

Seizing Life, episode 124
A Young Woman's Journey with Jeavons Syndrome
Guest: Kiley Flowers
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy. Today I'm happy to welcome Kiley Flowers to the podcast. Kiley first displayed signs of epilepsy when she was in fifth grade, but wasn't diagnosed until age 13 when she experienced her first tonic-clonic seizure.

Kelly Cervantes: Her initial diagnosis was later changed to a rare form of epilepsy called Jeavons syndrome or epilepsy with eyelid myoclonia. Now 21 years old and a recent college graduate, Kiley is here to share her epilepsy journey, inform us about Jeavons syndrome, and tell us about the summer internship she just completed at CURE Epilepsy. Kiley, thank you so much for joining us today and from the CURE Epilepsy offices. So I am curious to know when and how epilepsy first presented in your life.

Kiley Flowers: Yeah. So I was 13 whenever I experienced my first tonic-clonic seizure. I was actually in the car on kind of a long car ride home. I was headed home from my cousin's track or cross country meet, and the last thing I remember was falling asleep. And the next thing I know, I wake up on the side of the road and I had thought we'd been in a car accident because we were on the side of the road and I see the ambulance to my right.

Kiley Flowers: My family's looking at me to my left, and I just feel super confused and they start asking me, "What color is the sky? What's your name?" Those kind of questions you hear after a seizure. And I had answered them all correctly so I was just super confused at what had happened. And then they told me, "You just had a seizure."

Kiley Flowers: And again, I started feeling really confused and I was pretty discouraged. And no one in my family had experienced seizures. No one had epilepsy. I hop in the ambulance and they take me to the closest hospital, which happened to not have the greatest resources. They gave me, I think an MRI.

Kiley Flowers: They didn't do an EEG on me, which in hindsight, I think that they should have. Would've led me to my diagnosis a lot sooner. But I ended up going to my pediatrician and they couldn't figure it out since I had no family history. So I was referred to a neurologist, and that's whenever I kind of started getting some answers. They did my first EEG there, and that's whenever I was diagnosed with juvenile myoclonic epilepsy.

Kelly Cervantes: Okay. And then were you started on medications at that point?

Kiley Flowers: Yeah. So I was started on Clonazepam to start. And on this I was experiencing a lot of depression. Within the first day I was telling my mom, I was like, "I feel hopeless, I feel worthless because of my diagnosis." And she was like, "This is just a side effect." And I was convinced that it wasn't.

Kiley Flowers: But that same day I was taken off of that medication and my neurologist started me on Keppra and Topamax. And I was still having seizures on the Topamax, so it was time to get a second opinion. So I went to St. Louis to a doctor and she started taking me off of the Keppra, which happened to be kind of a pitfall for me and started me on Onfi. On Onfi I experienced more of that depression, a lot of mental health side effects with that.

Kelly Cervantes: Yeah. First of all, people getting an epilepsy diagnosis don't often know much about epilepsy to begin with.

Kiley Flowers: Right.

Kelly Cervantes: But then you go in and you start these medications and the side effects can be extreme and terrifying. And I don't think that people are prepared for that. And this journey to try and find a medication that A, can control the seizures, but B, it has side effects that are tolerable, it can feel very isolating and like maybe you're the only one going on this journey, you're the only one that the medications don't work for when in fact the opposite is true. So you are put Onfi, it is not great. What are the next steps? What eventually led you, because juvenile myoclonic epilepsy was not the correct diagnosis. How did you eventually get that correct diagnosis and how old were you at that point?

Kiley Flowers: So it had been a few years. It was several months after I started seeing the doctor in St. Louis, whenever it was time again to get a new opinion. And my mom had found out about this epileptologist in our area. So I started seeing him and that's whenever a lot of my questions got answered. And he actually diagnosed me with Jeavons syndrome.

Kelly Cervantes: And explain to us what Jeavons syndrome is.

Kiley Flowers: Yeah. So Jeavons syndrome is a rare type of epilepsy that is characterized by eyelid myoclonia. So the eyelid myoclonia is also known as the eye flutters or the flickering. And this usually has early onset in childhood, which I started experiencing the eye fluttering in fifth or sixth grade, but it wasn't until eighth grade whenever I experienced a tonic-clonic seizure, and that's when it was noticeable.

Kiley Flowers: So with it being early onset in childhood and it just being kind of like the eye rolling, it can be misdiagnosed as ticks or behavioral issues. And oftentimes people may think that a child is just being sassy or they're rolling their eyes, but that's again, that's a misdiagnosis. And yeah, this is usually a lifelong thing. Some people experience the tonic-clonic seizures, some people grow out of them whenever they become adults.

