

Seizing Life, episode 58
The Best of Seizing Life 2020
(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: [00:17](#) This week, we revisit some of our favorite guests and discussions from the past year, in our Best of Seizing Life, 2020. Christin Godale, a PhD candidate at the University of Cincinnati, spoke with us about growing up with epilepsy and how her experiences have led her to pursue a career in epilepsy research.
- Christin Godale: [00:36](#) I was diagnosed quite young, around two, when my mom first saw that I was having absence seizures, the kind where you just stare off blankly and then it disrupts what you're doing. And she first noticed it when I would play with my toys, I would drop them, and she didn't know what they were. I was taken to an epileptologist and I was diagnosed with epilepsy. And even in the '90s, that was quite a diagnosis. We weren't as far advanced with our research and clinical understanding of the disease at the time. And it was hard, I'd say, for my family and myself.
- Kelly Cervantes: [01:17](#) You were diagnosed at such a young age. What was that like, growing up with epilepsy? How did it impact your childhood?
- Christin Godale: [01:26](#) It impacted it, I'd say, positively and negatively, positively in the sense that I got to spend a lot of time with my family. My mom would make these overnight EEG visits so fun. She got me an Easy-Bake Oven one time. We did crafts. But the next day, when I went in and I had to miss school or... it was hard. But growing up with it, at first, I didn't really understand it. And as a young child, that didn't bother me very much, missing out on a bunch of stuff, but it wasn't until I was in middle school, it became harder to live with. I struggled in school.
- Kelly Cervantes: [02:08](#) Did it impact the activities that you were able to participate in?
- Christin Godale: [02:12](#) Yeah. I wasn't able to do any sleepovers and I was just so afraid of all my peers seeing me have a seizure, and of course, that happened, and I lost a lot of friends because of... I had epilepsy and I had seizures. And at the time, I was always mad, like, "Oh, why am I losing friends?" But as an adult, I understand why seizures are really scary for adults, let alone kids. And I remember one time. I was in middle school and I had a seizure, and then I remember kids mimicking me have a seizure, and it was hard.

- Kelly Cervantes: [02:54](#) I can imagine the stigma that you felt along with that, so how was it when you got to high school? Did it get any better? Did you tell people after they witnessed the seizures in school, in middle school?
- Christin Godale: [03:14](#) So when I got to high school, I still tried to hide it. So I moved to a different city. My dad got a new job and I had a new chance to start off fresh. No one knew I had epilepsy. I'm going to hide it for as long as I can. I did that. But then again, you have a seizure, you lose friends, and it's the same thing all over again. And it was hard. I mean, I know that's a simple thing to say, but it was hard growing up with epilepsy, it really was. [crosstalk 00:03:47]-
- Kelly Cervantes: [03:46](#) What changed to mind to start telling people that you had epilepsy, versus keeping it a secret?
- Christin Godale: [03:54](#) Oh, there are a couple things. But I remember when I was in high school, I had really bad status epilepticus event, so I was hospitalized. It was bad, but my neurologist actually encouraged me to start to learn about the disease. They gave me books. I'm in the hospital with all these electrodes on my head and having seizures, but I'm reading about epilepsy. My doctor then invited me to an advocacy event they were having at the hospital. And I was just volunteering, and I came into contact with this young boy, and he obviously had epilepsy. He was nine or something.
- Christin Godale: [04:44](#) And he looked at me and he's like, "You have epilepsy?" And I responded, "Yeah," and then he began to ask me all of these hard questions, like, "Can you get married? Can you have a job? Can you go to school? Can you have friends? Can you do all this stuff?" And at the time, I wasn't sure, but of course I said, "Yes." And after that event in my life, I began to reevaluate how I viewed the disease and that really started my advocacy journey. And in college, that's what made me so open about it. And as a blossoming neuroscientist who wanted to study the disease, it wouldn't look too great if I started to hide it from the very beginning of my academic journey.
- Kelly Cervantes: [05:38](#) What advice would you give to children, students, teenagers who have epilepsy?
- Christin Godale: [05:47](#) For the children who have this disorder, I would just like to say, one, don't be afraid to talk to someone about it and don't be afraid of feeling rejected because you have epilepsy. And I say that because I wish someone would have told me that, and I think it would have made my childhood much more fun. And you don't have to be ashamed, you really don't. I just wish that

someone told me that. I know it's a simple reaction, but that's really what I wanted to hear when I was five, six, seven. I just wanted someone to tell me it would be okay and that my life wouldn't be ruined if I had a seizure.

