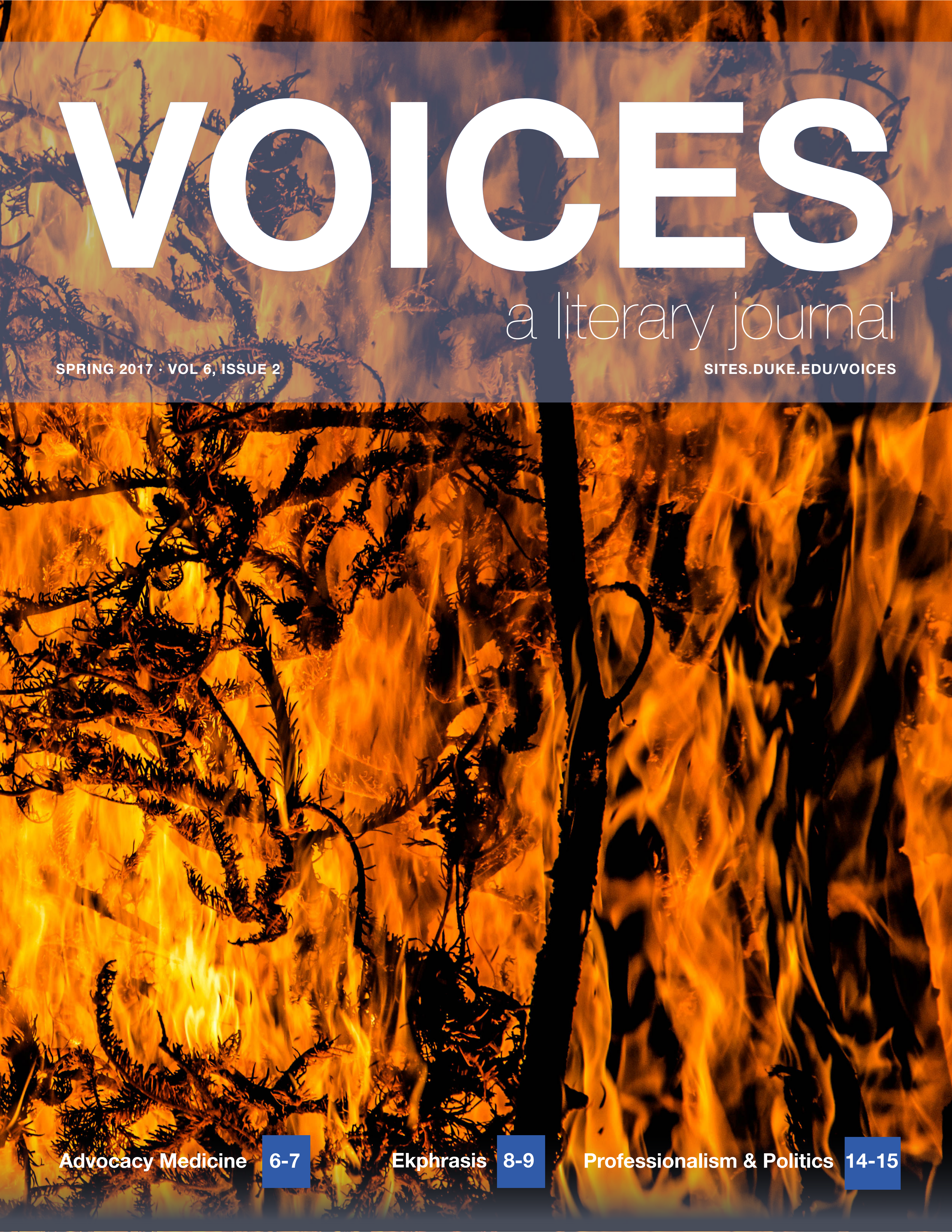

VOICES

a literary journal

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VOICES

letter from the editors

Healthcare is ultimately a team effort. The hospital functions as an unit composed of hundreds and thousands of individuals. From students to nurses, and doctors to social workers, a patient's care never truly lies in the hands of one person, but that of many.

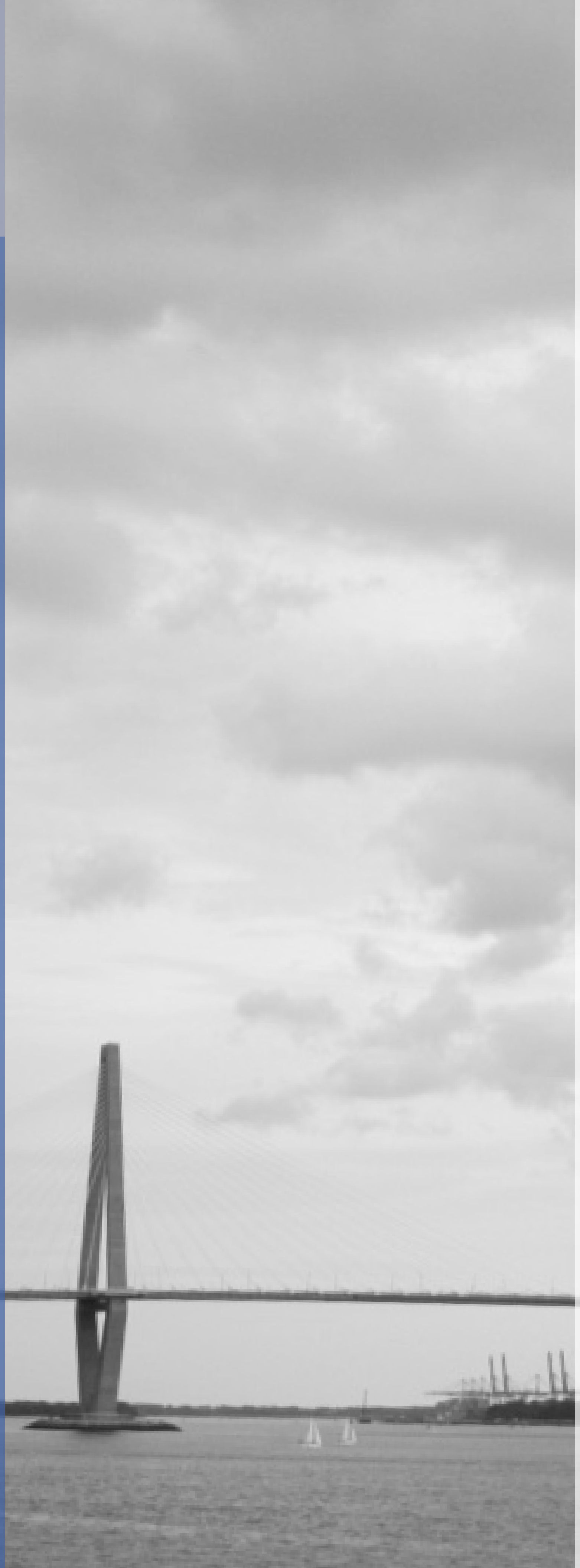
In this issue, we present the writings and artwork of individuals across the medical campus, from medical and physician assistant students, to doctors, social workers, and advocates. We are proud of the diversity of the effort that it took to make this issue, and we hope that it will only continue to grow as we mature as a publication.

