

Seizing Life, episode 65
Finding Balance: Managing Epilepsy and Work
(Transcript)

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
- Kelly Cervantes: 00:18 Today I'm happy to welcome Lauren Panco to the podcast. Lauren is the vice president of marketing for WCG, a global organization that specializes in clinical research services for drug development companies. Part of the company's mission is to help drug developers bring treatments and new medicines to patients quickly, safely, and effectively. A mission that is close to Lauren's heart after being diagnosed with generalized idiopathic epilepsy at the age of 26. Lauren is here today to discuss her journey to diagnosis, the impact that epilepsy has had on her work and personal life, and how she has dealt with these challenges.
- Kelly Cervantes: 00:57 Lauren, thank you so much for joining us today. So you weren't diagnosed with epilepsy until you were in your mid-20s. Can you describe and explain what that first seizure was like?
- Lauren Panco: 01:13 That first seizure was tough, that's the best word that I'll use. I was, it was December of 2016. I was coming home from a friends gathering for the holidays and unpacking the car. And so I was moving from the car into the home, going through the garage. And from this point forward, I will tell you, none of this story is mine. It was my fiance's who recalls the story for me, where he was trying to get my attention. He needed help unpacking something, and he just kept calling my name, and I wasn't responding to him. And the next thing he knows I've dropped what is in my hand, which was a big glass pitcher. Thank goodness it didn't break into a million pieces, but he sees me move from my feet and fall backwards, straight onto my back, and I hit my head on the concrete in the garage.
- Lauren Panco: 02:00 Next thing I know I'm waking up in the hospital, I'm in a stretcher in the middle of the emergency room, and they're asking me a series of questions. "What's your birthday? What's your first and last name? Who the current president is?" And Kelly, I will tell you, I didn't know a single thing. I couldn't answer any of their questions. And so that was a lot of embarrassment and a lot of fear that I had pretty immediately. So at that point I was admitted to the hospital for additional review and testing. So again, it was a very fearful moment.
- Kelly Cervantes: 02:34 I can imagine. Now, you had never up to this point had any other seizures that you knew of, this was a brand new thing to happen to you at the age of 26?

Lauren Panco: 02:46 Correct, brand new thing.

Kelly Cervantes: 02:48 Wow. And so you are in the hospital, you have no idea what's going on, even your own name. What are the doctors telling you has happened at this point?

Lauren Panco: 03:02 They're not telling me much. There are multiple nurses, ER docs coming in, seeing me, asking me the same series of questions, "What my birthday is, what my name, who the president is?" And I'm continuing to not remember and continuing to get more and more frustrated and embarrassed because of that brain fog that I'm experiencing. But it's a couple of hours, Kelly before the neurologist who was attending at that time comes in to see me. When she came in though, I will be very frank with you, it was a very cold conversation that we had and her bedside manner felt very cold. And the reason that I say that is because she came in, confirmed that I did have a seizure based on the explanation of my fiance that I was convulsing, I was shaking. Again, and I did have that brain fog. I had bitten the sides of my tongue when I tensed up, but she was very careful not to use the word epilepsy.

Lauren Panco: 03:57 But which she did say that she felt was odd was that as a healthy 26-year-old with no pre-existing conditions, she felt like it was likely that her hypothesis was that I had a brain tumor. And that was the reason behind having the seizure at that point.

Kelly Cervantes: 04:14 So there's no mention of epilepsy? You've, I'm assuming not had an MRI at this point, and she's immediately jumping to brain tumor, which I'm sure is just horribly comforting?

Lauren Panco: 04:28 Horribly comforting, terrifying, let's use all those adjectives, absolutely. So you're right. There was no MRI. There was no additional testing. I was hooked up to IVs that were just taking my blood, but that was about it. She did say that she was going to schedule an MRI, but that schedule didn't happen till about 24 hours after she and I had had that initial conversation. So I'm in the bed feeling embarrassed, because I can't remember my own name, but now add in the anxiety and terror, because who am I to trust but this attending neurologist to say, "Yeah, I've got a brain tumor."

Kelly Cervantes: 05:02 So you get the MRI the next day after 24 hours of pure stress and hell. And what do the MRI results say? I'm assuming that as you're speaking to us today, you don't have a brain tumor?

