

# KALEIDOSCOPE

EXPLORING THE EXPERIENCE OF DISABILITY THROUGH LITERATURE AND THE FINE ARTS

Number 80  
Winter/Spring Online 2020



## WINTERSCAPES

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*"Taco Tuesday" by Deanna Altomara*

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*"Remembering Ronnie" by Anita G. Gorman*

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*"Choosing Irresponsibility" by Sarah Bat*

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*Kaleidoscope, beginning in 1979, pioneered the exploration of the experience of disability through the lens of literature and fine arts. Fiction, personal essays, poetry, articles, book reviews, and various artistic media including two-dimensional art, three-dimensional art, drama, theater, and dance are featured in the pages of various issues.*

*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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# WINTERSCAPES

DEBRA JOHANYAK

It's that time of year when wintry weather reminds us to slow down and savor cozy pleasures. Our theme for Issue 80 of Kaleidoscope is "Winterscapes." January is the perfect month for enjoying seasonal outdoor fun, no matter whether you live in the frigid North or along the balmy southern coastline. Then, settle indoors with a relaxing beverage and dig into the current selection of stories, articles, and poems that comprise our current issue.

Winter offers a fresh start by ringing in the New Year on January 1. February brings us heart to heart on Valentine's Day. The promise of spring in March awakens renewed energies and excitement. Our contributors' thoughtfully-crafted works invite you to share unique perspectives on life from those who are managing a disability or caring for someone with a special need.

This issue's featured essay, "Taco Tuesday," by Deanna Altomara, provides an insightful glimpse into the life of a teenager with autism who is learning how to balance a restaurant serving job with high school studies.

"Choosing Irresponsibility" by Sarah Bat, reflects on the choice between doing the right thing versus doing what we so badly want to do. Should we ever make the "wrong" decision when it feels so "right" in the moment? Sarah shares her experience in this thought-provoking piece that will likely leave you questioning some of your decisions as well.

Anita G. Gorman's "Remembering Ronnie" pays tribute to a unique and unforgettable friend. Sometimes we treasure a friendship not because of what someone does, but because of who they are. You may be encouraged to look up an old friend or make a new one with characteristics that are unusual but endearing.

Artist Odessos was born with a hearing impairment and has worn hearing aids since age eleven. He believes his hearing status "certainly was a contributing factor" to his artistic development . . . giving rise to "more personal expression and desire to belong." His subjects include landscapes, fantasy, cartoons, and architecture. Favoring acrylics, some images portray serious environmental messages while others are lighthearted and scenic. He says, "The viewer must decide what he sees."

Poems offer lyrical themes of self-expression and reflection that we can appreciate. "Holding On," by Shirley Adelman, speaks of "winter afternoons" when just existing is enough. Jólét's "Snow" reminds us of the "magic stillness" of "joyful snow" and being "reborn." "A New Normal" by Kira Compton ponders the idea that life comes with surprises and adjustments, some less welcome than others, but all with challenges and opportunities.

Out with the old, in with the new—this winter issue introduces new literary landscapes to explore. We hope you will enjoy this inspiring collection of writers and artist along with their amazing work that creates new images and ideas to creatively imagine after a brisk walk in a winter wonderland or an afternoon on a sunny beach. As you begin the New Year in respite from daily year-long cares or reinvigorated to embrace goals and dreams anew, join us in surveying bold new visions of life as it is—and as it should be. ♦



Debra Johanyak

KIRA COMPTON

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## A NEW NORMAL

My mother asks if I am feeling fine  
and I say “yes” because the real answer  
is not one she would really want.

The real answer is that  
I am feeling fine because  
there is a new fine.  
A new normal.

It is normal, now, to pump  
intravenous medication in my arm  
so that my body does not kill itself.

It is normal, now, to know that  
azathioprine and Imuran are synonyms  
for something that’s supposed to  
make the Remicade work.

It is normal, now, to skip a meal  
a day of meals, so that  
I will not be sick the day  
of something important.

It is normal, now, to know  
when and where to rotate  
self-injection sites.

It is normal, now, to shut  
my eyes against the pain and  
will it to go away because  
I am out with friends and  
really don’t have time for this  
right now.

It is normal, now, to stand  
alone in a dormitory shower  
and ask God what the hell  
was he thinking?

I am normal, most days.  
I am happy, most days.

And maybe there is silver hanging in these clouds:  
I really don’t have to worry about old age, anymore,  
do I?

My mother asks if I am feeling better,  
and it is normal, now, to smile and say,  
“Yeah, I’m feeling fine.”

# TACO TUESDAY

DEANNA ALTOMARA

The librarian unloads the stack of books balanced in the left crook of her arm, one at a time, popping each one into its place on the shelf. “Do you know the Dewey Decimal System?” she asks quickly, not turning to look at me. I’m glad she doesn’t look at me.

I look at my shoes as I nod, “Yes, ma’am,” because Alaina, my therapist, taught me that was a nice thing to call ladies who are older than me.

“Wow,” the lady pushes herself off the ground now and turns, with her face kind of opening up, getting wider in the mouth and eyes. That means . . . she’s surprised? Why is she surprised? I’m fourteen years old. I learned the Dewey Decimal System when I was in reading class in fifth grade. Of course I know the Dewey Decimal System. “Where did you learn that?” she asks.

I squeeze my eyes shut, trying to remember my elementary school classroom, and Mrs. Barnes, who was my teacher then. Nerves are still pouring through me, making me feel electric with every breath I take, so I’m trying to hold my breath. I rush out, “Room 102, Davidson Elementary School, 500 Cortland Row, Sycamore Hills, New Jersey.”

The lady’s eyes get wider again, and my pulse picks up. I know I’m missing something important in this conversation, and I have no idea what it is. “Wow,” she says again, “You have some memory!”

I—I think that’s a compliment? I don’t know. My hands are sweaty. They start flapping a bit at my sides. I can’t control it. “Thank you, ma’am,” I say.

She smiles, and that’s a good sign! She’s happy. She pushes the cart full of books toward me, and explains, “You should have no problem shelving these, then. They all follow the Dewey Decimal System. When you’re done you can come to the office behind the circulation desk and find me; I’ll be at the computer in the back working on circulation. You just come find me, and I’ll give you more books to shelve.”

Slow down, what did she say? The words went by so fast, fluttered away like leaves on the wind, disappeared before I could grab them. I can’t hold my breath anymore; it’s coming too fast. I grab the cold metal of the cart and begin running down the aisle, sprinting to the biography section because I like biographies, and they’re nice and far away in the quiet corner of the library, and books tumble off the cart, land with a loud *plunk* all ugly spine-open, but I don’t look back; I leave them on the floor and run to the biographies with my cart. When I get there, I let go of the cart, and it slides forward a few feet and bangs into a shelf, and a clump of books fall to the ground—like *crash!*

Oh no, I jump back and almost hit another shelf. I’m breaking books, and it’s only my first day of work-study at the library. I’m breaking books, and that’s not good, and my sweaty hands are shaking, flapping with all the bruised-up energy I can’t keep inside me. Then I hear panting and

the lady turning the corner, breathing hard, into my aisle, clutching a few of the books I spilled to her chest. “You can’t run like that!” she says. “This is a library!”

Then she looks at me and for some reason her tone changes. “Here, we’ll just clean up these books, and then you can put them away.”

I don’t understand; is she angry at me? She doesn’t sound angry, but she should be since I broke the books, and I want to make her happy, and what she told me to do was to put the books on the shelf and then come find her . . . find her . . . where was I supposed to find her . . . I don’t know . . .

---

## **I’m standing there flapping and breathing fast when the lady catches up to me and grabs my flapping hands . . .**

---

But she told me to put books on the shelf, and I want to make her happy, so I grab a book from the cart and check the Dewey Decimal number, but it’s not a biography, it’s a cookbook, and they belong all the way in the 600s. My left hand is still flapping as she’s kneeling to pick up the books I crashed, and I start sprinting to the cookbooks with my flapping left hand, and then she’s calling my name, “Mason, wait! Mason, where are you going?” And she gets up and starts running after me.

Oh no, I have to put this book away, she doesn’t understand! I find the cookbooks and scan for the spot on the shelf where the one in my right hand belongs, and I shove it in there good between the salmon recipes, nice and cozy where it belongs. I’m standing there flapping and breathing fast when the lady catches up to me and grabs my flapping hands, cooing, “Mason, it’s okay, don’t run, I’m here to help, accidents are okay . . .”

But her HANDS. Her HANDS, they’re on my wrists, stopping them from moving, like I’m wearing chains, and I’m jerking away—I don’t WANT TO BE TOUCHED LET GO OF ME LET GO LET GO LET GO

And SUDDENLY there are SCREAMS in my ears and they’re so LOUD and HIGH-PITCHED they STING THEY STING ME my screams and I TUMBLE to the GROUND and the carpet is BLUE and BLACK and SCRATCHY and my WRISTS are too WARM where she TOUCHED them, too WARM, it’s almost as if she’s still there GRABBING me and then she IS and-and-and-and-  
and my hands are over my ears, and my head is between my knees and I am screaming.

\* \* \*

Something about baking makes me happy. This means that my heart beats faster, I talk more quickly, and I want to keep doing it. I could keep doing it for a long time. Sometimes Mom slides off her big yellow oven mitts and says, laughing and sighing at the same time, “Mason, that’s enough for one day.”

Now that I’m older, I don’t scream and cry when this happens, at least not most of the time. When Mom says that, these are the steps Alaina taught me to follow.

1. Mom says, “Mason, that’s enough for one day,” and laughs and sighs at the same time. This means she is tired, so
2. I say, “Okay, Mom.”
3. Then I count the ingredients as we put them away so that everything is cleaned up. Mom washes the baking pans in the sink with bubbly soap. I don’t like that feeling of soap and bubbles scratching and tickling on my hand, so Mom always does it. But Alaina says one day, probably soon, I’ll have to start helping. She says I’ll wear long special gloves.
4. When we are finished cleaning up, I go into the living room, sit down, and play with my blocks. If the timer in the oven beeps because something is ready, I go up stairs and make sure Mom knows. Then I go back and keep playing.



These steps help me calm down. It's called *coping*. I have a lot of coping strategies, and they are all written out in a special notebook I keep in my backpack. It is a cardboard notebook with Darth Vader on the cover, and that makes me happy. When I get scared or upset or nervous, Mom or Alaina or Brandon always says, "Go get your notebook." But by now, I've pretty much got it memorized.

So when Mom says what she does that night, I don't know what to say. So I walk out of the kitchen and go get my notebook.

What Mom said was, "Mason, Brandon says he found a new place he thinks you'd really like for your work-study. Do you remember Taco Tuesday's? He says you can work there with Joy."

And when she said that my heartbeat got very fast and my face felt very hot and my hands started moving at my sides, so I went and got my notebook. And I didn't melt down. I sat down between my blocks and grabbed all the red ones from the bag, one at a time.

"I'm sorry," I say. I'm looking at the ground, but Mom is standing there, and she sits down next to me. "I didn't mean to ruin the job. I'm sorry."

She sighs and picks up one of my blocks, turning it over in her fingertips. "Don't be sorry," she says, "it wasn't your fault."

My favorite movie is *The Lego Movie*. I recite my favorite line to Mom. It is Metalbeard yelling, "Wiping yer bum with a hook for a hand is really hard! This be impossible!"

Mom smiles, trying to make eye contact with me. "I know it's really hard," she says, "But I believe in you."

\* \* \*

At Taco Tuesday's, our boss is named Steph. She has curly blond hair. She smiles really big when she sees Joy and me come in with Brandon, our Life Skills teacher. Joy and Steph met last week, and I'm really surprised when Joy squeaks, "Hi, Steph." Joy is usually pretty shy.

"Why do you have a boy's name?" I ask.

For a second Steph makes a funny expression, and then she's smiling again. "It's short for Stephanie."

Brandon says, "Mason, that question could be a 'Hot Topic' for some people, since it has to do with gender."

"Oh," I say. "Hot Topics" are named for a reason. If you blow the match the wrong way, you get burned. "Don't play with fire," I add.

Brandon nods, knowing exactly what I mean. And he and Steph talk for a few minutes, and then Brandon talks to us, and he wishes us luck, and leaves.

Steph shows me how to clean the tables and sweep the floor. The customers clean up their own trays and baskets, but they also usually leave behind all their crumbs. First, Joy wipes the table and then the chairs with a wet cloth. Then I get the broom and sweep away all their crumbs.

---

## **I have a lot of coping strategies, and they are all written out in a special notebook I keep in my backpack.**

---

The first table Joy and I clean is pretty easy. Then yay! It's time to go home! I can't wait to tell Mom about cleaning the dishes from the table.

\* \* \*

Things have been going good for a week when we get into trouble. I mean, before that we were still making a ton of mistakes. Joy kept bumping into people and spilling whatever was in her hands. The plates would hit the ground with a clash like an explosion in my ears, so whenever that happened I took my break. A walk outside, just five minutes, because that is what my notebook says to do when I am too nervous. I don't think Joy has a plan like that, or at least not yet. When she drops something, she sprints to the bathroom, locks the door, and won't come out, sometimes for fifteen minutes. I asked Steph why she doesn't just use her special key and force Joy to come out, but she said all Joy needs is time. Also, that bathroom key is only for emergencies.

But the first real trouble we get into is when we are watching the old man. Joy and I are waiting with our bucket by the soda machine for people to leave so we can clean up after them. One guy is sitting by himself, with a scratchy gray beard that is speckled with tortilla-chip crumbs.

I say to Joy, "I didn't know old people like tacos."

Joy shrugs. "I g-guess they do."

I watch the crumbs trickle down the man's beard and onto the floor. He sees me watching him, and his eyes seem to narrow, and my spine crunches up because I am nervous, and that is what happens when I am nervous. I remember Alaina teaching me how it's rude to stare, so I try to say something so that maybe he won't be mad. I blurt out, "Please be clean. Your beard has crumbs."

He scowls, and even I know that's a very bad sign. Joy tries to grab my hand, which is starting to flap, but I smack her away.

"Come over here," the man growls and throws his napkin down on the table. Oh no, my face becomes hot; my hands are like butterflies flapping at my sides. I slowly step over. Joy hesitates, then follows. He barks, "What's your name?"

What? This isn't a normal conversation where you introduce yourself to your talking partner and find a common interest. This doesn't seem like that kind of conversation, so I don't know why he is asking for my name. I wish Alaina were here. I'm scared. Alaina would know what to do. "I'm Mason Jacob Sudmeister. What's your name?"

The man is blunt, "Don't fuck with me." My hands are flapping, flapping. "You don't know the week I've had."

Huh? I don't understand, I don't know what week he is talking about, I just met him! I didn't do anything. I didn't. My heart hiccups into my throat, and my hands are flapping. The man calls me a "retard" under his breath, and then I'm breathing too quickly, too quickly, my chest is flapping my hands are pounding because I can't breathe—

And then I'm on the cold ground, gray tiles and yellow taco crumbs CRUNCH-CRUNCH beneath me—

And then there is Steph, next to me, her blond hair falling in front of her face. She is whispering, "It's okay, you can go take a break—"

A break. *Oh my gosh, thank you Steph, that's brilliant.* She is like Lucy in *The Lego Movie*, saving Emmet. Lucy's words bubble from my lips—"Come with me if you want not to die"—because I understand that Lucy and Steph, they're really doing the same thing, saving Emmet and me from certain destruction.

And I can suddenly gasp for breath and run for the door and take a long, long walk.

\* \* \*

The chair in Alaina's office is soft and plushy, pea green laced with brown *fleur-de-lys*. Her bookcase has some psychology textbooks and some colorful picture books and a stuffed giraffe. Blocks are spilled across my lap. Alaina doesn't have as many blocks as I do, and she doesn't have my favorite *Star Wars* set. But she promised me she'd get any set I wanted if Steph and Brandon both say I'm working hard at my job and at school.

I am sticking the gray bricks together, *click click click*, to make a spaceship, or at least to get as close as I can without my favorite *Star Wars* set. *Click click click*. The sound is soothing. "I don't understand why he got so upset." My voice cracks a bit, and I swallow, because even though Alaina has seen me cry a million times, I don't want today to be one of them.

---

**And Alaina knows me so well, I don't have to say anything for her to know what I'm thinking. I hate "gray area."**

---

She says, "It's not appropriate to call people 'old' or say they're 'messy.'"

"But it wasn't my fault! It was true! I was just trying to help—"

"Shhh," she whispers. She is trying to help, I know, not just because she is Alaina, but also because she told me to listen to people's low and soft voices, because when people speak like that, it usually means they're either sad or trying to help. She whispers, "I understand that's the truth. But remember that just because something is true doesn't mean it's appropriate to say. Gray area, right?"

I put my blocks down on my lap and cover my eyes. We've had this conversation before. And Alaina knows me so well, I don't have to say anything for her to know what I'm thinking. *I hate "gray area."*

I wish other people could read my mind as well as Alaina. It would make things so much easier. It's like I'm speaking a different language than everyone around me, on a different planet. I try to say something, anything, and then they look at me with big, wide eyes, which Alaina says means shock.

I shock people. But I don't mean to.

Alaina reminds me of her tips on the gray area of honesty: if you think it could be inappropriate, better not to say anything; try to imagine someone saying that to you; I know that's hard, but try; don't say the truth if it hurts someone; don't say it if it won't make the conversation more enjoyable for your talking partner.

But then she surprises me, and says, "But that man was also incredibly rude. How he reacted was completely inappropriate. It's not got anything to do with you if someone is having a hard time. It doesn't give them the right to act like a jerk, but you just have to remember that it's because of something bad in their lives, not you." And then she adds, "And I'm proud of you for handling it so well. For taking a break when you needed it."

And I'm so shocked and so happy I almost forget to smile to show her that she made me feel good.

\* \* \*

We have been working at Taco Tuesday's for five months. In the mornings, Joy and I go to school and do all our regular classes—math, reading, Life Skills—and at 12:04 p.m. the bus pulls up outside to take us to work for the afternoon. Sometimes the bus comes at 12:03 or 12:05, and that's okay, because we have to be flexible. But sometimes the bus doesn't come until 12:06, and that's when my hands start flapping, because I don't want to be late to work.

We get dropped off there, and Steph comes out with her big smile and says hello. She helps us pick out Taco Tuesday's aprons to wear, and helps Joy tie the knot behind her back. She doesn't need to help me tie my knot—I'm a pro at that! Last month, Joy and I graduated to actual cleaning. I was really nervous at first, because I hate when my hands are wet and soapy, and I can't dry them—they get so itchy! But Brandon and Steph got me a pair of special rubber gloves that go all the way up to the elbow, so I can wear them when I clean. When I told Alaina this, she became very excited and said now I can start helping Mom wash the dishes after we cook together. And I have been! Now, I'm a pro at that, too.

First we wipe the soda machine clean, and then all the free tables, and then we mop the bathroom floor. One day, when Joy and I are mopping, Joy starts shaking. She puts down

her mop into the soap bucket, walks into a stall, and slides the lock shut. The stalls are gray plastic, and the ground is white tile.

I knock on the stall door. "Um, Joy?" I am trying to think of something to say that won't hurt her feelings or be a "hot topic." After all, we are in a bathroom, and the only topics hotter than that are religion and politics. I think *Please don't go to the bathroom right now*, but maybe that is a little too hot. I think a moment longer, and settle on, "Is everything okay?"

---

## It's like I'm speaking a different language than everyone around me, on a different planet.

---

Her foot is tapping the ground, and it echoes against the walls. She doesn't say anything, and I start to get the tiniest bit frustrated—we have work to do!—so I repeat my question.

