Seizing Life, episode 110 Epilepsy Can't Stop Young Girl's Competitive Spirit Guests: Christiane, Christy, and Lawrence Tsane (Transcript)

Kelly Cervantes:

Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy. Today on Seizing Life, I'm happy to welcome the Tsane family. Christiane Tsane began experiencing seizures at the age of six. Despite medications, these initial absence seizures progressed to tonic-clonic and focal seizures. Now, 11 years old, Christiane refuses to let her epilepsy stop her from doing things she loves, including competitive running. With the support of her parents, Christy and Lawrence, Christiane has continued to compete despite her seizures. In 2021, Christiane was one of the final eight runners in the Junior Olympics, ultimately finishing sixth in the country in the hundred-meter competition. The Tsanes are here today to share their epilepsy journey and discuss how they are balancing seizures, medications, and quality of life. Christiane, Christy, Lawrence, thank you so much for joining us today. I want to start off with you, Christiane, and find out what you remember about your first seizure.

Christiane Tsane:

Okay. I don't remember much of my first seizure, but I had it when I was six years old. My dad, he was walking me to school. Well, he was taking me to school, then at some point I stopped walking. He was talking to me, but I wouldn't respond to him. Then at some point I snapped out of it and I started talking to him.

Kelly Cervantes:

Lawrence, what were you thinking when this happened?

Lawrence Tsane:

To what she was saying, I was just taking her to school and I was walking with her, and I assumed that she was next to me. Then I realized at some point I was walking by myself. Then, when I turned around, I realized she had stopped. I didn't know why she had stopped, and I thought maybe she saw someone that she knew, so I walked back and I said, "Hey, Christiane, what's going on?" She wasn't responding to me. Her head was kind of going left and right like this, as if she was playing games with me. Then I put one knee down to kind of be at eye level, and, "Hey, can you see me?" She was still doing the same thing. She wasn't even responding to me at all. I was calling her name and she wouldn't respond.

Then after maybe 10 seconds, she snapped out. I knew something happened, so I called my wife. I said, "Hey, something just happened here. She didn't respond to me for about 10, 15 seconds. I don't know what that is." My wife didn't believe. She didn't believe me, of course. She thought I was making it up. I said, "No, I'm not making it up. Something happened. I don't ... " She was fine then, so when my wife started talking to her, she was responding as if nothing ever happened. I was like, "I guess maybe it was me," and we just moved on from there. That day, to me, I didn't really think it was an issue. I felt something happened, but I wasn't really sure whether it was me or her. I don't know. It was just one of those situations where it was hard to understand what just happened.

Kelly Cervantes: What happened from there? I know there was another incident a few months

later.

Lawrence Tsane: Everything seemed fine until, I'll say maybe four months later-

Christy Tsane: About November.

Lawrence Tsane: Yeah, that we saw. Maybe something was happening in between, because we

didn't really know what happened. Then she was on the couch, she was drawing, and then my wife was sitting there and she was drawing, and all of a sudden her head started going left and right again, just like that. My phone was right next to me and I just grabbed it, just to say, "Okay, I've got to capture this because I don't know if it's me or her." I just started capturing it, and my wife was sitting next to her and she didn't notice that, so I just started recording it, and then at the end I just touched her to say, "Look to your left." Then she looked, and then she realized, yeah, she was still doing that, and then she said, "Give me the red pencil." She didn't know what the red pencil was, so, "Give me the green color. She didn't know what the green color was. That's when I knew something was up, but I had it on video too, so at that point, there was no more

issues as to what had happened.

Kelly Cervantes: I mean, that is so smart, to take video of that situation. I mean, that is just the

number one advice that I give to any parents who are concerned or questioning. Kudos to you. Christiane, when you would sort of snap out of it, as you were saying, were you scared? Did you know what was going on? Could you see that

your parents were concerned, or do you not remember?

Christiane Tsane: That's going to be a hard thing to say. I don't remember it at all. If only there

was a time machine.

