

Advocate Like a Champion: Spreading Epilepsy Awareness and Standing Up for Research

Seizing Life, episode 023 – Transcript

Kelly: [00:00](#) Hello, I'm Kelly Cervantes and this is Seizing Life.

Kelly: [00:13](#) So often we want to make a difference but don't know where to begin. On today's episode, Andrew Sterr will share how he is making an impact on epilepsy awareness through his running team, The Brain Troopers, Andrew received an associates degree from the Fox Valley Technical College and is now attending Illinois State University for his Bachelor's Degree. His many interests include but are not limited to horticulture, firefighting, stained glass art, running and of course, epilepsy advocacy. Andrew, thank you so much for joining me today to chat about your experiences.

Andrew: [00:49](#) Thanks for having me, Kelly. Glad to be here.

Kelly: [00:51](#) So having witnessed my daughter's seizures and how they've racked her body and her life, I am always in just complete and total awe of people who are diagnosed with epilepsy and continue to live life to the fullest and don't let it stop them. Can you tell us about how epilepsy entered your life?

Andrew: [01:15](#) So one thing that a lot of people aren't aware of is the types of epilepsy, the types of seizures. So many people drift to think that you drop on the floor and start having convulsions, when that's not the case at all. So for a long time before I started getting treatment for epilepsy, I was having seizures that I didn't even realize were seizures. The earliest one I can remember myself having, I was in I believe the third grade and let's see, what are you like, nine, I think, in the third grade. And we didn't start treating them however, till around 2008 and because like I said, for a long time we didn't realize they were seizures. They were pounding headaches that I thought was just because I didn't get enough sleep, which was the cause of them, which is a cause of many types of seizures is lack of sleep.

Kelly: [02:11](#) So what did they look like?

Andrew: [02:13](#) Almost more like a stroke type of appearance. I'm just kind of dazed out, not very verbally responsive, extreme headache, like a nine out of 10 scale. And the best cure for it, for me is just I have to sleep it off. I can sense when I'm having them. So in a way that's almost a blessing, I can feel that I'm dysfunctional and prevent myself from doing any sort of activities that can in other ways harm me if I were to have the seizure while doing so.

Kelly: [02:46](#) And what is that seizure type called?

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Andrew: [02:49](#) Partial seizure or non-convulsive seizure. There are a couple different things they can be called and that's like I said, just such a thing that people are unaware of is how broad of a topic it is.

Kelly: [03:04](#) Absolutely.

Andrew: [03:04](#) That there's so many different kinds, it happens in so many different parts of the brain. It's not just-

Kelly: [03:10](#) The grand mal that everyone is familiar.

Andrew: [03:13](#) Exactly. Exactly.

Kelly: [03:14](#) And you mentioned, your first memory is having the headaches when you're in third grade. What grade were you in when you finally got the epilepsy diagnosis?

Andrew: [03:27](#) When we officially started, seizure treatment would have been in about the eighth grade, I want to say.

Kelly: [03:33](#) So that's five years.

Andrew: [03:35](#) Five years.

Kelly: [03:36](#) Of having seizures. And you didn't know that they were seizures?

Andrew: [03:41](#) Exactly.

Kelly: [03:42](#) So how did they diagnose you? How did they figure out that that's what it was?

Andrew: [03:47](#) So for a long time, like I said, most people think seizures are convulsions. So that's why that didn't even enter our minds with me and my family. So that's why something wasn't done right away.

Kelly: [04:01](#) Of course, I cannot even imagine your parents, if they had known that that's what it was. Of course they would have. I think that speaks to the lack of education and knowledge in the general public that the general public doesn't understand that there are other kinds of seizures and that having these insane headache. And also, being eight years old, how well can you actually articulate and verbalize what's going on? So no discredit to your parents in any way, shape or form. But what was that experience like when you finally got that diagnosis? Do

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you remember what you felt when you heard the doctors say that it was epilepsy?

