Seizing Life, episode 59
Epilepsy Advocacy and Education: Determining the Care You Need
Guest: Anita Meeks
(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 Anita Meeks to the podcast. Anita was recently diagnosed with epilepsy at the age of 50 following a tonic-clonic seizure. Prior to that seizure Anita had no idea that she suffered from epilepsy. But, once diagnosed, she began to understand previous experiences that she now believes were seizures.
Kelly Cervantes:	00:36	Suddenly faced with epilepsy and the challenges that come with it, Anita found herself dealing with the side effects of medication, searching for a neurologist, trying to learn as much as she could about epilepsy, and recalibrating her lifestyle to better manage her seizures.
Kelly Cervantes:	00:52	She's here today to tell her story, share her experiences as a newly diagnosed patient, and offer advice on self-advocating for patients and caregivers. Anita, thank you so much for taking the time to chat with us today. We really appreciate you being here.
Kelly Cervantes:	01:08	So, I understand that you were actually only diagnosed with epilepsy recently after you had a tonic-clonic, formerly known as a grand mal seizure. Can you tell us about that seizure, and coming to your diagnosis?
Anita Meeks:	01:28	Sure. Thank you for having me.
Anita Meeks:	01:30	So, Labor Day weekend, it was a Friday evening, I was asleep, but in the middle of the night, I'm not actually sure exactly what time it was. But at some point, I'm thinking maybe early mornings, 3, 4, 5 o'clock I had felt this tingling sensation in my legs. And I'm thinking I'm just dehydrated. I'm tired. I hadn't been sleeping well. And so, I didn't really think anything about it.
Anita Meeks:	01:58	And then, I had went to go stretch, so I just tried to start my body out a little bit. And when I went to stretch, all of a sudden, there was this sharp pain that I felt. And it started at my feet, went all the way up to my head. And all of a sudden, I felt myself make a weird noise, like a moan, or just really something came out in me that was uncontrollable, this noise. And I had bounced on the bed a couple of times, I remember that. And after that I was out, and don't remember anything from that point on until the next morning, around 10 o'clock, my son was

		waking me up. We had had plans to go to the beach that weekend.
Kelly Cervantes:	02:50	Wow. So, when you woke up, what did you think had happened?
Anita Meeks:	02:54	Well, I was kind of in a daze. I wasn't fully awake. I was tired, confused. I didn't feel right. I felt just kind of out of sorts. I felt weird. And my girlfriend had just happened to call me and I told her, I said, "I'm not sure, but I think I may have had a seizure last night, but I don't remember. I don't know if it was a dream." And she goes, "Well, why do you feel that way?" And I explained to her what I had just explained to you. And she was like, "Oh my gosh, you definitely had a seizure. You need to call your doctor."
Anita Meeks:	03:28	So, I called my doctor right away, and they're like, "You need to go to the hospital." So she had thought maybe I had had a stroke. And so, she wasn't real sure. So, my girlfriend picked me up immediately, took me to the hospital. They did all kinds of testing. Again. I still wasn't 100%. I was a little bit off, but I don't think anybody would have noticed it as much as I would have. So, after several tests, they sent me home. They didn't really give me a diagnosis. They just told me to see the neurologist first thing after the holiday,
Kelly Cervantes:	04:08	What happened when you saw that neurologist?
Anita Meeks:	04:12	I didn't see the neurologist right away. I had an EEG first thing Tuesday morning. And within an hour, maybe an hour and a half, the neurologist called me right away, which I thought was strange because I mean, I'm like, "How many doctors call you that quickly after a testing, unless something is completely wrong?" And the first thing he had said to me was, "I have a question for you." Those were his first words to me. He goes, "As a child, did you ever get in trouble for daydreaming or dazing off and not paying attention in class?" And I said, "No." And I started becoming annoyed. I'm like, "I don't understand this question. This isn't making sense to me. What does this mean?" He goes, "Well, my dear, you have epilepsy." And I'm like, "Oh what? Epilepsy?" And he's like, "Not only do you have epilepsy, you've had it your entire life." And I'm like, "Whoa, wait a minute, how can I be 50 years old and just now clinically be diagnosed with epilepsy? This doesn't make sense to me."
Kelly Cervantes:	05:14	I can't even imagine the shock that you must have felt receiving this diagnosis. Did you have any previous knowledge? Did you