To begin, we remind ourselves of the wonder of medicine amidst the routine of daily life with a poem by Rachel Ballantyne titled merely as the date of its creation. Then we transition to the wonder of modern science as it changes and inspires our lives in Josh Davidoff's poem on his personal experience with deafness.

Afterwards, we delve into advocacy as we emphasize the momentousness of seemingly insignificant daily events, with Dr. Neelon's ekphrasis of the neglected fall of Icarus in *Breughel's Icarus*. Healthcare doesn't exist in a vacuum, it is part of a complex microcosm that includes politics and advocates. We have to be constantly aware of that as Jerry Lee and Hussain Lalani deliberate on the 2016 presidential election, and Marissa Happ and Joanne Zeis reflect on their experiences as advocates for healthcare issues.

We hope you enjoy this issue as much as we have working to put it together. And as always, if you have any interest in writing for or joining the Voices editorial team, please let us know at *dukemedvoices@gmail.com*.

Your co-Editors-in-Chiefs,
Rui Dai
Vinayak Venkataraman



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associate editors

faculty editors

BACKGROUND PHOTOGRAPHY CREDITS:
COVER: Aarti Thakkar, MS2
CREDITS/CONTENTS: Leslie Chang, MS3+

9/24/2016

I sailed a rowboat to the edge of the world, where the atmosphere meets open space
Launched straight up, as the smoke unfurled, as the waves grew small and the clouds uncurled
I found myself in that place.

Then at the cusp where the sunlight streamed and the edge of the world goldenly gleamed
and my breath was frozen in the still night air,
I lifted my arms, tossed back my hair
And my boat tipped forward past invisible edges, like a thousand needles on a thousand ledges
and I trimmed the air like I sculpted hedges

For a single moment I was one of the stars, and the sunlight pierced my eyes and my scars,
and I caught my breath in the breathless void, and the sun slipped behind the edge, destroyed.

Then I shot towards the ground with incredible speed, as though I were riding a flaming steed, with the wind in my hair and my hair on fire and each muscle stretched and tuned as a wire, and I charged the earth as the earth stood still, racing the ice down an endless hill, and the coastline grew sharp and I thought I heard waves, and the dead raised their eyes from their ancient graves, as I roared and I sliced and I bled and I raved,
And i burst to the ground with my head unshaved

As I lay on the grass looking up at space
And the breeze brushed the years and the tears from my face
I sank back deeply and felt each blade
Like a mammoth's fur, like the earth had frayed
And I heard an owl weeping in the night
And gravity held me and pressed me tight
I remembered and sung what I'd heard before
As I seeped down to sleep inside the core.

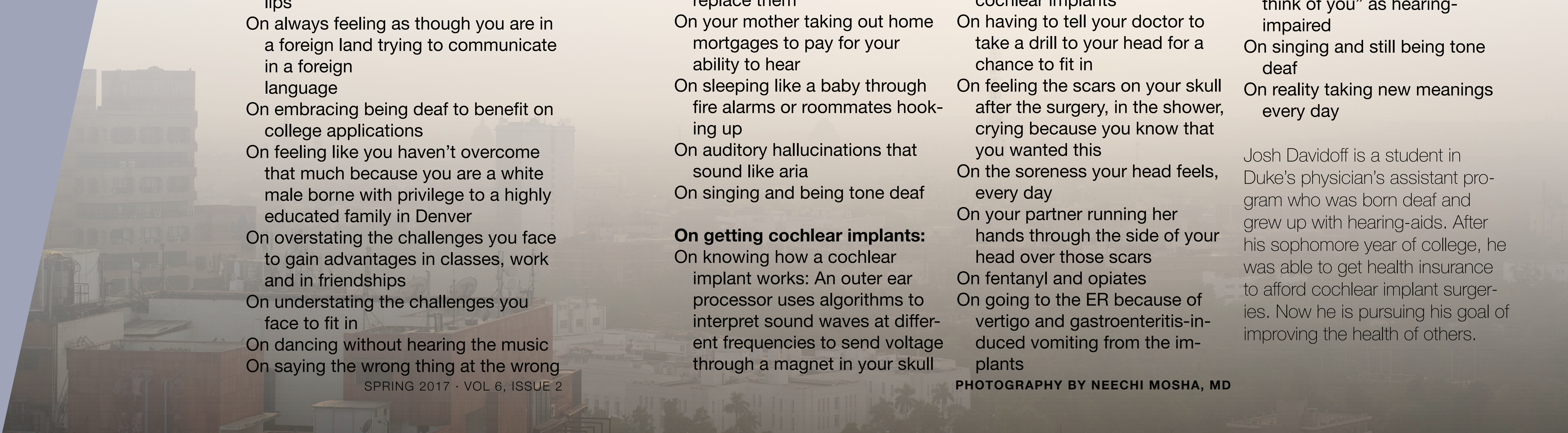
Rachel Ballentyne is a third-year medical student/computer science PhD interested in writing fiction, writing computer programs, and rewriting genomes.

