

# KALEIDOSCOPE

EXPLORING THE EXPERIENCE OF DISABILITY THROUGH LITERATURE AND THE FINE ARTS

Number 90  
Winter/Spring 2025



## A CLOSER LOOK

*"My Legs" by Bonnie Ruane Wheeler*

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*"The Blue Pony" by Val Valdez*

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*"To Have and To Hold" by Diane Bell*



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Elliott Gorski, *Casual Red/Green Katydid*, 2019, digital photography

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*This award-winning publication expresses the experience of disability from a variety of perspectives including: individuals, families, friends, caregivers, healthcare professionals, and educators, among others. The material chosen for Kaleidoscope challenges stereotypical, patronizing, and sentimental attitudes about disabilities.*



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# MY LEGS

BONNIE RUANE WHEELER

**M**y legs are curled up in the womb, pressed to my chest; blooming cells ache with the dream of running.

My legs are so bendy at two years old—I sit on the floor in an acrobatic split. They are a part of me—but not ready to stand—so I am labeled a “lazy baby.” My legs and I are misunderstood.

At four, I love that my legs are attached to my feet. My legs carry me to all of the best places. Ten toes wiggle in the grass. Ten toes burrow in the sand. Pink, warm, and happy, my legs, feet, and toes love to tap.

On the first day of summer vacation, my legs climb a favorite maple tree in the backyard, where I dream of climbing other trees. By the last day of summer, my legs have skinned knees. Mom and Dad yell that my head is in the stars and I’m uncoordinated, so I’m sent to ballet class. Donned in pink tights like the other eight-year-olds and practicing pirouettes, my legs remain unsteady at the bar. I see the other girls—dance comes so easily to them. Their knees don’t hyperextend, their muscle tone isn’t low. They have energy for days, while I only have a willingness to smile.

I’m sixteen, and I’ve been shaving my legs for three years. As I walk down the corridor of the science wing, my freshly-shaved legs tremble when I walk past the boy I had once given my heart to, remembering how my legs folded beneath me when he handed it back.

My legs look great in the Levi’s I wear at a party—at least, that’s what the tall guy in the corner tells me. His directness causes me to flush, yet I step in closer. Nine months later, my legs want to run to him. He’s waiting for me at the altar, looking spiffy in his suit and just as nervous as I am. April is perfect for weddings, and ours is held outside. Friends and family stand beside us—watching as we meet, toe to toe and chin to chin, sealing our vows with a kiss.

Hot legs and cold feet, winter lovemaking is a dance my legs finally understand.

Motherhood comes with movement. My legs pace in the nursery—knowing when to kneel, knowing when to still. My legs carry me as I wrestle with fears. Am I strong enough to become the mother Miranda needs?

I know one thing. I’ll never call her lazy.

Years pass, and one child becomes three. Running, running. My legs are always running after children through sun-streaked days, running into piles of crunchy leaves, running up and down stairs because I don’t want to miss a single moment with them.

I examine my legs as they soak up the sun on the porch outside our first home. I imagine playing connect the dots with each freckle. With our children playing in the yard, Jerry looks at me, and his grin becomes sheepish. He’s remembering the sensation of my legs wrapped around him



earlier that day—the same legs that have scars, cellulite, and knobby knees are his favorite parts to explore.

Legs on vacation.

Legs walking at graduations.

Legs in the ocean.

Legs on shore.

Legs standing in line at Walt Disney World and Universal Studios.

Despite the chronic pain and too many falls, my legs have carried me to so many places. I've walked the beaches in Waikīkī. I've strode through San Francisco's Chinatown. I've climbed down into the tunnels behind Niagara Falls to catch a glimpse of its majestic cascades. I've ridden the gondola, the Funiculaire du Vieux, in Québec. I've soaked my legs in a clawfoot tub at the historic hotel, The Driskill, in Austin, Texas. I've toured the Christmas light display at the Gaylord Opryland Resort in Tennessee. I've hustled through a dozen airports and bus terminals—my legs, although slower than those around me, have taken me everywhere I've strived to go.

At fifty-one, my legs are still bendy; that never changed—the answer as to why came when I least expected it. Despite the effort of my legs to carry me around—I was born with a genetic disorder, vascular Ehlers-Danlos syndrome, that creates issues with connective tissues—a diagnosis even my legs can't outrun. The condition causes arteries and hollow organs to rupture and fail, but it also causes joints to dislocate and muscles and tendons to be weak.

Years of being criticized for falling and not being athletic had diminished a healthy sense of self—but no longer. Despite everything, my legs have tried their best. They are still trying, but it has become more complex. My legs are now blue and cold, and I scream in pain. I'm so uncertain of everything.

The vascular surgeon worries. Surgery is a great risk. It may be safer to let my legs go. I don't know what to say when he asks me if I'm ready to do it now. I am still reeling from the news. "You'll eventually beg for me to take them," he says, not in an unkind way. His legs work like they're meant to, but he's seen others like me. He grants me time to make peace with the inevitable, but I'm unsure if I'll ever get that far.

My legs move slowly as I leave his office—I depend on a cane to help carry me to the car. I wish I knew how to decide between two bad options: sever them entirely—or risk an arterial rupture that would be deadly in the operating room. With a list of accomplished life-saving surgeries behind me—how is it that I never considered potential amputation? I've lost pieces of me—spleen, uterus, gallbladder, sections of the small bowel, corneas, fragments of the aorta and iliac artery, and an outer thigh. Though painful, I parted with them all by depending on resilience and positivity to pull through. I don't feel resilient or optimistic about this one, although I hope to find it in me.

I am home looking out the window, watching heavy snowflakes coating the trees. Instead of letting my legs feel the sting of wind gusts, I cover them with a soft blanket and feel the warmth of Odie, a four-year-old Chiweenie, dreaming happily beside me. I don't know who I will become without my legs, but at this moment, I am complete. ♦

# LITMUS

MIO AOKI-SHERWOOD

**H**ello. You have reached Litmus International. To speak to an operator, say or press “one.” For liability questions, say or—

One.

**One moment, please. You will be connected with the next available operator . . .**

*Hello, you’re speaking to Litmus operator 6250. This call is being recorded for quality control purposes. How may I assist you?*

Hi—I’ve never done this before, so . . . I’m not exactly sure how to go about it—

*Oh, of course. It’s fairly straightforward. You say a statement—please make sure to phrase it in the form of a statement, not a question—then I’ll put it through the Litmus processor here and give you your answer.*

I don’t know what to start with.

*You may begin however you like. Our clients often open with less challenging statements, then gradually work their way up to the harder truths.*

Yes. OK. Am I—is this how it’s always going to be for me?

*Please phrase it in the form of a statement.*

Right, a statement. I haven’t been . . . haven’t truly felt like myself in a long time.

*Just a moment . . .*

*True.*

Yes. I knew that. Just testing this whole thing out.

Am I ever going to—I mean, I’m going to be happy again. Feel like myself again. Someday.

*I’m sorry, Litmus can only verify what you already think you know. We do not deal in objective truths, nor can we predict the future.*

What? If you can only tell me things I know, then I don’t see the point of this.

*Litmus International externalizes the process of introspection for clients. We tell you the things that you know, or think you know, deep down, but that you may not want to hear.*

Well, that’s kind of . . . bullshit. I don’t need someone to tell me what I already know.

*False.*

More bullshit—now you’re going to tell me I’m lying?

*I am only relaying the answers provided by the Litmus processor. Litmus is designed to reveal the lies we tell ourselves. If you no longer wish to engage our services, you may end the conversation and hang up.*

No, no, wait, I’m not done yet . . .

That day in the rowboat, I . . . pushed her in.

*Half true.*

Does that mean half of the statement is true, or that the whole statement is half true?

*I can't answer that, unfortunately—*

This is ridiculous.

*But, if you would let me finish, I will tell you something important . . .*

*She misses you, Ana.*

What are you talking about? And how do you know my name?

*How do you know your name, Ana?*

For Christ's sake, can you please stop with the games and just answer my questions?

*I don't answer questions. Litmus evaluates statements.*

OK, then evaluate this: Six years ago, on that day, at 6:25 in the morning, we went out in the boat. About an hour and a half later, I came back to shore without her.

*True.*

I survived, and she—Luci—didn't.

*. . . False.*

She couldn't have survived. Your Litmus processor must be broken.

*Fal—*

No, I don't want to hear it.

*That's precisely the issue. All right, Ana, I shouldn't do this, but I'm going to help you along here.*

And what does that entail?

*Tell me what's true.*

I thought that was your job.

*Exactly. Now, please, just tell me what you're certain is true about Luci and that day on the boat.*

Fine.

We went out in the little rowboat right before sunrise on a Thursday, at 6:25, like I already said. I was rowing, pulling on the oars over and over until my shoulders burned, and my hands were shaking, and the whole time Luci said nothing, just stared at me with big dark eyes. When I stopped rowing, I looked down into the water. I couldn't see the bottom.

We were fifteen years old, but in that moment, Luci looked so much younger. So naive. So content.

It was cold, for an August morning. The sea was deep blue, deadly calm. Someone, something, was whispering to me.

And then Luci was drowning.

*True. All of that, true. But it's not the whole truth.*

I know, I wasn't finished.

That day on the boat was the last time I saw Luci, and the first time I'd been apart from her. We grew up together, you know. She's there as far back as I can remember, right by my side, this little girl in dirty purple rain boots that she refused to take off.

She loved the rain—she was a water baby. It calmed her somehow, the feel of the water on her skin, kept her from feeling too much. I think it dulled the world around her. She used to stand outside whenever it rained, her eyes closed, letting it all wash over her, letting everything else fade away until all she could hear was the sound of raindrops splashing onto the sidewalk around her, and all she could feel was the water running down her face, cleansing it.

I don't know what she felt when she was drowning. She probably didn't like the water quite as much right then.

*Good, but still not the whole truth.*

What happened to “just evaluating statements”?

*Do you want my help or not?*

I don't know, do I?

*Can't answer that, it's not phrased in the form of a statement.*

You're a smart-ass, you know.

*False. I'm a Litmus operator. Now, I'm already overstepping my bounds by pushing you in the right direction, Ana. The least you could do is listen to me.*

I'm listening.

*What happened to Luci?*

Lots of things happened to her. I mean, something was always happening to her, because she was . . . she noticed things other people didn't. The exact blend of colors in a painting. The shape



of the pebbles at the beach. The pattern of the tiles on the floor of the school hallway.

But sometimes all the noticing made it difficult for Luci. Sometimes there was too much information coming at her, a confusion of voices talking over each other, grain of sand stuck in her sock, a bright light overhead that hurt her eyes, and she couldn't handle it, and her feelings would just explode out of her. It was hard seeing her in those moments, when I understood what was happening, I understood *her*, but other people didn't.

And then there were also lots of things she didn't notice. The way people talked about her, the way they looked at her like there was something wrong with her, the way she could never fully fit into their world because she didn't care about being the way she was supposed to be. I noticed these things, though, and I cared. So I started to resent her a little bit, resent the way she was so . . . Luci, and the way she didn't want to be anyone other than Luci, because she loved herself.

I loved her, too, but I don't think I loved her enough because I came back to shore without her.

*You're avoiding the question. What happened to Luci that morning?*

. . . Something that should never have happened to her.

*True. Do you want to know what else is true? Rhetorical question, don't answer. Truth, that morning in the boat, Luci was there when you rowed out. Truth, when you stopped rowing and looked down into the sea, you couldn't see the bottom, so you knew it was deep enough. Truth, Luci said nothing the entire time, even as you stood up on the bench of the rowboat.*

*Truth, your hands were shaking.*

*Truth, the sea was silent and there was no one else around.*

*Truth, you were drowning.*

No—that's not—

*Ah, I'm not done, Ana.*

*Truth, you were fifteen years old, and at that moment you thought you were going to be fifteen years old forever—your body sinking into endless blue, lungs on fire, eyes stinging. Truth, the sea whispered to you: it called you human, and it called you whole, and you didn't fully believe it, but something pushed you upward anyway.*

*Truth, when you reached the surface and breathed again, your chest felt like it had been ripped apart.*

*Truth, you heaved yourself back into the boat, your clothes sopping wet, your dark eyes a little duller than they had been before, hair clinging to your face, coughing up water.*

*Truth, you rowed back to shore without Luci.*

Hold on. That makes no sense. How would you—or Litmus, or whatever the hell—even know that? You weren't there. Luci was the one who was drowning, I saw it.

*Half true.*

I left Luci to drown.

*True.*

Yes, I know it's true, because I was there. Now you're just making shit up, telling me I drowned, but actually she drowned, but—

*Those two things are not mutually exclusive.*

What two things?

*Can't answer that.*

Of course you can't.

I'm quite sure that I never drowned.

*True, you didn't drown. You were drowning.*

And Luci just magically disappeared, I suppose. Because she was there when the boat left shore, and she wasn't in the boat when I got back.

*Again, half true.*

This is a complete waste of time.

## **You're avoiding the question. What happened to Luci that morning?**

*That's false, and I don't even have to tell you that. You know it's not a waste of time, or you would have hung up by now.*

Whatever.

*Do you want to know what happened to Luci?*

She drowned. I just said that, and you said it was true.

*False—you said you left her to drown.*

Same thing.

*False.*

*When you were sinking to the bottom of the sea, the water pressing in on your skull and filling your lungs, do you know why you were suddenly able to push yourself back up to the surface?*

No, I don't know, and neither do you, because you weren't there.

*False. False on all counts.*

What?

*You could swim back up because you were lighter. And you were lighter*

*because you left a piece of yourself at  
the bottom of the sea.*

*When the sea whispered to you, and  
called you human, and called you  
whole, and you didn't believe it, you let  
yourself splinter apart.*

*You left a girl with big dark eyes and  
purple rain boots down there.*

*She sank down, down, not  
understanding why, squeezing her eyes  
shut, covering her ears.*

*You left her to drown.*

*And—still she loved herself, even when  
you couldn't.*

*Do you know what else the sea  
whispered to you, while you hung in its  
arms?*

No.

*It whispered your name.*

*It called you, Luciana.*

Don't do this to me.

Do what?

Please.

*Sometimes the truth is hard, even when  
we already know it.*

Please. I don't want it.

*I'm telling you what you need to hear,  
what you need to believe this time.*

*Last time, you were drowning, and then  
you weren't, because you made the hard  
choice to live. But you didn't choose  
fully. So I hope that this time you will  
choose fully, that you will let that  
drowning girl come up to the surface,  
and love her, and believe—you are  
human, and you are whole, and you are  
wholly human, Luciana.*

Luci's gone.

False.

*She's still here.*

*I'm still here.*

*Sitting at the bottom of the ocean,  
drumming my fingers on the sand.*

*Drowning, and as long I'm drowning,  
you will never breathe fully.*

*Drowning, but not drowned.*

Luci? . . .

Hello?◆

Our podcast features  
conversations, readings,  
and information from the  
authors and artists of  
*Kaleidoscope*.



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reach and connect with readers  
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# THE END OF THE ROAD

KATHARINE YUSUF

“Is there a reason we’re in such a hurry to accomplish everything on our first day here? Can’t we save this one for later?” I implore Jason as we pull into the Department of Motor Vehicles. “After visiting the title company and the two banks, I’ve run out of energy.”

“Tomorrow is Saturday, so this was our only day to go to the bank or sign our house papers. We need to get these things out of the way while I have time,” Jason curtly replies. He is wound so tight and struggles to keep his voice even. “When I start work Monday, I won’t have time to drive around and open accounts or get our licenses.”

“We don’t have to go anywhere else after this, right? My brain has already turned to mush, and my body isn’t far behind.” Pointlessly rubbing my temples, I attempt to thwart my inevitable headache. I sense my multiple sclerosis (MS) has slowly begun wreaking havoc at this point and is weakening me from the top down.

“This is the last place,” Jason says, turning toward me. The tension drains from his face and is replaced with concern. “I’m sorry, sweetie. I know this has been a lot. Are you going to be okay? The move has been a whirlwind, but we’re almost done. I promise you can sleep until the movers get here next week.”

I glance wearily at Jason. *Whirlwind? You don’t say. You get a job offer in July, give me a single weekend to find a new*

*house in August, and move me cross country from Kentucky to Seattle in September. For that stress and craziness, I need and deserve at least a month of uninterrupted sleep.*

Nevertheless, I give his hand a tight squeeze, hoping to hearten him and embolden me. I ought to be able to do this one last errand before I completely cash out. There’s a reason Jason calls me “Super Nicky.” Taking a deep breath, I pull up every ounce of energy from deep in my core, clear my pulp-filled head as best I can, and reach for the door handle.

Since I’m moving at sloth speed, Jason is already there waiting to clutch my hands and steady me as I swing my stronger right leg out. The weak half-noodle left leg is next. I have to do some begging, pleading, and bargaining to get my legs to agree to the task—*you can be horizontal and weightless for days, if you do this one last thing.*

*Pl-ea-se.*

“Are you sure you don’t want to take your wheelchair?” Jason asks, worry swimming deep in his eyes. “We don’t know how far we’ll need to walk, and you’ve already had a long day.”

He knows my answer when I look at him with single-minded determination, but I humor him with a reply anyway, “This is one place I definitely need to be walking into. I don’t want the added attention a wheelchair brings.”

Locking arms, Jason and I begin the slow walk across the parking lot to the office's entry. Concentrating on every step, I push aside my fatigue and try to bring life back into my tired limbs. Forcing myself to stand a little straighter when I'm tired is akin to trying to straighten a car dealership's dancing puppet, but I grit my teeth and do my best. I focus on the task in front of me and know I can do it. Besides, transferring my license should be quick and easy: give them my information from Kentucky and get my picture taken. No big deal.

Pulling open the glass door, Jason helps me enter an expansive waiting room, consisting of rows of chairs facing groups of cubicles. Glancing around, I come to the painful realization I will have to cross this wide, open space to reach the mini offices. Sitting me down, he goes to sign us in and gives me time to strategize. I become AAA for a moment and plot the shortest route from point A to point B. My decrease in steadiness increases my chance of falling, so distance directly correlates to my discomfort level when walking in front of people. Large open spaces with nothing to grab or touch for extra balance are unforgiving. The least amount of time on exhibition is preferable.

When our name is finally called, I reach for Jason's arm and shakily get to my feet. Embarking on the treacherous walk across the exposed landscape to the representative's desk, I struggle to lift my cement-block-weighted feet. On full display for all to see, I feel like a sideshow at the circus—the entertainment provided to relieve the waiting customers' boredom. Self-consciousness takes hold just as beads of sweat start to form on the back of my neck and directions begin running through my head: *Don't let anyone see how hard you're gripping his forearm for support. Walk slowly. Put one foot in front of the other. Be sure to pick up your feet. Keep your head up, look natural, and keep talking.*

"I hope we don't have to take a driving test." I jokingly whisper to Jason as I sit down. He laughs stiffly, knowing the seriousness and full implications of my jest. Although I haven't driven in seven years, I cling to the delusion that, if absolutely necessary, I will still be able to. I keep my keys in my purse and license in my wallet, just in case.

The woman behind the desk, Rhonda, simply smiles and assures me there is no driving component, merely a straightforward vision test. My mouth runs dry as one hurdle

is replaced with another—albeit shorter—one. There is no such thing as a "straightforward vision test" in my world. That's the one exam I have a history of failing, and unlike calculus, I can't study and retake the test. *Eyes, you have one job. Focus on the letters in front of you.*

Fixing a false grin on my face, I tentatively hand over my precious Kentucky driver's license. We commence mindless chitchat as Rhonda starts entering our information. Jason is the first one to peer into the white, adult viewfinder. He has no problems rattling off the glowing line, "E, D, F, C, Z, P."

That doesn't seem so bad, my muddled brain rationalizes. I simply have to read one line, six measly letters. Even I should be able to stumble through that.

Taking my place in the hot seat, I press my head against the machine, stare into the light, and see . . . a whole lot of bright nothing. Fatigue has consistently affected my eyes harder, but this is a bit extreme. When your eyeballs unexpectedly decide to snooze, the phrase "falling asleep on the job" is taken to a new level. I sit back and rub my eyelids, regretting my decision to wear contacts. My glasses don't stress and tire my eyes nearly as fast. Attempting to read the script again, time freezes, paralyzing my lungs, as I once more see nothing.

I sense my psyche cracking, allowing panic to seep into my swirling mind. This can't be happening. Not now. Why can't I make out even one letter? This is too important to fail. Why didn't I memorize Jason's answers? I accidentally do that at the eye doctor's office all the time; why didn't I think to do it here?

Overcome with the idea of losing my license, my last connection to self-reliance, my breath returns in hyperventilating gulps. Fright clouding my eyes, I look at Jason and distraughtly whisper, "I d-don't s-see anything."

"Nothing? Not even dots?"

I frantically shake my head as I strive to slow my breathing, "I know I'm tired, but my eyes don't want to work at all. This has never happened before."

Drumming my fingers on the counter, I unconsciously match the beat of my thudding heart. Jason places his calming hand

on my shoulder, attempting to soothe me, as he explains the situation to Rhonda. I perk up when she offers to enlarge the text. Do I really get another chance? Puffing out my cheeks to calm myself, I release a slow, controlled breath. I cross my fingers under the table and make a second attempt.

**He is trying to be nice and supportive, but I am brutally aware he has no clue the significance of that little two-by-four-inch piece of plastic.**

Staring into the white device on the table, my chest tightens anew and my breathing becomes labored. I barely see six tiny black fly specks. She may have enlarged the image but to me, the result merely looks like the lens got dirty. Squinting, I try to make one dot transform into a letter, but no such luck. I am once again the blindfolded kid who got an extra swing at the piñata, but misses for a second time.

“Does that help at all, hun?” Rhonda asks with a hopeful smile on her face.

Misery sinks in as I slump back from the machine. Rhonda grasps the defeat, anguish, and despair written plainly across my face and suggests we test my reflexes and reaction times instead. Wiping the previous outcomes from my mind, I choose to stay on this emotional roller coaster and feel my mood start to brighten. My reflexes are pretty good I think—at least they are when the doctor hits my knee with the little hammer thingy.

The revelation that I must be a sad, pathetic case if she’s willing to give me yet another chance tinges my elation. When we walked in, maybe I was leaning too much on Jason. Hmm, or perhaps she saw my foot dragging a bit and felt sorry for me. Regardless, she’s nice enough to give me a third chance, so I need to take advantage of it. Desperate to hold on to this sliver of my past, I’m again begging my body to work and thus far—as if it’s an old beater car that I’m trying to start when I’m late—the engine won’t turn over.

