

Seizing Life, episode 95
Growing Up with Epilepsy leads to Making Movies About It
Guest: Miles Levin
(Transcript)

Kelly Cervantes:	00:00	Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy. This week on Seizing Life, I'm happy to welcome Miles Levin to the podcast. Miles has lived most of his life with seizures, having been diagnosed with epilepsy as a child. He is a filmmaker and epilepsy advocate who wrote and directed the short film, <i>Under the Lights</i> , and is currently working toward turning it into a feature film. Miles is here today to talk about his experience growing up with epilepsy and how representation in movies and television can play an important role in educating the public and removing the stigma that often accompanies an epilepsy diagnosis.
Kelly Cervantes:	00:53	Miles, thank you so much for joining us. I am so, so freaking excited to have you on and to be able to talk about your incredible short film, <i>Under the Lights</i> . Which everyone, as soon as you are done watching this interview, if you have not already watched it, please go find it on YouTube. And I'm sure we'll get lots of other direction and places that we should visit to support the film. But before we get to discussing the film, I want to get a little bit of your background, Miles. What is your experience with epilepsy and how did epilepsy come into your life?
Miles Levin:	01:31	Yeah, I was diagnosed about age four. And I saw probably near a hundred physicians before I was 18. And so my epilepsy is still a mystery. I was one of those one third of people that didn't respond well to existing treatments. And it was a very, very long road of ... I spent more time in a clinical setting in a doctor's office than I did being a kid. So epilepsy was a huge, huge part of my childhood, more than it should have been.
Kelly Cervantes:	02:14	That really sucks. I'm sorry. What was your family told at the time of diagnosis?
Miles Levin:	02:23	Yeah, I think like many families, we were told, "Hey, it is probably a one off, don't worry about it." And then I started to fail the gold standard medications and I was instructed, "Don't worry about the side effects. It's probably not that bad. Have more, have more, have more, have more." And it took a very long time to convince doctors that my body just didn't fit the textbook, that I needed to be treated with extra care. It took a long time convince people I needed to be started on an infant's dose of medication because I really was that sensitive. And it led to a lot of confusion. It led to my mom really having to lead the way with the research. And thank goodness she did. She's one

of those super moms that really dropped everything to try and find the right care.

Kelly Cervantes: 03:30 And what was your experience with the providers you worked with, certainly in the beginning?

Miles Levin: 03:39 Yeah. One disappointment was that it took a decade for anyone to even tell us that specialists exist. No one-

Kelly Cervantes: 03:48 Oh, like like an epileptologist?

Miles Levin: 03:51 An epileptologist. No one said that word, no one added that to our vocabulary. People didn't tell us about IEPs for school. A lot of that came out of personal research, which was a shame because we probably could have saved a lot of time. And luckily those specialists have bigger toolboxes and sort of a lot more ideas to work with. But we still hit a lot of roadblocks. And it sort of ended up just being, for me, the best car is trying to take care of yourself. It's the usual, the exercise, the hydration, the going to bed on time. Which as a teenager, when I was a teenager, is a difficult thing to adapt to because it means you can't do any of the things that other kids are doing. It means that you start to feel those sacrifices build up over time.

Kelly Cervantes: 04:46 Well, and if you don't, if you rebel like a normal teenager, does, the consequences are pretty severe.

Miles Levin: 04:52 Yep.

Kelly Cervantes: 04:53 You learn the hard way real quick

Miles Levin: 04:55 And you learn whether the risks are worth it. And there's a lot of like really interesting family discussions of, this one time for this one thing, do we risk it because it is important. And it's all part of the epilepsy journey.

Kelly Cervantes: 05:14 Yeah. And that's heavy to be the family member that those conversations are revolving around.

Miles Levin: 05:20 Yeah, absolutely.

Kelly Cervantes: 05:21 Also, especially as an adolescent. How did epilepsy affect your social life? You talked about all these things that you weren't able to do that your friends were doing. What was that impact on you socially and emotionally?