"M-Mason?" she says, and I notice her voice is soft and low, which means she is either upset or trying to help. I think it's the first one. "Y-you're my only friend."

"Oh." I say. That makes sense, even if I don't understand what this has to do with anything. I'm the only kid who talks to her, just like she's the only kid who talks to me.

"I'm weird," she says.

I consider that for a second. "Yes," I finally agree, "I'm weird, too."

"I want friends," she whispers, "I want to be p-popular. I want people to like me and make me friendship bracelets and boys to ask me to the dance."

Hmmm. "Do you want to go to the dance with me?" I ask.

She starts laughing, laughing her head off in the locked bathroom stall. What? Why? Laughing is a happy thing; I thought she was sad! I am confused.

Joy says, "Y-you're nice."

I agree.

Then her voice gets really high, like she's balancing on the edge of a blade, and gives a little gasp, and I think she's crying. Maybe I misunderstood her laughter. I do that a lot. Maybe she really is sad. "Mason, I-I d-don't want to be weird."

I'm not sure what to say, but I know how she feels. I don't want to be weird, either. I say, "You're my best friend."

The stall door flings open and knocks me over, and Joy is suddenly smothering me, her warm arms all over my body, wrapping me in a giant hug, her cheek against my chest. I fall over, and she falls down too, and I scramble away on my hands and feet like a crab, screaming, "PERSONAL SPACE, PERSONAL SPACE!" The tiles are cold and white and wet and I jump up, oh no, I'm wet, and my hands are flapping. But I remember my notebook, and force myself to take a very long, very deep breath.

Joy gets up too, wiping her hands on her jeans. "Oops," she says, "I forgot about the arm's-length rule."

Steph comes running, her sneakers slamming against the floor, and she bursts into the doorway. She gasps, "Is everything okay?"

Joy and I both say, "Yes" at the same time. And then I realize I'm smiling, and I didn't even have to remind myself.

\* \* \*

Every year, Sycamore Hills High School has a special awards ceremony in front of the whole school. Everyone gets very excited, because it means they get to skip afternoon classes. But Joy and I have to miss work instead, and that makes me sad. I'm so anxious all day long about not going to work that I accidentally have a meltdown during lunch when I realize that I can't have my favorite bean taco today. Brandon sits with me and calms me down, and reminds me about being flexible. He reminds me to take deep breaths like my notebook says, and to go for a walk outside for five minutes. That doesn't solve my problem—I still don't have my bean taco—but at least I can breathe again, and my hands aren't flapping anymore. When the time for the award ceremony comes, everyone in the Life Skills program is offered ear plugs. I am happy to have ear plugs.

The school auditorium is packed, which makes me nervous all over again, but Brandon sits with us near the back in case we need to take a break. The ear plugs muffle the sound of the crowd marvelously. The ceremony starts late, at 12:34 instead of 12:30. I don't like it, but I take a deep breath. Flexible, be flexible.

First they do the English awards, and the best student in every class comes up, gets a certificate, shakes the principal's hand, and smiles for a picture. Then they do math, and history. No one in Life Skills gets any awards for those, except for Lizzie, who is very smart and in all the advanced classes even though she never talks. We're all proud of Lizzie, and stand up and clap for her. At the end of the ceremony, just when I'm getting anxious to leave, something odd happens: a woman with blond hair walks up on stage, and the principal hands her the microphone. I don't recognize her until Joy whispers, "That's Steph!" And then I realize it is, only today she is in a dress instead of a Taco Tuesday's apron, and her hair is down, not pinned back.

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**At the end of the ceremony,  
just when I'm getting anxious  
to leave, something odd happens:  
a woman with blond hair walks up  
on stage, and the principal hands  
her the microphone.**

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"Hey guys," she begins, "My name is Stephanie Muller, and I'm the assistant manager at the local Taco Tuesday's. This year, I also had the honor of working with some part-time Taco Tuesday's employees from the Life Skills program. And today, I'm here to tell you a story about that." Joy is vibrating with excitement, jumping up and down in her seat, her red hair bouncing all over as she gives little claps. "Two weeks ago, two of our best workers called in sick on the same day. That meant I had to take over the register, but I couldn't do it alone. So I asked the students for a little help. Who here has a job?" About half the kids in the audience raised their hands. "You guys know just how scary working in the real world can be. It's especially terrifying when you're asked to do something you've never done before. So when I asked Mason and Joy—" My name. My hands start FLAPPING all over my lap. Steph continues, "to prepare and serve tortilla chip baskets to the customers, I could tell they were terrified. But instead of running away, Mason asked me to show them how to do it."

I can remember clearly the white plastic gloves she gave us, the crunch of the chips as I distributed them into plastic-lined baskets, the thud of my heart as I put them on people's tables without a word and hurried away as fast as I could, and sometimes they stared at me, just like people always

do. I remember the crash when I dropped one of the baskets, and chips scattered all across the floor like an explosion, and I was breathing fast, and Steph called over to me that it's fine, someone will clean it up, you can go take a break. But she doesn't mention any of that.

Instead, she says, "And for the next two hours, Taco Tuesday's ran smoothly. People never had to wait for their chip basket—Mason and Joy were always prepared—and my life was made a lot easier. If it weren't for the two of them that day, we wouldn't have been able to keep up with the lunchtime rush. And that's just one example of the amazing work ethic and personality these incredible students have demonstrated this year. Mason and Joy, would you come up to the stage to accept this award?"

And the room is alive with thunder, energy coursing through the seats and into my veins, my flapping hands, my fast breath. The earplugs are a blessing; they dim the sound just enough that I don't burst into tears. Brandon smiles at us, tilting his head toward the stage, and then I'm pushing past people in the chairs and running up the aisle, and Joy is behind me, jumping. People are standing on either side, cheering, "Go Mason! Go Joy!" as I rush past them, my hands in the air. Oh my gosh. Blood in my face, in my ears, fire in my chest—a good fire—as I dash up the stairs onto the stage, and I feel like I'm a spaceship rocketing into the galaxy, alive with power, ready to vanquish my enemies. I

feel like I'm in outer space, light and shaky, as I grab the certificate from Steph and hug it, the smooth embossed paper, tight against my chest. The principal reaches out to shake my hand, but I jump away from him, so he shakes Joy's hand instead, and I'm jumping with joy onstage with my gold-embossed certificate. He smiles and waves me in to come take a picture with him and Joy, which I do, and I put the biggest smile on my face that I can squeeze in, and then I see Mom, next to the photographer with her own camera—Brandon must have known I was getting this award! Brandon must have told her! And I run down the stairs so fast I nearly trip and everyone is cheering, and I run to Mom, but she knows not to hug me, she is just smiling wide as the moon just like I am, and then I am singing my favorite song—

And for the first time, it seems like the world is singing with me. ♦

*First published in Words for Charity (2019) and winner of Pen2Paper Disability Fiction Award. Reprinted with permission of the author.*

## Call for submissions

## KALEIDOSCOPE

*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

Email submissions to [kaleidoscope@udsakron.org](mailto:kaleidoscope@udsakron.org) or online at [kaleidoscopeonline.org](http://kaleidoscopeonline.org).

JOAN SELIGER SIDNEY

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## REGRETS

I stare out the window of my pine-paneled study.  
 Half the hemlock waves in wind, the rest hides  
 behind the side of the house. What others see—  
 smiles or frowns, dress-up or dress-down clothes—  
 conceal or reveal what I choose to show.  
 I shudder to remember how I hid the truth

of my illness from Mom and Dad, afraid truth  
 would hurt them. Holocaust survivors. An A+ student  
 through my Ph.D., I believed I had to be perfect, not show  
 I had MS, a disease their sixty-ish neighbor couldn't hide.  
 Despite her life bound to a wheelchair, she was clothed  
 in love from her husband and mother. Mom and Dad saw,

admired their devotion. But Mom's words chain-sawed  
 through: "What a terrible old age for her mother!" True.  
 As my legs grew weaker, how could I disclose?  
 "I'm too busy to walk with you," I lied, staying in my study.  
 "Your legs will forget how," Mom said, not hiding  
 her annoyance. But how could I let my jello-legs show?

A mistake I can't take back, too late to show  
 how, in my late forties, I tried to protect them from seeing  
 my leg muscles tighten, refuse to make another step, by hiding  
 in front of my desktop computer screen to block truth  
 or by pulling pachysandra from the walk outside my study  
 on hands and knees, sweating in summer clothes.

Dad passed at eighty, two years later. I tore my clothes,  
 sat *Shiva* with Mom, letting our love show.  
 From our hearts we talked, sitting on the sofa in my study.  
 "We thought you didn't love us. We didn't see  
 you couldn't walk." I pulled Mom close. "Not true!  
 I didn't want you to see and suffer, so I hid."

"Come live with me in Delray Beach. Stop hiding.  
 I'll care for you, bring this nightmare to a close."

*If only this could come true.*

*But I know MS is showier;*

Secondary Progressive, my neurologists saw.  
 Not even Mom's love could undo medical studies.

A lifetime can't hide mistakes that don't show.  
 This truth pursues me like a door that won't close.  
 Alone in my pine-paneled study, this is what I see.

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# EXTRA CANDY CANES

PAULINA COMBOW

It was my sophomore year of college, and I was openly crying while calling my mom from outside the elevators in a lobby on campus. I had just learned the Study Abroad office needed a \$1,000 deposit that week, or I wasn't leaving the country (and probably not Kentucky) that summer. She was eerily calm, telling me not to worry. We could figure it out. I wailed, "How can you be so calm? We don't have \$1,000!"

Her tone remained steady as she softly replied, "I'm pregnant." I didn't realize it then, but this was the day I became a different person. I'm the oldest of four. My sister Portia is six years younger than me, and my brother Colton is seven years younger than her, so maybe I should have seen this coming. She stuck with the formula. Eight years had passed since she'd last given birth, and it was time to breed! But I was twenty years old, the age of my mom when she gave birth to me, making her forty. *Who has a kid at forty?*

I missed most of my mom's pregnancy, being in college, then Europe, then back to college. I wouldn't be around to change diapers and put him to sleep, to babysit as I had with my other siblings. I wasn't even home when she delivered. He came early. Breech. That's feet first if you don't understand birthing lingo. I got a voicemail from my aunt one morning that I had a new baby brother. Insert pounds, ounces, and inches accordingly. I didn't understand those measurements. I planned on finishing classes that week,

then heading home for the weekend to meet my tiny new brother, Cameron, a name my mom chose from an email of my approved boy names starting with "C." I didn't trust her to choose a name after me, Paulina, Portia, and Colton. Just let one of your kids be able to find a keychain with their name on it. The night before I was going to come home, my mom called me, crying. This was the first time I'd spoken to her since Cam was born. I'd been communicating through family members. My heart sank. What was wrong? The woman who always remained calm and steady, the family's rock, was completely shaken. She finally revealed to me what she had known for months. Cameron was born with Down syndrome.

I didn't know anything about Down syndrome, but I just said the first thing that came to mind, "So what?" That doesn't change anything. I don't know what bad news I thought she had, but Down syndrome seemed so minor compared to everything I had cooked up in my head.

After college I moved back to my hometown and even bought a little house in the same neighborhood as my parents, something eighteen-year-old me would have sneered at. It felt almost like I was living back home. I was broke, so I ate dinner with my family every night and mooched off their Wi-Fi and cable. Of course, living in a small town there was a rumor going around that my mom had only pretended to be pregnant while I secretly gave birth to Cameron and passed him off as a sibling. We weren't living a

plot from *Desperate Housewives*, so we just let people think what they wanted. People in public always assume I'm his mother. I guess the ages do work out better. Anytime someone looks at Cam and then refers to my mom as "Grandma," I just like to step back and watch them dig their own graves as she firmly corrects them. "No, I'm his mother. They're both my children." That's when they usually start looking around for the hidden cameras. Sidebar: don't assume every caregiver is a parent. They could be a relative, friend, nanny, or even a kidnapper. Don't assume!

The summer I moved back home was also the summer Cam had open heart surgery. It's common for people with Down syndrome to be born with holes in their heart. Cam was no exception. He'd been taking medication for it since birth, but at 18 months old, the doctors felt he was strong enough to have his ribs cracked open and the holes and valves repaired. I think that was when I truly bonded to him. There were complications, and times when all we could do was hope and pray, but he came out of it a different kid. He had more energy than ever before, and he's proud to show off the now white scar down his chest.

Since then I've moved to Nashville, only an hour away. Cam stays with me on weekends where he has laid claim to the guest room as his personal space.

People feel completely comfortable asking if he's adopted or if we have the same parents. It's none of their business, but I think you can look at us and tell. Few people have blond hair, blue eyes, freckles, and a nose you can barely stick a pinky finger into. Seriously, I can barely wear glasses. The oddest thing is the look of pity people have in their eyes when they see a child with Down syndrome. Cam does not want anyone to feel sorry for him. The truth is he's got a pretty sweet life, probably better than yours. Once my mom asked me, "Do you think Cameron knows he's different?"

I replied, "Yes. I think he thinks he's a celebrity." He doesn't see himself as an outsider, but more likely above everyone else. How could he not? He's been given special treatment his entire life, some needed and deserved, and other times it was just a perk.

The day I realized just how much special treatment he received was when I took him to meet Santa at Bass Pro Shop one Christmas season. Anyone who has been to Opry Mills in December knows it's a chaotic nightmare, but somehow offering free photos with Santa brought people from all over Middle Tennessee. We walked in, saw the line wrapped around the inner perimeter of the megastore, and said, "Well, maybe there's another less popular Santa we can talk to at Kmart."

We walked back out of the store when a young female elf chased us down and said, "Wait! Did you get to see Santa?"

"No," I replied, "The line was too long."

She got a spritely twinkle in her eye and said, "That's ok, because special boys and girls get to go to the front of the line!" That changed everything. She escorted us past screaming kids and exhausted parents to the front. We marched right up ahead of people who had been waiting days, I presumed. Cam plopped onto Santa's lap and had a chat about what he wanted, then Santa proceeded to give him TWO candy canes.

I heard a kid behind us whine, "Why does he get two candy canes?"

I whipped my head around and spouted, "Extra chromosomes equals extra candy canes." Okay, I didn't say that, but how cool would it be if I had? After that we were drunk with power. We went to Chuy's for dinner and were beyond distressed when they informed us it would be an hour wait. I guess you can't win 'em all.

Personally, I never want kids. Cam will always need me in some form or fashion, and I'll always need him. My mom says if I did have a baby, Cam wouldn't let me keep it anyway. I already forced my mom to make me his legal guardian. The thing I have learned the most from Cam and the way people treat him is that we shouldn't treat kids with special needs so special. We should treat all kids that way. ♦



# COMMITMENT DOESN'T COME WITH AN ESCAPE PARACHUTE

SUSAN YANGUAS

I took my elderly dad out for a rare father-daughter-bonding breakfast one morning while visiting my parents. Over the course of the meal the conversation turned uncharacteristically serious, and I found myself asking him what he wanted to be remembered for after he was gone. He thought for a moment and then replied, “Sticking around to take care of your mother.”

This was a man who had immigrated to America when he was seventeen. He struggled to get a GED in his adopted language, went on to become a fighter pilot during WWII, and flew missions in the South Pacific, where he was shot down behind enemy lines and came home with a metal plate in his chest. He subsequently learned the electrical trade on the G.I. bill and worked two jobs to put his kids through college. But he didn't want to be remembered as a hero, at least, not a war hero.

\* \* \*

Growing up, my mom was the one the neighborhood kids went to when they skinned their knees. Not only did she know just what to do, having trained as a registered nurse, but her gentle presence was calm and reassuring. And it was a good thing she had that training, because she was always patching up my father. Those were their roles: he'd fix things around the house, and when he hurt himself in the process, she'd fix *him* up.

When they reached retirement age, all of that changed. In a cruel twist of fate, my mother became a paraplegic, and he became her caregiver.

She had been having trouble walking, and a routine surgical procedure to alleviate pressure on her spine from a malformed blood vessel unexpectedly left her paralyzed from the waist down. It was a major blow to the whole family, but an especially huge adjustment for my parents. My sister and I lived five hours away, so we were unable to help out regularly, and it fell to my ill-prepared father to care for my mother.

Now, I love my dad dearly, but he's not at all the nurturing type. On the rare occasion that he tried, his clumsy attempt to comfort amounted to a heavy-handed pat on the back that would nearly knock us over.

My father's new vocation had a rocky start. Some of the trial-and-error home health care routines were a total disaster (such as the rolling commode chair), some laughable (duct-taped clothing), and the remaining attempts actually became workable practices. My dad would rig up all sorts of contraptions to make life easier for the two of them—from coated electrical wire pull-straps so my mom could raise the legs on her wheelchair, to a series of lights and mirrors that allowed her to catch a glimpse of her nether regions. He was really proud of his homegrown techniques, even declaring that he ought to patent some of them.

“The accident” not only forced my mother to withdraw from her busy life; it also required my dad to curtail his activities. He tried to keep working at the trade he loved, coming home at lunch to check on her, but it was a strain. The added burden of preparing all the meals, doing mountains of laundry, and assisting my mother with countless tasks took its toll. In moments of discouragement he’d lament the fact that he’d been robbed of his golden years, when he had planned to travel—but he never blamed her.

As time went on he not only became her legs, he became her proxy—going to parties and funerals he never would have attended otherwise, to “represent the family.” She would grill him when he got home on who was there, what was served and discussed, and how everyone looked. He even participated in the local garden club’s annual flower show at my mom’s insistence—cutting blooms from their garden under her direction, building miniature props for the arrangement, and delivering the finished product to the church hall. For weeks afterward he boasted about winning first place!

Despite my dad’s best efforts, we almost lost her a couple of times. I believe she pulled through solely by the sheer force of his will. When she was in the hospital, he’d go every day to make sure she was getting top-notch treatment. He imperiously confided to me that he had to teach the nurses there how to dress her bed sore and show them how to use the Hoyer lift to get her in and out of bed. I’d witness him, in his tactless way, bossing them around: this old man with no medical training lecturing the RNs about the correct way to do a certain procedure. He’d sidle up to one of them, poke a stubby finger at what they were working on, and say, “I see you’re using Baza® [anti-fungal cream] on her. You’ve got too much there. You know you should just use a little, right? Because if you use too much, it slows down the healing. I only use this much—” (he’d make a tiny “O” with his thumb and forefinger) “and rub it in good. I speak from experience.” I cringed the times he stormed the nurses’ sta-

tion and demanded in a loud voice that my mother be given the Tylenol she rang for half an hour ago. Oddly, though, he was her comfort and the one she’d ask for—more than her daughters, the compassionate nurses, or the kind social worker—despite the fact that he’d change her TV to the station he liked (a boxing or tennis match) and then fall asleep in the guest chair, snoring loudly, while clutching the remote out of her reach.

He’s been taking care of her for twenty-three years now, and his devotion has allowed them to live independently into their late eighties. Ironically, they probably wouldn’t still be together if it weren’t for her disability. I always marveled at how their marriage—which was never affectionate in good times—withstood this incredible strain and even became stronger because of it. The intervening years haven’t softened him any. They still argue all the time. She nags him; he’s gruff and unsympathetic. And yet, it works for them.

When people hear that my parents have been together for almost sixty years, they often say, “They must really love each other.”

