

Seizing Life, episode 131
Regenerative Brain Cell Therapy: One Woman's Journey to Seizure Freedom
Guest: Annette Adkins
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy.

This week's Seizing Life brings you an episode recorded at the 11th Annual Epilepsy Awareness Day at Disneyland. This event is a two-day epilepsy awareness and education expo with physicians, patients, families, epilepsy organizations, and exhibitors from across the country. It culminates in a third day of fun at the Disneyland Park for those living with epilepsy and their families. I've been attending for several years, and if you or your family are touched by epilepsy, I encourage you to check out this amazing event.

This year while I was there, I had the pleasure of speaking with Annette Adkins about her experience participating in a new epilepsy therapy currently in clinical trials. Annette is a true trailblazer as one of the first two people to have undergone regenerative brain cell therapy for epilepsy. She's here to tell us about her epilepsy journey, how she came to be involved in this ongoing clinical trial, and about the encouraging results she has experienced with this new treatment.

Annette, thank you so much for joining us today. To start things off, I'd love to hear the story about how epilepsy first entered your life.

Annette Adkins: Yes. Well, it entered my life late in life, so 2014. It was the end of the week on a Friday. I wasn't feeling any different, just told everybody goodbye at the end of the day and headed off to home. My regular evening making dinner, and went to bed that night and it happened in my sleep.

So it was a large seizure, so I would call grandma At that time. My husband knew about it only because I started to obviously move and then I was foaming at the mouth, and so of course he called 911 right away. I was taken in and it was a severe seizure that they could not get me out of, so I was intubated and I was held in the hospital from a Friday night until a Monday. They extubated me, I believe, on a Sunday.

Kelly Cervantes: Mildly terrifying.

Annette Adkins: It wasn't so much for me because I wasn't the one having to deal with it.

Kelly Cervantes: Right. Your poor husband.

Annette Adkins: Yes.

Kelly Cervantes: You had never had another seizure up to that point.

Annette Adkins: That's correct.

Kelly Cervantes: If you don't mind me asking, how old were you when that first seizure happened?

Annette Adkins: Okay, so I am 60 now, take away 15, so-

Kelly Cervantes: 45.

Annette Adkins: ... 45. There you go. My math isn't so good.

Kelly Cervantes: Annette, the reason I ask that is because I think it is so important that people understand that epilepsy can enter your life at any point. I think people can hear about epilepsy and think, well, that doesn't impact me, but what I hope that people understand is that it can impact anyone tomorrow. And so thank you for sharing that piece, because I do think that that's incredibly important for people to know.

So you wake up, you're in the hospital, and what are you told?

Annette Adkins: So in that particular instance, I really had no idea what was going on because it was so severe. So my first thought when it came Monday morning wasn't where am I? I just looked at my watch and said, "I've got to call work. I've got to get to work." I didn't really understand the severity of the situation because my husband had to explain to me what had happened because several days had gone by.

Kelly Cervantes: Were you diagnosed with epilepsy at that point?

Annette Adkins: No, it was unclear at that point. They wanted to do follow up on me to see if there were continual seizures.

Kelly Cervantes: And were there?

Annette Adkins: There were. They were just continuing to happen. Smaller ones, and then as I learned the signals, the signs of seizure, metallic taste in my mouth and nausea, I learned more clearly that that wasn't a time for me to do whatever it is I needed to do. It was, if I was a place that could be watched, take my Ativan and go take a nap.

Kelly Cervantes: I wonder at what point were you given an epilepsy diagnosis? What were you told? What did you understand about it yourself?

Annette Adkins: So over a period of six months, we monitored how many seizures that I had, had occurred in that amount of time. She was a neurologist, but not a specialist. The one that had been on call-

Kelly Cervantes: An epileptologist?

Annette Adkins: Yes, on call at the hospital. Providence was where I was at at that time. But we started the seizure medications at that point. Actually, she had put me on one in the hospital. I was on Dilantin, and then we gave it three or four months. That didn't do anything, and I continued to have seizures. Usually, after the end of a long day, but a lot of times it would be in the middle of the night, or just as I was doing something and got very stressed out or tired. That's when those occurred. So then that diagnosis is what they decided would be an appropriate, so that they could start more monitoring and more care for me, so we could go further and deeper into what that might mean.

Kelly Cervantes: Yeah. So you have this epilepsy diagnosis and they're trying these medications. Are they working?

