

***Seizing Life®*, episode 114**
From LGS to Surgery to Just Being a Kid: A Mother Shares Her Son's Epilepsy Journey
Guest: Colleen Jendreas
(Transcript)

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

Today on Seizing Life, I'm happy to welcome Colleen Jendreas to the podcast. Colleen's youngest son, Owen, experienced his first seizure at five months old. This began a journey that saw Owen's seizures change and progress into infantile spasms and ultimately tonic seizures resulting in a diagnosis of Lennox-Gastaut syndrome or LGS when he was three and a half years old. Colleen is here today to share Owen's journey with us, discuss how two particular interventions have made a significant difference in his quality of life, and offer some insights and advice for other parents of children with epilepsy.

Colleen, thank you so much for joining us today. I am so psyched to be able to talk to you. You are one of my oldest Instagram mom epilepsy friends that I made so early in the journey, and so I'm really excited to learn from you and to share your and your family's story. So with all that said, can you tell us about your son, Owen, and how epilepsy first entered your lives?

Colleen Jendreas: Yeah, absolutely. Thanks for that intro, Kelly. Always fun to chat with you. I know we go way back. So really honored to be here and love chatting about my favorite topic, my special guy. So let's see. Owen, he's five years old. He's my third kiddo. He is the light of my life, and when he was five months old, he started having seizures. So that is where our epilepsy journey began with him.

Kelly Cervantes: And I understand that seizures didn't just gradually roll into your life. It was a little more sudden and explosive, if you might say.

Colleen Jendreas: Yes, you hit the nail on the head with that. Owen actually experienced something called explosive onset epilepsy, and it is literally as terrifying as it sounds. So when he was five months old, he started having focal seizures one night. I spotted them pretty immediately and they just were one after another, about one every half hour, one every hour. And I feel really blessed because I recognized it immediately and I made my way down to our local children's hospital, which is CHOC Hospital that stands for Children's Hospital, Orange County. And again, so lucky that CHOC has a level four EMU. So EMU stands for Epilepsy Monitoring Unit.

Kelly Cervantes: And what does that mean, a level four EMU for those who may not be familiar with that terminology?

Colleen Jendreas: Sure. Well, I mean, I had to learn it too. A level four EMU, what makes it so special is that it's a comprehensive epilepsy center. So they're not just going to do epilepsy treatment. They've got a lot of advanced diagnostics, and then they've also got the epileptologists on staff. So those are neurologists with special training in the treatment of epilepsy. They're going to have things like

video monitoring, EEGs, they're going to have all the imaging technologies, things like MRIs, PET scans, MEG scans, CAT scans. Forgive me that I'm diving right into the acronyms.

And then the other great thing about a level four EMU is they're also going to be able to get you in touch with some of the associated specialties that go along with epilepsy. So right away we were able to see specialists like genetics, metabolics, neurosurgery, developmental specialists. I mean, really if you are dealing with epilepsy, especially hard-to-control epilepsy, a level four EMU is absolutely where you need to be.

Kelly Cervantes: Yeah. As we know all too well, epilepsy often comes with a lot of other comorbidities and issues alongside of it. So you're not just dealing with one specialist, you are dealing with a contact list full of them. You get Owen into the hospital and he's diagnosed with epilepsy. What did your journey look like from there? Was he put on medication? Did they work?

Colleen Jendreas: Oh, boy. That first day, it was a marathon's stay. We were there for 17 days trying to get Owen's epilepsy figured out and treated. We did a number of loading doses of various medications. We powered through all the frontline medications that they used to treat benign and easy-to-control epilepsy and Owen was just failing those one after another. And it was a traumatic experience, to say the least. It was so intense and we were getting through all of that. We were talking to all the specialists and like a lot of people, when Owen was first diagnosed, what I knew about epilepsy was that it wasn't terribly serious. That's what everybody who isn't in purple ribbon world thinks about epilepsy. So I found out right away that that was completely inaccurate. So yeah, we got through a ton of medicines and when they weren't working, they went ahead and diagnosed him with refractory epilepsy. So we jumped right into that scene.

Kelly Cervantes: Yeah. Do not pass go. Do not collect \$200. You are off to the races. So I know that you're trying all of these medications, his epilepsy is refractory, the medications aren't working, and then around 18 months old, you ended up getting an infantile spasms diagnosis, which is actually kind of unusual at 18 months for that to show up.