In trepidation of the upcoming evaluation, my intestines tie in knots and my stomach gradually moves north. Trudging out to the rental car with Rhonda and Jason, I have flashbacks of walking to my college finals. However, no exam ever gave me anxiety like this, building and intensifying with every step. There is not a redo in this situation—no next semester. This is a hard finale.

“Nicky, climb into the driver’s seat, start the car, and get comfortable. I’m going to evaluate some things while we

sit in the lot,” Rhonda instructs when we reach the Nissan Sentra. “Now, when I say ‘GO,’ I want you to press on the gas pedal as if you were driving. When I say ‘STOP,’ switch to the brake as quick as you can. OK?”

Rhonda’s test doesn’t sound hard at all, “Yeah. I can do that,” I answer optimistically. Sliding in behind the wheel, I take a moment to let the feeling sink in. No matter the vehicle, the driver’s seat can bring to mind many an escapade of my youth. The seat is like slipping on my favorite sweater: familiar, comfortable, and steeped in good memories. Starting the engine, I wave at Jason who’s standing on the sidewalk, giving me a thumbs-up. I got this.

“Ready . . . Go.”

I push on the gas.

“Stop.”

I switch to the brake.

“Alright, let’s try that a few more times. Get ready . . . Go.” I again punch the gas pedal toward the floor as hard as I can. “Stop.” I slam on the brake.

Rhonda pauses to scribble something on her clipboard, but I think she just wants to give me a rest.

Like I need it. I feel like I never took a break from driving.

“One more time, ready . . . Go.” For the last time, I rev the car’s engine. “Stop.” My foot moves to the brake pedal.

Thinking I did pretty well, I don’t pay much attention when she heads back inside without saying a word. I know my reaction times weren’t the fastest, but I’m sure they are passable. My mood starts to brighten, resulting in a beaming smile as Jason walks up to the driver’s door to help me.

“That was pretty good, wasn’t it?” I crow. “I knew . . .” My voice falters and my light dims as soon as I see his face. His brown eyes are filled with a muddle of sadness and regret as he looks at me and slowly shakes his head. We start to retrace our steps across the parking lot, and my brain spins with confusion, “But my foot was moving so fast. I know I did okay.”

Squeezing me tighter as we walk, Jason kisses me on the cheek. “You may think your foot was moving fast, but the rev of the engine told another story. Don’t worry. You don’t use your license, so an identification card will be perfectly fine.”

He is trying to be nice and supportive, but I am brutally aware he has no clue the significance of that little two-by-four-inch piece of plastic. A ticket to open roads and freedom



since I was fourteen, my license has always been directly connected to my independence. In my small rural hometown, little splurges—restaurants, movie theaters, new faces—were at least twenty miles away, so driving was a necessity. That coveted piece of plastic affirmed my ability and bestowed on me the privilege of leaving and exploring outside the confines of the city limits. Countless miles on asphalt made the open highway my dear friend and confidante. I've shared more of my secrets, heartbreaks, and tears with the roads across the country than my best slumber party girlfriends.

My license is also the last corner of a security blanket I've been holding onto from my "normal," pre-MS life. Piece by piece, each square of this quilt has been slowly ripped from my life like a tooth from a mouth with no novocaine. Now all the sections have been officially ripped away and dissolved leaving my broken body bare and exposed. I detect a cocktail of failure and embarrassment, with a dash of defeat, forming in my stomach. The more it churns, the more I lean against Jason's shoulder. By the time we reach Rhonda's desk, I'm leaning heavily on Jason.

Avoiding all eye contact, Rhonda does not mention my mighty strike out and proceeds to finish Jason's license. While he is getting his picture taken, I sit and do my best not to crumble. My body is overcome with fatigue, my brain is muddy with emotions, and my vision is bleary due to unshed droplets. Simultaneously mortifying and humbling, my confidence is crushed, pushing me precariously close to the edge. Nonetheless, I fight to hold my emotions together while we're in public. Crying will merely increase the humiliation and embarrassment exponentially. Besides, no one can understand the depth of this loss and pain.

When she finally addresses my five-ton elephant, Rhonda turns to me with a disappointed look on her face and what I'm positive is an accusation in her eyes: *Why did you waste my time if you knew all along you were going to fail?* Her judgmental appraisal shames me, digging the knife in my chest a little deeper. The silent reprimand almost causes the flood to break the dam. Instead, a new, deeper anger sparks and takes hold. She knew I couldn't see, yet tested my driving reflexes anyway just to demean me more. I refuse to give her the satisfaction of seeing me broken.

"After multiple tries," Rhonda informs me, "you didn't meet the necessary requirements for a Washington license. I'm only able to give you an identification card. I guess you can come back and try again if you want, but you will have to reapply. You can't skate by with your Kentucky one again."

*Save it, lady. I don't want or need to hear your condescending memorized script right now. I'm a thirty-seven-year-old woman—not a pimply teenager. And you know I can't reapply so why would even say that? Just take my picture so I can leave.*

Jason helps me stand in front of the blue background. I'm unable to balance on my own at this point so he has to lean out of the picture while still holding my waist.

"Hold still. Try to stop shaking. One . . . two . . . three," I hear Rhonda count. Finally, I'm done and can get away from this petty witch before I scream. I want to go mourn in peace. Fatigue is overpowering my temporary block and now tears of anger and loss are starting to pool together around my bottom eyelashes again, about to run over.

"We need to take that again. And try smiling this time."

Is it that hard to take a picture? I just know she's doing this on purpose for payback. She can clearly see I'm barely standing and holding it together, so she wants to extend this as long as possible. I'm not able to hide my heartache at this point. While I struggle to smile on the outside, my inside world is in turmoil. This is a grin you try to give at the funeral when everyone keeps asking, "How are you doing?"

"One . . . two . . . three," Rhonda counts again.

I'm not doing another, so she'd better be happy with this one.

After paying our fee, I stagger to the door with Jason's help. I don't care who might be watching at this point—I lost my dignity twenty minutes ago. Walking into this building, I held my head high as if I was entering my boss's office to discuss a raise. Leaving, I have my tail between my legs and my pink slip.

We barely reach the car when the waterworks start. I can't hold my anguish in any longer. A piece of me, of my history, has been pulled out and is officially gone for good. So what if I didn't *use* my driver's license? Simply knowing the card is in my wallet allowed me to keep that chapter alive, gave me the comfort of my delusion, and let me believe MS hadn't totally upended my life. Now my license and independence are gone. That history is unceremoniously closed, and now a future of dependence starts. ♦

*Previously published in More Stories from our Center: Lives Challenged by MS (Spring 2024). Reprinted with permission of the author.*



ANNE MIKUSINSKI

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## TO BE CONTINUED

My spirit  
 Hovers  
 Half-past dead  
 Searching for the  
 Next (or Last)  
 Exit  
 The quickest  
 Out  
 The best  
 Ending  
 To a story that has veered  
 Too far off course to be  
 Salvaged.

My once-white flag  
 Droops  
 Now gray and soggy even  
 Surrender  
 Has lost its  
 Allure.

A period of silence follows  
 Until  
 A question emerges:  
 "So what now?"  
 And nudges me to answer  
 "Continue."

ROSELYN PEREZ

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## MY FAVORITE MELODY

Like fragments of a song that filter through my window,  
 You are on the tip of my tongue,  
 A melody I know I know,  
 If only I listen long enough.  
 I hear you in my silent spaces,  
 In my still moments, you move me.

It is a surprising compilation, rapid and delicate as hummingbird wings,  
 The beat inspiring a fledgling hope,  
 And quiet terror at the improbability.

It is an unexpected joy,  
 Making me wish I knew how to dance,  
 Or had the courage to move anyway.

Calling out to you,  
 Across a crescendo of insecurities,  
 My voice falters, falls back in my chest.

As you leave me to myself again.  
 I rewind back to the start.  
 Try to memorize the sound of you.  
 Even as your harmony slips beyond my reach,  
 I leave my window open, should you want to reach me once more.

# A CHEMICAL IMBALANCE

ZACH PIETRAFETTA

**D**r. Ernst Sullivan, chief terraforming officer of NASA's mission to Bahazar, sat in his office on the newly terraformed planet. He looked at his wall and observed a Venn diagram. It had four overlapping circles labeled: "available solvent," "energy," "appropriate environmental conditions," and "environmental requirements." In the middle, the perfectly balanced center, within all four circles, "habitable."

Ernst turned quickly to the Para-Terraform 7.0, as it ran its elemental equilibrium equation. "The oxygen levels on Bahazar must decrease," Ernst anxiously repeated three times like a wizard casting a spell. He flipped a switch; the oxygen levels were supposed to decrease . . . they didn't.

Trembling, Ernst toggled on his keyboard through surveillance video of the five zones of Bahazar—agricultural, industrial, pleasure, fitness, and siderian. The siderian zone was malfunctioning.

In para-terraforming Bahazar, Ernst had recreated the Great Oxygen Event,

which occurred on Earth 2.5 billion years ago and led from anaerobic life to aerobic life. He did this by first tapping into water sources beneath Bahazar and populating them with cyanobacteria. The cyanobacteria multiplied rapidly, but at a controlled rate, and started to produce the first oxygen on Bahazar. This was the beginning of a new Eden.

In scanning the siderian zone, Ernst detected that the cyanobacteria were multiplying at an exponential rate, rapidly producing excessive oxygen like an uncontrollable virus. At this rate, the atmosphere would become toxic in two hours. Bahazar's 500 inhabitants would suffocate.

*Terraforming. Terror forming. The balance is off. They must have mutated.*

Ernst crawled under his desk, rocking back and forth, muttering to himself, "Goldilocks. Goldilocks. Goldilocks."

## Just Right

As a child, Ernst would lie in bed as his mother read to him. Fairy tales. Ernst remembered them all vividly, but one

among them captured his imagination: *Goldilocks and the Three Bears*. At five years old, Ernst was transfixed by one line in particular:

"I'd like the porridge to be not too hot, nor too cold, but just right."

The idea of "just right" deeply fascinated Ernst. He was obsessed with straightening things—soap bottles, cups, chairs, pencils, shoes in the mudroom, anything out of order. For Ernst, this meant adding order to chaos. The idea of a feel-good middle zone, a perfect medium, relaxed his anxiety. It could make the fear stop, for a moment.

Ernst suffered from unwanted sensations, obsessions that drove him to repetitions.

## OCD (Others' Conceptions of the Divergent)

### Patty

I wake up in the middle of the night one Saturday to come downstairs and see Ernst perseverating on the thermostat.

“The right temperature, right temperature, right temperature.”

Ernst is having another OCD episode.

“Lower the temperature to approximately fifty-eight to sixty-two degrees. There’s no need for an excessive heating and cooling system. We just need enough heat to protect the pipes,” said Ernst while scratching his cheek. I noticed that his cheek was getting quite sore and red, on the verge of bleeding.

“Ernst, calm down; this is your obsession, not life-threatening.”

My words have little impact on him: he continues to chant his lines like a parrot mimicking an authentic human being. As his older sister, it pains me to see him a slave to his anxiety.

“Ernst, let’s get you out of this. 5-4-3-2-1. Focus on five things you can see. We’ve done this before. This will regulate you.”

Ernst turned reluctantly away from the thermostat, directly toward me.

“Thermostat.” he murmured.

“Great job, Ernst. What other things do you see?”

“S-s-space heater,” he stammered. “Pictures on the wall,” Ernst yelled out loud.

“Shhhhhh, Ernst. The rest of our family is sleeping. Keep going.”

“I see a window. I see my sister,” Ernst said. I could tell he was relaxing, his stress hormones no longer surging.

“OK, Ernst, now focus on four things you can touch.”

“The thermostat, I can touch the thermostat,” he said with rigid fixation, as he threw himself at the thermostat.

“Let me press the button to turn it on and adjust the temperature,” he yelled.

“The right temperature, right temperature, right temperature.”

Ernst begins scratching his cheek again fiercely, while toggling the temperature control. I am losing him. I am not able to soothe him.

“Mom, Dad, wake up and come here right now. Ernst needs your help,” I scream out in desperation.

### *Milo*

Ernst and I park our bikes by the side of the field. Biking always relaxes him. That is, until we have to park our bikes. This triggers him. He has to line it up exactly even with mine; it can’t vary at all; it can’t be on uneven ground.

I have to distract him, so I take his hand gently. “Big bro, listen to the wind blowing through the wheat field. Ernst, it’s OK.” We start to walk across the field together, a rich field of wheat we like to visit. It is a beautiful summer day; Ernst and I are wearing shorts and T-shirts; the wheat is rustling, the wind is blowing, and the birds are chirping.

“Ernst, what do you hear?” I asked him.

“I hear cicadas in the distance rubbing their wings together like high-pitched whines. They make nature fascinating with their endless swarming numbers each spring and summer,” Ernst’s voice echoed across the field.

“Good,” I said with encouragement.

Ernst is starting to soak up the world; this is good for him.

“Now, can you think of two more things that you can hear?” I asked him.

“I hear the birds singing their sweet song: it’s the glory of the pursuit of thriving. That sweet song they sing. I love being outdoors with you, Milo.”

“Do you think you’re a poet, Ernst? I know you have that in you.”

“I now hear the wheat rustling all around us. It feels so good on my body; nature is an almighty being; she conjures up her own witchcraft to help produce a vibrating sound.”

Ernst’s eyes narrow. He drifts off into a dream-like state. I ask him, “What are you thinking about?”

He answers, “I hear the jazz song ‘Witchcraft’ by the Bill Evans Trio.”

Sobbing, I realize that even though I can’t fully understand how Ernst is feeling, I feel for my brother, a deep abiding love.

### *Stephen*

I clean the toilets at the conference center, rotating the brush left to right, left to right, left to right, three times. That’s what it takes. I wonder if Ernst gets it from me.

**“Ernst, calm down; this is your obsession, not life-threatening.”**

### *Katherine*

Opening the trifold blue and white pamphlet the doctor sent home with me, I read aloud to myself. Bold green letters jump off the page and assault my eyes:

**OBSSESSIONS, COMPULSIONS, ERP THERAPY.**

The words begin to spread out like a map, charting a new direction for me.

“Exposure and response prevention therapy or ERP was created specifically to treat OCD, and it works by interrupting the cycle of obsessions and compulsions. In ERP, you’re encouraged to gradually and carefully

confront your obsessions, sit with the discomfort you feel, and resist the urge to act on compulsions.”

Confused, my mind rushes through all that was certain and all that I didn't know. It was certain that Ernst had OCD: he received the diagnosis from his doctor. I didn't need the diagnosis—I knew he had been paralyzed with fear since he was five years old. But is it possible to help him?

## A balanced equation. A chemical equation could bring order to chaos.

Will our insurance cover this?

*Sit with the discomfort you feel; sit with the discomfort you feel; sit with the discomfort you feel.*

I read on:

The 5-4-3-2-1 technique: focus the patient on five things they can see, four things they can touch, three things they can hear, two things they can smell, and one thing they can taste. It shifts the patient's focus from anxiety-provoking thoughts to the present moment.

*Maybe, we can do this ourselves.*

### Saving the World

Ernst's repetitions assured him that catastrophic disasters would be avoided.

At one point, Ernst felt compelled to straighten every chair in the house, bursting into his siblings' rooms to straighten their desk chairs, straightening every dining room chair even with people sitting in them. At another point, Ernst felt the urge to repeatedly say, “MC13 is the gene that makes my mother and older

sister's natural hair red.” He would say that every time he walked through a doorway in his house. If he didn't, he feared death. Another ritual he performed was rubbing his eyebrows every time he had a thought about world destruction; with every thought, he would rub his eyebrows intensely fifteen times, until they eventually fell out. At some point, like his eyebrows, the habit faded away, leading only to another one.

### Terror Forming

Fifteen-year-old Ernst hid, shivering under the table in the large conference room. His eyes had to be closed perfectly. No light could come through or else the Earth would be destroyed. Ernst hoped that his father wouldn't find him. A janitor at the local conference center in Houston, Texas, Ernst's father brought Ernst to work with him to give his siblings a break. Ernst challenged his siblings; they were perplexed by his obsessions, repetitions, and rigid behaviors. At his father's work, Ernst would escape to hide in private, dark, soothing spaces in the conference center. These spaces relaxed him—for at least a moment, he could feel a lack of terror.

Under the table in the conference room, as he rocked back and forth, Ernst heard footsteps filing into the conference hall. He could hear a microphone squeal as someone began:

“Good morning, welcome to the tenth lunar and planetary science conference and the first terraforming colloquium. We all know that current global climate patterns are unusually inhospitable and can be expected to worsen even without artificial damage unless purposeful steps are taken to counteract these natural trends.”

*I must be dreaming.*

Ernst's paralyzing fear of global crisis was the topic of a day of speeches and conversations from a range of

scientists, astronomers, and industry experts. He held tight to the base of the table, avoiding the flailing feet of these strange adults. As they scrawled in their notebooks and clinked their glasses for hours upon hours, one phrase among the millions struck Ernst:

“Other worlds in the solar system can be transformed to host earth-like biospheres, to become ‘new earths.’”

*The earth wouldn't just die? Could a nearby earth replace it?*

Another speaker bellowed, “The traditional science fiction term for this concept is ‘terraforming.’ Its definition includes the artificial introduction and maintenance of ‘earth-like’ conditions on other planets in the solar system and beyond to serve as new habitats for future humanity.”

Ernst's mind went numb.

*Terror forming. Terraforming.  
Destruction could lead to creation?*

Suddenly, Ernst's anxious body was calmed.

### A Chemical Balance

Mr. Ricardas walked to the front of his tenth-grade classroom. A metal table was piled high with a mysterious sand-like substance.

Ernst was panicked while he watched: orange sparks threw the oxide crystals into the air, producing an effect that looked like a miniature volcanic eruption. He saw a world exploding.

Then, his teacher wrote this equation on the board:

Ammonium dichromate,  
(NH<sub>4</sub>)<sub>2</sub>Cr<sub>2</sub>O<sub>7</sub>, decomposes when heated to produce chromium(III) oxide [Cr<sub>2</sub>O<sub>3</sub>], nitrogen gas, and water vapor:  
(NH<sub>4</sub>)<sub>2</sub>Cr<sub>2</sub>O<sub>7</sub>(s) → Cr<sub>2</sub>O<sub>3</sub>(s) + N<sub>2</sub>(g) + 4H<sub>2</sub>O(g)

A balanced equation. A chemical equation could bring order to chaos. He relaxed in his chair and breathed deeply.

*This will solve so many problems.*

### 5-4-3-2-1

Thirty-two years later, pioneering a mission to escape a dying Earth, Dr. Ernst Sullivan sat under his desk, beguiled and terrified.

*What chemical reaction could reduce oxygen? Carbon dioxide. How do I produce it?*

His colleague, Dr. Clementine Sandoval, had developed the agricultural sector on Bahazar.

Ernst realized that the most expedient way to reduce oxygen was through rapid production of carbon dioxide. The most available resource to reduce carbon dioxide was the biomass on the planet.

Ernst crawled out from under his desk. He had to do the unthinkable: burn the crops.

*What would she think? Would her heart be broken?*

He looked for his pill bottle on his desk; he fumbled for it and tripped, striking his head against the desk. He felt the rush of blood and a warm trickle from his forehead into his eyes. Bleary-eyed, he opened the bottle and gulped down three tablets of Paroxetine. “Goldilocks, Goldilocks, Goldilocks,” he anxiously repeated three times.

He looked at the control panel with angst and fury. Overwhelmed, he thought about the balance of oxygen on Bahazar. Ernst’s finger hovered above the turquoise button—the vaporize protocol. He contemplated pressing it. A range of mixed emotions washed over him, as he considered destroying Clem’s beautiful crops.

*How would Clementine feel if I did?  
How would she feel if I didn’t? How  
will we survive without them?*

Ernst remembered earlier that day seeing Clementine going about her routine in the agricultural sector. He was struck by her dazzling beauty, her long, flowing, bright red hair, gorgeous alabaster skin, and pale blue eyes. In the seven years since they met, Ernst’s ardor had not lessened; instead, he had grown more captivated like a clownfish paralyzed by a sea anemone. Foolish in love, Ernst was so enamored with Clem that he could never imagine destroying what she had worked so diligently to create.

Ernst crawled out from under his desk and stood with resolve.

### 5-4-3-2-1. ♦

*Author’s note: OCD is not just a stereotype of being neat; it means imbalances between chemical messengers, or neurotransmitters. Glutamate and gamma-aminobutyric acid (Gaba) in certain brain regions. Chemical imbalances can transform a planet; these imbalances can also transform a person.*

TIM MURPHY

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## PUDDLE LEFT BY THE STORM

If I can do this,  
so can you.  
But neither of us  
should have to.

If you can survive  
this disease,  
you can live  
through anything.

But survive  
to what end?  
For if someday  
you walk free

from the vice  
of its symptoms,  
as you glimpse  
a reflection

in the puddle  
left by this storm:  
who  
would you see?

# TO HAVE AND TO HOLD

DIANE BELL

**W**e were young when we made those vows. At the time, they seemed so romantic, so precious, so idyllic. The person who officiated our wedding said that vows are something we make in a time of joy when things are easy, and you have your entire life together ahead of you. You make vows when things are easy because you might not make them when things have fallen apart.

Those words, that idea, didn't resonate with the same meaning back then that they do now. To have and to hold was all about romantic love. I am yours; you are mine. We are in love. Let's hold each other.

**Tenth anniversary—the year of tin or aluminum, symbolizing the strength and resilience of marriage.** Two children—one with early onset severe mental illness, the other traumatized by the fact that she was the younger sibling of said offspring. What did *to have and to hold* mean in those years? It meant holding on for dear life. Holding on to the only other person who loved these children as much as I did, who would put in the emotional blood, sweat, and tears necessary to try (unsuccessfully) to meet everyone's needs. To give each other grace when we lost it and to be grateful for this partnership. Even though we probably both looked at each other wondering what we had gotten ourselves into. We held.

**Thirtieth anniversary—the year of the pearl, symbolizing love, purity, and wisdom of marriage.** Life is less hectic; children are grown and somewhat out of the nest. One child needs oversight and support, financial and concrete. The other needs emotional support to come to terms with the emotional fallout from her childhood. We play tag team; you go here, and I'll go there. Meet you at dinner for a glass of wine and some unwinding. We keep holding on.