On Deafness

On Growing Up with Hearing Aids
On the cacophonies
On auditory hallucinations of ringing sounds
On being one of two deaf brothers borne to completely hearing parents
On knowing that you might pass deafness to your children
On letting deafness define you
On actually being "hearing-impaired"
On being shunned by the deaf community while growing up because you wanted to be part of the "hearing world"
On growing up in and out of Deaf culture: you are deaf to the hearing and hearing to the Deaf
On people smacking their lips, patronizing their words, repeating their statements, touching you to get your attention, giving you unwarranted sympathy, and asking "did you hear me?" consistently while communicating with you
On desperately staring at someone's lips to try to understand them
On people acting as if you are flirting with them because you stare at their lips
On always feeling as though you are in a foreign land trying to communicate in a foreign language
On embracing being deaf to benefit on college applications
On feeling like you haven't overcome that much because you are a white male borne with privilege to a highly educated family in Denver
On overstating the challenges you face to gain advantages in classes, work and in friendships
On understating the challenges you face to fit in
On dancing without hearing the music
On saying the wrong thing at the wrong time
On being excluded by friends when you struggle to fit in
On excluding yourself, in loud situations, because you embarrass yourself
On anxiety from not understanding what your friends are laughing about
On feeling as though you are only partially there
On your friends treating you like you don't have a disability
On relying on text messages and Facebook to build friendships
On giving up on friendships based off of the clarity of their voice
On struggling to flirt with the tall, auburn-haired, freckled, neuroscience-majoring, hippie babe, because her voice is sultry and seductive and you can't even begin to comprehend it
On going to classes, understanding little to nothing, and teaching the course material to yourself
On going to classes and turning off your hearing to sleep
On your hearing aids being stolen and the $8000 payments to replace them
On your mother taking out home mortgages to pay for your ability to hear
On sleeping like a baby through fire alarms or roommates hooking up
On auditory hallucinations that sound like aria
On singing and being tone deaf

On getting cochlear implants:
On knowing how a cochlear implant works: An outer ear processor uses algorithms to interpret sound waves at different frequencies to send voltage through a magnet in your skull (completely bypassing defunct sensorineural hearing loss ears), where it travels through an electrode with 24 outlets (each one programmed to match your hearing loss) in the cochlea to electrically stimulate the auditory nerve to transduce sound to the brain
On knowing how they really work: they give hope
On being told that you could never afford the surgeries
On spending 20 years of your life trying to get insurance to cover the surgeries
On the right audiologist helping you get the insurance
On politicians talking about government assistance as benefiting the "welfare state"
On being inspired to get cochlear implants because the struggle to communicate with your girlfriend's friends is a detriment to your relationship
On breaking up with her and getting your cochlear implant surgery two days after
On being able to communicate with those friends after the cochlear implants
On having to tell your doctor to take a drill to your head for a chance to fit in
On feeling the scars on your skull after the surgery, in the shower, crying because you know that you wanted this
On the soreness your head feels, every day
On your partner running her hands through the side of your head over those scars
On fentanyl and opiates
On going to the ER because of vertigo and gastroenteritis-induced vomiting from the implants
On being a "bionic person"
On how relearning to hear sounds like space invaders beeps
On the philosophy of David Hume and neural plasticity leading to the magical moments where the beeps turn into "sound"
On hearing new sounds that you never heard before in your 20 years of life
On hearing a truck driving down the street as though it was a turbine engine in your room
On hearing hummingbirds fly outside your window
On hearing your dog snore
On hearing your favorite songs as if you'd never heard them before
On going to classes and how hearing almost everything feels like cheating
On talking with friends and connecting on a level you did not think was possible
On knowing that your hearing can get better and better every few years
On still struggling to hear in social situations and classes
On being told that people "don't think of you" as hearing-impaired
On singing and still being tone deaf
On reality taking new meanings every day

Josh Davidoff is a student in Duke's physician's assistant program who was born deaf and grew up with hearing-aids. After his sophomore year of college, he was able to get health insurance to afford cochlear implant surgeries. Now he is pursuing his goal of improving the health of others.



PHOTOGRAPHY BY NEECHI MOSHA, MD

Medical Urbex

My husband and I are urban explorers. We go into abandoned buildings – the saggy, unloved ones – and shine light in the dark corners. Our cameras find beauty and order in the chaos. We share the results with others.

It's profoundly satisfying.

Now let's make a few substitutions, so that rare disease is the focus of my efforts instead. Research and writing becomes that shining light, and a computer – not a camera – helps to create and distribute the final results. Welcome to my world: What I do with photography on weekends is a natural extension of my health-related calling over the last 20 years.

So what do I do? I'm a medical information "concierge" for people with a rare disease, and for health care providers who may not have time to research the unusual. I dig up the evidence-based materials and the specialists that people need to move forward with treatment. I'm a medical/health writer who can translate impossible medicalese into plain English. I'm also a known advocate for people with Behcet's disease. None of these jobs, though, is full-time. Instead, I make my living as a pharmaceutical case manager. I cram these other tasks into my "free time."

I never expected to be an advocate for anyone. Becoming a medical-information search specialist and a patient advocate was the direct result of being very sick, and being very sick wasn't part of my life plan after college.

I was 23 when I started having serious health issues. As I looked for answers, many doctors thought I was looking for attention instead. "Find something else to do with your time," they said. In their eyes, I was too focused on my health.

Uveitis. Oral ulcers. Genital sores. Skin lesions. Rashes. Pain.

I lined up specialists, but none of my specialists talked to each other. The U.S. healthcare system didn't help: Whenever I switched jobs and acquired new health insurance, I was forced to leave the few doctors who were trying to make progress with my diagnosis. I had to start from scratch, again and again.

Headaches. Superficial thrombophlebitis. Cataracts. Tachycardia. Vitreous hemorrhage. Peripheral neuropathy. Pain.

Add new health problems every few months. Rinse and repeat.

One primary care physician finally suggested Behcet's disease as a diagnosis, but immediately dismissed it. "You're white," she said, "and you're not from the Middle East. It's too rare." I'd done my own research for years and already felt it was the most viable option, but this 'zebra' diagnosis was always out of reach. I was continually shuttled into categories that didn't fit, but made my doctors feel more comfortable. They could send me for tests, believe that they'd helped me, and move on to other patients who had problems they could actually solve. I was an incredible time sink for people who had no time to waste.

I finally made an appointment in Boston with a worldwide uveitis specialist who had a background in immunology. I handed him my long list of symptoms, knowing well enough to keep my mouth shut and allow him to reach his own conclusions. Invariably, doctors never wanted to hear the name of the zebra bearing down on them.

"I know what's wrong with you," he said. "You have Behcet's disease."

The relief I felt was immediate and overwhelming – but at the same time, it was now me who had no time to waste. How many other people were jumping over the same diagnostic and treatment hurdles that I'd been facing for 17 years? What could I do to help?

I joined the American Behcet's Disease Association and put my writing and medical-search skills to work. I'd always wanted to read about Behcet's patients' experiences, but a book like that didn't exist. It was the start of my single-minded focus. I spent a year compiling and editing interviews I'd conducted with other BD patients. The interviews were eye-opening, especially when patients described interactions they'd had with physicians prior to diagnosis:

A doctor told me I was creating this illness because motherhood was 'not a challenging enough' job.

