

Seizing Life, episode 81
The Best of Seizing Life 2021
Guests: Elissa Moore, Lauren Panco, and Jon Sadler
(Transcript)

Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy. This week on Seizing Life, we revisit several of the compelling conversations from the past year and our best of Seizing Life 2021 compilation episode. Elissa Moore spoke with us about her son Cormac's long and difficult treatment journey following his epilepsy diagnosis at the age of nine. 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: 00:49 Really not well, I do remember the night-

Kelly Cervantes: 00:51 Which is unusual with Keppra. I mean, it works wonders for some people and for others there's major behavioral side effects.

Elissa Moore: 00:58 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, if before he might have said, I'm going to throw this shoe at you. Now. It was like, I'm throwing this 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: 01:47 And you have three other children in the house.

Elissa Moore: 01:49 Absolutely. And I mean, I felt like we had to protect ourselves from him. It was just really sad. It was like a bandaid 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: 02:03 And throughout this, you don't have a pediatric neurologist to consult.

Elissa Moore: 02:09 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.

- Elissa Moore: 02:47 And you just want to talk to a medical provider. I was shocked that it was literally, well, just up the dose. And I couldn't believe that when you have an infant and the infant has a situation, the 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 just keep upping the dose." So once we got that referral to the epileptologist, I felt a little bit better.
- Kelly Cervantes: 03:27 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.
- Elissa Moore: 04:00 Completely.
- Kelly Cervantes: 04:00 And other neurological conditions.
- Elissa Moore: 04:02 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 chronic 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, "Oh, no big deal." I'm not a stranger to the healthcare system. I come from a family of physicians. I feel very comfortable in healthcare. And here I was completely unable to push the ball forward, to get answers.
- Elissa Moore: 04:55 We were with an epileptologist at a level four units, the doctor ordered this genetic test and said, "Okay, Keppra's 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 chronic 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. And again, I was handed the genetic report and told we were on the right track.

Elissa Moore: 05:56 And I started doing with 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 like the a hundred degree heat here in Charlotte. But that was the start of kind of this 15 day period of decline where he would have some different seizures. He had tonic chronic 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 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.

Elissa Moore: 06:56 I mean, I just couldn't get through that physician's office and I'd go to the ER, 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. And I've close with... 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 Cormick and felt that he had to do something. He had to rip him out of Charlotte. And so we went up to Wake Forest and were admitted into their EMU in July at 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."

Elissa Moore: 07:48 He's basically that 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, 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.

Brandon: 08:32 Hi, this is Brandon from CURE Epilepsy. Did you know that one in 26 Americans will develop epilepsy in their lifetime. For more

than 20 years, CURE Epilepsy has funded cutting edge patient focused research. Learn more about our mission to end epilepsy at cureepilepsy.org. Now back to Seizing Life.

- Kelly Cervantes: 08:52 We spoke with Lauren Panco about managing epilepsy while balancing work demands and an active social life.
- Lauren Panco: 08:58 Every seizure that I have had and unfortunately I've had more than two. I don't remember what has led up to them. I don't have auras afterwards. I don't remember. I have that brain fog just like I experienced in that first one. And so being able to go back to say, "Okay, in the past 24 hours, let me write down what I was feeling. Had I had any alcohol? Did I have any sleep patterns that were off? Was I having a stressful day at work?" And I can tell you the biggest pattern that I've seen that I believe in my personal triggers are lack of sleep. So sleep deprivation, that hyperventilation, that that comes about, and then stress as well.
- Kelly Cervantes: 09:38 You talk about stress and sleep deprivation. And I feel like these are two, just very blatant facts that come with adulthood and working professionally. They're just sort of difficult to evade. How has epilepsy did your professional and personal life specifically in the workplace?
- Lauren Panco: 10:01 Yeah, the workplace piece is tough, but I will tell you, I was very open with my HR representative, with my boss and with a couple of colleagues, I was very specific about the colleagues that I chose to open up about this diagnosis. And that truly has made all the difference. But I will tell you, there's also been times where I've been fearful of, "Okay, is this going to set me back in my career goals and aspirations? Am I not going to get that next promotion? Is someone going to take away projects from me because maybe it's too stressful and I'm working a couple of extra hours during the week?"
- Lauren Panco: 10:37 Those are fears that I have, but I've also been open and honest and saying with those colleagues in HR and my boss, please give me the benefit of the doubt. Please trust me, and that I can do my job. And so there are times where I may have to shut off a little early, but I pop back on later at night when I'm feeling better. So it's sort of this give and take. And I've really had to learn about my body and the work that I do with my profession to be able to say, "Okay, here's what I can and cannot accomplish within a given day and a given week." But it's that open and honest communication that I think is extremely important that's led me to where I am now in my career.