- Kelly Cervantes: [06:44](#) Former U.S. Army Captain, Patrick Horan, and his wife, Patty, recounted the devastating traumatic brain injury that Patrick suffered while serving in Iraq, and the challenges to his recovery process caused by the onset of post-traumatic epilepsy.
- Patrick Horan: [06:58](#) 2007, that's when I'd been in a wreck for a year. And then one night, we were going at night to do a recon to make sure the bad guys weren't setting IEDs for the next day. So it was about two o'clock, three o'clock in the morning. I went with one of my soldiers and we were going to go downstairs to get some water, Gatorade, and all this stuff, and bring it back upstairs.
- Patrick Horan: [07:31](#) And when we were about to go downstairs, across the street, I guess, I'm not sure why, but [inaudible 00:07:41] two Iraqis shot at us. And my soldier, he jumped down, and it was too late for me, and I got shot right through my night vision that I was wearing, and so exploded. And then from there, it all just went into my...
- Patty Horan: [08:04](#) Helmet?
- Patrick Horan: [08:06](#) My helmet, yeah, or my brain, also. And I-
- Patty Horan: [08:10](#) Well, there's a small flap in the helmet, so the bullet actually snuck inside the helmet.
- Patrick Horan: [08:17](#) And I passed out. I don't remember any of that. I think it was about two months. But one of my soldiers, he was trying to call me on the radio, and then he ran back upstairs to my soldiers who had come over to see what I was doing. My soldier, he took off my helmet and just saw that half of my brain was just gone. It was destroyed.
- Patty Horan: [08:50](#) Yeah, they couldn't tell where the injury was, so they took off the helmet, which probably wasn't the best idea, and half his skull came off with it.
- Patrick Horan: [08:58](#) It was incredible. From there, it was about 10, 15 minutes away, we went to Baghdad, and then less than 10 minutes later, I was in a helicopter going to Balad. And I landed there 45 minutes later, and they did the surgery right away, took off 40% of my skull.

Kelly Cervantes: [09:23](#) You clearly have a traumatic brain injury. Did anyone mention post-traumatic epilepsy to you at this point?

Patty Horan: [09:30](#) So one of the things on the list of probably 30 things that could go wrong is infection, swelling, unable to maintain the pressure on the brain. One big thing was seizure, so they did say, if Pat has a seizure within the first three weeks, that he would most likely pass away. So that was my first introduction to epilepsy, or post-traumatic-

Kelly Cervantes: [09:55](#) And did they say anything to you about what happens if he has a seizure after three weeks, or to be on the lookout for that?

Patty Horan: [10:02](#) No. I mean, that really stuck in my mind, and he did not have a seizure, and prophylactically, they gave him Keppra in the ICU for the first couple of weeks. So thankfully, at that point, we know epilepsy occurred.

Patty Horan: [10:19](#) We were in Chicago. He did a lot of intense rehab. And they did give me this really great book on brain injury recovery, and it had all sorts of things, from the coma scale, how they emerge out of a coma, and cognition levels. And it was a great book, and there was a section on epilepsy. No one really spoke to me much about it in Chicago, just gave me the book. And I remember seeing the page on it and thinking that it was a possibility, but I just felt like, oh, maybe that's not going to happen to us.

Kelly Cervantes: [10:55](#) But it did, unfortunately.

Patty Horan: [10:56](#) And it did.

Kelly Cervantes: [10:58](#) And can you tell us what happened when that first seizure occurred?

Patrick Horan: [11:02](#) Patty said she woke up around two o'clock in the morning, and just all of a sudden, I was having a grand mal seizure. And Patty had no idea what a grand mal seizure was, so [crosstalk 00:11:15]-

Patty Horan: [11:15](#) It was probably the scariest moment in my entire life, honestly. I thought he was dying. It was four and a half months into recovery, and I thought, what in the world? He came back alive from the [inaudible 00:11:30] wound. We worked really hard, and now he's going to die tonight. That's...

