

Seizing Life, episode 87
Finding Solutions and Pursuing Passions with Drug-resistant Epilepsy
Guest: Channing Seideman
(Transcript)

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
- Kelly Cervantes: 00:17 Today on Seizing Life, I'm happy to welcome Channing Seideman into the podcast. Channing experienced her first seizure at the age of nine and was subsequently diagnosed several months later, beginning a treatment journey that continues to this day. Channing is one of 30% of people living with epilepsy who do not respond to current medications. She is here to share her journey and tell us how she has managed to safely pursue her passion for skiing and horseback riding, despite her diagnosis. Channing, thank you so much for joining us today. I'm so excited to be able to talk to you, after having followed all of your advocacy and fundraising efforts online for all these years. I want to start by asking you about your very first seizure. How old were you, and what were the circumstances surrounding the event?
- Channing Seideman: 01:11 Well, thank you so much for this opportunity, Kelly. I had my first seizure when I was nine years old on June 27th, 2003 and my brother and my dad and I were playing Conquer the World Risk, which is why we were staying up so late, not [inaudible 00:01:28] risk. Out of the window on our front porch, we saw strobe lights and we had to go see what was going on. We saw a drunk driver getting pulled over. He was getting tested, they were doing all the normal tests and he was doing the, walk the line test. The next thing that I remember is, I was pulling up to the emergency room and I was in my dad's arms. I had asked my dad, why are we at the emergency room?
- Kelly Cervantes: 02:04 What did he tell you?
- Channing Seideman: 02:05 Honestly, Kelly, I don't remember.
- Kelly Cervantes: 02:09 I think that's probably pretty normal. So, you're at the emergency room and I imagine the doctors start doing tests. When and how were you ultimately diagnosed with epilepsy?
- Channing Seideman: 02:25 Five months later, I had then turned 10 at that point. And it was November 28th of that same year, 2003. I had my second tonic-clonic and we found ourselves back at the emergency room. After having had multiple tonic-clonic seizures, we got a diagnosis of epilepsy.

Kelly Cervantes: 02:45 So, you get this diagnosis of epilepsy after the second tonic-clonic and they're five months apart. You have these five months where I guess you're thinking it was just a random occurrence and then it happens again. What did your journey look like from there?

Channing Seideman: 03:10 Yeah. After getting the diagnosis, I had never heard the word of epilepsy before and they told us it was likely I was going to either grow out of it or it would be controlled with only one medication. My apologies, Kelly, my VNS is going off.

Kelly Cervantes: 03:28 No worries, whatsoever.

Channing Seideman: 03:31 For a few years, we were kind of... We held out that hope that yeah, I would outgrow it or I would be able to find that medication that would manage it. I did continue to break through with the tonic-clinic seizures. And because we lived in a small mountain town, there were no local specialists around, there were no large medical centers. To find a specialist, we had to drive to Denver.

Kelly Cervantes: 03:59 How long of a drive is that?

Channing Seideman: 04:02 It's a four hour drive and we tried several specialists and every specialist we went to, we got the same answer. We got one third get better, one third get worse and one third stay the same. Then there was one specialist to even told me to collect stamps, when she heard that I was a horseback rider.

Kelly Cervantes: 04:23 Instead. Because, here you are, clearly have a passion for skiing and you're horseback riding. Those are two very active sports, so she told you to collect stamps instead.

Channing Seideman: 04:36 She did.

Kelly Cervantes: 04:38 Lovely.

Channing Seideman: 04:40 In 2007, is kind of when our journey really began.

Kelly Cervantes: 04:45 How old were you at that time? I'm sorry.

Channing Seideman: 04:48 I was now 14 years old.

Kelly Cervantes: 04:54 I want to hit pause here, because I think that this is all too common. You have your first seizure tonic-clonic, that you're aware of really, at the age of nine. It's now five years later, you are 14 and you're saying that this is when your journey really

started? It's entirely too common, but it's really frustrating to hear that you're going four or five years before you feel like your epilepsy journey really started?