*Love?*

There are never any terms of endearment uttered between them; no soulful looks, passionate embraces, or tender kisses. Not even a warm smile. But every once in a while I’ll catch a glimpse of something . . . I’ll turn as I’m leaving her hospital room and see them in an unguarded moment. He’ll stop on his way out to look down at her and lay a gnarled hand on her shoulder. She’ll look back up at him with serious, trusting eyes; something will pass between them—something I’m not a part of and never will be. It looks to me like commitment.

And maybe even love. ♦

# CAMERA

JULIANNA SIEMSEN

**M**y first memory goes like this:

There is a stream that flows through our backyard. The clear water burbles softly as it flows over smooth stones. I spend my hours taking pictures of these rocks with my toy camera. I am trying to learn each rock by heart. They are all so different. Gray, powder blue, lavender. Oval, triangle, crescent. Some are speckled; some glimmer with flecks of crystal. Each has its own pattern of pores and bumps and ridges. Sometimes, the people around me make burbling sounds with their mouths. I burble back as best I can, but they never seem to be pleased.

One day, they sit at the kitchen table, crying. A few days later, they take my camera away.

\* \* \*

I am older now. My high school has two posters on the glass doors at the front. One says "Diversity" in large, whimsical colored-pencil letters. The other says "Inclusion." Fleura and Nel-

son and Adam and I are not allowed to walk through those doors. Instead, we go through a side entrance behind a dumpster, where nobody can see us. The air smells like rotten banana peels, and I hold my breath.

We have two teachers, Mrs. Hunter and Mr. Dalrymple. Mr. Dalrymple is nice and brings us animal crackers sometimes. He mostly just sits in the back and uses the computer. Mrs. Hunter is the one who does the teaching. Today she is wearing a T-shirt that says, "It takes a special teacher to teach special students." She passes out pictures of Winston Churchill to color. On the back is a short paragraph: "Winston Churchill was the president of England. He spoke with an English accent. Winston was a good writer. He also helped the United States win World War II. Good job, Winston!"

"Actually, Winston Churchill was the prime minister, not the president," Nelson blurts out, "and he also let three million people in India starve to death."

Mrs. Hunter sends him into the "quiet room," which is really a dusty storage

closet, and locks him inside. Only after two hours does she let him out.

We don't get lunch until 1:30, after the normal students' lunch hour is over. Mrs. Hunter makes us all hold hands as we walk to the empty cafeteria. Fleura's hand is delicate and soft as a rose petal, and my fingertips tingle when they touch hers. Mrs. Hunter's hand feels slimy, like a writhing worm.

The server gives us each a tiny, flavorless cheeseburger. It's about two inches across. The schools are supposed to serve low-calorie lunches, so they do.

We eat in silence. Fleura and Adam furtively hold hands under the table, where Mrs. Hunter can't see. Nelson pulls out a book called *Madness and Civilization*. Mrs. Hunter makes him put it away.

A girl with thick, shiny, perfectly curled hair dyed a pale silver stands outside the cafeteria, leaning against the wall. She is wearing yoga pants, Ugg boots, and an oversized red sweater. I watch as she pulls out a flask from the pocket of her sweater and takes a swig. Luck-

ily, Mrs. Hunter isn't looking.

I catch her eye and smile at her. She looks away, but smiles back.

After lunch, we get a few hours of (relatively) free time. Nelson gets to "play on the computer," while Fleura rereads one of the few books we have in the classroom. Mrs. Hunter won't let Adam on the same side of the room as her, so he draws the four fish that swim in the tiny, dirt-encrusted fish bowl next to the sink.

I'd like to be taking pictures with this new camera I got for my birthday, but I'm not allowed outside the classroom, and there's nothing for me here. I sit next to Nelson. "I'm writing a polemic on how the diagnostic construct of oppositional defiant disorder marginalizes neurodivergent students and contributes to the school-to-prison pipeline," he says.

Polemic? Neurodivergent? "Could you, uh, repeat that?"

Nelson glances over at Mrs. Hunter, who is playing a game on her phone, and lowers his voice.

"So, in theory, school is supposed to help prepare you for college and for 'success,' whatever that means. But if you have a mental disability, then the school system sets you up for failure. They punish you for little things and bring in the police for everything and make it so you have nowhere to go but jail. It's called the 'school-to-prison pipeline.' That's what I'm writing about."

"Has that happened to you?"

"Mm-hm. At my other school, someone beat me up, and I got arrested. And expelled. That's why I'm here now."

"Do you like it here better?"

"Not really. It's all the same. Like, it's obvious they don't care about teaching us anything. They're just pretending to care now that it's not politically correct to kill us anymore." His voice is even and wry, but I can see the pain in his eyes.

I nod. Nelson's put something into words that I've noticed, but never been able to describe, never been able to be angry about.

\* \* \*

"Normal" kids skip school all the time. They might not get away with it, but judging from the way I always see groups of students lounging in the hallways or smell them smoking behind the bushes, they probably don't get locked in the storage closet for it.

As we get off the bus, Mrs. Hunter looks away for a moment to help Adam with his shoes. Now! I dart into the swarm of normal people heading through the "Diversity" and "Inclusion" doors. Nobody notices I'm not supposed to be there. Normally, I hate crowds. They're noisy and smelly, and I can't stand being bumped. Today, though, that just makes it more exciting.

We flow through the hallways like a stream. I keep bumping into people. Some apologize. Some give me dirty looks. They are like the rocks in my

backyard, all smooth and round and beautiful. I feel like a plastic bottle, a pollutant.

The morning bell rings. I duck inside the bathroom so nobody can ask me why I'm not in class. The stench of Lysol and urine overpowers me. I don't know how anyone else can stand it in here. I pull my shirt over my nose and breathe through it. It doesn't help much.

After ten minutes of agony, I open the bathroom door to check if the coast is clear, then step out into the hallway. The photography students are wandering around, cameras slung over their necks.

I pull my camera out of my backpack. Maybe I can blend in.

"Hey!" It's the girl with the gray hair. "What's your name?"

"Adeline."

"Adeline? That's pretty. I'm Heather."

"Nice to meet you."

"I like your eyes," says Heather.

"Thank you." I don't think anyone's ever complimented me before. "I like your hair."

"Thanks," she smiles. "I did it myself. So are you in this class? I haven't seen you in here before."

I shake my head.

"You're skipping?"

I nod.

“Do you want to go to my house?”

“Sure.”

I can't remember the last time I've had a real conversation. I don't know how to do this at all. “So, why did you skip today?” I ask. I realize it's a silly question the moment it's out of my mouth.

“I get headaches whenever I go to class,” she explains. “Nobody believes me when I say that, but it's true. I'm failing most of my classes, but there's no point in going. My head hurts too much for me to pay attention.”

“Is school the only place where your head hurts?”

“Uh . . .” Heather pauses. “I haven't actually been anywhere else for a while, since my friends don't—um, yeah, now that I think about it, I went to the mall a few months ago to buy my brother a birthday present, and it hurt then.”

“I see,” I say.

“You know what's weird?” she asks.

“What's weird?”

“I don't even know you, and yet here I am telling you something I've never told people I've known for years.”

“Hm.” I think I should say more, but I don't know what.

“Like, I can't talk about this with anyone else. My friends don't even want anything to do with me. They just laugh at me whenever I say anything. It makes me feel like I can't do anything right.”

In all the social skills books I've been forced to read, it's okay for people to laugh at you. It's just a sign that you need to change. I don't think that applies to people like Heather, though.

“I'm sorry,” I say.

“I'm sorry I'm ranting at you like this,” she says. “Like, we don't even know each other.”

“It's okay,” I say.

At Heather's house, we watch *Stranger Things*. I'm not allowed to watch TV at home because it's “inappropriate” and “your brain is damaged enough as it is.” She gives me strawberry ice cream, which I'm not usually allowed to have because my parents mistakenly think I'm lactose-intolerant. It's the best thing I've ever tasted.

“You're doing something with your hand.”

I look down. I am. I'm tapping each finger on my leg, one by one, like I'm playing the piano. I didn't even realize I was doing it.

“Sorry,” I say, and stuff my hands under my legs. I had always learned to sit on my hands or keep them in my pockets. Why had I forgotten?

“Don't apologize,” she says. “I'm doing the same thing.”

And she is.

“You know, that's actually kind of cool,” she says. “Like, not to be fake deep, but it makes me feel like we kind of have a connection. Like, I'm not saying we're soul mates or anything because that would be creepy to say to someone I just met . . . I don't know. I just think we click.”

This is not how the social skills books said that conversations would work. We're being . . . honest. I want to tell her that I feel the same way, but I don't know how to explain anything or what I should say, and what I shouldn't.

I glance at the clock on the wall. It's already 7:04 in the evening. I don't have a cell phone (“Who would you call?” sneered my stepfather last time I asked for one), so Heather lets me borrow hers.

“Hi, it's Adeline. I'm at my friend's house. Can you come pick me up?”

“Friend?” my mom repeats, incredulously. “I didn't know you had friends.”

“Well, I do.”

“What's the address?”

I hand the phone to Heather, who tells her what the address is. Mom hangs up without saying goodbye.

“How could you do this to me?” she asks in the car. “And I thought you were doing so well!”

I think of the rocks in the stream, the people in the hallway. “I felt like a plastic bottle,” is all I can say.

“I don't know what that means,” says Mom. “We've talked about using appropriate metaphors, right?”

I nod sullenly.

“How many times have you missed school before today?”

“Three days.”

“Three days?”

“I had a fever, remember?”

“That's not what I meant.” She gives an exaggerated sigh. “Were those the only times?”

“Yeah.”

“Well.” It's clear she doesn't believe me. “You need to have a consequence to make sure you don't do this again. I'm going to take your camera away.”

“Okay.” There’s no point in arguing.

“Give it to me.”

“Okay.”

“Now,” she insists, even though I’m already fumbling through my backpack to hand it to her.

\* \* \*

The next day, I bump into Heather and tell her about what happened to my camera. I also tell Nelson about Heather and her headaches and how she can’t go to class because of them. “I have the same problem,” he tells me. “It’s caused by loud noises and fluorescent lights. I have to wear earplugs and tinted contacts to stop them.” He pops a contact lens out of one of his eyes to show me. It’s the color of maple syrup.

He puts the lens back in his eye and blinks a few times. I think about the

things he was talking about earlier. The school-to-prison pipeline. “Can people get arrested for truancy?” I ask.

“Sometimes,” he says. “If a judge orders you to go to school and you don’t, then yes.”

Fleura is using sign language to ask Mrs. Hunter a question about an assignment. Mrs. Hunter doesn’t even know sign language, so Adam has to translate. “I didn’t ask *you* for help,” Mrs. Hunter snaps at Adam. He sighs. Fleura glares at her. “Now stop having such an attitude.”

Heather catches up to me just as I’m about to get on the bus. I tell her about the earplugs and tinted contacts. She says she’ll check them out. Then she reaches into her backpack and hands me a disposable camera.

“I know it’s not great,” she says, “but I hope you like it.”

“Thank you so much,” I say.

“Are you a hugger?”

“Not really.”

“Me neither,” says Heather.

“Get on the bus,” snaps Mrs. Hunter. “You’re wasting everyone’s time.”

I wave goodbye to Heather. She waves back. I climb onto the bus and watch her get swallowed up into the crowd.

\* \* \*

That night, I return to the stream in my backyard. There’s a new rock there that was never there before. I don’t know how it got there. It’s a translucent teal color, with sharp edges and a slick surface. I cradle it in one hand and snap a picture with the camera Heather bought me. Then I place it gently in the water. It’s nothing like the other rocks, but it belongs there. ♦

JAMES B. NICOLA

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## THE YEARS SHE PLAYED BRIDGE

This year she didn't play bridge.  
 But this year I've gotten to know her better and better.  
 And she's right, were any of her bridge friends to see her  
 she'd be embarrassed, not remembering the last card played.  
 Oh, she remembers that first blind date with the man  
 that became my father, meeting under the Grand Central Terminal clock.  
 (In those lean years you played bridge if you couldn't spring for dinner.  
 They played bridge.)  
 But the last card played escapes her worried grasp.

Before this year, she tried to play bridge  
 with me.  
 She kept on asking Am I Here? or Where am I?—  
 when she played a hand, that is.  
 And I had to make sure she followed suit when defending.  
 It was no problem, but the playing got slower and slower  
 the last years she played bridge.

The last years she played bridge  
 were followed by the times  
 she tried to play bridge, but didn't, really.  
 The times she tried  
 were followed by the time she wouldn't.  
 The time she wouldn't  
 was followed by the time she couldn't. The time she can't.  
 These are the years she doesn't play bridge.

I take out the bridgeware from time to time,  
 the tablecloths, napkins, coffee mugs, pie plates and tumblers  
 all in fours, two red suits, and two blacks.  
 And she remembers a lot about the years she played bridge,  
 things other than bridge, mostly.  
 I listen over pie and fresh-perked coffee  
 crumbled and spilt over diamonds and hearts:  
 I am here because of bridge, after all,  
 and am grateful.

## SHOEHORN

I will be your shoehorn.  
And I shall be glad.  
You were once my shoehorn—  
When I couldn't slip my heel in by myself—  
And I hope you were half as glad.

I will be your driver.  
You were once my driver.  
I hope I didn't drive you crazy.  
I hope it was as much of a delight  
As driving you has been/will be  
For me.

I will be your house chef.  
You were once my house chef.  
And I will help you chew, just as  
You chose soft food in jars  
Back when, for me.  
I will make your food easy to swallow  
And save what you don't finish in glass jars  
For the morrow.

And I will be your cane, your crutch,  
Your escalator/elevator,  
And tuck you in at night  
As you tucked me  
With water at your side  
To last the night,  
And, in the middle of the night,  
Set back the toppled table at your side,  
Toss out the broken mug shards,  
Clean the carpet for your feet, and fill  
New cups with cool, fresh water, and then sit  
And stroke your hand until you sleep again,

That in the morning, I might be your shoehorn,  
Carry you downstairs for cream of rice  
With fruit mashed in, that later I  
Might drive you somewhere  
In a span of sunshine  
Down the country road  
By the tear-shaped lake  
And we have ourselves  
Another Banner Day  
Dosed with *ohs* and *ahs*  
And such  
Persistent  
Joy.



# A BROTHER'S LOVE

J. J. STEINFELD

In the hodgepodge that passes for my life, there has been one constant: my love for my older brother, Barton. Through my marriage and divorce, through the death of my father and my mother's hasty remarriage, through my numerous "career" changes, through the dissatisfaction and restlessness and loneliness that paint my life, there has been Barton. There's no doubt in my boozed-up mind that I would have let go a long time ago, and not minded my drowning one bit, if it wasn't for Barton. I stay in this city, live alone in a small apartment, because I couldn't bear to be far from my brother.

Barton, my Barton, he's always there, in that same building, in my mind. Sure he's changed over the years, but not like the world, not the way regular people change who live ordinary lives and grow older according to Nature's plan. He wouldn't have changed nearly as much if all those medical people wouldn't have tampered with him so many times. My older brother may be fat and nearly bald and have breasts like a woman; he may roar far less frequently than in the old days, not nearly as loud, but goddamnit, he still does roar once in a while and sometimes lets out those other growling and grunting and howling sounds that used to upset my parents to no end, and got Barton put away in the first place, thirty-five years ago.

The doctors remain surprised to this day that Barton is still alive—or functioning, as they like to call it. They used to predict that he wouldn't make it past twenty-five or thirty,

and now he's forty-five and there's no sign of death in his eyes. I wouldn't be surprised if Barton will outlive me, outlive everyone on this planet. I can just see him, if there ever really is a nuclear war, getting his old roar back, and roaring away as the mushroom clouds spread. Only Barton, who has never learned words or definitions, will make sense at the end. Sometimes, after drinking too much, I fear my brother will somehow be silenced before then—after all, medical science with its breakthroughs and manufactured miracles is relentless, thirsty for conquests. Thank God I have the tapes of him. Too bad I don't have recordings from the early years of my brother's life, when no one on earth could roar louder than he could. The first time I made a tape recording of Barton was when I was already twenty-nine, after he had been in the hospital for twenty-three years. I don't know why I didn't get the idea earlier. For years his outbursts had been growing less frequent and losing much of their intensity. I made only three tapes, and it took me months to piece those together. They are precious to me. I listen to them when I need to calm down or regain my footing or simply to drift through time. Nowadays it would take ten visits with Barton to get enough sounds to fill even five minutes of a single tape.

My wife, after a few playings, refused to listen to the tapes. I played them to her out of love, to help her understand not only Barton, but me, also. If I did happen to play a tape of Barton with her and the kids within earshot, she would give me the coldest stare and say, "Just keep your brother's voice

away from us,” as if I was holding a loaded gun to their heads. Perhaps it was those tapes that finally convinced my wife to leave me. Barton and the tapes are part of me, more than any earthly love or long-dim vow to remain together until death do us part.

My clearest memories from childhood are of Barton: the head-banging and roars and screams and marvellous howls shaking our house, me loving that human thunder. To this day, if I hear a sudden loud noise, I think it’s Barton banging his head against a wall. What an indestructible head he has. The few times I tried rapping my skull against a wall, out of curiosity or some silly childish attempt to communicate with my brother, all I gave myself were headaches. The head-banging was the first of Barton’s problems the doctors managed to cure.

The only times I remember my parents fighting was over Barton. Perhaps they would fight over other things when I wasn’t around, but as far as I was concerned they had the best marriage possible. That’s why I was so shocked that my mother remarried less than seven months after my father died. I wasn’t expecting a lifetime of mourning, but everything happened too fast. “Barton has aged me so much; I want a chance at a new life,” was how my mother announced to me her upcoming remarriage. Now, with hindsight kicking me in the ass, I know it was what happened to Barton that kept my parents glued together for so many years.

The fights over my older brother play back in my mind, as if I have them on tape, like Barton’s voice. My mother would shout that Barton would kill me, her beautiful baby, unless he was put away. “We can’t do that to our son,” my father would say. Then my mother, usually in tears, would state her case: “You don’t have to stay home all day with Barton, waiting for him to explode, to do something terrible, to make those noises . . .” I wasn’t sure what “put away” was then, but I knew it was bad. My parents argued for months before the decision was made. I had gotten used to the arguments. What I couldn’t get used to was the silence, that awful silence without my brother in the house.

I remember that confusing day long ago more clearly than I remember most days I have gone through in the last year. I was lying in bed, early in the morning, and waiting to hear Barton’s voice or the banging of his head against a wall, but I heard nothing. I had learned to sleep through the sounds, but my days started and ended with my brother’s roars and head-banging. Then one morning there was no sound. “Barton, Barton,” I went around the house calling, then screaming.

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**It wasn’t until years later that I found out the hospital stay would never end, and the cold, dark word for my brother’s disappearance was *institutionalized*.**

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My mother grabbed me and held on as I screamed my brother’s name, she telling me that Barton was safe and sound, that everything would turn out for the best. My father told me he would take me out for some ice cream, and I could have as much as I wanted. I calmed down somewhat, but I kept calling my brother’s name until my parents told me that Barton was in a hospital. “Where I was born?” I asked. “Where my tonsils were taken out? Where Daddy got his sick stomach fixed?” My mother shook her head “no” and didn’t say anything right away, her eyes looking at my father. “Daddy will explain it all to you,” she finally told me. At the ice cream place, my father explained as best he could to a six-year-old why his ten-year-old brother had to go to a hospital for a long, long time. It wasn’t until years later that I found out the hospital stay would never end, and the cold, dark word for my brother’s disappearance was *institutionalized*.