- Patrick Horan: [11:35](#) So she ran outside when I... in the other room, looked for a nurse, and it took a couple minutes to find a nurse. And then the nurse went with Patty to my room and the nurse was like, "Oh, he'll be okay, he'll be okay. He'll stop. He's just having a seizure."
- Patty Horan: [11:56](#) Yeah, she identified it as kind of normal for the brain injury that he had, but it was a full body, very violent convulsive seizure. But at least, when it did surface, he was in bed, we were in a hospital, we could get medical quickly. It was pretty amazing that night too, because it stopped and the nurse went away, and then 10 minutes later, it started again. So it was this rolling seizure situation, which was extremely dangerous.
- Patty Horan: [12:24](#) They call the paramedics from Northwestern, throw him on a gurney. We're running at two in the morning through all these hallways, because there's these secret passageways from RIC to Northwestern. So they had to get him on a Dilantin drip as soon as possible because it could cause more brain damage. So it was an exciting evening, to say the least. But all of the rehab that we'd worked on for months was just gone in a blank. [crosstalk 00:12:52]-
- Kelly Cervantes: [12:51](#) Yeah, that was going to be my very next question, is just, how did the appearance of seizures impact Pat's recovery?
- Patty Horan: [13:03](#) It was hard. I mean, most of his seizures were in the first couple of years, and that's when we were working the RNS and the brain was putting itself back together, he was making the most gains. But then, we'd get these horrible grand mals and we were doing all sorts of different medication regimens, trying to figure this out. So it really got in the way of recovery and it was very deflating.
- Brandon: [13:26](#) Hi, this is Brandon from CURE Epilepsy. An estimated 3.4 million Americans and 65 million people worldwide currently live with epilepsy. For more than 20 years, CURE Epilepsy has funded cutting-edge, patient-focused research. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.
- Kelly Cervantes: [13:49](#) We spoke with Dr. Andres Kanner, director of the International Epilepsy Center at the University of Miami Miller School of Medicine, about the relationship between epilepsy and mental health.

- Kelly Cervantes: [14:00](#) Can you break it down for us, just on a very basic level, how mental health and epilepsy are connected?
- Dr. Andres Kanner: [14:08](#) There is a very close relationship between what we call psychiatric comorbidities in epilepsy. Psychiatric comorbidity is a psychiatric condition that tends to occur more frequent in people with epilepsy than in the general population. And of these comorbidities, the most frequent ones are mood, which includes depressive disorders and anxiety disorders, are the most frequently encountered conditions.
- Dr. Andres Kanner: [14:45](#) Now, that would imply that when you suffer from epilepsy, there are psychological consequences, but it's actually much more complex than looking at mental health phenomenon as a consequence of the epilepsy, because very often, the person who suffers from epilepsy has already suffered from a history of mood or anxiety disorder or other psychiatric conditions before the onset of epilepsy. And then, they may experience these psychiatric conditions after their seizure disorder has become manifested.
- Dr. Andres Kanner: [15:34](#) Not only are people with epilepsy at greater risk of developing certain psychiatric conditions, but if you have a history of depression, anxiety, attention deficit disorder with an inattentive type, you've got an increased risk of developing epilepsy. So you can, in fact, start identifying the bidirectional relationship between these psychiatric conditions and epilepsy.
- Kelly Cervantes: [16:07](#) When I was preparing for this episode, to learn that, that it's bidirectional, I was shocked by that.
- Dr. Andres Kanner: [16:15](#) The fact is, the majority of people with depression and anxiety don't develop epilepsy. But when you look at the risk that people who've had these psychiatric conditions develop epilepsy, it's higher than that of the general population. So if you have, for example, major depressive disorder, your chance of developing epilepsy compared to the general population is twofold higher. If you have a history of having an anxiety disorder, the risk that you have of developing epilepsy compared to the general population is also between three and threefold higher.
- Dr. Andres Kanner: [17:01](#) Now, that doesn't mean that these conditions are causing the epilepsy. The most likely scenario is that the pathogenic mechanisms that are apparent in these psychiatric disorders occur as well in epilepsy.