One neurologist wouldn't see me without my husband. Upon hearing that I had just moved, he told me that my whole problem was relocation adjustment. Without examining me, he gave my husband literature on free-floating anxiety and told him this was the problem.

I self-published my efforts in the book, You Are Not Alone: 15 People with Behcet's. I was amazed by the response. It seemed that patients' experiences touched a vital nerve in the Behcet's community, opening a dialogue that was long overdue.

My first Behcet's book was followed by two more; the most recent won a 2015 National Health Information Merit Award for Patient Education. I researched and wrote each of my books carefully, always mindful that I'm not medically trained. I made sure that Behcet's experts reviewed my books prior to publication. While I wasn't qualified to dispense medical advice to patients, I still had the ability to translate dense, evidence-based research studies into language everyone could understand.

Each positive email or social media post that I received from patients, physicians and support groups gave purpose to my work. And now? Behcet's is no longer the bane of my existence; it's become a lifelong commitment to service.

I went back to school in my late 50s to earn a Patient Advocacy certificate from UCLA. My goal was – and still is – to help as many Behcet's patients as possible. No one else should have to suffer for 17 years, as I did, without a diagnosis and proper treatment.

But here's the good news: The tide is turning for patient engagement in rare diseases. The best health care providers are willing to listen to their patients, to accept personal experiences as learning tools. Above all, they're realizing that some patients have a depth of knowledge about their own disease that many physicians can only dream of.

Make the most of it. I did.

Joanne Zeis is a member of the American Behcet's Disease Association, the International Society for Behcet's Disease, NORD, the Alliance of Professional Health Advocates, and the American Medical Writers Association. She is a graduate of UCLA's Patient Advocacy certificate program and holds a B.S. in Psychology from Tufts University.

In 2006, Joanne was the sole recipient of the American Medical Association's Citation for Distinguished Service award, for her ongoing work on behalf of Behcet's patients. The Citation is the highest national award given each year by the AMA to a non-medically-trained individual.

Joanne's most recent book about Behcet's disease was the recipient of a 2015 National Health Information Merit Award for Patient Education. Joanne has been living with Behcet's since 1979 and advocating for patients' needs since 1998.

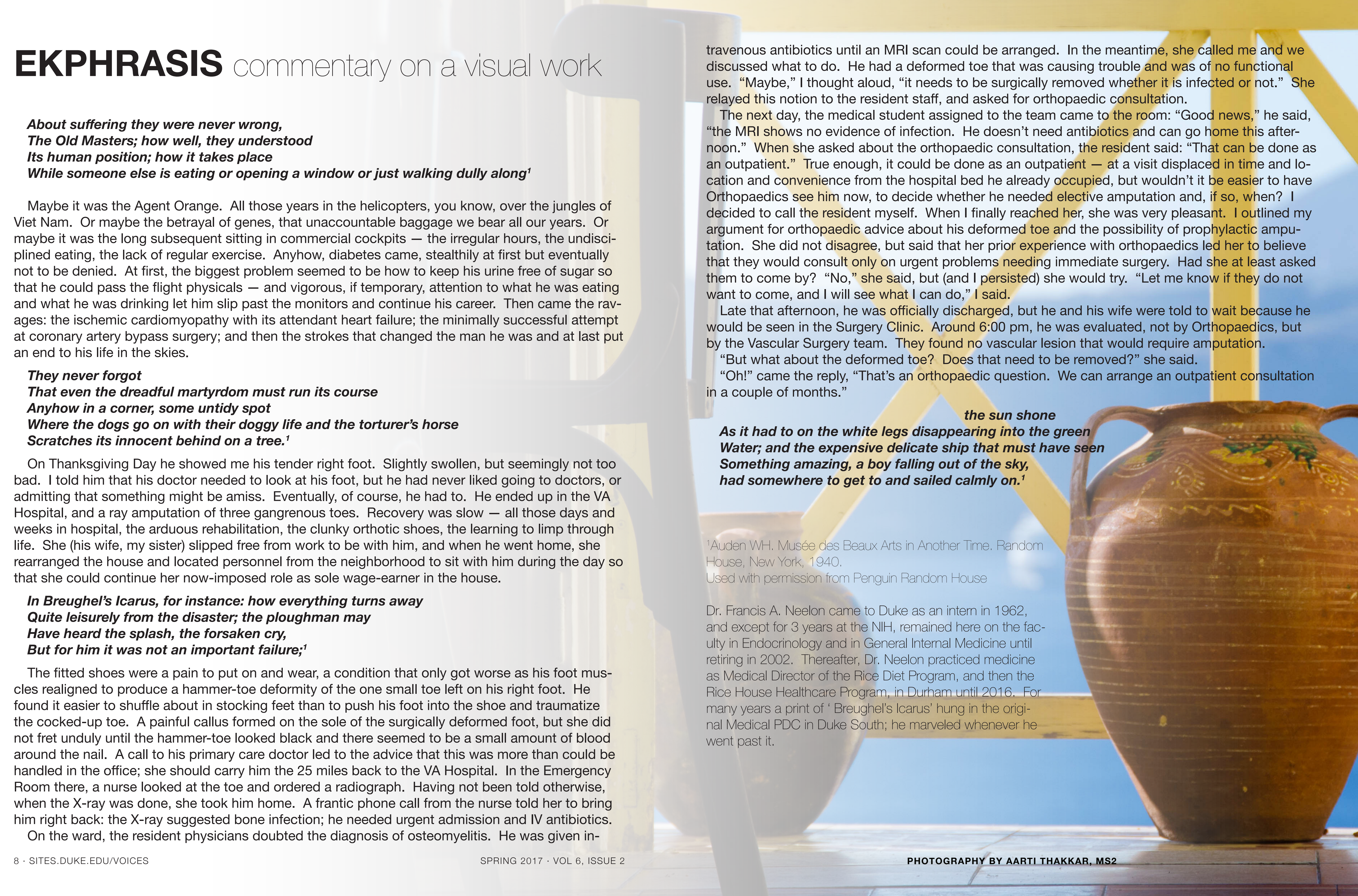
A Doctor Who Says "Um"

I want to be a doctor who says "um"
A doctor who,
being human,
reveals his humanity in his imperfections
A doctor who,
having compassion,
makes his compassion known by spending time
A doctor who,
having calm,
moves deliberately through the world
each step and each word chosen with care.

