Seizing Life, episode 141
Overcoming Seizures to Pursue a Neuroscience Degree and Help Others Living with Epilepsy
Guest: Matthew Summerfield
(Transcript)

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

This month I'm happy to welcome Matthew Summerfield to the podcast. Matthew has lived most of his life with epilepsy and is now working towards a career in the epilepsy space. He's here today to share his journey from childhood onset through college to his pursuit of a PhD and his current work in a Cure Epilepsy funded research lab. Matthew, thank you so much for joining us today. To get us started, why don't you tell us how epilepsy first entered your life?

Matthew Summerfield: Yeah, I will. Thanks for having me, first of all. I'm very appreciative of the opportunity. So yeah, so epilepsy first entered my life in February of 2011. That's when I had my first seizure. It was a normal Saturday morning for me. I got up to do some homework. I think my parents were still sleeping or getting ready, it was like 7 AM. My older brother was still asleep, so it was just me. And then my parents heard some crashing around. They thought it was just the boys wrestling or playing hockey in the house in the morning like we always do. But really it was me having seizures and so I had several of them just going in and out. And then eventually they subsided and I woke up later in a hospital bed, and that was the end of the first introduction to seizures and epilepsy for me.

Kelly Cervantes: And how old were you at that time?

Matthew Summerfield: I was 11.

Kelly Cervantes: So you get to the hospital and what are you told?

Matthew Summerfield: Initially that "Matthew, your son had a seizure, just keep an eye on him for a while, and if he has another one that lasts longer than five minutes, bring them back in. But if it doesn't last longer than five minutes, you're fine." We did not leave the hospital with a diagnosis. They just kept me for 24 hours for surveillance to see if I had one in the hospital, they'd be right there to see it, but I didn't and I left the next morning.

Kelly Cervantes: Did they tell you to schedule an appointment with a neurologist?

Matthew Summerfield: No, they didn't. They really didn't do any help. They actually said, "Don't talk about it." And that really didn't sit well with me or my family. So we went to the Epilepsy Foundation of Michigan for some answers to our many, many questions.

Kelly Cervantes: So when did you get your epilepsy diagnosis?

Matthew Summerfield: Probably six months to a year later when I got into a child neurologist, got an EEG done, did an MRI, started discussing more about what was happening because I then had more and more seizures and were able to catalog what did they look like, when were they happening, did I remember anything, things like that so we could come in with some more knowledge that they could help us with.

Kelly Cervantes: And talk to me about what your treatment journey looked like. So you have that first seizure, it is six months or a year later before you get an epilepsy diagnosis. Is that also when you started medication?

Matthew Summerfield: Yeah. Yeah. So once I got into a child neurologist, the medication treatment started. It was really luck of the draw when it came to medications, especially as a lot of people with epilepsy know and doctors know and researchers know that, well, there's a lot of medications out there and they all don't work the same for every single patient. And so really it was try this, let's try that. Let's up the dosage on this one. Let's try these two together. And so yeah, it was really rough for the first couple of years because I wasn't sticking with anything. It would work for a little bit and then just stop working or it would make things worse, and we really didn't like those ones. So yeah, that's how treatment looked like for the first couple years.

Kelly Cervantes: I think it's so hard for people to understand. It certainly was for me, when my daughter was first diagnosed, I really thought that we would just give her a medication and it would all be better. It's hard to understand in the beginning or for a layperson to understand how many different kinds of epilepsy there are and all of the different causes and why one medication might work for someone but not for another, even if they're having the same seizure type. It really is this spectrum disorder that is so incredibly difficult to treat. And until you are introduced to this world, I think that's so hard for people to understand. Along that line, I wonder, you're 11 years old, 12, 13, you're going through all of these medications, you're in middle school, which is hell on earth for most of us. How did that impact you socially? Did you talk about it with your friends, with your teachers? I know you mentioned that one of those first doctors said that you shouldn't talk about it, but I have a funny feeling you didn't take his advice.

Matthew Summerfield: Yeah. No, I didn't. I didn't. Yeah, middle school's tough for anybody, but when you have the added effect of several anti-seizure medications with you every single day, it makes things worse. It didn't prevent me from telling people about it. Obviously, I wanted to be safe, I told my friends, I told my teachers, my coaches, stuff like that. It just made sense to me to keep people informed. But it did affect my concentration at school, just my ability to think about things. And I remember they were thinking about holding me back, I think in seventh or sixth grade, and my parents were like, "No, he can do this. You just got to work with him for a second. It's not my child's thought process and he's not unable to do things. He's just sedated pretty much."

Kelly Cervantes: Yeah. Did you have an IEP?

