

Seizing Life, episode 123
Pursuing Effective Epilepsy Treatment and Running for Research
Guest: Clare Phelps
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.

This week I'm happy to welcome Clare Phelps to the podcast. Clare's daughter, Sophie experienced her first seizure at the age of three. Initially diagnosed with febrile seizures, Sophie's epilepsy quickly escalated in a sudden and explosive onset, requiring numerous trips to the emergency room in a short span of time. Clare is here today to share their difficult and often frustrating journey to diagnosis and treatment, in hopes that other parents and practitioners might avoid the challenges that Sophie and Clare have experienced.

Clare, thank you so much for joining us today. To start, can you tell us a little bit about your daughter, Sophie?

Clare Phelps: Sure. Sophie will be six in October. She is just the sweetest, kindest little girl, full of personality and just a sweet little kid, but she's been through a lot, which I think has informed her personality a little bit, but she's a sweetheart.

Kelly Cervantes: Yeah. So tell us about her epilepsy history and how you came to find this community?

Clare Phelps: Sure. So Sophie was a completely healthy, typical child. No family history of epilepsy. Nobody in my family's ever had a febrile seizure, so it was really nothing that we ever thought about. My husband and I took our first alone vacation away from our kids and we got a phone call from my mom, this is in March of 2021, that she had had a seizure in the setting of a fever. Brought her to the emergency department. It was just thought to be a febrile seizure, but she didn't have any signs of illness. And so that was strange, but a lot of reassurance and we were told, "Not to worry about it. This is normal in children of her age." And so we went on living our life.

Cut to the end of July of 2021. She had a fever at home. I came home from work and she just wasn't acting right and I felt like something was wrong. And I decided to take her to the emergency room, which I felt silly doing that, but I just felt like something was wrong. And I am on Lake Shore Drive in rush hour traffic in Chicago, and I hear this coming from the backseat and I turn around and Sophie has vomited everywhere, having a tonic-clonic seizure in her car seat, is gray, not even white or blue. She just looked gray. Pulled over. I was panicking. I thought I was watching her die, to be frank.

And that kicked everything off. Called 911. It took them a while to get to us because where we were on Lake Shore Drive, it's very congested and it was rush hooured. And so by the time EMS got to us, she was still disoriented, but she was getting back to her baseline. And so by the time they got us to the children's hospital, she was alert, but still wasn't quite right. So told the team at the

Emergency Department that she had had history of febrile seizure, she had a febrile seizure.

And so they sent us to the waiting room, which was shocking to me, but I'm thinking, "We're at what's supposed to be the best children's hospital. This isn't your house, you just need to go with the program." And so we sat in the waiting room for two hours and then she had a second seizure in the waiting room. So ran her back. The only room they had open was their resuscitation bay, and I was very angry.

Kelly Cervantes: Understandably.

Clare Phelps: When Sophie in the beginning had these seizures, she would completely stop breathing and she would need ventilation from a bag mask. And so they're bagging her and they give her Ativan, and that was the start of our journey.

Kelly Cervantes: Just slightly traumatic. I've been there. I've been there on the side of the road waiting for the ambulance. I've been there with the bag. It feels like you're thrown into another universe. It's almost out of body.

Clare Phelps: Right. And with epilepsy, especially with drug resistant epilepsy, it doesn't stop. So she keeps having seizures. So it's like these traumatic experiences happen over and over and over again, and it does wear on you.

Kelly Cervantes: Yeah. And you know they're going to happen, and there's nothing that you can do about it. Sophie has now had two seizures, although they seem to be related to having a fever. What were you told in the hospital at this point?

Clare Phelps: So we were told that now because she had had two seizures in 24 hours in the setting of a fever, that now she had complex febrile seizures, which put her at a different risk category for going on to develop epilepsy. And they watched us overnight. I was told to get an outpatient EEG.

Kelly Cervantes: But they didn't do an EEG in the hospital overnight?