		know anyone with epilepsy? Did you know anything about seizures, or anything of the sort?
Anita Meeks:	05:28	No clue. None whatsoever. In fact, I don't even think I knew what epilepsy was.
Anita Meeks:	05:33	When I first got off the phone with him, I pulled over in a parking lot because I was just so terrified and I cried. And I didn't know really what it meant. And I didn't even know what I felt like. It was so scary. I'm like, "How is this going to affect me as a single mom, as an individual who's been independent? How is this now going to affect my future? And what does this mean for me?" So, I kind of froze in time.
Brandon:	06:05	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.
Brandon:	06:25	Now, back to Seizing Life.
Kelly Cervantes:	06:29	You're getting through the initial shock. You get to that very first neurologist appointment. And what information does he share with you about epilepsy, about your diagnosis? And how he plans on treating it, or she?
Anita Meeks:	06:43	So, interestingly enough, nothing. It was like, "Here you go. Here's some medication. I want to see you back in three months."
Kelly Cervantes:	06:52	It breaks my heart to hear that because, unfortunately, I think we hear that all too often from patients. And it's gut wrenching.
Kelly Cervantes:	07:02	So, he doesn't give you much information about epilepsy. What does he tell you? What does he give you?
Anita Meeks:	07:08	Well, he doesn't give me much. So he says, "Okay so, here's your medication, and gave me the dosage which, I didn't know at the time, was a high dosage. And, I guess, he wanted to prevent it from happening again, and again, and again. So, the conversation was very short and sweet. There was no education, there was no background on it. I went home, just took the medication as if it was an antibiotic, as if I was sick and I'm going to feel magically better, was my mindset.

Anita Meeks:	07:40	And so, when I took the medication, I just was so lethargic. I couldn't get off the couch. I was exhausted. I didn't care about my responsibilities. I just didn't care about anything. I just was so spaced out. And then, I called my doctor about a week... the same neurologist. And I said, "Look, this isn't working for me. I can't live my life like this. This is not the life I'm willing to give into. I'm just not." And he tried to convince me that your body needs to adjust. And I'm like, "Well, that's still not good enough for me."
Anita Meeks:	08:18	And so, he didn't advise this, I kind of took matter into my own hands, and I was willing to take a risk. I started lessening my dosage little by little. And when I first started doing it, I started to feel better. I didn't go completely without my medication because I knew how important some of it was, but I just felt like I was drugged out. And I didn't like that feeling. So, I started off with 500 milligrams less and I started to feel just a tad bit better. So, I thought, "All right, I'm just going to go a little bit less," and so I did.
Anita Meeks:	08:58	And then, during that interim of me starting to feel better mentally and physically, still was not a 100%. I still didn't have the energy that I typically would, but I had just enough clarity mentally that I started eating, drinking, and sleeping epilepsy. Researching, which led to another thing, which led to another. It became a full-time job for me because I knew the life that I did not want to live. And I wasn't going to allow this to define my future.
Kelly Cervantes:	09:28	Right. Now, I mean, I have to preface here by saying we never recommend that anyone titrate their meds on their own. That said, did the doctor ever tell you that there were other medication options-
Anita Meeks:	09:43	No.
Kelly Cervantes:	09:43	That were out there that you could try? So, there's just a serious lack of information here coming from this doctor. I'm assuming that SUDEP was never mentioned?
Anita Meeks:	09:53	No. And I had actually learned about SUDEP on my own because I was prone to nighttime seizures, I came across that. I'm like, "Oh my gosh, this fits me to a T." And I want to back you up, I want to backtrack just for a second. I don't want anyone to think that I'm encouraging them to take less medication than what is advised. That is not what I want. I think, if anything, I just want people to not give in, or give up and to become their

own self-advocate, whatever that means and researching other doctors, or other opinions.

