I AM THE DIPPY BIRD

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My water bottle is covered by the Americans with Disabilities Act. I could legally carry it through a TSA checkpoint, though I would not trust the blue-shirted agents to believe my laminated card.

"I have Sjögren's," I could tell them, without expecting them to know the foreign-sounding word. If they took away my bottle, my mouth would start to blister and my throat would start to stick. Would the agents think my coughing was pretend?

I rarely travel anymore, but when my little family used to navigate the checkpoint, to stimulate saliva I would chew a stick of Trident spearmint gum. I would leave a sip of water in my bottle before setting it in the plastic tub, and in the body scanner I would hold an eyedrop vial in my fist. My child, Indigo, knew to walk ahead of me through the scanner, ready to grab my bottle and pass it to me like a runner's baton, and my husband, Jason, would follow behind to push our luggage through.

I understand my disability is strange. We call something strange when we cannot explain it. It is secretive, too, since four million Americans have Sjögren's, and only a few times has someone heard of it when I have said its name. Many of us are white like me, cisgender female, diagnosed in our forties. Our T cells squawk, "Foreigner! Foreigner!" at our lacrimal and salivary glands, and muster our B cells to swarm and attack them. A rheumatologist told me Sjögren's emerges when genetics and hormones encounter a certain environment, but isn't that the definition of our lives?

Each of us with Sjögren's whips up our own ensemble of symptoms, our immunological self. We might need a sip of water to chew something sticky like rice, or a mouthful of water to eat anything drier than soup. Our eyes might enjoy soothing drops once a week, or burn with grittiness every hour of the day. Arthritis might visit one wrist, or we might not be able to walk. For me, it's like being the Dippy Bird. When I was a child, my next-door neighbor had a mechanical bird with a top hat, a real feather for a tail, and a glass belly filled with red liquid. My neighbor would place a cup of water by the toy and let me push down the red flannel beak. When I lifted my finger, the Dippy Bird bounced up, but that wasn't the part that fascinated me: when the dampness on its beak evaporated, the bird would dip its head again, forever and ever until the water ran out.

I don't know why I am so dry. I don't know what it means.

My mother’s face was often wet when I was young. She had reasons to cry, growing up in a missionary boarding school, then marrying my father. She pretended not to be essentially a single parent, but sadness seeped into her Swedish work ethic: *Det är modet att fortsätta som räknas*. (It is the courage to keep working that counts.) My mother wept while fixing dinner after a long day at work and sobbed while hemming hand-me-down pants for her daughters. By middle school, I hated the dailiness of my mother’s bawling. *Do something about it. Don’t just cry.* I have wondered if wanting to not be my mother is what made my crying evaporate.

As free-flowing as she was with her tears, my mother did not want to see them in me. When I was grown and ran a preschool, and she worked as one of my teachers, more than once she told this story to the parents who clustered at pick-up time: “When Ren was little and got cranky, I would tell her, ‘Go to your room and come back when you have a smile on your face.’ This one,” my mother thumbed toward me, “never made it halfway down the hall. She would turn around with tears on her cheeks, and say, ‘I’m ready.’ This one could make herself happy.”

I don’t remember standing in the hallway, yet I have almost always been able to choose happiness. Maybe I was a four-year-old in love with my mother and I dried up my tears for her. Just as likely, it wasn’t her training, since my sisters were free with their tears. Nature, nurture, or mind-body connection, it was a gift for me. Who wouldn’t want to be happy? It’s not that I didn’t feel sadness; when tears welled up behind my eyes, I marinated in them, before emerging into happiness again. Maybe it was not a loss, my inability to cry. Maybe other people use their tears to keep themselves from feeling. However it happened, I grew to adulthood and rarely let myself cry.

Then, in my thirties, Jason and I had a preemie, and Indigo had back-arching, red-screaming colic for five hours a day. My tears streamed out on those long afternoons. One evening I heard Jason’s key in the lock, so I wiped my face and swooped my infant over my head and under my legs, up and down to calm the screaming. By the time Jason walked into the kitchen, we were wailing baby and mama again.