- Kelly Cervantes: [17:21](#) Up until recently, I really do feel like the conversation around epilepsy has been around the seizures. And it's really only been recently that the scientific community has looked at epilepsy as how it is affecting the entire person, and in this case, mental health. Are steps being taken to connect these two, to have psychiatrists available, are... because an epileptologist is not a psychiatrist. Those are two very different practices. How do they work together, and is that happening, and how can we make it happen?
- Dr. Andres Kanner: [18:00](#) It's important that the neurologist who's treating the patient with epilepsy become part of the evaluation of the psychiatric profile of the patient, as part of the comprehensive evaluation of the seizure disorder and of the patient, and not relegated to the therapist, psychologist, or psychiatrist.
- Dr. Andres Kanner: [18:28](#) When you look at the journey of a person with epilepsy after the diagnosis is made, there are a lot of psychological processes that the patient goes through that we also fail to recognize, and that also can then perpetrate psychological issues for a long time.
- Dr. Andres Kanner: [18:53](#) And the best example is, for example, the issue of accepting the fact that when you have a seizure and when you're told that you have epilepsy, you lose your predictability in life, right? When you've told you have epilepsy, you don't know when you're going to have another seizure, or if you're going to have another seizure. And the first thing that we, as neurologists, epileptologists, or clinicians have to help patients and family members deal with, is the acceptance of the predictability of life has been lost.
- Kelly Cervantes: [19:36](#) So how should a neurologist present the mental health issues to a patient, and when should they be presented?
- Dr. Andres Kanner: [19:47](#) This is something that should be part of the overall initial evaluation of the patient with epilepsy. I think any patient with epilepsy should undergo a careful evaluation as to the previous history of psychiatric illness, mainly mood disorder, anxiety disorder, attention deficit disorder and psychosis, but also all the family psychiatric history. That should be part of the evaluation of any patient with epilepsy.
- Dr. Andres Kanner: [20:20](#) And the reason that that is very important is because the presence of a previous psychiatric history, or a family psychiatric history, should be a red flag for the physician to anticipate that that individual may be at increased risk of experiencing further recurrence of these psychiatric conditions in the course of their

life, and that's just because that's a natural course of these conditions.

- Dr. Andres Kanner: [20:49](#) But if you have a family psychiatric history, that also puts you at increased risk of experiencing these conditions under certain situations that put you at increased level of stress, such as having a diagnose of epilepsy, the big changes that are associated with a diagnose of epilepsy, where you can't drive, you cannot do a whole variety of things. If you have a genetic predisposition for mood or anxiety disorder, that can bring those conditions up to the surface.
- Kelly Cervantes: [21:24](#) CURE Epilepsy Taking Flight grantee, Dr. Gemma Carvill, explained how genetic discoveries in the lab may lead to precision care in the doctor's office. Tell us about the research that you're doing now.
- Dr. Gemma Carvill: [21:36](#) It's a completely crazy idea that, if it pans out, could really transform clinical care for patients, well, in our case, clinical care for patients. And so, the idea that we had was that we may be able to use cell-free DNA as a biomarker. So most places where people have come across cell-free DNA is with noninvasive prenatal testing. So previously, particularly with advanced maternal age, you would have an amniocentesis, right? And that's a particularly invasive procedure, and the idea there is to look for any sort of chromosomal abnormalities.
- Dr. Gemma Carvill: [22:14](#) But there are lots of risks associated with amniocentesis, and so what a colleague of mine had this great idea that he could look in the plasma. So if you separate out blood, you get this top layer that's called plasma. And in there is what's called cell-free DNA. And cell-free DNA comes from a cell that has died and burst open, and when that cell bursts open, the DNA is released, eventually, into the plasma. And it exists as really short, little fragments of DNA, so roughly around 150 nucleotides, so really, really small.
- Dr. Gemma Carvill: [22:48](#) But what you can do is then study that DNA, so in the case of noninvasive prenatal testing, you can actually find fetal DNA in the plasma of mom, and then you can use that to determine whether the fetus has a potential chromosomal abnormality. So cell-free DNA has completely transformed NIPT, and now it's the first-line test. Amniocentesis is not done anymore.
- Dr. Gemma Carvill: [23:14](#) So following on from that, we had the idea that perhaps we could use cell-free DNA from patients with epilepsy. So again, here, the idea is, at least in a subset of individuals who are having seizures, those seizures can lead to cell death. And then,

when cell death occurs, those short little fragments of DNA may exist in the cerebrospinal fluid, as well as in the plasma of that individual.

