

***Seizing Life®*, episode 109**
After Decades of Seizures, an Epilepsy Diagnosis Begins to Provide Answers
Guest: Ara Carbonneau
(Transcript)

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

This week on Seizing Life, I'm happy to welcome Ara Carbonneau the podcast. As a baby, Ara contracted meningitis that produced febrile seizures. Though she recovered from the meningitis, years later as a teenager, Ara began experiencing seizures and lived for many years without an official diagnosis of epilepsy, until a neurologist connected the meningitis and another incident in her childhood to the development of seizures. Ara is here today to share the details of her epilepsy journey in hopes that it will help others searching for answers. Ara, thank you so much for joining us today. So epilepsy first centered your life as a child. Can you tell us about that time?

Ara Carbonneau: Yeah. I was approximately seven months old and I had developed an unusually high fever. Pediatricians kept sending my mom back and forth saying that I had probably had picked up some flu or something. And my mom had had some medical training as a mental health tech and felt that doctors were probably not right as my fever just kept spiking. So they took me to the emergency room and they suspected I had meningitis. And so they went ahead and did a spinal tap and within the hour they found out they were right. I did have a viral aseptic meningitis. They literally cleared the entire emergency room within about five minutes because it's that catchy, like anybody can get it just sitting next to me in an emergency room. So it became a public health situation and I began to seize at that point because my temperature was over 106.

Kelly Cervantes: Oh my God. I cannot imagine how terrifying that must have been for your mother. You said that you started having likely febrile seizures because of the high temperature. Obviously you recovered from the meningitis. Did you continue to have seizures immediately after recovery or did they take some time for them to reappear?

Ara Carbonneau: Yeah, I didn't really have seizures after that. I was in the hospital for about three weeks. I did have some residual events that weren't particularly seizures, but where I actually passed out and was unable to be brought out of like a comatose state when I was five years old for about approximately three days.

Kelly Cervantes: Oh wow. But at the time doctors didn't suspect that that was seizure related?

Ara Carbonneau: No, they didn't put together the two. Even though my parents had mentioned that I had had... They'd asked if I had had any kind of head trauma or injury, and they had mentioned that I had a sincere, very intense case of meningitis, but that seemed to be swiped away as if it couldn't be.

Kelly Cervantes: So you have this incident at now, kindergarten, five years old. When was the next time that any type of seizure or post meningitis symptoms occurred?

Ara Carbonneau: Yeah, it was about 10 years later. I was in my school library. I suddenly felt very tired, much like I felt when I was five. Just very, very exhausted and felt the need to put my head down. I'd been studying for some final exams in that spring, and that's the last thing I really remember. The next thing I remember was waking up at St. Mary's Children's Hospital in Long Beach. Apparently I had been seizing having tonic-clonic, grand mal seizures for several hours on and off and on and off, and they finally had to give me some medication to literally slow down my heart and lungs. I wasn't going to survive. I mean, my heart and lungs couldn't take that kind of back-to-back situation. And on top of everything else, my father was deployed at the time on a business conference to the Navy. And so my parents weren't with me. They had to leave with my younger sister who was only 13.

Kelly Cervantes: Oh my goodness. So you are having back-to-back seizures. You're in the hospital. What are you and your family told at this point as to the cause of these seizures? And were you diagnosed with epilepsy at this point?

Ara Carbonneau: First of all, it's very important to know I was not diagnosed with epilepsy at that point. What they really kept centering in on was the concept of the idea that I must be a teenager who must have taken some drug or that I was on drugs. And my parents absolutely denied this, not because they just said, "Oh, we simply trust our child." She's like, "She's a student athlete. She gets tested at school." My school did a drug testing program. "She gets tested on a regular basis. We just don't think she isn't taking drugs. We know she isn't." So there was no use of the word epilepsy, just the fact that, "Well, she's having seizures and we don't know why and we're going to run as many tests as we can."

Kelly Cervantes: Did the doctors at that point start you on anti-seizure medications?

