduced L ventricular function; L ventricular thrombus; hyperlipidemia; gout; chronic polyarthritis; mature cataract; and history of cocaine, marijuana, and alcohol abuse.

What scattered social history we could find did little to brighten the picture. Mr. Z was undergoing housing resettlement, his previous neighborhood having been where his own brother had been shot. When it came to his medical visits, Mr. Z regularly refused urine drug screens and had admitted to using cocaine. Heads swimming, we arranged our first home visit.

The wrought iron barring the heavily curtained window rang hollowly as we shook it. Apparently, this had worked for Mary Hansen, a registered nurse with Duke who had worked with Mr. Z before. We had spent at least half an hour hammering on Mr. Z's door, half an hour wishing we weren't soaking up the wet summer air. But it was our first meeting. And we were going to get our patient's attention, one way or another. The door screeched open.

Mr. Z sported a dark T-shirt and jeans. We were expecting a man of roughly middle age. His

features told a different story. His arms were thin, scarred by recurrent gout attacks. His right eye was milky. We made our introductions in the halting, unrefined cadence of nervous first year med students. His speech, filtering through the few teeth he had left, was hardly any clearer.

We followed Mr. Z into his home, keeping pace with his shuffling limp. The entryway was dim, with little of the sweltering heat following us inside. Together, we whittled down an extensive medical history to the issue at the top of our patient's list - his right eye cataract. We called in an appointment with the Duke Eye Center and chalked up our first meeting as a success.

Over the next few months, it became our afternoon ritual to check Epic for the week's appointments and to schedule transportation covered by Medicaid. Clearing the requisite ophthalmology consultations, our patient had finally been cleared for an extracapsular cataract removal.

On the fateful day, the afternoon glare threatened to wash out our laptop screens. We pulled up Mr. Z's scheduled operation on the EMR. But where we expected the usual byzantine surgical itinerary: "CANCELLED BEFORE INDUCTION." Our patient had used cocaine in the days leading up to his operation.

We asked Mr. Z about cocaine during our next home visit. "I didn't know that I couldn't do that! [The nurse] started asking me questions before the surgery,

and I didn't want to die on the table!"

"What have you done before to avoid using cocaine?" we asked. It turned out Mr. Z liked taking walks to his cousin's house nearby. That was on the few occasions his leg pain did not keep him shuttered indoors. Cocaine staved off boredom. Cocaine took his mind off the pain. And when no amount of cocaine or pain meds did the trick, Duke ED was always open.

The recommendations we had planned to share with Mr. Z gave way to a cat and mouse game, chasing after the elusive strategy our patient would be willing and able to follow.

"If the [football] game is on, I don't know if I'll be able to keep off [the cocaine]."

Or, "How about starting the next Monday... no... Tuesday after?"

Our goals had shifted beneath our feet, complete abstinence turned into remaining clean in the two weeks before surgery.

While working with Mr. Z, we also became acquainted with "NO SHOW", yet another dismal status waiting in the EMR. In our disappointment, it was easy to wonder aloud to one another, "How did he avoid his appointment this time?"

Of course, it was not so simple. Between us, Durham Transportation Services, Medicaid, Duke, and Mr. Z, five parties were involved in arranging one patient's medical visits. We did a fine job blindsiding one another, from the last minute reschedules we missed, to cancellations Mr.

"High-Utilizer"

Z had never gotten word of, to transportation that arrived at his doorstep for an appointment everyone else knew was not happening.

One thing was simple to understand. Mr. Z did not have the independence to schedule his own appointments. He had precious few phone minutes to spare for keeping abreast of his many visits, let alone any unpredictable changes. Without a clear line of sight to his appointment schedule, Mr. Z had little on which to structure a drug abstinence routine. His cocaine usage only exacerbated preexisting conditions like congestive heart failure. The result was a cruel synergy between Mr. Z's comorbidities and socioeconomic challenges, warping even a simple, vision saving procedure into an untenable idea.

