

Special Report:
Epilepsy Awareness Month

Mom on a Mission

One mother's heroic struggle to understand and treat her daughter's epilepsy

BY SUSAN HAYES

ACCORDING TO the Centers for Disease Control and Prevention, about 1 percent of the U.S. population suffers from epilepsy, a medical condition characterized by seizures. Every year, however, 120,000 children under the age of 18 develop the disorder. To better understand the nature of epilepsy, P&C spoke with Susan Axelrod, chair of CURE: Citizens United for Research in Epilepsy (and wife of David Axelrod, senior advisor to President Obama). Mrs. Axelrod founded CURE in 1998 after numerous treatments proved ineffective with her daughter, Lauren, during her childhood. Lauren is now 29 and has been seizure-free for ten years, but remains developmentally impacted.

PARENT & CHILD: *Epilepsy first came into your life when Lauren was a baby. Can you describe what happened?*

SUSAN AXELROD: She had been remarkably healthy, but one morning when she was 7 months old, I found her limp in her crib, and her skin was a grayish-blue color. I picked her up and she went into a seizure. She stiffened, her eyes rolled back, and there was a lot of saliva collecting around her mouth. I knew something was wrong, but like most people, I had never seen a seizure before. I took her to the emergency room, and Lauren had another seizure while we were there waiting.

P&C: *In basic terms, what is a seizure and what is epilepsy?*

AXELROD: We have nerve cells in our brain called neurons, which give off electrical charges. A seizure is when they misfire. It's like an electrical storm in the brain. Usually, after the second unprovoked seizure, it's called epilepsy.



Unprovoked means the seizure wasn't brought on by some other medical condition such as a high fever. But there are different types of seizures and different types of epilepsy. That's why it's such a complicated issue.

P&C: *Is a seizure always obvious?*

AXELROD: No. Kids especially may have absence (pronounced "ab-sants") seizures, which used to be called petit mal seizures. They don't look so much like body movements. You might just see a child have a blank look or space out. Those kids might get misdiagnosed with ADHD or labeled as kids who don't listen.

P&C: *What kind of doctor treats epilepsy in children?*

AXELROD: Pediatric neurologists and epilepsy specialists called epileptologists. At CURE, we don't give professional advice, but we do suggest getting to a specialized professional as quickly as you can if you think your child might have epilepsy, because seizures may bring on more seizures. Plus, the specialists have experience using newer drugs, some of which have gentler and kinder side effects than the older ones.

P&C: *What do epilepsy medications do, and do they work for everyone?*

AXELROD: The medications that we have now are 

anticonvulsants. They just control the seizures. But despite all these new meds, 30 to 40 percent of people with epilepsy still continue to have seizures.

P&C: What was Lauren's experience and treatment like?

AXELROD: Keppra, which is a drug that was approved when Lauren was 18, turned out to be her magic bullet. Before that, we tried more than 20 different drugs in various combinations, a special diet, and brain stimulation. When she was 15, she underwent a 7-hour neurosurgical procedure to try to identify the part of the brain in which the seizures were occurring. The hope was that if they could identify the area, it could be surgically removed to stop the seizures. But once again we came up empty-handed. It was really the low point.

P&C: How did you deal with the disappointment?

AXELROD: After about 18 years of total despair, I thought, I can either wallow in this or I can look forward for future sufferers. I had met a couple of other moms who also had daughters struggling with epilepsy. One had looked at the National Institutes of Health (NIH) budget and found out how little money was being invested in epilepsy research. But we decided it was not enough to just petition the NIH for more money. We wanted to fund our own research. So we said, "Let's start an international organization!"

P&C: Why call it CURE: Citizens United for Research in Epilepsy?

AXELROD: Nobody was really thinking about curing epilepsy. At the time, the epilepsy community was working hard to advocate for the people who, with some support, could get out and live normal lives. That left out people like my daughter and those who are much worse. The fact that the spectrum is so broad makes it harder, but I've always said that no matter what your degree of impact or disability from epilepsy, it seems like the one thing that should be universally supported is research. It's going to help everybody.

P&C: CURE has raised more than \$15 million for epilepsy research. Can you tell us about some of the work it's funded?

AXELROD: One of our early grants was to a researcher in Italy to study how the inflammatory effect is involved in

epilepsy. It's turned out to be a huge area of interest now. We've funded work to figure out ways to deliver treatment to the focal point of the brain so that you don't have to blast the whole brain with medication. We've also partnered with the Department of Defense to study prevention of epilepsy after brain injury because so many of our veterans are returning home with traumatic injury to the brain.

P&C: Does CURE also work to raise awareness?

AXELROD: Yes. Our original mission statement was all about research, but at our first benefit in 1999, so many people said to us, "We had no idea this was so devastating; we thought it had been cured," and "We thought if you had a seizure it was because you didn't take your meds." So we went back and added the awareness component to our mission statement. It's a significant part of what we do, but not of our budget—we really want the money to go to research.

P&C: Where can families dealing with epilepsy find support?

AXELROD: We like to refer people to epilepsy.com, a website that was started by a man whose child has epilepsy. It's chock full of information and offers online resources. The people who are drawn to CURE want to help raise awareness and money for research.

P&C: Do you have any advice for parents as to how to provide time and attention to the siblings of a child with epilepsy?

AXELROD: Try to spend time exclusively with your unaffected children whenever possible. Caring for a child with epilepsy can take up huge amounts of your time and attention. For a child to always feel like he's second isn't good for his psyche. When I was raising our kids—Lauren and her first brother are only 19 months apart and I had our youngest four years later—I had no qualms about tending to Lauren's needs first, foremost, and all the time. I always felt that the boys would be OK. But I've talked to other parents in similar situations, and we saw some of the negative impact it had on our boys as they got older. **P&C**

To learn more about CURE, visit www.CUREepilepsy.org.

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Lauren Axelrod (with mom) no longer suffers from seizures. She lives and works in a supported residential program in Chicago.