Alex Hish is a first-year medical student. He enjoys running, watching movies, and eating peanut butter and jelly sandwiches.

PHOTOGRAPHY BY AARTI THAKKAR, MS2

EKPHRASIS commentary on a visual work



About suffering they were never wrong,
The Old Masters; how well, they understood
Its human position; how it takes place
While someone else is eating or opening a window or just walking dully along[1]

Maybe it was the Agent Orange. All those years in the helicopters, you know, over the jungles of Viet Nam. Or maybe the betrayal of genes, that unaccountable baggage we bear all our years. Or maybe it was the long subsequent sitting in commercial cockpits — the irregular hours, the undisciplined eating, the lack of regular exercise. Anyhow, diabetes came, stealthily at first but eventually not to be denied. At first, the biggest problem seemed to be how to keep his urine free of sugar so that he could pass the flight physicals — and vigorous, if temporary, attention to what he was eating and what he was drinking let him slip past the monitors and continue his career. Then came the ravages: the ischemic cardiomyopathy with its attendant heart failure; the minimally successful attempt at coronary artery bypass surgery; and then the strokes that changed the man he was and at last put an end to his life in the skies.

They never forgot
That even the dreadful martyrdom must run its course
Anyhow in a corner, some untidy spot
Where the dogs go on with their doggy life and the torturer's horse
Scratches its innocent behind on a tree.[1]

On Thanksgiving Day he showed me his tender right foot. Slightly swollen, but seemingly not too bad. I told him that his doctor needed to look at his foot, but he had never liked going to doctors, or admitting that something might be amiss. Eventually, of course, he had to. He ended up in the VA Hospital, and a ray amputation of three gangrenous toes. Recovery was slow — all those days and weeks in hospital, the arduous rehabilitation, the clunky orthotic shoes, the learning to limp through life. She (his wife, my sister) slipped free from work to be with him, and when he went home, she rearranged the house and located personnel from the neighborhood to sit with him during the day so that she could continue her now-imposed role as sole wage-earner in the house.

In Breughel's Icarus, for instance: how everything turns away
Quite leisurely from the disaster; the ploughman may
Have heard the splash, the forsaken cry,
But for him it was not an important failure;[1]

The fitted shoes were a pain to put on and wear, a condition that only got worse as his foot muscles realigned to produce a hammer-toe deformity of the one small toe left on his right foot. He found it easier to shuffle about in stocking feet than to push his foot into the shoe and traumatize the cocked-up toe. A painful callus formed on the sole of the surgically deformed foot, but she did not fret unduly until the hammer-toe looked black and there seemed to be a small amount of blood around the nail. A call to his primary care doctor led to the advice that this was more than could be handled in the office; she should carry him the 25 miles back to the VA Hospital. In the Emergency Room there, a nurse looked at the toe and ordered a radiograph. Having not been told otherwise, when the X-ray was done, she took him home. A frantic phone call from the nurse told her to bring him right back: the X-ray suggested bone infection; he needed urgent admission and IV antibiotics.

On the ward, the resident physicians doubted the diagnosis of osteomyelitis. He was given intravenous antibiotics until an MRI scan could be arranged. In the meantime, she called me and we discussed what to do. He had a deformed toe that was causing trouble and was of no functional use. "Maybe," I thought aloud, "it needs to be surgically removed whether it is infected or not." She relayed this notion to the resident staff, and asked for orthopaedic consultation.

The next day, the medical student assigned to the team came to the room: "Good news," he said, "the MRI shows no evidence of infection. He doesn't need antibiotics and can go home this afternoon." When she asked about the orthopaedic consultation, the resident said: "That can be done as an outpatient." True enough, it could be done as an outpatient — at a visit displaced in time and location and convenience from the hospital bed he already occupied, but wouldn't it be easier to have Orthopaedics see him now, to decide whether he needed elective amputation and, if so, when? I decided to call the resident myself. When I finally reached her, she was very pleasant. I outlined my argument for orthopaedic advice about his deformed toe and the possibility of prophylactic amputation. She did not disagree, but said that her prior experience with orthopaedics led her to believe that they would consult only on urgent problems needing immediate surgery. Had she at least asked them to come by? "No," she said, but (and I persisted) she would try. "Let me know if they do not want to come, and I will see what I can do," I said.

Late that afternoon, he was officially discharged, but he and his wife were told to wait because he would be seen in the Surgery Clinic. Around 6:00 pm, he was evaluated, not by Orthopaedics, but by the Vascular Surgery team. They found no vascular lesion that would require amputation.

"But what about the deformed toe? Does that need to be removed?" she said.

"Oh!" came the reply, "That's an orthopaedic question. We can arrange an outpatient consultation in a couple of months."

the sun shone
As it had to on the white legs disappearing into the green
Water; and the expensive delicate ship that must have seen
Something amazing, a boy falling out of the sky,
had somewhere to get to and sailed calmly on.[1]

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[1] Auden WH. Musée des Beaux Arts in Another Time. Random House, New York, 1940.
Used with permission from Penguin Random House

Dr. Francis A. Neelon came to Duke as an intern in 1962, and except for 3 years at the NIH, remained here on the faculty in Endocrinology and in General Internal Medicine until retiring in 2002. Thereafter, Dr. Neelon practiced medicine as Medical Director of the Rice Diet Program, and then the Rice House Healthcare Program, in Durham until 2016. For many years a print of ' Breughel's Icarus' hung in the original Medical PDC in Duke South; he marveled whenever he went past it.

PHOTOGRAPHY BY AARTI THAKKAR, MS2

Advocacy in Medicine

Too often in academia, we spend significant amounts of time reading about, discussing, and listening to lectures on the foremost challenges impacting our world today. And while this process is educational and informative, there remains one lingering question – So, what are we going to do about it?

More importantly – what can we, as individuals, do about it?

Let me tell you about my path to action and why advocacy is important in medicine and public health today.

It was a Thursday morning in the middle of August. I was sitting in my Public Health Policy class at the Bloomberg School of Public Health. Our guest lecturer was Sir George Alleyne, Director Emeritus of the Non-communicable Disease (NCD) Alliance and former director of the Pan American Health Organization (PAHO). He stood before the class of 250 students and began a large-group discussion on the burden of non-communicable diseases (NCDs) globally. The next hour was different than the majority of our lectures, no PowerPoint slides to be found.