- Dr. Gemma Carvill: [23:38](#) So what we're trying to do is ask the question, can we find cell-free DNA that originated from the brain in the plasma of individuals with epilepsy? And the idea there is, we could potentially develop it as a biomarker. One of the big challenges in epilepsy is that one of the only real biomarkers, if you will, is having an EEG, or having an MRI, in the case of looking for structural abnormalities. And those are pretty tricky techniques, right, or approaches, rather, because you need to go into the hospital, you need to be monitored-
- Kelly Cervantes: [24:14](#) They're very time-consuming.
- Dr. Gemma Carvill: [24:16](#) Exactly, exactly. And there is no peripheral biomarker. There's no way we can look in the blood and see if an individual has had a seizure or not. So it's a completely crazy idea, but everybody thought that looking for cell-free DNA, well, fetal cell-free DNA, in the blood of moms, was crazy. And now, it's main line. So we're hoping to try and apply some of these ideas to see if we can use cell-free DNA as a biomarker in epilepsy.
- Kelly Cervantes: [24:42](#) So it is diagnosing epilepsy using the blood, which is different than, say, doing whole-exome sequencing or whole-genome sequencing where you're looking more for the diagnostic cause. So this way, you don't have to spend three to four days in the hospital, or longer, waiting for that seizure to happen. You can just test the blood and diagnose the epilepsy from that.
- Dr. Gemma Carvill: [25:11](#) And you can potentially tell if an individual is having seizures, yep. So it's a long, long way from being in the clinic, but that's kind of the end goal of, if this were to work and we could find that cell-free DNA, this is one potential application.
- Kelly Cervantes: [25:24](#) I've only been a part of this community for the last four years, and even the testing and the knowledge that has become available in genetics in those four years is outstanding. From being deep inside the genetic research piece of it, what are the changes that you have seen in the last 10, 15 years?
- Dr. Gemma Carvill: [25:46](#) Mm-hmm (affirmative). So I started in this field about probably 10 years ago now, and back then, there were a handful of genes that we knew caused epilepsy, maybe 10, 15, not very many at all. And some folks within the community even doubted whether genetics was going to play a big role in epilepsy. And

now, 10 years later, we can do exome sequencing, we can do genome sequencing. I think what's been really exciting to watch is, one, for a lot of families, we can find an answer, and that's, at least in the early-onset pediatric epilepsies, that's anywhere between 30 and 50% of cases.

Dr. Gemma Carvill: [26:27](#)

The other part has been that we're really going to, in the next five to 10 years, start seeing where, once you can identify a genetic mutation, that there are going to be precision therapy choices. Another good example is perhaps SCN1A, so here, if you have a mutation in this gene, there are certain medications that should be avoided.

Dr. Gemma Carvill: [26:45](#)

So I think, more and more, as we identify more individuals with mutations in these genes, we can start to get a better sense of which medications work, which ones don't, but then also moving forward, thinking about novel therapies. There's exciting work in antisense oligos where they are trying to target specific genes to prevent seizures, and there will be a lot more tailored therapies based around those genes. In the next five to 10 years, like I said, I think that there are going to be precision therapies for some of these epilepsies. I think that is going to be one exciting area of research.

Kelly Cervantes: [27:24](#)

We would like to thank all of the guests who joined us on the Seizing Life podcast during 2020. Though we couldn't sit together in a kitchen and discuss issues face to face, we truly appreciate the time, energy, advice and expertise that our guests have shared with us throughout the year. We hope you will consider supporting CURE Epilepsy and our mission to fund epilepsy research by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.