The third morning of silence in our house was broken by a yapping puppy my parents brought home for me, in their adult minds, to fill the emptiness. I named the dog Barton, but avoided the animal. After two weeks of neglect by me, my parents gave the puppy away.

I often wonder what would have happened if Barton had never been put away. I don't think he would ever have hurt me. I'm not saying he didn't give me some bruises, but what brothers don't fight. It caused a great deal of concern in my family when I named my first son Barton, as if I might be afflicting or dooming the poor child. My little Barton never roared or howled or even gave the wall a tiny Morse-code tap with his beautiful head; next year he's off to university. My wife never fully understood my need to name our first son Barton. She didn't consider it an ugly name—she calls him Bartie—even if she couldn't stand the sight of my brother. Besides, she got to name our daughter after a long-dead grandmother of hers, and the name of our younger boy was her choice, also. Because of my ex-wife's unbending refusal to cooperate, my children have never met their Uncle Barton. I now see them about once a month, sometimes less often, even though I have the right to visit my children every weekend if I choose. I simply don't have the desire to go to the West Coast, where my ex-wife moved after the divorce, and she refuses to visit here anymore.

After that silent, frightening first morning, and the distracting trip to get ice cream, it was eight more years until my parents decided I was old enough to see Barton again. I used to complain and cry, developing tantrums that had never appeared with Barton around, but my parents told me time after time that they couldn't take me to see Barton until I was older, that my brother was not feeling well. No matter what I said or did, my parents had only the calmest, most reasonable responses: *Be patient, the years go by quickly . . . When you're a big boy . . . We mustn't rush what's meant to happen later . . .* In the beginning my mother used to visit Barton nearly every day, out of motherly obligation, I guess. Then she fell into a routine of once a week until she remarried and moved a three-hour plane flight away from us. My father went whenever he could, usually every second or third day. His final visit to Barton was a couple of days before his heart attack. I hope he heard Barton roaring in his ears while he was dying. I don't say that out of anger or bitterness; maybe at the end he would have appreciated Barton, as I have learned to appreciate my brother. And I hope my mother, nearly seventy now, doesn't have a single dream without a memory serenade from her older son.

Barton's absence from our house seemed to define my youth and now regulates my memories of youth. I used to get into more than my fair share of trouble because of Barton, even if he wasn't around. Once, when I was nine, instead of going straight to school, I walked through a horrible rainstorm all the way to the hospital where I had had my tonsils taken out, a mile from our house. The woman at the admissions desk asked me what I wanted, and I told her I had come to see my brother, Barton, who was not feeling well and had been put away. Where were my parents, she wanted to know, but I refused to tell her. After looking for the name in her files, the woman told me there was no one named Barton anywhere in the hospital. She called over other hospital staff, and they all tried to find out what I was up to. I insisted on seeing Barton. I even roared for them, trying to demonstrate how my brother sounded. I remember some of them laughing and smiling. One nurse even roared back at me.

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***Special.* So many words have  
been destroyed for me by the way  
my parents used them when they  
talked about Barton.**

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The people at the hospital all thought I was cute and adorable, but I told them I wouldn't leave unless I could visit my brother. When someone put a hand on my shoulder, I ran away, down a hall. I looked into as many rooms as I could, until I was caught. Someone called my house, and my mother came to pick me up. On the way home, I remember her telling me that I could have been put in jail for what I had done. "Put me in jail," I told her bravely. I imagined jail cells full of boys who weren't allowed to see their brothers. I went twice more to that hospital, sneaking around and searching by myself, getting caught each time, until my mother told me that Barton was in a special hospital. *Special.* So many words have been destroyed for me by the way my parents used them when they talked about Barton.

On my fourteenth birthday, as a present, my parents took me to visit my brother at the hospital, the special hospital, a short drive from our house. I recognized Barton, but I couldn't believe how much he had grown. He was twice my size, and looked like he had been eating steadily for the last eight years. His face was so white it looked painted on. Pure white except for the dark-blue skin under his eyes and a few

reddish blotches here and there. “Watch yourself, please watch yourself,” my parents told me when I started to walk over to Barton. He was sitting on a small couch, looking neither sad nor happy. I was a little scared, but I didn’t stay scared for long. I hugged my brother, yet he hardly noticed. Barton smelled like he had just gone to the bathroom in his pants, exactly like he smelled when he lived at home. I told him it was my birthday, and he made some of those faces he used to years before and had in my dreams while we were apart: his lips twitching and moving all over the place, eyes closing and opening, head bobbing like it was on springs. Then he roared, and I knew it was my brother. The roar lasted a half minute or so, not like the long ones when we were kids, but it was still Barton’s roar. He made more sounds and drooled all over my shirt, but I didn’t care about the mess. Even my brother’s smell, in its own way, made me feel good.

When I stopped growing, I was the same height as Barton, but I’m sure he weighs a good hundred pounds more than me. My hair is still fairly dark and thick, and I used to keep in pretty good shape, before I really took to drinking, but deep down in my heart I believe that Barton and I would look very much alike if he hadn’t been locked away for so many years. When I look at the photographs of the two of us as kids, the rare times my father or mother managed to hold Barton still long enough, you can see a strong facial resemblance. You can still tell we’re brothers, if you bother to look closely at our eyes.

Sometimes I drive up to the hospital after visiting hours, take along a few beers, and just sit in my car, drinking and watching Barton’s window, imagining myself in the room with him. As a teenager, when I was finally allowed to use the family car by myself, the first place I drove to was the hospital where Barton was kept. I parked so I could see the window I thought was Barton’s. I knew the floor, but not the exact room in those days. I had always met my brother in the visitors’ room. Every single time I went to see Barton he was heavily sedated, or whatever they did to make him fit for visitors. I’m amazed my parents didn’t sign some consent form to have Barton’s vocal chords removed. But I bet he’d still make some sound, somehow.

My wife, when we were engaged, went to see Barton once. I never asked her again. I don’t know what kind of relationship I wanted her to have with her future brother-in-law—affectionate, friendly in-laws hardly seemed suitable or enough—but I wanted them to meet. I was so excited before the meeting. I had told her all about my brother, prepared her to meet an extraordinary, mysterious human being, and she even bought him a little get-acquainted present. But I guess there is no adequate preparation for meeting Barton.

I neglected to take into consideration that she didn’t love him. The sounds and noises I had become accustomed to, thought I understood as a real language, frightened her. She wasn’t exactly charmed when my brother smashed the present between his palms, then tried to stuff it into his mouth, gift wrapping and all. The last thing in the world my brother needed was a pair of cuff links, anyway. His dosage of medication must have been too low that visit or the sight of a different face too stimulating, who knows. For over a week after the visit my fiancée wouldn’t speak to me, and I began to fear the wedding was off. Then she called and said she was sorry for her insensitive behavior, and I forgave her quickly. But she wouldn’t talk about Barton anymore. She’d listen to me talk about my brother, but held back any comments of her own.

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**My brother has never been in love,  
never earned any money, never  
driven a car, never taken himself for  
a walk down a city street.**

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It’s hard to imagine anyone’s life being more narrow than my brother’s. When we were real young, my parents took Barton and I for drives in the country or out to a beach, but those trips became rare as we grew older. I figure twenty miles is the farthest out of the city my brother has ever been, and that was before he was ten years old. Over the last thirty-five years, an escorted trip around the hospital grounds for Barton is probably the equivalent of a space journey. My brother has never been in love, never earned any money, never driven a car, never taken himself for a walk down a city street. I haven’t been able to decide if this is good or bad, but I think about it often. The first time I made love to a woman, I was picturing in my mind Barton watching me, wishing he could also experience what I was experiencing. It bothers me that Barton has never had a lover, even though I don’t know what that would achieve. He would need a woman who could make incredible sounds like him. That would be some lovemaking duet, I imagine. But they would need an isolated, unpopulated island, a million miles from here, or God knows what people would do to them.

After my wife took the kids and left me, I used to ask the doctors if I could take my brother home with me and was always told that the specialized twenty-four-hour-a-day care he required couldn't be given at home, or by a single individual, no matter how loving that person was. My brother has probably had every treatment in the book, and some well outside the pages of any standard medical text. Over the years I've talked with so many doctors about Barton, and they all start sounding the same after a while. I got myself one beauty of a black eye from a doctor last week. After I complained that Barton was getting worse—worse to me being the long silences, the drug-induced lethargy, the extended dazes that the doctors and nurses and attendants love—this doctor tells me, “We've done our best, given the realities of the situation. This is the only way your brother can function, even in an institutional setting.” I told the doctor that I wouldn't be surprised if his medical assessment was pretty close to what the Nazi doctors said when they were questioned about the purpose and effectiveness of their work on Jews. The doctor who gave me the black eye apologized after he decked me, probably afraid he was going to get sued. I'd be curious to know if that pugilist of a doctor is Jewish himself.

I wish I could make a sound half as wonderful as Barton used to, and still can on occasion. Throughout my life I've made attempts to imitate him, but I can never get close. The sounds come from deep within my brother. Despite what the specialists have told me, I'm sure his sounds mean something. It seems that every time there is a crisis in my life, I want to make a sound like Barton could. When my wife told me that she was leaving me, I wished more than anything I had Barton's ability. She refused to discuss her decision, and all I could do was nod silently and sadly. I went to visit Barton that afternoon, and told him all about what was going wrong in my life. I swear he understood.

In the old days, I used to keep waiting for Barton to say something, even to start chattering away about ordinary things. I'm not denying it was only wishful thinking or just plain deceiving myself, but I really did expect some kind of miracle. Now I'm glad he's never spoken a word. It doesn't please me that he hardly roars or growls or howls now, but I thank God that he's not completely silent. And it isn't that people haven't been trying since he first opened his mouth and shook the walls. I'm tempted to bang my head against a wall next time I visit Barton, to see if he remembers, to see if I can bring back what was stolen from him, and from me.

Maybe I've made too much out of my brother, or I feel some deep guilt about his thirty-five years in hospital, but if I ever understand him and his soul, then I'll understand myself and my family, and maybe even the world. To me, Barton's the secret. The secret to everything that matters in this world. ♦

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MARY REDMAN

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## THE CHANGELING

He sits in his umbrella stroller,  
 a boy half-marred on one side  
 as if the stuff of his making, like wax,  
 began to melt, but then recalled itself,  
 cooled, and formed again  
 but not quite.

Fiercely, I wheel him into the shop  
 for vacuum sweeper bags.  
 Fluorescent bulbs light the room,  
 but I keep my sunglasses on,  
 protection from prying eyes. I watch  
 as if through a two-way mirror,  
 check glances and imagine strangers  
 surmise some reckless choice  
 gave me this child  
 instead of the perfect one  
 I had expected.

Today a clerk smiles at my son  
 and says,  
*What beautiful blue eyes, he has.*  
 Caught off-guard, I push  
 my smoky lenses up,  
 blink at the sudden light,  
 and wonder at the way  
 the world sometimes surprises.

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 with permission of the author.*

JÓLÉT

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## SNOW

Vivid brightness,  
 city street.  
 Magic stillness,  
 what a treat!  
 Falling snow  
 of coconut  
 Joyful snow,  
 of joyous cut.  
 A diamond present  
 that no one counts,  
 but God and I.  
 I must surmount!

The moment's past,  
 but its sense still spoken.  
 All of life and it's still not broken.  
 So clean and fair, it now still seems.  
 I was reborn, within that scene.

# REMEMBERING RONNIE

ANITA G. GORMAN

I remember Ronnie Hazel. He made the people at St. Michael Parish in Canfield, Ohio, laugh. He was part of our community when he lived in the rectory with his brother, our pastor, Reverend Terrence J. Hazel. We celebrated Ronnie's fortieth birthday with a big party in the parish hall. And when he died, we mourned and missed him and remembered Ronnie with fondness at still another big party: instead of traditional calling hours, we had an Irish wake in that same parish hall with food, drinks, live music, and reminiscence.

Ronnie was our friend. He was special. He had Down syndrome.

Ronald James Hazel was the last of five children born to Mary Irene Hazel and H. Kenneth Hazel. He was born on December 12, 1962, and when their father told the other children the news of Ronnie's birth, he sounded subdued, not as happy as he had been when his four older children were born. Soon his siblings came to know that Ronnie was different, different in a way that not everyone appreciated.

Irene, however, quickly became Ronnie's champion, his teacher, and his advocate, as well as his loving mother. Dad soon accepted his son, and the four other children loved Ronnie from the start. Small for his age, he had a crown of abundant blond hair that reminded his siblings of Dr. Zorba from the *Ben Casey* television series.

Ronnie's doctors were pessimistic about his ability to learn anything and to function in our complex society. Ronnie's mother, however, thought differently.

At first Ronnie seemed like any other baby, but as he grew older, the other children could see that he learned ever so slowly. Whether slow or fast, Irene was determined that Ronnie would acquire as many skills as she could teach him. "He can learn anything you can learn," she would say to the other children, "it just takes him a little longer."

Irene made up games that Father Terry now thinks should have been patented. She devised flashcards so that Ronnie might learn arithmetic and reading. She created table games. One game was called Hearts Full of Love. Into

a red pillow shaped like a heart, Irene stuffed questions for Ronnie to answer. Ronnie enjoyed playing games with his mother, and he learned. Irene, Father Terry recalls, was a pioneer in creating educational games, almost a forerunner of *Sesame Street*.

When it was time for Ronnie to go to school, his IQ was tested, and it was just a bit too high for Mahoning County's school for children with developmental disabilities. Ronnie therefore was sent to a public school on Youngstown's south side. He did not thrive there.

His classmates made fun of him and did not accept Ronnie. One day his classmates told Ronnie that it was their teacher's birthday, and they were going to decorate the classroom.

"Ronnie, here, take this toilet paper and throw it over the light up there. It's the teacher's birthday!"

And Ronnie did what his classmates told him to do. He laughed as he decorated the entire classroom with toilet paper. The other children laughed, too, but they were laughing at Ronnie, and he didn't know it.

When the teacher entered the room, she was furious. Irene was notified and drove to the school to pick up her son. When she arrived, he was lying in the vestibule between the outside and inside doors, completely unsupervised. Irene, always Ronnie's advocate, sprang into action. Now a young widow, she hired a lawyer, and before long Ronnie was enrolled at what is now known as the Leonard Kirtz School, where students with various disabilities are nurtured and educated.

This school was the right place for Ronnie. He thrived there. He had friends. He stayed on for many years. Sometimes he would get annoyed with the other students, but for the most part he was with friends, and he continued to learn, but at his own pace.

Father Terry's first assignment after ordination was teaching religion at Youngstown's Ursuline High School. Ursuline had a CCD program for kids with disabilities originated by Sister Nancy Dawson, OSU. Father Terry would prepare Ursuline seniors to work one-on-one with the children, while the children's parents would have coffee and doughnuts, and share their lives with each other on Saturday mornings. Every student would have a partner. They would assemble in groups of four in the Ursuline High School gym where they would enjoy short segments of art, music, or drama that would always involve a lesson to be learned. Ursuline seniors would take turns doing the presentations. All of the kids enjoyed the mornings. The parents enjoyed having an hour of freedom, plus they formed a support group that enabled them to share their worries and their joys.

Because of this highly successful program and the efforts of Ronnie's parents and siblings, including his brother Father Terry, Ronnie learned his faith.

One day when he was fifteen and a student at the Leonard Kirtz School, Ronnie's hands and lips turned blue. He was diagnosed with a heart defect, the same sort of defect that is now corrected when children with Down syndrome are very young. Ronnie's family was told that Ronnie had only a year to live. In fact, he lived another twenty-five years, enjoying himself and making other people happy.

Ronnie's dad had died too young. In the end, so did Irene. Ronnie then went to live with his brother, Father Terry. It was 1996, and Father Terry was the principal of St. Thomas Aquinas High School in Louisville, Ohio. Ronnie befriended the staff and students at the high school. He had his own pad of paper with the heading "From the Desk of Ronnie Hazel," and he would send notes to the staff regularly while Father Terry was busy running the school. Everyone in the school, whether student or staff, was Ronnie's friend. They never knew when Ronnie would suddenly do or say something amusing. One day, Ronnie came to a religion class taught by Father Terry. After about eight minutes, Ronnie got up and said, "Don't listen to my brother. He doesn't know what he's talking about." The other students said, "It's OK, Ronnie. We don't listen to him." Fortunately, Father Terry has a sense of humor.

Although there were no pets in the Hazel household when the kids were growing up, Father Terry had two dogs

in Louisville, Bernie and Sally. When Sally died, Father Terry found another West Highland Terrier to keep Bernie company. That is when Mr. Spock arrived. Ronnie loved Spock and Bernie, and Bernie and Spock loved Ronnie.

And so in 1997, Father Terry, Ronnie, Bernie, and Mr. Spock arrived at St. Michael Parish in Canfield, Ohio. The rectory at St. Michael's would be Ronnie's last home.

At St. Michael Parish, Ronnie made new friends. And when his fortieth birthday arrived, we had a great big party for him in the parish hall. I asked Father Terry if forty dollars for Ronnie's birthday would be an appropriate present. "Yes, but make sure it's all in one-dollar bills. That's how Ronnie will know that it's a really big present."

Recently we learned that Iceland has eradicated Down syndrome. This, the news media told us, is progress. But the eradication of Down syndrome happened because mothers chose to abort their "not-so-perfect" babies before they were born. Other Ronnies never laughed, cried, talked, or loved. They never said insightful and beautiful words, such as Ronnie did one day after his mother had died. He knew it was his mother's birthday.

"We have to have a cake," he said.

"No, Ronnie, Mom's in heaven. She doesn't need a cake."

"It's her birthday, so we're going to have a cake." And they did, and in that act they celebrated the lives of Irene, Ronnie, and all God's children. ♦



# UNEARTHING ARTIFACTS

SANDY PALMER



The artist's depiction of Odessos.

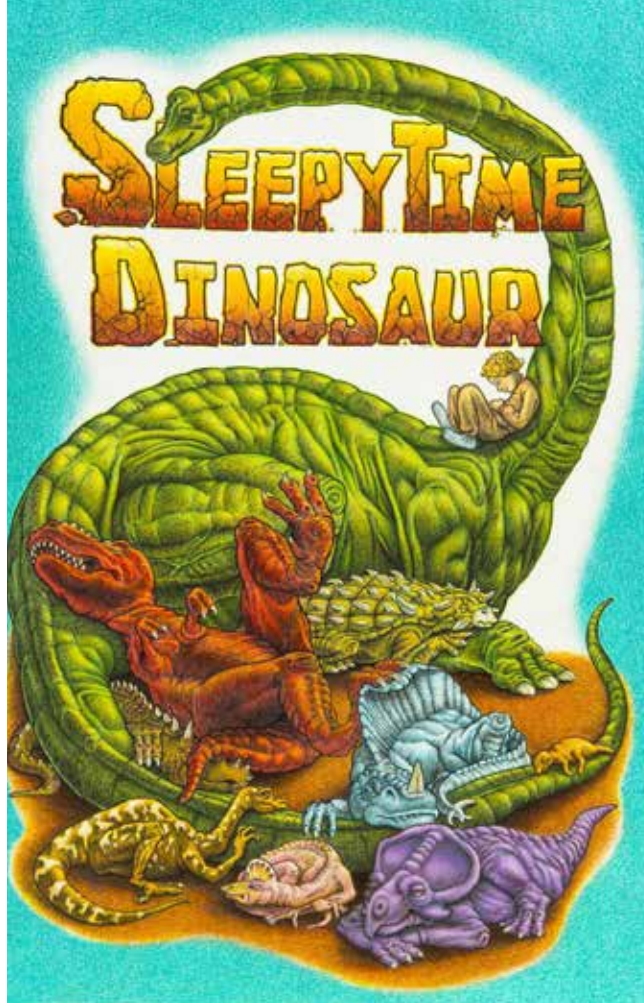
*"I can recall getting scolded for drawing on walls and furniture before being handed some paper, so I would assume my artistic compulsion was naturally embedded."*

~ Odessos

**E**xplosive sonic booms mimic thunder on sunny days without a cloud in the sky. Jet engines roar overhead, occasionally reverberating, and rumbling throughout the night. Such sounds are commonplace when

you live on an air force base. Odessos spent the first half of his childhood moving from one base to another—in the midst of perpetual noise and a flurry of activity. When he was ten years old, his father retired from the military and moved the family away from the cacophony of machinery and all-night test runs to the silent hills of the Ozark wilderness where the artist says, "The only sound at night was the drone of insects." The rolling hills, scenic surroundings, and silence were an extreme

departure from the life he had become accustomed to on military bases. Odessos found himself nestled in the middle of nowhere and says, "The forces of nature gave me leverage I could compare to the concrete world we had been living in, and the remoteness encouraged imagination and artistic discipline." The move provided a change in social structure as well, and combined, "greatly influenced a positive attitude and balance to my artistic endeavors."



