A Child's Severe Reaction to a Vaccine Alters Life

Something was wrong with Porter

By Sarah Bridges
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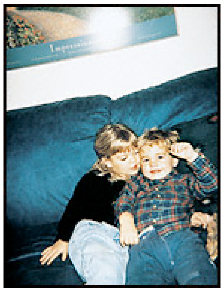
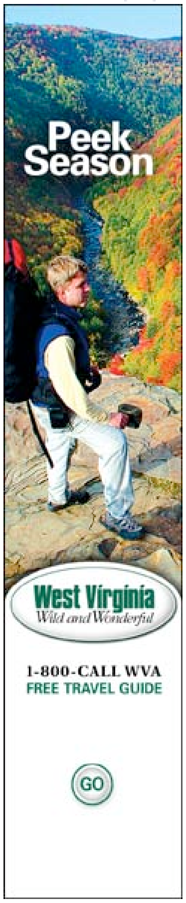


Porter, here at age 2 with big sister Tyler, suffered his first seizure at 4 months. (Photograph Courtesy the Author)

This is the lesson you don't get in the parenting books: Sometimes bad things happen from doing the right thing for your baby.



Porter's high-pitched scream woke us at midnight. When I ran to the nursery and picked him up, his sleeper was damp and his head flopped to the side. My husband grabbed the phone and punched in the number for the pediatrician.

"Hurry," I yelled, even though Brian was dialing as fast as he could. He reached for Porter, then handed me the phone. "It's the nurses' line," he said.

"What's the problem?" a voice on the other end asked calmly.

"Our baby has a fever and is listless. He was fine today," I said. "The doctor said he was perfectly healthy at his well-baby appointment this afternoon."

"Did he get his vaccines?"

"Yes."

"It's probably the shots -- fevers are typical after the DPT."

"But he isn't waking up."

Her voice changed. "Get to the emergency room -- I'll tell them you are on your way."

Brian pulled Porter's 2-year-old sister, Tyler, out of her bed and strapped her, still sleeping, into her car seat. The freeway was empty as we barreled to the hospital, the windows in the car opened for air. Porter lay on my lap with his eyes closed, and my legs felt hot under his body. We turned past the bar with the sign that read, "THE BEST TIME OF YOUR LIFE."

A nurse met us at the emergency room entrance and carried Porter to an examining room. Within minutes of arriving, Porter began a 90-minute grand mal seizure. Watching helplessly, I was pressed against the wall as a doctor jammed a breathing tube down my son's throat. Porter, just 4 months old, lurched on the table while nurses stuck syringes of Valium into his arms.

After a minute, the doctor turned to me and said, "Don't worry, we'll stop it. I'm sure about that. It's just that we may need to sedate him to the point that he'll quit breathing." In that instant, in that one sentence, everything I took for granted vanished.

At first, the doctors thought Porter would be fine. They said it was a bad reaction -- a rare side effect to the pertussis vaccine, which can cause seizures in some children and brain injury in others -- but that brain damage was so rare we shouldn't think much about it. Of course, I couldn't think of anything else but the worst-case scenario. When Porter awoke in one piece, he seemed alert,

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but beyond that we were guessing. The day after his seizure the pediatrician asked, "Does he still do the same things he did before the reaction?" My mind went blank as I struggled to recall what exactly a 4-month-old did.

After 72 hours in the hospital Porter was smiling again, and by the end of the day he was allowed to go home. Porter seemed fine, and I told everyone who asked about him how lucky we were.

And then two weeks later he stopped breathing.

I was home alone getting ready for work and drying my hair as Porter lay beside me on a blanket. When I smiled down at him, Porter's eyes were frozen and his lips were blue. I screamed and put my cheek against his mouth to check if he was breathing. I didn't feel anything. I grabbed the phone and punched in 911, tapping my foot through two slow rings.

"Emergency, can I help you?"

"My baby stopped breathing."

"Tell me what he looks like."

I screamed, "His face is blue!" as I clutched Porter in my arms.

She said loudly, "You need to stop yelling so I can help you." I forced myself to concentrate as she guided me through baby CPR, and I did the two-fingered presses until I heard the rescue truck pull up outside. We lived a block from the station, so the firefighters came first, tromping up the stairs in blue coveralls and boots. A case like a tackle box banged the wall beside me as they circled around Porter and then moved me out of the way. A man dropped to his knees and took over for me until Porter started breathing -- one quick little gasp.

We scrambled into the ambulance and the paramedic tucked a bear onto the stretcher beside Porter, saying, "The church ladies make these." I watched the numbers on the oxygen gauge flash every few seconds -- holding my breath, fixated on the monitor.