- Kelly Cervantes: 11:17 I love hearing about a work environment that has been supportive of your epilepsy, because I think so often we hear the horror stories. And so I really want to highlight this and find out what specifically has your employer done? Or how have they responded? In what ways, are there accommodations that you have requested that have helped you? What does this ideal work environment look like so that we can educate other bosses and other employers to emulate that experience?
- Lauren Panco: 11:55 Yeah, that's a great question. And I'll tell you a couple of quick stories. So the first one is when I came up... When I left the hospital in 2016 after my initial diagnosis, it happened on a Saturday and I called my HR rep just to say, "Hey, they're keeping me overnight. I'm not going to be at work on Monday, but I'll be there on Tuesday." I was being super optimistic about what my recovery would look like. And so when I got into the office, she was very careful about just watching me to make sure that I was okay, that I was healing correctly. Not only had I had a seizure, but now I'm on new medication that is literally affecting your brain. And so she wanted to know how was Lauren recovering? So she came with me to a couple of meetings.
- Lauren Panco: 12:39 She was there just to watch and not being intruder, but just to make sure I was okay, and that was so calming. But also what she said to me is at about 11:00 AM on that Tuesday that I returned, she said, "Lauren, you do not look well. I need to take you home." And so she immediately helped me pack up my bags and she drove me home. And so that ability for someone to recognize in an employee, you are not doing well, and I need to stand up for you if you're not going to yourself. Because I was never going to be the one that says, "I need to go home." She did that for me and I will forever or be grateful for that. The next thing that happened is, I shared with you that I lost my license for about six months.
- Lauren Panco: 13:20 And so what that meant is I was leaning on my fiance, his family to drive me to and from work, but they had to do that around their own schedules. So I was coming to work early. I was leaving late because I was trying to accommodate them instead of being a burden. And so what ended up happening is I was saying hello with my breakfast and saying goodnight with my dinner to everyone at work. And they were like, "Lauren, you're supposed to be careful about the hours that you're working and the time you're putting in, because this is so hard on your body right now. What can we do to help?" And they blatantly asked for that and I said, "One of the things that I would love your help with is maybe looking at a regular Uber or lift service. I'll

pay for it. But I just need your help and support in saying at nine o'clock, I'm going to come in and at four o'clock every day, I'm going to leave, help me set those boundaries."

Lauren Panco: 14:10 And they did an amazing job with that. And in fact I will say they actually went above and beyond and getting me a car service every single day.

Kelly Cervantes: 14:18 That's really incredible. Now, have you had the experience of having a seizure at work and if so, how was that received?

Lauren Panco: 14:27 Yeah, so that, that actually has happened. It happened about three years ago. We, as an organization get together, it's a lovely experience at the beginning of every year to plan for the upcoming calendar year. There's about a 150 of us that gather in Princeton, New Jersey, where our corporate headquarters are. And we're there together for about three days to train in a room together and on the very last day. And I think that this was a result of me being stressed in preparation for the meeting and tired from all of the events that happen at this sort of kickoff meeting.

Lauren Panco: 15:04 I had a seizure in my chair and I fell over onto one of my colleagues. And she called out for our chief medical officer who happened to be in the room. Our CEO cleared the room with all of the other a hundred individuals. But I will tell you what better way to wake up from a seizure than to see your chief medical officer who was a prior attending surgeon, being the one to look at you and say, "We're going to get you help. We're going to get you to the hospital." However, at the same time though, having a seizure, a grand mal seizure in front of a hundred of your colleagues is extremely embarrassing. And a lot of them at that point had no idea that I had epilepsy because it's not like I walk around with a purple badge that says, "I'm proud of who I am." But it is a hidden diagnosis at the same time.