Matthew Summerfield: No. No. My school resources were lacking and to defend everybody, I was a bit hard-headed, I'm like "I can do this. I'm fine. I'm normal", because in the sense I took medications every day and that didn't make me feel great. And so I just wanted to go to school and be a normal kid. Right?

Kelly Cervantes: Yeah. And along those lines, you continued to play sports. How did that impact you on the ice or other sports that you were playing, and how did your doctors feel about that?

Matthew Summerfield: Initially, they were like, "Matthew will be lucky if he graduates high school. Don't expect him to get a job. Sports, let's lay off sports, that's dangerous with epilepsy. And listen, we will give you that one. If, I don't know, Matthew did swimming..." Which I didn't. I'm a terrible swimmer, but I played hockey, which for those that don't know anything about hockey, you're covered in pads. It's like the best sport if you had a seizure, you wouldn't be injured, right? It's great. And I loved hockey more than anything else at that time in my life, and it was the only way to escape what my reality was. Right?

Kelly Cervantes: I think you bring up a really incredible point about the quality of life with epilepsy and how maybe playing sports wasn't the safest thing for you to do physically. However, it helped you emotionally, it helped you mentally. It allowed you to still have a social life, to be a part of a team. All of these other aspects, I think there's such a balance when we're treating epilepsy that is not just the medications, but it is that balance in finding a quality of life where you can still enjoy the things that make you happy, that you can still have a life. Otherwise, you're all drugged up on the medication, and if you're not enjoying it, it's hard to reconcile that. So I think that quality of life, that balance there is just so important.

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 talked about how you shared with your friends and with your teachers. In high school, did you continue to do that? Did you get better control of your seizures? How did your epilepsy evolve both in the way that you spoke about it and the way that it affected you?

Matthew Summerfield: Yeah, yeah. It evolved I would like to say a little better, probably around first year of high school, second year of high school, my seizures became less frequent, which was really nice. I started taking Keppra, which listen, those with epilepsy that are on Keppra love Keppra, there are some downsides. The Keppra rage does exist, but it was at least for me, very helpful. And with that, I was able to just feel normal. My quality of life went up, and obviously I was still very vocal about it, talking to my teachers. That's when I became more and more involved with epilepsy awareness and I felt that I was in control for a bit. Right?

Kelly Cervantes: Yeah. But tell us about Matthew's Mob.

Matthew Summerfield: Yeah. So the Epilepsy Foundation in Michigan, they do these summer strolls for epilepsy and the closest one to me was 15 minutes away from my hometown. And at these events, people, they make your own team, and usually it's like JJ Jerry's group with a Jay or something like that. And I'm like, okay, it's got to be fun or something like that. So Matthew's Mob, I'm not that creative, but at least I got that across. And so we attended that probably in the first year I got diagnosed with epilepsy, and we had a small group and we got introduced to everybody else.

And we're like, oh, we can fundraise money for epilepsy research that's underfunded and very much needed. And so years after that, we just forged our own path for trying to increase awareness and fundraise money for research by doing benefit dinners or silent auctions. And then in high school, I did epilepsy awareness hockey games where we had a 50/50 raffle and a bake sale, and all the proceeds would go to the foundation and I made my own jerseys for that. And it was a way to combine a lot of things, a fun event, something everybody would enjoy, and then maybe, just maybe they learned something about epilepsy and I think it worked pretty well.

Kelly Cervantes: Yeah, I love it. I love that you made your own jerseys. That's so much fun. After high school, it was your dream to go into the military, which can be a challenge for someone with epilepsy. Talk to us about that journey.

Matthew Summerfield: Yeah. I just always wanted to be in the military, and we'd have recruiters come to our high school during lunch and talk to us and the Marines, which is where I wanted to go, I just always wanted to be a Marine, they're like, "Hey, the military academy is more lenient with medical waivers." Because I brought up that I had epilepsy. I'm like, "It's not great. Right?" And they're like, "Well, there could be a way around it." I'm like, "Oh, 'could' I like that word." And so I worked at getting an appointment to the United States Military Academy. It's quite a long process, and you send in an application to get an application. And then in the initial application, I made it very well known that I had epilepsy. And I'm like, "Listen, maybe if all things go well, my epilepsy magically goes away."

This could have happened. And strangely enough, I didn't have any seizures during that period. And then August, right before my senior year, I think is when I got my medical waiver denied, and that's through the Department of Defense for a history of epilepsy. We can't guarantee you that you won't have another seizure. I'm like, I get it. That makes sense, which is fine. Tough pill to swallow, but I've been taking medication my entire life so I can swallow a lot of pills, it's fine. And then strangely enough, just to put salt on the wound, I had a grand mal seizure, at the time I called them grand mal. Now there's called tonicclonics. I get it. I had a tonic-clonic like a month later in school, and I'm like, "Oh, tough." So yeah, so listen, but you got to roll with punches. You can't give up.