Once at the hospital we learned that the original seizure wasn't a fluke but the first in what would become an intractable seizure disorder. This time Porter had stopped breathing, as people sometimes do, in the midst of an intense episode. As they hooked Porter to a breathing monitor we would later take home, a doctor in clogs pulled me aside. I recognized him immediately -- he had treated Porter during his first hospitalization.

"I filed a report with the CDC about Porter's reaction to the pertussis shot. Do you know about the National Vaccine Injury Act?" I shook my head. "It's a program set up by Congress to compensate for the medical needs of children injured by vaccines. I think you might want to look into it." With that he handed me a phone number and turned down the hall to answer a page. I tucked the paper into my pocket, reassuring myself that it wasn't that bad. After all, they said Porter just had epilepsy -- and I knew that could be treated.

Following the second hospitalization, Porter began taking phenobarbital. I cringed at the thought of giving my 5-month-old a barbiturate. The readings I had done on it studying for my PhD in experimental psychology suggested that it could impair a child's intelligence. Porter's neurologist put these fears in perspective when he said, "The New England Journal of Medicine just did a big study of the drug and found that it may lower IQ by five points. I don't think that small a drop is even noticeable." I mixed the crushed pills into jam that night and fed them to Porter.

While I understood that the majority of people with a seizure disorder respond to medication, Porter's seizures continued unabated. By the end of his second year he'd been hospitalized 14 times to stop seizures -- some of which went on for hours. Though Porter received no definitive diagnosis during this time, the early language and behavior problems he was experiencing indicated he might have autism -- something we gradually came to believe was true.

After 12 different medications, two more years and no change in the seizures, I came to stop investing hope in traditional medicine. Reading broadly on the subject of health, I came across the books of Andrew Weil and decided a natural approach to eating might make a difference. One morning I stripped the processed food out of the pantry, bought organic, got a water filter and threw out the microwave. We added vitamins to Porter's diet, scrapped the Froot Loops, stopped eating meat and stocked up on tofu.

The whole family got into the act, and it soon became clear that the new diet was affecting Porter's sister, Tyler -- more than we guessed. One day, while Tyler was eating tofu pups, our babysitter told me, "The minute you went out this morning Tyler pulled me over to the freezer."

"What did she want?"

"She didn't say anything at first, she just opened the door and pointed. After looking around she said, 'Quick, Mom's gone, can we have some bacon?' "

Despite giving up meat for tofu, the change was worth it. The natural diet seemed to be working. For 24 days straight Porter went without a seizure. I gave the doctor weekly updates, and he encouraged me, saying, "I'd love it if you find something that works for Porter. It's obvious I can't figure it out."

But just as quickly, the diet stopped working. The first time Porter had a seizure after we began the diet, I blamed it on something else (he was sick or tired), and carried on as if nothing had happened. But then he had another seizure that night, and it was impossible to deny.

I saw the doctor the next day, and again he raised the medications, saying, "They can always go higher." Giving Porter an extra dose controlled the seizures for several weeks with one drawback: The medication revved him up, and his activity level soon eclipsed the original problem. Additionally, as a good-sized 4-year-old, he was capable of significant destruction. At least beforehand there was time to take a breath after a seizure. Now I dreaded the unstructured time of weekends. One particular Saturday was typical of the way our days were taking shape: By 9 a.m. Porter had microwaved a fork and scribbled on the walls. Then I heard clapping and ran into the bathroom to find that he'd stuffed the toilet with toothbrushes and Kleenex. He giggled and said, "Don't touch knives," as the bowl overflowed.

As I sopped up the water with towels, Porter darted past me and threw kibble around the living room, yelling, "EAT DOG."

We needed to get out of the house, so I loaded the kids into the car to drive to an indoor park while Brian unclogged the toilet. Upon arrival, we piled our coats on a metal bench and lined up for the slide.

At the top of the slide steps, a boy Porter's age asked him, "Do you want to go first or should I?" Porter flapped his hands and jumped up and down. Then he turned around and bolted down the steps, knocking over a toddler.

I set her back on her feet and said, "Slow down, Porter."

He looked at me and answered, "Hi, Porter."

"Right -- slow down."

Porter climbed on the platform behind him, grabbed the fire pole, and jumped. He hung there, stuck, unable to figure out how to slide to the ground, until I lifted him down.

"Don't do that," I told him. A minute later he was dangling on the pole again. We repeated this four more times until I was distracted taking a drink of water. I looked back just in time to see a hearty woman in snow boots falling on her back with Porter on top of her. The only warning she had was when Porter yelled, "Jump!"

"I am sorry," I said, as I pulled the woman to her feet.