Colleen Jendreas: Right. Getting the infantile spasms diagnosis is without a doubt, the just worst moment of my life. I mean, when you have a baby with refractory epilepsy, you're doing the hardcore Googling thing and you know honestly the worst case scenario is getting that infantile spasms diagnosis. And the older Owen was getting, and we were having a string of pretty good control at that time, I really thought maybe we were going to be out of the woods with that. But at 18 months, we took him in for a regular EEG because we were seeing some unusual behaviors and some strange episodes. And you don't take those things lightly when epilepsy is in your life. I was just completely taken off guard when the doctor came in and told us that it was in fact infantile spasms.

Kelly Cervantes: And what did the treatment look like for that?

Colleen Jendreas: Well, treatment for infantile spasms, it's a medical emergency. So it's really intense. And these epileptologists, they really try to try to get these spasms under control right away. The implications of this kind of diagnosis are so serious and it's indicative of lifelong challenges in development with controlling seizures. So the first thing they started Owen on was Prednisolone [inaudible 00:08:05] injections. So that's a steroid. And literally I had to inject my little 18-month-old baby with these steroids, and it was over a nine-week course. For us it was Christmastime and the steroids, they lower your threshold for illnesses and the timing just couldn't have been worse. Christmastime, everybody's picking up bugs left and right, and this is pre-pandemic. So we're doing the steroids, we're getting through it, but honestly, we were still seeing the clusters. And every day my heart is just breaking.

Kelly Cervantes: But you were eventually able to get the clusters under control. What drug was it that helped.

Colleen Jendreas: Yes. So after the steroids, we were put on another drug called Sabril. Sometimes that's referred to as vigabatrin. I'm worried I'm going to mispronounce that one. It's a mouthful.

Kelly Cervantes: I think that one's vigabatrin. [inaudible 00:09:08].

Colleen Jendreas: Vigabatrin. VGB, okay?

Kelly Cervantes: There we go.

Colleen Jendreas: So yeah, Owen was put on VGB and we did get control of the spasms. That was really exciting, but like most treatments, it came with some negative side effects.

Kelly Cervantes: And how developmentally was Owen doing at the time? Did you see regressions even after that first explosive onset? How was he doing developmentally?

Colleen Jendreas: When he was a year old, he at that point had actually had seizure control for about six months and this was before the IS developed. We were starting to notice some missed milestones. He wasn't crawling. He's a year old. He even then had a hard time sitting up independently. He wasn't really on track with starting solid foods. Definitely we were noticing those things. We were warned to keep an eye on them. We were seeing them again, heartbreak. And honestly, once we got that infantile spasms diagnosis, his development, it was like we put the brakes on. There's been, even today, not a whole lot. That is how devastating that diagnosis is.

Kelly Cervantes: Yeah, it's one of those just really ugly ones that you just can't even, I think, completely understand how crushing it is to development until you see it in your own child and what it is capable of taking from them.

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: I know that Owen then went on to receive a Lennox-Gastaut diagnosis, however he... And correct me if I'm wrong, but he's still... It's so confusing in the epilepsy world, you have a Lennox-Gastaut diagnosis, but that's a clinical diagnosis. It's not a underlying diagnosis. And if you can just explain that, how you got this clinical diagnosis, but that you still don't really understand what's causing it all.

Colleen Jendreas: Yeah. There's so much nuances that go on with epilepsy and really all neurological issues, honestly. And it's something you have to get used to when your child is diagnosed with epilepsy and you're researching and you're really realizing there's very few firm answers. So when Owen was, I want to say about four years old, he did get the LGS diagnosis. So that's a clinical diagnosis. That one, I'll be honest, it was a little less traumatic than the infantile spasms because at that point we really knew it was coming. He had developed tonic seizures.

So after the spasms are under control, Owen was still experiencing occasional focal seizures. And then these tonics showed up. And really the tonic seizure, that's like the trademark of LGS along with the developmental issues that he was having. So when that diagnosis came along, I mean, at that point, our greatest fears were realized. It's a life-limiting and a life-threatening syndrome, and it's something that we have to accept and we treat it. And even though it's sad, I think we really just try to find pockets of joy alongside this difficult circumstance. So when that diagnosis happened was really when our epileptologist went into high gear and we started talking about surgery.

