

Seizing Life, episode 133

Best of 2023

Guests: The Tsane Family, Dr. Dave Clarke, Mariah Mayhugh (Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes and this is Seizing Life, a podcast produced by Cure Epilepsy. Today on Seizing Life, we revisit some of our favorite episodes from 2023. Before we begin, I want to take a moment to let you know that in 2024, Seizing Life will become a monthly podcast. We will be publishing new episodes on the first Wednesday of every month. Additionally, Cure Epilepsy will be launching a new monthly video series on our YouTube channel and website.

The new series, entitled Epilepsy Explained, will feature a different epilepsy expert on each episode providing short, lay-friendly answers to questions from our community about a particular area of epilepsy. Doctors and researchers will cover questions about seizures, diagnosing epilepsy, epilepsy medications, surgery, and many other topics. New episodes of Epilepsy Explained will be published on the third Wednesday of each month.

Again, new Seizing Life episodes on the first Wednesday of the month, and new episodes of Epilepsy Explained on the third Wednesday of every month. I hope you'll continue to listen to or watch Seizing Life, and check out Epilepsy Explained in 2024. Now, onto our best of 2023 compilation episode. In February of 2023, we spoke with 2021 Junior Olympic finalist, Christiane Tsane, and her parents about the impact of seizures on her education, training, and competition.

Now, Christiane, I understand that even with your epilepsy diagnosis and uncontrolled seizures, you have not let that slow you down, literally, and you are a competitive runner. Tell us about your competitive running.

Christiane Tsane: I got into running when I saw my sister, Andrei, was running with her friends.

Kelly Cervantes: What events do you run?

Christiane Tsane: I run the 100 and the 200.

Kelly Cervantes: I understand that your dad is your coach. How do you like having your dad as your coach?

Christiane Tsane: I like my dad being my coach because he teaches me new things, he teaches me new skills. He helps me to be the best runner that I can be.

Kelly Cervantes: I don't know that there is a much better recommendation or referral there that you can hear, Dad. That's got to make you feel pretty great. I understand that you have not always been her coach. Talk to us about that decision to transition.

Lawrence Tsane: Yeah, the decisions really came from a little bit of desperation. When your child's going through all these different things, their memory's being impacted, their school is being impacted, and you start to wonder as a parent, what can I

do? She was running, she was doing very well, and that's when I realized, okay, from time to time, she may have seizure at practice with the team that she was running with, and I realized we may need to isolate her a little bit as we're trying to figure out things in the house.

I started walking out with her, knowing when to stop, because I could tell when it's about to happen, and knowing when to push her a little bit. This is all really an uncommon ground to me, because my wife and I, we kept talking about it. I was like, "I don't know if I'm doing the right things. I don't know if we're doing the right thing," because we search online to try to see what person do we know that's doing sports that has epilepsy? We looked online, looked at Google, social media, we couldn't find anybody.

Then the doctor was saying, "Yeah, if she's okay, do it." I was like, "Okay, I'm going to do it." Sometimes, just like she said, it was very discouraging. We start practicing, she has a seizure. I have to come around and come home. The day she's supposed to practice, she had a bad seizure the night before. Okay, I have to postpone it. I kept just not giving up and just walking out with her, and she was such a soldier, encouraging me as well. When she's good, you can see what she could do. Then that's really her attitude that made me just keep going.

I didn't know what I was doing, really, quite frankly. Then that's how I ended up really coaching her, and she's doing very well. She was doing well. We were managing the seizures, the competition. She's had seizures right up the starting line when she's about to run. I had to learn how to deal with that, to deal with that, and talk to her, and make sure she was okay with it. Yeah, just a unique journey, just learning as I go, quite frankly.

Kelly Cervantes: I think we've buried the lead a little bit here, because when you say that Christiane was doing well, what you mean is that she actually made it to the final round in the Junior Olympics. That's huge. Can you tell us about that?

Lawrence Tsane: She had qualified for the 100 meter and long jump, but the 200, she failed to qualify because she had a seizure during the qualification round. That was a tough one for us to swallow. Then when it came to decide whether we needed to go, it was kind of a hard decision for us, but she had worked so hard that we felt that, you know what, if we don't go all the way, that would not be respecting all the work that she had done.