**Thirty-fifth anniversary—the year of coral, symbolizing the longevity and success of marriage.** Coral is now endangered. You, dear husband, develop all kinds of emergent health issues just as the COVID-19 pandemic has shut down the world. Fever and cough? Must be COVID-19, stay home. Don't come to the hospital. That goes on for months until you have a stroke. I hold your hand in the hospital—when they finally let me come see you. You can't speak and you never fully get your voice back. Your memory and executive functioning aren't what they used to be. But now, you hold on to me and I pick up the slack.

Over our lifetimes, we lose bits of ourselves, bits of our dreams, and sometimes entire parts of ourselves. But they don't diminish the ties. I thought I had lost you. I just lost bits of you. Big bits of you, but not you. I have you and I still hold you. Promise.

We still have and we still hold. ♦



# WHERE ARE THE ADULTS?

LINSEIGH GREEN

Only two weeks into university and your new computer has stopped working. The youth at tech support frowns.

“How much time do you have?”

“I have a Broadway show at two.” A faint discomfort nudges your stomach. You scan the glossy storefronts lining the second tier of Columbus Circle. Would it hurt any of them to carry water?

Tech youth smiles up from testing the keys. “Oh, neat! You know I like seeing those plays and stuff but I’d go more if I could find people to go with, you know? I mean, could you imagine going by yourself?” He shakes his head. “Wouldn’t be caught dead doing that!”

You titter politely and wonder if you really are supposed to feel pathetic for, indeed, going to the theater alone. You turned eighteen exactly a month ago, meaning you’re more seventeen than eighteen, meaning you hardly count as an adult and can therefore not be expected to know these things. An

hour later, you find yourself lodged between two middle-aged couples. It’s quite obvious you’re alone, but you are merely a backdrop in other people’s shared experience. Either you stick out or you’re invisible. The smell of burgers invades from the right, creeping and potent. The source is in fact not a greasy bag from Junior’s but your neighbor’s body. The house dims, and the smell gets louder, festering into something resembling the byproduct of an extended belch. Tides of nausea threaten your stomach. The dull pain begins to sharpen, deepen, just below your navel. The spectacle can only do so much to help you escape.

By intermission, the knife has fallen into a pattern, working its way back and forth through your abdomen as if it was carving a roasted Christmas pig. Pain is tossed between your abdomen and your throat like a ball game. You find a chair outside the ladies’ room and catch your breath. You wonder if you’ll last through the second act. But the idea of abandoning a Broadway musical is blasphemous—if not because of the exorbitant price, then the stubbornness

to remain in the cradle of delightful theater. Never one for acting solely on your own judgement, you turn on your phone and call home. Your mother picks up. She thinks you should leave, lie down.

The knife slides in further. Helplessness slowly sets in and the world expands. You can’t swim in it. You can barely float. “Help,” a voice gasps. *Help, help, now. Help.* Can the ushers get you an ambulance? Surely it hasn’t come to that. You approach one, but the most you can say is that you need to go home.

“But I would really like to see the rest of the show—I really don’t want to leave—”

They wonder how crazy this child can be to consider putting off seeking medical attention to see act two of a musical comedy that parodies Shakespeare and boasts sixteenth century kick lines. Their supervisor gives you their card and begs you to take care of yourself.

You burst through the doors and into Times Square. It's too bright; it's too much; you can't swim.

"Don't hang up," your mother instructs.

As you head for the 42nd Street station, you consider approaching one of the police officers for help. Is that all you'd say? "Help," and then everything would be taken care of? Then you consider their bulletproof vests; their helmets with clear shields over their faces; the machine guns held at the ready. Their gear has intensified since ISIS released a video threatening to attack New York. What if you startle them? Approach them in the wrong way? You'd seen too many shootings of unarmed black people that summer. Times Square begins to tilt. You head underground.

The phone call drops. The subway car is packed with passengers immersed in self-induced aloofness. *Sit down. Sit down.* A slither of exposed metal between two women. You wobble toward it, but a man pushes past you and dives for the seat. People glance at you, registering that something isn't quite right. But it's filed away as quotidian New York strangeness and they "unnotice" the girl crumbling within herself, swaying from the pole. You wonder if anyone will offer you a seat or ask if you need anything, but the city wills you invisible.

Union Square. As you struggle above ground, you redial your mother.

"I don't think I can make it."

"Where are you now?"

"I'm in front of Whole Foods."

"OK. You're almost there."

How long will it be before you collapse in the middle of 14th Street? You try to gauge how bad it will be when your head hits the asphalt. "I can't do it. I can't do it."

"Yes you can. Keep walking."

Somehow, you're stumbling forward while drowning.

"I can't make it, Mom. I can't make it."

"You're so close."

Miraculously, you reach the revolving glass door of the freshman hall on 12th Street. Your hand shakes over the keypad. The numbers blur together. As soon as you step out of the elevator and enter the "suite," you bend over the toilet and vomit for a while before changing into your pajamas and lying down. Your roommate enters. You warn that you're not feeling too well. You don't want her to feel uncomfortable or alarmed.

She shrugs. "OK." Turns her back to you and sits at her desk.

"Dad's just called up to the school. An RA is going to come check on you. Don't hang up."

You don't think that's necessary, but the RA on duty arrives anyway. She looks annoyed, but she asks what's wrong. It's got to be one of three things: alcohol abuse, overdose, or pregnancy. You're a sheltered Southern prude, but she only half-believes your story.

"So before I can call 911, I've gotta get clearance from the nurse and security

downstairs. I'm gonna put you on the phone with the Health Center. Hold on."

She hands you her phone. The nurse sounds just as annoyed as the RA looks. "Have you been drinking? Doing drugs? Do you think you might be pregnant?" You tell her no, no, no, but she doesn't believe you. She repeats the questions over and over, as if, the fifth time around, you'd say, "You know actually, now that I think about it, I *did* do drugs today."

Half an hour passes and you wonder if it would have been wiser to have simply called 911. The pain escalates. You can no longer maintain the decorum necessary to swallow your incomprehensible vocalizations of agony. Your teeth chatter; your body shakes with mounting violence. Control slips.

Your roommate twists around in her chair and watches you in horror. *Great*, you think, *she thinks she'll be living with a freak the rest of the year.* The RA suddenly realizes she's working with something serious. Her irritation is redirected from you to the nurse. She snatches the phone and demands to know what's taking so long.

"Look. All we need is for you to say we can go ahead and call an ambulance." The RA's eyes flicker with something livid. "I have a student here who is literally shaking in her bed!" she yells, gesticulating in your direction. "Since you've been on the phone, I've been watching her get worse! We really don't have time for this. We just need your permission." She spends the next several minutes arguing with the nurse, who refuses to comply until she has

confirmed which poor life choice you made to land yourself in this position. At this point, you can barely talk, but you manage to latch onto a few waves connecting your thoughts to your voice, and you scream your answers at the phone.

An hour has passed. The nurse finally relents and the RA calls the security guard in the lobby.

“No—listen, I don’t have time for these questions. That’s none of your business. All you need to know is that we have EMTs on the way. That’s all you need to know. OK?”

**When you are experiencing such a degree of pain, all the straight lines that make us civilized human beings are stripped back until we are left with a raw, writhing animal.**

When she gets off the phone with the dispatcher, she crumples into her hands. She carries enough anger and frustration for the both of you, so you can keep sobbing and shaking in peace until help arrives.

At some point, the EMTs enter.

“What’s the matter here?”

The only sound you can manage is a breathy, “*Huhuhuh. Huhuhuhuh.*”

“Hello? What’s going on?”

Can’t they see you writhing about like a dying insect? Does it *look* like you can carry a conversation?

“Ma’am? Ma’am, we need you to cooperate here,” their voices grow hostile. “You need to answer us.”

You respond by looking them in the eye and vomiting. They launch into action and are gentler with you, as if they suddenly notice you’re legitimately ill. You’re loaded into one of those narrow wheelchairs that can be unfolded into a gurney and rolled out of the room. The elevator doors open. A few freshman glance up from their phones. When they see you, their eyes widen. You wonder if, the next time you arrive at a Netflix party or game night, they’ll still see you in pajamas, shaking wildly, flanked by EMTs. How long will it take to disassociate yourself from that image?

You’d always imagined that ambulances moved with impressive speed. They have a god-like power that renders them exempt from typical civilian traffic laws. But it feels like the vehicle is sitting more than accelerating. When it does advance, it seems to creep forward like any other car on 12th Street. Are they even using their siren?

“Alright. We’re gonna need to see some ID, insurance.”

“In my bag,” you manage to reply.

“OK, can you get them out?”

You glance down at your arms, which are strapped to your torso. “They’re in my wallet.”

It feels invasive to have a stranger leafing through the very thing you spend most of your public life guarding, but you don’t have much of a choice. You must let go, if only for a moment. The RA is riding with you. This gives you at least a little bit of security. The following week, you’d receive an invoice for a wealth of art supplies. You’ll have to tell the card company yes, you’re certain you didn’t go shopping on September 14 because you were in the hospital. Yes, you’re certain.

\* \* \*

When you are experiencing such a degree of pain, all the straight lines that make us civilized human beings are stripped back until we are left with a raw, writhing animal. It’s quite Freudian, actually. It is an ultimate state of not caring. Nothing matters when your vision is narrowed to the immediate tip of the now; the mind has been switched into a primitive survival mode. And as your brain bursts into flame, the world grows increasingly distant and pointless. Half of the present has lost connection; it’s merely a static black screen, but a mile away you hear yourself begging for more morphine. The nurse says, “No, unfortunately we can’t do that,” and the blackness ignites to red as desperation gnaws ragged holes through your nerves. The animal’s eyes flash through your own. “I need it,” it hisses, “I need it *now!*”

The pain flashes so loudly through your body that the red cools to black and drags you into its gravity. You harden to plastic. One too many wires makes one feel inorganic. Passive. Miss America is being crowned. It’s September. Surely the pageant isn’t in September. Surely the reality of occurrence has been disjointed from the reality of time. Black. The RA is asked if she’d like something to eat. A PB&J?

“No thank you.” She hunches over a textbook. The nurse insists. You hear yourself slur a plea for the RA to go home. It’s late; she doesn’t have to stay the whole time.

“Actually, I have to. That’s part of my job.”

You decide you don’t want to be an RA after all. The crinkling of plastic wrap. Black.

\* \* \*

A large cup is in front of your face. It’s filled with contrast. You’re instructed to drink all of it.

You've done this about four times in the past two years. It tasted fine at first, like Gatorade. But once you'd finished, they returned with another cup. Another. Another. Your stomach can only withstand portions suited for a child. The liquid gathered into a boulder inside of you. It sent a throbbing signal from your abdomen to your throat.

"You need to drink, honey. Every last drop."

The cup rattled in your hand. Your mouth refused to accept it.

"Drink!"

As you were wheeled out of the room, you began to vomit blue.

The nurse tells you they'll bring a second cup in a bit; get started with this one. You stare at its contents. Brown this time. Not blue. You drink.

\* \* \*

The CAT scan itself is easy. They'll huddle over the images to study what is going on inside of you, but you already know. It is the same story every time. Scar tissue. Inflamed intestines. Probably some kind of obstruction. Then they'll prepare for an emergency operation and change their mind at the last minute. You'll be told no, it has nothing to do with the necrotizing enterocolitis. That only pertains to babies. They don't know what's wrong with you, but they do know what it's not. "Honey, I don't know what to say. You seriously need to be taking better care of yourself. Watch your diet. Not so many burgers and fries, OK?" You haven't touched either in years.

The curtains part. You brace yourself for another lecture.

"OK, so we're gonna do another one, so we're gonna start again with the contrast, OK?"

You'll later discover your images were incomprehensible and induced a bit

of fear, warranting the back-to-back CAT scans. Even further down the line, someone will tell you you've been exposed to a dangerous amount of radiation for someone so young. You'll find that retroactive red flag utterly useless.

**A nurse walks you through the inorganic matter. Your vitals. The tube through which you're being fed. This is the most alarming. Your initiation into thinghood is complete.**

After the results of your second scan are reviewed, you're loaded into an ambulance and transported to a hospital on the Upper East Side. Black.

\* \* \*

A blur of light. A robotic beeping somewhere in the background. You lift your arm. It's held back by a multitude of tubes. The resistance stings gently. Heavy. This certainly isn't your dorm. This isn't the emergency room. How did you end up here?

"You're finally awake."

The room comes into focus. Your bed is surrounded by young people. A collective light bulb goes off in their heads—about what, you haven't a clue—as you blink at their faces. They've got that glint in their eyes, that grave thrill of discovery you've experienced yourself after witnessing how hydrogen peroxide reacts to potassium iodide. But in this case, the hydrogen peroxide is you.

Your audience scribbles something down in their notebooks. For the first

time since yesterday at 2:00 p.m., you give a damn about your appearance. What kind of mess has your hair contorted itself into? Are your eyes puffy with sleep? This is invasive. You need a mirror.

One of the clipboard-wielders is wearing a white coat and carries a distinct air of authority. A surgeon. He shakes your hand with enthusiasm.

"Wow. Can I just say we are so excited to be working with you!"

Why is he excited? He's grinning like a child presented with a gold sticker. Are you missing something?

He herds his students out of the room, saying they'll give you a chance to rest. A stack of papers land on your lap. You're instructed to sign here; initial there. A month and a day ago, a parent would have done this on your behalf. You read over the print, which is mostly jargon you can't make sense of, wondering if you are doing this properly. Adults are supposed to review such documents with a degree of skepticism. They take longer to return them than the institution expects; they must ensure the wool isn't being pulled over their eyes. But how can you adequately advocate for yourself if you're uncertain as to what your rights are? It wasn't as if a manual of proper adulthood was installed on your eighteenth birthday. You return the forms and hope you did the right thing. The anxiety is akin to that of waiting for a grade. Nobody hands them back or says, "You've done this wrong," so you assume that's a good sign.

A nurse walks you through the inorganic matter. Your vitals. The tube through which you're being fed. This is the most alarming. Your initiation into thinghood is complete. The nutrients trickle in through your arm like a watered plant. Your mouth is a desert. It stings.

"May I have some water please?"

“Nope. No food, no nothing.”

“I understand, but may I have at least just water?”

“Don’t worry, you won’t get dehydrated.” The nurse nods toward the sack of nutrients hooked on a pole. “That’ll give you everything you need for the next few days.”

“Days?”

“Your colon is inflamed and it isn’t letting anything through. If we put anything on top of that, we’ll only make it worse. So until we get that figured out, you can’t take anything orally.”

You flip back through your history of hospital visits and search for patterns. This doesn’t match anything. Not this particular brand of pain. Not the observers. Not the tube feeding.

The nurse leaves you alone with all your new mechanical friends. What day is it? You were at a Sunday matinee yesterday—though now it feels like ages ago—which means—crap. Find your phone. Where’s your phone? You spot your purse on the plush green chair beside you. If your parents were here with you, they’d be taking turns sitting in it, trying to latch onto snatches of sleep. You test the limits of the tubes and manage to grab the bag without falling out of bed. You pull out your phone and begin to compose apology emails to your professors. Will they forgive you for being in the hospital for one, two, three days? The program’s policy allows for only two missed seminars, even if you have a legitimate excuse such as illness. This is, of course, waved for the likes of Karlie Kloss, who would be enrolled in your roommate’s fashion course for an entire semester without bothering to show up once. You’ll remember the evidence of the supermodel playing hooky all over Instagram every time you contemplate whether or not you can safely make it to school without collapsing; whether

or not you can make it through a class despite the pain. Miss more than two seminars and you fail. No exceptions for the commoners.

\* \* \*

The next couple of days pass in a blur. There is something about utter boredom combined with illness that drains you. Your grandmother comes to visit with her sister one afternoon. For a few moments, you relax into a child again. Real adults to protect you; to ask the right questions. As they leave, your aunt arrives. She’s brought some crossword puzzles, sudoku (which, after ten years, you still don’t know how to approach), and the past few issues of *Reader’s Digest* (your mom must have told her about your obsession with the magazine). And then you’re alone again. You sleep.

\* \* \*

You might have to undergo surgery, but a gastroenterologist is going to examine you just to make sure. He comes. Examines. Declares an operation unnecessary. As he opens the door to exit, you see the surgeon, his students, and a gurney waiting for you. He turns them away. Your brain kicks up into a storm. Safe on the path you may be, you cannot help but think about the other part of the fork. In the alternate reality in which the GI says yes, they will need to slice into you, you would have been whisked into the hall right then and there, without a chance to gather your thoughts or call someone you love, an adult NEC survivor, a rare specimen indeed, freshly plucked from the formaldehyde.

Exciting.

“You should feel lucky,” a nurse comments that evening. “You would’ve ended up with a nasty scar going all the way across your stomach. Imagine going to the beach like that.” He shudders. “And *that* would be there *forever*.”

Anger, or at least irritation, steams inside you. “You mean like the one I already have?”

**You flip back through your history of hospital visits and search for patterns. This doesn’t match anything. Not this particular brand of pain.**

As you learned, attending the theater solo is “supposed” to be pathetic, you are now caught up with the fact that the scar that underscores your navel is “supposed” to be hideous. You used to wear bikinis for the express purpose of rendering it visible. In your earlier years, you *wanted* people to notice. You co-opted the fandom of Harry Potter (though you’d never read any of the books) and marketed it as social currency. To have a scar meant you were the chosen one. It was evidence that you’d struggled through something fierce. It meant strength. If your skin was smooth and unscathed, you hadn’t truly lived.

But now, as you half-watch yet another episode of *Master Chef*, you wonder if, for all of this time, you were supposed to have been ashamed of your body.

\* \* \*

The next morning, you are visited by an angel. It’s a different gastroenterologist this time—amiable, reedy, reminds you of a dad with an arsenal of terrible jokes.

“You go to NYU? Really?” He grins. “I went to NYU!”

Apparently, even in a city in which probably one in ten people has some connection to your university, this



coincidence is a very big deal. As with every other person who has examined you, you try the age-old question on him:

“Is it OK if I have some water?”

You brace yourself for a “no,” but he considers you for a moment.

**You’re parched, you’re craving something vicious, and it drives you crazy. What you wouldn’t give to bite into something, to chew, to taste.**

“You know what? For a fellow NYU member, I think we can make that happen!”

For that brief moment, the \$71k annual tuition seems somewhat worth it. When the angel’s visitation ends, you are blessed with a plastic cup of apple juice. Your mouth is so dry that your tongue makes a sticky clicking sound when you touch it to the roof of your mouth. Your throat is burning. Like a character from a castaway film, you gulp it down with desperation. It’s only been a few days, but your privileged ass wasn’t cut out for deprivation. Has apple juice always tasted so sweet and crisp and tart?

\* \* \*

It is 2:00 p.m. The hospital is quiet. A nurse asks if you’d like to try walking. She’s a kind, middle-aged blatina. There’s something maternal about her that makes you feel safe. Slowly, she helps you out of the bed. Your legs nearly give way. Since when were you not able to walk? You cling to the pole with your nutrient bag for support and shuffle into the hallway. The hospital

may be on the Upper East Side, but it is a drab relic from the early ’90s, from the manila and pastel color scheme to the understated paintings of flowers that constitute as “art.” The nurse guides you to the closer end of the hallway and introduces you to a cluster of her colleagues. When they see you, their faces crumple.

“Oh, baby!” they cry.

Is that how bad you look?

Your hair must still be some sort of nest. Your face hasn’t been washed in who knows how long. But as you creep up and down the hall, catching glimpses of other patients through open doors (you inherited your mother’s disregard for privacy), it hits you. Old. Old. Old. Each room contains someone who could be your grandparent, or perhaps great-grandparent. You, on the other hand, are eighteen-but-more-like-seventeen and look young enough for people to think your ID is fake. Here you are, like a temporal orphan with no one to claim you, hardly able to walk, clutching onto a pole for dear life. The nurses don’t treat you as an everyday sight because you aren’t. You look like you belong in the pediatric ward.

As much as you enjoy the company of these self-appointed mothers and aunties, you quickly become exhausted after a few minuscule laps. Your 103-year-old great-grandfather could have done better. You are a senile adolescent. The nurses shake their heads.

“Look at you! There is no way. You’re not going anywhere for at least a few more days. Just look at you.”

\* \* \*

That evening, you’re allowed to eat dinner.

The thing about being fed through a tube is, despite what they say about you getting “everything you need” through your arm, your mouth, throat, and brain

don’t seem to get the memo. You’re parched, you’re craving something vicious, and it drives you crazy. What you wouldn’t give to bite into something, to chew, to taste. Have a picky eater on your hands? Feed them intravenously for a short while and watch their standards disintegrate to dust.

Meat has practically been eliminated from your diet, but unseasoned chicken has never tasted so heavenly. Divine mediocrity.

\* \* \*

It’s approaching midnight. Comfort is found in half-sleep and the reassurance that at least another day will pass before you’ll be released into a city that runs at the speed of light when you can only creep. You’ve graduated from thing to dependent child.

An outstretched hand is in your face. The surgeon.

“I just had to catch you before you left and personally say goodbye.” You shake his hand and let him pump your arm elatedly, but what on earth is he talking about?

“Goodbye?” Didn’t he get the memo?

“And I just wanted to say how much of an honor it was to work with a patient like you. I mean, really. Your case is just fascinating.” Then he does something that tips you into the well of the absurd. He expresses how disappointed he is that he didn’t get to take a closer look at you with that operation. And you thank the stars he didn’t. You become a thing once more. A missed opportunity; a discarded lesson plan.

As he gushes, a nurse enters. She’s about business. Hands you the discharge papers and orders you to sign them.

“Wh—I’m leaving *now*?”



You mention you were told it would be days before you'd be well enough. The nurse grows impatient. The surgeon is amused. Time to go *now*.

"May I at least wait until morning so someone can come pick me up?"

Your closest relatives are in Harlem, but you don't have their number. The next would be Long Island. You couldn't rouse your grandmother to drive forty-five minutes to the city in the middle of the night.

"No. You've gotta go now. Call a cab."

"I can't walk!" What could happen alone, at midnight, in the backseat of a strange man's car, too weak to look out for yourself? How would you make it from the car to your building? You start shaking, but it's different from what you had earlier.

The surgeon laughs. Folds his arms. "You know, most people wouldn't *want* to stay in the hospital."