Mugginess has since descended from a pale sky, heralding summer, bringing us nearly full circle to when we first met our patient. Once more, Mr. Z is taking the many steps between initial consult and surgery. Yet somehow, our view is different. Through Mr. Z, we now know that the gleaming expanse of glass in which we learn medicine does not have an intervention for a lack of phone minutes, or a personalized drug for each patient with a history of substance abuse. Mr. Z has grown beyond a constellation of poorly managed symptoms on Epic, instead becoming the gentleman in a faded denim jacket who waved over two medical students in the hospital lobby, greeting them

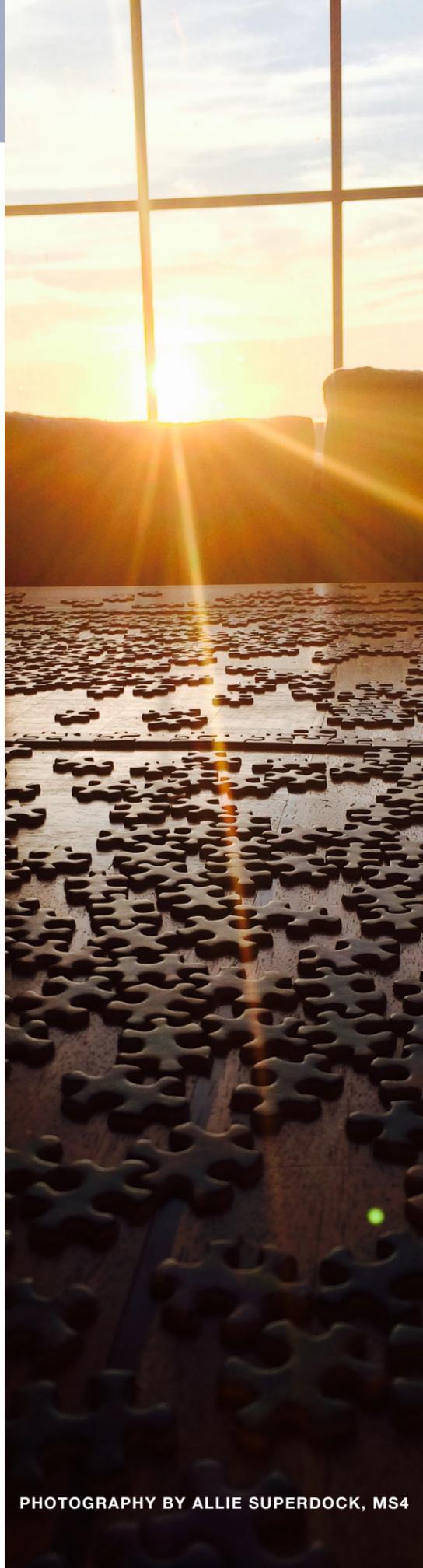
warmly with a "How are my kids doing?"

The difficulties that would color so much of our shared experience is streaked by personal moments such as these. Likewise, the templated labels we can hastily ascribe to our "difficult case" do not stick so well once we have left clinic and tested the air of our patient's neighborhood, or pulled our chairs across the linoleum of his darkened kitchen. Eyes open, we realize just how intimate our view of this one patient's life was. We find our frustration tempered and our resolve intact.

"You guys planning on still working with Mr. Z?" asked one of our Hotspotting coordinators.

My partner and I shared a glance. I shrugged, "We want to see this one through."

Sabran Masoud is a rising third year medical student who frequently gets lost and sometimes enjoys it.



HUMANS OF DUKE MED



Michael Peterson: “The thing that I’m always trying to do and that I want is for my son to remember that I was a big part of his life. That’s the thing that I worry about most because especially last year, during second year, there were maybe 4 or 5 days at a time where I didn’t get to see him awake because he went to bed before I got home or got up after I left in the morning. I just want him to remember that he’s loved and that I was a part of his life.”