Kelly Cervantes: Yeah. So brain surgery, MBD, and you ended up making the choice to move forward with a corpus callosotomy. What is that?

Colleen Jendreas: Yeah, that was a pretty big decision. The corpus callosotomy is a procedure wherein a neurosurgeon is actually going to sever the connective tissue between the two hemispheres of the brain. I know that sounds incredibly gruesome, but this surgery has been proven to be really effective for epilepsy and different seizure types. And because it's not a resection, it also at least hasn't been proven to have any developmental impacts. So when we got to the point of such... The seizures were getting so serious. Owen was actually having these horrible episodes where he would have a focal seizure while he was sleeping, and the focals were then generalizing, so spreading across the brain,

and they were becoming dangerous. So we needed to do something drastic and this is the treatment our doctor recommended. And honestly, we were out of medication options. We were seeing our son suffer these horrible episodes in the middle of the night when everybody was asleep and the situation was dire. When you're a parent and you're faced with something like that, it just we had to go for it. We had to go for it.

Kelly Cervantes: Well, and it's interesting because I think that we have this language around these brain surgery options that is drastic because brain surgery sounds alarming, but I think that it's also important to remember technology and science has come so far, even just within the last five years. I mean, since when we first looked at surgery for Adelaide, I feel like it has improved so much and the ways that they can do it as minimally invasively as possible. It feels drastic because it's brain surgery, but it's not always as wild and detrimental potentially or risky as we may initially think. And it's one of the few potential options for a cure that we have in some cases. What was the result for Owen?

Colleen Jendreas: Yeah. Well, I'll tell you what, in epilepsy world, as you well know, just being even considered or a candidate for surgery at all is something you actually want. So I know that sounds just wild. We were sitting around, we got two complete surgical evaluations done at two different hospitals. We didn't take this lightly, but we were honestly pretty excited that he was going to be a candidate for something that's potentially curative. Not everybody with epilepsy is a candidate, so we were really willing to try it. Well, guess what? We had fabulous results.

Kelly Cervantes: Woo-hoo!

Colleen Jendreas: We finally got a break, our little guy. So we go in for the corpus callosotomy. We have it done at CHOC. And like you said, with the new technologies, Owen was also a candidate for being able to do that procedure with a laser ablation. So that way we weren't talking full craniotomy. We had a neurosurgeon who did it with a robot. It's all very science fiction esque. But once the procedure was done, we stopped seeing those episodes at night. So now the focal seizures, when they do happen, they're far more rare when they do happen and they don't spread. So they have become sort of this benign issue. We aren't talking about watching Owen struggle to breathe at night, and we really honestly feel like it saved his life, and we're so thankful that those treatments exist.

Kelly Cervantes: And then you went on to get even more control with other devices. Tell us about that.

Colleen Jendreas: Yeah. Part of the surgical decision was not only the corpus callosotomy, but also that Owen would receive a VNS implant. So a vagal nerve stimulator. It's a tiny little device that they plant in your chest, and it's got coils that wrap around the vagal nerve and it delivers a regular stimulation to the nerve. And they've found that that can help regulate brain activity and therefore treat the epilepsy. And we get that on board for Owen about six months later. And just again, we've

had unbelievable results. I think between the corpus callosotomy and the VNS implant, we're talking about a 90% reduction in seizures for Owen. It is so lovely to just see him come alive and be so happy and live in his life despite this tragic circumstances, but we are just so thankful for all this seizure tech. I love it. I can't wait to see what else is going to be on the horizon in the future.

Kelly Cervantes: I mean, I have to say, personally, following your family and Owen's journey and watching those videos of him playing in water or running through a field, it's like they're the best ever. They never fail to put a smile on my face because that joy and that life was not guaranteed for him. You fought and you pushed and you have incredible doctors, and it really is amazing to see him living this level of life that you weren't sure he was going to get to.

Colleen Jendreas: Oh, I appreciate you saying that. And believe me, we don't take a minute of it for granted. We really focus on quality of life for Owen, and we're so happy with the treatment decisions that his epileptologist has made. We feel like it's just made things so much better for him. A diagnosis like LGS years ago was awful, and here we are, just having a joyful life and doing regular things and loving on Owen and watching him just get out there and have fun and be a kid.