- Channing Seideman: 05:27 Yeah. We were really holding up that this was not going to be... We were not going to fall into that 20% that's refractory. We're just... We can... It was not... That was, no.
- Kelly Cervantes: 05:42 Yeah, I hear you. I know, it's got to be the next medicine and that's the hope, right? That's what keeps us going forward. What was it that happened when you were 14, that you felt like a turning point?
- Channing Seideman: 06:00 When I was 14, we decided, okay, we're making this journey to Denver. We still haven't found that specialist that's clicking with our family. So, we decided to go to New York to the NYU Langone and Comprehensive Epilepsy Center. There we met Dr. Blanca Vasquez who works with Orrin Devinsky and she specializes in epilepsy, women and hormones. She was the first epileptologist or neurologist where I actually asked a question. That was the first time I asked a question about what was going on with me. It was amazing to have to be able to do that. That was a big step for me in my journey. The turning point was though, that was when we got our first VEEG.
- Kelly Cervantes: 06:49 I'm sorry, that's when you got your first EEG?
- Channing Seideman: 06:53 VEEG, video EEG.
- Kelly Cervantes: 06:55 Oh, okay. You've had EEGs before, but this was the first video EEG.
- Channing Seideman: 06:59 This was the first video EEG.
- Kelly Cervantes: 07:01 Five years later. It's so frustrating to hear about these lapses and care. I'm sorry, keep going.
- Channing Seideman: 07:10 It's true. But this was the first video EEG and we spent four days and four nights in the hospital. I did not get the tonic-clonic, we didn't see any activity on the video, but the video EEG did capture subclinical data and it captured enough subclinical data to give us a lifelong diagnosis of juvenile myoclonic epilepsy. That's something we were not prepared for. We were not prepared for that lifelong diagnosis.
- Kelly Cervantes: 07:46 Yeah. That is a tough one. I'm curious, how the diagnosis impacted you both when you received that initial generalized

epilepsy diagnosis when you were nine, 10, and then again, when you got the juvenile myoclonic diagnosis at the age of 14. How did these moments impact you both socially as a growing teenager?

- Channing Seideman: 08:21 Right. Physically the seizures impacted me, they left me bedridden, the tonic-clonic seizures in particular. It would take me days of being in bed to recover, not just from the seizures itself, but the headache. That post seizure headache, that can keep me in bed itself. On a more mental and emotional level, it was this absence seizures, the subclinical seizures, the myoclonic jerks, those small, just moments in time that have this incredible impact on your quality of life. But they're so small, just those two seconds of a brain fart and it can impact your entire day. Can impact multiple days of your life.
- Kelly Cervantes: 09:16 When I'm sure it impacted your school work and your friends circle.
- Channing Seideman: 09:23 Yes. So, then socially, like you said. I was never really a social butterfly, but I did have those friends in school, and it changed relationship. They became more of babysitters asking me constantly, "Are you okay?" I found my social life in the second families that I had throughout the community, barn family, I had my ski family and that's where I found my social family, because those were areas where I could relate with the people around me. I think, that's really hard with epilepsy in the social aspect. It's unrelatable unless you have it and that's very hard.
- Kelly Cervantes: 10:09 Yeah. It's tough to understand unless you're living it.
- Brandon: 10:16 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 over 20 years CURE Epilepsy has been dedicated to 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: 10:41 You mentioned these other families largely within the activities. You did not take up stamp collecting. You continued to ski and to horseback ride. How did you and your family find a way to do that safely?
- Channing Seideman: 11:00 For the skiing, there were two things we wanted to take into consideration. The first was, are you going 80 miles down the mountain, racing? Luckily, no, I was not a racer. I enjoyed the bumps. The second thing we wanted to take into consideration

was the chair lifts. Having a seizure on the chair lift, you can fall off.

Kelly Cervantes: 11:27

Mm-hmm (affirmative).

Channing Seideman: 11:30

Luckily, there was a local organization that helps people with disabilities on the mountain. They had come up with a contraption, which was a climbing harness that you could clip to the chair lift. This was a great serve for us, but the problem with that one was that it left you dangling from the chair lift, and that just didn't seem smart to us. What we did is we took the climbing harness and we added the daisy chain to it. So, we have the carabiner and then the front of the climbing harness and we put the daisy chain on. Then I throw the daisy chain over the backseat of the chair lift and bring it through where the seat and the back rest, kind of, meet. You kind of throw it through there and you connect it to the carabiner.

Channing Seideman: 12:30

So, it keeps you in that upright position. The daisy chain is also crucial, because when you switch chairs, you may need to tighten it and you may need to loosen it. And so that's how we solve that. For horseback riding, I wear a helmet, the highest rate of safety helmet, and I also wear an inflatable vest. So, if I were to come off my horse, it would inflate in 0.09 seconds before I hit the ground, protecting my neck and my internal organs, my back. I also wear a quick release stirrup, so I don't get dragged. So, we found solutions. It didn't impact my quality of life as much.

Kelly Cervantes: 13:18

That's incredible. I love that you are still able to enjoy these activities that you love, because I think that you talk about the mental health impact, but being able to not lose these activities probably, greatly helped your mental health and your positivity toward life.

Channing Seideman: 13:41

It saved that part of it, yes. That quality of life is huge.

Kelly Cervantes: 13:47

Now, have you ever had a seizure while skiing or horseback riding?

Channing Seideman: 13:54

Both.

Kelly Cervantes: 13:55

Oh my God.

