Seizing Life, episode 104
A Mother Shares her Daughter's Journey from Infantile Spasms to Brain Surgery
Guest: Monica Diaz-Greco
(Transcript)

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

Today, I'm happy to welcome Monica Diaz-Greco to the podcast. Monica's daughter, Emma, was diagnosed with infantile spasms in 2014. Following a course of treatment, Emma's spasms went away. However, after a couple of years of seizure freedom, a new type of seizure appeared sending Emma on a new treatment journey that included numerous medications, a VNS implant, and ultimately, surgery. Monica is here today to talk about infantile spasms and share her family's journey.

Monica, thank you so much for joining us today. To start things off, can you tell us when you first became concerned about your daughter, Emma, and what it was that you saw that concerned you?

Monica Diaz-Greco: We had first noticed Emma doing this little weird motion that kind of resembled the startle reflex probably when she was about four months old. At first, we thought it was exactly that. We thought it was the startle reflex. I had mentioned it to my husband, did you notice Emma's doing this funny little motion? And he had said, "Yeah, I recorded it. One day we'll show her and we'll laugh about it." But we didn't really think much of it. She didn't do it all the time. It was maybe usually a cluster of three every two, three weeks.

When she was seven months old, we were waking up from a nap and she did the motion again and for some reason it just didn't sit well with me, like something felt off. And so I googled this really long, convoluted sentence, baby does this weird motion hands go to the side, looks startled. It eventually led me to a YouTube video that a mom had posted of her child doing something very similar. In the description, it read if your child does anything like this, rush them to the nearest emergency hospital, like emergency department.

I freaked out. I called my husband at work and I said, "I'm taking her." The hospital in Toronto is the hospital for sick children. And I said, "I'm going to take her there right now." And he had told me, "No, call the pediatrician. You'll be able to be seen faster there." I called the pediatrician and I spoke to the secretary and the secretary had said, "Well, the pediatrician's not in, but his daughter is taking over his practice for today and she's an emergency room doctor at Sick Kids, so why don't you just bring her here? You'll be seen a lot faster."

And so I did, and she examined Emma and so she had asked for a video and there's where that video that my husband had taken so many months before had come in handy. But I was about to text my husband asking him to send it to me when he walked in, so he had sensed the panic in my voice and he left work and he met me at the pediatrician's office and we showed her the video and she called Sick Kids and she booked us for the next available EEG. We didn't have to go down to the hospital. Within less than 48 hours, Emma had her EEG and her diagnosis.

Kelly Cervantes: That is some incredible mama bear parenting right there. I will say your story is the perfect example of that. It is seeing something and questioning it, and that may be the intuitive piece, but then it's the action, it's the research and walking in prepared with the video. I mean, that is everything when it comes to getting that quick IS diagnosis, which we both know is integral in getting care. So, you get this IS diagnosis. You had done some research clearly to get to that place to fight for that, but what did you know about IS or epilepsy? Did you even know that IS was epilepsy?

Monica Diaz-Greco: No, I didn't know that. But I had Googled the heck out of infantile spasms and so I knew a lot going in, but I didn't know, or maybe I did. There was so much information coming at me at the time. All that really stuck with me is keywords like developmental regression, some children don't talk, some children don't walk, learning would be difficult, high chance of autism, underlying condition. It was more key phrases that stuck with me and they were all jumbled in my mind.

Kelly Cervantes: It's an overwhelming diagnosis. Like with all forms of epilepsy, it's a spectrum as to how greatly it can affect our children. What was the course of treatment that the doctors recommended and did it work?

Monica Diaz-Greco: Yeah, right away they had told us they were going to prescribe Vigabatrin (Sabril) to control her seizures. She started her medication that same day, it was October 9th, 2014. The next day, the 10th, was the last time we saw her have the spasms. When she had a follow-up EEG two weeks later, the hypsarrhythmia was pretty much gone. But they continued the medication for six months and then they eventually weaned her off of it. It worked right away. She was very lucky.