We decided to go anyways. It was 95 kids for her age group, from all over the country. We had to go through three rounds. The first round, they had to go from 95 to 24, and then the second round from 24 to eight, and then the eight went back for the finals. She was part of those eight, and she finished sixth.

Kelly Cervantes: That's amazing, Christiane. First of all, congratulations. That is quite the accomplishment. I want to take a step back for just a moment, because you mentioned earlier that she had had a seizure during the qualifiers for the 200

meter, and I believe she had had a seizure on the starting line. I'd love to hear from your standpoint, the education that you're able to provide and show to this entire Junior Olympic running world, that here is this amazing girl who is super fast.

She also happens to have seizures, but she can still participate and do all of these amazing things. There is no comparison for that level of awareness and education. I'm just curious what the response was back to you as people are becoming aware, and acknowledging her epilepsy, and how it impacts her, and maybe more importantly, how it doesn't impact her in some ways.

Lawrence Tsane:

No, definitely. One good example that I can use is during one of her competitions, she was running a relay, so it was a 100-meter relay, it's a team event. She was lined up, she was going to be on the second leg, and they were lining up, ready to go. Then I was about 20 feet to 25 feet away from her just watching, and all of a sudden, she didn't look right. She started looking up, and I started walking towards her, because I knew something was going on.

By the time I got there, if I wasn't there, she would've hit the ground. Then I caught her. I kind of talked to the officials real quick. I raised my hand and said, "She's not able to go." While I was talking to her, she went into a grand mal. She started shaking and all that, so most people saw that. No one on the team had really seen her going through a seizure.

After that, she's 35 seconds, she snapped out. I waited about a couple minutes, and then I took her out completely. I took her to my car, where she started to kind of fall asleep a little bit, and then she was substituted, obviously, because they had to run. I took her to the car. We waited for, I'd say, about 35 minutes or so. Then after that, she woke up from her nap. She was like, "Aren't we ready to run?" I said, "Yes, we are." She got up, the 100 meter was going to start, and she came in like nothing ever happened.

People were looking at her like, "Okay, didn't I just saw this child on the ground?" She took off running like there was not even a match. She won that event on Friday, came back on Saturday. She won the 100, and she won the 50 meter that day as well, and then she medaled on all three events. Again, the gap was so big that you couldn't even, the second one was far behind her. One of the coaches, they just came looking at her that day, like, "I saw what I saw yesterday and I can't believe she came back and she was running this fast."

Christy Tsane:

I want to add that during that race where she had the seizure from her, just the audience, her teammates, in the car, we were like, "Hey, Christiane, you want to go home? We can end it here. We can go home. You did amazing," but she woke up from her seizure and she said to us, "I want to go back out there." It wasn't us, saying... I was so impressed. I admired my kid so much, because she said, "I want to go back out there." I was like, "Well, I'm going to follow you. Let's go."

She went out there and did it. I remember seeing people just shaking their heads, like, "I cannot believe that I just saw what I saw." I was so proud that that was my child. I really was.

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: In July, pediatric epileptologist, Dr. Dave Clarke, provided us with a thorough overview of the specialists and services available at Comprehensive Epilepsy Centers. Can you explain the difference between, I believe there's four epilepsy centers, so one, two, three, and four?

Dr. Dave Clarke: Sure, sure, sure. They're gauged towards where you enter the system with epilepsy, and epilepsy does two or more seizures and/or on epilepsy syndrome, or the risk of having epilepsy. The initial place that you're usually seeing is either the primary care's office or the emergency room, and that would be a level one. They in turn tend to send you to perhaps a neurologist, and that level of care would be more of a level two.

Once you start getting into more subspecialty care, then you get to level three and fours. That's when you may have failed one or two medications, or you can't better define what the epilepsy syndrome or epilepsy type is.

Kelly Cervantes: Excellent. Can you further define the difference between a level three and a level four epilepsy center?

Dr. Dave Clarke: Sure, excellent, excellent. You have triad. Now, you have seen neurology, and know you want a higher level of care for the investigative studies to better define epilepsy syndrome, potentially doing other things, like maybe the diet, or further medications to advance that care. You'll get to a level three. Now, level three may not always have the diet, but some do. Some have the diet, and some have somewhat basic types of surgeries, taking out lesions and things like that.