Annette Adkins: Yeah, it seems to not be. We've given everyone a try, got the levels. Everything was within normal limits. Because as I was still having seizures, of course you want to assure that you're giving the correct amount of medication to make sure that you're treating the situation, and so then we would move to the next medication. It is sort of a stacking effect.

As they continually did not appropriately take care of the seizures, then we started going to a specialist. The specialist that I saw actually referred me to OHSU department because we were looking into doing the laser treatment.

Kelly Cervantes: I want to get to that in just a minute, but first I'm curious. You mentioned throughout this year long period where you're trying all these different medications, you were still working.

Annette Adkins: Oh, yes.

Kelly Cervantes: You're a pharmacist, and you were still working. Tell us, were the seizures cognitively impairing you?

Annette Adkins: When I would get to that point, it particularly seemed to be at the end of the day. But if it was in the middle of the day, my workmates knew I would need to leave. Because there's nowhere at work that you can take an Ativan and be monitored and go lay down. One instance, I remember being at work, and I was typing something. One of the people there with me said, "You don't look good." And I said, "Well, just give me a minute," and I was typing nonsense. Then I went into the dressing room and put somebody else's clothes on. Then I had the seizure. One of my good workmates called 911 and took me in. But that's how they understood that it was real. I think without being part of it, it's really hard.

Kelly Cervantes: It's hard for people to understand. It really is. It's a very difficult diagnosis that looks different in everyone. One person with epilepsy, you know one person with epilepsy, and if you don't know anyone, then it's so hard to understand without seeing it. You also at some point weren't able to drive anymore.

Annette Adkins: Right. Right away, I made that choice.

Kelly Cervantes: And so you would use public transportation to get around?

Annette Adkins: That's correct.

Kelly Cervantes: Tell us about that because you would still have seizures.

Annette Adkins: I believe that's probably the hardest memories that I have, is that riding on public transportation, it doesn't scare me, but there are interesting people might we say, on public transportation. I remember that I was told... I don't remember any of the times I was taken in, but I was told where the ambulance picked me up. So that's the way I could back up and say where particularly in my mind think about, where did that happen? Did I get off the MAX and then walk to an area that I was unclear of thinking I was going home. Because at one point I was picked up far, far from my home, and I was walking from the, I thought my Hollywood station to home. So I quite likely could have gotten off at the wrong station. It's just that unknowing, especially on public transportation is that I feel like not everybody is aware enough to make a call, because there's so much drug use out there that it could just have been someone like that.

Kelly Cervantes: Yeah. Now, which I mean the whole experience is terrifying. And at some point you made the choice to stop working. The seizures were impacting you so significantly that working was no longer an option. Tell us about having to make that, I'm sure, incredibly difficult decision.

Annette Adkins: Yeah, it was really hard because again, my workmates are wonderful. My patients really were part of my life, and home infusion, which is where all my work had been done. But leaving was really hard.

So I first went on intermittent FMLA so that if I felt poorly in the morning, I would be covered from work because I still wanted my job. But then it just came to the point that I needed to go on short-term disability, and I was evaluated in the EMU unit, so the epilepsy management unit. I'd been doing other testing prior to that, so I had to 24 hour testing at home for EEG. Then we did the EMU unit, and I believe first or second night, I had had had 11 seizures that he could see on the monitor and filming. So at that point, things had changed quite a bit for me for the position, as far as hours that I was working.

Brandon: 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 25 years, Cure Epilepsy has been committed to inspiring hope and delivering impact by 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: Now I want to get to the regenerative brain cell trial that you were a part of, and it's just so incredibly exciting. But before you got there, you were considering another treatment. Forgive me, I need to read it because this is the most letters I have ever seen in one word in my entire life. Amygdalohippocampectomy.

Annette Adkins: That's good. Yes.

Kelly Cervantes: So what is that, and what was your journey to go from that to this regenerative brain clinical trial?

Annette Adkins: So I was sent to Dr. Roslyn at OHSU, who was the surgeon. We were hoping to do the laser treatment, which is also pretty new out there, that they could just go in and touch those areas that were firing.

Kelly Cervantes: So they knew the doctors were able to determine exactly where in your brain the seizures were coming from?

Annette Adkins: I had had EEGs and many MRIs and all those had pinpointed to the areas. So at that point, we had to make a decision where to go. So it sounded like with all the meds not being competent enough to cover my seizures, our options were to go see the surgeon. And so we went in there for the purpose of doing the laser because it sounded the least invasive, but found out that even if he put three lasers in, there would be an area that would still fire because it was so damaged.

