

Seizing Life, episode 116
A Daughter's Diagnosis Inspires Concerts for Epilepsy
Guest: Matt Perrone
(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 Matt Perrone to the podcast. Matt has lived with epilepsy for over 30 years, but it wasn't until his daughter, Abigail was diagnosed at the age of four that he felt compelled to do something to raise awareness and funds for epilepsy. Having played in bands for much of his life, Matt created EpiPalooza, an annual multi-band concert that takes place in Charlotte, North Carolina. Matt is here to share both his and his daughter's epilepsy journey and tell us about EpiPalooza which is expanded to a second concert in 2023. Matt, thank you so much for joining us today. To kick things off, why don't you tell us how epilepsy first entered your life?
- Matt Perrone: Sure, thank you. So when I was 16, I had my first seizure. I woke up, just a normal day, went to go take a shower. And the next thing I knew I was having a seizure. I was unconscious, had a tonic-clonic seizure. The door was locked, my mom had to run in and unlock the door, and she found me having a seizure. The next thing I knew, I woke up and I was in the hospital and that was it. They didn't diagnose me until I had my neck seizure. So there I was 16, sophomore in high school, and really just didn't know what was going on. And that was how it first entered my life.
- Kelly Cervantes: Now, so you have the second seizure, you're diagnosed with epilepsy. What do you know about epilepsy at the time and what did your treatment journey look like?
- Matt Perrone: We didn't know anything. So prior to the second seizure, they were going to put a 24-hour EEG and see what it was, see how long it was going to be, see everything about that. And then I had that second seizure and that's when they diagnosed epilepsy. And when they shared it with me and my mom, we didn't know anything. And truthfully, they didn't really share a ton with us. I was talking to my mom recently and just kind of confirming whether it was what I remember or not, and they really didn't share a ton. And it's not like today where you can go look things up or have all this research and everything. And I certainly don't fault them at all. We didn't know what questions to ask, but just really didn't know a ton going into it.
- Kelly Cervantes: Did you get a specific diagnosis?
- Matt Perrone: I was thinking about that. I don't think so, but speaking to my neurologist as an adult, I think it was JME.
- Kelly Cervantes: Juvenile Myoclonic Epilepsy.
- Matt Perrone: Yeah. I think that that's what that I had or have.

- Kelly Cervantes: Yeah. So you get the diagnosis, you don't really know much about it. Were you able to get control of the seizures? What kind of medications and what were the side effects?
- Matt Perrone: Sure. Certainly, luckily and gratefully and fortunately I was and am able to get control. So he had prescribed Depakote right from the start. We never had to try different types of medications or anything. Had to try different dosages. And that certainly had its side effects of getting nauseous and would be vomiting and lightheaded and everything like that, get sent home from school and until we found the right dosage. But the Depakote certainly worked for me and was able to control my seizures. So those two seizures and knock on wood have been it for me and I'm extremely fortunate and extremely grateful for that.
- Kelly Cervantes: "Now, you're diagnosed with epilepsy at 16, which is a super simple, easy unemotional time in all of our lives," she says with dripping sarcasm. What was that like? How did it affect you socially? Did it affect you academically? Have you noticed any difficulty in your schoolwork, be it from the seizures or side effects from medication?
- Matt Perrone: Yeah, so academically, I was in honors classes and things like that since seventh grade or whatever. And I think that I noticed, well, this is all looking back, I didn't notice these things at the time. It's not like, "Oh, hey, I think that my reading went down or whatever." But yes, my reading comprehension just dropped. I couldn't really get that stuff going anymore. And my mom also shared that I had the opportunity to take the SATs untimed, but she said that I fought it. And I said that I don't want to do that because in life you're not necessarily going to always have these opportunities to get off to get to do all these things, which I believe her, but I don't remember that at all.
- And she said that she also feels that I didn't want to be singled out. So I certainly then had these emotions and things about this living with epilepsy. I definitely did not broadcast it. I obviously am quite different now. I'm very vocal about it and I think that everybody should, not everybody, it depends on how you feel inside, but I want to raise awareness about it and everything that I do about it because I want to be a voice for those that don't have a voice. That's how I feel. But then being 16, I certainly know that I was not wanting to just say, "Hey, look at me." I mean who at 16, no matter what it is, there's not many people that are just, "Hey, look at me, I might have seizures"
- Kelly Cervantes: You don't want to be different, right? I want to blend in and be like everyone else.
- 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: You talk about how fortunate you are that you were able to get control with the medication and that knock on wood, you've been seizure free, but that doesn't mean that you haven't gone without comorbid complications. And I think that this is so important to talk about because I think you bring up a really good point here where you were saying how you want to be an advocate and you want to raise epilepsy awareness. And to that point, your story is so important because you are in the majority, two-thirds of people are able to get control of their epilepsy, but they may not understand that there are all of these other comorbid complications, specifically mental health that go hand in hand with that. So even though you're not having seizures, that doesn't mean that you're still not being impacted by your epilepsy. And I think that not having that knowledge can be very, very isolating. I'd love to hear your experience and your thoughts on the mental health implications that you personally experienced and became aware of over time.