She looked dazed. "He's much faster than he looks."

I grabbed our coats and called Tyler to go.

She walked over slowly. "But we just got here."

"I know, but Porter's getting in trouble."

"We never stay at the park."

"Come on -- we need to go."

While unlocking the car, I told Porter to stay by my side, but a moment later he declared, "Home," and headed off across a snowy field. He marched toward a frozen lake and I raced to catch up to him, then led him back to the car and buckled him into the booster seat.

As we made our way out of the parking lot, Tyler asked, "On my birthday can I stay at the park for at least 10 minutes?"

Family life wasn't the only area affected by Porter's behavior. When his day-care providers told us that they could no longer watch him due to his hyperactivity, our social worker recommended a specialist, a professor in my psychology doctoral program and an expert in managing difficult children. He arrived at our house after dinner and sat on the floor to observe our family. Within moments, he laid out his straightforward approach: "Ignoring unwanted behavior is your best weapon."

Porter threw a block and hit him in the back of the head.

"What about tantrums?" I asked.

"Especially tantrums."

"Even in the grocery store?"

"Yes, stay detached -- just pick up any food he throws." I tried to picture doing this. "But, if he does cross the border of appropriateness, you'll need to act."

"What then?"

"You need to save the nuclear weapon for that -- the basket hold." This technique involves pinning your child's arms to his side and carrying him away.

I tried the doctor's advice the very next time we were at the Discovery Zone, when Porter saw a party and ran over to grab a piece of pizza from the birthday boy's hands. The psychologist's advice seemed great until I realized that I'm not good at ignoring screaming. And I'm terrible at tuning out the stares of other parents -- the ones who never carry their children through the produce aisle in a basket hold. Instead, I scooped up Porter, one arm and one leg, and carried him around the kids in the birthday hats and toward the parking lot. Walking past one 5-year-old boy in the group, I heard him ask, "Can I have an airplane ride when he's done?"

Another seizure, another hospitalization. I knew from our last hospital stay that the drugs would make Porter sleep for a day. We watched him anyway until lunchtime, sitting in his ICU room, Tyler stretched out on the floor building a tower out of tongue depressors. When we finally went to the parents' lounge to eat takeout pizza, Tyler skipped ahead of us navigating the way, still in her feety pajamas from the night before.

As we finished our meal, Brian sighed and said, "The screen door at home is ripped -- animals are going to get into the porch."

"We'll fix it later." I said it too loudly, and the family next to us stopped chewing and stared.

"When?" he asked. "We never have time to get anything done."

"It's not even that cold yet."

"I've got over 40 finals to correct -- I'm constantly behind."

"I can't handle thinking about anything right now," I snapped.

"It's not as if everything else in our lives stops." The woman next to us beckoned Tyler over and gave her a fortune cookie.

I heard her say, "Look out, they're stale," as Tyler pulled up a chair at her table.

"Let's talk about it later, Brian."

"You always get so cool and practical," he said.

"And you always sound depressed."

"I've already missed two weeks at work -- I only have two more sick days."

"They'll understand," I said.

"It's not that easy -- you always want to make it sound simple."

"We have to get through this, and then we can figure it out."

We both stood and cleared our plates, leaving our extra napkins under the note about prayer services.

Shortly after this, Brian and I nearly split up. But before giving in we tried marriage counseling and made a commitment to work harder. As we looked forward to what lay ahead, we decided to have another baby. I'd always hoped to have at least three children, and we believed it would be good for Tyler to have a sibling she could truly talk to.

But there was more to it than that. I secretly wanted a chance to make up for what had happened to Porter. I didn't blame myself -- I knew rationally that I hadn't done anything wrong. But on some level, being unable to help him year after year was equally bad. For this reason, I was determined to do everything exactly right for the next baby. It started with my pregnancy diet -- when Brian stopped at the grocery store on the way home from work, I gave him my list: "Spinach, lean meat, fruits, and cheese. NO JUNK FOOD."

Brian glanced at it and said, "What's this?"

"I'm off sugar. And can you get those eggs from the chickens who listen to classical music and run free?"

Our focus continued after our baby, Jackson, arrived. We carried him everywhere, and I nursed him for a full year. The day he turned 5 months old, I watched him as he lay across my lap, smiling. It struck me then: Jackson had brought something good and light to the family.

But it still didn't make up for what had happened to Porter.

Brian took a sabbatical from his teaching job to be home with the baby, though it was Porter who received most of the attention that year. His behavior became increasingly impulsive and required minute-to-minute supervision. And despite more medications, the seizures continued anytime, anywhere.

