

Seizing Life, episode 61
Community, Fatherhood and Seizures
Guests: Brittany and Alek Stewart
(Transcript)

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life. A bi-weekly podcast produced by CURE Epilepsy.
- Kelly Cervantes: 00:18 Recently CURE Epilepsy announced a strategic partnership with Epilepsy Canada. In honor of this partnership and in celebration of Epilepsy Awareness Month in Canada, we speak with Brittany and Alek Stewart in Meaford Ontario, Canada. Alek was diagnosed with epilepsy at 16 years old. He suffered from one or two tonic-clonic seizures per year until his mid- 20s, when an accident dramatically affected his seizure activity.
- Kelly Cervantes: 00:46 Alek and his wife Brittany, are here to tell their story with epilepsy and how they have come to partner with Epilepsy Canada, to raise funds for awareness and research. Brittany Alek, thank you so much for joining us today. Truly appreciate you sharing your joint story with us. Alek, tell us about your first seizure and your journey to a diagnosis.
- Alek Stewart: 01:10 So my first seizure happened when I was 16 years old. I had a few friends sleeping over. I woke up the next morning with very little sleep and I was laying in bed and I all of a sudden just kind of lost control of my left arm. And it was a very weird sensation, I guess. I didn't know what was going on and then all of a sudden my left arm just started to lift in the air. And the next thing I remember is my brother waking me up and taking me to the hospital. And then after several appointments with a neurologist and my general practitioner, it was then determined, he was diagnosed with epilepsy, so.
- Kelly Cervantes: 01:54 Where you able to gain control early on with medications? How was the time shortly after?
- Alek Stewart: 02:03 Yeah, it was actually... As far my case goes, it was I guess, good as you could ever ask for. First medication I was prescribed was epic vail and I was on that for about three or four years, and only suffering one to maybe three tonic-clonic seizures per year. And in my case, I thought it was great. So I just kind of went from there and as I moved along, is about four year period of being on epi vail and just suffering those one to three seizures per year.
- Alek Stewart: 02:38 I all of a sudden had this influx, it was about 10 or 15 seizures over the course of two weeks. And it kind of came into the blue and we didn't really know what to do. So it was just another appointment with the epileptologist at that point, and they

prescribed me on Lamotrigine, where it was again under control for a couple other years, so.

- Kelly Cervantes: 03:02 And how did your diagnosis, your seizures affect you socially, emotionally? Because those are pretty formative and pivotal years. You're 16 years old getting a diagnosis, young adult finding your way in the world. Meanwhile, you're navigating a chronic illness.
- Alek Stewart: 03:23 Sure. Yeah, so physically that was the easy part, was the bumps and bruises. But the emotional and the social anxiety and just emotion that I would get from not only the seizure itself, not after postictal state, it was just knowing that I could have a seizure. And at that point going through adolescents in high school, and if you're going to hang with friends or go to parties you... or at least I did, I always had that in the back of my mind, where I might have a seizure in front of them. And none of my friends at that point, that I was aware of, had ever suffered a seizure.
- Alek Stewart: 04:04 So the last thing I wanted to do was to someone in front of them and then have them deal with that. Because as many people know a tonic-clonic seizures, it can be pretty scary to witness, especially for the first time. So it was a pretty dark period of my life for the first few years. And again, going through adolescents, that's one of the last things you want to think about is dealing with some type of invisible illness, so.
- Kelly Cervantes: 04:34 Did you talk to your friends at all about your diagnosis? What did you know about epilepsy? Were you in a position that you could educate them?
- Alek Stewart: 04:42 No, I wish I could have. I was more focused on just being a kid. So epilepsy was... even though it was obviously very intertwined with my life at that point, it was... I would just focus on being a teenager and having fun in high school and college, and that was really it. And because of my lack of knowledge, or maybe it could have just been out of... I don't want to say embarrassment, but I'm assuming lack of knowledge is the only thing that I can think of at this point is the reason I really only kept it to close family and friends. So very few people, including my wife, that we went to high school together. She wasn't even aware of the situation.
- Kelly Cervantes: 05:29 So Brittany, when did you learn about Alek's epilepsy? I know you guys went to high school together. You actually knew each other long before that.

Brittany Stewart: 05:38 So I actually didn't find out that he even suffered with epilepsy until I was on my way home from the airport. My sister and I went on a trip to Europe together and her boyfriend at the time was somehow found out that Alek had suffered these strange seizures in about a week. And I hadn't really talked to him that much, other than a little, "Hey, how's it going?"

Brittany Stewart: 06:05 And so I touched base with him actually when I got home, and just learned a little bit more about him and just wanted to see how he was doing. And that's actually kind of... We started kind of hanging out and that's where everything kind of started from there.