And just like that, you go from legitimate patient to a child playing sick at the school nurse's office. A lozenge for a bit of theater. You are no longer useful and thus the pain, the swollen abdomen, the weakness, the spaghetti legs, are rendered invisible. It's all in your head.

A blurry memory glimmers. In the ambulance, or perhaps the ER, the RA had mentioned a number on the back of your student ID. The Wellness Center. *Call them when you're ready to come back.*

You dial the number with a quivering hand. Tell them you're ready to be picked up.

"I'm sorry, sweetie, but that's not our job here."

You ask if there's another number you were supposed to use. The woman on the other end says no. Well damn.

The woman, who says she's a counselor, notes the panic in your voice. You explain the situation, and she is infuriated.

"I can advocate for you."

As she calls the hospital, you call your parents. They, too, are horrified. They, too, call the hospital.

Your evictors march into the room. The nurse, furious, demands to know why you have some lady from NYU harassing her on the phone; why your parents are calling from Georgia. The counselor, bless her, is unrelenting, which buys you some time. Your parents call your aunt in Rockland to see if she can pick you up. Rockland County may as well be in another state. To get there, one must drive through New Jersey.

You tell the nurse a relative is on their way. It isn't good enough. When she isn't yelling at one of your defenders on the phone, she is standing before your bed, harassing you. The surgeon continues to imply you are treating the place like a hotel.

"I see you enjoyed that lemon bar, didn't you?"

The panic is surrounded by the fog of the surreal. You've made the mistake of being too alert, too stimulated during a nightmare. What have you done to make this real? What is going to happen to you? Where are your parents? Where are the adults?

In time, you'll discover Beyoncé gave birth in this hospital. A postpartum Chelsea Clinton will tweet her gratitude about the exceptional care she'd received. Surely *they* weren't thrown out in the middle of the night.

By the time your aunt arrives, you're a mess of tears and nerves. She's mad. Why are they making her niece leave at one in the morning? In the presence of a true adult, the curse is broken and

the nurse transforms into a sympathetic human being.

"Oh, trust me—I completely understand! I have a daughter in college, too! We worry about them."

Gratifyingly, your aunt doesn't buy it. You're dumped into a wheelchair and taken out into the rain. Your uncle leans out the window of their Land Cruiser.

"Are you kidding me?" There is nothing like an angry New Yorker. He thrusts a hand in your direction. "Look at this! Look at this! She can't even walk!"

You feel like an immobile shrimp in wet pajamas and three-day-old hair. Remains of bodily betrayal.

You're folded into the back seat; your mind has been refashioned by Dalí. In the morning, your grandmother will call your room and panic when an older woman picks up. When she rings your cell phone, you will hear her curse for the first time.

The car pulls away. Your limited sense of place expands. A stilled portrait of glowing shop windows with expensive dresses and handbags, awnings and moldings and swirling balconies delicately brushed by light. The selective play of the revealed and the veiled, accompanied the unnatural stillness of a pristine, orderly, and empty New York, is like a fantasy frozen in time. It doesn't belong. You make a mental note to return and stay with it someday, but part of you knows it is a temporal, intangible swatch of what may or may not be life, rather like a childhood memory stored in technicolor. ♦

ELLY KATZ

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## SPLICED TOGETHER

Let the dark illuminate.  
Let the still dance.

Light is the measure,  
if there is a measure.

Designing us accidentally with precision  
in the wake of our own abolition.

Kindling the child's darkness—  
nightlights plugged into corners cornering night.

Slender fingers skating through windows of grief falling  
into dancing us awake  
when dreams are no longer  
prelude but purpose.

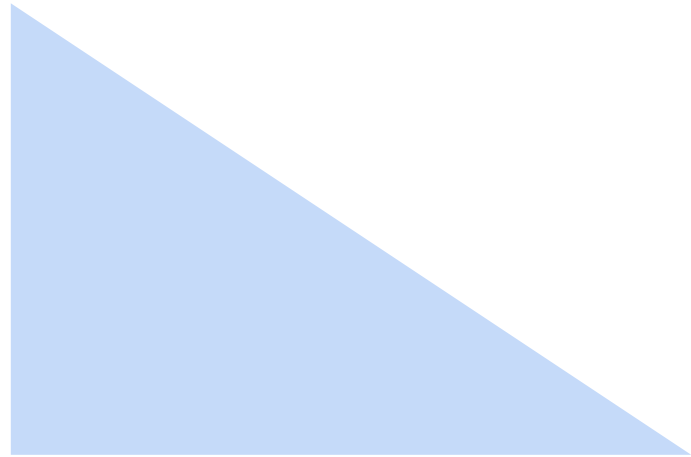
Dusk licks, traces silhouettes beyond the line of sight,  
growing us young,  
imagining us whole when everything  
breakable has broken.

Even questions question  
what to interrogate.

I want to germinate identity  
around a single word: grace.

I want to reconstitute the spectacular painting of me,  
a still life that still lives.

In a swimsuit tie-dyed neon pinks and blues.  
Legs sure walking sticks.



Hair tumbling in seas of sunlit curls wreathing shoulders.  
Goggles imprinting a sunburnt forehead.

Arms flowing down  
my sides.

I yearn to rush through time  
in reverse, hug her into endlessness.

I grab hold of my chest,  
as though the robin of my heart could fly its coop.

I am drawing her at the  
peril of panic painfully into my now:  
notes from the diaspora of me stolen by grief's burly hands  
that outdo my extensive vocabulary with its shadowy opacity lost in subtext.

A stranger's stare at me idle in wheelchair—  
a murder of a look that almost confirms  
I'm an atrocity, a function of some incorporeal,  
inchoate mathematics.

But I'm not idle, maybe immobile,  
but not passive.

I'm a human vessel filling over with beauty in my commitment to poems,  
their commitment to me.

Making me in my making of them worthy,  
lighting the way to curate sight.

Light is the measure,  
If there is a measure.

Let the dark illuminate.  
Let the still dance.



# WATER WORKS

GAIL BROWN

Lights flashed.

Crystalla closed her eyes. It hurt. It really hurt.

“Open your eyes. I have to see into them.” The doctor touched her shoulder.

She tried to comply. Light hurt. As did anything else. Even closed they hurt.

The doctor sighed and leaned against his desk. “Nothing we can do. Retinal damage. Won’t repair itself.”

“I can still do anything I want?”

“Most things. You have one-fourth of one eye to see out of, once it heals. It’ll take time.”

“Will it get worse?”

The doctor looked at her chart, and then back at her. “We don’t know. All your tests come back inconclusive.”

“So, you don’t know?”

The doctor shook his head and closed the chart. “No idea. It could be genetic. We won’t know without further tests, and insurance won’t cover the tests.”

“Do we need to know?” Crystalla covered her eyes with her hand.

“Only if you want to.”

“I need to know how to prepare for the future. Will I be blind?”

“You are legally blind. It may get worse. I don’t have any other answers.” He stepped to the door and opened it.

The glare outside the room burned as it pushed inward through her dilated eyes. Crystalla stood up and covered her eyes with her hand. Her mother would be in the waiting room. Hoping for a report that she would recover. She stumbled to the open door.

A nurse touched her elbow. “I’ll guide you.” With little more than a finger behind her elbow groove, she guided Crystalla to where her mother waited.

Her mother touched her arm. She sniffled. “We’ll manage.” Her voice was so thick with tears, that no more words tumbled out. She simply guided Crystalla out of the building.

That evening, at home, with the curtains tightly closed she waited for the storm. Her dream future as a surgeon wouldn’t happen. She not only hadn’t passed the vision test; the specialists had found more issues than any previous eye doctor she had been to.

Her dad sat down in the empty chair at the table. “What do you plan to do?”

She expected that question from her dad. He would never ask how she was dealing with it. Even if he understood that her feelings mattered.

“I’m going to research.”

“No time for that. It’s time for action. You have to schedule college classes in the next week.”

“Dad. One week is plenty of time. Would you rather I leap without looking? This is going to be about the rest of my life. I have to plan and prepare.”

“Do it already. Don’t think about it. You’ll think yourself into a depression.” He slammed the table with his fist.

“Dad. Stop. I am going to visit the low vision clinic as soon as I can get an appointment.” She groaned. He didn’t know the worst, and couldn’t handle it if he did.

“Have you called?”

“Yes. They are trying to find a time to work me in in the next few days.” Actually, she knew she could get in for a short appointment the following day, and a longer one in two weeks.

“If they don’t have time?”

“I’m to take a semester off. According to the college. Until my eyes settle, I have time to get the training I need, and decide on a new career.” A new career would be chosen. Soon.

“That’ll put you behind everyone your age.”

“Not really. I’m younger than all the students going into college this year.” It wouldn’t matter if she couldn’t be a surgeon. There was plenty of time.

“I’m not going to let you sit around and mope.”

“I won’t.”

“What do you think you’re doing now?”

Crystalla didn’t even have to have open eyes to feel the glare and accusations he threw at her. “I am resting my eye. The dilation drops are painful. I have to stay in the dark for twenty-four hours. At least.”

“I expect you to be out there making decisions tomorrow then.”

Better to humor him. “Okay. I am going to bed to rest my eye.”

“I mean what I say.” Her father’s voice lessened as she walked away.

He meant well. She knew that. Timing was tough to get right to make it in society. Especially as a woman, if she wanted to have children. Not knowing if the vision loss was genetic meant she would never choose to have children. She had already decided that. She curled up on her bed. A warm tear squeezed out of her eyes. So much fear. So much trouble. And all her father could think about was the future that was no longer hers. One she had never wanted.

Her mother slipped into the room and sat on the edge of the bed. “I’m here.”

Crystalla nodded.

Her mother didn’t need to speak for Crystalla to know what she was thinking. Her mother worried about her. An only child. Her parents’ late choice in marriage had meant they only had one child. Now, she was imperfect. Although it hurt, she’d do what she could for her daughter. Even though walking and talking was becoming increasingly difficult for her. Instead of seeing her graduate, have a career, and a family, she feared having to find a caretaker for her daughter, as well as herself.

Crystalla clinched her fists. She would find a way. A way to prove that even blind, she could lead a successful life.

Her mother sat in silence a while. She then patted the bed and left the room, closing the door gently.

\* \* \*

The counselor at the low vision clinic recommended Crystalla go ahead and meet with the college disability team. She arrived at the college she planned on attending. She reached the office and knocked on the door.

**"I need a new direction. I can't be a surgeon. And we don't know if my disorder is progressive."**

"Come on in, how can we help you today?"

She opened the door.

A man sat behind a desk and looked at a wall with his right ear toward the door. "Come in."

She stepped forward and expected him to turn and look at her.

He didn't turn. "Sit. Are you here to help, be helped, or both?"

"You aren't even looking at me."

He laughed. "I don't hear with my eyes. Wouldn't matter if my eyes looked at you. They wouldn't see you. My left CI is being repaired, so I have my working right one pointed toward the door to hear."

"CI?"

"Cortical implant so I can hear. What can I do to help you?"

"I failed my vision exam to be a surgeon." It was odd to realize that the man in front of her wasn't looking at her as she spoke. His perceived rudeness was the only way he could hear her.

"OK. How much vision do you have?"

"Poor. Less than one quarter of an eye."

"Are you looking to help others, or receive help?"

"I need a new direction. I can't be a surgeon. And we don't know if my disorder is progressive."

The man tapped on his keyboard. "Tell me about yourself. What do you enjoy?"

Too many tough thoughts and emotions over the last few days. She had never really wanted to be a surgeon. That had been her father's dream for her. His expectation. She preferred geology.

After several minutes of back-and-forth talk, the computer beeped. "A match. Water Works. Odd. They don't usually take anyone with useable vision."

"Why's that?"

"It's a tough job. In the dark. Rare to have lighting. Checking and cleaning out the drinking water lines."

"Really? Sounds like it could be automated."

"It could be. I have a few friends who do this. They enjoy it. A way to spend time without worrying about sight."

"What do I need to do?"

"I'll email you the information, and you can go by next week. They will better determine if you can do the work."

She gave him her email address and started to leave. "Can you see me at all?"

"You are a shadowy blur."

\* \* \*

The following Monday her mother dropped her off at the Water Works local office. This office was one of dozens scattered across the desert that allowed workers to stage cleaning and water safety checks.

Her guide would be Jondal. He would assess her ability and comfort in the dark caverns that the drinking water pipes passed through. Jondal handed her a long cane and showed her a few techniques for using it.

Within an hour, the brightly lit entrance was far behind her. She was deep in the underground cavern. At first, she had been able to follow the gleaming white lines of pipe. One on each side of her. Now, she unsteadily used a white cane to trace the pipe on her right side.

"We'll stop here." Her guide stopped. "Reach down and feel the clean out tube."

Crystalla bent over and reached out.

"Follow your cane to the tube, then across."

She found the clean out cap.

“Turn it to the right.”

“It won’t explode water all over me?”

Jondal laughed. “No. It is turned off in this pipe, though not the one on the other side of you. You can feel the difference. As well as the hum.”

Crystalla nodded. There was a hum. On the left side. She reached down and opened the clean out valve. There was a loop on the tie out cap that held it to the pipe.

Over the next hour, she carefully followed Jondal’s instructions for cleaning the pipe and verifying all contaminants had been removed. “There aren’t many contaminants.”

“No. Each pipe is cleaned once a week. We also have to verify that the slope and grade hasn’t changed as the tremors affect the water lines. Tomorrow, we go to the other side of the office area. One of the pipes there may need repair. You’ll learn to do that.”

Crystalla stopped walking. “Have sighted people ever done this job?”

“Yes. They didn’t like it. Too many were scared of the dark. We are used to it, so it doesn’t bother us. We have the experience and training on how to find our way, and what we need in the dark. They often don’t.”

“I’m still partially sighted, and I don’t have the training.”

“You’ll get it here. That’s probably why they sent you here.”

“My eyes do feel more rested today than in weeks.”

“They will.”

She wanted to ask so many questions about so many aspects of being blind. If she didn’t ask, how would she know? However, it felt intrusive. “Can we really do anything we want to?”

“Mostly. Driving and operating aren’t options at this point. Though, we can train machines to do the work for us. That would take out the human element in so many jobs.”

“We don’t want that. I’ll miss the opportunity I didn’t get.” Crystalla gently tapped the side line with her new cane.

“You’ll find new ones.”

“I still want to be a geologist.”

“Very doable. Come on, let’s go back to the office. We have a low light room where we talk about the geology involved in the Water Works tunnels.” Jondal stepped around her.

This could be a good beginning. A chance to let her eyes heal. And do the job she wanted. Not the one her father wanted for her. She smiled as she followed Jondal. He would be a good friend. ♦

*Previously published in Concurrent Earths. Reprinted with permission of the author.*

## CALL FOR SUBMISSIONS

**Kaleidoscope** magazine has a creative focus that examines the experience of disability through literature and the fine arts. A pioneer in the field of disability studies, this award-winning publication expresses the diversity of the disability experience from a variety of perspectives: individuals, families, friends, caregivers, educators and healthcare professionals, among others. The material chosen for *Kaleidoscope* challenges and overcomes stereotypical, patronizing, and sentimental attitudes about disability through nonfiction, fiction, poetry, and visual art. Although the content focuses on aspects related to disability, writers with and without disabilities are welcome to submit their work.

- Double-spaced, typewritten
- 5,000 word maximum
- Electronic submissions preferred

Submit online at [www.KaleidoscopeOnline.org](http://www.KaleidoscopeOnline.org) or via email at [kaleidoscope@udsakron.org](mailto:kaleidoscope@udsakron.org)





# BACKYARD TREASURES

SANDY PALMER

**K**aleidoscope celebrated its forty-fifth anniversary last year. During those decades we have gone from a small, in-house publication that was copied and stapled here in the agency to an award-winning publication that is now online and reaches people around the globe. As we reflect on how far we've come, it seems fitting to go back to our humble beginnings (a project providing a creative outlet for adults with disabilities in Akron), so we decided to take a look in our own backyard and found some incredible talent.

## Elliott Gorski

Elliott Gorski is an amateur photographer who uses his phone to capture images. Well, he uses his Android device and his unique perspective. He might quietly crouch down to the ground to capture an intriguing insect or an interesting angle. Other times he'll simply glance up and find beauty in things that are often overlooked, like something as mundane as a light fixture on the ceiling. He definitely has an eye for composition and says, "I really do it for fun but since I apparently have a knack for it, it has evolved into more than just a hobby." A few years ago, the close-up photo he took of a katydid (cover image) garnered



Elliott Gorski, *Contemporary Columbine*, 2024, digital photography

the attention of the manufacturer of the phone he was using. As a result, he received recognition on their website, a new phone, and some swag for capturing such a great photo.

Although he has no recollection of it, during his formative preschool years, he received an autism diagnosis. Anxiety and ADHD diagnoses followed. He is now eighteen and one of three brothers with autism. Their dad, Rob Gorski, is founder and CEO of The Autism Dad, LLC, a resource for parents raising children with autism and other disabilities. What began as a blog to help him cope with the challenges of raising three



Elliott Gorski, *Crystal Clear Lakeside*, 2020, digital photography

boys with autism has become an award-winning platform, including a podcast, that landed him on *ABC News Prime Time* and *The Tamron Hall Show*, among others. Father and son occasionally do episodes together.

According to Dad, “Elliott is kind, very smart, very creative, sensitive, and empathetic. He has a way of feeling what other people are feeling, which I think is where some of his anxiety and overwhelm come from. He would do anything for anybody. He’s very determined to chart his own path, not influenced by what other people think. He does what he feels is the right thing to do and I’ve always respected that.”

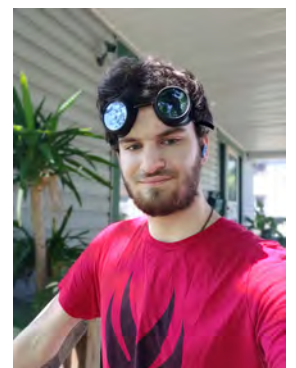
Gorski is a creative who likes spending time outdoors and says, “I’ve always enjoyed photography but never really thought about whether it helps me cope or not.” In response to that Dad says, “I think we sometimes find what we need to get through life without realizing that’s what we are doing. I think photography is one of those things for you.” As a young adult, he’s working to build his online photo store, *Autistic Eyes*, where high resolution images can be purchased for download. A link can be found on his Instagram page @**ElliottGorski** and on **www.TheAutismDad.com**.

As a teen who graduated from high school early, he is still figuring out what his future may hold. He has dabbled in writing a graphic novel and has a book in progress, but those forms of writing have recently taken a back seat to a new



Elliott Gorski, *Phenomenal Flora*, 2020, digital photography

foray into writing song lyrics. Since he has no background in music, he is thinking he may pursue that this spring at Stark State. Or, he may take a photography class. Whatever he decides, he will likely succeed if he follows his own advice: “The only limitations are the ones you put on yourself. If you believe you can do it, odds are you can.”



Elliott Gorski





Photo credit: Mitch Phillips

Hearts For Music performing at E. J. Thomas Performing Arts Hall in Akron for Mayor Shammus Malik's inauguration ceremony in 2024. Kitrael Chin conducting.

## Hearts for Music: A Special Needs Orchestra

Music can lower blood pressure, elevate mood, evoke strong feelings, and even give you the boost of energy you need when working out. Music is powerful. Kitrael Chin, president and artistic director of Hearts for Music knows that. He has seen its impact. As a board-certified music therapist for more than twenty years, he has worked with individuals across the spectrum of neonatal to end of life hospice care. Combining his genuine love for all people and his love for music, he established Hearts For Music in 2016. What began with one small group in Mantua, Ohio, has flourished to four groups meeting weekly—three in Ohio and one in Pennsylvania—and interest is spreading. His enthusiasm is palpable when he says, “There is no one so disabled that they cannot create something beautiful.” He provides people of all ages and abilities the chance to join in community, have fun, and make music together.

“If you close your eyes and I play a C note on a piano, you cannot see the disability, you only hear sound. The disability disappears. That was the basic principle behind Hearts For Music.” Because inclusion is so essential, there’s no age limit, no disability restriction, and no audition process. Everyone is welcome. Hearts For Music is a 501(c)(3) nonprofit organization and different from other ensembles in existence that usually require independent ability to play an instrument.

Most members choose instruments and play music using the Garage Band app on an iPad. Some touch the notes on the screen independently but for those who are unable to do so on their own, someone holds their hand and fingers are guided to touch the screen and activate notes. They also have members who play physical instruments like the cello, violin, keyboard, or drums. Whatever works best for the individual

is what they use and, “If we can’t find something for them, we’ll make something for them. We adapt.” He meets them where they are and finds a way to include everyone.



Photo courtesy of Cynthia Perrine

Journey and Cynthia during their first Hearts For Music performance at Summit Artspace.

“Another thing that is unique about the orchestra is that it is centered around families. Journey and her grandmother, Cynthia, are a beautiful example. Journey’s disability is the result of a catastrophic car accident that killed her parents. When she first came, I didn’t just see Journey, I saw Cynthia, and I could see she was grieving the loss of her family. Now it has become something for both of them. When Cynthia sits beside Journey and moves her hand to help her play it empowers both of them and gives both of them joy.”

Playing a combination of acoustic, digital, and adaptive instruments, this orchestra can perform a wide range of





Photo credit: Fred Blazek

Hearts For Music performing at the Akron Civic Theatre.

work from classical to country. On March 13, Hearts For Music will perform with Kutztown University’s orchestra. Under the direction of Dr. Peter Isaacson, the Pennsylvania university has more than fifty musicians in its orchestra. Guest artists typically sit off to the side when performing with an orchestra but when they join them in March, Chin says, “I want our musicians seated with the orchestra, according to instrument. Journey and Cynthia play the violin on the iPad and I want them seated in the violin section. I want complete integration. No separation.”

Their biggest event is coming up later this year. Hearts For Music has been invited to perform in Rome at the Vatican on April 29, 2025, for the Jubilee celebration of people with disabilities. They will be part of a larger ensemble, joining a dozen people with disabilities who live in Rome. “This will be the first multinational, multiethnic, multi-disability group to perform. Music unites all of us. You don’t need to speak the same language.”

Getting to Rome will require funding and, as a man of faith, Chin is trusting they will receive everything they need. If you would like to support their mission of love, inclusion, joy, and beautiful music, go to their website and learn more: [www.heartsformusic.org](http://www.heartsformusic.org).