Matt Perrone: Yeah. That is the biggest part for me, is raising that awareness, the relationship between mental health and epilepsy. And for me personally, that is what happened in 2020. It took a huge toll on me and those side effects and that relationship, unbeknownst to me for 25 years, 1993 and until the early 2020 or whatever, it was slowly building for me. I saw a therapist here and there for just a point or whatever, but never did I realize what the toll was taking on me, whether it was the epilepsy itself or the side effects from the medication. Depakote certainly has its set of side effects and it's also a mood stabilizer as well. It treats other people besides just folks with epilepsy.

But in early 2020, I started to have 15 different things that were going on in my life, whether it was the pandemic or workplace trauma or my daughter's epilepsy, all these different things that were going on. And it slowly started to unravel switching from Depakote to Topiramate, all these different things, and it just severely affected my mental health and I hit a wall. It affected me to the point that I took leave from work. I voluntarily gave my kids to my ex-wife. I just really had to climb out of a lot of things. And I didn't realize, it was then I learned about the effects of epilepsy and mental health, but it didn't leave me at a point of anger or anything. It left me saying, "All right, this is something that I can learn from and be an advocate from, once I crawl out of this place."

Kelly Cervantes: Yeah. I wish that there was more information or that more epileptologists were checking in on the mental health of their patients or raising the flags and the awareness that this is something to be on the lookout for. Thank you so much for sharing that piece of your journey because I do think that it is so important that people are aware and that there is help out there, and that it is not uncommon specifically for people with epilepsy to have specific problems with their mental health. And it makes sense, it's all in the brain, it's all coming out of the brain. Was there anything specifically that helped you, as you say, sort of crawl out of the hole that you were in?

Matt Perrone: Yeah. I mean, I went to therapy for five days a week for about two months every day. And that certainly helped me and helped stabilize me. But then when that

was done, I came up with a plan because when people are in AA, they have a sponsor or something like that. So I came up with a plan to find 10 friends of mine, and it was impossible for every friend to be reliable to call on me or whatever, because I had constant contact every single day, and I knew I'd be missing that come January 1st.

So I created a calendar, there's an app calendar or something like that, and I said, "All right guys, here it is. I opened it up for two weeks at a time, and all you have to do is just each of you just pick one day for two weeks and then call me, whatever time you want." I had to leave absence, so I had free time. And so these 10 friends, one of them would call me each day, and this went on for, I don't know, four months. So I have had an amazing group of friends that would just take an hour of their time once every two weeks to call me. And it just wasn't like, "Hey, Matt, what? Hey Matt, how are you?" It was just, we would talk about anything and they also felt that it helped them. So I wouldn't have been able to do anything without a network of friends.

Kelly Cervantes: I loved everything about that and think that is such an amazing idea, an incredible tool that any of us can employ when we are in a rough spot because I also think that it's something concrete. We do have friends and family who love us and want to support us, and then to be like, "This is how you can do it." To give people direction on how they can actually help you. I think that's something that people want because they do, they want to help us, right? Now, you mentioned this briefly earlier, but your daughter, Abigail has also been diagnosed with epilepsy. And that certainly impacted your mental health as well, because it's one thing to be diagnosed with epilepsy yourself, and it's another thing to watch your daughter now be diagnosed with something that you're all too familiar with yourself. Talk to us about that, how she was diagnosed and that impact on you as a father.

Matt Perrone: So she had her first seizure when she was four, just a month after her fourth birthday. And at that point, I was still married and she was just downstairs watching TV, and we were all in there, and she was supposed to have a friend come over. She was supposed to go to a friend's house, and it was like, "Okay, Abigail, let's go upstairs." And she was ignoring me. And it was, "Okay, Abigail, let's go, let's go." And this went on for a little bit, and finally I was like, "Okay, if you're not going to come, then you just won't go to your friend's house." So I lifted her up to bring her upstairs, and she was just looking the other way. And I'm just walking and walking. I'm just assuming that this four-year-old girl is just ignoring or playing or whatever.

And then I get her upstairs and I started to put her into bed or something, and she's just looking at the wall and I realize that she's unconscious. And unbeknownst to me, she's just having an absence seizure, a focal seizure. And I'm like, "She's unconscious. She's not just playing." And so I brought her to the ground and then she's just completely out of it. And she started to vomit and then that was it. I called down to her mom, and I called 911. And then she starts convulsing and having a tonic-clonic seizure, and the whole rest just happened

and the paramedics came, and then she stopped, and then she had another one, I think in the ambulance or on the stretcher down below.