Kelly Cervantes: That's incredible. In an infantile spasms diagnosis, there's sort of two aspects to it, right? There's the hypsarrhythmia, which is this bizarre brainwave pattern that they see in the EEG and then there's the visible spasms that you can witness. So, the Vigabatrin knocked out both of those?

Monica Diaz-Greco: Correct, yes.

Kelly Cervantes: That's incredible. What did Emma's life look like? So she's on Vigabatrin for six months and I'm sure it came with all of the usual side effects. Yes, you get rid of the hypsarrhythmia and the spasms, but it's no joyride. What did those six months look like and what did Emma's life look like once she came off of the medication?

Monica Diaz-Greco: Because they're pretty aggressive with the dosage of the Vigabatrin, it goes up pretty quickly, she did have insomnia. She would cry a lot, inconsolable during the night. The only way I could get her to sleep was driving around, so I'd be driving around at three o'clock in the morning trying to get her to sleep. I was still on mat leave, it's a year in Canada, and my husband had to work. He wanted to help, but he needed the sleep because he needed to be at work the next day, so it really was me driving through the city trying to get her to calm down, try to get her to sleep.

But the whole time I'd be crying. All I could think about was I need to calm her down. She had core muscle tone and I had asked for speech therapy and OT before she was even a year old. Well clearly, they said let's wait for the speech therapy, but they did give her OT and PT, which she was eventually discharged from that when she learned how to walk. I wouldn't say there was regression in her development, it just sort of stalled a little bit or it was slower. Then the crying and the insomnia was definitely a difficult part of it because I couldn't do anything except drive around to make her feel better.

Kelly Cervantes: But that did pass. You got through it and the infantile spasms went away. What was her life like after those six months? Did you start to see her making progress and developing?

Monica Diaz-Greco: Yes and no. The speech was always something that was a little delayed and we were told that a lot of IS babies have speech delays. That was a little bit difficult. She was a late walker, so she started walking at about 16 months, but I thought the worst was over. She looked great. She didn't lose her peripheral vision, which was one of the side effects of prolonged use with Vigabatrin. And so, I thought it was over. I thought, okay, we might have a couple of hiccups with her learning and I'll get her the support that she needs, but it's done. In my mind, I thought it was over.

Kelly Cervantes: But it wasn't.

Monica Diaz-Greco: It definitely was not.

Kelly Cervantes: Unfortunately, this is all too common. Once a child has had one type of seizure, regardless of whether it's infantile spasms or another kind of pediatric epilepsy, they're at higher risk for the seizures of an entirely different type to return. It sounds like that was the case with Emma, unfortunately. When did you first start seeing seizures again and what did they look like?

Monica Diaz-Greco: It was July of 2017, so it was about two years later. I noticed that it was a very slight head nod and her eyes would slightly close, but it was so subtle that, and they weren't very long, that by the time I would tell my husband or anyone who was with me, look, she did it again. They would look, she wasn't doing it anymore.

Kelly Cervantes: And how old was she at this time?

Monica Diaz-Greco: She would've been three years old.

Kelly Cervantes: It had been about two, two and a half years since she had infantile spasms

Monica Diaz-Greco: I was so sure that I saw something and she was still being monitored by the neurology team at Sick Kids Hospital, so I had mentioned it and they scheduled her for epilepsy monitoring unit to see her for a couple of days. It was September of 2017. She had these epileptic spikes in her brain pattern and that was the beginning of a very difficult couple of years.

Brandon: 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: I understand that when the seizures returned that it was not quite as easy to gain control of the seizures this time around. What were you told in terms of diagnosis and what were the treatments like that you went through?

Monica Diaz-Greco: Well, MS seizures were unclassifiable. Here's another thing that she's different from everybody else. Also, through the years she had so many tests trying to figure out the reason for her IS and we've never found out why. There was a lot of unknowns. I couldn't even tell you which was the first medication she was on because it seems like she's been on absolutely everything that was possible to give children. As you know, it's a cocktail of medication. I felt like there was two years of adding something, taking something away, adding a little bit more, let's try this, let's try that. There were so many and there was a honeymoon period that we would see with every one of the medications and we thought, okay, this is it.