Clare Phelps: No, they didn't. I was very angry in the Emergency Department because this was the beginning of me feeling like I was not being heard by the medical team. I felt like I just watched my child die in our car trying to figure out how do I do chest compressions on a toddler in a car seat? And then you sent us to the waiting room and then she has a seizure in the waiting room. And I just felt like nobody was taking her seriously. So this started a lot of false reassurance and trying to pacify us, while also telling us everything was fine. And I knew everything wasn't fine because I've seen hundreds of people have seizures and I knew that something was wrong.

And so they said, "Oh, you don't need a neurologist. You can follow up with us in follows clinic and get an outpatient EEG." So we got an outpatient EEG. EEG

looks fine, more reassurance, "Hopefully we'll never see you again. Go on and live your life." And then the next day she had more seizures. And this kicked off a fast and furious experience of multiple admissions, multiple meds over the next few months.

Kelly Cervantes: I want to clarify something because you mentioned that you had witnessed hundreds of people have seizures, you are a nurse practitioner.

Clare Phelps: Yes.

Kelly Cervantes: And so you do have medical knowledge, you have this background, you have experience working with medical staff and medical teams, and yet still, this was your experience.

Clare Phelps: I felt like I was failing as a parent because you feel like you have to walk this very delicate line in communication because you don't want to alienate yourself from the care team. You want everybody to be on the same page. You want to be collaborative. You do not want to be adversarial. I was very aware of the label difficult. I did not want to be labeled difficult. But at the same time, time, she was getting very fragmented care, poor follow-up. She got readmitted four times in a month and everybody kept telling me, "Oh, everything's fine, everything's fine. We see so many kids with epilepsy and we know what we're doing." And it's like, "But you can't tell me that this is a typical presentation and that this is the trajectory that a child who's previously healthy and has no family history of epilepsy, they're supposed to go on to get their diagnosis." So it was very, very frustrating.

Brandon: Hi, this is Brandon from CURE Epilepsy. Did you know that 30% of those diagnosed with epilepsy do not respond to current medications? That is why for 25 years, CURE Epilepsy has been committed to inspiring hope and delivering impact by funding patient-focused research to find a cure for epilepsy. Learn more about our mission and our research by visiting cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: So what did it take for you to ultimately get a diagnosis of epilepsy? And was Sophie on any medications at this point? Had anything been prescribed?

Clare Phelps: So after the second hospitalization, the one that happened in mid-August, she had more seizures at home, and then she had a seizure in the Emergency Department that was actually witnessed by a neurologist who happened to be down there to see her. And they observed that perhaps there was some focal features also when she was seizing, because she would put... One of her arms would be straight and one of them would come in. And of course this was a Friday, and so she loaded her with Keppra. And then we were admitted. She had a video EEG. She didn't have any more seizures. And so we were discharged the next day on Keppra.

And then readmitted, maybe it was seven days later. She had had seizures at home again. We had paged the fellow pager. She went to the ER, she got loaded with Keppra. Again, they discharged us home from the ER without neurology even seeing us. And I'm already like, "This is not right. I'm going to call the neurology office in the morning, calling patient relations." And before the neurology office even opened that next morning, she was seizing again. And so get in touch with somebody, back to the ER. She gets admitted. This is the end of August.

They were able to get her an MRI done that day, which I know is not easy. More Keppra. She now at this point is on the highest dose of Keppra for her weight. And it has only been a month. We get an MRI. The MRI was negative, but she at this point on EEG was having interictal discharges. And so we get admitted on a Friday, now it's Saturday, and she didn't have any more seizures, but she's having these discharges. And so the fellow comes to talk to us and says, "She may have epilepsy, but the attending's going to come by later and we'll talk to you a little bit about it." And it's a Saturday in the hospital. I know he's covering the entire hospital, but then the nurse comes in and tells us that they have a discharge order. And I'm like, "Well, nobody's come by and talk to us." And the attending had gone home. And so we had to call him. They had to call him to come back in and talk to us.

And it was a big production because here I am, this is the third time she's been admitted in a month. We get all this reassurance, "Everything is fine." And now she has epilepsy.