Photo credit: Kaela Ku Photography

Lily Sargent

## Lily Sargent

Many little girls dream of becoming a ballerina, toes pointed, arms lifted, gracefully leaping and twirling across a stage. Lily Sargent grew up in Tallmadge, Ohio, and was one of those little girls. She watched her older sisters dance with their tutus and she followed suit when she was two years old. “I was not good,” she says with a chuckle. “I was always a little clumsy and spacey, so my parents thought it would help me with my balance and coordination.” Some delays were noticed by her elementary school teachers and by third grade, testing revealed she had dysgraphia (difficulty with written communication and the formation of letters), double vision, a microdeletion on the tenth chromosome, a heart defect, auditory processing issues, and a vestibular discrimination disorder. “I don’t have a natural sense of balance. There’s a delay between my inner ear and brain, and how my brain processes information. I find my balance through my eyes and touch. I had to create my own sense of learning, understanding my body, and moving that would help me



Photo credit: Mark Homing and Co. Photography

Lily Sargent on stage during a performance.

succeed. There were a lot of challenges and a lot of things I had to process but ballet was always a little light in my life that helped everything make sense.”

During many years of therapy for multiple diagnoses she was given tools that would help her process information and one of those tools was sign language. “That’s where my interest in American Sign Language (ASL) began and a love of the language manifested.”

She joined Cleveland Ballet in 2017 and during that time she taught classes at what was then the School of Cleveland Ballet. Simultaneously she decided to work and pursue a degree in interpreting. She obtained her degree and passed her EIPA (Educational Interpreter Performance Assessment) exam last year and moved to working full-time for the Academy of Cleveland Ballet as its director. Two dreams have come to fruition, and she hopes to merge both passions someday by having a dance class for individuals who are deaf or hard-of-hearing. “We’ve been talking about how to get that moving. I firmly believe dance is for everyone and each person has the right to learn in the way that best fits them. Having classes in ASL or sign-based, depending on the user, is what our organization is trying to achieve and what I feel passionate about.”

While the directorship and working with the Academy of Cleveland Ballet is her full-time job, she is also a character

artist in productions when needed. She actively teaches children who are between two and three years old, the age she was when she began. The Academy of Cleveland Ballet offers classes for students up to twenty-four years of age and there is an adult dance division as well. “People think you have to look a certain way to be a dancer, and I find that’s not the case. There are many dancers who have learning or physical disabilities. There are many who are short or tall or from different backgrounds. I feel blessed I am able to connect with such a diverse and beautiful community. Dance is a universal language. If you want to pursue it and you are willing to work and fight for it, you will be happy.”



Photo credit: Kaela Ku Photography

Lily Sargent with students at the Academy of Cleveland Ballet.



A radiant smile reveals her joy and the affinity she has for her profession. The road to becoming a ballerina wasn't easy. On stage, and in the classroom, it may look effortless but it has taken a considerable amount of effort. In a discipline where fluid movements seem to defy gravity it may seem curious that she says, "Ballet was a huge anchoring point for me." The young girl who struggled with balance found stability and strength in dance. She has always followed her heart and is now excitedly embarking on a new venture as she makes plans for her wedding this summer. Her life hasn't been a fairy tale but there is something magical about the role ballet has played in it and this journey she is on. For more information about the Cleveland Ballet or its Academy, visit [www.CleveBallet.org](http://www.CleveBallet.org).

## Heather Wicks

Bold, colorful creations fill portfolios and boxes in the cozy, home studio space of Heather Wicks. Marbled paper, wood-cut prints, pastel drawings, watercolors, and collages are all carefully stored. Her drawing table faces a window with the view of an idyllic backyard in Akron, Ohio. The blue

pedestal bird bath, flowers, and trees visible through the window are incorporated in some of her artwork.

As a young girl living in New York she would often visit The Met and the Museum of Natural History with her aunt. This fostered an appreciation for the arts that she cultivated over the years. "I've been an art connoisseur for as long as I can remember." Evidence of this can be seen on the walls of the quaint home she shares with her husband, Rolf, where beautiful artwork hangs in every room.

With a degree in art from the College of Wooster she describes her style as "abstract expressionism." She taught art to children of all ages at multiple schools, was an activity therapist for adults with mental health issues, and then became an ordained minister. As a minister she led women's retreats and encouraged people to illuminate scriptures and make them beautiful by creating artwork to reflect the message. "The art teacher in me always manages to come out somehow." She was an interim minister for twenty-five years and retired at seventy-nine.

Wicks is now in her eighties and legally blind. She has age-related macular degeneration (AMD), which blurs central



Heather Wicks, *Patten Bay*, 2022, watercolors, 6" x 8.5"



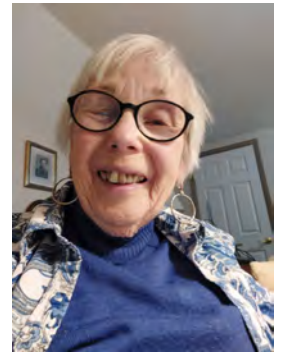
Heather Wicks, *Still Life with Cardinal*, 2023, pastels, 12" x 18"

vision. "After the diagnosis, I did not create anything out of discouragement."

As a member of Crown Point Ecology Center, in Akron, Ohio, where environmental protection, spirituality, and sustainability are embraced, an instructor encouraged her to take a pastels class, despite her vision loss. She was reluctant at first but hesitantly agreed. The fact that she had never worked with pastels before gave her an extra nudge. If it didn't turn out well it would be because she was new to the medium, not because of AMD. To her surprise, the result was better than she expected. "The class liberated me to realize I could still draw what I can see, even though I now have less sight."

She has also participated in the Creative Aging Institute's workshops, conducted by the Akron Art Museum, where she and Rolf have explored various forms of art along with other local seniors. In addition, she meets once a month at her church to create artwork with others who share her passion to create. Art has been so beneficial to her, she has packed up her supplies and taken them to visit her daughter, who is battling cancer, as a means to relax and share the experience and benefits of creating with her. Art is therapeutic, healing, freeing.

While she set art aside briefly following her diagnosis, she is now immersed in art again and feeling joyful. She can't produce the same level of realism or detail she once did, but that doesn't really matter. She is producing beautiful art and enjoying the process.



Heather Wicks

When a kaleidoscope is turned, bits of colored glass shift and reveal fascinating, intricate patterns. Each rotation transforms the design. As a publication, we share work that we feel shifts perceptions people may have of disability, just as colors move within the cylindrical chamber of a kaleidoscope. Circumstances throughout our lives also shift, causing us to adapt to whatever comes our way. These artists have experienced an array of changes and learned to take the good with the bad and embrace life, seeing beauty in all its various colors. ♦



# SUPPLEMENTAL NEEDS

VIRGINIA ISAACS COVER

May 2002

**M**uch as most people want to know what lies in the future, there are times when that future brings pain and uncertainty.

The morning starts the same as any other in the Gold household. Dave lets me luxuriate in bed for an extra fifteen minutes while he dresses and showers. I am lying on my back, holding my hand on my expanding belly to catch the tiniest movement of the baby, our unexpected good fortune.

The bedroom door slowly squeaks open. I close my eyes so that Adam, our six-year-old, will think that he is surprising Mommy when he climbs into bed with me. Adam slides under the covers. Then he puts his hand on my tummy, remembering that we told him last week that he would become a big brother.

“Mommy,” he asks. “When will the baby come out to see us?”

I open my eyes, grin at him, then pull him close to me. “Honey, babies come

out when they’re ready. Probably about when we get snow. Time to get up and get ready for school.”

I toss off the covers and sit up on the side of the bed. Now that I’m in the second trimester, my pregnancy nausea is almost gone, but I still can’t stomach coffee. Putting on a robe, I take Adam down to the kitchen.

“Tea, madam?” Dave asks. Dave doesn’t drink coffee, only the occasional cup of strong Irish breakfast tea. He already has tea brewing in the teapot, a ritual that he instituted as soon as I discovered that I was pregnant again. Dave pours my tea with a flourish, then lightly butters the toast for me. Monday is Dave’s morning to get Adam off to school. My only responsibility on Monday is to get myself into the office.

“Mommy, is the baby a boy or a girl?” asks Adam.

“We’ll know soon,” I tell him. Addressing Dave, I add, “Trudy tells me that results usually take two to three weeks, so it could even be this week.”

Prenatal testing was recommended because I’m forty. My obstetrician, Dr. Trudy Marshall, apologetically referred to me as an “elderly multigravida,” a mom who becomes pregnant again after age thirty-five. But after two years of infertility treatment, including three failed rounds of IVF, this pregnancy was a surprise.

Although Dave and I regard this as a miracle pregnancy, we agreed beforehand that we would be unable to raise a child with a significant disability. But I can’t bear to think there could be a problem, so I haven’t. This morning, I’m anxious to get into the office to prepare for a meeting. I am the director for administration and finance for Hudson Valley Medical Center, just north of New York.

Monday morning is routine: I read my email and work on my presentation for staffing the psychiatric ER. Mid-morning, I need the snack that I packed to satisfy my growing appetite and head to the lunchroom to get it from the refrigerator. Halfway down the hall, I hear my phone ring.

“Would you get that, Karen?” I call as I walk into the lunchroom. Karen is my assistant, a gem without whom the Psychiatry department would probably cease to function.

“I’ll hold it for you,” Karen tells me. “It’s Dr. Marshall.”

My amnio results, I assume. I hurry back to my office and pick up the call.

“Hi, Trudy. So, is it a boy or a girl?”

There’s a slight pause, “It’s a boy.”

Another pause.

“Rachel, you remember seeing the genetic counselor before the amnio? She probably discussed a few other conditions that could be picked up on testing. Having to do with extra X or Y chromosomes, usually not as severe as something like Down syndrome. Your result shows a boy with an extra X chromosome. It’s called Klinefelter syndrome.”

I get up from my chair holding the receiver, walk around the desk, and close my door. My throat tightens.

“You still there?” asks Trudy. “Humans usually have two sex chromosomes, either X and a Y for a male or two X’s for a female. Any difference in that number, two, is referred to as sex chromosome aneuploidy.”

I vaguely remember this, but I can’t recall anything else that the counselor told me. I think back to the karyotype, a photo of three chromosomes where there should only be two.

Trudy tells me that my baby boy has Klinefelter syndrome, forty-seven chromosomes instead of the usual forty-six. She tells me that she is reading from a genetics text. It states that men with Klinefelter syndrome tend to be tall and that they are almost always infertile. They may have slightly reduced IQs, although mental

retardation is rare. Often, children with Klinefelter have delayed speech, as well as learning disabilities, low muscle tone, poor coordination, and, sometimes, emotional problems, gender dysphoria.

I sit in my chair with a feeling of unreality, of time slowing down, of my happiness at being pregnant shattered by this sudden knowledge. This isn’t the perfect baby we dreamed about. I can’t think of anything to say or to ask; my mind is numb. I try to absorb this terrible new development.

A sudden lump in my throat makes it hard to speak. I take a deep breath and emit a strangled-sounding question, “What are my options, Trudy? What do I tell Dave?”

“Of course, you have the option of terminating the pregnancy,” Trudy replies. “This would be a second trimester abortion that we would need to do in the hospital. But the range of functioning in Klinefelter syndrome is quite broad. I think you and Dave need to speak with the genetic counselor as soon as possible. In fact, Soundview has an opening this morning.”

“Yes. I’ll get hold of Dave,” I tell her. I can feel my pulse beating in my ears. I feel a wave of nausea.

“There’s no need for you to confirm the appointment. We’ll do that for you. I do need to tell you that given that you’re at seventeen weeks, you’ll need to make your decision quickly.”

We hang up, and I call Dave’s phone. He’s still at home after dropping Adam at school.

“Dave, I got a call from Trudy. The baby’s a boy.” My voice catches, but I force myself to continue. “Oh, Dave, he has an extra chromosome. Something called Klinefelter syndrome. We have an appointment this morning to see the genetic counselor. Dave, I knew this was too good to be true.”

Dave jumps in, “Wait. What do we know about this diagnosis? What did Trudy tell you?”

## Trudy tells me that my baby boy has Klinefelter syndrome, forty-seven chromosomes instead of the usual forty-six.

Very briefly I tell him—low muscle tone, speech delay, learning disabilities, infertility. The characteristics all jumble together, superimposed on a baby fluttering in my womb. My anxiety makes speaking difficult.

“Honey, I’ll stay home and wait for you. Rach, we’ll get through this. I love you. See you at home.” Dave sounds as shaken as I am.

“I don’t know how,” I reply. “I just don’t know.”

I hang up and try to think about what I will tell Karen. I need her to cancel the meeting this afternoon. I gather my briefcase and my coat and walk over to Karen’s cubicle. Leaning down, I tell her that we have news from my OB that the baby has an extra chromosome. Not Down, but another syndrome. I need to leave to talk with a genetic counselor. I ask her to keep this quiet, to talk confidentially with Jim. I write “Klinefelter syndrome” on a piece of paper and tell her to give this to Jim.

Karen slowly rises from her chair and comes around her desk to hug me.

“I’m so sorry, Rachel,” Karen says quietly. “You have been through so much trying to get pregnant. I’ll be praying for you and Dave.”

We look at each other. I can't say anything. I feel tears coming on. I nod, turn, and leave the office.

The ride down the elevator and the walk through the parking structure pass in slow motion. I unlock my car, get in, and start the engine. I drive out through the exit, waving my magnetic card to lift the gate. My world has changed in minutes. I'm unable to cry.

## I find myself beginning to cry, silently.

I drive the four miles to our house, a modest brick Cape Cod on Church Street in White Plains, a close-in, suburban town north of New York City. For a minute, I sit in my car in the driveway, looking at Adam's swing set in the backyard. I wonder if we will be installing a baby swing next spring. Taking a deep breath, I exit the car.

Dave meets me as I enter through the side kitchen door. He already has his jacket on. We silently hug. I am not only overwhelmed, but am also green with nausea.

We drive to Maternal-Fetal Medicine in a nondescript medical building attached to the hospital. Dave opens the door to the office suite for me. The waiting room is empty. We walk to the reception window. The receptionist looks up, a concerned expression on her face.

"Mr. and Mrs. Gold? The genetic counselor, Heather, will be right out for you. Please take a seat. Dr. Berggren is also here today, and he'll spend some time with you."

She smiles at us. I hang up my coat because my pregnancy makes me perpetually overheated. Dave shrugs that he would rather keep his leather jacket on. I look around the room: modern, blond oak furnishings. Mauve

and gray upholstery and carpeting. Light-filtering blinds. Then I notice that there are photos of babies on the walls: singletons, twins, even a set of triplets. They are all smiling and looking totally "normal." No apparent genetic defects. How unfortunate for expectant parents here to discuss their baby's genetic anomaly. I can't think of him as a mere fetus. He's a baby, his little kicks reminding me that he is there.

Heather opens the door to the waiting area and, indicating for us to follow her, says, "I am so glad that you could come right away. We're going to meet first with Dr. Berggren. Here, in the conference room."

Heather is as I remember her. This time she's wearing a jean skirt, a Fair Isle sweater, penny loafers instead of Birkenstocks, and a calm, competent manner. I now wish that I had paid closer attention to the "other" genetic conditions that amniocentesis might identify. We're here to discuss one of the "other." It doesn't seem real. I wish this excruciating experience would vanish.

She ushers us into a small room with the same mauve and gray color scheme, a conference table, and high-backed leather chairs. Fortunately, the paintings on the wall have a nautical theme. We don't have to have this discussion with adorable and presumably "normal" babies looking down at us. I sit next to Dave. He reaches for my hand and squeezes. I find myself beginning to cry, silently. Heather reaches for a box of tissues and hands it to me.

Just then, Dr. Berggren enters the room from a side door, holding a file folder. He's a tall, gray-haired man. I notice that he has on an outfit identical to Dave's: khakis, light blue Oxford shirt, tie slightly askew. He acknowledges us and takes a seat as he begins speaking.

"I know that this must be very difficult for you, Mr. and Mrs. Gold. Please tell me what Dr. Marshall has told you about the amnio findings and what you

understand about your baby's genetic condition."

I start, realizing that my voice is strained and sad, "Dr. Marshall called this morning and told me that we have a boy. He has an extra X chromosome. Something called Klinefelter syndrome. He's likely to be tall, possibly learning disabled, infertile. I don't believe that I've ever heard of this condition before, even though I have a master's in public health. It must be rare."

"Actually," responds Heather, "Klinefelter syndrome affects about one in six hundred live male births. Extra X and Y chromosome conditions are as common as Down syndrome."

Dr. Berggren pulls what I recognize as a karyotype from the folder.

"This is a photo of the fetus's chromosomes," he says, showing it to us. Using his pencil, he points to two chromosomes that looked like skewed X's. "These are the two X chromosomes where there should be only one."

He pulls several photocopies from the folder. "I have some summaries of information here from genetics textbooks. They all say much the same thing."

He shows us page with a full-frontal photo of a naked man with his eyes blocked by a black box. Using his pencil again, Dr. Berggren points out the man's hips and his breasts.

"This morning, I spoke with a colleague who's an endocrinologist," he continues. "He has several patients with Klinefelter syndrome. His experience is that while they don't have mental retardation, as you see with Down syndrome, they don't do very well in school. Some of them have severe psychiatric problems, and few marry. In fact, because their levels of both testosterone and estrogen are aberrant, and because the hormone levels influence brain development, this is



thought to contribute to homosexuality. In some cases, they have gender dysphoria or transsexual identity, although I don't know if this is simply speculation or if it's confirmed by research."

He stops and looks around the table, perhaps gauging whether this extraordinary information is registering with Dave and me. We say nothing, waiting for him to continue. I realize that I'm on emotion and information overload.

"My general impression is that these men can have challenging lives with not a lot of happiness. On the other hand, they are usually healthy. I understand that you had treatment for infertility, so I'd understand if you want to continue this pregnancy. But I consider it my duty to give you a realistic portrayal of Klinefelter syndrome. I will tell you that most of my patients with the education levels that you and your husband have attained decide to terminate their pregnancies."

Dave interrupts, "Aren't there articles with case studies or population studies that we can read? This is shattering news to us. I'd like to see clinical data. Are there any families we can talk to before making a decision to have an abortion?"

Heather has been looking increasingly uncomfortable. Now she jumps in, opening a folder containing legal-size copies, pulling them out to show us.

"There hasn't been a great deal of research on sex chromosome aneuploidy until recently," she tells us, handing a sheaf of photocopies to Dave, who begins paging through them. "I've copied a few recent studies for you. These are studies of 40,000 cases of newborn screenings carried out in the US, Canada, and Scotland. I think you'll see that there's significant variation in the levels of functioning of these kids. While two-thirds may have some special education needs, one-third have no learning disability. Some only

discover the extra chromosome when having an infertility workup."

**Baby Boy Gold is turning his slow somersaults in my uterus, lightly kicking, as if he wants to make sure I understand who he is.**

Dr. Berggren weighs in again, "Heather is admittedly more optimistic about the prospects for a child's future when we know that disability is a likely outcome. I'm more pragmatic about the impact on a family of having a child with a good probability of disability. Klinefelter boys have IQs that are about fifteen points lower than those of their siblings. They often can't succeed in the same sort of professions as the rest of their family members. On the other hand, you live in Westchester County where there are excellent schools. You can probably give this child all the benefits of special education and therapy if he needs it. When he's ready to start puberty, you'll want to take him to a pediatric endocrinologist. Some boys go through puberty on their own. Others need help with extra testosterone. But, eventually, most men with Klinefelter syndrome need supplemental testosterone, although the treatment won't reverse infertility."

He pauses, and looks over his reading glasses, particularly at me. Then I notice him checking his watch. Tapping his pencil. I wonder if he does this sort of prenatal counseling visit often. He doesn't seem especially comfortable delivering this news.

"Unless you have additional questions for me, I'll leave you to discuss this in more detail with Heather. But I do want to warn you that there are many people who believe that men with Klinefelter

syndrome tend to sexual deviance, even pedophilia, or other criminal behavior. That may not be true, because the studies were based on inmate populations and were therefore biased. Nonetheless, if you decide to continue this pregnancy, I feel I should warn you never to tell anyone."

He stands, walks over to shake my hand and Dave's, and leaves the conference room, closing the door. I look at Dave. We'll probably have a discussion later in the car about Dr. Berggren's bedside manner or lack thereof. For now, I want to hear what Heather has to say. I want to look at the data. What are the real chances of a disability that we couldn't handle? And is this a shameful diagnosis that we will have to hide from everyone, including our families?

We wait for Heather to give us some good news, something to hang onto. Baby Boy Gold is turning his slow somersaults in my uterus, lightly kicking, as if he wants to make sure I understand who he is. Heather smiles at us. She starts speaking, calmly and softly, in contrast to Dr. Berggren, who was so direct.

"I know that it's difficult to have hopes and dreams for a perfect baby and then, suddenly, learn that there's a chance that baby may have some special needs. In your case, this is all the more difficult because you had prenatal testing to rule out a more significant disorder, such as Down syndrome or even more severe and fatal conditions like Edwards or Patau syndromes. Instead, you learn that your boy has something much milder that may or may not cause some disability—usually not intellectual disability, but perhaps slower development or perhaps a learning disability, perhaps not."

There are tears sliding down Dave's face. I reach for a tissue for him and take his hand. Heather pauses, giving us time to consider what she is saying, then adds, "We aren't talking here about Tay-Sachs, where the child will deteriorate and die after a few years. Or

anencephaly, where the fetus develops with only a brain stem. We aren't talking about a child who can't grow up to become independent and self-supporting. But it appears that these boys do mature more slowly. They often take longer to graduate from college, if they do attend, and longer to establish themselves in careers."

## **We get into the car, both silent with our thoughts as we head back to White Plains.**

My voice cracks with emotion as I ask, "If some men don't even know that they have this genetic disorder, then it must not be so terribly bad. What percentage, do you know, find out only because they experience infertility?"

Heather replies, "We don't know for sure. Maybe 10%. Another 10% find out due to prenatal testing. For the rest, there may be genetic testing for other reasons. This isn't a genetic disorder where children look syndrome-y. Just remember that some have significant learning disabilities, while others obtain graduate degrees."

I can't help but wonder if Heather has kids. She is wearing a wedding band and a simple diamond. I also see a multicolor, knotted cord bracelet peeking out from her sweater sleeve that looks like something a child would make at summer camp.

Dave looks at me and asks, "What do you think? I'm fine with a child who may have a mild disability. After all, does parenthood guarantee that we'll have a Supreme Court justice as opposed to an electrician or a cashier? Does it matter? Can he have a happy and satisfying life? Isn't that the question here?"