But then the seizures would come back and the seizures would change. I don't know if it was a result of the medication or if it was because she was growing at the same time, so sometimes she would freeze in place. She did have a lot of cluster in the morning, just in the morning when she would wake up. Head nods, her eyes would appear closed. Then there was a time when she was losing bladder control. But we were desperate and I think that's the best way to describe it. We would've tried anything.

At one point, they had recommended the keto diet, which is very different than the keto diet that everybody talks about. Medical keto diet is very strict. I remember at the beginning Emma would have apple sauce and there'd be MCT oil like floating at the top. By the end of her time on keto, because the diet was getting more strict and more strict, it was literally applesauce floating in MCT oil. It was not appetizing and Emma started to fight us on it.

We also tried CBD two different times with two different specialists. We even went back to Vigabatrin because it had worked once, so maybe it'll work again.

But that one was hard for me because I was so afraid that she would lose her peripheral vision. But we were trying to weigh the consequences of what's better. We'd rather stop these seizures and that became a priority. So yeah, we tried everything. I feel like we've tried everything.

Kelly Cervantes: What was Emma's development and personality like during this time?

Monica Diaz-Greco: It got gradually worse, but she appeared to be in a constant fog. There was not much learning happening, I would say, because she did not appear like she was completely with it. We did continue with speech therapy and the other therapies, but we weren't seeing a lot of progress. Learning was exceptionally slow. When she wasn't having her seizures or when she was out of that episode, she did smile a lot. And we always remark, jeez, this child is so strong, she smiles through everything. She's stronger than she needs to be. But the best way to describe it is she was in a fog. She would go to school and I think she was zoned out the entire time.

Kelly Cervantes: It's so hard to know is that from the side effect from the medications, is that from the seizures? What is going on there? That balance and trying to understand it is just so frustrating and it's so difficult I think especially for us caregivers and parents when you just want to connect with them and have them be able to connect with you. Now, I know that Emma is doing significantly better now. What was the turning point and what helped?

Monica Diaz-Greco: First, we tried the vagus nerve stimulator and she was the first person in Canada to receive the new SenTiva model, which had been around in the United States for a while. But in 2019, it was finally released for use in Canada, and so she was the first person. Again, we saw a little bit of a honeymoon period. We did notice she was slightly more alert and we know that it helps with cognitive abilities with a prolonged use of it, so even though the seizures came back, we still felt that that was beneficial to her. But I would say as we started 2021, the seizures were really bad and she started to fall. When she started falling, then she had to wear a helmet. It was at that point that her-

Kelly Cervantes: How old was she at this point?

Monica Diaz-Greco: She was seven. Oh no, sorry, six turning seven. She was wearing a helmet, had to be with someone at all times because she could fall at any moment. At that point, her neurology team at Sick Kids recommended a corpus callosotomy.

Kelly Cervantes: Explain what that is.

Monica Diaz-Greco: Basically, it's severing the nerves that are connecting the two hemispheres of the brain. The nerves allow information to travel from one side to the other, but also seizures can pass from one side to another. Because she was falling and they were never able to fully detect what side her seizures were originating from, but they know that it would go over to both hemispheres and cause her to fall, they thought by severing that then it would stop the drop seizures. When they told us about the surgery, I can't say it was easy, but we trusted our team and we trusted her doctor, so we didn't really require a lot of time to think about it. It was, yep, if you think this is what she needs, we'll do it.

Kelly Cervantes: You speak to something, there is this desperation and it is. I want to go back and just highlight what you said about there being so much pressure. I think that it is meant to be an empowering sentiment when medical professionals tell a parent that they know their child best and it can be empowering and they're not wrong. However, the weight that comes with that. We are not medical professionals. We didn't go to school, although I love to say that I have a PhD in Adelaide. It is a lot of pressure to put on families to make a decision like irreparable brain surgery. But you went forward with it. She had the surgery and what was the result?