Kelly Cervantes: And no one has bothered to tell you what that means or what the next steps are. They're like, "Great, you have epilepsy, go home."

Clare Phelps: No education, nothing. And her seizures were so severe, it was terrifying. And so I'm just like, "What is going on?" You feel like you're living in the twilight zone. So anyway, that was the first time we were told she probably has epilepsy.

Kelly Cervantes: And were you referred at that point to an epileptologist?

Clare Phelps: No. So we were told, "Epilepsy in children of her age," at this point she's almost four, "Is not that uncommon and most kids can be managed by a general neurologist. And then there's the subset of children that are difficult to manage, and those are the children that we refer to epilepsy."

Kelly Cervantes: It makes you wonder and think, and I know it will cross my mind all the time, the amount of pushing and advocacy and research and phone calls that I had to make on behalf, and it sounds like you had certainly and could probably continue to make. What do you do if you don't have English as a first language? What do you do if you don't have a medical background? How do you navigate this? It breaks my heart sometimes to think about the children who don't have

someone with the ability to fight for them the way that a lot of these kids need because epilepsy is so misunderstood and just not well understood.

So you have an epilepsy diagnosis, they tell you you don't need an epileptologist yet. You quickly find out that you do indeed need an epileptologist. You finally get in to see said epileptologist, and what happens then? What are you told?

Clare Phelps: We were brought back into the hospital and we met an epileptologist and it was like the heavens were behind her. She was so great. I felt like once we got to see an epileptologist, at least we were being taken seriously. And she felt that Sophie had both focal and generalized features. So Sophie's epilepsy or her seizures start in one area of her brain and then they quickly spread. So started her on a focal agent and another generalized agent while she was still on the cover. So started her on Onfi and Trileptal, and then she continued to have seizures in the hospital, even while we were starting her on that. And so she got loaded with Fosphenytoin, which quieted her down, but nobody really had any answers in terms of the etiology of her epilepsy. We were told this was very unusual. They at this point did get an Invitae panel.

Kelly Cervantes: Which is a genetic panel.

Clare Phelps: Yes. So that just showed... They call them variance of unknown significance. So we did that, unfortunately continued to have seizures. We get readmitted two or three more times, and at this point I in the background am looking for an epileptologist at a different center to get a second opinion. And the medical team is telling me that this is very unusual and that we should also get a second opinion because at this point, it's early September and she's on three anti-epileptic medications and still having seizures.

Kelly Cervantes: So you get a second opinion, and are you told anything different there? And I understand you didn't stop there. You might've gotten third and fourth opinions as well.

Clare Phelps: Yes.

Kelly Cervantes: Which I fully support and highly recommend.

Clare Phelps: Yes. So we find a new epileptologist, and we end up switching centers to be with Dr. Marcucilli, who's our epileptologist now, who has been wonderful. He's like, "Let's try a different drug." He's like, "I've got tricks up my sleeve. We're going to try to figure this out." He really took control of the situation.

Unfortunately, one of the medications that we tried led her to develop pancreatitis. So she came off of that in January and then we went out of state for third and fourth opinions.

Kelly Cervantes: I think most people think that you take one pill for epilepsy and then it's controlled, but one-third will have intractable epilepsy, meaning it can never be controlled. And then as you are going down the line of these medications, just how serious these drugs can be and what drug may be lifesaving for one person will have these horrible ramifications for another. You mentioned Onfi earlier. Adelaide, my daughter had a horrible reaction to Onfi. You cannot always predict reactions. These are heavy, heavy duty drugs that we are giving to small children, and we have to because there's no other option.

Clare Phelps: Right.

Kelly Cervantes: But it's wild and it's scary, and sometimes the drugs are worse than the seizures themselves, but you have to try them. So what additional information did you get from these third and fourth opinions?

Clare Phelps: So when we went for our third opinion, I guess, at this time, most of her procedures were coming from the left side of her brain. And so I was really optimistic that she would be a surgical candidate for a resection or an ablation since they were focal and then they would generalize. And so the center that we saw for the third opinion said, "Let's just see another EEG, and then we'll take it from there." And so we get the EEG, we go to Mayo, they do a whole two-week outpatient EEG, and then you do the EMU stay. And her seizures had switched sides.