Odessos, *Sleepytime Dinosaur*, 2017, colored pencil/ink/marker on 1-ply Bristol board, 11" x 17"

This eccentric artist does not seek personal renown. Being the focus of this article is not really his cup of tea, but we've found some middle ground in promoting Odessos and the brand he has created while not revealing the identity of the artist. Quite frankly, he would prefer that people pay no attention to the man behind the curtain and just focus on the work. He believes, "Ideas of merit are not original in the sense of their origin; they are floating in the air for anyone to grasp . . . they will be thought of by someone sooner or later, if not by you. It's almost as if they do not belong to us to claim and use for ourselves alone."

Born with a hearing impairment, wearing hearing aids since he was eleven years old, Odessos considers the impact it may have had on his art and says, "It most certainly was a contributing factor to my artistic development due to the obvious enhanced isolation that results from it, which gave rise to a more personal expression and desire to belong . . ." Certain tones are difficult for him to process, even with hearing aids, and he says, "Although I may hear the person, there are times I cannot understand them if they do not speak clearly enough." However, one-on-one communication is usually not a problem once he is familiar with someone's

speech patterns. Seclusion has cultivated his imagination, which is able to flourish without interruptions, but it has hindered efforts to promote his art.

Commercial house painter by day, artist by night (and sometimes into the wee hours of the morning), this self-defined "late bloomer of advanced age" has years of experience, providing a well-spring of material to draw from when he picks up a pencil and begins to create. One idea, years in the making, is a children's book he has written, illustrated, and hopes to have published. In *Sleepytime Dinosaur*, readers discover fun facts about various dinosaur species





Odessos, *Raid on Ploesti*, 1996, acrylic on canvas, 30" x 46"

and the commonality that, at the end of the day, the creatures would lay down to rest, just as we do. "Most people don't realize children's books can be more contemplative in moral applications than adult books at times."

While attending Ringling School of Art in Sarasota, Florida, Odessos received more inspiration from the other students than he did from the actual classes. Although he has never spent much time marketing his work, he has spent a great deal of time doodling, drawing, painting, and creating some fascinating images. Intricate details are woven seamlessly into images that the artist feels speak for themselves and no longer need the creator once they

are completed. He is wary of personal attention, fearing "that it may interfere with conceptions" people may form about the work.

Odessos is fueled by a combination of everyday experiences, books he has read, and viewing the work of other artists that collectively ignite a competitive desire to improve his craft and "do better" next time. His subject matter is diverse—landscapes, fantasy, cartoons, architecture—and he is meticulous. Favoring acrylics, some images portray serious environmental messages while others are lighthearted and scenic. Each one seems to tell a story the viewer must unearth while sifting through thoughtful detail. He says, "The viewer

must decide what he sees." Meaning and message seem clear in some, obscure in others. Mysterious. Much like the artist who wishes to remain hidden, saying, "Odessos encompasses the ethos of my work, being so varied, like a mist you can't quite make out."

To see more of his work go to [odessosart.com](http://odessosart.com). ♦



Odessos, *To the Last Drop*, 2009, pencil on paper, 8" x 11"



Odessos, *Assaim Dragon Squadron*, 1980, pencil on illustration board, 15" x 20"

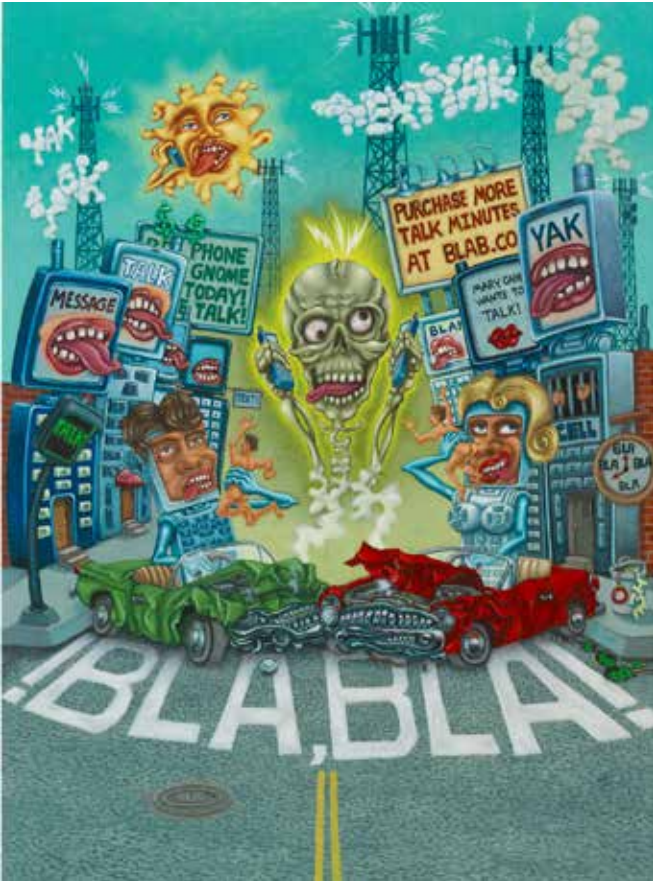




Odessos, *Area 51's*, 2014, acrylic on Bristol board, 17" x 15"



Odessos, *Branson Town*, 2018, ink/colored pencil on Bristol board, 30" x 33"



Odessos, *Bla Bla*, 2004, acrylic on Bristol board, 16" x 22.5"



Odessos, *Moscow 1812*, 2004, acrylic on canvas, 32" x 50"

# A WORD WORTH REPEATING

J. D. CHANEY

Ed Chambers sat at his desk, exhausted from being on his feet for nearly seven hours. With nearly forty years of teaching English under his belt, he had to admit this was definitely a younger man's game. The popular teacher was known for his animated antics: standing on his desk in dramatic portrayal of Henry VIII or strutting down the aisles with a toreador's cape in hand to emulate an Ernest Hemingway character. He'd even aligned an entire front row of desks to simulate trench warfare during World War I—all just to open the imaginations of his eighth graders when it came to spelling. "You had PRIVATES, CORPORALS, SERGEANTS, LIEUTENANTS, CAPTAINS, MAJORS, COLONELS, and GENERALS," he barked. "Memorize those words, as they're part of Friday's spelling test."

His students, eager to please, usually came through for him, leaving him with the pleasant task of rewarding them with the requisite A's and B's. But it had not always been that easy for

Chambers. As a young English teacher, he struggled to get his students to submit to his curriculum. Clearly unimaginative and rote, he taught by the book, droning on about the biographies of writers, handing out spelling lists, diagramming grammar lessons, and generally putting the class to sleep. But one rainy evening while he sat in his favorite chair watching a Marx Brothers movie and correcting spelling tests, he had an epiphany. He saw silliness—instructiveness silliness. Despite the juvenile behavior Chambers was absolutely glued to the TV, laughing unabashedly. That following day, he came prepared: raincoat, pipe, cane, fedora, and a half-dozen other articles that he intended to use to get his points across.

It was a total success. The class, first unaccustomed to the staid Mr. Chambers, didn't know quite how to react. But within twenty minutes he had the class where he wanted them. Soon, the entire class knew who Sir Arthur Conan Doyle was as well as his most famous character, Sherlock Holmes.

The following years became more outrageous, the classes, more intense and eager to learn.

Chambers was a showman who also happened to be a teacher, and no one was more supportive than the parents, and of course, his principal, Julia Bernstein. And it was because of his genius as a teacher that Mrs. Bernstein entered his room late one January afternoon. He noticed that she wasn't alone. Accompanying her was a handsome, dark-haired woman in her mid-forties. She walked, almost silently, her tired brown eyes glancing about the room.

"Mr. Chambers, I'd like you to meet Mrs. Cindy Selleck." The teacher thrust out his hand, shaking hers in return. Once they were all seated, the principal continued. "Mrs. Selleck here has a child with a type of Tourette syndrome." The elderly teacher shifted in his chair, knowing exactly what was coming. Bernstein was going to saddle him with this walking, talking time bomb. *Shit*, he thought to himself. *And guess what lucky English teacher is going to get him.*

The woman cleared her throat. "I thought I'd tell you a little bit about Tod's Tourette's. He has echophenomena disorder. Basically, he repeats aloud phrases or endings of sentences. It can manifest at any time and can be quite loud. Additionally, he has the usual tics and odd facial expressions." She paused a moment, seemingly anticipating his thoughts. "And no, he doesn't shout out swear words. That's a different type of Tourette's."

Clearly relieved, Chambers lied, stating, "Wasn't even thinking about that. I was just wondering, how are his academics?"

"Oh, Mr. Chambers, Tod's quite bright. His grades are excellent. Unfortunately, we had to move in the middle of the year because my husband's company transferred him to here in the Bay Area."

"And how did he get along with his classmates?"

Now it was Mrs. Selleck's turn to shift in her seat. "He . . . uh . . . he had a couple rough patches with some kids in his class making fun of him. And his teacher, Miss Baker . . . well . . . she was very young and inexperienced. We attempted to settle Tod's problems with the principal, but some of the taunting continued."

Rubbing a hand over his face, Chambers exhaled deeply. "I can't guarantee it won't happen here, but I promise I'll do everything I can to see that he fits in."

Mrs. Selleck rose and again extended her hand. "That's all I can ask for, Mr. Chambers." Then squeezing his hand a bit tighter stated, "I know you'll like Tod because he loves to please."

When both the principal and Mrs. Selleck left his room, the teacher fell back into his chair, seemingly exhausted. "I have a feeling this will require an extra glass of wine tonight."

He didn't bother to tell his wife that evening, instead holing up in his den, trying to get a grasp of how he'd be handling the issue with his class. He sat in his favorite recliner, wine in hand, eyeing the cluster of beech trees that overlooked his backyard. "What am I going to do?" he heard himself say. A kid with his kind of disability could ruin an entire class. He rose from his chair and began pacing back and forth, back and forth. He heard his wife yelling from the kitchen, "Supper's ready."

"Coming," he called back. And as he set his empty glass down and began to exit his study, he suddenly stopped, his head snapping upward. His eyes widened, and a slow smile began to emerge.

"Good morning, class," Chambers exclaimed. "Take your seats. Let's hurry it up." He watched as his students scurried about, straddling their desks, positioning their books and writing pads.

"As you can see, standing next to me is a new student, Tod Selleck. The curly-haired redhead waved shyly to the class, blinked hard three or four times, then nervously stepped closer to Chambers, half-hiding behind his back. The teacher continued, "Tod is coming to us from Seattle, Washington, so the

first thing we're going to teach him is to become a 49ers fan and forget those terrible Seahawks."

This brought a wave of laughter from the class, and Chambers looked down to see a faint smile on the boy's face. "Tod, you may have that desk over there." He pointed to the empty far desk, left, in the second row. Once the boy was seated, Mr. Chambers moved to the front of his desk, leaning lazily upon it. *Now's as good a time as any*, he thought. "Class, Tod has a very unusual gift. There's a medical term for it, but the most important thing to remember is that he's going to keep us on our toes. What I'm talking about is his command of English grammar. Once in a while he'll yell out a word or words that may or may not be the same. Or he may repeat what he hears from a complete sentence. When this happens, I want you to focus on the last word you hear and quickly raise your hand, telling me what part of speech it is. Do you understand?"

He watched the class as they began looking at one another, then at young Tod, unsure of what was happening. Tod, for his part, hearing his condition described as a gift, stared delightedly at Mr. Chambers, his jaw moving from left to right. And, as if on cue he blurted out, "UNDERSTAND . . . UNDERSTAND . . . UNDERSTAND."

The room grew eerily quiet for what seemed like an eternity before a singular hand rose in the air. It was Alicia Kenelly, his top student. Chambers took in a deep breath, unsure if his explanation had hit home. This could very well be a disaster. "Yes, Alicia," he said pointing at her.



“Is it a verb?” she queried. Chambers could feel all the tension lifting off his shoulders.

“Absolutely correct. Bonus points for you.” Looking about the room he sensed a massive wildfire of competition slowly smoldering from each student. The class was waiting eagerly for Tod to spew out another word or sentence from which they could feed upon. And they didn’t wait long. The young student, feeling more confident with every passing second, did not disappoint.

“Points for you! Points for you.” This time a dozen hands shot into the air.

Chambers, thoroughly pleased and excited himself, forgot to pick the first hand he saw and instead shouted, “Anybody . . . last word part of speech?”

A chorus of “PRONOUN” broke through the air, followed by unabashed laughter and giggling, and through the merriment another student turned toward the new boy. “Tod, can you do another one for us?”

For nearly thirty minutes Tod, Mr. Chambers, and the rest of the class played this bizarre game of parts of speech. As the newness began to wane, basically because Tod was not feeling as compelled to repeat words for the moment, the students settled down, returning to the day’s curriculum. However, five minutes before class was to be dismissed, Tod struck again, compelling the class to declare that an adjective was the rewarded word this time.

Just before the dismissal bell rang, Mr. Chambers addressed the class. “Well, class, what you took part in was an understanding of what echophenomena is. A fancy word, huh? Nothing more than the repeating of words, or a string of different words. Do you think that’s such a bad thing?” A voracious shaking of their heads gave him his answer.

“I think he’s kinda cool,” chimed in Raj Hutpoor. Tod, clearly pleased with himself, smiled broadly at the student.

“Yeah, that was fun,” said another. And as the bell sounded, several of the students surrounded Tod, high-fiving him and whisking him out into the hallway and down the corridor.

“Still got it,” postured Chambers, beaming from ear to ear. “Still got it.” ♦

CLARISSA SIMMENS

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## THROUGH A GLASS, AUTISTICALLY...

Woke up from a dream  
Lifetime-long  
A Blues-in-the-night song  
Relief, at first, remembering  
And being re-diagnosed  
Autistic  
It all came back  
The '80s therapist:  
"Son is autistic  
So are you"  
Denial  
Dream-time  
About me  
Would, of course,  
Want to encourage him  
Although I felt it was merely  
Creativity  
Now, now I accept  
My uniqueness  
Hah! Good synonym for loneliness  
For being pelted  
With rolling eyes  
Impatient sighs  
And me  
Living in the dream  
That I was just like you  
And you  
And you  
But no  
But no, not true  
But no, please  
No pity  
No lies  
I yawned and stretched  
Got out of bed  
And heard the truth  
Inside my head  
Where do I go from here . . . ?

LYNN GUTTMANN

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## FATIGUE

is a phantom  
 who lulls me  
 with her  
 rocking horse  
 lullabies

*come down  
 sweet,  
 float down*

into silken damask sheets  
 a carpet the color of ice  
 adorned with a hundred spices

*lay down, my lovely  
 stay down, my lovely  
 slumber, Sleeping Beauty*

ebony  
 crows cackle  
 blue  
 jays screech  
 bright yellow  
 butterflies laugh

Dali's clock croons,  
*Don't get up.  
 Don't get up.*

The curtains whisper,  
*Keep a closed eye.*  
 The comforter gently reminds me,  
*Alas, time & tide brook no procrastination.*  
 The French door shrugs,  
*Before I close, you better be up standing.*  
 The pillow declines!

Prince, my flamboyant Prince,  
 come,  
 with your flashing sword,  
 imbibe a slug of cognac and  
 tell phantom Fatigue where to go.

*Previously published in Wordgathering 50th Anniversary  
 Issue, 2019. Reprinted with permission of the author.*

## BROWN SUGAR

If I button a cuff of the floral-print blouse  
that a nurse dressed my mother in  
to distract her from fidgeting  
with the hospital gown snaps,  
she allows me to feed her a spoonful  
of oatmeal sprinkled with brown sugar  
I brought from home.  
Only white sugar where she is.  
Then my mother unbuttons the sleeve cuff,  
folds it over, and demands, *Button it.*  
But I insist, *Only if you eat another spoonful.*  
Resentfully, she surrenders.  
The unbuttoning is everything.  
Her false teeth float in a Styrofoam cup  
on the nightstand while she slurps cereal,  
her mouth collapsed like a sinkhole  
in her face. Thin skin shrunk skull-tight,  
swollen purple-veins throbbing  
at her temples. Her body,  
her only house now, and the eyes  
light up for brown sugar when I visit.

GALEN SKYE

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## FOR ME, THERE IS NO SOUND

For me, there is no sound.

Your tender voice bounces off  
Vacant walls of crumbling plaster.  
Silence is an empty canvas where  
The paint of your voice never sticks.

Your eyes tell me  
Things I really need to know.  
The soul's windows;  
Reflections of life and love,  
Despair and delight,  
Weaving the threads of the world into  
An intricate tapestry.

For me, there is a timbre to the words you speak.

Within the eloquence of your gaze,  
The texture and color of your words  
Are brought forth with hands and face  
As great strokes upon the canvas of my life.

# TRAVELING WITH THE SPHINX

FAY L. LOOMIS

I have longed to take a walk since I had a stroke a year ago December, a walk longer than the few steps from my kitchen door into the garage that shelters my car. I used to walk six-tenths of a mile round trip daily to my mailbox, before I was suddenly and swiftly slammed by a stroke. The word *stroke* comes from the Greeks who described a paralyzed person as one who had been struck down by violence—most likely by the gods, perhaps by a lightning bolt from Zeus.

I decided to set some goals to help me travel through a second dark winter. One involved taking walks again: First, to my closest neighbor's driveway by spring, to the next closest by summer, and finally to the mailbox by fall. When I shared my desire with my daughter, she said, "I bet you could make it to the first driveway right now."

Stunned by her bold suggestion, I demurred, and shrunk back into the wooden possibility that I might never walk normally again. I had expected by now to be living my familiar life,

yet each task of the day imprinted the knowledge that I was not. Almost like scheduled events, a weak muscle would become injured—knee, rotator cuff, neck—and push recovery further into the future and me back down the rabbit hole of depression and worse. *Was I once more being too ambitious, only to be disappointed by failure?*

A few days later, on an especially cold January day, I was lured by the brilliant light to stand outside and soak up the sun. To my surprise, I began slowly ambulating with heightened focus toward my neighbor's house, supported by my regal golden cane. As I picked my way over gravel, I could hear Dan, my physical therapist, say, "Walk slowly, cautiously. Don't take any risks."