Once you are to get to a higher level, further investigative studies to determine, is it a localization of focal epilepsy as it's now called, and whether you could potentially do epilepsy surgery, both palliative or definitive, or get more involved in the genetics of epilepsy, engage more with in-depth neuropsychological evaluations and things like that. That's when you get to that level four.

Kelly Cervantes: Should everyone try and get to a level four center, or are there certain people that you recommend aim for a level four?

Dr. Dave Clarke: Yeah. Let's start from I guess what I described as the ideal patient to get to a level four. If you have gone through two medications, based on prior studies, it's known that if you go to a third or put two medications together, the probability of seizure freedom, if the correct medicines are used, are often less than 5%. In those cases, it is suggested nationally that you have a surgical epilepsy workup.

Even before getting to that, you have to go into what we described as a phase one or epilepsy monitoring unit. As you would know, but maybe not everyone else would know, not everyone is amenable to that epilepsy surgery. We don't want to just focus on that, say, 15 to 20% that you may help in that capacity.

We really want to get to that larger population that are very difficult to treat, that we have to focus and better define what they may have, vis-a-vis genetics or otherwise, whether they would be a great person for, say, the diet, any special medications that could tag its specific epilepsy syndromes, and then we define if they're not more generalized or more related to those syndromes, which ones could actually be helped significantly by epilepsy surgery.

Kelly Cervantes: We've talked a little bit about epilepsy centers, specifically level four epilepsy centers in previous podcast episodes. I know that at these epilepsy centers, it is more a team approach to patient care. Can you describe what that means, and the different professionals that a patient and their family may come across when they enter a level four epilepsy center?

Dr. Dave Clarke: I love these questions. It's definitely a multi-specialty deal you're walking into here. You don't treat the epilepsy or the seizure. You treat the individual who happens to have epilepsy. In order to treat that individual, because multiple circuits are involved with the seizures, and something causes the seizures, there may be many other aspects of the brain that are affected.

Therefore, you have to lay this foundation to look at all those aspects of care. You need neuropsychology, because you want to see what that neurocognition is like. You need to definitely address the social determinants. You need a social worker. That family or parent may not be able to navigate that care. A nurse navigator would be very helpful.

An epilepsy surgeon is required if you need surgical care, a dietician, as a pediatric epileptologist, child life, us, the epileptologists, but there are many others: the nurse practitioners, the EEG technologists, and so forth, in that you want this comprehensive approach, so that when that family comes in, you can really look at the overarching view of the person with epilepsy, and take care of not only their needs, but the needs of other persons that may be affected within the family household.

Kelly Cervantes: Yeah, you brought up so many incredible points there. I want to highlight first that at these epilepsy centers, you're not just treating the seizures, you're treating the patient. I think that that is so important. As so many of us know,

epilepsy is far more than seizures. It impacts so many different parts of our life, and mental health you talked about. I think so many times, I've heard so many patients talk about the comorbidities with mental health, but more specifically how difficult it can be to find a therapist or a mental health professional that understands epilepsy.

At these epilepsy centers, you have a much better chance of finding those professionals. It can be incredibly difficult to coordinate multiple doctors' and specialties' schedules. How does that happen within these centers to get all of this care to the patients?

Dr. Dave Clarke: Fortunately, the National Association of Epilepsy Centers have outlined many of those essentials, and that's morphing. New recommendations are actually going to come out later this year into next year. That care coordination, as you suggest, is integral. I'll just tell you the flow at our center and many centers. A neurologist, and/or parent, or primary care physician reaches out. We have a clinical coordinator or epilepsy coordinator that reaches back to that person, find out the details, then they call a parent, because they have to negotiate many things.

They have to figure out when somebody has to take off work, or if it's a significant other, husband or wife, when they may have to do something differently. When can the child come in, per se, from school? When will they be in? When will they be out? You have to look at quality of life also. If somebody needs to come in urgently, getting that person in urgently. They define what they're going to go through within the hospital. They speak directly to the providers involved, vis-a-vis the nurse practitioners and epileptologists.