So long treatment of a amygdalohippocampectomy has been done for years. So they thought that that was the only choice at that point, so my husband and I had to contemplate. But we really felt like this has taken up so much of our life and kept us from doing the things that we want to do that if that will help, let's just do it.

Kelly Cervantes: And you almost did until this other option came along, the regenerative brain.

Annette Adkins: The regenerative brain, yes.

Kelly Cervantes: Yes. Explain so people can understand what the requirements were for you to participate in this study.

Annette Adkins: What they wanted for this particular study was 14 seizures a month or more. So I keep a log of all my seizures, so it runs anywhere between 14 and 16 or 18, depending on the week.

Kelly Cervantes: My guess is they also needed to know where the seizures were coming from in the brain. Was that a part of it, too?

Annette Adkins: You have to be an MTLE.

Kelly Cervantes: Which is mesial temporal lobe epilepsy.

Annette Adkins: Yes.

Kelly Cervantes: So it's a specific type of epilepsy where the epilepsy is coming from in the brain. That I feel like is the big one that people have to check and have to know [inaudible 00:14:22].

Annette Adkins: You have to the criteria as far as fitness and blood work and that sort of thing. So you would be going in to have an EEG and several other tests, obviously, an MRI, to evaluate the situation that's going on and to make a final diagnosis and agree with the diagnosis that has been made by your neurologist.

All of the studies were done at our hospital, and then that information was sent to the company Neurona, and then they evaluated me as a participant. And so I wasn't automatically in just because I had the correct diagnosis, I had to fit all the rest of the criteria that they had for their study in order to be included. I did become a candidate quite quickly, but we had to wait until the next patient had gone through, at that time, three months, because they wanted to assure because he was the first that there were no untoward effects.

Kelly Cervantes: You are one of how many people who have had this procedure?

Annette Adkins: Well, so far, three have been conducted and I believe they have two more candidates.

Kelly Cervantes: Okay. Three people in at least the US if not the world, who have had this procedure done. Were you nervous at all? Were you hesitant when they presented this to you? What was your response?

Annette Adkins: I don't know if I said it the first day, but I know I said it the second day. "Let's go for it!"

Kelly Cervantes: I love it so much. And I know that to so many other people that would sound absolutely bananas, but I think that until you have lived with seizures and you understand how much epilepsy can affect your life and how much it takes from you, that you can't understand...

I remember wishing that we could have brain surgery on my daughter. I'm like, what mother wishes that your child could have brain surgery? They couldn't localize where her seizures were coming from, so she was never a candidate.

But I only laugh because I understand, you get to this point of desperation and you're like, "Brain surgery? You're going to put some more brain cells in my brain and make it better. Sounds great. Let's give it a go." I think it speaks to how impactful epilepsy is on our lives that we're willing to take these risks. What did the surgery, what does it actually entail?

Annette Adkins: Surgery was a piece of cake.

Kelly Cervantes: Well, of course, you were knocked out.

Annette Adkins: Me, I just breathed some air and was filled with the gas, and I was gone. But no, to be real, that it was very easy. The surgical part of it, they asked me what I wanted done with my hair, and I said, "Just shave it all off." It's a lot easier that way for them. So from what I've heard, they took me in, they rolled me into the ER, I took the breath, and then I was out. But there were people watching from all over the country, obviously, being a very new thing. I had that cage put on, so there were like six screw holes or something. And then this is my recollection of what I was told. They placed a catheter in the back of my head and then fed it in to where the end of the hippocampus was, and then slowly release those cells into cover my hippocampus.

Kelly Cervantes: So these were new cells being placed onto your brain-

Annette Adkins: New human cells, correct.

Kelly Cervantes: ... placed onto your brain to then the idea being that your brain would then start to generate those cells on its own? Am I getting that right?

Annette Adkins: Well, the way that I understood it is that the cells would actually sort of cap the ones that were firing so that they would cause those to stop. Now, I'm not the physician-

Kelly Cervantes: Almost like a permanent bandaid.

Annette Adkins: ... [inaudible 00:18:18] but yeah, that's the way that I understood it, so that the firing would stop.

I don't expect regeneration. I do know that I was told that what loss I have. And that's fine. It's just going to be part of life, which I just need help for. Just a little bit of help from people to get me straight on words and that sort of thing.

But no, the surgery, I went home the very next day.

Kelly Cervantes: Wow.

Annette Adkins: So very nice. They came in, and Dr. Burchell signed me off with all the tricks they use. Look here, look there. And so really nice to get home the next day. That made it a lot easier. Initially, part of the surgery, I was not scared at all. Just knowing how much of my life has been taken away with illness. I was ready for anything.