Dr. Len White: “I see beauty in the brain, especially at the level of cells and circuits. The first time I saw neurons under the microscope, I was absolutely hooked by the beauty of it all. And then to think about the function of those circuits brings in a whole different realm of beauty. It has enthralled me for the last 31 years!”

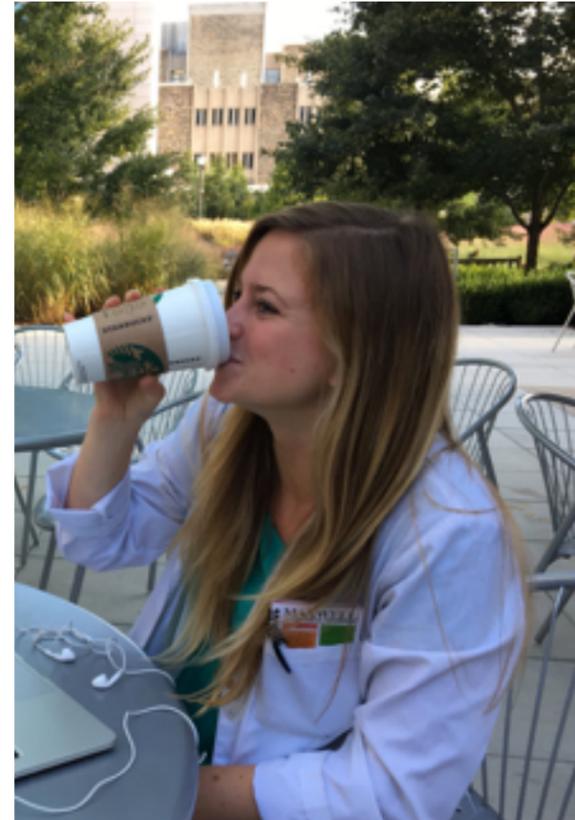


Chizoba Nwankwo: “For cautious peeps: If you have to think about it twice, you should probably do it. For adventure seekers: if you have to think about it twice, you probably shouldn’t do it. With regards to fear as a concept, it’s just really waste of time, so you know you got to just nix those thoughts and use that time to be productive.”

Karishma Sriram: A 2nd year medical student attempting to show the beauty and sincerity of people through the Humans of Duke School of Medicine (follow @humansofdukesom on Instagram and Facebook)



Trey Sinyard: “I’ve been thinking lately about how our brokenness is actually what brings us together. The strongest relationships that I have are the ones where I’ve shared the most of my brokenness, where I’ve opened up about my imperfections. What’s so ironic is that I’m reluctant to do that for fear of rejection. That which I believe will lead to rejection is actually that which leads to the strongest and closest friendships.”

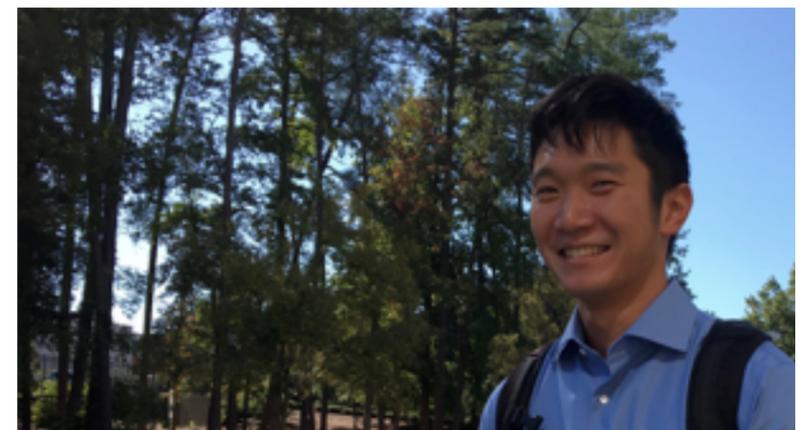


Kelsey Corrigan: “I’m new on radiology, and no one knows me. But this morning, the attending came up to me and was like ‘I think you’re the new med student, and you look tired. Do you want a cookie?’ And he just gave me a cookie! I was very tired and hadn’t eaten breakfast– it was so simple but so nice.”