Ara Carbonneau: Well, yes, and most of it at that point initially was all in IV form because they were having to use what they call, I guess emergency seizure meds, like anti-seizure meds, because I literally had lost my ability to walk. I had cuts all inside my mouth. I could barely talk. My arms and joints were completely nearly useless because my body had just undertaken such a intense amount of physical trauma to it just from the seizures alone. And I had no idea how long I was going to be there. To be honest, that post seizure feeling that you have, I still couldn't put it back together where I was, what was going on and what had happened. And to be honest, no one was talking to me. They were talking to my parents and others, but no one came in and told me what had happened. So I was kind of clueless.

Kelly Cervantes: Wow. And powerless too. I imagine how that must have felt to not understand what was going on and not to be communicated with. So you're in the hospital, you've had these seizures, they have you on IV medication. Eventually you're discharged from the hospital. What are you told going forward? Are you warned to look out for more seizures? Did they send you home with prescriptions? What happened?

Ara Carbonneau: Well, I had had several different rounds of medications they tried in the hospital and I had a couple reactions to a couple of the drugs. So we had gone through about three or four drugs before I even left the hospital. And when I got home from the hospital, they had tried me on a couple combination drug therapies. I just kept breaking through them. They just told me at that point they were just going to have me make an appointment with a local neurologist. Not really a pediatric one or just... I just got handed off is the only good way to describe it. And at first there were some doctors that were discussing the idea that maybe I had seizures related to stress or something. They didn't really have any kind of diagnosis they sent me home with. Just that she's got general seizure disorder of some sort, but maybe she'll just grow out of it. Maybe when she stops having a stressful environment, she'll just stop having seizures. But no real sense of a follow-up except see neurologist.

Kelly Cervantes: The generalized seizure disorder diagnosis just gives me shivers of my spine because it is as far as I can tell, not a real... That is epilepsy. But without the right terminology, how do you advocate for yourself, or how do your parents advocate for you? You said that they started you on a medication or various medications, but you were still having these breakthrough seizures. How did that affect you? You're a teenager, you're in high school, you said you were an athlete. How did that affect you academically? Socially?

Ara Carbonneau: Well, a lot of ways. First of all, I developed something that a lot of people with epilepsy developed. I developed photophobia, so I couldn't really... And here it is, living in Southern California, I had to wear sunglasses. They had to foil my room because even the smallest bit of sunlight coming through my room could trigger a seizure. They had to put bells on my bed because of the fact that I would fall out of bed and have a seizure. My mom would come in and just listen to me breathe because I think she had that kind of fear. My military drill team experience ended, my possibilities of wanting to join the military like my father ended. Things just tanked. It felt like you were going down a drain and you couldn't stop.

Kelly Cervantes: Yeah. It is no wonder that there are so many people with epilepsy who have anxiety and depression when you consider how drastically these diagnoses affect your life, and especially in your case where you weren't even given a proper diagnosis. Also worth mentioning that at no point during any of this does there seem to have been any correlation back to your pediatric meningitis.

Brandon: Hi, this is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over \$90 million to fund more than 280 epilepsy research grants in 17 countries. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: I want to understand first, we heard how drastically the seizures and your undiagnosed epilepsy was affecting your life. Did the doctors when you left, did they give you any recommendations or ideas of ways that you could control your seizures through lifestyle changes, getting enough sleep, that sort of thing?

Ara Carbonneau: Well, my mom was a little familiar because of the fact she had had experience with my adopted dad who'd had a head injury. So he had had some seizures, but because of the fact that I wasn't getting a proper diagnosis, the doctors thought it was all lifestyle. Like if I just stopped this, this, this... Like basically stopped living is essentially how I looked at it. They didn't want me to swim and they didn't want me to be out after a certain time. And it wasn't helpful advice to a teenager trying to live some sort of lifestyle. I didn't know where to start. And the doctors and no one else helped me with my lifestyle about how suddenly I had these gaps in my school schedule because I couldn't do those things anymore. My doctor said, "Nope, that's not an option." So I just came back in the fall as almost a completely different person. Certainly not of my own choosing and certainly with not much direction, and my parents just not knowing how to console me.

Kelly Cervantes: Yeah. I mean, it's a flip of a switch and all of a sudden you are leading an entirely different life. Now, I understand that at some point your family moved to Connecticut and you got enrolled in a study and there were some massive realizations that came from that. How old were you when you moved to Connecticut, and what did that study... What was that study and how did you learn from it?