Kelly Cervantes: No. And it didn't stop you from moving forward. You attended Hope College in Holland, Michigan, which is, we were talking earlier, one of my favorite places in the world. Talk to us about how you ended up at Hope College and what you studied there.

Matthew Summerfield: Yeah. It was recommended by a friend of my mom's that she took her son, look at Hope College. It's a nice small college. He'll like it. I'm from a small high school. Big universities are like, there's too many people here. And they offered a degree in neuroscience, and I was interested in trying to figure out as much as I could about epilepsy. That was my goal. I didn't really know what that meant. Maybe it meant being a doctor. And I'm like, I could do that. And so I went there. That was my intent. I studied on the pre-med track, it's unofficially officially called, studying neuroscience and psychology and biology and chemistry.

Kelly Cervantes: That transition from high school to college or high school, living at home to not living with your parents anymore. That's challenging for anyone. But when you have epilepsy, when seizures are a part of that transition, it can be even more challenging. And not to mention that those early 20-something years, the risks for SUDEP increase as well. What advice do you have for teens, for parents who are about to move out of their parents' house to gain some freedom and independence, and moving in with a roommate or whatever that looks like. What advice do you give to them? Are there certain things that worked for you to help make that transition more successful?

Matthew Summerfield: Yeah, there's some key pieces of advice that I always like to give. And I'm like, listen, take them if you want, they'll help you. And one of the biggest ones, and I'm like, you're going from, let's say your home nest, your mom and dad, they love you very much. You're going to college where not a lot of people know who you are. Everybody's there for their own reasons. And so, one of the biggest things you got to do is to create another team of support. When you're, say a freshman, you have a roommate or two, and you usually live on a floor with a bunch of other people, and there's an RA that's in charge of you guys, making sure you guys are okay and whatnot. Listen, this is when you got to start defending for yourself, advocating for yourself and say, "Hey, I have epilepsy. I do take medications."

Or if you have some sort of stimulator, you talk about that. You have to make your new friends, your new community well-informed about your situation. It's not just like, "Hey, I have epilepsy." And they're like, "Oh, cool, whatever." It's like, "No, do you understand what epilepsy is? Do you know what a seizure is?" And if they don't, then be like, "Okay, listen, this is how you appropriately respond to if I have a seizure, here's my mom and dad's number, call them. Then you can call 911, stuff like that." You got to build that team. And second, you just have to be very aware of what you're doing, which sounds crazy, but keep a log of how you're feeling. Did you take your medications on time? Did you drink enough water? Did you eat enough?

How stressed are you? What does your quality of life look like? College is tough, man. I get it. I was there. It's tough, but you got to look out for you right now and make sure you have a good group. I was fortunately blessed to have a great group of friends that were always checking on me, but you develop that team and they'll take care of you. And probably the last piece of advice is every college campus, university should have a disability services offices, our office, and reach out to them with any help that you may need, any accommodations that you may need, especially say if it's transportation needs or anything like that, or academic accommodations, they're more than willing to help. But yeah, it's scary but you can do this.

Kelly Cervantes: Yeah. The support system is there. You just have to seek it out and ask for it.

Matthew Summerfield: Yeah.

Kelly Cervantes: Talk to us about the research that you're doing in Iowa, the lab and what you're working on.

Matthew Summerfield: Yeah, so I realized that, well, medical school might not work well given all the stress and the time commitment and just what that in combination might reveal about someone with epilepsy and could cause some seizures, particularly in my case. But I'm like, what can I do to help those with epilepsy without being a doctor? And my advisor at the time, he's like, "As a doctor, you can only help with what's available to help. As a researcher, you can go find things that are new to go give to what can be used for help." You can find Treatment C that doesn't exist yet." And I'm like, "Okay, I can see that. Well, where do I go for that?" He's like, "Well, anywhere." I'm like, "Yeah, but where do I go for that specifically about epilepsy though?" And that led me from Hope College to Iowa.

So I work in Dr. Gordon Buchanan's lab here at the University of Iowa, and we study specifically SUDEP, so sudden unexpected death in epilepsy, specifically, why does SUDEP happen? Why does it happen in specific cases and circumstances, but not happen for everybody with epilepsy, right? I know that's a very big question is why. Underneath that is like, well, what is the mechanisms that, I don't know, are impaired during and after a seizure that don't allow the individual to properly recuperate or get back online, as I would like to say, after a seizure? So we're doing our best to answer these questions, but it's tough.