Peter Weng: “I liked how Horton the elephant went out of his way to protect the tiny people of Whoville, who he couldn’t really see. It makes you appreciate that there’s so many things that we can’t just see.”



Rheaya Willis: “The sound that lulls me to sleep? Haha. The sound that lulls me to sleep is the sound of the patriarchy crumbling at my feet”



Ordinarily Extraordinary

It was a birthday party. January 26, 2014 was a celebration of life. More than four decades of friendship was shared between my parents and their friends that weekend. They took to the Adirondack Mountains for fun, fellowship, and a good 'ole 57th birthday party for my Mom. The day began with sips of hot coffee and chatting about family, work and the ways of the world. It's a picture perfect Adirondack day; blankets of fresh fallen snow, clean, crisp mountain air, clear blue skies, and majestic mountains surrounded the group. The design of the day was ideal for recreating the same magic of exploring, relaxing, and frolicking they had enjoyed as teenagers. Life was good. Life was normal. It was ordinarily extraordinary.

900 miles away, my family was going about our typical Sunday routine. We were behind schedule, trying to corral two kids under 5, wrestling to get clothes on, all in an attempt to make it to church on a Sunday morning. Through the hustle and bustle of the daily grind, we were living in the real, ordinary times of life, lacking feelings of extraordinary anything, save the occasional bit of extraordinary frustration and exhaustion. But, life was good. Life was "normal."

After the skiing birthday party concluded, my parents headed home to find that one of their beloved cats had fallen ill and was going to need medical attention. My mom's cats are truly children to her, so her descent into distress upon finding one

ill was inevitable! She rushed around, frantically looking for the phone number to call the emergency vet. As she picked up the phone, the day that began as ordinarily extraordinary quickly did a 180. As the veterinarian's receptionist picked up, my mom found her speech jumbled and her ability to communicate non-existent. Like a light switch flipping from on to off, my mother transitioned instantly from perfectly healthy one minute to unable to speak coherently the next, changing our family's world in the process. Life would never be ordinary or normal again.

Back in South Carolina, my family was enjoying a post-worship treat. As we sat in the drive-thru waiting on our milkshakes, my cell phone rang. On the other end was my dad's voice. With me as their only child, it was difficult for my parents to hide anything from me. I didn't have to listen to the words my dad spoke to know that something was terribly wrong; the tone of his voice said it all. "I'm here with your mom in the Emergency Room, he said. They have done some testing and found a mass on her brain." My ice cream appetite vanished and was replaced with an overwhelming nauseated feeling. I was consumed with emotion, yet paralyzed. What had my Dad just said? I just talked with my mom a few hours prior and she was completely fine. I was in shock, utterly perplexed. The phrase "mass on brain" does not belong in a sentence with

"my Mom" as the subject. My husband and my kids knew something was wrong, but I tried to keep my composure in front of them, as my Mom is the center of my children's universe. How was I going to be able to tell them? Hell, how could I convince myself that this was real? Our day began so "normally." How could the day be ending in such an unsuspecting, horrific way? In the blink of an eye, life was forever changed.

In a high-speed ambulance ride, my mom was immediately transferred from our local community hospital to Albany Medical Center, a 57th birthday present she never wished for. No one could have ever dreamed up this story plot - if anything was going to strike suddenly, based on our family's health history, a heart attack would've been her golden ticket into the Pearly Gates. A brain tumor was on nobody's script for my mom's story.

I was emotionally distraught, mentally over capacity and feverishly trying to wake myself up from this awful nightmare. As I began to call some of my family members and closest friends, I found myself having difficulty speaking and putting together coherent thoughts. Is this what my Mom felt like? How could I expect my family and friends to understand me when there was no part of this situation that made any sense? My husband's birthday was just hours away and instead

of celebrating, I found myself, alone, in the airport, waiting to catch one of the first flights out of South Carolina. The flight was brief, yet it seemed like eternity had passed me by. My mind was racing simultaneously in 10,000 different directions and my thoughts were deafening. I just needed to get there. I yearned to feel ordinary and "normal" again.