Nevertheless, I found myself picking up the pace. The weight of my affected leg disappeared, replaced by lightness in body and spirit. Sun now at my back, I cast a three-legged shadow that called to mind the riddle posed to Oedipus by the Sphinx as he travelled to Thebes. The king must either solve it or die.

"What is the creature that walks on four legs in the morning, two legs at noon, and three in the evening?" asked the Sphinx.

"Man. As a baby he crawls on four legs, walks on two legs as an adult, and in old age walks with a cane as his third leg."

Upon Oedipus' reasoned response, the angered Sphinx threw herself over a cliff and died. An alternative version says the Sphinx devoured herself.

I know about anger, violent as the gods, that seeps through my psyche. Should despair devour me, I know how I want to die: crawl into a snowbank and let hypothermia take over.

A smile crept across my face, and I walked faster and with greater ease. When I reached the foot of my neighbor's drive, I leaned on my third leg and soaked up the beauty of the moment.

Facing the sun, I headed back up the grade toward home with considered effort. My weak knee buckled, strength drained from my legs. In a déjà vu second, I felt I was back in the emergency room, my limbs thrashing uncontrollably, not knowing whether I would live through the night.

*Can I make it? Why did I attempt this challenge? My medical alert button doesn't work outdoors.*

My panic increased when I remembered there was rarely anyone on this private road.

*Slow down. Relax. Tighten your leg muscles. Will energy into your body. Keep your eye on the dark opening in the garage. You'll be so proud of yourself when you get there.*

Soon, shaking with exhaustion, I leaned against my vibrant red car—red as my stubborn determination—and laughed. I, like Oedipus, had outwitted the monster.

*Hey traveler, look at you. You did not die. ♦*

JAMES B. NICOLA

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## TO MY MOTHER, AILING AT 90

Her daughter is the Ocean  
Her mother is the Rain  
She is the lowest thing of her domain

and yet, like you, unstoppable.  
Her blood is neither blue nor red,  
but as the nearly unseen dew.

She inches, rushes, cuts  
through empires' thickset stone.  
Like you, in bed, she goes on, fierce, alone

with one determination:  
to touch her child, that she  
might rise and fall, evaporating sea

that drenches from the sky  
fulfilling, as with tears,  
her drops, like love, as nameless as the years.

Her end's the vast beginning  
that dominates the earth,  
whence all that breathes, it's said, springs forth.

One of her names is River.  
Her aliases: Life and Time,  
who tap my cheek and make me what I am.

What can I do for you now  
but weep, and wet your finger  
that you might feel, and flow a little longer?

# PASSIVITY

KATHERINE E. SMITH

It was too early to be awake. The night sky clung to the window frames as if trying to remind me that I should be asleep. I wasn't ill, but that morning, I was expected at the hospital. It was around three in the morning and I was sitting in a straight-backed wooden chair in our dining room. My mother's fingers pulled and twisted my hair, forcing it into two French braids. In a bid to secure my passivity, my mother had popped in a video of *Little House on the Prairie* so she could work my thin hair into the pattern without my objection. I watched the flickering images on our small television screen with waning interest. Thoughts of scalpels, surgeries, and open wounds intruded into my mind. The next time I would wash my hair, a hospital-issue washbasin and dry shampoo would be used, as I would no longer have the ability to stand.

They called the surgery a *bilateral osteotomy*. Incisions would be made along the sides of both hips to fix each ball and socket. In addition, hamstring

releases would be done on my femurs, knees, and groin. Twelve cuts would be made in all, an ironic fact since I was twelve years old.

I wasn't upset about the surgery—I knew it had to be done for the greater good of my body, but I wasn't prepared for all that I would lose.

There was no getting around the surgery if I wanted a shot at walking as an adult. If I didn't have the surgery, I'd be using a wheelchair in a few years' time. It was either deal with the pain now or deal with it later. There was no other option. I liked either-or scenarios. I still do. There is no room for questioning, for doubt, for waffling of decisions. You just do what needs to be done.

The ride to the hospital was quiet. Since it was early, few cars wound their way down the highway. The stars winked, keeping their night watch. Slowly, the rural side roads and mountains gave way to a city landscape.

When we pulled into the hospital parking lot, the glowing numbers on the car's digital clock read 4:25 a.m. I had five minutes before I was to register for the procedure. I climbed out of the car and stumbled just a bit. My father grabbed my elbow, warning me, almost scolding me, to be careful—as if I had any choice in whether or not to fall. I realized, similar to a prisoner on his way to death row, that my steps were numbered. This was one of the last times that my legs would be well enough to hold my own weight, even if they did stumble on occasion.

The waiting room was dim and empty. Even though I was the patient, if my name was called, it was my parents who rose to answer the inquiry. It was odd. I was in the hospital, I was waiting, but *I wasn't the necessity*. My body was what was important, not me.

Check-in must have gone smoothly because I remember walking into a hospital room. The walls were the color of oatmeal, bland and uninteresting. The main feature in the room was a bed, in which I was instructed to place my

body. I think I only laid on the top layer of the bed because I knew this bed wasn't for sleeping. I wasn't sick, but I was about to be incapacitated. I could move, I could run, but I was directed to the bed.

As I laid in the bed, my parents and a retired pastor from our church prayed over me, yet another sign that I was to embody the sick role.

In the pre-op room, a nurse brought me a heated blanket. The blanket prompted my mother to tell a story about how she had gotten a heated blanket after she had given birth. This story was a reminder that I was doing things out of order. Normal bodies didn't need heated blankets and surgeries. Normal bodies weren't cut into unless an injury occurred due to sports. I didn't have any problems. Nothing was wrong with me besides the x-rays that showed my hip socket pulling away from the ball. If I didn't have the surgery, the doctor cautioned that I would lose the ability to walk, but as I lay in the bed, the heated blanket draped over me, I felt like a fraud. I could have gotten out of that bed. I could have walked into the room instead of being rolled in like an invalid, but my body was already being prepped for passivity.

I looked at the clock as a papery cap was placed over my hair. It was 7:00 a.m. My friends would be eating their breakfast, combing their hair, donning their jackets, in preparation for another ordinary day of school. The contrasts between my routine and those of my classmates were not lost.

A nurse walked briskly into the room, standing over me with a checklist.

"Do you have any earrings in?"

I shook my head, remembering that I had taken my pink floral "starter" earrings out at home. I knew that metal wasn't allowed during surgery.

"Do you have any secret belly-button piercings? Things your mom doesn't know about?"

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## Silently, I apologized to my body for what it was about to go through.

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I waited. I looked for the hint of a smile. She wasn't kidding.

"No," I said meekly, realizing that any semblance of privacy was gone. I couldn't hide anything here. After the actual surgery, I would realize that along with consent to perform the surgery, the doctors and nurses had permission to see my body. I would be embarrassed, knowing that my two or three pubic hairs would be seen when the nurse would check on the incisions to the pelvic bones. I would be particularly mortified when the nurse, or doctor, happened to be male.

I suppose I was wheeled from pre-op to the operating room. My rolling bed, the one that I had been laying on since my arrival in the hospital room, was placed parallel to the operating table.

A different nurse, her voice kinder than the last, asked if I could move from the bed to the table. Though no one said anything, I knew, as I moved my legs, knees, pelvis, and hips, that it was a monumental moment. I was polite; I moved my body quietly. I learned that it was best if the disabled body was passive. If the body was passive, it didn't draw attention. If the body was passive, others might be more willing to help in a crisis.

It was the last time I would move independently for months.

The steel table was cold, and the lights seemed brighter. Silently, I apologized to my body for what it was about to go through.

When I woke up from anesthesia, I didn't feel the pain of cut muscles and tendons, of bones that had been forced back into place or sawed in two. I heard coughing, hacking. The woman in the recovery bed next to me, though the curtain was drawn between us, sounded elderly. I should have felt sorry for her, perhaps her situation was more severe than my own, but I just wanted her to stop making so much damn noise. Instead of pain, it just felt like there were nerve endings on the outside of my body. Every sound was too much.

I knew where I was, and I knew that I had just had surgery—the surgeon had told me it was three in the afternoon and that I had done well. Trying to be polite, I had tried to smile at him, but my face was swollen, with a yellowish tint, from the anesthesia. I'd always liked this doctor. I'd seen him since I was two years old. I had always gained amusement from watching his breath tickle his mustache hairs when



he would talk. I saw this doctor twice a year, and at Christmastime he would often enter the examination room with a holiday bow perched atop his bald head. That morning, the doctor's scrub cap had been colorful, as if left over from a 1980s fabric collection. It looked *groovy*.

Several nurses in the recovery room crowded around, asking if they could get me anything. I hadn't had anything to eat or drink since the night before. I asked for water as the hospital bed groaned to a sitting position. The water was brought on a small sponge, a wise move, since the water didn't stay down. It was as if every level of my body was rebelling, screaming that something was wrong.

That evening, I felt everything. It was as if my body was made of shards of broken glass, and the slightest movement or sound would shatter it.

My mother sat in the corner of the hospital room, talking in hushed whispers to a church member who had come by

to see me. Feeling a thousand miles away, it was better just to lie still, hoping quiet would envelop me so that I could tune out the conversation of my mother. My head turned to the left, my gaze fixed on the darkness of the outside window. It was night. Visiting hours were drawing to a close, something I was grateful for. Darkness had bookended my experience. Darkness had heralded change early that morning when my mother braided my hair, and darkness now goaded me, making me reflect on all that had changed in a little more than twelve hours.

The night itself, though, even when the visitors had left the floor, was no better. Various alarms screamed. Fluorescent light from the hallway bullied its way into my open room. Everything was too much. My body was literally broken. And sleep had abandoned my metaphorical ship. I tried to imagine my body, under the covers, under the layers of plaster and wound dressing, but I couldn't. That body didn't belong to

me anymore. It had been tampered with and was now fragile. I didn't know how to claim it.

Pain isn't always what you think it will be. Pain isn't always loud or angry. Sometimes, pain forces the body into submission, pain becomes a quiet paralyzer. There was nothing that I could do. I couldn't wail. I couldn't cry. All I could do was lie there, staring hopelessly up at the ceiling, which had been painted with the image of two dolphins. I tried to imagine the dolphins as my friends. I tried to think of names for them, but it was as if my brain had shut itself off, going into a safe mode.

I would later learn that the night nurse had forgotten to tell me, or my mother, that I had a morphine drip at my disposal. And, so, with gaping incisions covered with cotton dressing, I waited for the morning. There was no medication; there was nothing I could do but lie in medicalized silence. I adopted the sick role. I became passive, an object to be acted upon by others. ♦

SHIRLEY ADELMAN

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## HOLDING ON

Winter afternoons,  
     Post concussion:  
 Light glaring  
     From windows,  
 Trips me up.  
     Dizzy, staggering  
 From sink to table,  
     Exhausted from,  
 Trying not to fall.  
     I hold onto Whitman,  
 Like a child grasping  
     a parent's hand.  
 Finding solace,  
     In his words:  
 "I exist as I am, that is enough."

SHIRLEY ADELMAN

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## No, No

In the arms  
 of another,  
 the little girl  
 cried, "No,  
 Mommy No,  
 No, Don't go,"  
 as her mother,  
 boarded-----  
     a bus.

I fell back  
 to the gurney,  
 calling out,  
 "Let me----go----  
 ---Let me-----go"  
 -----before,  
     an  
         es  
             the  
                 sia,  
 took me----  
     away.

# CHOOSING IRRESPONSIBILITY

SARAH BAT

The summer before my senior year of high school, I had somewhat major knee surgery. For the majority of the vacation, I was laid up in bed with my left leg in an isolator brace, working on AP summer homework and wasting time on the Internet. But toward the end of summer, my (at the time) long-distance boyfriend came to visit from out of state, and I was stubbornly determined to have a good time. So with my then-boyfriend, my mom, and a pair of bedazzled crutches in tow, we set off for San Francisco's Ocean Beach. See, my mom was born in Oakland and used to build boats for a living. I love the ocean. Water is in my blood. I love the drive down Geary Street, through the San Francisco hills, watching the ocean peek over the horizon, rolling down the windows to smell the salt in the air get closer and stronger.

So, I had a singular goal in mind that day: walk along the edge of the ocean. This meant I had to get to the edge of the ocean from the concrete steps leading down into the sand. Sand is not

really a substance that takes well to crutches, so I abandoned mine with my mother, and set off all by my stubborn self. The brace on my left leg prevented me from bending my knee more than a few inches, so with each step, as I sank into the sand, I swung my left leg up and around to take another step forward. It was agonizing. I don't know how long it took me to make it to the part of the beach where the sand was damp to where it was a little easier for to move, but I did it. I made it to the edge of the water. And I didn't just stand there. I walked along the water for a few minutes. I felt the ocean breeze. The crisp chill, the salt smell that settles into your skin. I toed off my flip flops, ones I shouldn't have even been wearing, and buried my toes in the cool, damp sand. The waves lapped gently over my feet, and I watched idly as the sand streamed out to sea once more. And then, when the ache set in, I turned around and walked all the way back to the concrete steps.

For the rest of the day, my left leg ached and burned as I walked. The aftermath of my beach jaunt sat heavy behind my kneecap, like a fist tugging at my nerves. I leaned heavily on my

crutches, and frequently needed to stop and rest. But I didn't regret it. I'd done what I'd set out to do, what I had wanted so badly to do. My physical therapist would have likely had my head for it, having told me mere days before that I needed to be on my crutches for several more weeks, minimum. But as much as he was right, I also needed to dip my toes in the ocean. I needed to know I could push myself and make things happen.

This is not meant to be inspirational. Sure, I stubbornly did something I probably shouldn't have, but that's not brave. That's irresponsible, which is what this is really about. When you have a disability, you have to pick and choose when you can be irresponsible. Sometimes, you do things you shouldn't because you have to for work or school. Sometimes, you do things you shouldn't because you deserve to still live your life and have fun.

It's important to note that no one should use me, or anyone else, as an example of what they can or can't do as a person with a disability, or what they

are or aren't capable of. My limits are my own, I know what they are, and it's my choice to cross them for whatever reason. I just want everyone out there to know it's okay. It's okay to draw the line in the sand and refuse to do something, but it's also okay to overextend yourself to have a little fun. Fun is important. Sometimes, in the name of fun, you have to say "screw it" and put yourself out of commission for a few days.

I still struggle with walking long distance. I have a genetic disability, and it affects my joints. In day-to-day life, I am mindful of this. I wear my orthopedic insoles. I only wear sandals with arch support. I have two sets of ankle braces, one for tennis shoes and one for my sandals. When I'm home, I keep my legs propped up to reduce swelling. But

if I spent my entire life only making responsible choices for my disability, I would never enjoy myself.

The first time I attended a poetry slam, it was the middle of an especially cold and wet winter, and I was on prednisone. Prednisone is an immunosuppressant, not exactly the kind of medication to be on if you're going to go be in a room full of people a week after the snow melts. But I was bound and determined, just like that day on the beach, to have a good time despite my medical circumstances. So I went. And it was one of the best experiences of my life. I made the decision to switch from the open mic to the slam contest, something I never would have had the courage to do even a year before. I met

two of my favorite poets. I competed against one of them. I arrived home exhausted, so exhausted I ended up missing class the next day, but that night on the phone my mom said I was the happiest she'd heard me in years. Then, that Wednesday I got a fever. Then a cough. I ended up missing several days of school because I got a terrible chest cold, and I know it must have been because I went out that night. But it was worth it.

When you have a disability, sometimes you have to make the choice between the right thing to do and the thing you want to do so badly you can feel it burning you up from the inside. Sometimes, you have to walk to the beach, even if it makes your leg burn and ache. Sometimes, you just have to do something, even when your body protests. ♦

# VISITING WITH KRIS

ROSEMARY WOODEL

**T**uesday morning I drive out Hwy 53 to Pickle Simon Road, then take a left on Blueberry Lane. The shade of the big tree on the left of the double-wide trailer's driveway will keep my car halfway cool in this Georgia summer heat.

When I ring the bell, Bill, Kris' dad, appears. His thin chest is bare. How can such a small person carry his twenty-six year-old son many times throughout each day? But when Bill opens the door for me, his biceps bulge. "Kris is in his room, waiting for you."

Kris sits in his wheelchair, staring at the computer, his back toward me. He is playing bingo online, trying to win the \$20,000 jackpot.

"You're into bingo now?"

"Yep. I'm hooked. I was up till four this morning playing. That's why I'm kind of tired. Plus I'm going to the VFW on Fridays and Sundays. I usually spend about \$15 for ninety minutes of fun."

"Have you won anything yet?"

"Nope. But I have a good time whether I do or not. Except when I'm missing only one spot, and somebody else wins first."

"But that feeling of hope is hard to resist, isn't it?"

"Would you like it better if I stop playing bingo while you're here?"

"Well, yes, 'cause then I can see your face."

"Then back me up. Right. Now turn me toward your chair."

From his neck down, the only body parts Kris can move are two fingers of his left hand. I maneuver his wheelchair gingerly. I am a pretty poor driver and dread crashing Kris into furniture. At twenty-six he is almost a senior citizen in Duchenne Muscular Dystrophy circles. As he instructs, I position his left hand over the edge of the metal bar holding him upright. He is leaning to his right at a 30-degree angle but does not want me to straighten his body. His little white-socked feet stick out at right angles, protected by a sheepskin carpet on the footrest of his chair.

We talk some more about his bingo experiences. (Topics we have discussed in the past include religion, death, love, sex, travel, music, poetry, family, and friendship.) Kris and I talk about Las Vegas, where he would like to go sometime. I describe my February trip there: the dancing fountains, statues made of flowers, gondolas floating in Venetian-like canals, the free entertainment. Kris' face is full of wonder and desire. When I relay my single gambling experience in the basement of a casino, he disdains my feeble efforts at juggling four bingo cards at one time. "I do six at once."

“Well,” he says after a pause, “I think my service at church went well.”

“How you organized it was perfect. Your singing, of course, was very good. Ending with, ‘I Did It My Way,’ was brilliant. And what you wrote was insightful. But the thing that impressed me most was how you spoke. Reading about how to give a speech and the practice sessions we had—it all paid off. You spoke slowly and had appropriate pauses. I could understand everything you said.”

“Yeah, I really tried hard for that ’cause I know I speak too fast and like a redneck.”

“And lots of folks were crying, too,” he says with a sneaky smile. (Kris loves evoking feelings.)

“I know *I* was,” I admit.

“Yep. I knew you were. When I played that mushy song about friendships.”

“Well, crying’s good. It releases endorphins.”

“I know what *they* are. Hey, will you ask my dad to move me to the bed?”

As Bill moves Kris from the wheelchair to the bed, Kris gives directions in shorthand. “Leg. Pants. Arm.” His dad knows exactly what Kris means. Kris lies on his back with a yellow sheet folded over him. His legs are bent at the knees, splayed out as if he were caught in the middle of a frog kick. Kris asks me to move my chair so our eyes can connect.

I notice the poster of a motorcycle at the foot of his bed and sing him the silly Arlo Guthrie song, that begins, “I don’t want a pickle. I just want to ride my motorsickle.” He laughingly says that it’s a really stupid song.

We talk about plans for his memorial service for awhile. Then Kris asks if I would bend his fingers.

“Sure. But you have to tell me what to do so I don’t hurt you.” I take the sheet off his right arm to expose his hand. His bent fingers are thin, but elegant. They look unused; they *are* unused. I tell him he has really nice, long fingers.

“Thanks. If I could move them, I could play piano really well.”