Soon after, I learned about a magic bullet -- a way to feed your child that kept him seizure-free and off medication. I was introduced to the "ketogenic diet" a month before Porter was 4, when a mother in my seizure support group played a clip from "20/20" profiling a doctor who was using high-fat meals to control epilepsy. This was an about-face. No more Newman's Own Organics -- now the focus was on 90 percent saturated fat entrees.

I called our neurologist the next morning, and he agreed that the diet was worth a try, though he warned us from the start that he didn't have high hopes. But there was one catch to the ketogenic diet: You need to starve the patient for a few days to kick-start the ketosis -- the state in which your body is burning its own fat for fuel. This requires hospitalization as a precaution. We checked into the hospital on a Thursday morning and began watching videos on a wheeled-in VCR. Over and over I answered Porter's pleas for food with, "We'll eat in a little while." After 24 hours Porter became docile, rolling over only occasionally to grab my arm and ask quietly, "Bagel?" By the 48-hour point they began serving 1/3-size meals, and Porter was ecstatic. When the tray arrived and I pulled the cover off to reveal four tiny piles, I was startled. There was a teaspoon of applesauce, a tablespoon of whipping cream, a bite of scrambled egg and a glob of margarine on a saucer. Porter ate it all in seconds, wiping his mouth with the back of his hand and looking for more. We stayed at the hospital for another two days, eating butter and cream and watching for seizures.

Once we got home the excitement over this new approach began to dim as we fed Porter mayonnaise while everyone else ate lasagna and French bread. He was agreeable initially, lying on the living room floor next to a boombox listening to music with his face in his hands. He held a blanket and ran his fingertips over the edges, staring at us as he did it, a hundred miles away.

We held out on Porter's high-fat diet until the first seizure happened nine days later. When several followed, he went back on multiple medications.

Throughout this time we tried testing -- testing his behavior, his coordination, his speech, his urine, his enzymes, his liver, his metabolism and his brain as 5-year-old Porter's other difficulties became more apparent. While other kids his age played T-ball and learned the alphabet, and had long since been toilet-trained, Porter was stalled at the level of a 2-year-old. Most obvious was the strange way he communicated.

When I got Porter ready to leave the house, he would hold a foot out to me and say, "Tie your shoe." More irritating was the way he became locked into phrases -- repeating them over and over like a record skipping.

He'd say, "That's funny. That's funny. That's funny. That's funny."

As I was running one morning with Porter in the baby jogger, he started in, "Stupid head, stupid head, stupid head," in a monotone voice. I tried to ignore it, jogging faster, hoping the runner's high would kick in. But 20 minutes later he was still at it. "Stupid head," I heard from below me.

Finally I'd had enough. I stopped the jogger, got down on one knee, and leaned in close to him. "Stop saying that, Porter, it isn't nice." There was a pause as I stood back up and started running again.

A minute later I heard below me, "Dummy head."

After years of daily seizures, canceled vacations and midnight trips to the hospital, my marriage broke up. Brian moved out, and we began an arrangement of equal-time shared custody of the children.

It was during one of my weeks with the kids that Porter was hit by a car. I'd taken them grocery shopping and had just buckled Porter into his seat. As I turned to load groceries he wriggled out, slipped through my arms and dashed into the street. I called his name, and it seemed to hang in the air, and in the next moment I heard brakes squeal and Porter scream.

An old man's voice yelled, "Oh my God!"

I dropped the groceries and ran around the car, asking the man, "Was he hit?" Porter was crumpled on the street. Cars stopped and people gathered around us as I knelt on the wet pavement holding him in my arms.

A woman bent down and said in my ear, "An ambulance is on its way, hang in there."

"Mama," Porter whimpered. I took off the helmet he now wore to protect his head in the event of a seizure. People pulled blankets out of their cars. Porter clutched his foot and cried. The police arrived first, then the ambulance. An officer stood over us and jotted down information in a tiny notebook. He asked, "How did it happen?"

I answered, "He's autistic and hyperactive."

He closed his pad and said, "It was an accident, then."

The initial examination indicated that his foot was broken, but otherwise he would be all right.

A month after Porter's accident, we summarized all of his medical records as we filed his vaccine injury with the special governmental court in charge of these cases. Despite the interventions, his seizures were intractable and his other disabilities unchanged. Results from his special education testing confirmed what we'd suspected for a long time -- Porter was severely retarded. The government received our petition and immediately conceded. A vaccine injury had caused permanent brain damage. As part of the settlement the government set up a trust to provide for all of Porter's medical needs. In support of the case, Porter's doctors wrote letters sharing what they saw for his future: All three agreed he would never hold a job or live independently.

