Seizing Life, episode 44
It’s Personal: Christin Godale’s Path to Epilepsy Research
Guest: Christin Godale
(Transcript)

Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Citizens United for Research in Epilepsy, CURE.

Kelly Cervantes: 00:18 Today, I'm excited to speak with Christin Godale, a PhD candidate in the University of Cincinnati's neuroscience graduate program, where she focuses on epilepsy research. Christin is also an epilepsy patient who was diagnosed at a young age and dealt with both seizures and stigma for most of her childhood and adolescence. She's here to tell us about her journey with epilepsy, her decision to become more public about her experiences and her goal of attaining a PhD to become an epilepsy researcher and help find a cure.

Kelly Cervantes: 00:48 Christin, thank you so much for chatting with us today. I am just so excited to talk to you, someone who has epilepsy, who is now studying it and going into research. I just think this is going to be a really fascinating conversation as you have experienced both sides of the spectrum here. I want to kick it off by finding out, when did you have your first seizure? What was receiving your epilepsy diagnosis like?

Christin Godale: 01:20 I was diagnosed quite young around two, and frankly, I don't really remember what it was like to have my first seizure since I was so young. But I remember it was hard growing up with it. My mom first saw that I was having abson seizures, the kind where you just stare off blankly and then it disrupts what you're doing. She first noticed it when I would play with my toys, I would drop them. She didn't know what they were. I was taken to an epileptologist and I was diagnosed with epilepsy. 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. It was hard I'd say for my family and myself.

Kelly Cervantes: 02:13 You were diagnosed at such a young age. What was that like growing up with epilepsy? How did it impact your childhood?

Christin Godale: 02:22 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, it was hard because I'm sure you've experienced what it was like to do an overnight EEG.

Christin Godale: 02:54 But it's hard to watch your child or be the child on the bed and they're flashing all these lights at you. I's 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: 03:21 Did it impact the activities that you were able to participate in?

Christin Godale: 03:25 Yeah. I wasn't able to do any sleepovers and I was just so afraid of all my peers seeing me have a seizure. Of course, that happened and I lost a lot of friends because 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. 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. It was hard.

Kelly Cervantes: 04:07 Middle school is hard regardless. There's no amount of money you could pay me to go back and relive middle school, but to then have epilepsy and going through middle school with that, 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: 04:40 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 that 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. It was hard.

Christin Godale: 05:08 I know that's a simple thing to say, but it was hard growing up with epilepsy. It really was. And it wasn't until I was in college, I started to be more frank with people. And I talked about it. I talked about epilepsy like, "Look, I have epilepsy. This is a seizure." That was the first time that I remember being an official advocate for the disease and telling people about it. And I think that's what we're here to do.

Kelly Cervantes: 05:35 What changed your mind to start telling people that you had epilepsy versus keeping it a secret?

Christin Godale: 05:43 Oh wow. There were a couple of things, but I remember when I was in high school, I had a 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. I was just volunteering and I came into contact with this young boy, and he obviously had epilepsy. He was nine or something. He looked at me and he's like, "You have epilepsy?" And I responded, "Yeah."
Christin Godale:	06:43	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?" At the time, I wasn't sure, but of course I said yes. 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. 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.
Brandon:	07:32	Hi, this is Brandon from Citizens United for Research in Epilepsy, or CURE. Since 1998, CURE has raised more than $70 million to help fund more than 235 research grants in 15 countries around the world. Learn more at cureepilepsy.org. Now, back to this episode of Seizing Life.
Kelly Cervantes:	07:51	Was there a difference in the way that people responded when you told them upfront in college about the epilepsy versus how they responded in middle school and high school?
Christin Godale:	08:01	Of course, yeah. I think it also has to do with the level of maturity of my peers from one time to another, but everyone was very accepting of it. If I had a seizure, they were fine. They followed my seizure action plan and they called my mom or they called the ambulance when needed, and no one was really afraid to work with me or be my friend. I was very thankful for that.
Christin Godale:	08:34	Well, versus in high school where I didn't tell anyone and when I had a seizure, it was a totally different reaction because they didn't know. And it was like, surprise.
Kelly Cervantes:	08:45	Right. I guess, what advice would you give to children, students, teenagers who have epilepsy, and also to their parents to help guide them through those years? Are there things that you wish you would have done differently? Are there things that you found that worked for you? Because those years are so hard regardless.