Channing Seideman: 13:58

The horseback riding experience, I was at a competition in Colorado. It was a jumping competition and we were going over a jump. I was in midair and I lost my vision. This was a smaller

seizure, but it impacted my sight. My horse knew, she knew what was going on. She knew that I wasn't with her, but muscle memory kicked in and I was able to stay on. Once we came back to the ground, she walked. She brought me rail. I still couldn't see, but I knew she had brought me to the rail. I could hear the crowd and the judges as we walked by them. I still couldn't see, but I could know where I was. She took me to the end gate where my parents and my trainer were.

- Kelly Cervantes: 14:55 Wow.
- Channing Seideman: 14:57 That's not the only time I've had a seizure on a horse and they've known every time, they've stopped every time and they've taken care of me every time.
- Kelly Cervantes: 15:04 Wow. And on the ski slope?
- Channing Seideman: 15:08 On the ski slope, I was fortunate enough to have the opportunity to hang out with ski patrol and go into the back country and go beneath those closed ropes where you're not allowed to go. That was a lot of fun. On our way up to one of those runs though, I did end up having a seizure and I got the bumpy toboggan ride down instead. But, I was in safe hands and nothing bad happened and I still had a great morning on the slopes. I'll take that.
- Kelly Cervantes: 15:50 You are so brave.
- Kelly Cervantes: 15:53 I am beyond impressed with you. Now, tell me about your treatment journey. What medications have you tried? We know you have a VNS. What has sort of your treatment journey been like, up to this point?
- Channing Seideman: 16:14 My first drug I was on was Lamictal, but then I also had tried Zonegran, Topamax, [inaudible 00:16:25]. We tried all of those before the video EEG and combinations of both of all of them. But once we got the diagnosed with juvenile myoclonic epilepsy, we started Keppra, because it targeted that epilepsy. I, unfortunately continued to break through.
- Kelly Cervantes: 16:49 Have you ever experienced a duration of seizure freedom?
- Channing Seideman: 16:53 Between 2013 and 2019. I went six years tonic-clonic free.
- Kelly Cervantes: 17:02 Wow. What do you attribute to that time period?

Channing Seideman: 17:09 I was on a significant amount of medication to control those seizures.

Kelly Cervantes: 17:13 Did you who have side effects from that substantial amount of medication?

Channing Seideman: 17:18 Yeah. So, once you get the meds to be able to manage the seizures, but once you are on that many meds and that dosage of medication, then the side effects can impact your quality of life more than the seizures.

Kelly Cervantes: 17:39 Yeah. It's a balance. What were some of the side effects that you experienced?

Channing Seideman: 17:44 So, all the side effects, all the medications had side effects such as dizziness, fatigue, nausea, [inaudible 00:17:55]. There were a couple that had more severe side effects. Depakote, it's been known to mess with your reproductive system. Valvatol has as a history of causing aplastic anemia. We never thought we'd be on either of those drugs. My cocktail now includes both of them.

Kelly Cervantes: 18:19 They're pretty heavy duty drugs, I'm familiar with both of them. What ultimately, led you to try the VNS and what has your experience been with the vagus nerve stimulator?

Channing Seideman: 18:34 It was the side effects that ultimately led the VNS, because of the side effects were having on my quality of life. That's when we took a really good look at the VNS, with the hopes that, by having the VNS, we could then maybe decrease a medication and try and get rid of some of those side effects. The VNS is interesting because we don't know what it's doing and it's not doing, but we've heard many stories where people have turned their VNS off, because they don't feel like it's doing anything, and their seizures have come back with a vengeance. While I don't know what it is and is not doing, I do think it's doing something.

Kelly Cervantes: 19:22 What are the side effects like with the VNS? Because... Excuse me. As we know, all of these treatments have side effects.

Channing Seideman: 19:30 Yeah. The main one with the VNS is I can lose my breath or get short of breath. One of the settings on the VNS is an autoStim that detects your heart rate. There's obviously a correlation between that increased heart rate and those to tonic-clonic seizures. Should it detect that an increased heart rate of a certain amount within a certain amount of time, it will send off

an extra burst of simulation on its own. When I ride, especially when I get my breath up and I'm exercising, it can set off that VNS and I can definitely get short of breath. There's also the side effect of the godfather voice, or as my brother would call it, C3PO.

Kelly Cervantes: 20:24 Sort of digitizes the vocal chords a little bit.

Channing Seideman: 20:27 It does, yes.

Kelly Cervantes: 20:30 What are your seizures like today?

Channing Seideman: 20:33 So today I struggle with the myoclonic jerks on a daily basis. I also struggle with occasional drop seizures and occasional absence seizures, as well as the subclinical. There are also those breakthrough tonic-clonics that I have.

Kelly Cervantes: 20:50 How often are you having those?

Channing Seideman: 20:52 I'd say the drop seizures are more frequent these days, but the tonic-clonic seizures, I'm going to say Kelly, once or twice a year these days.