So now she's having seizures from the right side of her brain, which was devastating because that ruled her out as a surgical candidate because not to sound grotesque, but you cannot resect or ablate that much of a child's brain. So now it's multifocal epilepsy with secondary generalization, and that really changed the trajectory of her treatment plan.

Kelly Cervantes: So what is Sophie's life like today? You have this... I call them an insurance diagnosis. You have a name for her type of epilepsy, but it is not telling you why these seizures are happening. She's on medication. Do you have better seizure control? How is she doing developmentally?

Clare Phelps: We are lucky in that after starting one of, I don't know, the 10 medications we've tried, one of them did make it so that her seizures were only nocturnal. So she only has seizures at night or if she takes a nap during the day, which is still not great because she's still having seizures, but it at least has improved her quality of life. We still have to watch her very closely, but it allows her to have perhaps a little bit more independence.

She has really struggled because of her epilepsy. It's caused a lot of damage. So this was a child that had... typical child, knew how to do everything and has motor dysfunction, fine motor dysfunction. She has a really difficult time communicating. She has a pretty bad stutter. She has cognitive delays as a result of all of the seizures that she's had and the medication. And so it's hard. It's a

struggle every day. And frankly, she's miserable many days because the medications are really hard on her or she's had seizures and she doesn't feel well. She still has probably five to 12 seizures a week.

Kelly Cervantes: Which is a lot. One seizure a week, a year is too many in my opinion. So Clare, I wonder, what is Sophie's understanding of her epilepsy? How have you explained to her what is going on in her brain?

Clare Phelps: She understands that she has epilepsy. She understands that it's made her go to the hospital or have a new diet, be on keto, have to take medications, but she loses consciousness when she has seizures. So I don't think she fully understands what's happening. And I have tried to get every developmentally appropriate book about epilepsy to explain it to her, but she doesn't want to talk about it because I think it has such a negative connotation to her because it's caused her to have a lot of discomfort and have to do things she doesn't want to do.

I will say when she got her VNS, the rep brought her a teddy bear that had a little generator in it, and once she got that and she was like, "Oh, my epilepsy button, I have an epilepsy button." And then she was like, "Oh, I got a teddy bear for my epilepsy. I have epilepsy," which is the first time I've ever heard her say, "I have epilepsy." But she was like, "Oh, I have epilepsy." I'm like, "Yeah, you have epilepsy and it's okay, and we're going to take care of you and you can still do all the things you want to do, but this is just part of your life." And so it's hard to tell what she can really understand, but we're slowly, I think, getting there. We're slowly getting her maybe to talk about it a little bit more.

Kelly Cervantes: Are there any resources or organizations out there that have helped Sophie or helped you or other family members along the way?

Clare Phelps: What has helped Sophie I think has been school. So she's in school. She has an IEP. She has a one-to-one aide. She gets a lot of support in school, but I think just allowing her to have as much interaction with her peers as possible and allowing her to have joy and joyful experiences, I think has been the best for her.

For us, honestly, CURE Epilepsy has been one of the organizations that has helped me the most. I'm not even saying this because I'm on the podcast, but in the beginning I would watch all of the podcasts because I didn't know anybody that had a sick child, anybody that had had epilepsy or seizures or had to deal with any of this. And so that was isolating and being able to hear on demand stories of parents that have gone through similar issues with the medical system or just how terrifying it is having a child with epilepsy, that was really helpful.

And then connecting with other moms. I didn't even know there was this huge community of epilepsy moms out there, but finding other moms, even from across the country with kids that have drug resistant epilepsy has been tremendously therapeutic.

Kelly Cervantes: There is a really, really strong and supportive community out there for anyone who is looking for it. There are some amazing, amazing parents who are cheerleading for each other and doing some amazing things to support one another. I know that you ran the 2022 Chicago Marathon for CURE Epilepsy, which is mind-blowing to me. I'm not a runner. I can't even fathom doing that. How did that come about? What was that experience like for you?