One morning in those early days of parenting, I heard Indigo crying and I hurried down the hall. Jason had already picked up our newborn, rocking and murmuring. As I moved closer, I heard my husband whisper, “There’s nothing to cry about, puppy.”

I reached out and slid my arms under Indigo, pulled my baby to me, and turned away from my husband. “You can cry if you want to,” I said.

Colic ended many months later, and soon after that, so did my tears. Had I used them all up, carrying my baby up and down the staircase, bouncing, bouncing, staring out the window?

My diagnosis was a fluke. When Indigo was in first grade, we went for a hike up Cougar Mountain, an hour east of Seattle. I scratched my eye on the branch of a tree and the next day the scratch had not healed. I saw an ophthalmologist, who noticed me sipping my water. After treating the scratch, he told me, “Your eyes are very dry. You should see a rheumatologist.” He would not tell me why.

I searched online when I got home: “Very dry eyes, drinks lots of water.” A trail of links led to a black-and-white photo of middle-aged Swedish women who wore dark glasses, carried jugs of water, and had something called Sjögren’s. I skimmed the description and thought, *that sounds awful*. Several weeks and lab tests later, a rheumatologist diagnosed my dry eyes, dry mouth, and arthritis; my balance issues and light sensitivity; the fatigue that I thought was working-mama ordinary.

“You have Sjögren’s Syndrome,” the doctor said without looking at me, as if she were telling the time. I wanted to argue it couldn’t be true, but as quickly as my rage erupted, it disintegrated. My anger is locked up as well as my tears.

"Got it. Thank you," I told the doctor, taking notes while she toppled my life.

Toward the end of our visit, with her back facing me while she wrote a prescription, the rheumatologist said, "Half of my Sjögren's patients use a wheelchair in five years."

I stared at the back of her white coat, breathing, breathing, before asking, "Do you think it will happen to me?"

"You should prepare for it," she said.

"OK. Thank you."

When my sisters and I were young, our mother bought us a four-foot-tall inflatable clown. We punched the clown in the face and it fell to the ground, then it bounced back up since the bottom was weighted. We were supposed to hit the clown instead of each other. I am a bounce-up clown. I decided while on the exam bed, pressed down by the upcoming wheelchair, that however my Sjögren's unfolded I would not let my sadness take over. A Swedish proverb says: God gives every bird a worm, but he does not throw it into the nest. I would look for a way to be happy.

Back home from the rheumatologist's, while preventing my seven-year-old from bringing more caterpillars into our house, I wondered if I would have to close my preschool. I didn't want to walk away from what I had created. That evening I shared my thinking with Jason, rat-a-tat-tat through the symptoms, the diagnosis, the lack of a cure. I mentioned the possible wheelchair.

"If it happens, we'll move to a place that isn't on a hillside. I'll want a snazzy-looking wheelchair, but they're probably expensive, so I can just yarnbomb the wheels."

Jason stayed quiet. He must have thought my temporary eye patch was the thing he had needed to worry about.

"The doctor said the best prevention is moderate exercise," I said. "She told me to walk every day, but dancing with the preschoolers is better than walking. If I keep my preschool going, maybe this Sjögren's will never progress."

Jason listened. He reached out to hold me. He did not tell me what he thought, but I already knew. I tend to believe what I want will come true, while he waits to see the evidence.

My mother had my sisters and me memorize Bible verses when we were young, like this one from the book of Isaiah: "You shall be like a watered garden, and like a spring whose waters do not fail." I no longer believe in my mother's religion, yet I would love to believe in that. I guzzle my water. I soak up my eye drops. I wish I had a natural spring inside me.

I grew up in California, where record-breaking drought has shriveled the rivers and lakes. (In Swedish, the *sjö* in Sjögren refers to a lake.) These days, I hear stories about thirsty land from my friend Theresa, whose family has a ranch in central California. When we met in college, she told me, "We have water."

"Don't we all?" I asked, city slicker.

"We have well water," Theresa said.

When her ancestors bought the ranch, it came with rights to pump down to the Solano Subbasin, an unlimited water supply. Then came over-pumping, protecting the salmon, sales to bottled water companies, and decades of drought. The hydration you think will last forever sometimes can run dry.