Kiley Flowers: So luckily I've been fortunate, I've been over four years seizure-free, so hopefully those kind of stay out of my way. I do sometimes experience the Jeavons syndrome, eye flutters, but that's usually if there's trees passing in the

sunlight. And I kind of experience the flashing lights, but it's very well controlled luckily with my Keppra and Lamictal combination. It's definitely not as bad as it used to be.

Kelly Cervantes: And tell me how old you were when you finally got the Jeavons syndrome diagnosis?

Kiley Flowers: Yeah. I believe I was 17 at this point, so it took a few years for that to come about.

Kelly Cervantes: I just want to highlight that piece for a minute, that you're talking about you were in fifth or sixth grade when these eye flutters and eye rolling started. It wasn't until eighth grade that you got the epilepsy diagnosis and you were 17 when you got the correct epilepsy diagnosis. So we're talking six, seven years before you got the correct diagnosis, which could then lead you to be on the correct medication to try and control all of these pieces.

Kelly Cervantes: And I think that is just, it is one aspect of this epilepsy journey that can be so frustrating because here you are, you have these seven incredibly formative years as a teenager where you are undergoing these side effects and the depression and everything that goes along with that, not to mention just the anxiety of when the next seizure is going to happen. How did that affect you in school and socially?

Kiley Flowers: In school, I had to get a 504 plan because I was missing a lot of school due to medication side effects, sleeping a lot because my epilepsy kind of made it that way. I had to leave school early a lot of the time. And so I was given this 504 plan to have some accommodations and be able to turn in my work late or have extra time on tests if I needed to.

Kiley Flowers: And unfortunately with my administration, it wasn't the best for me and I didn't really feel like I was being seen or heard there. And socially, I did kind of go from different friend group to different friend group because it was hard for me to stay with one since I was missing out a lot. And that really made it difficult for me. Yeah. So there were more complications than just the seizures for sure.

Kelly Cervantes: Right. Seizures, side effects and a social life.

Kiley Flowers: Right.

Kelly Cervantes: Were there activities that you participated in that you had to stop and how did you cope with that?

Kiley Flowers: Yeah. I played volleyball since I was in elementary school and I was libero for my volleyball team and that was very rewarding for me, very fulfilling. That's where all my friends were, but I was told I couldn't play anymore because I could have

a seizure on the court and that was kind of really hard for me to hear. So I was doing nothing. I had no hobbies.

Kiley Flowers: I couldn't play sports, which I loved. So I kind of picked up some hobbies along the way. I started taking piano lessons, I did guitar lessons and kind of just doing things that I wasn't really typically interested in. And I think that helped me a lot. And I think that people with epilepsy could benefit from kind of doing things that they're more able to do physically. So that was something that really helped me.

Brandon: Hi, this is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over \$90 million to fund more than 280 epilepsy research grants in 17 countries. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: Now, did you tell your friends? You talked about sort of going from friend group to friend group, were they aware of your epilepsy?

Kiley Flowers: Yes, people were aware that I had epilepsy. I remember in eighth grade, whenever I was first diagnosed, I got little bracelets, epilepsy awareness bracelets, and I passed them out. And so people kind of knew that it was a thing, but they didn't really know I think the severity of it.

Kiley Flowers: And I would tell people. If it was a new friend, I would say, "I have epilepsy, I've had seizures before." I wouldn't really go into the nitty-gritty of it. It was just kind of something that people generally knew about me. And teachers did know about it too because of the 504 plan. So yeah, people were aware of it for sure, but.

Kelly Cervantes: And how did they respond to that knowledge? Do you feel like you were treated any differently or it was just sort of part of who you were?

Kiley Flowers: I think that I thought people treated me a lot differently. I think people saw me maybe as different than I used to be. I didn't really particularly feel seen or heard though, and that might've been my own mental health at the time.

Kelly Cervantes: Yeah. I want to talk about that a little bit because something that we've spoken a lot about recently on the podcast is epilepsy's effects on mental health and that comorbidity between those two. How was your mental health at that time?

Kiley Flowers: I think it was hard for me to decipher what was side effects and what was really me. I think most of it was side effects of different medications that weren't working for me. There were times where it was a lot more difficult and I wish I would've spoken up more. I remember a time, I think it was Memorial Day of 2017 whenever I had family over at a party. And I wasn't really participating in it, so my mom came to check on me and she was like, "What's going on? You don't seem like yourself."