Clare Phelps: So I had run the Chicago Marathon twice in my 20s, long time ago, and running has always been very grounding for me, and I was really struggling when I decided to run. It's hard having small kids to begin with, but then having two small kids in, one of them has drug resistant epilepsy. And everything we went through, it was therapeutic for me to run, number one. And it gave me dedicated alone time. I knew every week I had to hit my long runs, and so that was dedicated me time. I knew I had to do that.

And then I felt so helpless because nothing I was doing or trying to do was working for her. And so I thought, "Well, if I can't cure her epilepsy or help her medically, at least I can raise awareness and I can hopefully raise some money for an organization that is trying to push the bar forward with research."

Kelly Cervantes: Yeah, I feel like I'm talking to me five years ago, six years ago. Everything that you're saying is so spot on. What advice do you have for parents who are coming up across a new epilepsy diagnosis?

Clare Phelps: Yeah, I would say number one, get a second opinion. You are not married to the first center that you go to, and then you have to find, especially if your child has difficult to control epilepsy, you need to find an epileptologist that is going to be there with you in the dirt, on those really bad days when your kid is unstable and it's going to hang by your side and not give up. That is number one.

And then the other thing, I actually heard this on another podcast. I was at pediatric palliative care physician and he said, "I wish parents had more confidence." And that really struck me because there were so many moments, whether it be starting her on medication or keto or making the decision to do the VNS or another hospital stay where I just felt like, "I can't do this. There's no way I'm going to be able to do this. She can't do this." I just felt like we couldn't handle it or, "How am I going to get through this?" And then you do it and you do get through it.

And it doesn't mean that it's easy and it doesn't mean that you're going to do it without help, but have the confidence that you are going to be able to get through those really hard times and make those difficult decisions with your child, and that your child's going to be able to do it too together. Even though it's hard and it's not all fun over here, you can do it and you can get through it.

Kelly Cervantes: I love that so much. Have the confidence. I think that is such amazing advice because you can and you will, and we do it all for our loved ones. And it's

amazing what you can push yourself through when the end goal is ideally better quality of life or answers or whatever the goal is. Given the incredibly difficult and frustrating journey that you had to get your diagnosis and within the medical system, I wonder what do you wish clinicians knew about epilepsy and to help the patients and caregivers along the way?

Clare Phelps:

I think when you work in a hospital every day or you go to clinic and you work in healthcare, it feels almost monotonous to you and it feels mundane. And what is monotonous and mundane to you could be somebody's worst day of their life or is turning their life upside down. And I think recognizing the severity of what your patients are going through and that not everybody fits into a box, right? There's that old saying, when you hear footsteps think horses not zebras, but sometimes the zebras are out there and you can't just treat every patient with this blanket treatment.

You have to really listen and partner with parents and take the time to understand what's happening and maybe delve a little bit deeper and think really what's going on here? And I think having that respect for their situation and the want to form a partnership with them and collaborate is just really so crucial.

Kelly Cervantes:

Absolutely. Clare, thank you so very much for sharing your family, Sophie's story with us today. It means so much and I know that hearing your story is going to help so many other families out there just to know that they are not alone in this, and to learn from your experience and your drive and your passion to fight for Sophie and to have that confidence that you can do this. Clare, thank you. Appreciate you so much and wishing you and your family the absolute best.

Clare Phelps:

Thanks so much for having me. I appreciate it.

Kelly Cervantes:

Thank you, Clare, for sharing your daughter's story and for supporting epilepsy research by becoming a CURE champion. CURE Epilepsy was started 25 years ago by mothers like Clare, who were frustrated with the status quo of epilepsy care. Our goal is to find cures by funding the most promising science out there. Every day researchers are working to help patients with drug-resistant epilepsy get control of their seizures. If you would like to help us achieve our goal of a world without epilepsy, please visit cureepilepsy.org/donate. CURE Epilepsy, inspiring hope and delivering Impact. Thank you.

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