Then once that person comes in and get monitored, once they're going from there to their next mean of management, be it surgery or otherwise, you need somebody to follow that track and, I shouldn't say hold their hand, because it's sometime led by the parent, which is very appropriate, but follow exactly what needs to be done over time, getting to that end game.

Kelly Cervantes: In August, Mariah Mayhugh spoke with us about her epilepsy journey, from hiding her childhood absence seizures, to becoming a passionate and active advocate for epilepsy awareness, education, and representation.

Mariah Mayhugh: I wound up enrolling in college classes when I was 15, and then when I was 17, I was in a college level English class, and they were teaching us how to write research papers. At the same time, I was in a CNA class to get certified as a CNA. In the CNA class, we were on the unit learning about epilepsy and seizure care. That's one of the first times I'd ever really heard epilepsy discussed outside the hospital. It was starting to make me curious about my own condition.

Then when I was in this English class and we were assigned this research paper, the prompt was, write a paper that interests you, about something that

interests you, but that you know almost nothing about. The point was to teach us how to research things. I was like, "I'm going to research childhood epilepsy because I'm interested in it, I know nothing about it, aside from I have it, and I'm not going to have to tell anyone it's me. Literally anyone could pick that topic."

When I started writing that paper, I learned for the first time that I wasn't alone, and that there were so many kids out there struggling. There were so many kids that felt so lost, and alone, and ashamed of their condition, just as I was. I just remember this feeling of wanting to crawl through the computer screen and hug them, because I wanted them to know that they weren't alone.

It was frustrating me, because I'd grown up around the whole campaign of breast cancer awareness, and Alzheimer's awareness, and all these different things, which are really important, but I'd never seen anything for epilepsy. It was making me so upset, like, "Why isn't anyone doing anything about this?" Then I came to the realization that if you are that upset about it, you should do something about it.

Kelly Cervantes: I like that. You're a girl after my own heart. Mariah, I want to get into all of the different ways that you have become an epilepsy advocate, but before you could do any of these activities, you had to tell your friends and people outside of your family about your epilepsy. How was that received?

Mariah Mayhugh: Yeah. I think that one of the most impactful moments was actually when I was telling my mom that I wanted to be an advocate. My whole life, she'd known me as like, "Oh, my gosh, don't tell anybody." I remember I got my research paper back, and I just remember I read the whole paper to her out loud, and she was like, "Wow, that's so cool. I love all the research that you did into that," blah, blah, blah. I wound up infusing some of my own story into it.

She said, "I think that's really interesting that you put some of your own story into that, in that you were okay with your teacher reading that." That was a perfect segue for me to be like, "I think I really want to start sharing my story more and start being more public about my journey." She was so supportive of that. She was like, "I am here for you. Whether or not you want to keep this completely to yourself, or you want to be an advocate, I got you." It was really cool.

Kelly Cervantes: That's amazing. How did your friends respond?

Mariah Mayhugh: My friends took it really well. I remember I would just kind of tell them one-on-one. I would just be like, "Hey, I've got something that I need to share with you, and it's really personal." I would tell them what epilepsy was. A couple of them knew what epilepsy was. There wasn't as much explaining, and I was really worried that they were going to be upset with me for having not told them or whatever, but they really weren't.

It also just came at a really nice time with high school graduation and whatnot. I wound up not staying in touch with a lot of people anyway, and just transitioning into that new life, that new chapter of adulthood, and also advocacy.

Kelly Cervantes: Yeah, absolutely. You get to sort of start fresh a little bit after high school and reinvent yourself, and that is exactly what you did. Now, tell us what those first steps of advocacy looked like for you.

Mariah Mayhugh: I was like, "I don't know what I'm doing." I had no idea. I had this very vague vision of like, "I want to be an advocate," but I just didn't know how to get from point A to point B at first. I just started Googling stuff, and I found this epilepsy 5K that was being held in Colorado Springs from the Epilepsy Foundation of Colorado. I went to my parents and I was like, "I want to go to this. It's in three months or whatever. Will you go to it with me?"

They were like, "Of course." We went, and I just remember that feeling of seeing everybody all in purple, and all the different tables and booths and stuff with different resources. I was like, "How did I miss this all this time? This is amazing."

Kelly Cervantes: Yeah, it's incredible when you go looking for it, how present and active the epilepsy community is. Your advocacy efforts just began with that 5K, and then you sort of took off running, literally beyond that 5K.