I am crying too much to respond. An event like this certainly does strip bare one's attitude toward parenthood. Choice isn't theoretical anymore. I have always been a feminist but how could I possibly abort this little baby floating in my uterus because he might have learning disabilities?

Dave, Heather, and I continue talking about parenthood and the prospects of having a child who may need early intervention or special education services, but as we talk, it no longer seems like the dreadful tragedy that I envisioned on first talking with Trudy. We look over the case studies from the March of Dimes, but I'm very bothered by Dr. Berggren's advice not to tell anyone. Why would this genetic condition be so stigmatized?

"Heather, why the emphasis on keeping the diagnosis quiet? What's so shameful about an extra chromosome?"

Heather is quiet, clearly deciding how to answer.

"I struggle with this myself, and with how candid I should be when counseling families," she says. "Many, especially fathers, equate fertility with masculinity. Particularly in some cultures, infertility brings into question a male's manhood. There's also some evidence that homosexuality may be somewhat more common in XXY than in the general population of men. We know it's a distinct minority, but no one seems to have studied this question, nor the question of what portion might have gender dysphoria, or live as women."

Dave asks, "Can you tell us what percentage of expectant parents terminate? And is it because of possible learning disability, or is it because of the sexual issues?"

"I can tell you that some studies indicate that as many as 75% of fetuses with XXY are terminated," Heather responds. "I can't tell you why."

"Infertility or the possibility of a gay son doesn't really bother me," answers Dave. "I'm much more concerned that we're able to handle learning disabilities."

"Same with me," I say.

We continue our discussion. Heather is a great listener. It's also clear that she can't make this decision for us. Only Dave and I can determine if this is a manageable disability, should there be any special needs. Heather also cautions us about information on the Internet. She tells us that there's one small advocacy organization, Klinefelter Syndrome Association, or KSA, that has some resources including support groups, a ListServ, and a newsletter. Otherwise, she warns us against looking at sensational pages that exploit myths about XXY. This information isn't scientifically vetted, she tells us. We continue to talk with Heather, taking down contact information for what few resources exist for expectant parents like Dave and me, thrown an unwelcome curve ball, a major diversion from the joy of pregnancy.

Then Dave looks at me and squeezes my hand. He's silent for a moment and then says, "Heather, thank you for all the time you've given us. And for these articles. I don't really have any more questions. Rachel?"

I shake my head that I don't. I know we're ready to leave and to make our decision. We push back our chairs, stand, and Heather follows us to the waiting room, where I get my coat. None of us speak. Heather hugs me, then Dave. And we leave the office.

We get into the car, both silent with our thoughts as we head back to White Plains.

After several miles, Dave asks me, "Do you think we should keep this to ourselves or tell our families?"

I respond, “I’d rather say nothing right now. If a problem develops with speech or anything else, we can always tell our families then. But why worry our parents if it’s really nothing? Let’s keep it quiet. But if he does have some issues, I can’t imagine keeping it all to ourselves, as though he’s some sort of freak.”

Dave is reheating some soup for our lunch. He has his legal clinic to supervise this afternoon and needs to leave in about fifteen minutes.

“I’m not going back to work,” I tell him as I play with my soup spoon. “I can pick up Adam from after-school. I’m just not in any shape to go back into the office.”

Dave stoops to give me a kiss. “Love you. We’ll pick this up again this evening.”

I decide that a walk in the neighborhood will be refreshing, if not head-clearing. I change into sweatpants, which now barely fit around my middle, and a maternity T-shirt that has an arrow pointed to my bump and the word “BABY.” I reflect how this pregnancy is probably more constant to me than to Dave. I walk around with it, feeling the fetus kicking, knowing that there is a little being in there.

Dave and I continue our discussions that evening after Adam is in bed. Dave’s main concern is the extent of learning disability we may encounter. While Dave falls into a sound sleep shortly after we get into bed, I do not get more than two hours of rest. Even that is interrupted by my awakening, crying, at three in the morning, remembering what we are in the process of deciding. But I want to keep this baby more than anything. I know that I will not have another chance at pregnancy.

Quietly creeping downstairs, I make myself a cup of tea while paging through the photocopies of the multi-site studies of children with extra X and

Y chromosomes. Maybe Dave and I are putting too much faith in statistics, but it does appear that the chances of having a child with severe disability are small. Severe disability to this couple whose lives revolve around academics really means intellectual disability. I don’t think that I view infertility due to XXY through the same lens as the parents who seem to focus on that as their greatest concern. The studies feature vignettes of the lives of over thirty children, some followed through age sixteen. Based on probability, which sounds devoid of emotion, our chances of having a child who can have a happy life are good, I think. I hear Dave coming downstairs. It’s about four in the morning.

“Did you get any sleep?” Dave asks. “I see you’re reading through the stats on these kids.”

“Terrible. I may have slept from one to three. Then I woke up crying.”

Dave kisses me, wrapping his arms around my shoulders.

“Rach, let’s sit on the sofa. I’ll get us both some more tea, and we can talk.”

I move into the living room with the photocopies while Dave is putting water on. I also hear him making toast. He comes in with a tray for us complete with honey, sets it on the coffee table, and sits down next to me. He strokes my cheek, and we’re silent for a few moments, holding hands. Then Dave starts looking at the March of Dimes studies.

I watch my husband. He’s wearing faded plaid flannel pajama pants, and a worn looking Stanford basketball T-shirt. He’s medium height with dark, curly hair in what we used to call a Jewish Afro. He keeps it shorter now than when we first met, probably because his hairline is beginning to recede. Dave’s a law professor, with a specialty in land-use planning. I know he values academic achievement and that he wonders

how a child with learning disabilities would do in a household like ours. Adam taught himself to read by age four. His kindergarten teacher had him doing second grade math to keep him engaged.

“What’re your thoughts?” Dave asks. “In some ways, it’s more your decision than mine. I also want this baby very much, but I don’t want to put us in a position of possibly taking on severe learning disabilities and emotional problems. Is that fair to this child? Is that fair to Adam?”

## **I know that I will not have another chance at pregnancy.**

While I had settled in over the past hour with the thought that we could give this child a pretty good life, I suddenly wonder if Dave is deciding the opposite—that it’s too risky; that we should be content with one child. I decide to tell him exactly what I am thinking. Much of my thoughts are colored by revulsion at destroying the tiny being in my belly. He’s somersaulting and occasionally kicking, fluttering away. I decide that I cannot have a termination.

“I simply can’t have an abortion. I may have been a feminist since age eight, but this has nothing to do with feminism. I’m making this decision as a mom. My reading of the studies makes me optimistic about a reasonably normal life for this child. Learning disabilities are so common anyway. We could have a kid with completely normal chromosomes who might develop schizophrenia or childhood cancer. There are never any guarantees.”

Dave takes a deep breath. “Then I’m in agreement. I appreciate that you, not I, are carrying this baby. I do have concerns about raising two brothers

who may have very different abilities, but it seems that wildly different is not likely to be the case. And they'll be six years apart anyway.

I'm sipping my tea, nibbling on the toast, and looking out the window at the headlight of a cyclist passing the house. How different today is from yesterday morning when I didn't know any of this and didn't need to make a decision.

"You're comfortable with this?" I ask. "I don't think that I can live for another day with the uncertainty of what we're going to do. I want to decide. To tell Trudy we're continuing."

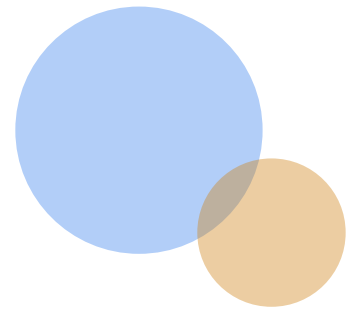
"Then I'm with you." Dave takes my hand and moves toward me for a kiss. I nestle against him. It's still very early, and I'm suddenly so sleepy that I curl up on one end of the sofa. When I awaken, I find that Dave has covered me with a blanket. He and Adam are coming down the stairs.

"Should we tell him?" Dave asks me.

I nod.

"Adam," says Dave. "You're going to have a little brother." ♦

*Excerpt comprised of beginning chapters of Supplemental Needs: A Novel, published by Bold Story Press (March 2024). Reprinted with permission of the author.*



PHILIP ANDREW LISI

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## JACK AT BAT

Jack looked up at the bulletin board just outside the cafeteria.

*Tryouts today!*

Jack in his chair, hands gripping the wheels, wearing his Giants uniform, from head to toe—orange, black, and white.

That morning, Mom's steady hands lifting each leg, unfurling his right foot, bending it gently out of its curled position, slipping on the jersey while supporting most of his body weight at the edge of the bed.

The hat was easy—

Jack could do that part himself, even though his muscles and nerves were becoming more and more at odds, like a miscommunication in the outfield.

But today his arms were strong, and his smile alone had the power to propel the pure white ball, out, out, soaring farther than it ever would again. His eyes moved like lightning around bases his feet would never touch. But Jack hit the ball today, and, perhaps, that was joy enough.

# THE GIVEN OF MY LIFE

MIA HERMAN

*“The physiological error called migraine is, in brief,  
central to the given of my life.”*

-Joan Didion, “In Bed”

\* \* \*

I have no idea how my day will begin when I wake up each morning.

Some days, my head is so sensitive I can't brush my hair. Other days, I wake with a dull ache, and until the pain passes, I can't brush my teeth, can't tolerate the taste and smell of artificial mint toothpaste.

I don't know what to expect when I go to bed, either. Which is why, on most nights, I sleep on my right side—just in case, hours later, my left temple starts to throb. I don't have the luxury of switching from side to side, of finding what position is most comfortable. And really, most nights, I don't mind. I don't even think about it.

But there are those rare occasions, those hours in the dark when I lie awake, unable to sleep, and I think of my future, hoping for a time when there will be somebody next to me. My migraines will affect him, too. If we want to fall asleep facing each other, or spoon a little after making love, I will have to lie on his left, allowing me to rest on the right side of my body. These are things that, as a couple, we will have to think about, consider, discuss.

Most people just argue over the blanket.

When I met Y during my first semester in college, there were a lot of reasons why I thought we could be good together. A lot of reasons why I thought, *this could work*. Both of us were classically-trained musicians. We valued education and academic excellence. And as a bonus, we even shared a handful of mutual friends. But I think my interest really piqued when I learned that Y was premed, that he was voluntarily immersing himself in the world of medicine and illness—a world I'd been thrown into without choice. That he, too, had suffered from migraines when he was little and had grown up with a mother who suffered as well.

I think it was these shared experiences that made him so mindful at the beginning, like when he explained that his mother—an internist—kept all sorts of medications in the house, including those for migraines. “One less thing to worry about when you're with me,” he'd said with a smile.

I could see that it made him happy, the idea that he was, somehow, making life easier for me. And this, in turn, led me to believe that Y had the potential to understand me, to understand the pain and loss and frustration without ever being told.

It was a Saturday night in December, three months into our relationship, and Y and I were headed out to meet some friends at an ice-skating rink. But soon after we turned onto



the highway, I could feel the familiar pulse in my left temple. Fast, strong, throbbing.

“Y, I’m getting a migraine. Can you pull over so I can give myself an Imitrex injection?”

“We’re already late. Can’t you do it while I drive?”

I could tell that he was trying his best to be patient, to keep the exasperation out of his voice; he hadn’t seen his friends for quite some time and was looking forward to the rendezvous.

I unbuckled my seatbelt and wiggled around until I managed to pull my leggings down. Then I ripped open an alcohol swab, ran it across my thigh. The moving car made it hard to balance, and my hand shook. What was usually a tiny pinprick turned into a long, thin slit. From the ghostly lights lining the highway, I could see the blood slowly starting to run.

I looked around the car, trying to find a tissue box.

“Y, where are the tissues?”

“Damn, I’ve been meaning to replace the last box.”

I sighed. I used a hand to wipe my thigh and then pulled my leggings up, knowing full well that the blood would soak right through.

After an hour at the rink, my thigh was feeling sore, so Y and I took a break. We sat down on the bleachers and he pointed to my hand; I’d forgotten to wash it off when we arrived at the arena.

He stared at the bloody patch on my palm. “I’m sorry about this,” he said suddenly. “And everything before. I was just excited to see everyone, you know?”

I gave a small smile and nodded. “I know. It’s OK.”

“It’s frustrating that you get sick so often.”

We sat there in silence for a little bit longer, and one thought skated round and round in my head.

*Frustrating for you? Try being the one who’s sick.*

\* \* \*

Migraines force me to prioritize my life in an extreme sort of way. Each day I make seemingly-insignificant decisions; I am perpetually choosing and ranking—my chores, my loved ones, my academics—in order of importance. But as the college semester continued, I noticed myself choosing and prioritizing more than ever. The migraines were coming three or four times a week, and I was still bouncing from one medication to the next. It was a constant game of catch-up, trying to compensate for the classes I missed and assignments I couldn’t complete.

A couple of friends had course schedules identical to mine, so whenever I was absent, they’d call to fill me in. Honestly, I think a part of me believed that I wasn’t capable of making up the work on my own. I believed that I needed their guidance, their assistance, to offset the gaps in my class attendance. And so I fiercely refused to be interrupted—no emails, no dinner, no TV—while I was on the phone getting notes or midterm reviews or study questions. Hours later, I’d call Y and we’d talk for a few minutes. But then I’d cut things short, claiming I had too much work to do or felt too tired to stay on longer.

When I look back now, I realize that I wasn’t fair to Y; I made him feel second-rate. But also, I chose education over him—not because he wasn’t important to me but because I thought he would understand. So when he left me a voicemail one night, about five months into our relationship, demanding that I call him back by eleven o’clock—“Or I’m going to assume we’re over”—the ultimatum left me dumbfounded.

I was in bed with a migraine. I don’t remember what time we ended up speaking, only that it was well past eleven. He yelled, asked me why I never picked up at night, asked me who else I’d been talking to.

“JUST TELL ME, DAMMIT!”

When we broke up, I felt a number of things: guilty, because I should’ve made Y a priority; deflated, because it was the end of my first college relationship; and scared, because I thought Y had understood my crazy life. And if he hadn’t been able to get it—if *he* couldn’t handle it—well, I wasn’t sure that I’d ever find someone who would.

\* \* \*

More often than not, I have no idea that a migraine is on its way until it has arrived, full-blown and angry. These are the moments when I am so mortified by my inability to control my body's actions that I am almost able to forget about the pain. Like the time I went to see a movie with some friends while spending my post-high school year studying abroad in Israel. The theater was packed and we were lucky to have gotten tickets, but a third of the way through, I had to leave.

"A, I have a migraine. I have to find the bathroom," I whispered.

"OK." Her eyes never left the screen.

Looking around for the nearest exit, I held my hand to my eye and applied pressure. I stumbled past the people in our row, out into the bright lobby. While my eyes adjusted to the harsh light, I suddenly knew: I wouldn't be able to make it. I took one quick step to the left and threw up.

People stared. Pointed. A few laughed. I ignored the reactions and asked, in broken Hebrew, for directions to the restroom. But nobody wanted to talk to me. Probably because I looked crazed, insane. My cheeks were flushed from the dilating blood vessels. My hand was covering half my face. Vomit dripped down my chin while tears mixed with snot.

When I finally found the bathroom, I threw up one more time. I leaned over the trash can for a couple of moments before wiping my mouth and moving to a stall. After closing the door, I pulled a needle from my bag and injected five milligrams of Imitrex into my leg.

And then I sat there on the toilet, crying. Long after the pain had gone.

\* \* \*

*Can you believe we're graduating?!*

*We did it!*

**YOU BETTER KEEP IN TOUCH**

My high school yearbook is filled with dozens of generic messages, but A had insisted that I leave two blank pages for her.

"Preferably the last two pages. You know, so I have the final say."

She filled the space until there was no room left to write, squeezing in every inside joke and every classroom disaster. Every up and every down.

*My Mia Marlee . . .*

*You were that girl I sat next to with the most gorgeous hair . . .*

*And then I found the math book you lost . . .*

*I hope the happiness in your life exceeds your enormous Beanie Babies collection . . .*

*I hope from the heart of my bottom that we remain close . . .*

*Promise me silently—no drifting apart allowed!*

After a gap year studying abroad, A and I began our college careers at different universities which, by default, left us with less time together. But one Saturday night, we arranged to meet at a friend's house party. It had been about a month since we'd seen each other, and during that time, I'd started a new migraine medication Topamax, an appetite suppressor, and the side effect was significant weight loss.

"Mama Miaaaa," A called out when she saw me, causing everyone to turn and look. First at her, and then at me.

She gave me the once-over. And then, "God you're skinny. If you bend over, I'm afraid you'll, like, snap in half."

**More often than not, I have no idea that a migraine is on its way until it has arrived, full-blown and angry.**

And because everyone was looking, I acted like the comment meant nothing. Like *she* meant nothing. I tried convincing myself that A was concerned for my well-being, that she must have been shocked to see a ten pound weight loss on someone so small to begin with. I told myself that none of this—the way she was acting, the way people were staring—none of it mattered if the medication worked. If Topamax could actually help me.

But hard as I tried, I couldn't ignore the feeling in my gut.

*Even A can't handle my life.*

She'd seen me through all kinds of adverse side effects: drowsiness, insomnia, excessive sweating, dehydration. She had even experienced some of those symptoms herself while taking meds for a gastrointestinal illness. I was sure she understood what it felt like, to be out with friends and wish for nothing more than to slip from the spotlight. To ignore your body. To pretend the pain doesn't exist.

I was sure about her the way I was sure about Y.

But I was wrong. On both accounts.

I wanted so badly to believe that our high school girliness, our high school sisterhood, would stay the same. That we—as individuals and as a unit—would never change.

*Promise me silently—no drifting apart allowed!*

I realize now that it was, of course, an impossibility.

I tricked myself into thinking that it was our choice of colleges, the physical distance, the limited time spent together that finally drove us apart. But really, it was A's phone calls that went unanswered for days. The text messages she sent while my phone was off. The emails I didn't respond to because I was at the doctor, or lying in bed, or making up classes I'd missed. And when the texts and emails and phone calls stopped coming, I can't really say that I was surprised. More like disappointed. And sad. Because this—the loss of her friendship—was ultimately a side effect, too.

\* \* \*

In recent years, I've come to think of Y and A as casualties; they are the relationships I've lost, sacrificed, because my life could not accommodate them. But the truth is, I didn't try to save these relationships, either. And perhaps I could have.

I could have fought for Y, could have asked him to be patient. I could have found a way to make more time for him. And the same is true of my friendship with A. Regardless of how tired I was, I probably could have squeezed in another email or text message here and there.

I just don't think I wanted to.

I think that by the time both of these relationships had begun to unravel, I was tired of trying to make each one understand my life when they so obviously didn't.

\* \* \*

C and I started a long-distance relationship about three months ago, and although we spend hours on the phone together, that time is no match for time spent in person.

I've worried about this, worried that C doesn't get to see how migraines affect my daily living. "I don't think you understand," I tried explaining recently. "If we have tickets to a Broadway show and I get a migraine, we might miss the first act. Or if you make reservations at a nice restaurant and a migraine hits, the place will give our table to someone else."

It is hard to admit that a part of me is trying to scare him off. I am afraid that C—or any new person I encounter—will come too close, will get a good look at the given of my life. And when they do, I am afraid that I will feel the loss, the soreness, all over again.

"I don't think *you* understand," C answers. "The way I see it, we might miss a show or lose a reservation because of bad traffic. Or a work deadline. Or a hundred other things. So just stop. Let's give ourselves a fair shot."

I hold the phone tightly, not quite sure what to say.

I think of Y, and I think of A. I think of all the pain, all the side effects. All the choosing and all the losing.

"OK," I say. "Let's give ourselves a shot." ♦

MARY HARWELL SAYLER

## DECISIONS! DECISIONS!

Despite dementia,  
he's a person with preferences  
who loves chocolate and ice  
cream and those little cigars  
even if he wants too many  
or too much too often.  
Who am I to tell him "No,"  
when, at this stage, such  
things seldom matter.

But taking the right pills at the  
right time mattered, and so did  
hiding his car keys and letting  
him think they were lost.  
Restoring the checkbook's  
accuracy mattered, and so did  
keeping a catheter in place  
in the hospital when he didn't  
understand the damage he  
could do by pulling out the tube.  
For some irrational reason,  
nurses thought they could make  
him understand, and he seemed to,  
but why did they expect him to  
remember their reasons? And so, he  
pulled the tube out—twice—before  
they decided on restraints.

I got him home as fast as I could  
and balanced the checkbook and set  
his meds into five rows with two  
to three pill bottles in each and  
marked the caps—one to five—  
and found disposable catheters  
that do not need to remain in  
because such things really,  
truly matter.

BRENDA BEARDSLEY

## WHAT LIES BENEATH

january hunkers down feather of snow imprinted by the night creatures  
beady-eyed squirrel quick stepping fox breathy twitch of cottontail  
mole sniffing its blind face toward the scent of the sun those tracks  
fade to tender dents on winter ground

inside i wait to heal  
walker beside me pillows nest everywhere  
dog follows me room to room

shadows crawl like new sorrows across what is left of snow  
dull in that peculiar manner of late-month-weary hiding what lies  
beneath spackle of brown leaves saffron dust from fall goldenrod  
dreys of dirt and sticks the clubbed ends from pinecones that plop  
from one branch to the next down to the palm of the ground

below my knee swaths of bandages  
part of me disappears  
part of me does not exist

the weather warms puddles collect a titmouse dips its ashen bill  
to sip in cups of snow each tree in the yard loses its frock of white  
that inches away from the trunk uncovers a bistro mess of moss  
and the piceous pellets from the night rabbit shafts of sunlight  
dissolve snow more ground emerging each day

# THE BLUE PONY

VAL VALDEZ

**G**ifted. Zara sees more than she can speak. Feels what others can't. She is slow when speed is needed. Or quick when it's not. No sync. She gazed at the vast sky. "Maybe it's a place for me? Where my slow and quick make sense." She climbed up a tree. Higher. The clouds pulled her inside. They praised her gifts. "What are they? I don't know." The clouds replied, *You will*.