- Lauren Panco: 05:17 Correct, I did not have a brain tumor. In fact, the scans came back clean, which was just such a blessing. But it opened a series of questions up that I needed to start addressing to say, "What is actually going on if that's not the case?" Because we all of a sudden went from worst-case scenario to, "Okay, maybe there is a best case scenario of why this is happening, but now what, why?"
- Kelly Cervantes: 05:44 So at this point you have very little information. Did they, once your MRI came back clean, did they do an EEG? At what point did you get the epilepsy diagnosis?
- Lauren Panco: 05:59 Great question. And I do want to add in one thing. So there was a period of time between when I was told that I had the brain tumor, before I had the MRI, that I was admitted into the neurological wing of the hospital outside of the emergency room. And the attending physician at that point also took away my license, because unbeknownst to me, in the State of Pennsylvania, when you have a seizure, your license is taken away for six months. And so it's the doctor's responsibility to actively take away your license and turn it into the DMV. So there's again another series of emotions that go on with that embarrassment and the fear of now a loss of independence. And so then I go into the MRI absolutely the next day, the scans come back clean, say, "We don't have anything, brain tumor's not there."
- Lauren Panco: 06:52 And then she scheduled me for an EEG. And so that luckily was the same night, so I could hopefully get some more answers. And the EEG was a very interesting experience, because I had never had one before, right? No reason to as a healthy 26-year-old. So I'm laying in the room and it's very dark. And the radiologist does an amazing job of telling me exactly what she's about to take me through. And this was probably the first time that I felt like I really had good care. She just did a great job explaining what was about to happen.
- Lauren Panco: 07:23 And so it was about an hour long EEG where she said, "Okay, for every 10 minutes we're going to do something different to see if any neurological brain activity happens as we do things like flashlights in your face, or make you count backwards from 10 multiple times, or have you breathe heavily for about 10 minutes, or just have you lay there and pretend like you're sleeping. So let's see what happens."
- Lauren Panco: 07:48 And after that EEG the results came back that I had seizure activity when the 10 minutes of heavy breathing or hyperventilation occurred. So they were able to at that point

diagnose me with epilepsy, because they saw a second seizure activity, again during that hyperventilation.

Kelly Cervantes: 08:07 Now this is a little confusing, because it's my understanding that you are a marathon runner. And I imagine that there is probably some heavy breathing occurring while you are running 26 miles? So what do you know about your epilepsy now? And you know, what your triggers are? Have you done genetic testing? Do you know what's causing it or have any other answers today versus when you were initially diagnosed?

Lauren Panco: 08:38 It's a great question, and it's something that I've yearned the answer for in black and white. Like let's not live in that gray area, let's get the black and white answers. And it's taken about five years for me to get there, with a lot of different doctor's visits, more EEGs that are being run, a lot of research, a lot of conversations and support groups. But one of the things that I found out through multiple EEGs is that when I do hyperventilate, there is neurological and seizure activity. And so that has remained a constant. But to your point about marathon running, that doesn't seem to add up to me. There's just something off there, because I am a heavy breather when I run, as I'm sure most runners are. But at the same time, when I think about other triggers, this has been the beauty of having a seizure diary, because I will tell you every seizure that I have had, and unfortunately I've had more than two. I don't remember what has led up to them.

Lauren Panco: 09:33 I don't have auras afterwards. I don't remember, I have that brain fog just like I experienced in that first one. And so being able to go back to say, "Okay, in the past 24 hours, let me write down what I was feeling. Had I had any alcohol? Did I have any sleep patterns that were off? Was I having a stressful day at work?" And I can tell you the biggest pattern that I've seen that I believe are my personal triggers are lack of sleep. So sleep deprivation, that hyperventilation that that comes about, and then stress as well. So, that's been an interesting mix.

Brandon: 10:12 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: 10:35 You talk about stress and sleep deprivation. And I feel like these are two just very blatant facts that come with adulthood and working professionally. They're just, they're sort of difficult to

evade. How has epilepsy affected your professional and personal life, specifically in the workplace?