While listening to my classmates describe the variety of factors contributing to the growing burden of NCDs, I heard them share cross-cultural stories. NCDs impact people from all walks of life, regardless of their heritage, gender, or educational level. We discussed how cardiovascular disease is the #1 cause of morbidity and mortality globally, how the vast majority of deaths caused by NCDs are preventable, how social determinants of health affect health outcomes, and how low- and middle-income countries are disproportionately affected.

NCDs are "silent killers" and account for 38 million deaths annually. They are often less visually and emotionally relatable compared to a patient with Ebola or a newborn with Zika. This may account for the relatively minimal attention that NCDs receive in the media, and more importantly, in global funding. To me, this is unacceptable and irresponsible.

After class, a small group of students approached our lecturer to continue the conversation.

I remained in my seat, feeling unsatisfied. This lecture, like many before, was undoubtedly compelling, but it was not action-oriented. The challenge of NCDs was too important of an issue for me to walk away. Fortunately, I was not alone.

After speaking with Sir George, one of my classmates and I were inspired to start a chapter of the Young Professionals Chronic Disease Network in Baltimore (YP-CDN Baltimore). Our goal was to organize the student body and local professionals to advocate for the health of marginalized populations whose lives were negatively impacted by NCDs and whose voices were not being heard.

With overwhelming support from colleagues and friends, we have spread the word and actively engaged over 100 graduate students in medicine, nursing, law, and business. We picked an important advocacy issue - the rising cost of prescription drugs - and joined a local, diverse grassroots coalition led by the Maryland Citizens' Health Initiative (MCHI) to advocate for the Prescription Drug Affordability Initiative, a bill that will be introduced before the Maryland State General Assembly on January 11, 2017. Through this effort, we aim to start bringing transparency to cost of the prescription drugs and to facilitate discussions about affordability.

This story is just one in the grand scheme of advocacy. Furthermore, I strongly believe that all health care professionals and students are in a unique position to recognize the suffering and inequity their patients face and to act on it accordingly.

You undoubtedly have, or will in the future, come across patient stories and circumstances that capture your attention.

This may include the 45-year-old construction worker who cannot afford his insulin, the 22-year-old college student struggling with opioid use disorder and looking for medical help, or the 60-year-old grandmother with heart disease who is unable to afford healthy food. There are countless stories, and often, similar themes emerge over time.

Despite this, the underlying structural and policy issues impacting our patients frequently go unnoticed for some time. This is not surprising, considering the increasing pressure we face with less time per patient, more time devoted to documentation, and lower reimbursement rates. It is tough. But…

We can do better. And frankly, we must do better.

Hussain Lalani is a medical student (MS3+) at Duke School of Medicine and a current MPH student at Johns Hopkins Bloomberg School of Public Health. ncdaction.org/breaking_the_mold_and_taking_action

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AIDS Rider

Victor Frankl believed that to find the ultimate meaning in life, we must transcend ourselves and become absorbed in something (or someone) beyond ourselves. In the winter of 2001, a radio ad caught my attention when it asked for good-hearted individuals who wanted to "make a difference". It talked about hope, endurance and community… and I - amidst an element of mid-life angst - went to my phone and said, "Sign me up."

I had no idea what I had gotten into; a "bike ride" to support patients with AIDS seemed like a great idea. I was a relatively new MSW grad and hey, riding bikes is fun.

I discovered that I had signed up for the Heartland AIDSRide, a six-day, 550-mile bike journey from Minneapolis to Chicago.

I had never biked a distance greater than 15 miles.

I was connected to a team near my home, and we started training in March, to prepare for the event in July. After our first ride of 20 miles, I got in my car and every muscle in my body screamed with pain; muscles I never even knew I had. I cried all the way home.

My anxiety began to build and self-doubt assailed me like a cruel, unrelenting tempest. Physical as well as emotional safety were my considerations:

"How do I ever think I will accomplish this? What if I get hurt? What if I get left behind?"

"Will I be accepted, a forty-something, heterosexual mother of five?"

Our team captain, a young and extremely athletic leader, assured me that no one on his team gets left behind, ever. Something about the radiance in his face assured me of his sincerity. Winking as he adjusted his helmet strap, he told me to get ready for the ride of my life. And every member of my team displayed that same determination and altruism. Nobody at all, it seemed, cared about my age or sexual orientation. Everybody, on the other hand, did care about loyalty, generosity and the cohesive effort to support individuals with AIDS.

Day 1 began with temperatures in the 90s and the sun blazing upon us all. Water stations, snacks and sumptuous meals were prepared for all of us.

On Day 3 of the ride, one of our team mates died on of a massive heart attack. Jack was the one who had been arriving early each night into camp and setting up the tents for all of us until we arrived.

When we faced the most severe hill on Day 4, a wave of terror washed over us; many were already walking their bikes up the impossible incline. I desperately wanted to get to the top without getting off my bike but realized that people were walking faster than I was riding. I was on the verge of dismounting when I heard the familiar voice of my teammate Rocky, cheerfully announcing, "Passing on your left!" I looked up to see the determination and the agony on Rocky's face as he rode by, his IV bag hanging from a pole tethered to his handlebars. I would not be getting off my bike. With tears stinging my eyes, I pulled out of the line to get behind my brave teammate, following his lead. I could not announce my approaching presence to fellow riders but simply gestured to all that "I am with him."

I lost my fear and much of my self-doubt on the AIDS ride because wounded healers all around me demonstrated what love and greatness were all about: negativity fades away when surrounded by kindness and joy. I removed the word "impossible" from my vocabulary and today do not hesitate to say "yes" to tasks much bigger than myself.

In only two months, the twin towers would fall. Since that day we have faced increasing violence, hatred and assaults on the innocent. We shudder to realize that no one is truly safe on our planet and sometimes we fear that darkness has overshadowed the light.

Our world is broken, but when tempted to despair, I stop for a moment and close my eyes. I remember the summer of 2001 when my entire universe seemed friendly, when trust prevailed and differences took back seat to a larger reality… a "conspiracy of kindness", it was called… where team captains didn't hesitate to put themselves in harm's way to protect their members and strangers gave away signed checks to make sure riders met their pledge totals. It was the summer when the very hills clapped for joy and the gravel beneath our tires offered no resistance. Even the rocks cried out with hope.

I am one AIDS rider who will never forget.

Marissa Happ is a doctoral candidate in Clinical Social Work and committed to quality healthcare for all.