Anita Meeks: 10:30 So no, there was no education of other options. Because I knew the side effects could be not so good, and so I started on my own researching, and figuring out what I could do to offset the side effects of the Keppra, which is what I'm on. And so, I bombed a few of them. I did try medical marijuana. For a lot of people that works great. For me, I had an adverse effect. And then, so the pharmacist recommended something else, I tried that. Again, I had an adverse effect. So, I wiped that out of even being an option.

Anita Meeks: 11:18 So, then I started taking more of a holistic approach to help offset, so I could have the energy and start to try to live the best life that I can, and be as normal as what I was accustomed to living. And so, then I also, at the same time, was researching a neurologist that specializes in epilepsy. And by the time that I got to her, I had already figured out what was working for me because it was a couple months out before I could even get in front of her.

Kelly Cervantes: 11:49 I'm curious as you're eating, drinking, breathing epilepsy, are you seeing any symptoms, or any signs in your research that perhaps you had experienced in the past, and attributed to something else?

Anita Meeks: 12:06 Absolutely. So, that's a great question. After my diagnosis and during my research, I had a lot of ah-ha moments. I had several drop attacks where my legs had given out on me, and I just fell to the ground. And then, when I was much younger at 21, I had an episode that sent me to the hospital where they diagnosed me as having a minor stroke. But the bottom line is without a shadow of a doubt, I don't believe that that's what I had. I do believe I had a drop attack at that same time. So, I've had a lot of... I shouldn't say a lot. I've had probably about five or six drop attacks that I can recall over my lifetime span that I would just brush off as being tired, stress, making excuses and not listening, and really paying attention to some symptoms.

Kelly Cervantes: 13:05 So, I'm thrilled to hear that you, through your research, as well as educating yourself, you found your way to a new neurologist. Because I really do think with a condition like epilepsy, where so little is understood, where it can be so intricate and different from person to person that you really do need multiple minds working to find that. So, I applaud you on going out and finding that new neurologist. And what was that experience like with the new neurologist?

Anita Meeks:	13:37	It was great. So, I want to support you in what you had just said, because what I have learned through this whole process is just because you have a title doesn't make you an expert.
Anita Meeks:	13:48	And so, when I had found an epileptic doctor, she was fabulous. And she was confirming everything, and supporting me in all the research that I had already figured out on my own. And that's sad that I had to do that all on my own. And that's why I want to give hope to other individuals. Just because somebody says something, it doesn't mean that it's factual. If you have five people saying the same thing verbatim, and they don't know each other, then maybe we can consider that that's the reality.
Anita Meeks:	14:26	But if you put yourself in front of five doctors and you get five different results, and thoughts, and debates, and answers, then you have to really just keep digging, and find out what works for you. Because, as I follow these support groups, everyone's trying to follow the same path as to what's working for one person, where you can't because our bodies are all so different, our chemistries are so different. And I just want to give people hope not to give up and just assume one neurologist is the only neurologist because they're not all specialties in epilepsy.
Kelly Cervantes:	15:02	And so, I think you you've hit on so many points and I kind of want to pick a couple of them out, and highlight them for our listeners. And one is that all epileptologists are neurologists, but not all neurologists are epileptologists. So, just because you are seeing a neurologist that doesn't mean that that is someone who specializes in epilepsy. And really finding that neurologist that is a specialist in epilepsy can make all the difference in the world.
Kelly Cervantes:	15:29	How did you know that your neurologist was the right one for you?
Anita Meeks:	15:34	When I met her. You don't know somebody it's like a relationship, until you meet them and you have a face-to-face conversation, and you start sharing intimate moments and how they react and their thoughts, it's no different. So, I took a risk. She had a title of being a specialist in the epileptic community. She was a medical director. She seemed like she was a strong advocate for epilepsy. So, I'm going into this relationship with knowing, or feeling that she's going to be a great fit for me. And she just happened to be. So, you really don't know until you meet with them and you talk with them, it's no different than having a relationship with somebody.