Kelly Cervantes: And is this a field of study that you think you want to keep with, where does Matthew go from here?

Matthew Summerfield: That's a good question. Research is a lot of fun. Every day is a puzzle and you just day after day, you're trying to put the pieces together and maybe it makes sense, but at the end of the day, I would like to get back and start working with people with epilepsy again, that's my niche. I love person to person interaction, and I believe that's one of my strengths. And especially helping people conquer their new diagnosis, adapt to this new lifestyle, but try to maintain what they want in life.

Kelly Cervantes: Yeah. I can identify with you on that as well. What is the status of your epilepsy today?

Matthew Summerfield: So I would say arguably it's controlled with medication. Recently I've been having some events. I've just been calling them, they tonic-clonic, they could be absence seizures for all I know. I actually just completed a 72-hour EEG, yesterday I got off. So hopefully if that caught anything, it would be able to see something.

Kelly Cervantes: Well, I have to say, your hair looks fabulous for having had an EEG yesterday.

Matthew Summerfield: My mom's a hairstylist, so if I had bad hair, that would be a poor reflection of her work. So yeah.

Kelly Cervantes: So how has your epilepsy, it sounds like it is mostly controlled, some events here or there. Has it impacted your work in the lab at all?

Matthew Summerfield: Yeah, unfortunately, there's good days and bad days. The amount of medication and the type of medication I'm on makes me very, very tired, drowsy. I'm yawning all day long. I could have just drank coffee, I'm still yawning. I could be running, I could be yawning at the same time. It doesn't make any sense. And people are asked, "Are you tired?" And I'm like, "Always." Right? So there's that and it just having epilepsy and then being on medications, it can affect just comprehension and your cognition of a lot of things you do, just your thinking process and then retaining information. And if anybody knows anything about grad school, it's a lot of reading articles and remembering key details. And just for me, I just have to do it over and over and over again just to hammer out things to remember, which may be time-consuming, but that's unfortunately what I have to do. Luckily, I've been doing it for a very long time now, so I'm getting more accustomed to it. It is not as easy if I, say, didn't have epilepsy. Right?

Kelly Cervantes: Right.

Matthew Summerfield: Yeah.

Kelly Cervantes: And what is something that you wish that people knew about epilepsy?

Matthew Summerfield: Well, there's a shirt that I have from the Epilepsy Foundation and it says, "Epilepsy can affect anyone with a brain and anyone with a brain can affect epilepsy." I think that's just a great statement. But some people will be like, "Okay, what do you mean by that?" And I'm like, "Okay, well, obviously 1 in 26

Americans will develop epilepsy at some point in their lifetime." Anybody can develop it. And I love saying, whenever I'm talking to, especially my teachers or my professors, I explain that and I'm like, how many people are in this room, about 30 kids, right? That's your average US classroom. Odds are one of them will or has epilepsy. And I think that's an important part to just make people aware of how prevalent it is and what exactly it is. And that's probably the tougher part because epilepsy manifests itself in very, very different ways, especially the folks that have the absence seizures. It looks like they're especially in a classroom, daydreaming or not paying attention for a brief span of a couple seconds, but really they're having a seizure and that takes a toll on them.

Kelly Cervantes: Absolutely. It's an interesting point that you make. One student in every class has or will develop epilepsy, I actually was able to watch your TED Talk, and I appreciated the way that you spoke about, we are taught other first aid training, Heimlich maneuver, all of these things yet, so few of us have any understanding about what seizure first aid looks like.

Matthew Summerfield: Yep. Yeah. Preaching to the choir here. It's pretty simple stuff. But we have classes that you can be CPR certified, everybody knows what the Heimlich maneuver is and why it's used, right? These are life-saving maneuvers and processes that, well, let's incorporate seizure your first aid into this group. And it is just an easy placement of some life-saving techniques that will save lives. It is that simple.

Kelly Cervantes: Well, Matthew, I applaud your efforts. I can't wait to see where you go from here. Thank you so much for chatting with us today, and good luck.

Matthew Summerfield: Yeah, thank you. I appreciate it. Thanks for having me on.

Kelly Cervantes: Thank you, Matthew, for sharing your epilepsy journey and experiences with us. We wish you the best as you complete your PhD studies, and we look forward to seeing the impact you are sure to make on the lives of people with epilepsy. For more than 25 years, Cure Epilepsy has sought to improve the lives of people living with epilepsy by supporting research that will lead us to new therapies and cures. If you would like to help us achieve our goal of a world without epilepsy, please visit cureepilepsy.org/donate. Thank you.

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