- Andrew: [04:43](#) Well, I certainly didn't want to hear that it was epilepsy and at the same time, it was nice to know what the problem was at that time.
- Kelly: [04:50](#) I can imagine, it would have to be a relief.
- Andrew: [04:51](#) Because like I said, those five years, I figured it was just the only solution was that I wasn't sleeping. That's where there was that sign of relief. Now we know what the problem is and where to go towards it.
- Kelly: [05:06](#) And have you found a treatment that works? Do you have seizure control?
- Andrew: [05:11](#) I do have seizure control.
- Kelly: [05:13](#) Congratulations.
- Andrew: [05:13](#) Thank you, thank you. I'm on a medication right now and we were slowly increasing the dosage of it. And this past summer, I actually did have a grand mal seizure that for me ... I've had I want to say four in my entire life, grand mal seizures. And usually it was from the lack of sleep or a mis-dosage, because missing dosages, the number one cause of an epileptic having a seizure while they're on treatment. So I had been in the car with my father and he was driving and I had had a grand mal seizure and this one in particular for me was even more frightening than the other ones. So it was after that seizure that I had, we saw my neurologist again and he upped the dosage and divided when I'm taking the dosage. And since then I have been 100% free.
- Kelly: [06:14](#) That's amazing.
- Andrew: [06:14](#) So there's not even the slightest of headaches.
- CURE Promo: [06:19](#) Epilepsy affects 3.4 million Americans. Learn more about cutting edge epilepsy treatments and research at cureepilepsy.org. Now back to this episode of Seizing Life.
- Kelly: [06:29](#) Within the epilepsy community, stigma has been very well documented and discussed. Have you experienced any of that in your life?

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- Andrew: [06:39](#) It depends on the situation, that I might be stigmatized or not. A lot of times it might be with employment. There was one job that I had been working at. I kept it under the table and as I had at one point been talking with one of my coworkers ... When I can, I like to bring out how under control I am, what had happened to me and how successful it's been. And he's like, "You can't mention that or else you're going to be laid off, no question about it." So I had to keep that under the table and fortunately it was a temporary job so I was able to ease way before costing myself any sort of problems like that.
- Andrew: [07:30](#) And so it's mostly the employment type of thing that has me under pressure. With school and education, if anything, I almost find that more of the place to inform people and stuff. Like with professors right now at Illinois State, one of the first things I do at the beginning of semesters, I go to their offices, sit down with them, talk to them, explain myself, my condition, it's under control, what they should look out for if it were to happen and everything.
- Kelly: [08:02](#) And are they usually fairly responsive and open to the conversation?
- Andrew: [08:04](#) Absolutely.
- Kelly: [08:04](#) That's amazing.
- Andrew: [08:06](#) It really is. I'm really satisfied with how open and wanting to work with me. Like my first year at Illinois State, I had had an exam for one of my classes and this was before I started informing my professors.
- Andrew: [08:23](#) And that morning I had had a seizure and it was the day of an exam, so I needed to take the exam. So I settle it up and then I went to my professor's office and I said, "You're, you're going to realize what the grade was. And it's only because I had a seizure earlier." And it was her that suggested, Andrew go to this part of the university and they will help you have the accommodations that I need for the epilepsy.
- Kelly: [08:59](#) And what part of the university was that?
- Andrew: [09:01](#) It's just the access and accommodations department.
- Kelly: [09:05](#) So that if you do have a seizure, you can make those accommodations that you don't feel forced to having to take that test the same day as a seizure.

