

Seizing Life, episode 64
A Mother's Determination: Advocating for Your Child's Epilepsy Care
Guest: Elissa Moore
(Transcript)

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
- Kelly Cervantes: 00:17 Today, I'm happy to welcome Elissa Moore to the podcast. Elissa is an attorney at McGuireWoods and lives in Charlotte, North Carolina, with her husband and four children. When her son, Cormac, was diagnosed with epilepsy at age nine, it began a long and often frustrating journey through the medical system, a journey that she says opened her eyes to the need for better understanding of epilepsy across the healthcare system. Elissa is here today to talk about the struggles she encountered trying to get care for Cormac and share what she has learned in hopes that it will help other parents, caregivers, and patients as they navigate their own epilepsy journeys.
- Kelly Cervantes: 00:56 Elissa, thank you so much for joining us today. I want you to tell me about your son, Cormac, and how epilepsy first entered your lives and how he was diagnosed.
- Elissa Moore: 01:08 Thank you, Kelly, for having me and giving me the opportunity to tell Cormac's story. Cormac is my second of four children. He's red hair, blue eyes, all spitfire, very active, into sports, very physical. He was nine on the date of his first seizure, and up until that point, we really had no indication, or no warning, or anything that something like this would happen.
- Elissa Moore: 01:42 It was April 17th of 2019, and it was my oldest son's birthday, and so we were trying to kind of have a celebratory feel in the house. And I went to wake Cormac up at 6:40, which is normal, and sent him downstairs and tidied up upstairs. And all of a sudden, I heard a very loud noise, almost like a shout, and then followed... I heard my husband screaming for me, and I raced down, and there was Cormac, just on the kitchen floor in the middle of this very violent, what I now know as a tonic-clonic seizure, and it just wasn't stopping. I mean, I pretty much instantly called EMS.
- Elissa Moore: 02:26 Obviously, you're kind of racing, your mind is going through, what could this be? And I eliminated everything I could think of, like, he's not choking, this couldn't be a heart attack, but he's not conscious, he's turning blue. I mean, it was just, as probably many of us now know, I mean, it's just so terrifying. And I'm lucky, it was a stone's throw from the fire station, and also, the hospitals. They were there within four minutes, and the seizure itself was about five, and they came and did his vitals like,

"Everything looks good. He looks like he had a seizure, I guess. Let's put him in the ambulance and we'll go to the hospital."

- Elissa Moore: 03:06 And I went with him, obviously, in the ambulance, and got there and was kind of expecting that we would be admitted. I didn't really know what to expect, but I certainly didn't expect that, within the hour, we would be discharged and walking out. The [crosstalk 00:03:25]-
- Kelly Cervantes: 03:25 Within the hour?
- Elissa Moore: 03:26 Within the hour. I mean, the physician said, "Anyone can have a seizure. This is hopefully a fluke. His vitals look great. He passed all of our little neurological tests, so just head on home and call the pediatric neurologist and try to get in within the next week." That was really disturbing. I didn't understand. I, literally an hour before, saw him on the floor and thought he was... I mean, I thought he was dying and I didn't know.
- Elissa Moore: 03:56 So we walked out and Cormac had this massive headache. I mean, he was throwing up. I called pediatric neurology as soon as I got home, and they said, "Okay, we'll see you in about six weeks." I said, "That's just unacceptable." I said, "That is completely unacceptable. We need to be seen earlier." There was no option, no alternative. So I just started working my networks and my friends, then I was fortunate that one of my friends connected me with a pediatric neurologist who saw me later that day, kind of did the same thing. I don't know what else she could have done, but she said, "Oh, he looks good, and his neurological signs are strong and fine, so hopefully, it's a fluke." Unfortunately, it was not, and we're almost two years into this journey.
- Kelly Cervantes: 04:39 What did it take to get the epilepsy diagnosis?
- Elissa Moore: 04:43 One week later, literally to the minute, it was 6:50 in the morning, the exact same thing happened. He was down for five minutes, I called EMS. They did come promptly. And this time, we went to the other hospital's ER, and they did an EEG in the ER, and a resident popped in after the test and was like, "Hey, he has an abnormal EEG. He is diagnosed with epilepsy and here's a prescription for Keppra."
- Elissa Moore: 05:11 And I was like, "Well, I mean, wait a minute, what do you mean? What does this mean?" And he said, "Well, it just means his brain electro pattern is off, and this is not entirely atypical, and Keppra is successful with 80% of patients." It was just so