Kelly Cervantes: 16:14 I've not thought of it in that way. But I think that that is just such a brilliant way to think about it. You are in a medical relationship with them. But there are certain aspects of it, trust and communication, that are just as important as what you would find in a romantic relationship. And sort of making sure that you keep the same standards that you would are just as important. And I appreciate that analogy.

Kelly Cervantes: 16:43 You mentioned, earlier, your triggers, and different things that you found. What did you find for you that were some of your triggers?

Anita Meeks: 16:53 So, I had created a perfect storm, really, is what I had done. I was going through a horrific divorce. And then I had lost a lot of money in my business, and ended up having to go back to corporate America. And then, I started a new relationship that was not probably the best for me. And so, it was just so much, and it was just building, and building, and building. And it was getting more and more stressful. And I was binge drinking on the weekends to try to forget about all the stress that I was incurring. And so it just got worse and worse and worse, and it was just the perfect storm that was about to end.

Anita Meeks: 17:33 So, that's what created the grand mal seizures. So, those were my biggest triggers, was not only the stress, the insomnia, I was only sleeping maybe four hours a night, every couple of days, I wasn't sleeping well, binge drinking. Just anything and everything I could do wrong I was doing. And I was heightening my epilepsy that I didn't even know I had. So, it was just a matter of when it was going to all explode.

Kelly Cervantes: 18:02 You have decided to be very public about your epilepsy, and your journey. And I've said it before on this program, I've said it in public, I have always felt, for my own personal advocacy, that I felt a duty to do so because my daughter was disabled. And so, she wasn't at risk. It wasn't going to affect her professional life. It wasn't going to affect her relationships for her to be public and open about this. But there are so many people grown, otherwise, healthy adults who this could potentially... there is stigma, there is discrimination, there is misunderstanding. And so, I do want to acknowledge your bravery for being outspoken about it because that's no small task. Why?

Anita Meeks: 18:52 Oh my gosh, there's so many reasons as to my why, at this point.

Anita Meeks: 18:57 You hear a lot about caretakers and loved ones being the advocates. So, unfortunately, after you lose somebody it becomes a passion because you don't want people to go through the pain that you've gone through. Because I suffer from epilepsy, I don't want others to feel what I've gone through. And I feel their pain. I feel the discriminatory. I feel the judgment. And that's the reason why I'm so passionate about speaking on behalf of epilepsy.

Anita Meeks: 19:26 I look at this as a blessing because I still have a voice. I still have the energy, and the passion of helping others, and bring an awareness. For that exact reason, because of everything that I went through, and how much work I had to do on my own, I don't want people to go through what I went through. I don't want them to give up. And I don't want them to assume that because one neurologist says something that that has to be the way it's going to be the rest of your life. You have to be willing to put yourself out there.

Anita Meeks: 19:59 I'm not ashamed of having epilepsy. And just the thought of other people feeling my pain hurts me because I know how it felt. I totally understand the humiliation, the embarrassment, the shame that you feel internally.

Kelly Cervantes: 20:19 Your ownership, your empowerment is truly inspirational. And I have no doubt in the world that you have already touched so many people, and will continue to do so to bring them hope, and to let them know that they don't need to be ashamed. And I'm just so, so grateful for your voice. I think the patient voice is just so incredibly important. So, thank you for sharing your story with us. We so appreciate your time. And I look forward to seeing you on the advocacy trail in the future once this pandemic is over.

Anita Meeks: 21:02 Thank you. I appreciate the opportunity.

Kelly Cervantes: 21:07 Thank you, Anita, for sharing your story and experience.

Kelly Cervantes: 21:11 Unfortunately, Anita's experience is far too common for those who suddenly find themselves diagnosed with epilepsy. 1 in 26 Americans will be diagnosed with epilepsy in their lifetime. Currently, 3.4 million Americans and 65 million people worldwide suffer from epilepsy. Despite these numbers, epilepsy research remains drastically underfunded. CURE Epilepsy is dedicated to funding patient-focused research that will lead us to new therapies, and cures for the millions of people currently suffering from epilepsy. We hope that you will support our mission to end epilepsy by visiting cureepilepsy.org/donate. Your kindness and generosity is greatly appreciated. Thank you.

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