Kelly Cervantes: 15:58 Absolutely. So, Lauren, how is your epilepsy managed now? Are your seizures under control? Is there medications or diet or different things that you've found that have worked better for you?

Lauren Panco: 16:13 Absolutely. So after I saw the initial neurologist after my first seizure, I knew that that was not a neurologist I needed to continue with. So I did go and look for a second opinion, which I would encourage many individuals who are initially diagnosed to go and do.

- Kelly Cervantes: 16:31 I would even go as far as to say is even if you like the first neurologist you see to still go and get a second opinion, just because there are so many unknowns, I'm so sorry. I will let you continue. But I just, I think that is such, such an important point to make.
- Lauren Panco: 16:46 Thank you. So, I did go get that second opinion and I am so glad that I did because the bed manner was completely different. My care was completely different from that point on. And so we looked at things like diet and exercise and mindfulness. And I do follow a new diet now. So I'm gluten free. I am dairy free when I can be, but I will tell you, I enjoy some Ben and Jerry's every now and then. But one of the most amazing things that, that neurologist who I still see to this day told me is that we are not going to let epilepsy define who you are in your life. And it was such a profound statement that it's almost like the billboard of, what's in the mirror of staring at me every single day to say, I can manage this.
- Lauren Panco: 17:35 There are some things that in my life are different now. So I am on Keppra. I'm on medicine every single day. I have to watch my social life. And some of the alcohol intake that I have, the things that I eat, how late I stay up at night. So there are some differences, but I will tell you making those differences also makes me feel healthier. So all of it together is sort of this package of this new Lauren, but I don't look at it in a bad way. It's, these are great changes that I've had to make. And I do feel healthier every single day when I wake up.
- Kelly Cervantes: 18:11 John Sadler spoke with us about undergoing brain surgery after living with epilepsy for more than 40 years. And how this experience led him to a new calling as a counselor, to fellow epilepsy patients and their families. In your forties, you decided to undergo brain surgery. It's a big decision to undergo as an adult. I mean, it's a big decision to do regardless, but I think especially as an adult when you're established,
- Jon Sadler: 18:43 Well, not only established, but I had two sons. I was married, had two boys. They actually helped me make that decision. They didn't want me to have the surgery, but there were times like my oldest at the age of two recognized my seizures. Some of his first words were, "Oh, daddy." When I clapped my hands trying to kill a fly because that was... And my partial seizures, I would do this. And that's some of his first words. So that was kind of like, whoa. And then another time when he was older, he was about 13, I was driving him back from a scout camp and had a seizure while driving. And when I came out of the seizure, I was so happy I had my foot on the brake. And then as my

peripheral vision came back, I realized it wasn't my foot, it was his.

- Kelly Cervantes: 19:37 Oh my gosh.
- Jon Sadler: 19:38 And had we gone another a hundred feet, we would've plowed into some trees and stuff at the end of the road. And he had no seatbelt on. So, I was like, "Wow, I really have to take care." I mean, I was taking care of myself as best I could. My neurologist worked with me. They helped me out. Some new medications were coming along and out of a breakthrough seizure. They put me on Dilantin plus another medication. And finally the doctor said, "We're out of medications." And my doctor finally said, "You need to go to John's Hopkins." So I went over to John's Hopkins and my internal medicine doctor had me have an MRI of my head. And first day I walked in and showed it to the doctor there. And Dr. Krauss looked at it said, "There's the location. We know where your seizures are coming from."
- Kelly Cervantes: 20:32 That must have been a bittersweet moment because here you know that you are eligible for surgery, but that also means, oh my gosh, you're eligible for surgery-
- Jon Sadler: 20:42 Surgery. Right. So, he gave me a whole list of ways we could treat it and got it more medications and all that. And I was like, no, let's head towards surgery. So the big question then was what was the surgery going to do to me? And they said, "Look, it's so much damage in that part of your brain, we don't think you need to worry about it."
- Jon Sadler: 21:03 So I had the surgery done and the day after Dr. Krauss came into my room and he said, "Jon, what's a hundred minus seven?" And I looked at him and I said, "What's a hundred?" Here. I'm an engineer. Okay. So I'm like, finally I said, this number just appeared in my mind. I said 92. And he said, I said, "No, no, no, that's not right." And it took me a little while I got to 93 and then he goes minus seven. I'm like, "I have no idea." My memory was still there. But having taken out the hippocampus on the left side, that was my that's like the RAM in a computer. That was the RAM, the access, the information, in the front of my head. My mind now had to track a whole new way to get there.
- Kelly Cervantes: 21:54 So the information was still there. You just had to find the new road to get there.
- Jon Sadler: 21:57 That's it.