Monica Diaz-Greco: First of all, the surgery itself was a terrible experience. It happened during Covid, which added to the stress because only one parent was allowed in the hospital at a time. There were good parts about the surgery itself. It took less time than anticipated. She didn't require a blood transfusion. The doctor said everything went well. Shortly thereafter, she developed a fever and then they had to figure out the cause of the fever. Then she was throwing up a lot. She was crying quite a bit.

After a week at Sick Kids, she was transferred to a rehabilitation hospital and she kept having these crying episodes and she would throw up. I mentioned to the neurologist at the rehabilitation hospital, I said, "I think this is a seizure. I think this is related to some type of seizure." It was confirmed that it was a type of seizure. It manifested in a way that nobody had anticipated. She would cry, get very upset, throw up, and then the episode was over. Her surgery was June the 28th, August 3rd, we went back to Sick Kids for another EMU, and that morning she woke up, cried, threw up, we get to the hospital, hook her up, not only does she not have a seizure while we're there, but she never had one again, that type of seizure. August 3rd was the last time she had that episode where she would cry and throw up, and then she went nine and a half months seizure freedom.

Kelly Cervantes: Wow, so it was as if her brain or the seizures or whatever, just needed to catch up with the surgery or the combination of the surgery with the VNS. Regardless, I am thrilled that she experienced nine and a half months of seizure freedom. That's incredible. I mean that must have been amazing.

Monica Diaz-Greco: It was a hopeful optimism with a little bit of fear. You're always watching. You're cautious and you're always afraid to say, oh, she hasn't had a seizure for this amount of time, because you feel like you're jinxing it. But when we went back to the rehabilitation hospital after that visit to Sick Kids, everybody was saying what happened? She's a completely different child. And she was. She was more alert. She started to ride a scooter, she started to ride a bike. She actually left me because before she would not leave me, I had to travel everywhere, to go to the programs to participate in all the activities. I was able to sleep again after months. It was just amazing. She started to really take off at that point.

Kelly Cervantes: That's amazing for both of you on so many levels. Now, we know that her seizures did come back. Can you share with us what they look like now, how frequently she's had them and what, if anything, you're doing to treat them?

Monica Diaz-Greco: May 22nd, 2022, the seizures returned. It was a tough day. It was like head nods again, however, we used the VNS device, the magnet and it stopped it. They adjusted her settings after that day and she doesn't have seizures all the time. We sometimes go a month without seizures, maybe three weeks, that's worst. She'll start doing that little head nod again. It kind of looks like what it always did, but then we swipe her with the VNS device and it stops. It's the VNS device in combination with the corpus callosotomy that seems to have worked really well. Now, she's still on medications. They're going to wait a little bit longer before they start weaning her off. To be honest, she's doing so well that I'm afraid. I, ultimately, want her to be off the medication, but I'm afraid to. But yeah, a lot better. She was going from a hundred seizures a day prior to the surgery to maybe three a month.

Kelly Cervantes: Clearly you never want her to have another seizure again.

Monica Diaz-Greco: Yes.

Kelly Cervantes: However, in the grand scheme of things, this is a pretty remarkable outcome.

Monica Diaz-Greco: She has epilepsy, so that's the way I've been phrasing it. Ideally, we don't want her to have seizures, but the reality is she has epilepsy and epilepsy, you see it through seizures and it's better than it was before and we have to be thankful for that. But we also have to accept that she has epilepsy.

Kelly Cervantes: How is Emma doing today socially, developmentally, educationally? Tell us about her.

Monica Diaz-Greco: She's a little rascal. She is. She's a lot more alert. Even at the school, the principal had said she's a different child and we see that. Now, I'm not going to lie and say that the learning is completely where it should be, she's back on par. It isn't. She's missed out on a lot. Epilepsy has robbed her of a lot of experiences, a lot of her childhood, a lot of her learning. She had brain surgery last year. Let's give her time to one step at a time, learn things and get to where she needs to be and that might not be where other children her age are going to be, but where she needs to be. So, I'm happy.