Kelly Cervantes: That was going to be my next question. This is a serious surgery. This is no joke. They're opening your skull. They are in your brain. How did that work out for you?

Annette Adkins: It worked out great.

Kelly Cervantes: You just celebrated one year seizure free. I'm going to knock on all the things.

Annette Adkins: Yes, [inaudible 00:19:39] and give me a high five!

Kelly Cervantes: So you've not had a seizure since the procedure, which is incredible.

Annette Adkins: It is.

Kelly Cervantes: How do you feel? Do you feel any different? Aside from not having the seizures, has there been any sort of cognitive impact? You said that they can't reverse the damage, but how has that operation impacted you outside of just not having to have seizures?

Annette Adkins: Well, part of the way that I am in life is I do everything, as I kind of explained to you earlier. I'm the mom, I'm the cook. You don't come in my kitchen. I do everything. I reflected on that and I let help be given to me. So my family members, both my kids live in town, and they'd bring food over and come visit and run errands if they needed to. Of course, my husband's wonderful. Even though he doesn't know how to cook too many things, he's learned to do a lot of stuff. He's my rock. He's the one that can look at me and say, "It's probably not a good idea, Mom, to go for a walk today." We call each other Mom and Dad. But yeah, and I trust that.

Kelly Cervantes: So this is obviously a trial. You are one of three and it has only been a year post-op for you. Have the surgeons, the doctors, the researchers, have they been able to tell you what to expect? Do they have any idea of what you can expect down the road?

Annette Adkins: No. No, this is too new for us to know long-term what would happen. They monitor us for two years, and then we are given the opportunity for another 13 years of, I think it's a once or twice a year contact to see how things have gone, to make sure that we're still doing well. Because at that point, we should be off all of our seizure medications as well that weren't helping us anyway. I think a part of the medications, I would say, would be the only thing that I would have to tell someone, that they really knock you down.

Kelly Cervantes: The immunosuppressed and medication.

Annette Adkins: Yes, exactly. Some of the immunosuppressants can be quite difficult to tolerate, but they're necessary. We don't want to have a graft vs host disease or anything poor become of it. So it's very important that we monitor all of those.

Kelly Cervantes: So that'll come off, and then at some point, you come off of the anti-seizure medications?

Annette Adkins: We will. I just have not been given the plan for the taper off on those.

Kelly Cervantes: But the idea is that you are now seizure-free and can come off the medications and go on living your life.

Annette Adkins: Yeah, at 60, I'm getting over the halfway mark here probably, so I've got a lot I want to do.

Kelly Cervantes: Yes, I'm sure you do, being the doer that you are. If someone is presented with the opportunity for this procedure, what would you tell them?

Annette Adkins: It's worth your while to go for it and be seizure-free. I really believe that every one of us deserves that opportunity. I felt like I wasn't believed because everyone thinks that it's a childhood disease, just like diabetes in a way, as we were talking about. But they don't understand how as an adult-

Kelly Cervantes: And they expect it to be a pediatric onset, not an adult onset that you would start having seizures in your forties. But it happens, and it happens more than people think that it does, unfortunately, for whatever reason.

And so I'm just so grateful to you, Annette, for sharing your story, for being brave enough to try this procedure that, I mean, you could be one of the very first people that helps push science forward so that potential cures become available. Your passion and your bravery and your commitment, it's appreciated and it's valued, and I hope you know that.

Annette Adkins: I really appreciate you saying that. It's been such a special way that people have treated me that before I didn't feel that, and I'm really grateful to have been given the opportunity to help other people to know that there's hope.

Kelly Cervantes: Yeah. So find those epileptologists, ask them about it, bring them the study, and find out if you could be a candidate.

Annette Adkins: Yes, definitely, and it's so worthwhile. Why not try? Go. And that's why we're spreading the word, right?

Kelly Cervantes: Yes. Thank you so much.

Annette Adkins: Thank you for your time.

Kelly Cervantes: Thank you, Annette, for sharing your journey with us and for your courage to participate in clinical trials for this promising new epilepsy therapy. We wish continued success for you and for all the other patients taking part in the regenerative brain cell therapy trial.

For 25 years, Cure Epilepsy has been dedicated to funding cutting-edge, patient-focused research that will lead us to better therapies and ultimately cures for those living with epilepsy. If you would like to help support this research, please visit cureepilepsy.org/donate. Cure Epilepsy, inspiring hope and delivering impact. Thank you.

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