Teacher said, "All kids will paint a picture." Noble masterpiece. Zara imagined a gorgeous pony with her as its rider. Other kids drew stick figures living in square boxes. Yawn. Her painting would hang at the highest spot on the wall. The other artwork would make the teachers and parents smile. "How nice." But their eyebrows would arch at Zara's painting. "A beautiful pony with a lovely girl rider. So amazing." Mother would hug her extra tight. Then hang it in the family dining room beside Father's war medals.

Zara painted the pony blue. She wanted his eyes yellow. But dipped the brush in black paint instead. Dark spots stared at her. Fail! Make it right. Clean the brush. She painted another blue pony. Clean the brush. She painted her figure in orange sitting on it. The brush slipped. It mingled with wet green paint. Colors turned into mud. Fail again! Fix it.

Zara mixed more green in the dark spot. She added more orange to her figure, then more green. The lines grew fatter. Paper sagged. Make it right. Other children cleaned up. Zara asked for more paper. Teacher said, "Sorry, I haven't got time." Defeat whispered to her, *You failed*. Everyone looked at her. Fear tightened her throat. No words. Paint dripped from the sagging paper. Mud puddle on the floor. But Zara refused. She grabbed the wet brushes and painted on the wall. A large blue pony with yellow eyes appeared. Teacher yelled, "Stop." Zara refused, again. Other kids laughed. She smeared orange paint over her clothes. She whistled. The pony turned its head, looked at her. Jumped off the wall.

Teacher and other kids gasped. Zara climbed onto its back. They trotted out of the school.

Zara clung to its blue mane. The pony trotted quicker. Then slower. But it was her quick and slow. Now it made sense. Sync. The pony jumped into the air. A huge wind lifted them. Higher. Into the vast sky. The clouds pulled them up inside. They cheered. Proud of her. THUNDER! Her confidence exploded. "I painted a noble masterpiece." The clouds replied, *First of many*.

The blue pony stayed in the clouds. It would come to her. If she needed it again. Mother washed the orange paint off her clothes. Zara put a piece of paper on the wall next to Father's war medals. Her parents said, "It's blank." But Zara shook her head no. "It's a painting of me riding a blue pony." ♦



# THE END OF A DREAM

MIMI EAGAR

Others had recognized me as a perfectionist from an early age as noted by the comments of my kindergarten teacher. “Mimi is very hard on herself.” That truth was challenged during my recovery when I awakened Christmas morning 1985, at age thirty-nine, with a massive cerebral hemorrhage. Ten days of excruciating headaches, weakness, and chills were diagnosed by two doctors as the flu. I awoke that morning with my head jerked to the right and my eyes fixated on my right arm which pointed straight up in the air from a massive seizure. At the same moment I called out, “Help me Mommy, help me.” The words, which seemed to escape from my subconscious, sounded slurred, like they belonged to someone else. After thirteen years of working as a speech/language therapist and despite my critical condition, I called out to my sleeping husband, “Get an ambulance, I’m having a stroke.”

I had no way of knowing that my life before, dedicated to keeping my body fit with exercise and sports, would now be focused on learning to walk again and performing everyday tasks with the

left side of my body now paralyzed. At that moment any dream of a perfect future ended with the near fatal stroke that occurred with no prior risk factors or family history.

After my seizure I had an out-of-body experience. I saw myself floating up to the ceiling, over the family room. For the first time in ten days, I was totally at peace without the nonstop pain that held me prisoner in my bed for over a week.

It was like watching a movie with only myself and an EMT who kneeled next to my body as he talked on the phone relaying information about my condition to the hospital. A few seconds later I felt myself go back into my body and became aware that he lifted my left arm, which fell straight down to my side, paralyzed. I viewed myself from above and will always remember the incredible feeling of complete peace with all pain and fear gone. If death wanted to take me then I would have gone without a struggle.

What I didn’t realize was that my lifeless arm would never move again

on its own volition. My entire left side was paralyzed although I had limited movement in my leg. Many months later, with extensive physical therapy, I walked again but with a pronounced limp, aided by an ankle brace and cane. I also wore a sling on my left arm, to keep my shoulder in place.

I had to learn a new way of doing things with only one good side and I had to learn fast. My two daughters were only four and seven and needed my constant attention regardless of my new disability. I spent two weeks in ICU where they called me the Miracle Baby because no one thought I would live through the night. I then spent three months at Kessler, an excellent rehabilitation facility in New Jersey. We had just moved there four months before from New York when my husband’s job transferred him to the Garden State. At Kessler I assured all my therapists that I would not need any of the adaptive devices they showed me to help in my activities of daily living (ADL). Instead, I told myself and them that I’d recover fully and learning to use these accessible gadgets was a waste of time.

Denial was the only thing that gave me hope and helped me survive each day. I believed if I worked hard enough in therapy and enough time elapsed, I could lose the cane and brace and regain use of my left arm and hand. Any doctor who told me no amount of therapy would rehabilitate me to a full recovery, fell victim to my angry outbursts that they didn't know what they were talking about. It only made me work even harder.

My stroke not only affected my physical self, but changed my whole personality, with emotional lability. It's defined as rapid changes in mood with uncontrollable crying or laughing and a heightened temper. Now at age seventy-seven, I still experience these emotional explosions. They cause me constant embarrassment in front of others who have no idea why I suddenly burst into tears. I'm always trying to explain that it's my stroke causing these outbursts, to salvage any sense of dignity.

It is a common medical belief with strokes that any return of movement occurs within the first year. I fought that belief also. My motto became hurry up and wait. I couldn't wait until the first year passed to experience what I was certain would be perfection.

After I left Kessler, I learned to walk without my cane and take control of the household again. Two years later I filed for divorce and had total responsibility for the care of my daughters and myself. I had no choice but to succeed.

My loss of independence was one of the hardest things to endure. The DMV automatically revoked my license. My car had to be made accessible for one-handed driving. I installed a spinner

knob on the steering wheel to help in turning corners along with an extension for my signal to allow me to use it with my right hand only. I had to take driving lessons to learn how to operate my newly-adapted car and pass a driver's test to get back my license.

I formed a support group for brain injured young adults as I felt my skills as a therapist could help others, and it did. There were dozens of groups for older stroke patients who were at the end of their lives. But they had nothing in common with those of us who still had young children to raise despite our limitations. We offered each other not only friendship, but a place to share our unique problems that came with loss of mobility, independence, and completing most tasks at a much slower pace. Short-term memory problems from brain damage were also a common problem.

Thanks to computers, in their early years then, information about my group spread across the country. I received calls from many distressed family members who sought my advice in dealing with their spouses' strokes. Helping others with their problems somehow helped me with mine. I felt a purpose in life again.

Five years after that tragic Christmas, I resumed my career as a speech/language pathologist working full time with disabled children in the schools, as I had prior to my stroke. Thirty-nine years later I now use a power chair to get around safely after dozens of falls and hospitalizations. It is something the old me wouldn't accept, but it affords me the ability to go anywhere and to travel around the world on my own, which I achieved.

Today I remain far from perfect and continue to be hard on myself. I still only have use of one hand to function independently and now use some of the devices and techniques I refused to acknowledge at Kessler. I read somewhere that "human beings are a lot like teabags. They don't know their inner strength until they get into hot water." Any stroke survivor has had to call upon this inner strength every day of their lives. I know I have, and always will. ♦

M. S. MARQUART

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## ONE DISABLED PERSON TO ANOTHER

I mail my mother pictures of flowers  
 blooming outside my apartment,  
 flaming orange daylilies,  
 fragrant red roses,  
 opulent purple hydrangeas,  
 all aglow in afternoon sunlight.  
 Take a picture with my phone,  
 upload to an app that prints, stamps, sends it to her,  
 and then rest.

After her strokes, her English is fading, and  
 my teachers told her not to teach me Korean,  
 earnest commands so that my future  
 in white America wouldn't be ruined  
 by speaking something other than the dominant language;  
 now, it turns out they stole  
 my future conversations with my mother.

But we don't have the energy  
 to talk on the phone anyway;  
 speaking exhausts each of us,  
 her with her aphasia, and  
 me with my long COVID and myalgic encephalomyelitis.  
 We say quick hellos on FaceTime, and  
 she shows me that another photo has arrived,  
 waving it in front of the phone with a smile.  
 Comforted that I was thinking of her,  
 cheered for a moment by  
 our shared experience of nature's beauty.

*Previously published in Interdependence: Integral to Disability Justice (August 2024). Reprinted with permission of the author.*

TIM MURPHY

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## FOR THESE BRIEF MOMENTS

I measure time by the angle  
 dim slivers of light enter my room  
 each morning from behind  
 ever-closed curtains, by the way  
 their faint glow subtly shifts  
 through the day, until it fades  
 beyond the reach of dusk.

One year bedbound, I lose track  
 of the natural world, the only place  
 I didn't question if I belonged.  
 But strains of it still drift  
 through walls in birdsong,  
 distant banter of crows,  
 whispered echoes of rain.

Spring's finches grow  
 chummy in summer.  
 Each day, around noon  
 settling on the windowsill  
 just above my head, bathing  
 in the warmth of the sun  
 for much of the afternoon.

I can't see them  
 but hear soft scraping  
 of claws scampering about,  
 occasional fluttering of wings,  
 bickerings over who sits where.  
 And for these brief moments  
 I am not lonely.

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# TEACH

H. McCRYSTAL

“I hate you!”

Three words screamed with frustration and despair. Miss McKenzie didn’t take it personally. Sarah didn’t mean it. She never did. And still the noise reverberated through Miss McKenzie like a physical blow. Each word landing a punch, one, two, three, right in the center of her chest. Spittle landing on her cheeks like raindrops.

“Okay, Sarah,” she replied, trying to navigate how best to de-escalate the situation. To restore balance to the classroom with twenty-one other children looking on with equal parts shock and fascination. The boys willing Sarah to pick up a chair and throw it as she has been known to do; the girls looking aghast at how she could possibly be so awful to poor Miss McKenzie.

It was only seconds but felt like an eternity that Miss McKenzie looked into Sarah’s wide eyes trying to hear the unspoken words to understand what had provoked this outburst. It was very

nearly lunch time. Most of the children had finished the given task and were now onto the extension. The lesson hadn’t been particularly difficult and she had been sure that Sarah was more than capable of completing it. This was something she always had to factor into her lesson plans: how to extend Sarah’s understanding but not too much so that it overwhelmed. Each day was a series of baby steps, moving her learning in the right direction.

“Why don’t we step into the hallway for a moment?” she offered. Whatever had prompted it, she knew that Sarah hated being the center of attention and the silence from the rest of the class was deafening, the stares penetrating.

“I just needed to change one thing,” came a small voice at Miss McKenzie’s elbow. Zack, Sarah’s best friend, held out the eraser to his teacher, looking shamefaced, and the puzzle started to come together. She knew Zack hadn’t caused this. Whatever had happened with the eraser would have just been the final straw that broke the camel’s back, as they say. No, Sarah had been holding herself together for a while

now, possibly even days. Poor Zack had just knocked open the floodgates.

“OK, Zack. Thank you,” she said, taking the offending item from him. “Come on Sarah, let’s get your things.” She gathered up Sarah’s worksheet and pencil and guided her to the door, careful not to touch her. Sarah never liked it when she felt like she was being forced to do anything and who could blame her really.

On their way out, Miss McKenzie grabbed the Winnie-the-Pooh book she had tucked at the edge of her desk for precisely these occasions. It was a routine the whole class was familiar with by now.

Once outside the door, Sarah’s back hit the wall and she slid to the ground, hands balled into tiny fists of rage. Miss McKenzie didn’t reprimand her. What would be the point? No one was hurt. No one was even really offended, despite the looks of horror on some of the children’s faces. She held out the book and Sarah snatched it as if it were a lifeline. Sarah’s breathing began to regulate as she read the familiar tales

of the Hundred Acre Wood and Miss McKenzie stepped back inside the classroom.

Peace had quickly been restored within the four walls and the children had resumed their usual chatter whilst half-heartedly completing the task set. This was what she liked about children. They didn't hold on to inconsequential things. They trusted that their teacher would make the world right again and she did. How simple life was for children. Well, most children.

Her eyes fell upon the one child in the room who was not chatting away happily. Zack sat with his head down, shoulders hunched, and rather than deciding whether the word November did indeed need a capital letter or not, he was simply worrying the corner of his page. She bent down so that she was level with him and simply waited. She could tell he had registered her presence but didn't want to push anything. Zack was a sensitive boy. That was why he and Sarah got on so well. He seemed to understand her in ways few others did.

Finally he spoke. "I didn't mean to make her mad," he said, his eyes shifting momentarily to gauge the reaction of his teacher. To see if the trouble he was in matched the level of guilt he felt.

"I know you didn't. That wasn't what upset her Zack. Trust me," she replied trying as hard as she could to impart the honesty of her words to him. How could a seven-year-old understand what had just occurred? It seemed impossible. Hell, half the adults in the school couldn't, or rather wouldn't. She watched as his shoulders, which had previously taken up residence near his ears, suddenly dropped back down to their natural habitat as he took a deep breath. One that he had seemingly been holding since Miss McKenzie had ushered Sarah out into the hallway.

When she was satisfied that Zack had let himself off the hook, she instructed the class to pack away their things and

line up at the door for lunch. There was more than one door into the room and the usual path to lunch would not take them past Sarah. In fact, the hallway that Sarah sat in had very little foot traffic during the lunch hour. Thank goodness for small mercies. She watched the final little head bob out of the room across from her before turning back to check on Sarah. Hopefully she had managed to regulate herself again.

**She could feel the control that she had clawed back being ripped from her grasp once more.**

As soon as she stepped out of the door, it wasn't Sarah who caught her eye at first but a cluster of her colleagues looking through the half-glazed windows of the library, one of them beckoning her to join them. An internal groan lodged in her throat as she considered the possibility of pretending she hadn't seen them, before deciding that was unlikely to go down well. She turned and saw Sarah still curled up with her book and made the short journey into the doorway where the vultures were waiting to pounce. This time, it was her turn to take a deep breath.

"Oh, has she done it again?" asked Mrs. Bryant, a veteran teacher who meant well but always had a slightly patronizing tone to her voice, as if she knew with absolute certainty that had Sarah been in her class, such occurrences would never have happened.

"What'd she do this time? Hit one of the kids?" asked Miss Thomas, a teacher who hadn't been teaching much longer than Miss McKenzie but who wore her jadedness like a badge of honor.

"Or thrown a chair?" asked Miss Scott, the new teacher who always had to be part of the action. "I heard her all the way from my room," she said with a glint of eagerness in her eyes. *She's just young*, Miss McKenzie thought as she had on many previous irritating occasions whereby Miss Scott had verbalized thoughts that would have been much better left unsaid.

Miss McKenzie, struggling to get a word in, raised her hands as if she could physically stop the flow of unsolicited opinions. She glanced down the hallway to see that Sarah's head was no longer hunched over her book, but raised in defiance as she listened to these people, people who should know better, pass judgement on things they had no idea about. Who didn't want to try to understand. She stood and let the book, which had been sat in her lap, fall to the ground. She turned and ran.

Miss McKenzie turned back to the trio with disappointment clear on her face. Mrs. Bryant had a sympathetic look on her face, Miss Scott a look of anticipation, and Miss Thomas simply rolled her eyes. She turned and left them without another word. She would deal with that later. Now, she had to make sure Sarah was okay.

\* \* \*

Sarah's speed increased as she made her way through the corridors. She could feel the control that she had clawed back being ripped from her grasp once more. Her heartbeat was loud in her ears and her breathing was erratic. She couldn't take it. Nothing went right. Why did no one understand?

Why did she say she hated Miss McKenzie? That wasn't true. In that moment, Sarah thought herself to be an awful person. It was a feeling that was all too familiar.

Without her realizing, her pace had slowed and she found herself in a hallway. "Hall of Fame" was emblazoned above the display board



she stood next to. Perfect children's perfect work taunting her in its ease. She would never be on the Hall of Fame.

It had never made sense to her how some children were praised for churning out work with very little effort and yet the likes of her, and some others she knew, had to work a million times as hard and couldn't even come close. Surely the fact that she turned up and managed to sit through the school day should be up on that wall.

The lights were too bright in here. The chatter too loud. The guilt too much. With unthinking hands she gripped the edges of two pages of artwork in front of her and ripped it off the wall.

Good.

That was good.

It released some of the pressure, so she did it again.

And again.

And again until there was paper littered all around her.

Some part of her registered the shrill noise in the background but she didn't for one second realize that it was her who was making the noise.

Rip.

Tear.

Shred.

Until she had run out of energy.

Her breathing slowed once more and she looked at the destruction all around her. She knew she had done it but it also wasn't her. In an odd way she felt it was the world that had caused it. Like it was beyond her control. She looked beyond the mess to see yet more staring eyes. Judging eyes. Those eyes that had judged her before. She did not see the

kind eyes in the crowd that were trying to decide the best course of action.

She felt her heartbeat begin to pound again. Beat after beat until it was deafening. She pushed past, not being careful in the slightest about how she would get through the wall of judgement, just knowing that if she didn't get away, the damage would be far worse.

She hated herself for feeling like this. For being like this. If she could stop it she would but she didn't know how. Hell, none of the adults did, so why should she. They pretended to know everything. Surely they should be able to come up with a way to help her.

She stopped running when she reached the school fence. The noise and the chatter from her peers was somehow louder than her overactive thoughts. So loud in fact that she couldn't think at all. Those children, their laughter, their squeals of delight were completely at odds with the turmoil she felt. How had it gone so wrong so quickly?

She slipped behind the metal unit that housed the sports equipment and sank to the ground, much in the same way she had in the hallway.

She wasn't sure how long she sat there. It couldn't have been long but time seemed to have paused while she was tucked behind the metal panels. It was a warm day and the sun heated the surface of the container. She could feel little beads of sweat popping up on her forehead, but she didn't mind. It was comforting somehow.

The noise didn't stop exactly, but she managed to tune it out so it was just background noise and she was pleased that despite everything that had happened, the school carried on as if nothing was out of the ordinary. The monotony of the noise seemed to send her into a trance. A branch snapping nearby jolted her back to the present and her eyes focused on Zack who was stepping around the side of the

container. Of course, he would come to find her. He was the only one who knew about her hiding place.

**Some part of her registered the shrill noise in the background but she didn't for one second realize that it was her who was making the noise.**

Zack wasn't like her. He wasn't "neurospicy" as her parents liked to call it, but he wasn't like the others either. He wasn't lucky like she was. Despite her parents not really knowing how to handle her, she had no doubt they loved her. Zack's dad, on the other hand, wasn't nice to him and his brothers. No, Zack didn't quite understand what life was like for Sarah and neither did she fully understand him, but their differences from everyone else bonded them in a way neither had experienced before. He didn't try to understand her exactly. He just let her be, and that was enough.

He didn't say a word as he walked toward her. Just watched where he put his feet. The ground was littered with leaves and branches, having never been swept. Perhaps that was why Sarah liked it back there. She felt it was a place for forgotten things.

He sat down next to her and rummaged around in his pocket for a moment before pulling out an old piece of candy, wrapper still intact, and handed it to her. It was so backward. She knew that she should be apologizing to him. That's what the adults would say. But this offering was his way of giving her an opening and her accepting it was the apology itself. It was enough.

After a while of comfortable silence, Zack picked up a nearby stick, brushed the bracken that laid between their feet and drew a three by three grid in the dirt. They played tic-tac-toe on repeat without a word until the whistle blew to signal the end of the lunch hour.

Sarah supposed it was about time to face the music. She took a deep breath and exhaled the last of the morning's stress. She had been at this junction before. She knew she couldn't hide forever. That wasn't how it worked. She knew people would stare but she was resilient. She stood, stretching her arms up overhead, feeling stiff having sat for so long in the same position. The blood rushed back into her limbs. She laughed a little to herself, thinking about all these choices people made that they would inevitably end up paying a price for. Even if it was just getting pins and needles.

They emerged from behind the container and the glare of the sun blinded them both momentarily. Side by side, they walked back into the building.

Once they were in their classroom, Sarah felt safe again. Safe from the looks of teachers who had seen or heard of what had happened. She often thought that considering all these adults preached about kindness, they could be incredibly insensitive. She knew what she had done was wrong, but doesn't everyone make mistakes? The other children in the class didn't care and she appreciated that. Children were often far too preoccupied with what they were doing or thinking or feeling to hold on to anything she may have done.

Everyone was settled in and reading their chosen books quietly while Miss McKenzie took the afternoon registration. Sarah knew without a doubt that Miss McKenzie wouldn't

hold what she'd said or done against her. She wasn't like the other adults. She seemed to understand like no one else did. Still, she needed to do something to make it right. She didn't know what she would do next year when Miss McKenzie was no longer her teacher but that was a problem for another day.

She opened the book she had been reading, took the scrap of paper she used as a bookmark out and smoothed it across the desk where it was crumpled from use. Her pencil hovered over the surface while she thought of what to write. She could go with the classic, "I'm sorry," but somehow that seemed hollow. She wasn't good with words and often just hoped she could convey exactly what she wanted purely by the power of thought transference. Thus far, the only people that seemed to work with was Zack and Miss McKenzie. It would have to do.

She scribbled her message and stood, making her way over to the bin as if she were simply depositing something in there, thankful that she would be able to pass by Miss McKenzie's desk enroute. She fiddled by the bin for a moment before turning back and, as discreetly as she could, dropped the makeshift bookmark on her teacher's desk. Without turning back to see Miss McKenzie's reaction, she made her way back to her seat, head down all the way. When she was safely situated at her desk, she kept her head down for a few moments more before daring to look back up. When she did, she was surprised to find that Miss McKenzie was no longer seated but was walking toward her. No, not toward her, but past her to the bookshelf.

Much like Sarah had done herself, she stood there for a few minutes shuffling through the books until finally she pulled one off the shelf. She turned back the way she came and made her

way back to her desk but not before stopping at Sarah's and placing a book on the edge of the table.

Sarah's eyebrows knitted together in confusion. She thought it was odd that Miss McKenzie didn't say anything. Adults always had something to say. Particularly in situations like this. She slid the book toward her and flipped open the pages. It fell open on a page somewhere near the middle, the little scrap of a bookmark having held its place.

Once more, she smoothed out the creased piece of paper and read back her message: "Thank you." It was all she had thought to write. Not exactly the most creative, but she thought it would have to do. Underneath her seven-year-old handwriting was Miss McKenzie's neater and much more fluid response: "You are welcome."