Miles Levin:	05:38	I think I was probably naive enough to probably not catch people making fun of my seizures specifically. And I was fortunate, I never had a seizure, like a grand mal seizure in a classroom. I have absence seizures, petite mal epilepsy as well. And so that happens all the time. And I don't think I ever caught it. I say I got made fun of for other reasons. But it doesn't help when you can't relate to your peers because you can't participate. You can't go to that party. You can't go on even like the field trips, you're the kid who couldn't go on the field trip. I remember distinctly that it was a very big deal, this one field trip that I really wanted to go on. It was a family conversation. It was difficult. And to justify it, my dad came along.
Miles Levin:	06:28	And I remember late at night in the bunk beds, the other kids wouldn't stop talking. They wanted to stay up late and make jokes and stuff. And I was panicking that if I couldn't sleep, maybe I have a seizure and then it would be over. Forget social life. We're done. And I got furious and I got angry and their response was, "Well, if it's such a big deal, then why not just don't come?" Which is, it's a version of that is the common attitude of the way people deal with people with disabilities.
Kelly Cervantes:	07:05	Right. And what they don't understand is that, "Okay, well, don't come on this field trip," but it also means that like, don't go on this activity and don't go to that sleepover and don't go on that trip to see the concert with your friends. It's not just this one thing. It's how it affects your entire life.
Miles Levin:	07:25	Yeah.
Kelly Cervantes:	07:27	So Miles, you mentioned IEPs and how you weren't aware that accommodations were a thing that you could ask for. How did that affect you academically? I have to imagine, and please correct me if I'm wrong, but a lot of times you have seizures, absent seizures you mentioned, that's going to affect your memory and your ability to retain information I have to imagine.
Miles Levin:	07:54	So my biggest challenge was I needed extra time on tests because you're in the middle of writing a sentence and you need to figure out, okay, where was I? Math was the toughest thing because if you're in the middle of showing your work and you have to stop and then you don't know how you got there, so you have to do the problem again. And then you stop, and you don't know how to get ... Like how did I get here? So you have to do it again. And then you get frustrated so you have more seizures. Getting my homework done on time was brutal. And I was really, really trying. I was a great student. So luckily

these schools, again, I got lucky that once I knew that I could ask that they knew that that was something that they could and had to provide. And it wasn't usually a problem. But I just think of what would've happened if no one had explained that to us, if we hadn't come across that information. It would've been disastrous. It would've been absolutely disastrous.

- Brandon: 09:06 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: 09:30 I know that you started attending a camp for kids with epilepsy around this time. How did that help you with all of the sort of social, emotional understanding, and just being able to relate to other kids?
- Miles Levin: 09:48 Yeah. I have this vivid memory of my epileptologist saying, "Hey, I'm a doctor at this camp. It's all kids with epilepsy. You should go. You would love it." At the time it was in Yosemite. "We do all this amazing stuff. You should come and be a counselor." And I thought, "No. No way. I don't want to go spend a week focusing on the thing I like the least about myself." When I thought epilepsy camp, I thought like, "Oh, we're going to have this sad support group type dismal environment." And I went and I went back for seven years. And in the years after that, I went back just to visit. This year, I went for two hours just to be there.
- Miles Levin: 10:40 It was just a regular camp where these kids got to be kids for the first time in their lives. And I would make the video each year to try and get people to donate and support this thing. And you interview these kids and you say, "What does camp mean to you?" And they say, "Oh, I like basketball." "No, no, no, no. What does camp mean to you?" "Oh, well I like capture the flag." "No, no, no. It's not working." And the minute you turn the camera off and you ask these kids, "What does this mean to you?" You hear things like, "I'm 15 and I've never made a friend before." Or you hear, "My siblings are so afraid I'm going to get hurt when my parents are gone that they lock me away."
- Miles Levin: 11:24 And you hear all these stories that are a part of the epilepsy narrative, this quiet story that happens behind closed doors that people don't talk about because they can't talk about it. Because what's the world going to do when they hear that? They're going to continue to treat you even more differently. So

		I learned just how bad the stigma is. I learned just how lucky I am that I was, for whatever reason never told not to talk about it. And so I could. And I learned that if you can talk about it, you need to.
Kelly Cervantes:	11:55	Yeah. How have you managed the stigma piece of epilepsy? You say that you talked openly about it. Were you met with stigma?
Miles Levin:	12:07	Stigma is a simple beast. It's a disastrous problem, but it is a simple beast. It's a lack of information that leads to a fear response. People react fearfully to things they don't understand, which also means that the only thing it takes to solve is information. And most people identify as good people. Most people want to believe that they're have a good heart. And I've learned that when you talk about it with confidence and you sort of learn to curate your narrative to explain yourself, most people respond to that confidence with confidence. If it doesn't sound like a big deal, then it's not a big deal. But where it gets tough to ride the line is, how do you make sure someone has the amount of information without being in a position where you have to explain your whole life all the time?
Miles Levin:	13:06	And you hate to sound weak just to get someone to understand what you need. Someone hears the word epilepsy, they got all kinds of questions. And then you got to calm them down. And even if your epilepsy is not that pronounced or not that complicated, most of the accommodations most of us need are very, very basic things that don't cost anyone anything. And yet we're always in this position where we are trying to convince people that we're not scary. And that's like stigma adjacent. And that's something that I deal with all the time, that epilepsy is an invisible disability and you have a choice. You can gamble not to say anything and maybe nothing bad happens and maybe we don't run into anything where someone has a question. Or I can gamble that if I tell everyone, and if I'm careful about how I do it, that people will be confident and they will not be afraid and they'll give me what I need.
Kelly Cervantes:	14:06	And so you have to have a prepared script essentially for the different individuals in different situations all ready to go.
Miles Levin:	14:17	Yeah. And even in a situation where I just know, what are the chances that I'm going to have a grand mal seizure right in front of this person? Like in my case, regardless of that, you have to say something because otherwise you worry what kind of questions they're asking in their head that they're afraid to ask that make them fearful. And as an adult now, I don't drive, I