Ara Carbonneau: Well, I was in my early 20s and my mom decided, dad decided it would be a better idea that... I had been living a little away from them in college. And my mom said, "She's having too many seizures and I feel very uncomfortable her having that much distance." And my family had taken a transfer with the federal government and so that was going to make it easier. My dad had been seeing a neurologist for his epilepsy through the VA system and he told him about me. And he said, "I have a daughter with uncontrolled epilepsy." He gave her a little bio on me. And he said, "Listen, because you guys are family members, I can put this on a familial study like a family study." And he said, "Bring her in. We have some testing devices here at the Veteran's Administration that we're not even offering out to the general public. This is just part of a government program, but we're inviting VA family members. We can start there."

And that was introduced for the very first time to a man by the name of Dr. Richard Shire and something called a PET exam, which... PET scan. I had never heard of that before. So I went a combination with the Veterans Administration and Yale University.

Kelly Cervantes: And what did they discover from that PET scan?

Ara Carbonneau: Well, he actually put me in the hospital for a very lengthy time and he ran all sorts of exams. And when he came through the PET exam, I think he almost raced to my hospital room because I was inpatient at the time. And he said, "You just won't believe this." And he told my parents... He waited for my parents to get there and said what? He goes, "She has scar tissue inside her temporal lobes. And from the history that you gave us, I'm almost 100% positive this is a residual from her having viral aseptic meningitis." And he also let me

know, "It's incredibly rare to see this 15 years later. And then for the scar tissue to spread from a hippocampus into a hypothalamus. We just don't see it with tonic-clonic, grand mal seizures." And he said, "I'm so glad you came to me." He's like, "I've been looking for something like this."

Kelly Cervantes: That's incredible. And it just goes to how complicated and varied epilepsy is, and also the importance of getting additional opinions. You finally get to this doctor who gives you an answer and just goes to show not every epileptologist, not every neurologist is the same. And we need to keep meeting with new doctors to get those answers 'cause you never know what one doctor knows and another doesn't. Is this the point where you finally got an epilepsy diagnosis?

Ara Carbonneau: No. He was concerned about the fact that my previous EEG results had been what they called clean, which is to say I had a regular EEG. And then all of a sudden out in the middle of nowhere they started running EEGs where I showed some... what they called mild spiking. And so he wasn't completely sure how to put this all together. He said, "I know there's some damage, but I think we just kept using the word that she's got some damage to her brain, which is causing tonic-clonic, grand mal seizures." But using the word epilepsy, the only people I think were actually even close to using it might have been my mom because she'd been familiar with that world. I wasn't even admitted to the hospital as what they would call an epilepsy monitoring unit. I was just entered in as a general patient as if you had gone in for a surgical procedure or something. So there wasn't anybody walking around using that word.

Kelly Cervantes: So during this time, you are in college. So you're finding out this information, you finally, I imagine, have to feel seen and not... You can point to this cause finally. But at the same time, you're also a college student trying to live as normal of a life as possible. How was all of this affecting... I mean, you mentioned that your family moved to be closer. Did you let your teachers know? Did your roommates know? How were you communicating about your seizures?

Ara Carbonneau: I want to be honest with you, I was looking to become a teacher and I sat down with... I was getting sick a lot. And so I went and talked to a professor who was one of my... All teachers are required to take reading as educators. So I talked to her and I shut the door. I said, "I have something that I need to talk to in confidentiality, because I don't know where to start and I don't know who to talk to and I want to become a teacher. And I'm hearing a lot of people telling me that's just not going to happen and my doctors and others."

And she sat down and I explained to her what my health was and she said, "From this point on, I want you to let no one in the education field know about what's going on with you." I said, "Well, what's the reasoning behind this?" She says, "Because no one will ever hire you." Now, this was right around 1998, '97, '98, and she said, "The stigma out there is so strong you'll just never get a job. And I really recommend that if you aren't already considering secondary

education, you could because no one's going to want you in a classroom with a child who's under a certain age."

So it's like I got a dose of reality in my field about how people felt. And she had been a professor who supervised a lot of student teachers over a course of about 20 years. So I kind of took her advice.

Kelly Cervantes: That must have been so difficult to hear. So you hide this condition away, but you did enter the workforce after college. Tell us about that.

