JANE BERNSTEIN | SEIZURES

My dog, a little gray schnauzer, was sleeping in the corner of my room the day he had a seizure. He was stretched out on his bed, hind legs jerking spasmodically. Even before foam began to bubble from his mouth, I knew he was not running in his sleep, dreaming of rabbits or pursuers. I also knew there was nothing I could do. He was safe on his cushioned bed. I kneeled beside him and waited for the seizure to end. It was May. The leaves on the trees outside my windows were curled and fresh. A familiar feeling of helplessness washed over me.

The seizure was long—at least five minutes. When he stopped convulsing, he was sweaty and dazed. He did not go to sleep, as my daughter would after a seizure. He stood, unsteadily. When I touched him he jerked away. I waited for him to settle, but he was not the gentle creature he had been before the seizure. I worried he would bite me.

It was a Saturday, late afternoon, and the vet's office had already closed. I got his carrier from storage, thinking he'd be safer and more comfortable during the drive to the emergency veterinary office a half hour away. He liked this fleece-lined bag. Often, after I unzipped the side, he'd step in unassisted, happy to be in his cozy den. Now, though, he was agitated. When I put my hands on him, he turned and bared his teeth. I slipped on leather mittens and a down jacket before I tried again. At last, with some effort, I got him into the carrier.

When I stood, it was as if all the layers had peeled off

me, and what rose was a memory from a hot summer day, thirty-two years before. My daughter Rachel,10-months old, curly-haired and chubby, jerking forward at the waist. One time and then again, exactly as described in the *Merck Manual*: the flexion at her waist. The quick bow. Another. I knew what I saw but could not say aloud the words I'd been reading for months. By the next day, these seizures, infantile spasms, became more frequent, more alarming. Clusters of them, five times a day, then ten, then twenty.

Rachel had been born with an uncommon developmental disorder called Optic Nerve Hypoplasia. When she was first diagnosed at six weeks old, the pediatric neuro-ophthalmologist who'd examined her had said she was blind, and might eventually have light and shadow at best. Though that had been heartbreaking, blindness was something I could understand. It was part of a world I knew, one in which people could read and write, go to school, have interests, find love and work. Though I quickly wearied of friends trying to cheer me up with their blind musician stories—the only examples of success they could find—now I can say that I could imagine a life for my baby, if indeed she would be blind. Two months passed before I learned from a pediatric neurologist that other associated disorders often appeared with optic nerve hypoplasia, among them infantile spasms and intellectual impairment.

I found the description of infantile spasms in the

Merck Manual, a thick tome with a brown leatherette cover, and tissuey pages, like a Bible. "A kind of epilepsy seen in infants." And these words, "brain damage is usually evident."

Every day I sat in my attic office and read that description. Every day, I thought: Please not this. Anything but this.

But all this happened so long ago that I was surprised by the rawness of that memory when it pushed to the surface. I didn't know it still had so much power.

The waiting area in the emergency veterinary office looked the same as the ones in my doctor's and dentist's offices: chairs against the wall, with blue-gray Naugahyde seats, magazines soft at the edges, a yammering TV, mounted on the wall. Only here, a big man in shorts, his legs tattooed, stroked his giant dog's shaved belly. Three women were huddled in a corner, one with a wounded animal bundled in a baby blanket. I unzipped the carrier and Barry hopped on the empty chair beside me. I tried to distract myself with a section of the newspaper I'd stuck in my bag. But I could not read.

After half an hour, we were brought to a frigid exam room, where a cheerful technician in forest green scrubs weighed Barry and asked about his history. Yes, I knew he had a cataract, and sometimes he just stood in the middle of the room, as if stunned to find himself there, but otherwise, at thirteen, he seemed fine. The vet tech took Barry away, and I waited, shivering, until a ponytailed young vet appeared. She ticked off the possible causes for Barry's seizure, like someone who'd just memorized the text. It could be idiopathic, of unknown origin, though that was unusual in a dog his age; possibly his electrolytes were out of balance. A brain tumor or a stroke might be the cause. She suggested leaving him

overnight, so they could do blood work and observe him.

I started out of the exam room, feeling leaden.