When I got to Mom's room, I felt relieved. She looked like herself, minus being in a hospital bed, hooked up to some monitors. I was convinced. This was all a big mistake. Soon after I arrived, my mom's Neuro-Oncologist entered the room. We made small talk, as if we were at a birthday party. Then, he dropped the bomb that shattered this newfound pseudo-reality of mine. The tumor in my mom's brain was 4 cm in diameter, located in the parietal-temporal lobe of the left side of her brain. Surgery was a necessity and his gut feeling (pre-operatively) was a life threatening brain tumor. That being said, he could not be certain until he operated. He prepared us for a less than ideal outcome, but he remained cautiously optimistic that there was still a chance this mass "could be" benign. Desperately, I held on to that worldly HOPE for dear life while my soul clung to my HOPE in Jesus Christ.

It was Jan 29, 2014. We were sitting in the waiting room surrounded by many other families. Looking around the room, one might have thought we were all waiting for our number to be called at our favorite local buffet, not waiting for brain surgery updates. You could feel the tension

and see the anxiety as if it were smog settling down from the atmosphere. The surgery was supposed to last 5 or 6 hours, so my family and I were surprised to see my mom's neurosurgeon re-emerging after only 3. He approached us with a misleading smile as we sat anxiously in that cold, sterile waiting room, surrounded by complete strangers and grossly unprepared to receive the news that came next. I still clung to that HOPE. Certainly, I told myself, if he is approaching us in this public space, filled with other awaiting friends and family, it was going to be good news...right?

The surgeon told us that he was almost 100% certain that the mass was a glioblastoma. "I'm sorry, a glio what?" we stammered. Everything else that came out of his mouth after that was muffled, falling on deaf, stunned ears. My dad and I just fell to our knees and wept. Everything went silent and numb. Time stood still. I had an out of body experience, becoming a spectator of my own life playing out like a movie on the big screen. Then, reality pierced through the "dream." In that moment, my family and I had a choice; to live each day, fighting like our lives depended on it and not letting "cancer" define our story, or to cower in fear and merely survive for whatever time remained.

I remember hearing my uncle say to me, "You have just as much time with your mom now as you did before this diagnosis occurred. Tomorrow is not promised to anyone. This diagnosis does not change things just

because the journey has been labeled." From that very conversation, we chose moments over minutes, electing to live, not just survive. We chose love over fear and purpose over pain. We chose HOPE over despair, anchoring our lives in the promises of the Lord and putting our faith in His Sovereignty. We were not going to be defined by the statistics. We were going to run the race set before us with HOPE, purpose and endurance.

Over the next 8 months, my mom went through chemotherapy and radiation like a true warrior, never once complaining. She faced each day with renewed strength, grace and determination. But in September 2014, that Goliath that we refer to as GBM reared its ugly head again. With the help of my Mom's phenomenal medical team at the Robert Tisch Brain Tumor Center at Duke University, however, the news of this recurrence did not come with a grim death sentence but with the HOPE and encouragement of a Plan B, C, D, E, or even F. They were not giving up on my Mom and neither were we.

Continued on sites.duke.edu/voices.

Leryiah Arant is the daughter of a patient at Duke University Medical Center.

Inspired By You

Sitting with her on the hospital bed

She captured me,
This young woman,
Curled on the hospital bed,
Pale, in her fetal position,
Legs drawn up near her chest,
Yet her smile so strong and bright and welcoming.
She described her illness
Without self-pity, without bitterness.
Somehow, through her journey of physical illness
Her spirit shone brightly,
With hope for the future.
I could see in her eyes, that she had chosen
Joy and Meaning,
As she planned her future career in nursing.
I am in awe of this girl,
Of her grit,
Her resilience,
This beauty,
In the face of illness which could be crippling
But is not, for her.

Karen Jooste, MD is a Pediatrician at Duke who is as passionate about poetry, food and travel as she is about Medicine.