Kelly Cervantes: Yeah, 100%. I do want to shine a light though for a moment that Owen isn't your only kid. He has an older brother and sister. And epilepsy and the disabilities, they don't just affect the child, they affect the entire family. How has Owen's epilepsy affected his siblings?

Colleen Jendreas: I get asked this a lot, and I totally understand because it's such a unique parenting experience, not only having a kiddo like Owen, but then also having... He's got two older siblings, a brother and a sister. So Margo is nine and Gregory is 11. And Owen being the baby of the family at five years old, my older kiddos really had to go on this journey with mom and dad and they had to see some of the dark parts. They got to see some of the sadness. They know what epilepsy can do. They know about brain surgery, and it's a lot of trauma for the kids.

I try my best to make sure they're having as much of a normal childhood as they possibly can, but those are impossible things to achieve. But you know what, my older kids are... What this life has taught them is they are so resilient, they are so compassionate. And what we like to say is that they are totally woke to the... They are. This whole thing about inclusion and inclusive excellence, I mean, my older kiddos are flag-flying ambassadors for that whole movement. It's really something we can all embrace together, and I'm just so proud of them and I'm so happy that we found a nice balance to just keep our family happy.

Kelly Cervantes: There are just lovely, incredible, empathetic little humans that you are raising over there. So I often like to refer to you as the cheerleader for the epilepsy community, specifically on the Instagram world @keep_goin_owen. You've got to follow Colleen because she will back you up and be there in your corner and answer your questions. And your positivity is completely contagious and we are

all better off for it. I wonder what advice do you have for the parents out there who are facing a new epilepsy diagnosis?

Colleen Jendreas: It's so isolating in the beginning and it's so terrifying. What really helped me find a level of acceptance and beauty in this life was just, I tell people, you've got to find your tribe. You've got to get out there. You need to share your story, and you need to connect with other parents that are going through the same thing. I know that sometimes hopping onto social media and seeing some of those difficult outcomes can be really tough, but I saw some of that stuff in the beginning, and what I took from it was like, "Look at these families. They got a sad diagnosis, but they're still finding pockets of joy. They're still living life and having experiences." And when I saw that, I thought, "If they can do it, then I can do it too." And if I can help somebody, if I can connect with people and share this experience, I feel like raising awareness is really powerful. So that's so important to me.

Kelly Cervantes: Yeah. There's a quote that you had mentioned also that I think is so beautiful. Something that your epileptologist told you early in your journey. I wonder if you could share that for us. Do you know what I'm talking about?

Colleen Jendreas: I think so. Well, our epileptologist and I, we go way back. We've had a lot of years and a lot of conversations, but she did tell me early on, she said, "Don't forget to enjoy your child." What a just funny thing to say to somebody. But at that time, I was so focused on Owen's epilepsy that I wasn't seeing past to realize I just had this beautiful baby with me that maybe he was going to be a little different, but I was going to love him and I was going to love him for his differences. And those differences were going to change me profoundly. So I'm so glad she said that. It sticks with me, and I actually tell newly diagnosed people all the time the same thing. Don't forget to enjoy your child. I know epilepsy is so overwhelming, but there's still a person in there that needs your love and they're going to change you. I promise.

Kelly Cervantes: I love that so much and think that that is one of the best pieces of advice that any parent, especially with a medically complex epilepsy disability kiddo, can remember and hold in their minds and their hearts.

Colleen, you are incredible. I absolutely adore you. I can't wait until I get to hug you again in person. Thank you for being who you are and being the advocate that you are within this community. We are so grateful, and please give Owen a huge hug from me.

Colleen Jendreas: All right. Extra smooches.

Kelly Cervantes: Yes.

Colleen Jendreas: I ditto everything you say. You're my advocate, inspiration. You're just out there crushing it. I'm so glad we connected, and I'm so honored to be here too.

Kelly Cervantes: Thank you, Colleen, for sharing your experiences, insights, and advice with us as the mother of a child with epilepsy. 25 years ago, CURE Epilepsy was founded by mothers who were frustrated by the status quo of epilepsy care and the lack of advances being made in epilepsy research. Though CURE Epilepsy has fueled significant advances in knowledge and treatment during those 25 years, we continue our search for a cure so that children like Owen won't have to endure years of seizures and side effects from medications. You can help us achieve our goal of a world without epilepsy by visiting cureepilepsy.org/donate. CURE Epilepsy, inspiring hope and delivering impact. Thank you.

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