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- Andrew: [09:12](#) Exactly. So I'd have an excused absence, unexpected. So I'd go to my professor and say, "I wasn't here for the exam only because I had a seizure this morning." And they're very forgiving and understanding about stuff like that.
- Kelly: [09:26](#) What motivated you to be public about your epilepsy and why take that step?
- Andrew: [09:35](#) So with realizing how traumatizing it is and just how broad it is, there's so many variables and elements to the disease that need to be researched and need to be funded to improve and come up with a cure for the disease and stuff. And that's what really upsets me is what a minimum amount of money goes into research to find a cure for the disease, for how common it is. It's so much more common than people understand.
- Andrew: [10:09](#) And it's stuff like that. So it's one thing to know somebody with epilepsy but to live with it yourself and be as under control as I am, it makes it easier for me to get out and explain and say, "I know what this person is going through cause I've lived it and that's why I need to do something to help."
- Kelly: [10:30](#) We are all so incredibly grateful for you that you are. So tell us about Brain Troopers. Where did this come from? How did it get started?
- Andrew: [10:40](#) For a long time I had been wanting to get engaged with ... because you hear about cancer walks and all sorts of stuff like that. And I told myself and other people, I'm like, "I'd really like to get involved with an organization and start helping more and stuff."
- Andrew: [10:56](#) And that's where the event that happened this summer really caused me to do something about it. Because like I said, I've had four or five grand mals and this particular one scared me. So that's why after that I'm like, you know what, I need to start putting my feet where my mouth is and get engaged in finding stuff. And I did bunch of research on walks and races and stuff and like I said, very minimum stuff and I found a half marathon that I'll be going to in North Carolina in February and it's called, Race for Epilepsy. I'm like, this is great. This is exactly what I'm looking for. And I was a runner in high school and then stopped for awhile when I was in college. And it was when I saw that, I'm like, you know what?
- Andrew: [11:47](#) This is a perfect opportunity. I'm going to start running again and it's going to be all for epilepsy. And as I'm developing a

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name, I'm like, what would be a good name for my team? Because I wanted it to evolve, not just be me, but I'm trying to bring other people into it to because that's the only way we're going to make more for funding. If it's just me in the race, and being a college student, how much can I actually put towards, versus if we start expanding and bringing other people in and bring it all over different places. So even if a race isn't for the team, have a team for the race, so start expanding and developing.

- Andrew: [12:33](#) And when I developed the name, it was originally called the Brain Warriors. I needed to obviously incorporate epilepsy in the brain and it didn't have the ring I was looking for, for a team name. So I went to the thesaurus.com and I'm looking for synonyms of warriors and troopers comes up and I have a sibling in the army who's in paratroopers, so when I was including brain, I'm like, you know what? It just clicked.
- Kelly: [13:08](#) That's amazing.
- Andrew: [13:08](#) Yeah. I'm like the brain troopers is absolutely perfect.
- Kelly: [13:12](#) I love it.
- Andrew: [13:12](#) So I had somebody design the logo for me and everything and it's related to the army because I had once considered military. But obviously with epilepsy-
- Kelly: [13:23](#) Because of epilepsy, you can't join.
- Andrew: [13:23](#) Exactly. I am prohibited. So that's why I still do everything I can to also represent the military too.
- Kelly: [13:30](#) That's highly appreciated, especially since there's...CURE is also working on a study for post-traumatic epilepsy, which is a huge problem among our veterans.
- Andrew: [13:42](#) Exactly, I was just about to bring that up. Absolutely. Absolutely.
- Kelly: [13:43](#) They're coming back with brain injuries, which lead to epilepsy.
- Andrew: [13:47](#) And people don't know that because it's not to people's awareness and it's underfunded to pay for that type of research on those people who are defending our country coming back and this disease that's so common and so severe. And there's only treatment, there's not a cure.