Kelly Cervantes: 06:19 So your epilepsy brought you together.

Alek Stewart: 06:21 Exactly, exactly.

Brittany Stewart: 06:22 [inaudible 00:06:22].

Alek Stewart: 06:22 That's the silver lining.

Kelly Cervantes: 06:25 The best silver lining ever. So where were you when, Brittany, when you witnessed his first tonic-clonic seizure? Because you're right. They are incredibly difficult to watch. They can be violent and horribly scary.

Alek Stewart: 06:42 Yeah.

Brittany Stewart: 06:42 Mm-hmm (affirmative) So we been dating for about a year already before I actually witnessed my first one. I had seen some of the myoclonic jerks, but I had never actually witnessed a grand mal until about a year.

Brittany Stewart: 06:56 So we had gone to Niagara Falls and we went to go see [head concert 00:07:00]. And we were up late that night, got up early. He was having a rough day. We're wandering down to Clifton Hill to go for breakfast at one of those diners and we sat down ordered. And that's when I started to go into his first seizure that I saw, and-

Kelly Cervantes: 07:19 What was going through your mind at that point?

Brittany Stewart: 07:19 I was pretty terrified, I'm not going to lie. I kind of just... You kind of jump into that rule of what can I do, right? And we have talked about before in the past, what I should do in those situations. And I just remember getting up and helping him from the chair to the ground and just kind of helping his head, so his

head wasn't hitting the floor. And then he came to and yeah, I remember the waiter coming up to me after he had come to, and ask me if we would still wanted our orders. I kind of laughed, "Really? No we're going to go home. We're not saying for breakfast." But it was scary and they're still scary, I'm not going to lie. Every time I see one, it's still terrifying to me, but I think that's just our life with it right now.

- Kelly Cervantes: 08:15 I don't think they ever get easier to witness.
- Brittany Stewart: 08:18 No.
- Alek Stewart: 08:18 No.
- Brittany Stewart: 08:18 They really don't.
- Brandon: 08:23 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: 08:43 You had your seizures relatively under control, two or three of the tonic-clonics a year. And then there was an accident in your mid-20s. Tell us about that and how it impacted your seizures.
- Alek Stewart: 08:56 Yeah. So it was, as you mentioned. Yeah, it was... My seizures were very much so in my case, under control. Having a majority, most three tonic-clonic seizures a year was [inaudible 00:09:09]-
- Kelly Cervantes: 09:10 By the way, sorry to interrupt you. But I say that and you and you repeated it, but two to three seizures is not under control. Two or three tonic-clonic seizures should not be considered under control by any stretch of the imagination. Ideally we want complete and total seizure freedom, but I digress. I'm sorry, go ahead.
- Alek Stewart: 09:31 No you certainly, you're absolutely right. Obviously two or three seizures a year or two to three seizures too many. And I totally understand that every patient's situation is different. Someone might look at having 15 or 20 tonic-clonic seizures a year being under control, and if that's under control for them, that's fantastic.
- Alek Stewart: 09:51 As far as the workplace accident, I was... I have a very vague memory of what actually happened, but I was in my office. I had just been promoted within my company. So I moved my

position, my office was now in Toronto, which was kind of... It was kind of a catch-22. I was really happy where I was building my career, but at the same time knew one of my major triggers was sleep deprivation. And this job unfortunately required me to wake up at 4:00 or 4:30 every morning, and I wouldn't get home until about 9:30 at night.

- Alek Stewart: 10:31 So that over the span of a few months really took a toll on me. And I was suffering kind of an influx of myoclonic jerks. And then all of a sudden I had a tonic-clonic seizure at work. And it was in the bathroom, and I guess I was washing my hands and I unfortunately kind of collapsed and hit my head off the side of the sink. And that is really kind of all I remember until I was... I remember sitting at a table and kind of explaining to one of my colleagues that I had had a seizure. And then it just kind of... again my memory is so vague but it's from there to being in the ambulance and then handing it off to Toronto Western Hospital. Which was the hospital I see my neurologist [inaudible 00:11:21]. It was pretty scary, so.
- Kelly Cervantes: 11:23 Yeah, I can imagine. Was your work understanding? Have you had to deal with stigma at work?
- Alek Stewart: 11:31 Yeah. I think it's one of those things where you pretty much have to deal with stigmas surrounding epilepsy almost anywhere. It's just one of those conditions where I wish more people were educated behind it, because it is significantly more common than people are led to believe. So there was stigma and a lot of people, there were questions afterwards about the whole wooden spoon in the mouth. It's just, [inaudible 00:12:01] that's exact opposite of what you should do.
- Alek Stewart: 12:04 And it was simple things like that. My direct supervisor was fortunately he had seen and witnessed a few seizures in the past. So he was very understanding of it, which was... It made the situation a little bit easier.
- Kelly Cervantes: 12:22 After that accident, and your seizure activity increased. How did that affect your daily life?
- Alek Stewart: 12:26 And it really changed everything on a day-to-day level. They're still under the same situation as that day about six years ago, where they're not under control right now. I'm suffering about anywhere between three and five tonic-clonics a month. And now, which I had never suffered previously were now several petite models and about anywhere between... I know what we would say 10 to 30 or 40 myoclonic trips a day. So it can be pretty debilitating. But the day-to-day life were the things that I

almost feel I took for granted and the things that I almost lose comfort in doing.