Christin Godale:	09:14	Right.
Kelly Cervantes:	09:14	What is your advice?
Christin Godale:	09:18	Well, 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. I say that because I wish someone would have told me that. And I think it would have made my childhood much more fun. You don't have to be ashamed, you really don't. I just wish that someone told me that.
Christin Godale:	09:53	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, because that's what you think as a kid. You have something that you can't really explain to people and you aren't mature enough to really understand what it is. Just, it's okay. Other people have it and you'll be fine.
Christin Godale:	10:28	For parents, I'd like to say that I had great examples of just being proud of your child. My parents just loved me and they weren't ashamed of my epilepsy, and they encouraged me to be who I was. And they always told me it would be okay too. I know there are different kinds of epiclesis and some are worse than others, but that doesn't matter at the end of the day. It's just, it'll be okay. That's a simple answer, but if I was a kid today, that's what I would want to hear right now.
Kelly Cervantes:	11:12	Well, I they think there's something so incredibly powerful about hearing those sentiments, that epilepsy is nothing to be ashamed of, and it will be okay. But especially to hear them from someone who has epilepsy. And there aren't a ton of people out there who are doing that and are sharing their story.
Kelly Cervantes:	11:39	Is there a certain responsibility that you feel or that you think that epilepsy patients who are able live a full life, do they have a responsibility to be advocates and to be a voice?
Christin Godale:	12:02	I believe so. That's what I do, and I've made it my life mission to just spread awareness about the disorder. I know there's other people with epilepsy, like you just said, that can't do it. And if they can't do it, then you have to. I know that not everyone likes talking about difficult problems, but someone has to do that. I think if you're well enough and you can live life to a certain normality, then you should.

Kelly Cervantes:	12:39	I can't commend you enough for your willingness to speak out, and your advocacy. We've spoken with several college students who have epilepsy and going through that experience. What was college like for you? Did you ask for accommodations? What was your college experience like?
Christin Godale:	13:05	I didn't ask for accommodations in college. I actually didn't receive accommodations in grad school until I had a status epilepticus event in 2017. And the reason being is because I think I was too proud and I didn't want people to think, "Oh, you have epilepsy and that's why you need this extra time." I didn't want anyone to think that because I still, to this day, I believe I can do everything and anything as well as someone who doesn't have epilepsy.
Christin Godale:	13:41	But that really hurt me at the end because I had some problems with accommodations for some classes. And since I didn't have all the paperwork filled out, I had a hard time. So looking back, I would definitely tell any college students, go to your accommodations office immediately and just fill the paperwork out. Don't be like me. Don't wait, and don't let your pride get in the way. It just doesn't matter in the end. What matters is you're doing well in school, getting your grades and then going off to wherever you need to go.
Kelly Cervantes:	14:23	Have doctors been able to establish a cause for your epilepsy?
Christin Godale:	14:30	Yes and no. They've located some epileptic focuses in my brain as to what might be triggering these events. However, they believe that it is genetic. I know my great aunt and her brother had epilepsy, so I believe that's where it's come from.
Kelly Cervantes:	14:48	Have you done genetic testing?
Christin Godale:	14:50	I haven't.
Kelly Cervantes:	14:51	Why not?
Christin Godale:	14:53	Just, I can't afford it. It's not covered under my health insurance and we've wanted to do this over and over, but it's just so expensive. And I believe all adults and children should have access to this genetic testing. It's part of the diagnosis. It shouldn't be a luxury treatment option. It's part of it.
Kelly Cervantes:	15:15	Absolutely. I couldn't agree with you more. And the more as a scientist, the more data that we have on that genetics, the

		better treatments and potential cures we can come up with. Do you currently have seizure control?
Christin Godale:	[15:30]()	I don't. I still have seizures from time to time. I can't drive or anything like that. That's one thing I still have to live with, and it's a very obnoxious. I wish that I could just go to McDonald's get my snack and just come back. But I can't, and that's okay.
Kelly Cervantes:	[15:51]()	I want to talk about the research that you're doing. Let's talk about Christin the scientist. What is your focus?
Christin Godale:	[16:01]()	I study temporal lobe epilepsy, that's what you know as the most common form of focal epilepsy. It's very difficult to treat, and a lot of patients continue to experience seizures despite their antiseizure medication. So there is an urgent need to investigate this type of epilepsy, and possibly, develop new disease modifying therapies.
Christin Godale:	[16:26]()	I study the mechanistic target of rapamycin or mTOR pathway, and it's emerged as a very promising new target in our epilepsy field. So studies indicate that pharmacological inhibition of mTOR with an antagonist called rapamycin, it actually reduces seizure incidents and patients and in rodent models. The problem is we don't really know where rapamycin acts to produce these hopeful and positive effects.
Christin Godale:	[17:00]()	Rapamycin could act directly on these hyperexcitable neurons in the epileptic focus, or it could act on other targets in the brain. Or it could even act in the periphery. So disruption in the brain, specifically in the hippocampus stands out as a hallmark pathology of temporal lobe epilepsy. Hippocampal granule cells during the hippocampus, act to limit the flow of excitation through the hippocampal circuit.
Kelly Cervantes:	[17:32]()	What does that mean in regular?
Christin Godale:	[17:36]()	Oh, sorry. I'm like cool.
Kelly Cervantes:	[17:40]()	I was with you, and then you lost me a bit. You just [inaudible 00:17:44].
Christin Godale:	[17:46]()	Basically, so you have your circuit and you have a bunch of stuff coming in. These dentate granule cells actually filter all the information and they stop too much information from going into the rest of the circuit.
Kelly Cervantes:	[18:03]()	Got it.