Mariah Mayhugh: Yes.

Kelly Cervantes: Tell us about the children's book that you wrote, and some of your other endeavors.

Mariah Mayhugh: Yeah, so I went to this 5K and I was like, "This is amazing, and I have to keep doing stuff like this." Just, gosh, about six months after that 5K, it was March, and I'd heard about Purple Day. I was like, "I want to do something for Purple Day." I came up with this idea of doing 26 things, like one thing a day every day in March up until March 26th, and one thing to spread epilepsy awareness.

I made a bunch of little purple ribbons, and I passed them out to businesses. I hosted a little babysitting event where parents could come drop off their kids, donate 50 bucks for the evening. I'd watch their kids, and then the money would go to the foundation, stuff like that. I was doing one thing every day, and one thing that I really wanted to do was do a children's book reading at Pikes Peak Library.

I had learned so much at the library growing up. I was like, "This is a perfect opportunity to educate children." When I was preparing for this event, I was looking it up on our library's database, like children's books about epilepsy, and there was none. I was like, "Okay, I'm not surprised, but mildly frustrating." I

hop over to Amazon, Barnes and Noble, all the big ones, and I look up children's books about epilepsy.

The only ones I could find were about little boy protagonists that had tonic-clonic seizures. It was like, "I'm a girl that grew up primarily with absence seizures, and that's one that's a lot less talked about. Why is there no educational resources on this?" Just like I did when I wrote my research paper initially, I was like, "Okay, if you're frustrated about it, you got to do something about it," so I decided to write my own children's book about epilepsy, featuring a little girl with absence seizures.

Kelly Cervantes: That's incredible. What is it called, and where can people get it?

Mariah Mayhugh: It's called Mimi: A Story About Absence Seizures, and you can get it on Amazon, Barnes and Noble, my own website. There's a couple of little independent bookstores that sell it.

Kelly Cervantes: That's amazing. Congratulations. No small feat to write your own book. Then you decided to take your advocacy platform even further when you were crowned Miss El Paso. Tell us about that. Miss El Paso County, is that right?

Mariah Mayhugh: Yes. That's the county that I live in is El Paso County. A lot of people think I live in Texas. I do not. I live in Colorado. Yes. I decided to run for Miss El Paso County because I heard that there's a lot of stigma around pageants and around like, "Oh, it's literally just based off of your looks. It's a beauty pageant," like the Miss America Organization, particularly post 2018, really, has been working hard to change that narrative.

They implemented this thing called the Social Impact Initiative, and you had to come up with a really good social impact initiative. You had to do a ton of work in your community, and that's the primary thing that they were basing this all off of. I won the title of Miss El Paso County, and I actually just wrapped up my year as Miss El Paso County. It was a really amazing experience. I got to travel so much, I got to do so many events and spread so much epilepsy awareness, and compete for Miss Colorado, which was really cool, and talk about it on the Miss Colorado stage.

Kelly Cervantes: That's incredible. Tell us the name of the initiative that you worked on.

Mariah Mayhugh: Yeah, so the initiative was called DREAM, so it was Dedicated to Raising Epilepsy Awareness in Media, media encompassing books, literature, songwriting, movies, anything, to provide further representation. I won the title of Miss El Paso County, and I actually just wrapped up my year as Miss El Paso County, and it was a really amazing experience. I got to travel so much. I got to do so many events, and spread so much epilepsy awareness, and compete for Miss Colorado, which was really cool, and talk about it on the Miss Colorado stage.

Kelly Cervantes: Thank you to all our wonderful guests in 2023. We truly appreciate every single guest who shared their personal stories, challenges, and triumphs, or offered their insights and expertise. I also want to thank you, the Seizing Life audience, for the past five years of support. As I've said before, I don't wish anyone to become a member of this epilepsy club, but I'm so grateful for the incredible people, the patients, families, doctors, researchers, and advocates who comprise this amazingly supportive and dedicated epilepsy community.

Thank you for supporting our podcast. Here's to a healthy, happy, and productive 2024, in which we advance research and move closer to a world without epilepsy. Cure Epilepsy: inspiring hope, and delivering impact. Thank you.

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