- Alek Stewart: 13:14 We live within a walking distance to Georgia Bay, to the great lakes. But I don't feel comfortable with being in the water. And I think rightfully so, I don't feel comfortable having a shower at home unless [Britt 00:13:32] is within an earshot. And it's just things like that, that we like to try to take as many precautions as we can just to make it as safe as possible for, not only me, but for Britt, for our family.
- Kelly Cervantes: 13:44 Which leads me to my next part of the interview is that, congratulations on your baby. She is 16 months old now, is that correct?
- Alek Stewart: 13:56 Yeah.
- Kelly Cervantes: 13:57 Very exciting.
- Alek Stewart: 13:58 Thank you.
- Kelly Cervantes: 13:59 I have to imagine given the increase in your seizures after that accident, that there was a lot of consideration and discussions between the two of you and your doctors before starting your family.
- Brittany Stewart: 14:15 Yeah, we actually years ago, probably eight years ago, we went to just genetic counseling to see what the odds would be for, if we were to have kids, what their chances would be to have that [inaudible 00:14:28] without being diagnosed with it. And it was only an additional one or two percent more than the general population.
- Brittany Stewart: 14:36 Which is still significant, but low enough that we felt comfortable to want to have a family. But with a... In that control we kind of put it off for a little while to be honest, and just try to get him healthy and feeling better. But it got to the point where, in the end, a family is what we wanted and we decided to go ahead with it. Yeah, it was the best thing we ever did.
- Alek Stewart: 15:04 It was there was a previous to us actually having our daughter, my brother, and sister-in-law had their first. And that was one of my seizures initially were kind of not under control at all. And it was a pretty emotional time for me because with my niece, I didn't feel comfortable holding her. Just in fear that something might happen and it kind of broke my heart almost every day,

because it was something that I missed out on a big part of her life.

- Alek Stewart: 15:40 And it really did make me question if I could be a father and be a supporting father who would be around and be as hands-on as I want to be. So there were a lot of sleepless nights and a lot of conversations about it. And then it really came down to, I would rather be a father with epilepsy than not be a father.
- Kelly Cervantes: 16:06 And what ways, what advice would you give to other couples, who one or both of them have epilepsy and they want to start a family, what advice do you give them?
- Brittany Stewart: 16:17 We live in a bungalow house. So it's, we don't actually worry about stairs with him, with [Charlie 00:16:24]. And also we've got packing place set up and just things in order that if his, feels like something is not right, he can put her in a safe place. The one room that we hang out in all the time [inaudible 00:16:36] completely baby proof. So if anything were to happen, we know that this room is completely safe on her.
- Brittany Stewart: 16:42 In the end, if a family is what you want, you can make changes and you can lean on family. Family is there for a reason, right? They're there to support you. They want to be there.
- Kelly Cervantes: 16:52 Have you done genetic testing? I know you mentioned seeing a genetic counselor, but do you know a genetic cause or a brain formation issue that is the causing your epilepsy?
- Alek Stewart: 17:06 So we did a genetic testing, it was about two years ago. I guess or-
- Brittany Stewart: 17:11 Three years ago.
- Alek Stewart: 17:14 Yeah something like that, and we went through the family tree and did some blood work. A little bit of everything and unfortunately it just didn't come up with any answers that we were looking for, unfortunately. Which kind of left me with more questions, because that was one of the things that I was really hoping for. It's almost... It sounds strange to say it, but it's almost like we wish someone either within your family or a close friend also suffers with seizures just so they can emphasize with what you're going through. And unfortunately I with the gene testing, just we came out empty handed. But it's we're staying optimistic that hopefully we'll find some answers soon.

Kelly Cervantes: 18:00 Absolutely. I always recommend going back and doing genetic testing every few years.

Alek Stewart: 18:08 Absolutely.

Kelly Cervantes: 18:08 Because, my goodness that science is just moving forward in leaps and bounds. And it's so exciting to see.

Alek Stewart: 18:15 Couldn't agree more, yes.