- Lauren Panco: 10:57 Yeah, the workplace piece is tough, but I will tell you, I am extremely lucky that I work for an organization who first of all is involved in clinical research. And so the latest and greatest knowledge about epilepsy or any diagnosis I feel like I'm going to be at the forefront of. I'm going to know what's going on. But I recognize also that not everyone is as lucky to be in a profession such as that. And so it comes with different angles, but I will tell you, I was very open with my HR representative, with my boss, and with a couple of colleagues, I was very specific about the colleagues that I chose to open up with about this diagnosis. And that truly has made all the difference.
- Lauren Panco: 11:45 But I will tell you, there's also been times where I've been fearful of, "Okay, is this going to set me back in my career goals and aspirations? Am I not going to get that next promotion? Is someone going to take away projects for me because maybe it's too stressful and I'm working a couple of extra hours during the week?" Those are fears that I have, but I've also been open and honest in saying with those colleagues in HR and my boss, "Please give me the benefit of the doubt. Please trust me, and that I can do my job." And so there are times where I may have to shut off a little early, but I pop back on later at night when I'm feeling better.
- Lauren Panco: 12:21 So it's sort of this give and take. And I've really had to learn about my body and the work that I do with my profession to be able to say, "Okay, here's what I can and cannot accomplish within a given day and a given week." But it's that open and honest communication that I think is extremely important that's led me to where I am now in my career.
- Kelly Cervantes: 12:41 I love hearing about a work environment that has been supportive of your epilepsy, because I think so often we hear the horror stories. And so I really want to highlight this and find out what specifically has your employer done, or how have they responded? In what ways, are there accommodations that you have requested that have helped you? What does this ideal work environment look like so that we can educate other bosses and other employers to emulate that experience?
- Lauren Panco: 13:19 Yeah, that's a great question, and I'll tell you a couple of quick stories. So the first one is, when I left the hospital in 2016 after my initial diagnosis, it happened on a Saturday and I called my HR rep just to say, "Hey, they're keeping me overnight. I'm not going to be at work on Monday, but I'll be there on Tuesday." I

was being super optimistic about what my recovery would look like. And so when I got into the office, she was very careful about just watching me to make sure that I was okay, that I was healing correctly.

Lauren Panco: 13:53 Not only had I had a seizure, but now I'm on new medication that is literally affecting your brain. And so she wanted to know, "How is Lauren recovering?" So she came with me to a couple of meetings. She was there just to watch, and not be an intruder, but just to make sure I was okay, and that was so calming. But also what she said to me is at about 11:00 AM on that Tuesday, that I've returned she said, "Lauren, you do not look well. I need to take you home." And so she immediately helped me pack up my bags and she drove me home.

Lauren Panco: 14:23 And so that ability for someone to recognize in an employee, "You are not doing well, and I need to stand up for you if you're not going to yourself." Because I was never going to be the one that says, "I need to go home." She did that for me, and I will forever be grateful for that. The next thing that happened is I shared with you that I lost my license for about six months. And so what that meant is I was leaning on my fiance, his family, to drive me to and from work, but they had to do that around their own schedules. So I was coming to work early. I was leaving late, because I was trying to accommodate them, instead of being a burden. And so what ended up happening is I was saying hello with my breakfast and saying good night with my dinner to everyone at work.

Lauren Panco: 15:06 And they were like, "Lauren, you're supposed to be careful about the hours that you're working and the time you're putting in, because this is so hard on your body right now. What can we do to help?" And they blatantly asked for that, and I said, "You know, one of the things that I would love your help with is maybe looking at a regular Uber or Lyft service. I'll pay for it, but I just need your help and support in saying, 'At nine o'clock, I'm going to come in, and at four o'clock every day I'm going to leave. Help me set those boundaries.'" And they did an amazing job with that. And in fact, I will say they actually went above and beyond in getting me a car service every single day.

Kelly Cervantes: 15:43 That's really incredible. Now, have you had the experience of having a seizure at work, and if so, how was that received?

Lauren Panco: 15:51 Yeah, so that actually has happened. It happened about three years ago. We, as an organization get together, it's a lovely experience, at the beginning of every year to plan for the upcoming calendar year. There's about a 100, 150 of us that

gather in Princeton, New Jersey, where our corporate headquarters are. And we're there together for about three days to train, in a room together. And on the very last day, and I think that this was a result of me being stressed in preparation for the meeting and tired from all of the events that happen at this sort of kickoff meeting. I had a seizure in my chair and I fell over onto one of my colleagues. And she called out for our chief medical officer who happened to be in the room. Our CEO cleared the room with all of the other 100 individuals, but I will tell you, what better way to wake up from a seizure than to see your chief medical officer who was a prior attending surgeon, being the one to look at you and saying, "We're going to get you help. We're going to get you to the hospital."

- Lauren Panco: 16:58 However, at the same time though, having a seizure, a grand mal seizure in front of a 100 of your colleagues is extremely embarrassing. And a lot of them at that point had no idea that I had epilepsy, because it's not like I walk around with a purple badge that says, "I'm proud of who I am." But it is a hidden diagnosis at the same time.
- Kelly Cervantes: 17:23 Absolutely. So, Lauren, how is your epilepsy managed now? Are your seizures under control, is there certain things, medications, or diet, or different things that you've found that have worked better for you?
- Lauren Panco: 17:39 Absolutely. So after I saw the initial neurologist after my first seizure, I knew that that was not the neurologist I needed to continue with. So I did go and look for a second opinion, which I would encourage many individuals who are initially diagnosed to go and do.
- Kelly Cervantes: 17:57 I would even go as far as to say is, even if you like the first neurologist you see to still go and get a second opinion, just because there are so many unknowns. I'm so sorry, I will let you continue. But I just, I think that is such an important point to make.
- Lauren Panco: 18:12 Thank you, so I did go get that second opinion, and I am so glad that I did because the bedside manner was completely different. My care was completely different from that point on. And so we looked at things like diet and exercise and mindfulness, and I do follow a new diet now. So I'm gluten-free, I am dairy free when I can be, but I will tell you, I enjoy some Ben & Jerry's every now and then. You know, one of the most amazing things that that neurologist who I still see to this day told me is that, "We are not going to let epilepsy define who you are in your life."