Kelly Cervantes: Yeah.

Lawrence Tsane: Yeah, and that is correct, because when she snapped out, she doesn't know. I

mean, it's almost like something got lost in space and she doesn't know. When she comes back, she doesn't know, hey, she was out for about 10 seconds and

she just continues as if nothing ever happened.

Kelly Cervantes: What did you do with that video once you had recorded it?

Lawrence Tsane: Yeah, so the first thing I did is I called my sister. She's a doctor. I called her and I

said, "Let me send you this video. Just tell me, I don't know what this is." Then as soon as I sent it to her, she said, "Yeah, you need to talk to a neurologist. There's probably something going on, but you need to talk to neurologist." My wife, she called, and Christy made all the appointments, and that's when the

journey started really.

Kelly Cervantes: Christy, when you met with the neurologist, what did they tell you?

Christy Tsane:

Well, honestly, first we didn't do a neurologist. They wouldn't let us do the neurologist. We had to go to the pediatrician first, so, went to the pediatrician and she said, "Oh, I think it's absence seizures," and then she scheduled a neurologist six months out. Six months later we saw a neurologist, and they confirmed that it was. They felt it was epilepsy. They felt it was absence seizures. They didn't think it was focal or grand mal at the time, and they put her on some medication and they just sent us home. No education, they just sent us home.

Kelly Cervantes:

You go in, they tell you absence seizures, give her a medication. Were you alarmed? Were you worried? What was your feeling at the time and what did you know about epilepsy?

Christy Tsane:

I knew nothing about epilepsy. I've been a case manager, so I had clients with epilepsy, but I just assumed that epilepsy was curable. When I went to the appointment, she gave me a prescription for Keppra and she said, "You're going to take it for one year and after a year you're going to get off and she's going to be okay." I went away feeling very confident and I felt good. I had no information about epilepsy. I just had a prescription in my hand that I took to the pharmacy to get filled, and I knew that in a year we were going to be off the medication and she was going to be cured. That's all I knew, and I was secure in that ignorance, not knowing that that is not how it is.

Kelly Cervantes:

Yeah, I think it's so hard, because the doctors don't want to alarm the parents, of course, but sometimes it is not the common treatable epilepsy. I think that a lot of times, those patients end up falling through the cracks unless they can advocate for themselves or have strong parents to advocate for them. You're sent on your way with this prescription. Did it help? Did you see an improvement?

Christy Tsane:

It didn't go away. We would have them every two weeks, every 10 days, but it was focal seizures at that point. It was not absence. It was focal seizures and it was manageable. It was still manageable. We went to the epileptologist of course, after that, because we thought he could do a little better. He was like, "Yeah, I can do better. We can get rid of these. They're focal. We can do this." That was another journey.

Kelly Cervantes:

You started the arduous journey that I think so many epilepsy families are aware of, where it can feel like you are throwing darts at a dart board, just trying the next medication to see what helps, but of course, they all come with their own side effects, which is sometimes worse than the seizures themselves. What sort of side effects did you notice, Christiane? Do you remember how the medications made you feel in the beginning or how they make you feel now, even?

Christiane Tsane:

When I take my medicine, it makes me feel tired and sometimes it tastes nasty.

Kelly Cervantes: Yeah, I can imagine those. Not the highlight of your diet, I'm sure. What were

some of the other side effects that you noticed, Lawrence and Christy?

Christy Tsane: Rage. Lots of anger. Her personality completely changed. I mean, this is a very

sweet child. She's still very sweet, but her personality changed. She was so angry, so antisocial. Didn't want to talk to her friends, didn't want to do things, and that was what alarmed me to even go see the epileptologist, because I was like, "This isn't right. This is not the same person. I just traded in this for that, and we didn't get rid of the seizures, but now I have a different personality and

it's not a nice personality. It's an angry child, an angry six-year-old."