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- Kelly: [14:08](#) No. See you want to develop a team of runners and where do you see the organization going? Where do you want it to lead?
- Andrew: [14:17](#) For right now, I'd just like to be a team traveling together to events. Have the Brain Troopers registered as a team in the Chicago Marathon and the Marine Corp Marathon, so just kind of that. Eventually, I think it would be very exciting to have races for epilepsy versus just the team representing epilepsy and where I'm living in Bloomington-Normal, maybe develop a Brain Trooper 5K and all of the community comes together.
- Kelly: [14:56](#) I love it.
- Andrew: [14:56](#) So we eventually evolve into something like that. I feel like would be very exciting. And it'll take time, it's not happening next year.
- Kelly: [15:05](#) So if people want to get involved with the Brain Troopers, run with your team or try and get someone from the team to run in a race that they're hosting, how can they get in touch?
- Andrew: [15:17](#) People can go to events@cureepilepsy.org and they'll be able to be in contact with someone there who can then coordinate with me and one of their employees with how to continue to expand the team and make it more than it needs to be, to make it better.
- Kelly: [15:35](#) Amazing, so cool. And what has the Brain Trippers meant to you?
- Andrew: [15:40](#) It's certainly brought back a lost passion of mine. Like I said, I was in cross country in high school and drifted away and it's really brought back that ... it takes so much hard work and effort to do extremely long distance running like that. And to relate that to epilepsy, it's, it's not a one time, small thing. It's a marathon. It's a long term, long distance type of thing to deal with.
- Kelly: [16:14](#) And what advice would you give to somebody who wanted to get out there as an advocate, who wanted to fundraise, who wanted to get involved, what advice would you give them to get it all started?
- Andrew: [16:28](#) Google.
- Kelly: [16:31](#) Fair.

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- Andrew: [16:32](#) But seriousness in that because to get to where I'm still developing and becoming, it took so much, research and stuff and that's very unfortunate that I had to work so hard to find something to get organized and involved in. You don't hear a conversation about it at the grocery store or something. I had to dig for organizations and events and how to participate in them and who to contact.
- Kelly: [17:03](#) And CURE helped you a lot once you got going with them, they had a team that has helped you put that together.
- Andrew: [17:11](#) Of course. I love the industry. If I weren't a college student I'd be giving a lot more to the organization and that's where something like the Brain Troopers comes in, it is my way to give to the organization and to the disease without breaking my wallet too.
- Kelly: [17:31](#) Of course. And bringing awareness or getting it out there. Your other friends who are runners, you're opening up the circle and it's giving you an opportunity to talk about your seizures and maybe expose them to another side of you that they weren't as aware of before.
- Andrew: [17:49](#) Absolutely.
- Kelly: [17:50](#) One of the things that I really love about what you're doing is it is showing that we can all be advocates and we can all find ways to fundraise, but to our own talents and, and every bit helps. And it's not even every little bit. It is every single donation, every event, every piece of awareness. It all helps and it doesn't have to be huge and play to your strengths. You love running, you know runners. So you've created the Brain Troopers and I think that it's just so attainable. It is reachable and I think that it's so inspiring and I hope it inspires other people who are listening today to find that activity, that talent that they have and to build...
- Andrew: [18:43](#) To use it.
- Kelly: [18:44](#) Exactly. To build something out of that. Well Andrew, thank you so, so much for joining us today.
- Andrew: [18:51](#) My pleasure, my pleasure, Kelly.
- Kelly: [18:51](#) Thank you for the advocacy work that you do and I cannot wait to see where the Brain Troopers is headed in the years to come.

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Andrew: [19:00](#) Hopefully in the right direction.

Kelly: [19:03](#) No doubt about that.

Andrew: [19:04](#) Thank you.

Kelly: [19:04](#) Thanks.

Kelly: [19:08](#) What a joy to speak with Andrew today. His story is a great reminder of how epilepsy does not define a person. Through his trials with epilepsy, he remains a motivated young man bent on exploring ways to educate the general public on why research is so vital to help the 3.4 million Americans with epilepsy. If you are also interested in using your talents to help raise awareness and important funds for research, become a CURE Champion. Learn more about the CURE Champions program by visiting [cureepilepsy.org/cure champions](http://cureepilepsy.org/cure-champions). Thanks so much.

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