Kiley Flowers: I told her about the suicidal ideation that was going on, and that's whenever she was like, "This isn't you. This is a side effect." And at the time I really believed it was me, but I think that over time I learned that this was something that was a side effect. But I did go to therapy and that's whenever I was diagnosed with PTSD and anxiety. And that's not fun to hear, but I think that it gave me answers and kind of helped me understand why I was feeling the way that I did.

Kelly Cervantes: Something that we've been hearing from younger people with epilepsy is this sense of shame that epilepsy can bring into their lives. Is that something that you experienced and why do you think that is?

Kiley Flowers: Yeah. I think the root of this issue kind of stems from the lack of education around invisible illnesses in the first place and people kind of being intimidated by something that they don't really know much about, which can leave a person with epilepsy feeling isolated and kind of alone resulting in me not wanting to talk about it. So I did feel a lot of shame as a kid and I really shouldn't have because it was something that I couldn't control. So yeah, I think a lot of that issue kind of stems from the lack of awareness around it.

Kelly Cervantes: Yeah, I couldn't agree more. Awareness could just alleviate so much of those negative feelings if people just knew more. Right?

Kiley Flowers: Right.

Kelly Cervantes: Now you have graduated from DePaul University and this next school year you're going to be going back to finish a one year master's program, which is unbelievable. Congratulations.

Kiley Flowers: Thank you.

Kelly Cervantes: But I understand that you didn't always know that college was going to be in the cards for you. So talk to us about that and how you ended up being able to get to college.

Kiley Flowers: Yeah. I was told by a couple of my doctors that finishing high school would be really hard for me and that college may be out of the picture or if it was in the picture that I would really need to adjust around it and either be in a place where public transportation was available if I couldn't drive or be super close to home.

Kiley Flowers: So after I graduated high school, three semesters early, because I had taken the education kind of into my own hands after some challenges with administration in high school. I graduated early and was kind of like, "Well, I'm seizure-free for a little bit, so now what?" And I decided to apply for a community college and I got in. I finished that successfully and I had been seizure-free, so I decided to kind of expanding my horizons and looking at other schools, bigger schools. And my mom was terrified.

Kiley Flowers: My parents didn't want me to do it, but I was a very independent person. I loved independence, and I was stripped of that for a while. So this is something that I really wanted to do, and I was able to get into DePaul and live in Chicago mostly independently, which is a dream come true. Little Kiley wanted to do that. I was told I couldn't, and now I'm here. So it's really incredible and very full circle moment for me. So I think I doubted myself a lot during the application process, but I've taken it day by day and been able to accomplish a lot, so.

Kelly Cervantes: There are a few things more motivating than someone telling you that you can't do something.

Kiley Flowers: Right.

Kelly Cervantes: But you still had to do it safely and within certain parameters. It's going to college with epilepsy, you have to be much more careful about your health. How did you go about doing that, and what were some of the precautions that you took to make sure that you could stay safe and healthy? And did you get accommodations while you were there?

Kiley Flowers: Yeah. I kind of wish that I had advocated for myself more in high school. In hindsight, I think it would've helped more at the beginning to talk more about it and talk about how real it was. So I kind of took advantage of that opportunity when I came to school and I was telling the people that I was meeting right away, telling my friends. I'm like, "I have epilepsy. I've had seizures before."

Kiley Flowers: And I was scared being in a new place that I've never been before so I made sure to really say that and voice that. So yeah, I also told my professors on the first day. I'm like, "I have epilepsy. I don't have accommodations through administration, but... because I haven't experienced seizures in a while, but this may happen, so I just want to let you know in case I need an extension for anything." So I still let my professors know on the first day and they're very understanding about it. And I've had great friends here and they've kind of encouraged that independence more and it's been great.

Kelly Cervantes: I think it's amazing when you go out and you tell someone and you own your story and you have confidence and knowledge behind you, just how receptive people can be, and that that stigma isn't there because you're educating them and you're telling them and you're confident about it. And when you own a disability, when you own something that people don't have information about, it can wildly change the outcome of those social situations. So were you able to have a stronger social life while in college than you were in high school?

Kiley Flowers: Yeah, definitely. I think all of my friends have been super accepting, and I was never a partier in high school. I couldn't, and I never really felt interested in it because of that. So I've been lucky to have super great friends and everyone's been super accepting and that's something that I'm very fortunate of because it could have gone the opposite. But yeah, once you start really speaking up for

yourself, that's when people see that you are confident and see that you are able to have fun still, so.

Kelly Cervantes: Yeah. Knowing what you know now, what would you like to go back and tell your younger self?