don't drink. You meet someone and you tell them. "Oh, you want to go out for drinks?" Like, "Oh actually, could we do something else because I don't drink." And then it comes up that you don't drive and you've got to, oh, they probably think I have a DUI so I got to explain that now. And then suddenly you've explained your whole life and you look ridiculous. Oh, do I sound ridiculous? So you learn to have a narrative that is correct that doesn't scare anyone, that's also not a lie. That's the experience.

Kelly Cervantes:	15:19	It's a lot, it's a lot to prepare.
Miles Levin:	15:24	Yeah, it burns calories.
Kelly Cervantes:	15:25	All right. Now the part that we've been waiting for, I'm so excited to discuss Under the Lights with you. So for anyone who hasn't seen it, it is about a high school student who wants to go to his prom. He has epilepsy and it is photo sensitive epilepsy so he knows that the lights are going to make him have a seizure. But he is determined to attend the dance. What was your goal in making this movie?
Miles Levin:	15:54	Coming off of the camp and showing these camp videos, I would get up to speak at the Epilepsy Foundation of Northern California fundraising gala. And I would speak, and I would talk about what these kids would say and the stigma. And I eventually just started to realize I was accomplishing nothing. I'm talking to people who care. I'm talking to people who know. If you come to a fundraising gala for epilepsy, chances are it's because you already know about or care about epilepsy. Until the school bully, the educator, the employee, the employer, the people who don't know anything about epilepsy are in the room, we don't move the needle on stigma. So as a filmmaker, I knew that other much smaller minority groups were having way bigger success telling their stories and being heard through cinema because cinema and television are maybe the only places in our culture where people go out of their way to seek stories they haven't heard before.
Miles Levin:	17:05	That's what attracts them to click on it, to search it on their TV. "That looks new. I haven't seen something like that before." And they're not in a position where they're feeling like they're being educated. They're not being talked down to. They're just being entertained. And they walk away with a point of reference that hopefully is empathetic, is hopefully authentic. And then if someone has a seizure in front of them or they meet someone who has epilepsy, their first thought is going to be, "I think I saw something about that once."

Kelly Cervantes:	17:37	You're instilling empathy, because now they have knowledge.
Miles Levin:	17:43	What I say is I can't cure epilepsy, not personally. But there is medicine for cruelty, and it's empathy. And that is something that I can do. It's something we can all do. But I went to my foundation and I said, "I'm going to make a short film. And I just want to prove to you that this can be done," because there's a lot of skepticism when the only time we've seen seizures in movies and television is on a hospital show or on a horror movie. And cinema and television are responsible for a lot of the stigma we still face. When someone comes up and says, "I'm going to make a seizure movie," there's some concerns. And so I made this thing. And I had two goals. One, the epilepsy community is going to see themselves fairly honestly, authentically, and empathetically on screen properly. And for many people that will be the very first time. And I hesitate to say this, but more importantly, the world is going to see who we really are. And we don't have to explain ourselves anymore. We can just say, "watch this."
Miles Levin:	18:52	And the film played academy qualifying film festivals. It won awards. Kids who didn't have epilepsy came out of the woodwork Today, someone made an action figure of the main character and sent me a photo. Kids made fan art. They gave speeches, rap songs. And a lot of this was before the film came out. It's a 10 minute short film. It's mind blowing. And I was right. I was right that the public is ready for this. It just has to be packaged in such a way that they want it and it's their idea. And we had kids sending in videos saying, this is a direct quote, "If this movie had been available when I was 17, it would've changed my life." And so this is what I'm dedicating my time and my world to, is making my experience and the things that I've been through worthwhile.
Kelly Cervantes:	19:53	Yeah. Art matters. I want to talk about your experience making the movie because I've worked on a couple film sets and they're not calm, peaceful, restful work environments. Like they are long hours. It is stressful. As unionized as the industry is, you're lucky to get proper meals at proper times. That does not mesh well with proper epilepsy care.
Miles Levin:	20:30	No, it's a ridiculous career path for me to have chosen. And I've had to turn down endless opportunities that could have changed everything for me because we're replaceable. And if I don't have control over the schedule, and I have to say, "I can't show up at that time. I can't stay out that late," suddenly it's, "Well, we'll find somebody else." And so my solution to that was just, well, I'm going to learn how this is done and I'm going