She went skating six months to the day of her surgery and we were thrilled. We went on vacation. It was the first time that we felt comfortable enough getting on a plane because we always worried, what if she has a seizure on the plane? How long of a flight? We took a lot of things into consideration when we chose our destination, but she's living and she's happy and she's teasing her sister and she's playing with her friends and still speech delay, still goes to speech therapy, OT, PT. I'm trying to get her a tutor. She's on an IEP in school. But Emma is who she's going to be and she's been through a lot. I always say when I have a headache, I can't do anything. I can't imagine having surgery and being able to do what she does.

Kelly Cervantes: And having a disability or requiring services for delays does not make her less Emma or less amazing. Now, talk to us about, because you didn't just stop at advocating and being a mama bear for your own child, you have gone out and are fighting and trying to educate for other families and children, as well. Tell us about Emma IS.

Monica Diaz-Greco: I'm glad that you used the word fight because sometimes I feel like it is a fight. I'm fighting a lot and it's not always a bad fight, but it's just like this advocacy, this new role that I have. In Canada, there aren't a lot of support groups or really any that we were able to find for IS. We know there are some in the United States and in the UK there seems to be a lot of groups, but in Canada we found one Facebook group and they're great and a great source of support and I've made friends with a lot of the members. But in terms of a place where we felt like this is for us information, we didn't have that.

So, on Purple Day of 2018, we founded Emma IS and IS is the abbreviation from Infantile Spasms. Our tagline is, Emma is who Emma is. What we wanted to do was bring awareness about what IS is because people don't know. We didn't know. We didn't know how serious it is. We started off with just creating social media presence, and then as Emma developed epilepsy, then we moved into epilepsy awareness, as well.

We are now a non-profit organization in Canada, so that was a recent development. We presented a delegation to the Board of Trustees for the Toronto Catholic District School Board, both my children are students at the Toronto Catholic District School Board, to get Purple Day officially recognized as a day that everybody would know about and celebrate. That passed, so we were able to do that. Last year, I wrote... I'm an educator, I'm a teacher, I wrote lesson plans for grades K to 12 that teachers could implement in their classroom on Purple Day explaining what epilepsy is, what are some first aid treatments.

I have to tell you that a couple weeks ago, I met a child in grade three and first he had said, "Well, I know Emma." And I'm like, "Oh, that's nice." "Emma has epilepsy." And I'm like, "Yes, she does." And he's like, "I know what epilepsy is. It's when something happens in your brain and I think it's called a seizure." And I'm like, "Yeah, you're right. It is called a seizure." And then I'm like, "What would you do if you saw someone having a seizure?" And he said, "Well, I wouldn't put anything in their mouth. I would make sure that they're safe and I would call an adult." And literally, I wanted to cry because he had said that his teacher had used the lesson and he had learned about epilepsy and that was one moment where I was like-

Kelly Cervantes: You're making a difference.

Monica Diaz-Greco: Yeah.

Kelly Cervantes: You are making a difference, mama. I mean, that's amazing. We talk about so much, it's education and awareness and that helps fight stigma, it helps keep people with epilepsy safe, it has such an incredible impact and that's really amazing. I love that so much.

Monica, thank you so very much for sharing your experience, for sharing Emma's story, and for all of the education, advocacy, and awareness that you are doing for our community. It means so much to all of us. I know it means so much to me, personally as well. So thank you, thank you, thank you.

Monica Diaz-Greco: And thank you to you. You were one of the first people we started following when our daughter was diagnosed with IS and you're a source of inspiration for us and we always look to you, so thank you to you. This is a complete honor for me to be speaking to you today.

Kelly Cervantes: Thank you, Monica, for sharing your family's story with us and for turning your experiences into an organization that raises awareness and funds for IS research and offers support to families coping with an IS diagnosis.

CURE Epilepsy has been at the forefront of infantile spasms research, launching its Infantile Spasms Initiative in 2013 with $4 million in funding. IS continues to be a major area of focus for CURE Epilepsy, with a recent discovery of a promising new treatment for infantile spasms. If you would like to help support our search for a cure for IS, please visit CUREepilepsy.org/donate. Through research, there is hope. Thank you.

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