Caring for sick kids: Then and Now

During my second year of medical school, I went through the most emotionally intense period of my life as I grew close to an affectionate 8-year-old kid with a very poor prognosis. Two years later, I went through a similar experience as I became close to the family of a previously healthy 10-year-old with uncertain future. Both situations were similar, but I handled the second one much differently than the first. Reflecting on this difference not only helped me appreciate my growth, but also offered a lens into resiliency and burnout, two issues I had heard plenty about but never seen close up.

Then

I walked into the room and was greeted by a wide-eyed 8-year-old with scattered freckles and a broad smile. He also had aplastic anemia and was hospitalized with an infection. Though gravely ill, A acted like a typical kid and we became close. He confided in me about his latest crush ("Don't tell mom, it's a boy secret!"), his backyard soccer career, and his love of video games. A week into A's stay, however, we discovered that he had a fungal infection that was typically fatal. I was devastated by the news. After consulting with advisers, I spent the evening with him and his parents. Those few hours were among the most powerful of my life as I resolved to genuinely be there for a family I had only just met.

Though I shifted to other rotations, I continued to visit weekly during A's three months in the Bone Marrow Transplant unit. He never lost his childhood spirit though his illness worsened. Both parents were always welcoming; his dad greeted me each time I visited with a hug. They confided in me the raw emotions felt watching their son fight for his life and the isolation felt in a large hospital without nearby family. I took pride in being a constant presence amid rotating teams and in being a sounding board for their thoughts and emotions.

This role wasn't easy. Each day, I felt closer to a kid expected to pass. It was my first inpatient rotation with no prior reference. I could remind myself, with good reason, of the resiliency of kids, but I was also reminded each day by provider notes that few miracles could challenge his eventual decline. No note could stop me from convincing myself that my role was to help him make the most of whatever time he had left. A was an eight-year-old, doing and thinking about eight-year-old things – each day, he seemed to care most about beating me at Mario Kart. However, it was hard for me not to join his parents in thinking of the life he would never live. It took some time, but I eventually became comfortable being honest and vulnerable with my team, advisers, family, and friends. Even after opening up to them, I continued to "bring work home." I became emotionally invested to the point my mood was determined by his clinical state. There were some weeks I had to step back to avoid burning out.

Miraculously, A survived to receive a bone marrow transplant, clear his infection, and return home. His parents gave me a photograph of him wearing a "Man of Steel" shirt and a note saying that I was part of their family forever. Two years later, we continue to be part of each other's lives.

Now

B, a 10-year-old kid with a weeklong fever and worsening mental status, had made his way to the Pediatric Intensive Care Unit (PICU). Starting the week with cold-like symptoms, he had suddenly worsened over the past 24 hours. He now had rising tachycardia and worsening hypertension. He came in lethargic and each hour was rapidly becoming less alert. I walked into his PICU room expecting to have a short conversation, but he was nonverbal, minimally responsive to pain, and had marked autonomic instability, soon to be intubated. His parents were sitting beside his bed in total shock.

I couldn't help but think back to two years ago. It was timely; A's mom had just invited me to his 10th birthday party. His story had been on my mind in the PICU, especially with my new patient, B. Both were previously healthy, playful boys in primes of childhood who had become suddenly, severely ill. Both had multiple subspecialty services crafting dynamic treatment plans. Both kids had uncertain prognoses. Both parents — warm, friendly, supportive — found ways to remain hopeful despite uncertain odds. Even their names were in order of experience: A first, B second.

During his first two weeks, B continued to be minimally responsive. The pediatric neurologists had ordered an extensive workup, but were empirically treating for autoimmune encephalitis. High-dose steroids were followed by IVIG and nuanced neurologic improvement was assessed for each day. His body required dynamic support. The ventilator kept him breathing. Powerful IV medications enforced order to his deregulated autonomics. Fluid and electrolyte statuses were actively corrected. Full feeds were given via his ND tube. Antipyretics and antibiotics were called upon a couple times to stave off ventilator-associated infections.

I would pop my head in every morning before rounds. His parents took turns staying by his bedside overnight. Both greeted me with steady handshakes and warm smiles. "How you doing this morning?" They would often ask me, in thick Southern accents, before I could ask the same about their son.

I would reciprocate.

"Oh, we're all hanging in there," they would say, in tones reflecting measured hope. "We're praying he gets better, little bit each day. Everyone back home is praying for him."

"How has B been since yesterday?"

Each day, they would point to something he had done differently. I took these seriously. Whether it was noting how his eyes move towards them as they called his name or played music for him, or noting him squeezing their hands a little bit harder, their findings were appreciated and often confirmed by the neurology team.

During the day, I would check-in on them several times, keeping them updated on new developments. They saw several different providers and appreciated someone coming in at day's end to summarize the next steps. They asked great questions and unlike two years ago, I could answer most. They knew that progress would be slow, if at all, but remained hopeful.

We would always spend time talking about B. I wondered if it was difficult for them to be reminded of their son's vitality as he lay unresponsive beside them, but they were always eager to share. They brought him to life. He was beloved by his community. He loved his high school- and college-aged brothers but fought back whenever given a hard time (i.e. often). "He's a stubborn one, he is!" his dad would say. He loved country music and NASCAR and going out fly-fishing on the weekends. He was raised with strong Christian faith and brought up to maintain good manners. His father would smile when recounting one aspect of B's first hour here, "Even when he was so loopy, he'd always say 'sir' when answering the doc." Per Dad, he was your typical adventurous, fun-loving, Southern boy.

By the time I rotated off the PICU, B's exam had only slightly improved and he was started on cycles of plasma exchange. His parents encouraged my habit of continuing to visit a couple times each week. "We want you to hear him talk!" After two weeks of being unresponsive, he finally started to come to life. He no longer needed the ventilator. He could freely move his eyes towards sounds. He started moving on command, then moving on his own accord. He could wave. Soon, he was on the floor. The day after his transfer, I stared in disbelief as he wrote his name on a piece of paper. We finally had our elusive first conversation.

Within a week, B was discharged to a rehabilitation facility. I made sure to see him before discharge. I gave him a Captain America stuffed toy so he'd always remember his superhuman strength. He taught me how the cool kids "high-five" nowadays. Two weeks after discharge, his mom sent pictures of him up and smiling, a video of him climbing up stairs, and a lovely thank you note I will continue to treasure.