I gently massage the palm of his right hand and each finger, then carefully unbend each joint. “That feels really good. If *you* do it and then my aide comes and does it later, that will be a double dose.” After about ten minutes, I tell him, “I’ll do your other hand, but I’ll have to sit on the bed near your head to get into position.”

The fragility of his body is so apparent. Elbow bones shine through his pale skin. Have I ever seen all those bones in any other human being? I can easily circle his forearm with two fingers of my own hand.

While I’m unbending each finger and massaging whatever muscle I can find in among all the bone, I think what a joy it is to help someone feel better. When Kris asks me to do his legs, I’m not at all sure what that means, but he gives specific directions.

“Take off my sheet. Stretch out my leg. No, the other direction. Yeah, more. Behind my knee. That’s it. You have no idea how good this feels.”

“You could have asked me to do this a long time ago, you know.”

“Don’t know why I didn’t.”

After about ten minutes on his right leg, I say, “I have to do your left leg, or you’ll be unbalanced.” I squeeze into the narrow slot between his bed and the wall. “I can’t gain any weight now,” I say. Kris laughs.

His left leg, actually the left hip, is hurting him. We cannot get the same kind of relaxing stretch on that side. But even without that, Kris enjoys the muscle massage.

I hear country music coming from the living room. Kris’ mother is playing a tape, made by her now-dead sister while

she sang country music to a karaoke machine. Kris' aunt sings slightly off key. Nevertheless it is comforting to hear the old standards like "Your Cheating Heart."

Kris' mom comes into his room, bordering on panic. "Kris, the tape is kind of slowing down like it's getting damaged. If something were to happen to that tape I'd bawl forever. Can you do something? Like convert it to a CD somehow?" Kris opens his eyes, leaving his reverie. "Yeah, I'll look into it." Chances are good his intelligence and expertise at the computer will help him find the answer.

By now my back is starting to cramp because of my awkward position. When I return to my chair, Kris asks me to massage his back. "But first you have to roll me. Take off the sheet. Now grab my hip and my shoulder and push me toward the wall. Good. Pull back my arm. Move my head. More. That's it. Perfect."

Kris' narrow back is so contorted and bony I can hardly find a muscle to rub. His shoulder blades are prominent and meet in the middle of his severely-curved spine. I can barely get my hand between them. I am overwhelmed. What pain he must feel constantly! "That feels great," says Kris.

After about ten minutes, I move up his spine toward his neck. "Yeah, do my neck." His neck is so tiny it is like touching a newly-hatched baby bird. I feel most confident rubbing his head. The hard bone of Kris' skull seems the safest part of his body to touch.

"This has been terrific. I'm falling asleep. Thanks a lot. Come back soon, okay?"

"Absolutely."

I move my chair out of the way and leave quietly. ♦

LYNN GUTTMANN

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## INSIDE/OUT

I live within the four walls of myself  
 motionless with fatigue  
 silent as a tree in the forest

I sleep in & out of time  
 from shade into shadow  
 from shadow into darkness  
 absent  
 from my dear ones

I am that girl in the forest,  
 asleep in her coffin of glass  
 the lid is my casement  
 the walls of my room are its sides

my energy rises up  
 seemingly unbidden,  
 fragmentary, unpredictable  
 then sinks  
 only to rise again

I place my palm against the glass  
 the casement flies open  
 my dear ones kiss my cheek

We are the sky breathing laughter  
 the flowers exploding brightness  
 the forest and fields stretching to the horizon

for me this fleeting pleasure  
 is some times  
 enough.



Lynn Guttman, *Bedroom Window*, 2015, black ink

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# SOMETIMES IF YOU'RE LUCKY

SHARON FRAME GAY

Sometimes if you're lucky and everything falls into place, magic happens. For me, it is the nights when the stars are so bright they shimmer through the windows. If I am placed just so, I see them echoed in the mirror above my eyes. How hopeful they look, like flinty chips piercing the night sky, dancing so far away, such endless possibilities.

I peer up into the silvery length of mirror and smile. Stars are meant to be looked up to, our faces pointing toward the vast universe. So many times, I see the world upside down, but the stars remain where they are supposed to be. People come to talk, and I stare into their nostrils, the bags below their eyes, the jiggle of fat beneath their chins as they waggle with words. Some days I make a game of it. I'll look straight up into their faces, trying to visualize how they really look. Then, I'll turn my head sideways and see them when they take a step or two away, and gauge how close my guess was. Were they handsome? Fetching? Better upside down?

I'm content, warm and dry for the most part. Once in a while, my diaper seeps through before the caregiver Molly helps me when morning comes. She is filled with apology then, her large brown eyes distressed as she looks down on me. I smile back up at her. What does it matter, in this vast universe, if I get wet? How does this small thing factor into a lifetime of sorrow, pain, and yet such grace?

I have a television in my room, though I seldom watch it. I listen to the music of Mozart and Bach rather than canned laughter all hours of the day. I prefer nothing canned. Because this is what I live in. A can. A big silver bullet of a machine that has kept me alive now for more than sixty years.

The rest of the world has passed by. Effortlessly, it seems. When I crane my neck and peer out the window, I see people scurry along, their legs and arms swinging with each stride, heads bent and thrust forward as though a great wind were blocking them. Children skip. How fondly I remember skipping! For just one moment when skipping, you are weightless, flying, before touching down with a sneaker, or a scuffed brown shoe. To skip is to moonwalk in heaven.

Polio is such a strange word. Sounds like polo, but doesn't involve horses, mallets, or balls skimming the surface of a field. Nowadays it is merely an annoyance, children grimacing when they get a vaccination. A little pinch that comes and goes, rewarded with a lollipop. Oh, to have been able to get a small shot and escape this armored castle that holds me hostage in its grip!

Before polio chased me down and tackled me, I was an ordinary little girl. Susan. That's the name I answer to, although inside myself I have many names, such as Princess Light, Audrey, and Daisy. Names I make up when I play stories in my head, which I do all the time. Back before the iron lung, I played horses and hopscotch and rolled down the hill in my backyard. I climbed trees and swam, and even rode a pony a time or two.

Then polio skulked into town, a dark cloud hovering over the country's best and brightest. The children. It dared to ride on the breeze and infect us with droplets from its open maw, capturing us in the dawn of youth. It carried us out of our homes in baskets, or hobbling in braces, or for a few chosen by fate, placed us in the great iron lungs that dotted the world like huge silver bugs, swallowing up children and never digesting us. Like Rapunzel, we were kept prisoner, waiting in near sleep to be rescued by our prince, or the Grim Reaper himself.

At first I was frantic. I was only nine years old, so ill I could not take a breath, snatched away from my family as though somehow this was my fault. The hospital ward was littered with sick children, staring at each other, wide-eyed. We cowered under the covers, crying for our mothers, our fathers.

There were many of us in the big city hospital, children who were laughing and jumping rope one day, almost paralyzed the next. A lot of children died. But a great many survived, hobbling past my bed on their way home, legs in braces or arms withered, leaning on their family as the ward door closed behind them.

I waited for my turn, my turn to leave that narrow, sterile bed and gulp the autumn air in great breaths. I yearned to walk through my front door, lean down and pat my dog Sandy, and sit on the grass in the backyard, weaving the blades between my fingers, smelling the earth beneath me. But my time never came. I was loaded into a massive iron lung, face up. The machine breathed for me, loosening the wheezing in my chest. The incredible pressure lifted, replaced by the clanking and sighing of a mechanical mother, now forcing me back into her womb and holding me tight, defying gravity, protection from my own respiratory system.

I was a child, and children find ways to cope. At first, it was almost pleasant once I got over the initial fear. I felt better. Everybody was kind. My parents brought me books and teddy bears, radios and pretty ribbons for my hair. I spent the days playing stories in my head. I was a princess, a horse trainer, a crime solver, or a bride. It took several years to figure out I would be none of those things, particularly a bride. No man would hold me into the night, give me a child, come home from work weary and leave his briefcase by the door. There would be no dances or football games, nor awkward fumbling in the back seat of an old sedan. There was only the rustling and the sighing of the great iron lung, as it folded me into its metal breast, suckling me with air.

As the decades went on, I could leave the confines of my carapace each day, poking my head, then my entire body, out of the machine like a turtle, craning my neck and staring about. I was placed in a wheelchair and pushed around the hospital, then later, my home. The air swirled around me as I joined the world for an hour or two, legs dangling like a puppet as we swept down the hallways. Physical therapists worked with me for years. Once or twice they put braces

on me, and I stood and walked a few paces. It felt so odd to be upright, as though a leaf had fallen off a tree, then tipped on to its points like a ballerina and danced across the forest floor.

Although I was encouraged by family and doctors to emerge from the machine more often, I felt awkward and vulnerable outside its shell. Breathing wasn't as comfortable as it was in the iron lung. I had to struggle more for breath, and it was frightening. I hid the anxiety, though, as I didn't want to appear foolish. When placed back in my machine, I felt immense relief and something akin to freedom. How odd that the very thing that holds me hostage grants the only comfort I have ever felt.

I long for a man's touch, or the ability to run across a meadow. In my dreams, I do. I wake up aroused and frustrated, ripe with excitement. Then I hear the regular, steady breath that comes from my machine, and know it was only a dream, as I pound at the metal in anguish, tears running into my hair.

So many ask, "How do you cope?"

"How can I not?" I answer back.

For this is all I remember now. Life reached into her magic bag and granted me this. It was the coin I was given to spend. I cannot resent nor feel left out. It simply is. I leave no footprints on this earth, but my breath mingles and tangles with all living things. I am just as important, and just as inconsequential, as everybody else.

Sometimes, when I am lucky, and placed just so, the stars reach out from the mirror above and invite me to join them. I dream that someday, when I have spent all the breaths God has given, that this machine, my Mother Ship, shifts into a rocket, shattering reality and the window panes, as we aim for the moon. We break through the barrier of the atmosphere, into a universe where breath does not matter, where I can dance among the constellations and see the stars, face to face. ♦

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# JUST WANTED TO SAY THANKS!

PINALBEN “PINKY” PATEL

It didn't happen during my childhood when I walked around wobbly with a pediatric walker, smiling, and conversing. It didn't happen after I had an ER visit in my sophomore year of high school that led to an eleven-day stay at the hospital and a diagnosis of type 1 diabetes. It didn't happen two years later in my senior year, after I had another ER visit with a four-day hospital stay and a pacemaker implanted to regulate my slow heartbeat. It happened right after high school graduation, the summer before college began, that I grew up and saw the secret of my maturity.

Many people assume that a person who has dealt with a physical disability from birth or a young age is already grown up. My clumsy, drunken walk became visible when I was six years old. After much testing, I was diagnosed with a neuromuscular disease called Friedrich's Ataxia (FA).

In childhood, I learned that I was different, and different was not a bad word.

It just meant that I had to find my own way of being a kid. It was cool to be the only eleven-year-old in town with a walker! In 1992, elementary schools were not as accommodating to students with disabilities as they are today. So when I had to attend classes in a trailer with steps, I would laugh and confidently ask my classmates to carry my walker and books up the stairs. If one did not want to help, I would just ask another, but no one really minded helping.

My current friends with FA and other disabilities talk to me about how their childhood and adolescence involved teasing. I honestly, however, can't remember any mockery in my past. Maybe it did go on behind my back, or even right in front of me, but I played Mary Sunshine. I was adamant to avoid the snickering. I saw in the school halls that everyone was different; some kids were tall, some were short, some were fat, some were skinny, and I was shaky. I was unique and proud to be the only one. I thought my intentional, perky oblivion constituted grown-up behavior.

By the end of high school, it did not matter that other people had to see me naked daily. Of course, I wouldn't have minded if my personal-care attendants were young, tall, and muscular males, but fortunately for my parents my aides at school were females. High school graduation was at the grassy, bumpy football stadium. Since it was hard for me to drive my electric wheelchair, my chemistry teacher, who was also the football coach, pushed my chair during the ceremony.

Graduating from high school, I haughtily believed my maturity had reached a threshold, and there was nothing more that could happen to teach me life skills. I was going to college only for the academics; I wanted to study writing. Actually, my pompous mind thought I knew a lot about writing already, since I had more experiences to write from than my peers.

Applying to college was a trend for graduates, and I did not want to be left out. I also wanted to prove that

my disability did not affect my intelligence, so I registered with the college in my town, disappointed my parents wouldn't let me go to the flashier, out-of-state colleges like some classmates. I was exhibiting classic high-school conduct, because I just wanted to show off and do what everyone else was doing. I see now that my behavior in high school was not abnormal, extraordinary, or wrong for the time.

I had met a vocational rehabilitation (VR) counselor in my last Individualized Education Plan meeting at high school. On the day I grew up, she came to my parents' house to discuss my options for the future. She explained that, unlike high school, colleges do not provide personal-care attendants to facilitate the commuting to and from campus or for assistance in the restroom. She said I would need to find my own aides, and while VR would not help me find candidates, they would fund me to pay my helpers. I would be an employer, managing hours, cutting taxes, and creating payrolls! However, it was more terrifying than exciting because it was unfamiliar territory.

During counseling, I became aware of the fact that I was not as developed as I claimed. I took my support system for granted. I was not the only one dealing

with my FA for all of these years; my parents were coping with it, too. I know I was blessed with the smarts to have never needed homework help, even in my younger days, but my parents gave me the physical help I required. They were the ones who got me ready, monitored my medications, and drove me around to participate in school activities.

In all of my school years, the school system provided an attendant to help me with scribing, restroom needs, and getting lunch in the cafeteria. I did not have to supervise her hours. She, or someone else in her absence, would be at the gate when I got off the bus or car. It began to sink in that I had taken for granted the worry-free ease of having my parents and school authorities' assistance.

Living with a physical disability from a young age did make me mature, but it did not make me grow up. Maturity is shown by a positive outlook on life and the calm way of accepting problems in life. The moment of growing up, however, is an epiphany. Both maturity and growing up does not have anything to do with physical age. I grew up the moment when my VR counselor showed me the outcome of my decision for further education, and I saw that I have never been alone to deal with my disability.

I did go through college to finish a bachelor's degree, but I had a hard time finding attendants. Some of the people I hired would not show up when they didn't want to work. I was reminded time and time again with the unreliability of aides that without the physical help I received, especially from my parents, I would not be able to achieve anything.

My parents have done a lot for me physically, and I am grateful beyond words for their help. They put their work on hold and stepped in as substitute aides whenever my attendants did not abruptly show up during my college years. If they did not care for me, today I would be watching TV to keep myself busy in a nursing home at age twenty-eight.

Ever since the college experience, I am more forgiving of my helpers. I used to complain a lot when something didn't go my way, but now I let it go sooner. I still complain laughingly only to show my needs to a person who has not been around me. But I do not dwell on the matter, and that has made me feel much healthier and truly happier. I've always been good at putting on a fake smile, but now it's a true smile! ♦

# CONFUSION

B. E. PENGELLY

I live with people whose names I don't remember. We're eating breakfast. They smile at me and talk about people I don't know. The woman shows me the picture of a baby.

"Who's that?" I ask.

"Oh," the woman says, "That's Karen, your new great-grand-daughter. She's almost three months old now." I shrug.

It's cold in here. I go looking for my sweater. It's missing again. When I try to turn up the heat, the lights go on instead. I go back to bed; it's warm there. I fall back to sleep.

All of a sudden, I wake up. I gotta go! I grab my cane and struggle to stand up. I hobble into the bathroom as fast as I can, but I'm too late. They're going to be mad at me again. The woman says I make too many messes. I sneak back to my room, put on clean clothes, and hide all the wet stuff in my closet.

Then I look out the bedroom window. It's such a pretty day. Time to take a walk. After grabbing my coat and hat, I go to the door. Why is it locked? I don't like this. Suddenly, the man is standing next to me. I tell him to open the door. I want to go out.

He smiles and says, "I'll get my coat and go with you." But by the time he gets back, I don't want to go out anymore.

Now the man and woman are talking to each other. The woman is saying they must hide my shoes and my money. They've already taken my keys. And my car is missing. I'm a prisoner!

I start to scream, "Help! Someone, please help me!"

The woman hands me a candy bar. I stop yelling and eat it. It tastes good. They talk to me then. The man says they are protecting me. I could get lost or hurt if I go out without someone along. The woman says that having to ask for my things is a way to remind me that I should not go out alone. I don't like this. Then the man says he will take me to the park on Thursday. When is Thursday?

I've finished the candy. They talk together for a long time. I hear the woman crying softly, and she keeps saying she's had enough. Enough of what? The man answers her, saying that things must change. What things? I don't like change. Now they tell me they're going out but will leave my lunch in the kitchen. The man asks me to sit in my chair and watch TV until they get back.

A little while later, I'm hungry. I want food, but no one comes when I call. Where are they? I go into the kitchen. The food on the counter is cold, so I put the plate in the oven to warm it up. Nothing happens. I decide to eat it any-

way. The brown stuff is tough. I should cut it up, but I don't remember how. I throw it in the garbage.

Time for another trip to the bathroom. It takes a while, but I'm successful. Then I can't find the paper. I call, but no one answers me. So I use the washcloths instead and throw them in the tub. I'm worried. The woman will be angry again.

There might be a baseball game on the TV. I sit down in my recliner and pick up the remote. Damn! Why won't the TV turn on? Then I hear a voice say, "If you'd like to make a call..."

Finally, they're back, and they've brought a visitor. It's a short, middle-aged lady. She's dressed in white and asks them lots of questions. They talk for a long time, but I don't understand all of the words. I pay no attention to them.

Oh, the visitor is now talking to me. She asks my name. I tell her, "It's Bill. Bill Mr."

Now she's stuffing that long, black thing in her ears and listening to my heart. Then she places that wrap around my arm. I hate that; it always gets too tight. Now she's putting the fake clothespin on my finger.

"Ouch!" I cry out. She has grabbed my hand and stuck me. The man pats my hand and tells me not to worry. The visitor tells him that I am quite healthy.

"Bill," the visitor asks me, "Can you tell me what year it is?"

I think for a minute. Yes, I heard it on the radio. "1776," I say proudly.

"And now, Bill," she continues, "Who is our president?"

I don't know. "Who cares," I reply.

The visitor turns to talk to the man and woman. "It's dementia, probably Alzheimer's."

"Who's that?" I ask. But no one answers me. I ask again. I'm angry. I don't like people who don't answer me. I start to yell. Then I throw the phone at the visitor. It misses. I'm sorry. I start to cry. The woman is crying, too.

They talk some more. Then, the man goes into my bedroom and comes out with a suitcase. I ask if he's going away. "No," he replies. "This lady is going to take you for a ride."

Now I'm in the visitor's car. She gives me a candy bar. Then she tells me we're going to a senior care house and that I will live there from now on. She tells me that my wife and son will visit me soon. I'll have my own room, and the nurses will take good care of me.

I don't like this at all. I cry. I want to go home. ♦

UGONNA-ORA OWOH

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## GRANDMA'S DEMENTIA

Side by side, Grandma forgot her home, called it strange.  
 "Let's go" she said always as if feigning normalcy.

She was eighty-three and she had forgotten how the world  
 looked like, how the sky wore a new dress each day;

the street stench, the music of rain on the roof  
 as though angels were descending to take her.

Each day, she forgot the looks of something. She  
 forgot my face and her dementia wore me a new face,

and she said "ghost" in her native tongue. I missed those  
 moments of stability, her eyes caught against mine.

Now in the old people's home, I feel okay because  
 she is okay; God isn't knocking that fast.