For several years, Jason and I have visited a beach house on the peninsula, a ferry ride from Seattle across the Puget Sound. To build their house, the owners cleared land on a hill that dripped with springs; construction triggered a landslide. Now the rivulets are diverted with rock walls and deep-rooted plantings. Water for the house comes from the largest spring at the top of the hill, water forever and ever.

"When the zombies roam the earth, we'll all head to that house," said one of my sisters after a family gathering there. I'd only been thinking about how green everything was on the hill.

Out on the peninsula, loggers found a pair of trees whose branches twined around each other. (In Swedish, the *gren* in Sjögren refers to the branch of a tree.) When loggers cut down the two trees, they found a small boulder the trees had been holding ten feet up in the air. Jason and I are like those trees, but my branches hold Sjögren's directly, and his branches hold onto me.

Jason is used to embracing my strangeness, like the time arthritis seeped through my body. "Your whole body?" Jason asked. I slowly moved each joint and found one elbow did not hurt, so I focused on how good that elbow felt.

Another time my lips swelled out an inch from my face, and Jason had to speed me to the hospital. Hoarse voice, shallow breath, I apologized for my monster face to the nurse who checked me in. The E.R. doctor, hearing I had Sjögren's, told me it was a spontaneous allergic reaction. It could happen again, she said, "At any time, for no apparent reason."

Maybe I created my disease as a test for my husband: do you really love me?

Another symptom developed from the dryness in my nose. I have lost my sense of smell, a useful impairment when one works in a preschool. I can still taste food, but not very well. Jason does most of the cooking; he tells me the ingredients so I know which flavors I will taste. I miss the sensory input and I stockpile other sensations. I turn up the music. I drag my shoes through gravel. I use a peppermint shampoo that tingles so strongly I think I can smell it.

When the national Sjögren's convention was held in Seattle, several speakers said the syndrome might be triggered by environmental toxins, and I remembered the first time my body fought against me. For six months in my twenties, I lived in a town surrounded by farms that sprayed the air above their fields. I developed asthma and arthritis within weeks of moving there. A doctor told me pesticides may have been the catalyst, so I moved away and grew healthy again, except for the occasional need to lie down. Maybe Sjögren's is the languid unfolding of a poison, making me long for wetness.

I learned at the Seattle convention that, while patients can have any ethnicity or gender, my name and appearance may have sped my diagnosis. In 1930, a Swedish woman with arthritis, who sipped water constantly and had painfully dry eyes, consulted the young ophthalmologist Henrik Sjögren. He presented her hodgepodge of symptoms to the leading eye doctors of Stockholm, but they saw nothing special, leaving Henrik on his own. Except he was not: his wife, Maria, was an ophthalmologist, too, and intertwined her research with his. Maria located 19 more patients with the symptoms. Did a stoic heritage infect the women's bodies, or did an inability to cry create Scandinavian culture? The syndrome was named Sjögren's and, although it has been found in people all around the world, some doctors still think it is a Swedish disease. Most Sjögren's patients struggle for years to learn what is wrong with their bodies. The first time I showed a symptom to a doctor, though, after scratching my eye on the Cougar Mountain hike, I was told to see a rheumatologist. Was that a privilege of my Swedish name and yellow hair?

Sjögren's patients don't make enough tears, but for me not even a trickle. I use artificial tears more than 40 times a day. I can rip a vial off a five-pack and unscrew the plastic cap with one arthritic hand. I can squirt in eye drops while driving, both eyes open and watching the road. I know it is ill-mannered to use eye drops when in public, but if I were to leave the room each time my eyes grew scratchy-dry, I would never enjoy a conversation.

When I'm introduced to someone new, I tell them, "I have Sjögren's. My mouth doesn't make saliva and my eyes don't make tears."

"I've never heard of it," the person will almost always say. "What's it called again?"

"It's like *show girls* and *Ren* … Sjögren's." I do jazz hands when I say this. Then I ask if it's OK to put in eye drops.