Sticky iron, corpuscles
sometimes I find dried flecks at odd places-
not unclean
but I cannot wash myself
enough to set down rumination
-to uncouple as rail cars
leave the freight
on dead end sidings-
signal lights ooze down the line

Living rumpled carpet to
Antiseptic-contaminated answers,
Nourishment snakes
Velocity above me
-but into her wrinkled veins,
chains me to who became before:
Demented Demerol Dragon
floundering Poise defeated in
a world let down buzzing

How am I with every
one else
Patient
but me?

Isaac A. Bohannon, MD is an Otolaryngologist at Kaiser Permanente of Washington. Through her writing, she makes meaning from the living and dying moments of her profession.

Restoration to Flight

Five years have passed since I was diagnosed with Rheumatoid Arthritis (RA), and that time has brought with it more pain, shame, frustration, fear and angst than all my 49 years combined...So, why do I say that I actually see this disease as a blessing?

I don't see it that way all the time. But if I didn't get RA, I know I would have continued to beat myself up for failing to meet my inhuman goals. No wonder my cells got in on the action. My body had clearly been hosting an autoimmune cell-bashing party for decades. It continued until I woke up one 'morning-after', and allowed myself to finally see the household damage and put an end to it. I couldn't kick the cells out since they were mine, but I could create different House Rules, ones that wouldn't tolerate such abuse. I don't think I would've admitted how meanly I treated myself if it hadn't gotten as painfully raucous as it did. I thank my RA for convincing me to transform some of my self-criticism into self-compassion. It taught me to treat myself with some of the kindness that I extended so easily to others. For this, I am grateful.

Still, you might say, "Really? How can a chronic, progressive disease actually be a Blessing?" Transforming self-criticism into self-compassion is one thing, but the 'B' word is a profound one that shouldn't be referred to lightly. After all, it suggests actual joy.

At first there were little micro-moments of kid-like won-

der and joy, little flashes when I found myself in nourishing situations that I never would have experienced pre-diagnosis. Then, there would be untenable stretches of deep pain, fear, anger, self-pity, depression and isolation, all related to chronic illness. However, as time passed, I realized that my healing journey was filled with more post-diagnosis goodness than upset.

Don't get me wrong, I'm not mistaking myself for an angelic being who sports a halo above her head and sees everything in a rose-colored hue. I know that I can't land on that cloud any time soon,...but I do see myself as someone who is on a journey towards that puffy place of peace. So, given this trajectory, what I am trying to do now, is to accept, embrace and enjoy the time that spans between 'point A' (coming to a painful, limping halt) and 'point B' (soaring effortlessly with my own wings). The bottom-line is that I wouldn't have found myself at 'Point A' if chronic illness hadn't stopped me in my tracks.

I was sent several messages before I couldn't walk - the first was in 2002 in the form of my first auto-immune disorder - Sjögren's Syndrome. It was heard loud and clear throughout my whole system, but my eyes and lungs bore the brunt of it. Unfortunately, I didn't heed the call to stop working so hard - trying to prove something to myself as much as to the rest of the world. I just pushed on, with more than occasional sensations of hot glass and sand being

ground into my eyes, and wincing pain when I breathed. The pain was so great that I would hold my breath as long as possible before having to give up, gulp air and feel that tissue-tearing sensation around my heart. There would be a bit of respite before the cycle started again.

As it turns out, that pain was only a little aperitif served up before one heck of a Michelin-starred main course. My entire body went on strike and stopped functioning. It stopped acquiescing to my 'stubborn-as-a-mule' ways to achieve. I admit doing some impactful things in the International Development arena during that time. I worked in solidarity with marginalized populations whose voices were silenced - be they children, or people who were economically impoverished, socially-oppressed, differently-abled, displaced or ill. That all sounds well and good, but I silenced my own cries for help in order to hear theirs. Sometimes my arm wouldn't work and I would just joke that, 'it was OK,... I have another.' But, it actually wasn't OK. It wasn't OK at all....it was a message that went unheeded.