"Do you want to say goodbye before you leave?" she asked. I followed her into a pale, silent space, with gurneys and scanners, well lit, high tech as an OR. The only difference were the cages against the wall, empty except for Barry's.

He roused a little when his door was unlatched, and when I walked close, he stood and pushed against me, himself again, the dog I knew. My dog, my companion these last twelve years.

I'd found him on Petfinders.com, a matchmaking site connecting people and animals—Barrington, a 1-year-old miniature schnauzer, with soulful eyes and floppy ears. I called the shelter an hour north of my home in Pittsburgh, and asked about adopting him. They sent me a long form with questions about my house and yard, my experience with dogs, the ages of my children, if any, what other animals I might have. I'd had dogs before and answered with confidence until I got to the final question: What would make me give up the dog? "Unprovoked biting," I wrote.

A few days after I'd submitted the questionnaire, I called the shelter and was told that many people wanted this little dog. Then I regretted my answer and wished I'd written: Nothing. I would never give him up.

It seemed like a lie until I saw him for the first time at the shelter. He had what I thought of as an orphanage cut: in reality, standard for the breed, with a buzz cut body, a shaggy "skirt" and the kind of goatee worn by French impressionist painters.

At home, we shortened his name to "Barry." He was a funny little guy from the start, with no particular awareness of the outside world, with its rodents or birds. He made alarming gremlin noises when we walked up the steps, didn't know how to play, thought it was night if you threw a blanket over him. But he quickly learned to shake his paw before getting a treat and to roll over. His other talents emerged, too. He climbed onto tables to eat pasta or pears, and jumped high enough to snatch loaves of bread off counters. He never licked, but when he saw me after an absence, he grunted and pushed himself against me, grunting, his relief so profound I learned to sit on the floor when I came home so he could butt against me until he was reassured. I would never give him up.

I began taking him to class when I taught, brought him to dinner parties, drifting into what I saw as my current stage in life: older lady with her little dog.

Older lady with her older dog, I guess I should have thought.

That Saturday, I left Barry in his little cage at the vet's. My closed-up car was stifling. I put the empty carrier on the passenger seat and sat with the driver's side door open.

It had been Labor Day weekend when Rachel had been admitted to the hospital with infantile spasms. I had to stay with her and learn to give her shots. Her older sister was about to start kindergarten. I'd so wanted to walk her to school on her first day, and now I couldn't.

The dog, the past, the dog. I drove home, trying to shake the heavy, unsettled feeling.

Early that evening, the first text message from the vet arrived, and my spirits rose. "Barry is resting comfortably in his comfy, cozy bed. PLEASE DO NOT REPLY." A photo was attached of Barry curled on a flowered comforter.

The next morning, the vet called. Barry had another seizure. We should leave him for a second night.

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Twice a day for the next three months I injected Rachel in the belly with drugs that made her miserable. Her face swelled; her body grew rigid. She hummed and cried all her waking hours. Whatever I'd feared no longer mattered. There was only the present. Her immediate care. When I took her to the pediatrician, he hesitated before telling me the circumference of her head had not grown. I registered his discomfort but did not cry. All I wanted was for her to be pain free.

By Thanksgiving, we'd finished the treatment, and slowly Rachel began to get better. At a year and a half, she started to babble. At two, she learned to walk. I snapped a photo of her taking her first steps, wearing white, protective headgear and pink overalls and pushing a walker. She looked so adorable, I made a copy for my mother. When she asked me to take it away, I tried to convince her how great it was that Rachel was on her feet, happy, and determined. Maybe this was when I'd stopped thinking, "if only . . ."

But this was a lull: More than half the babies who have infantile spasms develop other types of seizures. Rachel was among them. The first was a life-threatening *status epilepticus*, the kind of seizure that goes on and on. She'd been in the wading area at the town pool when it started. A neighbor ran for help, and crowds gathered to watch. The lifeguard tried to move them back so a doctor, on her day off, could get through.

She had generalized seizures after that. Then partial complex seizures. We tried many drugs—phenobarbital, Dilantin, Tegretol—searching for one that worked. I carried vials of rectal valium, in case a seizure lasted for more than ten minutes, and we began discussing newer experimental treatments with her neurologist, possible surgery. And then a new drug was approved for children, and she started taking it. The seizures stopped. That was

twenty-five years ago.