RAYMOND LUCZAK

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## AFTER QUINTUS PEDIUS *circa the first century B.C.*

History says you are the first  
 deaf person recorded by name.  
 You were taught to paint.  
 Then you died young.  
 You were probably thirteen.  
 Nothing of your work survives:  
 not even a description.

Did you ever wander alone  
 in the teeming streets of Roma,  
 your eyes drinking in the sights  
 of men and women bantering?  
 Or had you found others of your kind,  
 hands recording more clearly  
 what you couldn't paint?

Somewhere in the cracks of Roma  
 the shadow of your pigments  
 runs a river deeper than the Tiber,  
 visible only when strangers, silent  
 until then, make connections stronger  
 than blood throbbing in their hands.  
 Language louder than stone.

DONNA BAUMAN

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## CONTAGIOUS

Joy is happiness  
we express  
with exuberance.  
Joy shows itself  
in our smiles;  
it reaches beyond  
arms' length  
to warm and console  
the hardest hearts.  
Yet, joy is easily lost.  
To keep this from happening,  
share it with someone else.

DONNA BAUMAN

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## IN THE HOUSEHOLD

Unconditional love  
isn't measured,  
priced, or held in account.  
It's given freely;  
from it we can expect  
discipline with purpose,  
rules with reasons,  
and we have the right  
to express a different opinion  
without fear of causing a disturbance.

GARY BLOOM

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## THE BLOOD BRAIN BARRIER

It's difficult to make it across  
the blood/brain barrier, unlike  
the translucent Mexican border, the  
blood/brain barrier is akin  
to the Berlin Wall. I've looked for  
years for ways to traverse  
this fence to the other side  
where my deep depression lies,  
undisturbed and unflinching,  
where nothing can reach it.



# UNEXPECTED TEACHER

LISA M. SMITH

Jonah sits across from me at Canton Chinese restaurant, and I am in awe. I've never seen anyone like him—a formidable yet wholly innocent presence. A large man, he seems imposing, and it's hard to discern what's going on behind the thickest glasses I have ever seen. His left hand clutches a glittering pinwheel, something he is rarely without, a sign of the obsessive-compulsive disorder that rules Jonah's life.

He is also deaf.

He is also autistic.

He holds his free hand up in the air in my direction, wanting a high five, and I raise my hand cautiously, expecting a sound slap as his hand is so much bigger than mine. Instead, his palm grazes mine like a moth's wing, and I grin. He shoots me a thumb's up, a Jonah-style exclamation point. At the same time he flashes a goofy smile and grunts "uh-huh!" Although Jonah is approaching forty, mentally he will always be a child. Such is his grace.

He now signs a simple human need: eat. He doesn't sign it so much as radiate it; food is the sole concern of any moment in which his eyes are open. Though one might think so from the repeated signing of "chicken-rice-red-sauce" and "brown pop," Jonah is not impatient. He just wants to make sure the agenda hasn't changed; following it to the letter is his security blanket, and he will sign and repeat the day's schedule ad nauseam:

"Bus tomorrow? New school?"

"Yes, Jonah. Tomorrow you will ride the bus to school."

"Speech?"

"Yes, speech therapy is tomorrow."

"Doughnut." A solid affirmation is needed on this one. You don't mess with Jonah and doughnuts. For him, little things are enough, and getting a maple bar is pretty dang exciting.

"After speech, we will get a doughnut."

"Bus? New school?"

"Yes, Jonah, yes."

No one knows his routine better than Amanda, who is my younger sister and his teacher. She is sitting across from me next to Jonah. I am in awe of her as well. I am proud of her patience, her ability to sign and read his overall mood, the ease and love with which she pulls him back into our world from the one he sees and giggles at when he looks heavenward.

I am convinced he communes with angels.

Our server comes with her pen and pad. As Jonah looks up and begins to sign his order, she does fairly well at reigning in the befuddlement behind her smile. Amanda watches him closely, verbalizing every sign: "Chicken. Rice. Red. Sauce," and then, "Brown. Pop." She signs kudos back to him—"Good

job, Jonah”—and says to the server, “That would be sweet and sour chicken and a root beer.” I think the server is grateful, at this point, to have something to scribble. I say, “Make it two,” and Amanda says, “Make it three.”

\* \* \*

People with autism spectrum disorders usually have mild-to-significant language, social, and communication delays. For example, they often avoid eye contact, shun physical affection, repeat words or phrases, fail to show interest in activities, and react unpredictably to sounds, smells, or tastes. They may display unusual behaviors, such as spinning in circles or rocking. Learning disabilities are common.

Someone forgot to tell this to Jonah.

With Amanda, he works on writing, signing, vocalizing (hearing aids in both ears help him hear his own voice), counting money, reading, playing games, and making crafts. He makes snacks. He’s game for shopping, watching the fish in the library’s pond, swimming, working out, roller skating, and of course the most ubiquitous activity of them all: eating.

Jonah gets upset once in a while, mainly at changes in his schedule, about which he will fret as if the world is cracking in two. Tolerating this anxiety for only so long, Amanda will eventually issue a gentle “enough” to help calm him, and then sign “Jonah is a good man” until his apprehension subsides.

\* \* \*

Jonah is now eyeball deep in his chicken and rice with red sauce. I

marvel at his vigor. If he had a snow shovel instead of a fork, he couldn’t down that rice any faster. He chuckles once in a while, but this doesn’t slow him down. Amanda and I can hardly keep it together. In an effort to arrest the runaway train, she places the fingertips of one hand on the wrist of the other and draws them back towards her elbow. This is the sign for “slow,” and Jonah knows it well. He acknowledges her by repeating the sign twice in rapid succession and continues to eat as if his food will be beamed away at any second.

Suddenly, fork meets ceramic, and Jonah seems both surprised and a little sad. He peruses my sweet and sour chicken, only about a third gone, and flashes the goofy smile. Amanda’s gets the once-over as well. Ever the teacher, she requires him to sign what he wants, and when she nods in approval, he grabs our plates and scrapes the food into a massive pile on his. Sadness dims his face once more as he signs to himself: “Slow. Slow.”

At this point Amanda socks him squarely in the shoulder. I am stunned by the force of it, but Jonah erupts into giggles and braces for another, which is delivered this time with extra flourish. He is in fits now, and Amanda signs: “See? Jonah is a good man.”

\* \* \*

We are strolling along the river now. Jonah’s pinwheel catches the wind, and he laughs. The three of us plunk down on a bench, and Jonah immediately signs “duck” and “water.”

“Yes,” Amanda says. “There are ducks in the river. Jonah, what do you want to do?”

“Walk? Come and go?”

Amanda signs “yes,” and Jonah stands. He ambles about ten paces, turns and comes back, ambles ten more, turns again. All the while he stares at his pinwheel as it shimmers and spins in the afternoon sun. On the next go around, he stops in front of Amanda and points to SpongeBob on his shirt.

“Shirt,” he signs, followed quickly by “handsome.”

We chuckle and Amanda signs, “Jonah, you’re the best.”

He grins, answers “yes,” and resumes his trek.

Jonah will not go to college or hold his dream job. He will not marry. He will not have children or buy his first car or have his own home—he will do none of the things that bring traditional happiness. I wonder aloud Jonah’s purpose, why he is here? I think for a bit before the answer comes to me: Jonah is a teacher—a humble example of genial grace, living simply, and loving without ostentation.

Jonah shuffles over and plunks down on the bench between us. He grins, socks me in the shoulder, and giggles. I crack up. “Ow, Jonah! That really hurt!” He rubs the spot for a second and then shoves his pinwheel in my face. It’s hard to laugh and blow at the same time, but I manage to make it spin to his satisfaction. ♦

MARIANNE PEEL

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## NOTES TO MY AUTISTIC DAUGHTER

I.            You are three and have not spoken,  
except for *minna minna minna*  
over and over again.

I study sign language  
for *mama* and *thank you* and *please*  
talking to you with my fingertips and words.

Paired like good wine and cheese  
or peanut butter and jelly,  
I invite you to come to this talking table.

II.            In my every-night dreams,  
I brush my fingers under my chin, then under yours.  
You follow my fingers with your eyes

And I see you mouth *thank you*  
soundless communicating  
with language on lips, minus the air to propel the words.

You sign *please*  
and take my hand,  
pulling me into a meadow

of blue-petaled flowers  
and baby's breath  
under a full and vibrating moon.

You sign *dance*  
and climb onto my feet,  
swaying us in the moonlight.

III.            In our awake world,  
I place the dusty contents of a Kool-Aid package  
on your lips and mine.

I am inches from your face,  
licking the Kool-Aid off my lips,  
urging you to engage lips and tongue and teeth.

But your eyes are glassy and far away,  
in a world I cannot see.  
I pry a floor-length mirror off the wall,

plop you in my lap,  
face us toward the mirror  
and lick my lips again,

making cooing, smacking sounds,  
delighting in the gritty sweetness on my lips.  
Your jaw is set and firm.

No amount of *mmmm good*  
will convince you to taste your own lips.  
You are wandering in a faraway place.

And so I hold you  
close against my soft places,  
singing *Minna Minna Minna*

along with you,  
following your lead,  
rocking to the rhythms you compose.

**Shirley Adelman** is a former high school and college teacher. A poetry and prose writer, her story “My Mother’s Eyes” received honorable mention in the Fifth Annual Dora Teitelboim Center for Yiddish Cultural Writing Contest, and was subsequently published by *Jewish Currents* and *Kaleidoscope*. Most recently her poetry appeared in *Canadian Woman Studies*, *Blue Collar Review*, *Nashim: A Journal of Jewish Women’s Studies & Gender Issues* and *Cell2Soul*.

**Deanna Altomara** holds degrees in human health, and English and creative writing. Her chapbook titled *The Happening: Reflections on the Amish Schoolhouse Shooting* was published by the National Federation of State Poetry Societies as part of its Edna Meudt Memorial Prize. Her middle grade fantasy novel, *Pi*, was published in 2015. She hopes her work will promote compassion and acceptance of all people.

**Sarah Bat** earned a B.F.A. degree in creative writing from the Pacific Northwest College of Art. Ehlers-Danlos syndrome influences all aspects of Bat’s life, including the ability to work. Bat identifies as queer and as a writer/artist with a disability. They love cats, deep sea animals, and books. If they were a color, they would be pink. They consider themselves a poet.

**Donna Bauman** has been writing for more than twenty-five years. Her articles and poems have been published in *Purpose Magazine*, *Mature Living*, and *Kaleidoscope*. Married for more than fifty-eight years, Bauman has a son and daughter, four grandsons, and one great-grandson.

**Gary Bloom** resides in Mississippi and earned both a B.S. and an M.S. at Minnesota State University. His articles, photography, and poems have been published in newspapers, magazines, and websites, including *Breath and Shadow*, *Grit*, *Cappers*, and *Collier’s*.

**J. D. Chaney** is a retired teacher, and holds a B.A. and an M.A. in history. He and his wife enjoy world travel, and he also likes to exercise as well as root for his beloved SJSU Spartans. He has won literary awards, including the McMuffin and the Writewell Award, for outstanding fiction.

**Paulina Combaw** is a stand-up comedian and writer in Los Angeles, California. She performs regularly at The Comedy Store, Flappers Burbank, and The Ice House Pasadena. She has been published in *The Washington Post* and *Nashville Scene*. Her biggest fan and inspiration is her brother Cameron, who has Down syndrome.

**Kira Compton** holds a B.F.A. from Emerson College. She was a finalist in the CRAFT Elements Contest, and in the Glimmer Train Family Matters Contest. Her published works include “At the Bar” in *Into the Void*, “The Boozy Muse” in *Creative Nonfiction*, “Let’s Spend the Night Together,” and “Amen, Amen, Amen” in *White Wall Review*.

**Sharon Frame Gay** was affected by observations of the effect of polio in the ‘50s, which influenced the writing of her story for *Kaleidoscope*. Her extensive travels as a child afforded her the opportunity to experience different lifestyles, places, and cultures while shaping her into a writer. Her short stories “The Lighthouse,” “The Actress,” and “Second Sight” won first place in The Writing District Competition.

**Anita G. Gorman** is a freelance writer, a substitute organist, and a retired English professor who holds a Ph.D. from Kent State University. Writing helps Gorman make sense of her lifelong observations of people, and she hopes her stories and essays will help others come to terms with difficulties. Her published work includes “Finding Bill” in *Finding Mr. Right* and “Baba Yaga and Barbara” in the *Scarlet Leaf Review*.

**Lynn Guttman** is an accomplished visual artist. When her fibromyalgia became more intrusive, she retired from her job as a municipal engineering and community development director. She writes poetry to express frustration, isolation, and anger that is tempered by her love for nature and family. Her works have appeared in the literary journals *Parentheses*, *Cleaning Up Glitter*, *Wordgathering*, and *Lifelines*.

**Debra Johanyak, Ph.D.**, is a college writing instructor and author of books and articles who enjoys working with various forms of fiction and nonfiction literature. Currently as editor-in-chief of *Kaleidoscope*, she reviews contributors’ submissions for each issue.

**Jólét** formerly had seizures when young. She loves writing and drawing, and looks forward to sharing her work with *Kaleidoscope* readers.

**Fay L. Loomis** lives in upstate New York. Her short story “Softly and Tenderly” was published in *Watershed Review*, while her poem “Lunar Sight” appeared in *Postcard Poems and Prose* as well as *Celestial Musings: Poems Inspired by the Night Sky*. Her short story “The Opal Necklace” was published in *Peacock Journal*.

**Raymond Luczak**, who is deaf, earned a B.A. from Gallaudet University. He is the author and editor of twenty-two books, including *Flannelwood: A Novel* and *QDA: A Queer Disability Anthology*. Being treated differently as a deaf person has influenced the integration of personal identity in his work.

**James B. Nicola**, a Yale graduate, hails from New York City. More than 1,000 of his poems appear in U.S. literary journals like the *Antioch Review*, *Southwest Review*, and *Atlanta Review*, as well as in several international publications. Nicola has received the Dana Literary Award, two Willow Review awards, and six Pushcart Prize nominations. He serves as facilitator/moderator of the Hell’s Kitchen International Writers’ Roundtable at Manhattan’s Columbus Library.

**Ugonna-Ora Owoh** is studying linguistics in Nigeria. Owah identifies as a queer poet, writer, and linguist who writes about identity, family, history, and love. Published poems include “Belonging” in *Frontier Poetry*, “On Ghetto Street” in *Barren Magazine*, and “Black Boy’s Miracle” in *Crab Fat Magazine*.

**Sandy Palmer** studied graphic design at The University of Akron and is a freelance artist who works with a variety of media. She contributes to *Kaleidoscope* as the writer of visual artist profiles, having joined the staff as art coordinator in 2002. Palmer is the full-time graphic design specialist at United Disability Services.

**Pinalben “Pinky” Patel** is a freelance writer with a degree in print communications. Published work includes the novel *Caste Aside* by Amazon Books. She has Friedreich’s Ataxia, which results in a loss of muscle function. She writes to show everyone that people with physical disabilities are not “imbeciles.”

**Marianne Peel** earned degrees from Michigan State University. Her poem “Notes to My Autistic Daughter” was recently published in an anthology on solo motherhood called *We Got This*. Her poems appear in *Muddy River Poetry Review*, *Belle Rêve Literary Journal*, and *Jelly Bucket Literary Journal*.

**B. E. Pengelly** is currently retired from her work as a wild-life artist. She has written short stories and a book titled *A Little Shiver* that was published by Rusty Wheels Media. Her short story, “How Not to Plan a Murder,” was published by *Pen in Hand Magazine*, and “One of Those Days” was published by *Herald-Mail*.

**Mary Redman** holds degrees from Ball State University. The oldest sibling in her family, she is the mother of a child born with multiple anomalies, a pivotal life experience that has taught her much. She has published poems in *Flying Island*, *Branches Magazine*, *Tipton Poetry Journal*, and *Snapdragon: a Journal of Art and Healing*.

**Joan Seliger Sidney, Ph.D.**, has multiple sclerosis. She works as a writer and teacher. Her work, “Body of Diminishing Motion,” was an Eric Hoffer Legacy Finalist, and *The Way the Past Comes Back* was published by the Kutenai Press. She received fellowships to the Vermont Studio Center from the Christopher Reeve Foundation and the Craig N. Neilsen Foundation as well as two artist grants from the Connecticut Commission on the Arts.

**Julianna Siemssen** earned a B.A. and a B.S. from the University of Washington Tacoma. Her writing goal is to show people things that can’t be explained, only felt. She loves fresh fruit, breathing the night air, and exploring new places. Her poems have been published in *One Person’s Trash*, *The Oddville Press*, and *Breath and Shadow*.

**Clarissa Simmens** holds a B.A. from Temple University and has an autism spectrum disorder. A mixed-race Romani herbalist, she is also a songwriter and a poet hoping words and/or music will heal her soul, and others’. She has published four books: *Chakra Madness & Other Colors*, *Chording the Cards & Other Poems*, *Miniature Worlds Sublime*, and *Blogetressa: Shambolic Poetry*.

**Galen Skye**, a writer and researcher, is hard of hearing and spends a great deal of time trying to explain to others what “hearing” is like to her. Since writing her first poem at age seven, she continues to express her thoughts in few words, believing style to be better than thousands of words. She sees poetry not only as an art of words but also as a way to create emotion with cadence and structure.

**John Smith** is a retired teacher whose poem took third place in the 2019 Smartish Pace Poetry Contest. He writes because, according to his self-styled elegy, he “can’t dance or build a house,” and he makes “poems the way some people trade stocks or dig holes.” His poem “Spillway” appears in the journal *Summer*, and he has also published a book titled *Even That Indigo*.

**Katherine E. Smith** earned degrees in English and disability studies. Her publications include “It’s a Pity and a Sin: Images of Disability, Trauma, and Subverted Power in Disney’s *Beauty and the Beast*” in *Word and Text*, and “Martyr, Mischreant, or a Modern Mama: Exploring the Archetypal and Realistic Images of Mothers of Children with Disabilities” in *Motherhood in Contemporary International Perspective*.

**Lisa M. Smith** earned an M.F.A. in creative writing. Her article titled “A Field Guide to Four-Year-Olds” was published by *Grand Magazine* while her essay titled “Women Hold Up Half the Sky” was published by *The Switchgrass Review*. Her sister’s and daughter’s work with children with special needs has influenced both her life and her work.

**J. J. Steinfeld** writes poems and plays from his Prince Edward Island home. He has published twenty books, including *Identity Dreams and Memory Sounds*; *Madhouses in Heaven*, *Castles in Hell*; and his latest: *Gregor Samsa Was Never in The Beatles*. Nearly 500 short stories and over 1,000 of his poems have appeared in anthologies and periodicals internationally. More than fifty of his one-act plays and a full-length plays have been performed in Canada and the U.S.

**Rosemary Woodel** holds an M.S.Ed. from the University of Miami. Her work has also appeared in *Military History*, *Back Home Magazine*, *Boom Athens Spring*, and *Parentheses International Literary Arts Journal*. Her work has received the Portia Steele Memorial Award for Excellence in Prose and has been juried into many art shows.

**Susan Yanguas** received a B.A. from Cornell University and is a writer, editor, and teacher. Her short stories have appeared in several *Chicken Soup for the Soul* books and in regional magazines. Her debut novel, *Bluff*, earned a B.R.A.G. Medallion from the Book Readers Appreciation Group.



Odessos, *Engine #463*, 1985, acrylic on canvas, 24" x 16"



Odessos, *Petit Pont*, 1996, acrylic on canvas, 9" x 11.5"

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