cavalier and so flippant that I just really thought, "Well, this is obviously something that happens and I guess, once again, I shouldn't be too concerned, and this drug works for 80% of the people, so I'm sure that will be fine."

- Kelly Cervantes: 05:45 I'd love to know where he got that statistic from. For the record, one third of patients diagnosed with epilepsy don't respond to treatment, so this idea that 80% of seizures respond to Keppra is just ludicrous to me.
- Kelly Cervantes: 06:00 So you get an epilepsy diagnosis off the cuff, this prescription for Keppra, and you're sent home. How did he respond to the medication?
- Elissa Moore: 06:13 Really not well. I do remember that I-
- Kelly Cervantes: 06:16 Which is unusual with Keppra. I mean, it works wonders for some people, and for others, there's major behavioral side effects.
- Elissa Moore: 06:22 You're exactly right. I mean, we experienced an unreal change in his behavior and no corresponding change to the seizures. I mean, the seizures continued. We had one massive seizure per week and Keppra did not touch that. But I saw this little guy who... I mean, if before, he might have said, "I'm going to throw this shoe at you," now it was like, "I'm throwing the shoe at you, and by the way, I'm going to go get a baseball bat, and I'm going to break the chair and I'm going to throw..." His behavior went from what I could defend as maybe typical nine-year-old boy anger to, okay, we've got a serious problem here, and he's dangerous.
- Kelly Cervantes: 07:12 And you have three other children in the house.
- Elissa Moore: 07:14 Absolutely. And I mean, I felt like we had to protect ourselves from him. It was just really sad. It was like a band-aid was ripped off his brain or something and all the inhibitions that he had worked hard in his life to kind of create were gone.
- Kelly Cervantes: 07:28 And throughout this, you don't have a pediatric neurologist to consult?
- Elissa Moore: 07:34 Not really. I mean, once they said, after that second ER visit, we needed to have a pediatric neurologist, I did connect then with the person that had seen us as a favor on that first day, and she became our treating neurologist. But by his, maybe, fourth seizure, she referred us up to an epileptologist, but I was

shocked that he would have these big seizures. And I would call, and I was still new to it, and I mean, I think you're probably... No matter how new to it you are, these are always upsetting and you're always feeling confused of, what should I do? And you just want to talk to a medical provider.

- Elissa Moore: 08:15 I was shocked that it was literally like, "Well, just up the dose." And I couldn't believe that, when you have an infant and the infant has a situation, that pediatricians have you come in, so it was just a different... I guess it could be the difference in having a chronic condition versus an otherwise healthy child that maybe has an ear infection. But I was desperate for somebody to see him, either after he had a seizure so they could say, "Okay, maybe Keppra isn't right. Maybe we shouldn't just keep upping the dose." So once we got that referral to the epileptologist, I felt a little bit better.
- Kelly Cervantes: 08:52 I also want to highlight something that you mentioned, that I don't think... I certainly didn't know. I learned as we were going through the motions that not every neurologist is an epileptologist. Every epileptologist is a neurologist, but there is a major difference there between someone who specializes in seizures, who can read an EEG, who understands triggers and the pharmacology of it, versus someone who treats headaches and other neurological conditions.
- Elissa Moore: 09:27 Completely. And our epileptologist, and I don't know for sure if it's all of the epileptologists, but our health system has them in a small town, about 30 minutes away from Charlotte, so we started traveling up there.
- Elissa Moore: 09:41 We were admitted to the EMU, and this physician, to her credit, instantly said, "We need to order a genetic test," because I'm here the whole time. I don't understand, why haven't we done an MRI? I mean, should we do a CT? Have we done blood work? Have we truly uncovered every stone? We're at five to six major, five-minute-long, tonic-clonic seizures. Why do I have zero answers still, and why isn't anyone taking this with a sense of urgency? I realize it's not your child, but I mean, we had a completely neurotypical child up until April 17th of 2019. And it's like, ah, no big deal. And I'm not a stranger to the healthcare system. I come from a family of physicians. I feel very comfortable in health care, and here I was, completely unable to push the ball forward to get answers.
- Brandon: 10:36 Hi, this is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over \$78 million to fund more than 260 epilepsy research projects in 16 countries around the world.