In the years after the seizures ended, and the constant anxiety about her well-being lessened, I was busy raising my daughter. Being Rachel's mother was unlike anything I'd imagined. It was hard, steady work trying to integrate my funny, inscrutable, explosive daughter into our family and the outside world, to figure out how she might learn. Every task was a struggle—getting her to dress independently, to eat without assistance, to stop interrupting with her endless fractured chattering, to learn rudimentary safety skills. It was difficult and relentless, until she moved from my house at twenty-two. Yet now I can say that my commitment to her never wavered. From this vantage point, it's easy to say I didn't have time to cry. But it was more than that, of course: she was one of us, a member of her family, irritating, comical, endearing. She was who she was.

That was why I was so shaken by the unlayering that revealed that deep core of grief. It was as if this sadness inside me had its own life, separate from Rachel.

But there it was, as soon as I sat in one of those Naugahyde chairs when I returned to the vet's office on Monday afternoon: all the nights I'd sat with the *Merck Manual*, reading "brain damage is usually evident," silently pleading, *anything but this*. My baby, jerking forward at the waist, arms out, once, twice, ten times, twenty. The pediatrician averting his eyes after measuring the circumference of her head. The seizure at the town pool.

The vet tech escorted me to the exam room to wait for Barry, and the feeling of helplessness returned: the electrical storm rages; the body spasms and flails. Saliva, foam. Seconds into minutes. You kneel and wait until it's done, and then you stroke her brow. Your fervent hope has no meaning. Your love is useless. Nothing. There is nothing you can do.

* * *

I brought Barry home on Monday and started him on the seizure medication the vet prescribed. The semester was over, so it was easy to stay close to him for the first few days, watching as he slept in the corner of my room. The drug he was taking was used by people, too. I read the side effects listed on the vial. Drowsiness was one. He did seem a little dopey at first. Also he had to take care when operating a vehicle or heavy machinery.

A week passed, then two. He seemed like the old dog I'd known before the seizures began, lounging in his dog bed for most of the day, legs drooping onto the floor. Still playful if I roughed him up. I didn't know how much more time I had with him, but for now, the medication was working, and I could relax.

One Thursday toward the end of May, I took Barry with me when I picked up Rachel from her social group. Lately, she had begun to enjoy his company. She liked to hold his leash when we were together, something that was possible now that all of us were older and less peppy. Before I drove her back to the apartment she shares with two roommates, a "community living arrangement" with twenty-four hour staff, we took him for his evening walk.

The air was crisp and cool as we started down a leafy residential street to the woodland park near my house. Though Rachel's vision is far from perfect, it's much better than the neuro-ophthalmologist thought possible. Her mobility skills are excellent, and if she is unsure of the terrain, she will loop her arm through mine, as she did that afternoon, when the sun poked through the tall trees and dappled the broken sidewalk. That's how we walked, her arm through mine, Barry's leash in her free hand.

When we reached a flat trail, I let Barry off the leash.

Rachel ran ahead in her funny, galumphing away, breathless, laughing, shouting his name.

I stopped and thought: This. Just this. A walk in the park on a lovely spring evening. It was so much harder to remember ordinary times, when there is no tumult or disaster. This, I thought. The rustle of young leaves, the deep, rhythmic barking of someone else's dog. My daughter with her unruly black curls and ivory skin, the fashionable glasses she secures tightly with a strap, her thick, orthopedic sneakers that fasten with Velcro, a voice so loud, the deer must have been startled.

I caught up with them in a clearing and clipped the leash to Barry's collar. Rachel took my arm, and the three of us continued on.

Just this, I thought, stroking her soft hand.

Rachel had roommates and a job, swam on a Special Olympics team, went to dances and casinos with her travel group, had a life I'd been unable to imagine, because I had never known anyone like her, lacked the wisdom and experience to see how broad the definition of a good life might be.

I wanted this uneventful time to live deep inside me, too. There was so much heartache in the past, and yet to come. But at this moment, Rachel walked beside me, her arm linked through mine, the dog trotting in front of us.

On this afternoon in the spring of 2016, we are all okay. My old dog is holding steady. For now, this moment, right now.