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Due to the similarity between A and B, I would often think to myself when with B: God, it's going to happen again. You just watch. You're going to get emotionally attached and get way off track like last time. These cases are your Achilles' heel.

My fleeting mind wasn't far off the mark — the hardest kids for me to take care of are the "previously healthy, now severely ill" ones. They have the greatest potential to send me into an emotional tailspin. During my time with B, however, the emotional hurricane that seemed to be brewing at a distance never made landfall. What changed? As I tried to figure out what change had taken place between my time with A and B, I landed upon a few words: presence, balance, knowledge, and perspective.

Presence. During my experience with A, I sought advice from a palliative care physician. He provided my guiding principle, "It's the patient's moment. Be present. They'll tell you what they need." At that time, I had interpreted "presence" to be physical presence.

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Professionalism, Politics, and a More Perfect Union

One day after the election, a fog descended. My body operated on rote. In the morning, my legs carried me past sullen shadows through a city painted in gray scale, and in the hospital, my hands were choreographed by some unseen puppeteer. My colleagues wore painfully familiar faces of austerity and defeat. I gave my friend a long hug, and we departed without saying a word.

This is one experience of the election. A mere thirty minutes away, the scene is completely reversed.

On November 8, 2016, our nation's 58th presidential election exposed an uncomfortable but incontrovertible truth: our most fundamental values of equality, justice, and prosperity mean entirely different things to different parts of this country. Within the politically homogenous bubble of my immediate medical community, friends and colleagues met this news with unrestrained anguish and genuine fear, particularly if they were minority, Muslim, immigrant, or LGBT. Women who expected the glass ceiling to be broken were forced to conclude that this was a repudiation of their gender. There was shock, outrage, and expletives, followed by calls to honor democratic ideals and moral principles, followed by more outrage asserting the prerogative to express emotion. "Never have I felt so hated in this country," wrote one. "This is the America we deserve," proclaimed another. Judging by the political discussions since, the future of reproductive rights, the Affordable Care Act, and stem cell research remains entirely in question.

I am learning to process these emotions in the context of this profession. In my training thus far, I've been taught that there is no right way to process emotion; a patient given bad news may cry, laugh, become angry or despondent – all of which are legitimate and valued responses to be acknowledged by their physician. In the same way, these visceral reactions – whether characterized by despair or jubilee – are equally valid, and deserve the empathy that is afforded to each emotion.

The greater challenge, however, is learning to cope with different beliefs. These beliefs may be entirely antithetical to one's identity or ethics, and those that carry these beliefs may be patients or colleagues in which our professionalism (if not our humanism) requires us to abide. No longer relegated to the purview of political scientists, the question of how to live amiably in a deeply divided and pluralistic society pervades the collective consciousness of this generation. Too often have I seen students, patients, and professors openly or clandestinely ostracized for holding minority viewpoints; too often have I experienced this myself. There should never be room for hate, but this also means that even some beliefs antithetical to a particular race, sexual orientation, or gender may be epistemologically sound – and there should be room for its expression, without condemnation.

On family medicine, I rotated through a clinic near Fayetteville, NC, where many political rallies were held. As with my preceptor, I was loath to discuss politics, but from time to time, my patients confronted me directly about my political views. Generally, the decorum for political discussions in the clinic is the same as any discussion on politics among strangers: say something generic, mention how politics as a whole is terrible, and try to avoid controversy while smiling and nodding. This time, however, patients invited discussion by wearing their politics on their sleeve (sometimes literally), and several times I eschewed decorum to inquire about their beliefs. With surprising candor, I learned that their deepest grievances were health-related – particularly about rising healthcare premiums and pro-choice Supreme Court decisions – and in the process of this inquiry, I learned more about the community than any reading could teach me. Though possible solutions to these issues are indeed political, the grievances that many patients feel are not. By attempting to understand people, what they cared about, and what they were afraid of, opportunities for frank conversation were created that enhanced patient trust. As an outstanding example, a patient who had been refusing to take medications for fear of side effects agreed to try after our conversation, citing that I had valued his perspective. In a time when most of the country is shouting past each other, and faith in established institutions is low1, don't patients deserve the opportunity to be heard this way?

I'm learning. Perhaps the key is aiming for understanding, and not to take a side – which is easier said than done, but can be achieved with relative ease due to the temporal nature of patient interactions. However, in schools or workplaces where political discussions abound, the stifling of minority viewpoints (whether consciously or unconsciously) often occurs because the prevailing wisdom is that it is easier to work with people in whose opinions you do not know rather than with people you actively disagree with. This classic error is associated with adopting more extreme attitudes over time[2], and without active prevention of these situations, I believe we are denying ourselves the extraordinary opportunity to embrace disagreement.

History provides an inspiring example. Fifty years ago, when Martin Luther King, Jr. marched on Chicago for open housing, leaders of the American Nazi Party, the anti-black, anti-Semitic National States Rights party, and the Ku Klux Klan, gathered in counter-protest with thousands of followers. King, who had been struck in the head by a stone only a few days earlier, marched through an all-white neighborhood while being pelted with "rocks, bricks, bottles, beer cans, apples, and firecrackers"[3]. At a critical juncture, he approached a group of 100 angry teenaged youths, and said, "You are all good looking and intelligent. Where did all that hate come from?"[4]

King knew, as we know now, that we must learn to live with people who disagree with us on fundamental things. Medicine has an astonishing ability to be apolitical, and too often we are afraid to make our deeply held personal beliefs known for fear of offending someone or being perceived differently. Instead, if this election taught us anything, we should not be afraid to say what we believe and still be accepting of people who believe differently.

Inviting and challenging the varied perspectives of our colleagues should be part of our medical training, as it remains a potential solution to our moral inarticulateness. Germane to both the immediate aftermath of this election and to the future, deliberate, regular, and sustained engagement in divisive issues prepares us to confront the growing salvo of post-factual or over-politicized health-related discourses, ranging from vaccinations, abortion, and universal healthcare, to homeopathy and physician-assisted suicide. We will undoubtedly talk to patients about one or more of these issues, and we must learn to do so with a respect that supersedes our views.

If this can be a microcosm of our nation moving forward, I would urge, in this moment of national self-reflection, the humility of asking our colleagues for their perspectives, and to consider, for a moment, your own to be subject to error and change. This is the hard work of democracy, of day 1 after the election, the rare window of opportunity for us to forge a more perfect union.

PHOTOGRAPHY BY LESLIE CHANG, MS3+

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