Three simple words and yet each one hit her straight in her heart. One, two, three words, making her feel wanted. Accepted. Miss McKenzie could've responded in any number of ways. She could've taken her back out into the hallway to talk about what had happened, she could've demanded an explanation, an apology. She could've even written, "You're welcome," and ultimately the message would have been very much the same and yet impossibly different. Sarah was welcome here, in Miss McKenzie's classroom, this she knew with absolute certainty. If only she felt the same everywhere she went. For now, it would have to be enough. She looked up and saw Miss McKenzie looking right at her. Seeing her like very few people did and she smiled.

Sarah smiled back.

It would be okay. ♦

# SUBJECTIFYING DISABILITY

LISA ZIMMERMAN

**T**his is the essay my therapist doesn't want me to write.

I wish I could say I don't understand her concerns, but I do. She fears it would place in the foreground something that most people who come to know me see only as a small part of me. It's never been what defines me, so why run the risk of letting that happen now? I imagine she wants to protect me from being typecast as disabled, and likely the recipient of all the associated projections I've worked for years to dodge.

I've countered that writing about my disability would be empowering; that it'd give me a way to openly claim a part of myself that I've tended to keep at arm's length. I imagine it as a coming out of sorts, a response to those who have confessed, "I always *knew* there was something different about you, but was afraid to ask."

Because my impairment is not stereotypically visible—there's no wheelchair or other mobility aids—the markers of my disability are more subtle and perhaps even perplexing. I have what is considered a mild case of cerebral palsy (CP), the result of brain damage at birth. Cerebral palsy is not a disorder *per se* but an umbrella term for a group of neuromuscular conditions. There is a spectrum of possible presentations, ranging from severe impairment to minor challenges with balance and coordination. Mine is on the latter end. I am one of the lucky ones, I have been repeatedly told—and I have readily agreed.

As camouflaged as my CP is, I have always been aware that others sense some sort of difference in me. Try as I might to filter it out, I've been painfully attuned to their unspoken curiosity and, at times, their pity. I suppose I've always *known* that people don't quite know what box to put me in. So my coming out is probably less of a revelation and more a naming of the proverbial elephant in the room.

My friends and loved ones often insist that I overestimate the visibility of my CP. I've been told that it's "barely noticeable" and stops being "an issue" once people get to know me. As far back as I can remember, I've clung to these reassurances like a life preserver. They eased my worries that the strained quality of my speech was a distraction; I could keep any shame about my irregular gait and tremor largely at bay.

Keeping my disability as unnoticed as possible has always been an implicit goal. I wasn't considered a child with "special needs" and, it being the pre-ADA 1970s, I rarely received accommodations. Grateful as I was for not being singled out, I *did* have special needs: completing a handwriting assignment, carrying my lunch tray across the cafeteria, writing on the chalkboard, surviving any part of gym class—all were struggles that I chose not to name. Asking for help felt like inviting shame and ridicule, or in the heyday of the Jerry Lewis telethon, being cast in the role of poster child. So I became creative in developing my own workarounds and ways to compensate. This exhausting self-sufficiency seemed like a small price to pay for acceptance and belonging.

While I have been impacted by my physical limitations, the bigger burden has always been my self-consciousness. No matter how much success I achieved, I could never shake the feeling that I was defective and that my defect eclipsed all else. At the same time, though, the steady stream of reassurances I've received to the contrary made these fears feel a bit like paranoia. There was something relieving in thinking that it was all in my head: if it was simply a matter of low self-esteem, there was a fix for that. As a teenager I became an avid consumer of self-help books and later of therapy. I learned the concept of "projection," which bolstered the argument that my otherness wasn't being tracked as much as I believed.

But inevitably the self-protective bubble would burst, usually after a comment from someone whose curiosity or discomfort could not be contained. The client who complained to my supervisor that they did not want to work with me because I "talked funny." The acquaintance who, after I'd mentioned my husband, exclaimed in disbelief, "*You're* married?" And the colleague who, before sending me a referral, asked, "Should I warn them about you?" This was before the term microaggression had entered the lexicon. Even if I had had this language at the time, I'm not sure if I would have seen it as applicable. They weren't being aggressive; they were being honest. I was always devastated. It was proof that my disability was, in fact, "an issue" and my otherness was indisputable.

I never felt I had a choice other than to pick myself up, dust myself off, and go back to hoping that I could "pass" more often than not. And there were, in fact, long stretches of time in which my CP remained outside of my daily awareness and seemed to garner little attention from people around me. These times felt like triumphs; noticeable or not, I had managed to transcend my physical differences, at least for the time being.

But my body had other plans. As I entered my forties, muscle and joint pain that started as an expectable nuisance quickly became chronic. I also developed esophageal spasms, which made eating solid food almost impossible for the better part of a year. Because CP had never posed health problems for me, I rarely even mentioned my disability to my doctors. I was wholly unprepared for the lack of knowledge, and in some cases sensitivity, I encountered when trying to find medical care. Even living in a major urban center, I was unable to find a specialist who saw patients with CP over the age of eighteen.

I turned to the Internet to fill in the gaps. My research quickly revealed that adults with cerebral palsy frequently experience

what is referred to as "premature aging," the result of living with excess stress and strain on the body. I also learned that I was not alone in my frustration with the medical profession's treatment of CP as solely a pediatric condition. Entire online groups were dedicated to information exchange and advocacy, many under the umbrella of the disability justice movement. Until then, the disability community had been an abstraction for me, made up of *really* disabled people, who I pictured to be low functioning and pitiable. What I discovered, however, couldn't have been more disconfirming: a diverse array of activists and academics, as well as many like myself, everyday people trying to unsnarl themselves from lifetimes of internalized ableism.

I was stunned when my new connections alerted me to the Center for Adults with Cerebral Palsy at NYU. After years of failed attempts at finding a specialist with the expertise I needed, I had assumed that further searching was futile. That this center even existed lifted burdens and gave me hope that maybe my "special needs" could be met after all.

I was unsure what to expect when I went to the clinic. As the appointment approached, I encountered a part of myself that had previously been muted. It was the part that wanted my difference seen, to be able to relax my vigilance and frantic efforts to pass, to fully inhabit my body in all its nonconformity. Suddenly, my fears turned upside down. I worried that my CP would be seen as too mild; that my needs would seem illegitimate compared to more challenged patients. Would there be a space for my pain, physical and emotional, or would I again be labeled a "lucky one" and left to my own devices?

The answer turned out to be yes. I found a recognition that required no explanation or justification. I was not an object of pity or inspiration. I wasn't an object at all. And yet, walking past fellow patients, often in wheelchairs, and sometimes with caregivers, I did not see myself reflected. There still wasn't a box that I fit into neatly and I didn't come away with a miracle cure for my pain. But somehow, there was a little added space in me: space for the part of me that wants my difference recognized to coexist alongside the part that longs for an anonymous normalcy. Perhaps there's room for more. ♦

*Previously published in ROOM: A sketchbook for Analytic Action (2024). Reprinted with permission of the author.*

MEG EDEN

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## COLLECT MYSELF

The dental technician gives me time  
to “collect myself”  
before trying the X-rays again,

as if I’m a spilled purse  
and not a shattered pre-kintsugi bowl  
that must somehow pretend

I can be put back together  
in a neurotypical-acceptable sort of way  
with a tissue and time

like some emotional MacGyver  
and keep all the pieces from falling out  
until I get back to my car.

I’ve been taught to fold  
my autistic parts  
into the unseen sides of paper cranes,

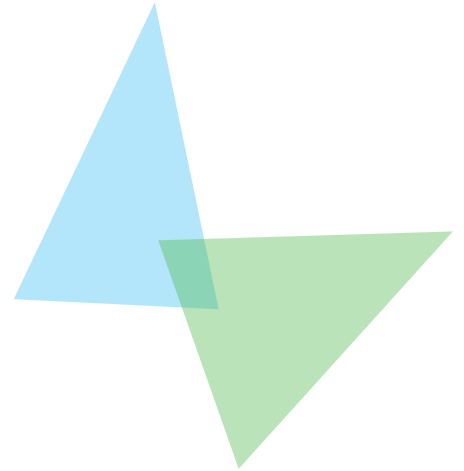
but sometimes I still unfold.  
It’s nothing new now—the receptionist  
knows me as the girl who cries.

The language girls learn at birth  
is *I’m sorry, I’m sorry*.  
For what we are? For failing—

at times—to be collected?  
I want to think I’m different  
but I haven’t changed at all.

When the technician says  
I’m making her look bad,  
I cry harder.

Maybe she’s trying  
to make me laugh  
but how can I be sure?



DIXIE L. PARTRIDGE

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## LINES FOR OUR LIVING NOW FOR J., WITH EARLY ONSET ALZHEIMER’S

Late evening I watched a great blue heron  
pinion itself like a pontiff in the sheen  
of water next the river island.

Dusk rose slowly from underneath the willows  
and in twilight the heron rose up, reflecting  
pinked wings . . . not graceful, but with such  
distinctive effort it turned to beauty.

Night dreams took me drifting  
over the roughage of river foliage,  
above the great glistening surface,  
steep with undertow, toward the sea . . .

as though wings could be my way,  
and optimism my nature.

\* \* \*

At the quilled fringe of saffron dawn:  
singular reflection came golding  
through an open doorway.

These are not lines about grief,  
or about endurance, or even about beauty.  
These are lines about the exotic lift of light  
from rising wings, from moving waters,  
and from poppies we planted by the porch.



# HOW MANY DOCTORS DOES IT TAKE TO CHANGE A LIGHT BULB?

GABRIEL HULL

**Y**ou go to the first doctor because your light bulb is out and she runs some tests. They all come back normal but she is kind and wishes she could help. “It’s clear your light bulb is out,” she tells you, “but I’m not sure why. You should see a light bulb specialist.”

The specialist is not kind. “The tests show that nothing is wrong with your light bulb. It simply needs to try shining harder.” When you plead with him to try changing the bulb, he laughs at you. “Don’t confuse your Google search with my years studying light bulbs.”

You’re getting desperate so you go to the more out-of-the-box doctor you normally would stay away from. He pokes your bulb with needles till the glass shatters. In answer to your bewilderment, he explains that sometimes things need to break more in order for them to start working again.

Finally, after it’s been so long you’ve half-forgotten the sight of a glowing bulb, you get in to see a super-specialist, the kind of doctor who really knows a lot about this specific issue with lights and has a reputation for getting them shining again. She starts by replacing the bulb that the last doctor shattered but explains that the issue was never with the bulb itself, but instead with the socket the bulb screws into. “These kind of things take a while to treat but we’ll get your light on again. I promise.”

So, with hope at last kindled, you begin the treatment for the socket. Months go by without light but you were told

to expect this so you patiently wait in the darkness. More months go by and skepticism begins to germinate. You express your worries to the doctor but she isn’t concerned. “I told you this would take a while.” You wait longer and longer till your patience is stretched thinner than too little jam on too much toast. Eventually, it grows long enough that even your doctor begins to suspect the treatment isn’t working and decides to try treating the wiring inside the wall, but this will take a long time too. When treating the wiring appears to not be helping, the doctor goes through more and more of the electrical network till she’s even trying to fix the power plant. You are as grateful for her commitment and help as you are frustrated.

Your light bulb begins to very occasionally flicker and the doctor takes this as a quite good sign. “It will now slowly start flickering more often and more brightly,” she promises, but you aren’t sure. It’s been so long and you’ve tried so many things to fix your light bulb, you suspect there could be any number of reasons behind the flickering. Maybe it simply improved on its own. This seems more and more likely as the promised improvements fail to manifest. Then, the flickering happens less and less frequently and eventually stops altogether.

You ponder trying to find yet another doctor to fix the light but you are now so very, very tired and it has been so long since you had light anyway. You decide to give it a rest. With time, you learn to appreciate the soft, kindly light of the moon. ♦

**Mio Aoki-Sherwood** of Robbinsdale, Minnesota, is a creative writing and environmental studies student at St. Olaf College with plans to graduate in 2025. Her works have appeared in the *Oakland Arts Review* (May 2024) and *Elegant Literature* (March 2024). Along with a passion for storytelling, she also enjoys drawing, painting, running, and watching squirrels. Aoki-Sherwood writes “to process my own experiences and the emotions and thoughts that I have about feeling like an outsider.”

**Brenda Beardsley** is a writer and nurse living in West Chesterfield, New Hampshire. Obtaining her M.F.A. in writing from Goddard College in 2014, her works have appeared in *The Examined Life Journal* (2016), *The American Journal of Poetry* (2018), and *Wordgathering* (2017), among others. Beardsley is a recent finalist for the 2024 Donna Wolf Palacio Poetry Book Competition thanks to her collaborative manuscript with Liza Wolff-Francis, “sky they yearned to call mine.” She is also the former editorial director of *Clockhouse*.

**Diane Bell** is a retired educator from Minneapolis, Minnesota. She has two writings to be published this year in White Stag Publishing’s *BloodLore Anthology*. Having spent years working with hundreds of children helping them develop their writing voices, Bell has decided to focus on her own writing. She states, “I believe everyone has something to say. Our words can be healing to ourselves and others.”

**Gail Brown** is an author residing in Louisville, Kentucky. Her works have appeared in *Concurrent Earths* (Fall 2021), *Tin Lizzy* (May 2024), and *Gamma Zaria* (August 2024), among others. Brain damage forced Brown to learn to read and write again. She finds that science fiction “brings hope and light through worlds of color dreams. It mirrors daily life as it could be.”

**Virginia Isaacs Cover** is a Maryland resident and a retired social worker. She has published two books, *Living with Klinefelter Syndrome, Trisomy X, and 47, XYY: a guide for families and individuals affected by X and Y chromosome variations* (February 2012) and *Supplemental Needs: A Novel* (2024). Cover’s work focuses on improving the lives of people with disabilities and their families, and her goals include creating communities that can help reduce social isolation while promoting acceptance.

**Mimi Eagar** is a retired speech and language pathologist residing in Connecticut. Her work is forthcoming in *Manifest Station*. Taking pride in her capabilities to be strong and independent, Eagar states that writing helps clear her brain of anything but the present. “I am less centered on perfection and more compassionate and accepting of my disability.”

**Meg Eden** is a writer and instructor living in Maryland. Obtaining her M.F.A. in creative writing through the University of Maryland College Park in 2016, her poetry collection, *Drowning in the Floating World*, won the Towson Prize for Literature in 2021. Using writing to connect with others, Eden states that hearing how others connect with her protagonists who have autism helps her feel less alone.

**Linseigh Green** is an actress, singer, writer, extended reality producer, and rare disease activist residing in London. Her works have appeared in *Enable Magazine* (2024), *Rarity Magazine* (2024), and *Rare Youth Revolution* (2023), among others. Writing because “it allows me to exhale,” she is the recent 2024 winner of the Black British Theatre Awards’ Disability Champion Award. Green is also a survivor of necrotizing enterocolitis and lives with a functional neurological disorder.

**Mia Herman** is a wife, mother, editor, and writer who says Judaism fills her life with joy and meaning. She resides in Woodmere, New York, and her works have appeared in *The Loveliest Review* (November 2024), *Alien Buddha Press* (June 2023), and *Barren Magazine* (June 2019), among others. Whether she’s writing about the challenges of motherhood or her mental health issues, she is always writing through the lens of her “disability-related lived experience.”

**Gabriel Hull** is an artist residing in Illinois. As illness touches “quite literally every aspect of my life,” his severe myalgic encephalomyelitis leaves him in bed most of the time. Writing on his phone a few sentences at a time, his work in this issue focuses on the journey many with a chronic illness often experience: “searching for a doctor who is sufficiently knowledgeable to care for conditions that are often complex and poorly understood.”

**Elly Katz** is a resident of New York City and was working toward a doctorate at Harvard when she needed a procedure to stabilize her neck. During the surgery, she experienced a brainstem stroke secondary to a physician’s needle misplacement. Surviving this tragedy helped her discover the power of dictation. Her works will appear in *The Stardust Review* (Spring 2025), *The Sacramento Review* (Spring 2025), and *The Awakenings Review* (Spring 2025).

**Philip Andrew Lisi** is an English teacher, poet, and occasional actor residing in Lancaster, Pennsylvania. His works have appeared in *Wild Roof Journal* (June 2024), *Carolina Muse* (May 2024), and *Third Wednesday* (February 2024), among others. Lisi lives with his family and their Wichien Maat cat, Hazel, who Lisi states has a great knack for taking over his laptop and yowling her way into his work. He believes, “poetry has, potentially, an efficiency and economy that can help people connect with one another more immediately than longer forms.”

**M. S. Marquart** is a mixed race Asian American poet living in New York, New York. Her works have appeared in *Pillow Writers Anthology 2* (December 2024) and *Interdependence: Integral to Disability Justice* (August 2024). Marquart's aim with her work is to explore the impact chronic illness has on individuals while shedding light on the hidden daily lives of people with myalgic encephalomyelitis and long COVID.

**H. McCrystal** is a primary school teacher whose work has appeared in *The Caravan Times* (2014) and *The Motorbike Times* (2014). She believes "words have the power to entertain, educate, and inspire." Writing because she loves it, she also enjoys traveling, animals, and nature. In her free time, she enjoys curling up in front of the fire with her partner and two cats.

**Anne Mikusinski** has always been in love with words and has been writing poems and short stories since she was seven. Her work was published in Vassar College's literary magazine *Chronogram*. Taking influence from artists such as Robert Frost, Dylan Thomas, and Nick Cave, she hopes that one day her writing will impress others the same way these artists have had an impact on her own work.

**Tim Murphy** is a bisexual poet and abolitionist from the Pacific Northwest who lives with long COVID and myalgic encephalomyelitis. His work has appeared in *Louisiana Literature* (May 2024), *Wordgathering* (January 2024), and *Gastropoda* (March 2024), among others. Writing as an act of political resistance, Murphy aims to "dismantle ableism and destigmatize what it means to be sick with no end in sight."

**Sandy Palmer** is a child of deaf adults (CODA) and a freelance artist who works with a variety of media. She contributes to *Kaleidoscope* as the writer of artist profiles, having joined the staff as art coordinator in 2002. Palmer is the full-time graphic design specialist at United Disability Services.

**Dixie L. Partridge** is a writer out of Provo, Utah. Her works have appeared in *Poetry Magazine* (January 1999), *The Georgia Review* (1997), and *BYU Studies* (2007), among others. Focusing on the "effect of landscape on us" within her writing, she says that having six children has taught her how to give to others, which produces joy.

**Roselyn Perez** is a vocational rehabilitation counselor residing in Fort Worth, Texas. Crediting blindness for forcing her to use her imagination for things she is unable to access, she also acknowledges ADD has allowed her to make connections and leaps in her writing "that wouldn't be possible otherwise." Her work has appeared in *Jersey Devil Press*, *My Favorite Apocalypse*, and *New Legends: Caster, Castle and Creature*, among others.

**Zach Pietrafetta** is a student residing in Wilmette, Illinois. He writes because he wants to make a difference by representing individuals who are marginalized and neurodivergent. Attempting to build worlds where those individuals share their perspectives, without stereotypes, is his mission. "It's important to empathize with others because it helps people gain a better understanding of what it means to be human."

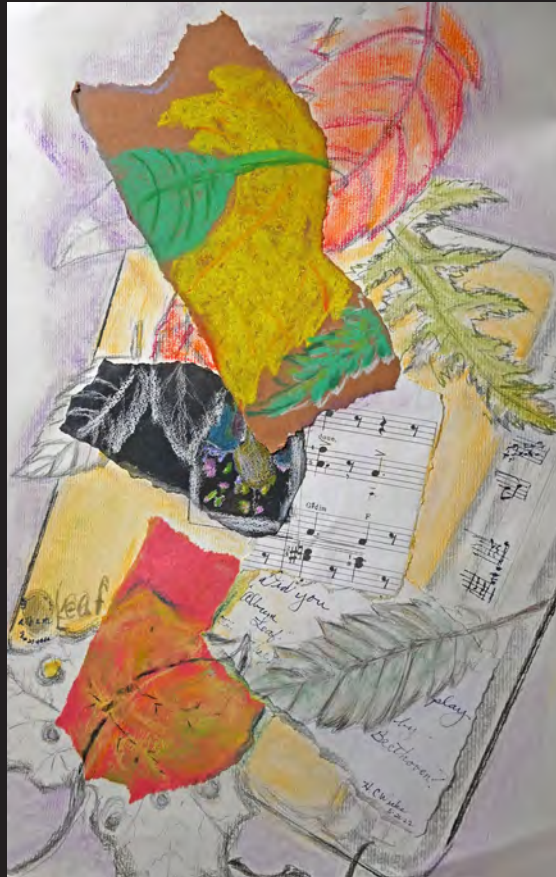
**Mary Harwell Saylor** is a poet and writer living in Pomona Park, Florida. Publications include poetry books *Highku: for lovers of God* (2024), *Haiku Happening* (2023), and *A Gathering of Poems* (2020). Two poems have been nominated for a Pushcart Prize and one poem has been placed in a haiku competition sponsored by the Society of Classical Poets. Saylor's husband has late stage Alzheimer's disease.

**Val Valdez** describes herself as "the demure lady in the corner, unnoticed and almost invisible, but with a mind that races like an Indy car." Residing in Killeen, Texas, stories flow from her in a stream of words, characters, and settings 24-7. Though the auditory processing disorder she has often leaves those who also have it unable to read or speak well, Valdez states, "I was blessed to be surrounded by books and stories. Books literally saved my life."

**Bonnie Ruane Wheeler** is a writer living in Connecticut who plans to obtain her M.F.A. from Fairfield University in January 2025. Her work has appeared in *Wordgathering* (August 2024). Viewing writing as a form of breathing, she spends her time volunteering to raise awareness for vascular Ehlers-Danlos syndrome when she isn't working on her next piece.

**Katharine Yusuf** is a retired pharmacist who has been living with multiple sclerosis for twenty-one years. Publications include the children's book *Grandma's Precious Memories* (2018) and two short story collaborations focused on MS. Yusuf says it was writing that helped her cope after losing her pharmacy career due to her condition. She finds joy in an afternoon spent with a good book and weekend camping excursions with her husband.

**Lisa Zimmerman** is a psychotherapist and writer living in the Metro Washington, D.C. area. Her work has appeared in *Voices: The Art and Science of Psychotherapy* (2015) and *ROOM: A Sketchbook of Analytic Fiction* (June 2024). She is passionate about "bringing disabled perspectives to professional conversations."



Heather Wicks, *Autumn Drift*, 2023, collage, 11" x 17"

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