Here's a part of the story I wish I could leave out: the day I realized that I could no longer take care of Porter alone. The morning I first considered it, I'd called in sick to work because Porter had been up much of the night prowling the house. Shortly before breakfast, he'd had a seizure, which made it impossible for him to go to his special education class. By lunchtime he was back on his feet, and I'd taken Jackson and him to the park before picking up Tyler at school. After a few minutes in the sand, Porter got bored and climbed the jungle gym. As I lifted Jackson out of the baby swing I saw Porter hanging from the top of the slide. His pants had come unbuttoned and hung around his ankles as he swung there grinning in his helmet. A minute later he had a seizure, falling off the platform and landing in the sand below. I ran to him and held him on my lap until the shaking stopped, trying to figure out what to do. I attempted to pick him up, but as a large 5-year-old, he was getting more difficult to carry. He was also in no shape to be moved, so we sat under the slide for 45 minutes waiting for him to wake up.

I looked at my watch and realized I was late to get Tyler -- and had no way to reach the school and tell them what had happened. Jackson whined beside me and pulled on my shirt to be held. I decided we had to go, hoisted Porter over a shoulder, and balanced Jackson on a hip. With stops and starts we made it to the car, only to realize I'd left my purse with the key in it back at the park.

I flagged a woman over and asked if she would go to the playground and find my bag. She stared at us for a moment -- Porter in his diaper passed out on my lap, Jackson on the ground with a blanket over his face -- before nodding and running back to the park. Then I sat on the curb and watched the other families walk to the park in their flip-flops.

A mother turned to her son and said, "Keep up, honey, you always walk so slowly." The boy skipped along, kicking a beach ball ahead of him. I strained to watch them until they disappeared over the hill -- I could still hear him laughing even after he was gone.

A few nights later, I invited our social worker over for dinner to ask her advice.

After an evening with the family, she said, "There is a woman in town that specializes in taking care of autistic children. She's done amazing things with some of the kids and is the best there is. Let me speak with her." What I didn't know at the time was that this woman, Ramona, had recently decided to stop taking new children. Each placement represented a potential 10- to 15-year commitment, and she thought it might be a good time to take a break from such care. But our social worker persisted, and Ramona agreed to meet.

Months later, when I asked Ramona what changed her mind about taking a new child, she said simply, "I met Porter." On the day of our first visit, Ramona greeted me at the door of her three-story Victorian, barefoot, with a warm smile, holding back the two dogs yapping behind her. She invited me in and sat down to talk, not stopping until the sunlight had faded outside.

I visited Ramona again a week later and spent an afternoon with her. As we talked, she told me about another child she cared for.

"He was 5 when he moved in here and never spoke," she said. "The doctors thought he wasn't able to because of abuse he'd suffered. We worked at it for quite a while and I was able to get him to open up." Ramona leaned forward. "What the doctors don't know is how he first started talking."

"How?" I asked.

"I was driving with him and heard a siren behind us, which I pointed to and said, 'Oh look -- there's a police car.' He smiled sweetly and turned to look. As the squad car passed us he stuck his head out the window and yelled, 'Motherf -- ing pigs!' That was my clue that he could talk if he wanted to."

As we spoke, Jacob, who lived with Ramona, walked into the room and snuggled next to her on the couch. "I have had good luck with some of the kids -- you know I helped Jacob get toilet-trained when he was 11. But it's because I'm not his mother that I can do a lot of it. Ignoring a tantrum doesn't rip my heart out."

After Porter and Brian met Ramona, Brian and I agreed that it was best for everyone to have Porter move in with her. But I saw that it wasn't that simple: While I knew in my heart that we were doing the right thing, I had never felt so guilty in my life.

Porter had his first trial overnight three weeks later. Ramona picked him up, and he yelled, "Bye, Mommy," as she led him by the hand to the driveway. I saw his helmet through the back window of the car as she drove off.

I sat on the couch after they left, holding a sweat shirt of his and crying, not moving until my legs were stiff. When the sun was completely down I called Ramona.

"How is he doing?" I asked.

"I know this is hard to hear, Sarah," she said, "but he hasn't asked for you at all. It's not like it would be for one of your other kids being away from home. You have to believe me when I say that it's good he is responding this way."

Porter moved in with Ramona soon after that, visiting us on weekends.

The following summer Ramona and I took Porter and Tyler and Jackson to a rented cabin. After a day of swimming we put Porter in the tub, and I sat on the floor next to Ramona as we gave him his bath. I trickled water on his head and washed his hair while Ramona scrubbed his feet one at a time. Porter clapped his hands as we did it and said, "Hi, Mommy."

In unison, we both said hello back.

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