Christin Godale:	18:03	So if those aren't active or if those are compromised in temporal lobe epilepsy, it's actually thought that they become hyperexcitable. So now, you have a bunch of information going into the circuit, nothing to filter it, and this is creating a disruption for the excitatory and inhibitory balance that is usually present in the circuit.
Christin Godale:	18:32	When this happens, and these dentate granule cells are all hyperexcitable now, we have a problem. With this mTOR pathway, it's been shown in the literature that the signaling is actually increased in these dentate granule cells during this epileptogenic period. And treatment with rapamycin can prevent also these pathological changes in the granule cells that contribute to this seizure development as well.
Christin Godale:	19:09	So we have all this stuff going on, and basically our hypothesis for this research is that the way rapamycin works to reduce its disease modifying effects that are so promising, is by blocking part of the mTOR pathway, specifically in granule cells. And to test this, we actually use a viral strategy to genetically delete this part of the mTOR pathway. Right now, we're trying to determine if this treatment that we've developed to understand what's going on, if it reduces seizure frequency, duration and severity. And whether or not it prevents all these morphological changes in the dentate granule cells that also contribute to hyperexcitability and temporal lobe epilepsy. So I mean ...
Kelly Cervantes:	20:08	Really, the potential for actually being able to help patients, it has to be so exciting for you.
Christin Godale:	20:19	Yeah.
Kelly Cervantes:	20:19	To be on the front lines and to know that you could be changing people's life with science and to know personally what that means.
Christin Godale:	20:30	Yeah, I'm really excited about it. And I know this research is very novel. It's really difficult actually, because there's not a lot of peer-reviewed literature about specifically what I'm studying, and it's been frustrating at times. Because anytime you do a new project, you have a lot of kinks to work out.
Christin Godale:	20:49	But I'm really thankful to be in a Dr. Steve Danzer's lab. He's been a great mentor, and I really wouldn't be able to be where I am or be the researcher that I am without him. Actually, I want to bring this up. In 2015, you actually invited him to a CURE

		event. He spoke and I actually saw that, and I'm like, "I want to be in this guy's lab."
Kelly Cervantes:	21:16	Oh my gosh, that's amazing.
Christin Godale:	21:19	Yeah. So CURE actually brought me to my current advisor.
Kelly Cervantes:	21:24	I love that story.
Christin Godale:	21:25	I know.
Kelly Cervantes:	21:25	That's amazing.
Christin Godale:	21:28	I know. I saw this, and I already followed CURE, and I was like, "This is the guy." Thanks CURE.
Kelly Cervantes:	21:36	That's so brilliant. I love that. I have to ask, with the current COVID pandemic, how is that affecting your research?
Christin Godale:	21:49	I know.
Kelly Cervantes:	21:52	Are you able to get into your lab? Are you ...
Christin Godale:	21:56	No, we shut down completely, I think, end of February. We were completely shut down for two months. It wasn't until last week that my institution actually allowed us to start coming, doing our experiments again. So I did my first experiment in two months last week. It felt good, but there's still a lot of limitations to what we can still do.
Christin Godale:	22:24	Right now my research is still pretty slow. And again, it's going to delay my research by four months. Thankfully, I do have a lot of funding, so I'll be fine. But for other researchers that don't have funding to sustain the support for their graduate students and postdocs, it's going to be a real problem in the research community, especially for our epilepsy researchers.
Kelly Cervantes:	22:53	I think that's something that's so important for people to understand is that just because you may have been out of the lab for two months, but that two months has compounded when you're dealing with research. Because you are sometimes working with organisms or mice models or anything like that, and now you have to go back and redo portions of these studies that are time sensitive.
Kelly Cervantes:	23:22	I know that weighs heavily on CURE as an organization, as we try and support the research community, that this has forced to

		set back for epilepsy research. It's heartbreaking. There's nothing to be done about it. You're obviously safer at home and that's where you need to be and not in the lab until it is safe to be there, but it's a tough casualty from this pandemic.
Christin Godale:	23:56	For all research. But I'm sure CURE and NIH and NSF and all these organizations, they should be understanding of our delays. I know when I submit my progress report to NIH, I'm going to say COVID delayed my research by X amount of months, and I can't do anything about it.
Kelly Cervantes:	24:17	You think everyone's going to be very understanding?
Christin Godale:	24:19	Yeah.
Kelly Cervantes:	24:19	At the very least they should be.
Christin Godale:	24:20	Oh yeah.
Kelly Cervantes:	24:21	Christin, thank you so much for chatting with us today. You are a delight and it was just so, so incredible to speak with you. Thank you so much for doing the research that you're doing, and I cannot wait to see the discoveries that you make in the years to come.
Christin Godale:	24:39	Thank you so much, and thanks for having me. It's a real honor.
Kelly Cervantes:	24:45	Thank you, Christin, for sharing your experiences as a patient and research student. Your story is an inspiring example of overcoming the challenges of epilepsy, and we wish you continued success as you earn your PhD and begin your career in epilepsy research.
Kelly Cervantes:	25:00	CURE knows the importance of supporting young researchers early in their careers. And even in the middle of this global pandemic, CURE funded research continues. We hope you will join us in pursuing our mission by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
Brandon:	25:25	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained herein is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs.

Brandon: 25:43 CURE strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with the patient's physician, or other qualified healthcare professionals who are familiar with the individual's specific health situation.