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- Elissa Moore: 10:57 We were with an epileptologist at a level four unit. The doctor ordered this genetic test and said, "Okay, Keppra is not working. We'll move over to Depakote," and by the end of that stay, had also added ethosuximide, with her theory being that he was having absence seizures that were leading to these tonic-clonic seizures. And at this point, if the first seizure was April, we are now end of June. And she was happy to report that the genetic test had come back and he had an SCN1A mutation, which is the mutation that is most commonly referred to... that you can have Dravet syndrome. And she was happy to see this because she was on the right track with treating his seizures with Depakote. We did not, unfortunately, see any change in the severity of the seizures.
- Kelly Cervantes: 11:53 And this is the epileptologist. This isn't a geneticist or a genetic counselor, this is-
- Elissa Moore: 11:57 No. And again, I was handed the genetic report and told we were on the right track. And I started doing the Facebook online groups, which have been really, really helpful, and really informative. So July 1st, my son threw up and wasn't quite himself. And we chalked it up to hundred degree heat here in Charlotte. But that was the start of this 15-day period of decline where he would have some different seizures. He had tonic-clonic seizures. Long story short, in that 15 days, I called the physician's office nine times and I went to the ER four times because he had stopped eating, he was sensitive to light, he couldn't stand the smell of anything, he couldn't eat, he hated to drink, he couldn't watch TV, he couldn't do anything. He laid on a couch.
- Elissa Moore: 12:53 And I knew that his medicine had gone toxic. I don't know if that's really the right phrase, but something, neurologically, was very wrong and I could not get through. I mean, I just couldn't get through to that physician's office, and I'd go to the ER, and his blood levels were always fine, his liver enzymes were great, he could pass neurological tests, but I just knew something was wrong. So I called my dad, and my dad's an academic physician at Wake Forest. I mean, we have a great relationship, but I hadn't wanted to really lean on him or put him in a position with his colleagues that was awkward. But he also saw Cormac and felt that he had to do something, he had to rip him out of Charlotte.

- Elissa Moore: 13:41 And so, we went up to Wake Forest and were admitted into their EMU in the middle of July. And we were admitted, the electrodes were put on, and within three hours, the team came in and said, "Look, he has encephalopathy. He's basically got brainwaves the speed of a two-year-old right now, and we really need to get him off of Depakote, and this could be a difficult time here." But they put him onto Onfi as they were taking that Depakote off, and so we were lucky that we didn't see any seizures during this time. And within about three days, his appetite came back, and he perked up, and he was back to normal. So I will forever be grateful to Wake Forest for getting us the help we needed, because nobody else was listening.
- Kelly Cervantes: 14:38 Well, and credit to you for continuing to fight and for trusting your instinct. So Wake Forest becomes your new place of care, but it's over an hour away, right, so how do you manage emergencies in the meantime?
- Elissa Moore: 14:56 Right, that was one of my questions to them when we got discharged. I said that exact question, "What do I do if we have an emergency situation in Charlotte?" And they just said, "You call EMS, you go to the local hospital and ask to be transferred." I felt pretty good about that. I thought that was a pretty good plan. So I was not expecting though, that we would challenge that plan the day after we got home. So we'd been gone for nine days, had just got back, and Cormac had a massive seizure. And so, we were at the ER that very next day, and I said, "I'd like to be transferred to Wake Forest," and they said, "No, I don't think so."
- Elissa Moore: 15:41 And I didn't really push it. I mean, it's not legal for them to deny that request, but I didn't push it because I do have three other children and my life here, and I was trying to keep things somewhat together. So I said, "I need you to be in communication with the Wake Forest doctor," and you would have thought I had asked them to communicate with somebody across Antarctica. I mean, it was like, "Ugh," and it was very difficult. And we needed a rescue medication in the ER, and they said, "Okay, let's put him on this one." It was an IV. And I said, "Can you please call Wake for us? Can you please make sure it's okay?"
- Elissa Moore: 16:18 And they finally got ahold of the doctor. It was late at night, and the doctor said, "Yes." I just had this feeling that there's something missing, there's some piece of information I don't have. And so, I kept saying, "Who do you give this rescue med to? If there's anyone that has seizures that won't stop, it's okay? Do you give it to kids?" Yes, they give it to kids. And I'm trying to