Kelly Cervantes: Again, kudos to you for recognizing that this treatment was unacceptable and

not working, and going and getting that second opinion, and also seeking out an epileptologist. I think so many people are unaware that not every neurologist is an epileptologist and that there is a difference. There's a big difference, and

finding that epileptologist is so important.

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: You're going through these rounds of different medications, and it sounds like

her seizures were sort of constantly changing and not necessarily for the better.

Talk to us about that.

Lawrence Tsane: Yeah, definitely. Even with medication, we felt that it wasn't getting any better.

We went from just having maybe one or two episodes to now having clusters, where she would have four, five, six in a row, and it was happening at night, so my wife and I, we couldn't sleep any longer. We had to figure out a way ... Now, this is becoming really, really difficult and really crazy, so how do we, first of all, make sure that we're awake to take care of her, and how do we make sure she's safe? We started organizing in the house and trying to say, "Okay, tonight is your night, if something happens, you're up," and that's really how we managed it. From a seizure perspective, she was really not getting any better. She was having these clusters, it was at night. Sometimes she'd have it the whole night and we'd have to call the ambulance, wakes up in the morning at the hospital asking, "Hey, why am I here?" We have to explain what happened because she doesn't remember, so yeah, we just fell into a situation where, wow, we

underestimated this condition, for sure.

Kelly Cervantes: I know that terrifying feeling of the nighttime seizures. Had anyone spoken to

you about SUDEP at this point?

Christy Tsane:

Never. No one ever talked about it, but we had been reading about it just because at that point, we had moved her into our room. We had moved her bed into our room to monitor her. We weren't sleeping but three hours a night, so while I'm doing my research at nighttime, probably like most parents, I'm reading about this thing, SUDEP, and I'm really concerned and I go to the epileptologist and I say, "What is this, and why hasn't anybody ever talked to me about it?" I was so afraid, but he was like, "No, that's very rare," but more than that, I was wondering, "Why didn't you tell me?" He was more like, "Well, we don't really need to tell you because if we don't think you're high risk, we don't think to tell you," but that didn't feel right to me, that you didn't even inform us. Tell us so I can expect it.

Lawrence Tsane:

Yeah.

Kelly Cervantes:

It's not right, because on top of that, there are things that you can do to help mitigate it, and if you're not given the information that it exists, then you can't do the behavioral controls. Making sure that she's getting enough sleep, making sure that she has the low stress, all of those things that we know help lower that risk, you're not aware of it. You can't even do that. It is unbelievably frustrating to hear that that was still your experience, even so recently,

Lawrence Tsane:

Yeah. We took measures obviously to protect her at night, but we started ... Have seen examples as to where, if you're not careful during the seizure, she can suffocate or she can hit her head, so we started thinking about her safety just outside of just the seizure itself. If something happened while she was sleeping, how do we make sure she's safe if you're not able to respond on time? We started cleaning her room, removing anything that could potentially hurt her if she were to feel disoriented or anything like that.

Christy Tsane:

We did some different things that doctors don't tell you. You have to research it yourself. The monitors out there, you've got to investigate it yourself, how to protect and keep your child safe.

Kelly Cervantes:

It never ceases to shock me how much knowledge and awareness falls on the shoulders of the patient or the caregivers, which I suppose is why podcasts like this exist today, so that we can talk to people like you and share that information and share that knowledge. I know that unfortunately Christiane's seizures progressed and continued to get worse. Talk to me about that, and when she had that first tonic-clonic seizure.

Lawrence Tsane:

Yeah, the first tonic-clonic happened. It was on a Saturday, if I remember that very well. She went outside. She had a mild seizure, like a focal, and then we brought her in. Then, as my wife was sitting on the couch with her, she just went into, I just saw ... For the first time, I saw her eyes roll into the back of the head and she went into a big tonic-clonic seizure. She was vibrating, she was shaking. I didn't know what to do. I didn't know we could get there. I thought she was, something was going terribly wrong. I just picked the phone. I just called and I was running around the house not knowing what to do. They

showed up, the ambulance. At that point, she was responding a little bit, and yeah, it was just an experience that I've ... Something I've never experienced before, and it was so scary. You don't know what to do. You don't know what's going to happen. I mean, I just can't describe it.