Ara Carbonneau: Yeah, I finished my bachelor's and then I got a postgraduate cert and a masters and got published all within that same few years.

Kelly Cervantes: Which is incredible as you were also trying to navigate this incredibly scary medical condition that you don't even fully understand.

Ara Carbonneau: Well, yeah, truly. And I didn't understand something that seemed very bizarre to me, which is I couldn't balance a checkbook. I couldn't do division or multiplication, but I could learn foreign languages simultaneously. I took Spanish and French same time. Even as a child, I could pick up languages. I could pick up just the most bizarre mass amounts of information. I could memorize entire textbooks. I was a history major and it just came to me like that. But you ask me the most basic logic question of putting blocks together and I couldn't do it. And so I decide that I'm going to become a public historian instead of... Because I can still be an educator in the public history space. And I first went to work for my county. Within a year, I had already gotten a job working for the Kansas Historical Society for the Kansas State House, which is essentially working for the governor and for the state legislature. And within a year, I had been offered a job working as a public historian and a museum educator for Congress.

Kelly Cervantes: That's amazing. So that job has you moving to Washington D.C. where your next medical breakthrough occurs.

Ara Carbonneau: Yes. I switched over a neurologist from being out here in the Midwest to D.C., and I kind of did my little research. I was going online looking at the background of various neurologists. And so this particular one I noticed went to Yale University and I thought, "Well, my last neurologist that I really liked in Connecticut went to Yale. I really think this would be a good idea." And so I made an appointment with Dr. William Gaillard. Now Dr. Gaillard's program in there at Georgetown University is what they call an inpatient/in-clinic program, which just means to say you have to apply to it. And so I applied for it. They sent all my medical records. When he saw the physician's name who treated me at Yale, he said, "Oh my goodness, you were treated by Dr. Shire." And I said, "Yes." He goes, "We went to medical school together at Yale." And I gave him a call.

So he said, "All the tests we ran, we're going to run them again. And we at Georgetown have even some better tests than the ones you had ran." So I went through a battery of tests. I was probably in and out of Georgetown for weeks just getting these tests done. And after he got the test done, I'll never forget what Dr. Gaillard said to me. He goes, "I've been waiting for you to walk through my office my entire career."

Kelly Cervantes: Wow.

Ara Carbonneau: And I asked him why. And he said, "Because you are the first adult living person I have met that had pediatric onset viral aseptic meningitis and lived." And he said, "I hope you aren't offended by saying that, but I think we're going to do some amazing things for you." And I think I nearly started crying.

Kelly Cervantes: I mean, I'm almost going to start crying hearing that. Just to find a doctor that understands and gives you hope. What did your life look like from there? Was he able to find a medication that worked?

Ara Carbonneau: Yeah. First he said to me, he goes, "I want to give you a diagnosis," which nobody had really done before. And I actually said, "Can you wait just a moment so I can get my parents on the phone because they really need to hear this." And so they did. We put on speaker and he goes, "Well, she has TLE, she has temporal lobe epilepsy. Which that part is not so unusual, but she has mesial temporal sclerosis in the hippocampus and the hypothalamus and it spreads. So her seizures, unless we can find a good source of medication, will only get worse and that's the reason they're getting worse."

And I should tell you that he trained as a pediatric neurologist. So as an adult, I was seeing a pediatric neurologist, and it's really what I should have seen from the get go. I should have always been seen... And he said that. He said, "You should..." And I asked him, I said, "Why is there no other neurologist who know about this?" And he said, "Because only pediatric neurologists are trained for this. So when they sent you to a neurologist, even when you were a teenager, they sent you to an adult one, a person who had never been trained for this and you've been seeing adult ones ever since."

Kelly Cervantes: And how old were you when you finally got your diagnosis?

Ara Carbonneau: I was about 36. So we're talking about 20 years since the first time I had been in that hospital in St. Mary's in Long Beach, California.

Kelly Cervantes: And they were able to sort of figure out the source of your seizures. Have you been able to gain control or at least better control?

Ara Carbonneau: We did. Knowledge was key on this one. Knowing when to take my medications, for instance, spacing them. Spacing them, for instance, 12 hours apart, seemed

to be something that was very important. Understanding though that I had to manage my stress level. And I went about six years or so seizure free.