think like, "What is it here that I need to know?" I said, "Wait, do you give it to kids or people who have a sodium channel mutation?" And they said, "No, we don't," and I said, "Then take it out."

- Elissa Moore: 16:50 And it made me realize then and there that, as much as I adore my Wake Forest doctor, when you're calling him at 10:00 at night from an emergency situation, he doesn't have the file in front of him. You are your kid's advocate. You absolutely have to speak up. I respect the nurses and the physicians, and I don't want to undermine them, but I also am best prepared at that moment with the information about my kid, and I have got to push the button.
- Kelly Cervantes: 17:18 It's a difficult concept. I mean, it took me months, if not a year, to really come to terms with, I know my daughter best. Even though I don't have MD after my name, I have earned a PhD in my daughter. So Elissa, what were the ramifications? How did it affect Cormac's academic, behavioral, psychological, because during all... he's gone through months now of seizures and pharmaceutical side effects. How did that affect him?
- Elissa Moore: 17:55 We started school in August in a very unstable situation. He is a complete fighter. He is the most determined, hardworking kid that I know. And he struggled. He was kind of your average student in third grade. And in fourth grade, which we were starting, he could barely hang on. And we were very fortunate that our school allowed our nanny to sit with him in the classroom. And she was just that extra set of eyes, again, a luxury that I know so many people don't have and something I want to change because it's terrifying to send your kid into the world, knowing that, without warning, he could collapse and injure himself. So we had the full-time nanny/aid sitting with him, we had tutors, we had all types of support for him to succeed in that environment. But academically, it was really challenging.
- Elissa Moore: 18:59 Psychologically, it was a disaster. He was in a talk therapy or a play therapy with no real impact. He was an amazing therapy kid. The therapists would say, "Oh, he's so fantastic. He's got all this down," and then take him out of therapy even for a minute, and it was back to this, I call it, and I don't know the real term, disassociated behavior. I mean, he was just angry, raging. It tended to have a little bit of a pattern, so I could anticipate that, every night at seven o'clock, we would have to have a two-hour battle.

Elissa Moore: 19:36 And because it was so clockwork like that, I did, at one point, think it was medicine-related. Doctors weren't really sold on that because if they had... He was admitted, at one point, back to the EMU to see if it could be a side effect of the medication, but nothing showed up, and also, that behavior went away in the hospital. So it was one of the struggles, was finding somewhere where we could get the seizures treated, but also kind of the full picture of like, we need psychiatric help and I need somebody to help me with this because I cannot figure out where to go.

Kelly Cervantes: 20:13 Where did you find help?

Elissa Moore: 20:14 So again, I just reached out to my connections and was so very fortunate to get into Mayo Clinic almost right before the pandemic. And it was just an incredible experience because it was the comprehensive, integrated approach that I had been desperately fighting for from the start. So we had consults with the epileptologist and with the nutritionist, with the genetic counselor, with psychiatry, we had the full workups of blood work, we had two EEGs and an inpatient stay. They checked the box on everything.