Kelly Cervantes: Now, was it easier to diagnose her because you had epilepsy or what did her diagnostic journey look like?

Matt Perrone: No, they didn't diagnose. She didn't go on medication either right away. They did the same thing, a wait-and-see, "Oh, she's young, this could be, it could just be a one-time thing." But it was certainly extremely scary. She slept in our bed for a couple of days. And we had a one-year-old as well, but I didn't want her to sleep in her own bed at all. But that was December 30th, and she had her next seizure in September.

Kelly Cervantes: And so then she was diagnosed with epilepsy and started on medications, I assume.

Matt Perrone: And we're not convinced that that first one was her first one. So based on the way that the others happened, initially, she vomited. So this first one was during the day, but all the rest were at night. And so she woke up one time, we realized before that she vomited in her sleep and everything. So we think maybe that actually was the first one. But yeah, all the rest were focal seizures. At night, she would go to sleep, and then she would like a half hour after, she would have focal seizures, vomiting during the seizure. And so she was then prescribed Zonisamide. And I guess the dosages weren't right or weren't working, and she proceeded to have nine more, so a total of 10 between September of '19 until June of '20.

Kelly Cervantes: And what was it that eventually helped to get better control of her seizures?

Matt Perrone: Upping the dosage, I think the frequency as well. I think at the beginning it was just maybe once a day. Upping the dosage, the frequency, and then June of 2020 with an increased dosage. And then we also changed her diet and changed the modified Atkins diet from just a normal diet to a modified Atkins diet.

Kelly Cervantes: I'm glad to hear that that helped get her better control. How is she doing now?

Matt Perrone: She has been seizure free for 18 months, so she had a breakthrough seizure about a year later after that, but she's been seizure free for 18 months.

Kelly Cervantes: That's amazing to hear. And I hope that she has continued seizure freedom via the diet, which I know can be incredibly challenging, especially for a young child. But it's encouraging to hear. I wonder, as someone who has epilepsy, what did you tell her? Were there insights that you were able to give her, ways you were able to help or comfort her that were unique to you in your experience?

Matt Perrone: When she first had her first EEG, I was able to say, "Well, Daddy had this, and Daddy has these from time to time." And when she would be taking medication,

I would say, "Daddy takes medication every day." At the beginning it would be just those types of things, I wouldn't go into detail about epilepsy and so forth. I mean, she was four years old. We didn't go too much into detail, but now I do, and we do talk to her about it a lot more, especially when it comes to her diet. So she's not on the modified Athens diet anymore, that went from June until about December. She's now just on no added sugar and no refined flour. So the no added sugar and the medication has been working great.

Kelly Cervantes: That's great.

Matt Perrone: But now I'm able to talk to her and describe, "Hey, when you go to school, do people ask you about why you bring your lunch to school and why you have different snacks? How do you describe it to them? What do you say, et cetera?" And this diet is part of your medicine and daddy takes medicine and things like that, and we talk about that. But to go back onto that I wasn't presented the mental health side of it. I'm able to look at her and say, "Okay, this perhaps is giving her anxiety whether she's talking about it or not." Now I can look at it through that lens. Well, maybe I didn't get it, but now I can be aware of it for her. So if something is presenting social anxiety and she doesn't even realize it, then I can be on top of it and see what can we do now.

Kelly Cervantes: That's incredible that you can be on the lookout for that for her. And I think important information for all parents of children with epilepsy to be aware of. So I know that your daughter's diagnosis was one of the impetuses or the major impetus for you to start doing some epilepsy advocacy, specifically founding EpiPalooza. Can you tell us about that?

Matt Perrone: Sure. Thank you. So she had her first seizure at the end of 2018, and I sent emails out January of 2020. So I started immediately. I just knew that I wanted to start giving back. Sadly, I took everything for granted prior to that, my own epilepsy, the community. As I said earlier, I didn't know anything about epilepsy, it just wasn't really something presented to me. It was, I take this magic pill and I don't have seizures. So I started EpiPalooza and I was like, "The only thing I know is music. I know music, that's all I know." So I called the venue that I've played before. I booked the venue, and then I just found some artists that I've talked to before. And they agreed to play, and then my band would play, and that was it. I put on that first show and raised some money and raised awareness because that's what I wanted to do, is people learn about epilepsy.