I would go to work with what I called a 'broken wing' - it was when an arm couldn't lift itself up to start the flying cycle, so I would keep it tucked protectively close to my body, maybe under a scarf, since a sling would have indicated that I was hurting. I found that a scarf was a formidable decoy, especially when it was a beautiful raw silk one that matched my outfit.

Finally, I heeded the message because my feet couldn't move anymore. And my feet couldn't move anymore because my knees couldn't bend, and my knees couldn't bend because any effort to make them do so was too painful to overcome the stand-still. It was an all-out mutiny, where every single cell conspired and collectively determined that the only way to get me to rest, was for my body to go on strike. So, strike it did. Not a little petty strike like we see in the States, but an impressively massive one that you see in cities like Paris where efforts are coordinated so strategically that they bring public transport to a halt.

It took a lot to bring me to a limping halt. It took the sensation of iron rods heated in the fire and then pierced into my bones, joints and tendons – where they laid throbbing before they were twisted and moved around to make the entry-point of the wounds bigger. That's when I admitted that I needed to entertain alternative ways to get through life since my way wasn't working out so well.

I started to see that when my body was engulfed in pain and my mind felt overwhelmed and defeated with despair, there was an untapped source of fuel to keep me pluggin' along. It seemed to come from the outside world – from everything but me. I guess that was key at the time. I needed to completely surrender to something outside of myself that I could rely on in the absence of my own 'umph'. I call it 'the universe's energy', which, for me is a mix of some of my favorite deities and a cou-

ple earth-bound teachers harmonizing nature and sending its goodness my way. It is an empowering and life-affirming force that makes me want to inhabit my body and connect with the flow of the universe.

Tapping into this source has proven to be the best sort of palliative care for me when I feel sidelined by disease and its stigma. Looking back, I now see that what I called the 'universe's energy' and my inner 'spirit' are actually the same thing. I just wasn't able to make that connection until I admitted defeat and completely surrendered.

So the journey continues onward and upwards. Like us all, I am just a story in-progress – sharing some of the chapters that have been written to-date. I share my story with others who are struggling with dis-ease, in hopes that they will feel less alone and more empowered to embody themselves...to start listening to the collective whisperings of a body that needs to heal. This is my primary 'audience' – we come first.

I am also compelled to share my story with physicians because I sense that so many of you want to hear the narrative behind our x-rays, but can't do so in the 10-15 minutes you are authorized to spend with us.

In bringing us together ('us' patients and 'you' physicians) to read this, I hope that 'We' can have a shared experience that sheds light on how disease presents itself on the level of body, mind and spirit. It truly is a 'package-deal' from the patient's perspective. We might come to Providers with a pin-pointed source of body pain,

but its impact can't be contained within a limb or an organ. It extends beyond a set of coordinates on a scan to penetrate our mind and spirit, too. While I acknowledge the egregious scope-creep here in regards to how medical domains are currently classified, I do hope that we can rally together to create systemic change that supports a more holistic approach to healing. A paradigm shift of that magnitude requires our combined energy.

For fear of placing societal well-being above my own – yet again, I will close by shifting my energy back to my own healing. While everyone embarks on their own path after being dealt the blow of an unfortunate diagnostic code, my journey suggests that the sooner we inhabit our bodies and acknowledge our pain, the sooner we'll be able to heal and fly again.

So, that's my pledge to myself hereon in, to listen so acutely to my body, that it never has to scream life to a stop in order for it to get my attention and guide me home. As my story revealed, my body will continue to lead, (regardless of my willingness to follow), but what makes me smile is knowing how much easier the journey will be without beating myself up along the way. At home within myself, I'll be able to soar, thanks to my newfound self-compassion and its majestic wingspan.

Elisabeth Abeson is a Duke IM Trained Integrative Health Coach who works exclusively with the Rheumatoid Arthritis (RA) community. Taking a holistic approach, she supports clients in healing their mind, body & spirit.



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