to get good at it and I'm going to make movies. And so when it's my set, it's my schedule. And when I get to choose the team, people want to be a part of it because they love me and they believe in me. And hopefully, because I treat them well. And if I can build a set that accommodates me, it also accommodates everybody else. It is a healthier set for everyone else. And I do take precautions, but I've never had a problem on one of my sets because it is designed to be fair.

Kelly Cervantes: 21:39

Yeah. You're changing the way epilepsy is viewed and also proving at the exact same time that maybe film and TV sets don't have to be such harsh places to work, that it is possible, shocking, to make good, incredible art, and also treat your employees like the humans that they are.

Miles Levin: 22:04

Yeah. There's a reason why we're not always hearing directors openly talk about their disabilities because they want to be hireable. And so this is like, I'm taking a risk here, but I want to help build a world where people understand that these kinds of accommodations, nine and a half times out of 10, it's just about listening. It's all usually totally doable stuff. And then you get to have a new voice telling your story. And that's an important, beautiful thing.

Kelly Cervantes: 22:35

So I understand that there is a feature film version of Under the Lights in the works. You have a script. Where are we at?

Miles Levin: 22:46

Yeah. So Under the Lights is in development to be a full length movie destined for streaming services. And I want to take what we did on the short and scale it up so that it is the biggest epilepsy awareness moment of all time and to make something that lives forever. And so we're in development, we're casting, we're putting a financing together. And I was one of five filmmakers picked to be flown to the Tribeca Film Festival in New York to pitch in front of AT&T and HBO and-

Kelly Cervantes: 23:23

That's amazing.

Miles Levin: 23:25

Yeah, it was exhausting. And the internet made its decision. They poured out, it was a landslide. We won the audience award. It was \$50,000. People resonate with the idea of hearing a story that has never been told that is universal and applies to everyone. And so right now, all we need to do is raise the money. And so I'm hoping people will watch the short. And if you believe in the mission, you can make a tax deductible donation on the website, underthelightsfilm.com, underthelightsfilm.com

Kelly Cervantes:	24:04	Perfect. Yes. And you can also watch the short there too, correct?
Miles Levin:	24:09	Yeah. It's all there. And you can also reach me that way.
Kelly Cervantes:	24:12	Perfect. Before I let you go, I want to know, what advice do you have for young people with epilepsy as they're going out into the world, as they're in high school, as they're going through very similar experiences that you have had? What can you tell them?
Miles Levin:	24:31	Yeah. You are more than your disability. And the first step is to invest the time that you have between seizures in things that you like about yourself or things you want. And the most striking thing of going to camp was hearing kids introduce themselves saying, "I have epilepsy, and also my name is." And the first thing that we can do is ask the question, do you like to cook? Do you like to garden? Do you like to knit? Do you like to draw? Use the time that you do have on those things because as soon as you identify as, I am this, I am this, I am this, my name is, and I also have epilepsy, and you can move that further down the hierarchy, then you become everything but epilepsy. So for me it's, I'm Miles, I'm a filmmaker. I, for whatever reason, like making cheese and I also have epilepsy.
Kelly Cervantes:	25:37	That's amazing. Miles, thank you so, so much for sharing your experience, for sharing your art. Please. anyone, everyone, go watch the short, watch it again. Thank you so much, Miles.
Miles Levin:	25:52	Thanks for having me. This was fun.
Kelly Cervantes:	25:57	Thank you Miles for sharing your experiences and insights about living with epilepsy. We wish you the best of luck in bringing the feature length version of Under the Lights to the big screen. As Miles discussed, he is one of the 30% of people with epilepsy who are not able to attain seizure control through current medications. For those who have drug resistant epilepsy, the best hope for new treatments is research. For more than 20 years, Cure Epilepsy has funded patient focused research, supporting more than 270 research grants in 17 countries. We hope you'll support our continued efforts to fund research that will lead us to a cure by visiting cureepilepsy.org/donate . Through research, there is hope. Thank you.
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