Kelly Cervantes: 21:06 I mean, that's a lot better, but I will say that any amount of seizures is too many seizures, period.

Channing Seideman: 21:14 Yeah.

Kelly Cervantes: 21:14 It's just those tonic-clonic ones tend to be the scariest. The drop seizures are no walk in the park either. The other ones still affect your life. I mean, at the end of the day, it is finding that balance with the quality of life and the side effects and the seizure. I mean, you're walking a tight rope every single day.

Channing Seideman: 21:36 Yeah. Interestingly enough for us, it's not... The tonic-clonic seizures are, yes, they look like the big and scary ones, but there's also those small seizures that for me, those are more scare than the tonic-clonic ones. Because, walking across the street, I could space out for two seconds or even in the shower these days, I'm dealing with heat as a trigger and just taking a shower... Because, I was in there for maybe too long, maybe the water was just a tad bit too hot. I had a drop seizure in the shower. Which is why sometimes, I do feel safer on a horse that I do crossing the street, because on a horse, I have a blow up vest and a helmet. On the street I'm very vulnerable to cars coming each direction.

Kelly Cervantes: 22:41 I think that is such an important message. I thank you for sharing that all of the seizures suck. Sometimes, the ones that look smaller are even more dangerous than the ones that look scarier. Now, Channing I know that you have taken your love of horseback riding and are utilizing that to raise money for epilepsy research. The event that you put together is called Dressage for a Cause. For the record, I just had to be corrected on how to pronounce that. I know nothing about horseback riding, but I have this awesome ribbon that you guys sent me. And I love it! It's on my desk. Tell us about this event.

Channing Seideman: 23:26 So Dressage for a Cause is the platform I use in my effort to fund a \$100,000 research grant for a cure, the taking flight award more \$19,000 into that goal. The event itself it's centered around in a horse show that takes place every November at the farm that I ride at. It is just that Kelly, it is my dressage riding for a cause to find a cure for epilepsy.

Kelly Cervantes: 23:52 You're incredible and taking the fight so public and being the advocate that you are, it's not always easy. I commend you for that.

Channing Seideman: 24:06 Thank you. It's thanks to the epilepsy warriors who give me that motivation and we honor those warriors by having their names embroidered into the saddle pad that I ride in. Unfortunately in 2020, it was a two day event. My brain didn't let me show up for one of those for the first day. I was devastated, because I didn't get to fight for my warriors, but the next day I had the post seizure headache day, and usually that prevents me from putting my helmet on, because it's just that bad of a headache, but there's those warriors on my [inaudible 00:24:42]. So we put that riding helmet on and we got it in there for the warriors. That's why I ride, for a cure.

Kelly Cervantes: 24:50 For the record, you're making me cry. You are a warrior in and of yourself and hearing you speak this way when you are battling yourself every single day is really remarkable. To that end, I'd love to know, you are now in your twenties, you have been battling epilepsy now for over half your life. What advice would you give to another young person who has recently been diagnosed or the teen who has this diagnosis and is trying to navigate adolescence? What do you want them to know? What have you learned?

Channing Seideman: 25:37 There's two things that come to mind. The first one is finding the right doctor, because you got to have that relationship. It's so hard to find that doctor that fits you, because it's so hard to accept it when you're first diagnosed. It's that E word that you

don't talk about. You got to find that right doctor, where you can ask, "What is going on with me?"

- Channing Seideman: 26:04 The second thing that would be my advice is, be solution oriented. So, that quality of life that you have isn't impacted more or is impacted as little as possible. There's always a solution out there. You may not be able to race down a mountain, but you can still ski on a mountain. Even if it's a compromise between the two, find the solution. So you can have that. So you can have something that you can go to when epilepsy gets you in that place. When it just brings you down and you can't get out of that funk. So you can have that place to go to.
- Kelly Cervantes: 26:53 Well, for the record, I think that you are remarkable and it has been an honor to speak with you today. Thank you for sharing your story and I can't wait to live stream one of your upcoming shows. That'll be great fun. Thank you, thank you, thank you, Channing.
- Channing Seideman: 27:16 Thank you for having me, Kelly.
- Kelly Cervantes: 27:21 Thank you Channing, for sharing your epilepsy journey with us. Your determination to find a way to safely continue horseback riding and skiing is inspiring, and we thank you and your family for supporting research through Dressage for a Cause. As we noted at the top of the podcast, one third of those living with epilepsy cannot attain seizure freedom through medication. That is why CURE Epilepsy has funded epilepsy research since 1998. We remain unrelenting in our commitment to help find treatments and cures that will bring seizure freedom to those living with refractory epilepsy, like Channing. We hope you'll support epilepsy research by visiting [Cure Epilepsy.org/donate](http://CureEpilepsy.org/donate). Through research, there is hope. Thank you.
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