Kelly Cervantes: Christiane, were you having seizures at school? How did it affect your

academics, your learning?

Christiane Tsane: Yeah, I had seizures at school and I didn't like it.

Kelly Cervantes: When would you have your seizures in school? Was there a certain time that

you would have them?

Christiane Tsane: It was mostly during specials.

Christy Tsane: Like PE.

Christiane Tsane: Yeah. PE. I would always have to sit out because if I did what my coach said,

then I would get dizzy and have a seizure. Then, the next thing I know, I would wake up in Nurse Bonnie's office. Then sometimes when she'd go somewhere, I would cry because everybody saw that and I'm embarrassed. I don't like it when

people see me have seizures.

Kelly Cervantes: Yeah, I'm so sorry. That really stinks. Lawrence, Christy, what did you notice was

happening at school? Socially and academically?

Christy Tsane: In the beginning it wasn't as bad. The earlier years, it was focals. We had 504s,

then they went into IUP. We had a lot of support and we did, my husband and I did a lot of work with her, a lot of work with the teachers, a lot of tutoring. It was very hands-on, it was, but it was a little easier because we didn't have as many seizures. It was a little easier to manage because we didn't have as many seizures at the time, but socially, I think friends kind of pulled back. I mean, people, they do love us. I know they love us, but I still saw my child losing friends, people. She's not getting invited to as many parties or sleepovers anymore, and so you saw that change. I would invite people to the house, of course, trying to keep things regular, but I did see a change in our life, in our social life, in our circle. Some people, I'd rather not talk about it because people just can't take it. They cannot hear it. They cannot bear that seriousness of this condition, so I try to keep it light, which I don't think I feel like I should have to,

but I feel like I keep it light at times.

Kelly Cervantes: It's so frustrating because it's your normal, right, and you should be able to

share it and talk about it. I think you said it when you were like, "Some people just can't handle it," or they don't want to handle it, and that's really isolating. 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 Andre, who 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 mean, 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. Now Lawrence, 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

is going through all these different things, their memory is being impacted, school is being impacted, and you start to wonder, as a parent, "What can I do?" You're trying the best you can to educate her to make sure that she can be a good student, but she has these issues that she's running into with medication and the seizures and the memory and all that stuff. You start thinking, "What else 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 a 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 working 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 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 thing, I don't know if we're doing the right thing," because we'd 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, and 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. On our way to practice, she has a seizure, I have to turn around and come home. 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 working out with her, and she was such a soldier, encouraging me as well, because when she's good, I mean, you can see what she could do. Then just really her attitude that made me just keep going, because I didn't know what I was doing really, quite frankly.

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Then, that's how I ended up really coaching her, and she's doing very well and she was doing well, and we were managing the seizures, the competitions. She's had seizures right at 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, but 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. I mean, that's huge. Can you tell us about that?

Lawrence Tsane:

Yeah, definitely. It was an interesting experience, I would say, for us, because even actually going into the Junior Olympics, we had so many issues, so many setbacks, and we were wondering on that day, even if it was worth going there, because it's expensive. You've got to book a hotel, all this stuff, buy a plane ticket. It was in Houston, so we wanted to make sure that we're not wasting our time, based on what we had saw prior to her being there. She had qualified for the 200 ... No, the 100 meter and long jump, but the 200, she failed to qualify because she had a seizure during the qualification round, so 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, and 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, and 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. Now, I know that you had been consulting with her doctors sort of throughout this entire process. What had they told you sort of leading up to this?