At the Sjögren's convention, I learned that my lacrimal dysfunction is in the top one percent. The dryness has damaged my eyes, of course: if you snap on a light, I will flinch. Jason sometimes hears me moan with pleasure when I put in my eye drops, but I try not to do that in public.

A panel at the convention debated genetic risks, and on my padded conference chair my elbows dug into my knees, my fingertips into my forehead. Once in a while, Indigo asks me for eyedrops and my chest pinches tightly with fear. I tear off a plastic vial, hand it to my child, and try to sound nonchalant when I ask, "Are your eyes dry?"

"I just have something in my eye, Mom. Don't worry."

I dread that my dryness could flow to my child. Preemie-Indigo needed therapy for delays, and rainbow-Indigo came out as queer in middle school. I know how to be a mama bear. I don't know how to wait.

In Swedish, *ren* as an adjective means pure, clean, and virtuous, as though I were destined to work with young children. My inability to cry does not fit with my profession. Preschool teachers are sensitive to the children, sensitive to the parents, sensitive. When I ran my preschool, parents and teachers were quick with their tears and their anger. I looked poised while they threw their voices at me, but my sadness was on hold. I must wait to feel big things until I am at home, where I have learned how to cry without tears.

One morning, the husband of my best friend from childhood called me at work. Diane had entered hospice a few days before, a thousand miles away.

"She is finally at peace," her husband said.

I felt the grief grow behind my eyes, so I told my staff I needed to leave and called Jason to pick up our child from school. At home, I stripped off my clothes while climbing the stairs to our bathroom. I waited for the shower to warm to the temperature of tears before stepping in, lifting my face, and let the falling water cry for me.

Sometimes a thing is so big I cannot hold it in until I reach the shower, and I let out a drippy-nose, hiccupping, high-pitched wail. When Jason hears me, he runs upstairs from his office and wraps his body around mine until I stop my shaking. He does not ask me questions, but I tell him anyway, word after word until the big thing is small enough for us to hold.

A friend of mine at work said, "You must feel naked without your water bottle," and I laughed to make her feel good, but that's not what it's like. If my clothing fell off of my body, I would feel embarrassed. If I don't have water near me, I feel like I could die.

Yet I have learned that needing too much water seems offensive to some people. Years ago, Marco Rubio gulped water when he gave the State of the Union response. A news anchor snickered, "Can't he finish his speech without guzzling?" At the Sjögren's convention, the meeting rooms had water, but the pitchers and glasses were at the back instead of on our tables. Even the conference organizers did not realize what we needed, and when my water ran out in the middle of someone's talk, I had to snake between the tables to reach the oasis. It felt like a walk of shame.

I never told my preschoolers about my disability, but every year at least one child would sense I needed water. One morning, while reading a picture book, I reached behind me for my bottle but it wasn't there. It was someplace in the room, so I shouldn't have felt afraid, yet one of my preschoolers responded to the change in my voice.

"I'll look for it, Miss Ren," three-year-old Rafe called out. He jumped up from the circle rug and was back with my bottle before my mouth grew dry.

Indigo was like that. My kid grew up with my Sjögren's, before it was diagnosed. Sometimes I would lay on the couch for hours, choosing to not think about the fact that I would go, go, go, and then I would crash. I didn't know I had diagnosable fatigue—aren't all parents tired? Baby Indigo crawled and brought me board books to read, and Toddler Indigo learned to refill my water bottle. When Indigo was seven and I spent a weekend in bed, my kid surprised me and did all the laundry, although the folding was atrocious. Years before, in my pregnancy class, while talking about our parenting goals, I said I wanted my child to be kind. Developing a disability is a handy way to raise an empathetic child.

When Indigo was two, we visited Santa's reindeer at Cougar Mountain Zoo. (In Swedish, *ren* means reindeer when used as a noun.) Jason and I showed our toddler how to let the reindeer nibble pellets we had bought from the dispenser. When the reindeer didn't notice little Indigo, I held onto the fence for balance and lifted my child, who had learned to not swing out too far from my body or I could fall over.

"We're helping Santa," I told Indigo.