Elissa Moore: 20:52 And also, I would say on the psychiatric side, I had been feeling that he was ADHD. I mean, his ability to attend to any task in school was basically none. And they did give him an ADHD diagnosis, which was helpful then, in treating that and bringing some ability... helping him focus.

Kelly Cervantes: 21:15 Well, and it helps with your IEPs for school and helps get additional therapies through the state. It's amazing an ADHD or an autism diagnosis can open a lot of doors for epilepsy patients, and just how common those comorbidities are. I mean, everything that you are describing, the ADHD, the emotional side effects, these are all very well known, very well documented comorbidities. How is Cormac's health, and how are his seizures?

Elissa Moore: 21:47 Well, so when remote learning began in March, I was somewhat optimistic that we would see a reprieve, but what I actually saw, and I think it was important, that he was actually having seizures every nine to 11 days. And they weren't full on tonic-clonic. They are still trying to figure out exactly what they are. But it just necessitated another inpatient stay at the end of this past summer, where we removed Vimpat and put Zonisamide, added that to his regime. And after a couple of tough weeks, I'm very happy to report we're in what they describe at Mayo as a

honeymoon period. So he has not had a seizure since the end of September.

- Elissa Moore: 22:31 I live every day, grateful for that. I don't put too much stock in it. I just am like, "Okay, it's another day," but it is amazing. The psychiatric episodes have decreased dramatically. I don't see a pattern anymore of a 7:00 PM meltdown. He still is a little obstinate sometime, and defiant, but I think it's a little more typical behavior for a now 11-year-old. And in school, he is hanging in there. I mean, speed processing is a problem, and memory is an issue, both of which I think are impacted by his drugs. But the other problem is speech fluency, and one of the side effects of Zonisamide, they told me, would be speech issues. And he has a stutter, but he is really great. He just doesn't think about it, doesn't worry about it, and I will take that over the seizures that we were seeing. So I really feel like he's back for the moment, more himself, academically and psychologically.
- Kelly Cervantes: 23:37 Well, that is amazing news, and so happy to hear that. And we'll all keep crossing fingers and toes that it stays that way and this honeymoon period extends.
- Kelly Cervantes: 23:47 What advice do you have to other parents who are on this journey, or who are just beginning?
- Elissa Moore: 23:55 I mean, I think to the extent that people are comfortable talking about that, using your connections, your social network, getting the message out there, like, this is not acceptable, it's really not acceptable, because I think the more you're willing to share with people, people are so gracious. I learned so much by just opening myself to literally every person that I could meet.
- Elissa Moore: 24:21 Cormac's story is nuts in a lot of ways. It was this explosive onset of an intractable generalized primary epilepsy, and just even typing those words into a computer, I got a lot of support groups that popped up. So that was really helpful. And I think the third thing would just... Read as much as you can. And I realize it's really hard to do all of these things, depending on where you live or what your situation is, but I think there are so many wonderful people out there who are willing to help. The more that you put yourself out there, the more you'll find.
- Kelly Cervantes: 24:59 Absolutely. That is all incredible, incredible advice. And I just appreciate, so much, you sharing your journey with us to let other parents know that it's okay to have the fight and that that's what it takes. And we wish you and Cormac and the rest

of your family so many well-wishes and seizure-free days in the future, and just thank you so much for being with us today.

- Elissa Moore: 25:32 Thank you.
- Kelly Cervantes: 25:33 Thank you, Elissa, for sharing your experiences and advice for others in the epilepsy community. As your story demonstrates, the journey to effective treatment of seizures can be long and challenging. In recent years, new drugs have offered relief to some patients, but too many others are unable to attain seizure freedom.
- Kelly Cervantes: 25:52 More than one third of all epilepsy patients do not respond to traditional epilepsy treatments and therapies. The best hope for these patients lies in epilepsy research that will lead us to better therapies, and ultimately, to cures. That is why CURE Epilepsy is dedicated to funding epilepsy research. We hope you will continue to fund the research that promises so much to so many by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
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