Kiley Flowers: I would tell her that epilepsy is nothing to be ashamed of and the seizures are not in my control. It was something that was going to decide what it was going to do whenever it wanted to. So I would say kind of talk about your mental health more, talk about how it's affecting you. Don't be afraid to stand up for yourself if you need to and yeah, just keep being strong.

Kelly Cervantes: And what do you wish parents and caregivers knew or understood? What would you tell them about caring for their loved one with epilepsy?

Kiley Flowers: Yeah. I think that someone checking in with how you're doing mentally means a lot because I think that's half the battle. When you're struggling with mental health and epilepsy, I think it's nice, yeah, I think it's nice to hear, "How are you doing? How's it going on upstairs?" And I think that would really benefit someone with epilepsy.

Kelly Cervantes: Yeah. Absolutely. Because it's so easy to hide it-

Kiley Flowers: Right.

Kelly Cervantes: ... too. Right? You kind of have to dig and push a little bit, and that can be uncomfortable. Now, you went through quite the odyssey just to get a diagnosis, multiple doctors, multiple opinions. What advice would you give to epileptologists and clinicians to help them better care for epilepsy patients and their families?

Kiley Flowers: Well, I would go and tell medical professionals that they need to tell people with epilepsy that epileptologists exist because it took our own research to find out that they are real and that they're out there. It took, I think five years for me to even learn about them, and that's something that I wish more people with epilepsy knew because I hear stories about it all the time that it took 10 years to find out about an epileptologist. And so I think that's where we need to start.

Kelly Cervantes: Yeah, absolutely. Every epileptologist is a neurologist, but not every neurologist is an epileptologist. And it is a big, big difference between seeing a doctor who has a broad specialty of the brain and someone who has specifically studied epilepsy and understands the different kinds of epilepsy and for example, knows the difference between juvenile myoclonic epilepsy and Jeavons syndrome.

Kelly Cervantes: Now, the reason that you are speaking to us from the CURE Epilepsy office is because you are just finishing up a summer internship with our marketing and communications program, which we are so lucky and fortunate and happy to

have you with us for the summer. So thank you for that. Can you share a little bit about your internship experience with us?

Kiley Flowers: Yeah. It's been great. I remember my first day here, my supervisor, she told me that CURE is working on a Jeavons syndrome project and kind of bringing awareness to that, and I was like, "No way, because I have that very rare form of epilepsy and I want to be hands-on with that." So I've been very fortunate to be working on something that is very personal to me, and I really didn't expect it.

Kiley Flowers: It has all been a very full circle experience for me because when I was diagnosed when I was 13, I was googling everything about epilepsy and I didn't know really much about it, but I found myself on the CURE website and it's kind of always been a resource for me over the years to go back to. And now I'm here after being told that I wouldn't have a big girl job. So it's been great.

Kelly Cervantes: Well, we are so fortunate to have had you. Tell us a little bit about the Jeavons project that CURE Epilepsy is working on.

Kiley Flowers: Yeah. So I've been able to kind of write a little bit about Jeavons, learn some of the research that they're uncovering, and I've learned about myself a lot, so that's been great. To be able to learn something about yourself every day is a wild experience. So yeah, definitely raising more research and awareness for Jeavons, and that's been great to see, especially at kind of the rapid pace that it's going at.

Kelly Cervantes: Yeah. It's been a quick project.

Kiley Flowers: It has, yeah.

Kelly Cervantes: And the goal of the project is to sort of streamline those symptoms and get that information out there in the form of white papers so that people can have a quicker path to diagnosis, which means a quicker path to the proper treatment so that they don't have to go through exactly the thing that you went through, so that they can go on to college and a big girl job and all of these things that you lived in fear of not being able to do.

Kelly Cervantes: So I think it's just so amazing and so exciting that you got to be a part of a project that will so directly impact people with your same condition. Kiley, we are just so grateful to have had you at the CURE Epilepsy office as our intern and to have had you share your experience with us today. You're a delight, and we just wish you the best, the absolute best.

Kiley Flowers: Thank you so much, Kelly. It's been a pleasure.

Kelly Cervantes: Thank you, Kiley, for sharing your story and informing us about Jeavons syndrome. Congratulations on your recent graduation from DePaul, and we wish

you the best with your future studies and endeavors. CURE Epilepsy is the leading non-governmental funder of epilepsy research.

Kelly Cervantes: Since 1998, we have raised more than \$90 million to fund patient focused epilepsy research and initiatives that will lead to a CURE for epilepsy. If you would like to help us achieve our goal of a world without epilepsy, please visit cureepilepsy.org/donate. CURE Epilepsy, inspiring hope and delivering impact. Thank you.

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