Lauren Panco: 18:52 And it was such a profound statement that it's almost like the billboard of, what's in the mirror staring at me every single day to say, "I can manage this. There are some things that in my life are different now. So I am on Keppra. I'm on medicine every single day. I have to watch my social life and some of the alcohol intake that I have, the things that I eat, how late I stay up at night." So there are some differences, but I will tell you, making those differences also makes me feel healthier. So all of it together is sort of this package of this new Lauren, but I don't look at it in a bad way. It's, these are great changes that I've had to make. And I do feel healthier every single day when I wake up.

Kelly Cervantes: 19:38 And now you're expecting a baby-

Lauren Panco: 19:40 Yes.

Kelly Cervantes: 19:41 Congratulations.

Lauren Panco: 19:43 Thank you.

Kelly Cervantes: 19:44 How exciting. But I imagine that was a big decision to make in and of itself. I've spoken to other women who have epilepsy and then make the decision to start a family. And there are a lot of factors that go into that. What kind of discussions did you have with your doctor, and how has the pregnancy been so far?

Lauren Panco: 20:06 Oh, I think I had my neurologist on speed dial. Like, "What do I do? How do I go about doing this? What prenatal vitamins do I need to take? Do I need to up my Keppra dosage?" We were chatting super frequently. And the great news is, is there's a lot of research around the drugs that are in market right now to prevent seizures and cope with them that most of them do not affect the child's birth or cause birth defects. And I was so grateful to see that and to know that and have that reassurance, because then it meant that my lifelong dream of becoming a mother wasn't off the table.

Lauren Panco: 20:42 And so I could say to my partner and husband, "Yes, let's do this." And so truly the only fear was, "Okay, if sleep deprivation is one of my triggers, let's figure out how we're going to manage that together." But if there is any underlying genetic testing that can be done, if I maybe have some sort of DNA that could be passed on to my child because I have epilepsy, I want to know that and I want to figure that out. So genetic testing was an important component of what was my early on pregnancy plan. So we did go through genetic testing and my high-risk doctor,

because I have epilepsy, said to me, "Okay, so you got two options. We can do a blood panel that tests about 30 different genetic diseases, or we can do one that we call a full blown panel that's about 300, maybe more."

- Lauren Panco: 21:33 And I said, "Oh, give me the full panel. I want to know. I want to know all there is to know." And they did have in that full panels a DNA with epilepsy. And so I said, "Okay, this is going to give me the answers that I need to know. Is there a chance that if I am a carrier of any DNA, that I could pass it off to my child?" Luckily again praise be that I did not come back and tested negative for any of those genes. So I know that my children will not be carriers, I'm not a carrier. So then I felt like I could really go on and say, "Okay, this is going to be a healthy pregnancy," and say that with confidence.
- Kelly Cervantes: 22:12 Well, I am just so excited for you to embark on this new journey of motherhood. I think you're going to be a phenomenal mother, and so uplifted by your positivity and your confidence and the way that you don't let epilepsy define you. And that you are living proof that life does not end with an epilepsy diagnosis, and sometimes it only gets better. So, Lauren, thank you so, so much for sharing your story, wishing you nothing but the best. And I really desperately need to see some baby photos when you have the baby.
- Lauren Panco: 22:50 Oh, all the baby photos. You got it.
- Kelly Cervantes: 22:53 Love it. Thank you so much.
- Lauren Panco: 22:55 Thank you so much.
- Kelly Cervantes: 23:00 Thank you, Lauren for sharing your story and insight about maintaining career and personal aspirations, while also managing epilepsy. Unfortunately, Lauren's pursuit of seizure freedom is too common among those battling epilepsy. One-third of people diagnosed with epilepsy do not respond to current medications. For these patients the promise of research is their best hope for a seizure-free life. That is why CURE Epilepsy has funded patient-focused research for more than 20 years. We are dedicated to finding new treatments and cures. We hope you'll support us by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
- Brandon: 23:49 The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. 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. CURE Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with the patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.