My own neighbor, I learned through this in my old house, her son has epilepsy. Things that just, the more you speak about it, the more Six degrees of Kevin Bacon there is. I mean, talk to somebody at church, and "Oh, my nephew has it." And that's what I try to get to tell people is like, "Hey, if you can't donate, please, I totally understand, but just spread it. You have no idea how many people are affected by this." I mean we know the numbers, one out of 26 will develop epilepsy at some point in your life. You look around your office, if you go to an office now, you look around your office and 26 people are right there. So I just want to spread it. And then now that it's grown larger for me, the

awareness part, it's really about for me, spreading the mental health aspect that we've talked about. So EpiPalooza is a concert and it's raising awareness.

Kelly Cervantes: And EpiPalooza has grown from that first concert. You're in its fourth year, and you live in Charlotte, North Carolina, but you are expanding to my current home state of New Jersey. Talk to us about that. I'm so excited.

Matt Perrone: I am excited too, to have the first world tour, as I've called it, and bring it to New Jersey. So me being born and raised in New Jersey, I thought that this would be a great time to hold a second event and do one in New Jersey. So this year it's going to be in Teaneck, New Jersey. And since I'm 30 years seizure free this year, I thought it would be just a great way to celebrate and hold one in New Jersey. So this year, there's two, one in New Jersey and one in Charlotte.

Kelly Cervantes: Cannot wait. Tell me what I can expect. I'm going to be attending with my 10-year-old son. What can we expect when we arrive?

Matt Perrone: Well, there's multiple bands. It's just a great night of music. And then we'll be having one or two speakers. I'm still ironing out the second speaker, but this wonderful girl, Sophia, she has a blog, Milo & Me, and I've met her through the Instagram channel that I do. And I try to get every year some people who live with epilepsy so that they can share their story. Because again, just being that voice for those that don't have a voice is just what I believe in so much is just so important. So yeah, I mean, that's what we have it. I think it's just a night that people can enjoy.

Kelly Cervantes: Now, I understand that it is a family affair and that your daughter Abigail is involved also. Talk to us about that. How does she get involved in the evening?

Matt Perrone: She gets involved in two different ways. The one in Charlotte, she won't be able to come to the one in New Jersey, but the one in Charlotte, she and I sing a song. It's a song that I wrote, and the first night I was just like, "Oh, do you want to come up with me?" But last year she came up and she gets a little shy, but she enjoys it. And then last year she had an assignment in school that said, what do you want to do in 22 years? One of the things she wrote was, I want to raise money for doctors, I think it was. And I mean, I saw that, and no, I want to raise money for doctors by drawing. And I mean, I saw that and it was just like broke my heart in a good way. And I was like, "How can I do something? How can I do something with this?" So I had her draw a picture, and then I put it on magnets and pins and buttons and then sold those. So this is the one that she drew last year.

Kelly Cervantes: I love it.

Matt Perrone: And then this year she drew one, which they're supposed to come today or tomorrow, and her theme was togetherness. She drew a house and stuff like that.

Kelly Cervantes: Cannot wait to see it. Matt, I wonder, as someone who lives with epilepsy and also being the parent of a child with epilepsy, what advice do you have for other parents who have a child with epilepsy or other parents who are living with epilepsy themselves?

Matt Perrone: I mean, one, everybody's journey is different. Personally, I know that I'm extremely fortunate. And as a parent, I do understand how scary it is, and that's even in our world where we still are really fortunate. Even when she was having seizures once a month, we're still so fortunate. I don't take any of that for granted, but I still like the advice from where we sit, I still just come back to the mental health because that's where it affected me so personally. So I just want everybody to know that because if you know it it's an avenue that maybe you can get on top of before it goes, gets away from you.

Kelly Cervantes: Yeah, 100%. The more you know the better you can be on the lookout, and then the better that you can treat it either in yourself or in others. Matt, thank you so much for sharing your journey, for sharing your daughter's journey, and of course, everything that you do as an advocate within the epilepsy community, specifically EpiPalooza. I personally cannot wait to attend, April 29th in Teaneck, New Jersey. And then I know that you have another concert in Charlotte, so anyone in the Charlotte, North Carolina area, June 3rd, make sure that you head to cureepilepsy.org. There's information there on the EpiPalooza concert, Google it, whatever you need to do, but get out. Let's support it. Matt, thank you so very much.

Matt Perrone: Thank you, Kelly.

Kelly Cervantes: Thank you, Matt for sharing your and Abigail's epilepsy journeys. And thank you for all that you're doing to raise awareness and funds for epilepsy through EpiPalooza. For 25 years CURE Epilepsy has been dedicated to supporting patient-focused epilepsy research with the goal of finding a cure. If you would like to help us achieve that goal of a world without epilepsy, please visit cureepilepsy.org/donate. Cure Epilepsy, inspiring hope, and delivering impact. Thank you.

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