KCNT1 EPILEPSY
FOUNDATION

Honoring Our Founders Five Years Later

How it started: Seth and Susan Greenblott

Seth and Susan Greenblott recall the day their infant daughter Lucy was diagnosed with KCNT1 epilepsy. Amidst their fear and disbelief, a clinician handed them a one-page ‘fact’ sheet about the condition.

“It said there were six kids in the world with this disorder and we shouldn’t expect for her to survive past several months or years. We started researching and discovered the information wasn’t accurate,” Seth says.

“We didn’t want parents to have that experience again. And, we wanted to find a way to improve her life.”

That desire, and advice from a pharmaceutical company CEO on the value of patient advocacy organizations in developing treatments, led Seth to found the KCNT1 Epilepsy Foundation.
“It was important to me that this be abstractly and objectively good. I felt like I owed that to my daughter. I wanted that to be her legacy: that her dad did something meaningful to help her and others.

th
Anniversary
e e e e

"[There's] nothing like your kid's life hanging in the balance to make you learn how to do something, figure something out, and be better than you would otherwise be," Seth says. "Desperation, fear, hope, those things qualified me. Being a business owner is problem solving everyday and that's how I looked at it."

Seth and Susan were soon joined by other KCNT1 parents and family members, and the work began. "We had people come from different perspectives, with different skill sets. What we had in common was we were kind of fearless because we were all in the same trouble," Seth says. "We didn't really have a clear mission in the beginning. Success was having a seat at the table. I wanted to be sure that anytime anyone who could impact this disease was having a conversation, we were in the room. I think we, as a Foundation, have achieved that."

Seth and Susan are proud of all the Foundation has accomplished but cite support for families as their greatest pride. Speaking about the recently launched sibling support group, Susan says: "I think one of the reasons we wanted to start the Foundation after getting Lucy's diagnosis was the lack of information out there for parents...It was very overwhelming. So providing that support and information to parents was super important, and providing support for the whole family.

"KCNT1 affects everyone in the family— extended family and grandparents, and siblings. I am super proud that the Foundation is giving that support to siblings who are young and trying to navigate this diagnosis with their sibling and their parents."

The couple also cites the Foundation's fiscal responsibility as a point of pride. "There are a lot of talented, committed people involved in the Foundation, and we take seriously that most of the dollars are coming from those most impacted by this disease and people who love them," Seth says, mentioning the Foundation has been almost entirely volunteer-led up to this point

“The amount of time and energy that has been dedicated on a volunteer basis is incredible. We try to make sure the money is doing the most good it can. I cannot think of another place you can give a dollar and get $100 of value. It is happening at the Foundation everyday. Your money is being stewarded properly and there is a lot of thought, and deliberation, and sometimes argument, about how to do that best.

“We’ve tried to be a little bit of everything and that’s from necessity,” he adds. “We’ve done a lot of community outreach. Sarah [Drislane] has done a phenomenal job launching and expanding programs, getting programming set up that really strengthens the bonds of the parent-patient community. That’s been really important both for those within the community, but also because having that community connected, organized, and able to share accurate information quickly, is really how we can shave time off progress to treatment.”

And, although the scientific breakthroughs are impressive, and the support and resources provided to families are crucial, it is the people involved that are the Foundation’s greatest strength. “I am really proud to be with a group of people who are doing stuff–like crazy stuff, but crazy stuff because normal rules don’t apply. And, I guess I am really proud that I set that in motion in an abstract way. That was what I wanted to leave as a legacy for Lucy.”

Looking ahead to the next five years, Seth and Susan eagerly anticipate more scientific progress toward treatments and an eventual cure, and increased support for parents and families. “We have a lot of irons in the fire,” Seth says. “We’re sort of on the edge of the next step with several things. I am hopeful one of those will gain traction and we can do what we can do to move it forward. That’s my hope. We have some promising things that have moved forward but not quite where we need to be. I am hopeful one of those will get us over the next hurdle and get help to our kids.

“There are more promising days ahead. The Foundation is not giving up and families should not either.”