By the age of three, my child knew when we went for a walk, we needed to stop when we got to a curb so I could ease myself down to the street. After Indigo grew big enough to help me with my balance, my child never stepped off a sidewalk without reaching back a hand toward me, as though asking for this dance. For Indigo, my Sjögren's is a mother tongue, while for Jason the language was acquired in adulthood. If we are not already holding hands, my husband will step off a curb and walk a few paces, then remember and head back to where I teeter on the edge of the six-inch cliff.

When Indigo started middle school, I expanded my early childhood center. One Saturday morning after moving to a larger facility, I unpacked boxes while a troop of Boy Scouts did volunteer work outside. Unable to leave until the Scouts had finished, by two o'clock I was crawling through the building, dragging the boxes behind me. My bones hurt, and I used my hands like paws since my fingers and wrists were swollen. I knew I should stop and my body did it for me, in the hallway, where I lay for an hour on the laminated floor.

A bigger preschool meant more parents, more employees, more issues to solve. I no longer had time to dance with the children. Every morning when I woke, I lay in bed and felt my body. Was it a pain day? Could I move? Within a year of expanding the preschool, if I tried to walk for half an hour, I spent the rest of the day in bed. My rheumatologist said I should go on disability, but I didn't feel I had the right to leave what I had built; when Sjögren's could have cushioned my life, I stubbornly chose to not use it. I decided if I wasn't going to let myself stop working, at least I would find a way to make my body move. I began leaving work with enough time to walk a few blocks, and within a few months I could stroll for an hour. I didn't leave the preschool for several more years, but I slowly set boundaries, more and more until I finally said goodbye.

Now I take tromps around Seattle, and Jason usually comes with me. We have walked from our home in Capitol Hill two or three miles to the Space Needle, to Pike's Place, to Pioneer Square. If you don't know Seattle, that's mostly downhill. We stroll to restaurants and bars, dog parks and museums.

"Ma'am, you can't bring that in here," an art museum docent said one day, pointing to my water bottle.

I pulled out my laminated card, but it wasn’t enough to allow me in the room. I told the story of my dryness, why I cannot “simply use the water fountain on the second floor,” as the docent had suggested. The docent waved me in.

One afternoon, a few blocks from our home, a woman walking her dog called out to Jason and me. “You’re the hand-holding couple,” she said. “I’ve seen you walk past my house a bunch of times.”

Would our hands have let go if I did not have Sjögren’s?

I see my friends. I volunteer. I visit my mother at her memory care. Each month she slips further into dementia, but her caretakers give her chocolates and hugs. During my visits, I write down her words to send to my sisters. “I love that tree,” she said one time. “It goes all the way up into the blue.” Some things don’t make sense, but we accept them anyway.

My mother remembers her early years, but not the missionary school; she remembers being a mother, but not an unhappy wife. Besides *uff da*, said like a swear word, my mother long ago forgot any Swedish she learned as a child. A Swedish proverb says, *Ögon som inte gråter ser inte.* (Eyes that do not cry, do not see.) My mother has reversed the saying; she no longer remembers, so she no longer cries. Sometimes when I forget something, I think I will get Alzheimer’s, too, and I wonder: if it freed my mother to be happy, will it liberate my tears?

I would not trade my happiness for tears because my Sjögren’s, that foreign-sounding word that has too many meanings, has not been as awful as it could have been. I am grateful I can walk. I am thankful for my eye drops, and for Trident spearmint gum. I am amused that my penchant for happiness found its match in a disease.

But I wish I could cry tears of sadness. I wish I could cry tears of joy: tears for weddings and stomach-shaking humor; for Indigo’s graduation and purple lupine on a hillside; for Ella Fitzgerald singing “Come Rain or Come Shine,” and sappy TV commercials, and a friend’s much-wanted pregnancy; for my husband’s hand on the small of my back.

Ren Cedar Fuller won *Under the Sun*’s 2022 Summer Writing Contest and was a finalist in the 2022 Terry Tempest Williams Prize for Creative Nonfiction. Her essays have appeared or are forthcoming in *Hippocampus*, *North American Review,* and *Under the Sun.* See her essays at *https://rencedarfuller.com.*