Kelly Cervantes: 21:58 So how long did that take for you to recover those lost abilities?

Jon Sadler: 22:06 A total of nine years.

Kelly Cervantes: 22:09 Wow.

Jon Sadler: 22:10 Fortunately, where I worked, they had a big evaluation that had to be done on a project and that revolved all the numbers and everything. And they said, "Jon, we don't care how long it takes you if you go to it." What would've taken somebody three weeks to meet three months. But the more I was doing it, the more I was learning, the more I was rewiring my mind, my brain. The biggest thing that happened to me though, is I started meeting other people with epilepsy. And initially it was kind of a little one on one thing. And people hear about what I'd been through and they came and got in touch with me. But what really inspired me, it was about four years after the surgery was a fellow that I met through work who had a son, a four year old son who had a lot of the same surgery and medications I've been on with intractable seizures.

Jon Sadler: 23:03 And he looked at me and after I sat there and he tells me his son has epilepsy. And it was a over a minute. We sat on the phone before I told him that I did too. Because I was in this argument with myself. "Should I tell them? No I shouldn't. Yes, I can't." And when I did, I didn't realize how much hope I inspired in that person. And back in my college days, I was going to university of Rhode Island and saw the word hope on this state seal. That's what pulled me through all of that. And then being able to turn around and give hope to somebody else that my whole world just flipped over. I no longer had to be quiet and silent about my seizures.

Kelly Cervantes: 23:43 Which has to have been so liberating and sort of very easily lead me into my next question here, which is, I understand that during this recovery process, you also decided that you were going to get a master's degree in counseling, which just seems like the most daunting thing while you're in recovery, while you have this job, while you have a young family. But it sounds you were inspired to sort of move in this other direction. Tell us about that.

Jon Sadler: 24:17 Well, I'd just mention the talking to this person with a child with epilepsy and he got back to me many times thanking me. And then he'd tell me things about his son had a seizure at a swimming pool and I said, "Sunglasses might help because of the reflection of the light in the pool probably triggered the seizures." I didn't realize how much I knew with then could

share with other people. So my counselor said to me, he said, "Jon, you really ought to consider become a pastoral counselor." And I was like, "What's that?" And anyway, I looked into it, it seemed to fit me really well. So I applied to Loyola university and I wasn't sure whether I'd get in or not, but to make a long story short, I got in. My first class was in humanities.

Jon Sadler: 25:02 The professor was an older gentleman. I failed the first exam because my memory issues and he had these fill in the blank questions. And I could give you the first letter to the answer, but I couldn't spell out the rest of the word. And another fellow student made sure I told the professor everything that was going on. And he immediately, he said, "Well, we're not going to count that exam. What do we need to do?"

Jon Sadler: 25:29 And I said, "Don't give me a multiple choice of A, B, C, D. Give me a whole list of words. You can put 20, 30, 40 words on there and I'll find them and I'll know the answer. I'll recognize it." So what he did was he, for everybody in the next exam, he had nine to 10 words to fill in the blanks. And some of them were very similar, but I got, I mean, I managed to get a B on the exam. What really got me though was, what inspired this man to help me so much. And it wasn't until the very last class that he shared with everybody about how his mother had epilepsy and how it inspired him to become a pastoral counselor.

Kelly Cervantes: 26:18 We would like to thank all of our incredible guests on Seizing Life during the past year. Their willingness to share their epilepsy experiences, insights, challenges, hopes, and expertise are what make our show possible. Thank you also to our listeners, we hope that our podcast has provided you with information recommendations and a sense of community during this past year. And we hope you will consider supporting CURE Epilepsy efforts to fund research by visiting cureepilepsy.org/donate. We greatly appreciate your support and generosity, and we wish you all a happy and healthy 2022. Through research, there is hope. Thank you.

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consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.