And then I had a very stressful day, April 12th, 2011, won't forget that one. And I was just having a lot of family stress going on. So I said, "You know what I'm going to do? I'm going to go try to get some stress out and I'm going to go run on my treadmill." And that was probably not the best idea to do. I was getting ready for a road race. I wanted to run a 5k. I wanted to do the things that doctors before told me I couldn't do. And I don't know how long I'd been there, maybe about five minutes. I got myself up to about seven miles an hour and then that's when I crashed and had a tonic-clonic. It was a reminder of my limits and my neurologist and I had to talk about that there are limits. I'm not indestructible because I started thinking in my mind that he'd given me my world back so I could do anything.

Kelly Cervantes: Right. It's hard. You had six years of hope, and the really crappy thing about epilepsy is that can develop a false sense of security. But at the end of the day, until we have a cure for epilepsy and we certainly don't yet, then you do have to live within the boundaries that epilepsy sets on your life and that it is an invisible disability. Correct me if I'm wrong, you've not had another major tonic-clonic since that day in 2011. Is that correct?

Ara Carbonneau: Yes, April 12th, 2011. It's amazing. It's how people with epilepsy can tell you almost like anniversaries, especially when they start building some time for that to happen. When I came back from D.C. and met my neurologist at University of Kansas, which is just like Georgetown, it's an in-clinic program, you have to apply. I will tell you that I took a little break to go up to University of Iowa to teach a PhD fellow there. And I was seeing neurologists there who terribly misdiagnosed. They missed a big diagnosis. And KU, University of Kansas caught it when I got here. I was born with a brain malformation in the other side of my temporal lobe. So now I have damage in the left and I have damage in the right. And I'm now starting an EEG from spiking on now both sides of my brain. And we've only found that out in about the last year.

So I'm still coming to grips with the fact that I have a brain cyst in one side of my brain and damage from the meningitis on the other. I am so glad I never had the procedure to remove my temporal lobe. It would have been devastating.

Kelly Cervantes: Wow. It's amazing and terrifying what we can discover as science progresses and with each different doctor. You have been through the ringer to say the least, but you have pushed forward with determination. You have lived your life within boundaries as was necessary, but you have continued to live your life and you are a wonderful example of continuing to move forward and staying positive and never giving up. So I would love to hear from you what advice you have for others in the epilepsy community. Whether they've been recently diagnosed or they're fighting for a diagnosis, what do you tell them so that they can find that piece and that positivity in their journey?

Ara Carbonneau: Well first of all, do something that my family kept doing, which is if you don't hear from the physician or doctors what you need to hear, in other words a diagnosis, something that's telling you what is going on here, then keep moving, keep moving on to another physician. I know that's hard to say. Sometimes people are in communities where that's the only neurologist. And I've talked to many people who've said, "Hey, this is my only neurologist." Don't be afraid to walk in and simply stand up to your neurologist and saying, "This isn't working for me. This isn't working for us. This is not a livable state." That's key.

And then the next is to set goals. Set goals. Say, "You know what, we're going to do this. We're not going to stop life because epilepsy happened." When my parents had a huge argument 'cause I wanted to go travel overseas and I wanted to study in Ghana, I was like, "It's a Third World country, there's no way." And my dad's like, "You have to let her do this." So you have to be able to take risk, but measurable risk. So we talked about my medication schedule and talking about my team and them knowing about my health. And so take measured risk. It's okay to take a risk because not living life is not an option either.

Kelly Cervantes: 100%. Ara, thank you so much for your advice, for sharing your journey with us. You are an absolute delight and I am so thankful to have been able to speak with you today.

Thank you, Ara, for sharing your epilepsy journey with us. As Ara's journey makes pointedly clear, getting an accurate epilepsy diagnosis is vital to finding effective treatment. But to get an epilepsy diagnosis, we have to say the word epilepsy. A seizure disorder is epilepsy. If we don't say the word, we can't treat it and we can't find a cure for something we don't talk about. This is why CURE Epilepsy would like to invite you to take part in our Say the Word #SayEpilepsy campaign. Share your epilepsy story on your social media using the #SayEpilepsy, and then tag CURE Epilepsy in your post. Together we can raise awareness of epilepsy and together we can fund the research that will lead us to a cure. Thank you.

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