Kelly Cervantes: 18:15 I know you mentioned that when you were younger, you weren't as knowledgeable about your epilepsy, but you have gotten significantly more involved in the epilepsy community in the last few years. Talk to us about what motivated you to become an advocate.

Alek Stewart: 18:32 The story can actually be connected to my mom. We all recently relocated to our current area, in Ontario. And my mom started up a conversation in [inaudible 00:18:45], "Do you know if there's any epilepsy support groups at all within our region?" And I wasn't aware at that point. So it was a quick Google search just to find out that the last epilepsy support group or really anything, it was about two years prior. And we're an area 200,000 people. So it's kind of mind boggling that there wouldn't ever be just even a seminar by monthly or quarterly, just to kind of gather people together and talk about living with epilepsy, what has changed for them.

Alek Stewart: 19:27 So when we noticed that there was a very, very better need for it and lack of it, we just decided to start social media platforms. And it really just started as a blog and me talking about my story, living with it and telling her story about being a spouse with someone with uncontrolled seizures. And then fortunately, that just kind of snowballed. And we had dozens of families reach out and tell their story and it was amazing.

Alek Stewart: 20:01 It was something that we didn't really expect. We didn't know who was going to kind of connect with us, but we just figured even if we connected with one family and made them realize that they weren't alone in this, that would have been perfect. So every other additional family or patient was [inaudible 00:20:23] which is gravy for us.

Kelly Cervantes: 20:25 I imagine, you had talked about how much it can help to... There was no one in your family who had epilepsy that could understand it. So I can only imagine how important having that community around you is. Brittany I wonder as the spouse, so

much of the attention is placed on Alek and his disease, but this absolutely affects your everyday life as well. And I wonder how having that community of understanding families benefited you as well.

- Brittany Stewart: 20:56 It's been pretty amazing. I had so many people come out and talk to me about advanced situations that epilepsy, whether its loved ones themselves or just friends and just having even that communication. Once people aware of what we're a part of, people kind of come out of the woodworks and start talking a little bit more than they probably would have never talked or expressed about before.
- Brittany Stewart: 21:22 So it's been actually really nice in that aspect because, right, people don't usually think about everybody else involved. They always think about the person suffering, but it is very much the whole family that is affected by it. So it's actually been... It's been really amazing and much more support than I ever thought I would've gotten.
- Kelly Cervantes: 21:46 So Alek, Brittany, tell me about how you found Epilepsy Canada, and what it was about their organization that inspired you to want to work with them.
- Alek Stewart: 21:57 So with the kind of overflowing support of within our social media and from the community, we just tried to figure a way that we could do a little bit more in any which way. And we eventually reached out and got in touch with Gary Collins from Epilepsy Canada. And over half a dozen conversations, we were trying to figure out a way to really bring something to this region where it's very much youth. And there were talks about walkathons and just any real events that we could do.
- Alek Stewart: 22:32 And it was later determined that we were going to be hosting a golf day. Something that would just be family friendly and no competition really is just something that would be fun for anybody of any skill level. And it went over significantly better than we had ever kind of envisioned. We didn't really have... I think our original goal was if we could raise!
- Brittany Stewart: 23:00 \$10,000.
- Alek Stewart: 23:01 Yeah, \$10,000 for epilepsy research, that would be fantastic. And we actually nearly hit \$18,000 to raise for epilepsy research. And I guess with my situation with having uncontrolled seizures, epilepsy research to me just seemed almost a no brainer and that's not a pun intended. It was just

one of those things where if someone else can go through life, not or at least finding a medication that works for them and helps control a seizures, that's all we want. That's really the main goal, so.

Brittany Stewart: 23:42 Yeah, research is so important to us. That's how Alek hopefully will be able to control his seizures one day and we stay optimistic that, that's going to happen. And so for us raising money towards research, was number one.

Alek Stewart: 23:58 Yeah.

Kelly Cervantes: 23:59 You guys thank you so much. You are an inspiration and I don't mean that in some cliché way, I am genuinely motivated by the two of you. And what you've done for your community, I think is pretty remarkable. So thank you again for talking with us today. I so appreciate you sharing your time. Give that little girl some extra cuddles and snuggles, and I hope to be able to see you guys in person someday.

Alek Stewart: 24:32 Well, thank you so much for having us.

Brittany Stewart: 24:38 Thank you.

Kelly Cervantes: 24:38 Thank you Alek and Brittany for sharing your experiences with us and for your efforts to raise awareness and funds for epilepsy research.

Kelly Cervantes: 24:45 CURE Epilepsy and Epilepsy Canada have entered into a strategic working relationship that formally commenced in January. This partnership will further both organizations ability to advance epilepsy research and find a cure. We hope that you will support our mission to end epilepsy by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.

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