Lawrence Tsane:

Yeah, so from their perspective, we felt really encouraged, so we didn't have anyone discouraging us for her participating, but we felt a little bit scared because we didn't find any other parent or any other child that was going through what she was going through. Sometimes during practice she would have seizures, and we just wanted to make sure that we were doing the right thing for her. At the same time, with all the other challenges that she had, even with school and other activities, we felt that we needed to stick to something for her. We needed to stick to something. She was talented and we just felt, "You know what? She's having seizures while sleeping, she's having seizures while playing, she's having seizures while watching TV. If she's having seizure while practicing sport, I guess it's part of the challenges that we face on a daily basis, so we may as well just figure out a way to deal with it." For the most part, most doctors or people we spoke to were very encouraging in terms of her doing sports with epilepsy.

Kelly Cervantes:

Yeah, it's talking about that quality of life and that balance, right? It is maintaining her mental health, too, and participation. 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 can't help but think, as unfortunate as that situation is, and I know how disappointing that was, 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, and 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. Yeah, and that is a good question, because this journey has been ... Even for us parents dealing with her every day, it has been a learning path for us as well. 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, and 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 then all of a sudden she didn't look right. She started looking up and then she just ... I started walking towards her because I knew something was going on, and 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 saying she's not able to go, and while I was talking to her, she went into her grand mal. She started shaking and all that, so most people saw that, and it took her probably, I'd say, about 30 to 35 seconds to get out of it.

The coach of the team came in running as well, trying to figure out what was going on. He knew that she had epilepsy but never really saw her ... No one on the team had really seen her going through a seizure. After that, 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 was ... 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 about, I'd say about 35 minutes or so. Then after that she woke up from a nap and she was like, "Are we ready to run?" I said, "Yes, we are," and then the 100 event was going to take place right away, because while we were waiting in the car, actually, we were worrying because we didn't know if she would be able to get back and run, and if she wasn't able to get back to run, it would've been over for her as well.

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 see this child on the ground?" She took off running. 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. Then she medaled in all three events. Again, the gap was so big that you couldn't even ... The second one was far, far behind her, and one

of the coaches, I mean, 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 in front of 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." She woke up from her seizure and she said to us, "I want to go back out there," so it wasn't us saying, you know. I was so impressed. I admire my kid so much because she said, "I want to go back out there," and 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.

Kelly Cervantes:

That's incredible, and I wish that none of that had to happen. I wish that that wasn't an education that her teammates and everyone on that track had to experience that day, but Christiane, that's pretty brave right there. In fact, that ranks up there in the top five bravest things I think I may have ever heard. I think you're pretty incredible. I'm curious about the status of Christiane's epilepsy today. Have you been able to get any better seizure control or manage the seizure frequency? Do you have more information about her epilepsy or what is causing it? Basically, how is she doing today?

Christy Tsane:

It's one day at a time. I mean, she's still having seizures. She hit 11 and puberty increased the seizures and the type of seizures, so it has been tough since the age of 11. It was since last year, and we went to Cleveland Clinic last July and she was diagnosed with polymicrogyria, so we know why she's having the seizures now, so that's good, but the only option we've been given is possibly surgery, but unfortunately she's not a surgery candidate because if they do operate, she'd lose 50% of her vision and she would lose her ability to ... She'd be paralyzed on the right side of her body, so that's just not an option for us. I feel like she has to make that decision when she's older as well, to see what she thinks. If it's worth the risk, I think she needs to make that decision when she's 18 or so. Yeah, we're just trying to manage right now, honestly. We're just trying to manage the seizures right now.

Kelly Cervantes:

Yeah. Well, and you can always hope that technology advances and maybe the outcomes are better in the future. I wonder, what advice would you give to other parents who are journeying down this road?

Lawrence Tsane:

I always go back to when we first got diagnosed. I know every case is different, and I talk to my wife about this sometimes and I'm saying, "If she only had two seizures in three years, I don't think I'd be the same person today." I think each case is different. I still think you have to take it seriously, even if you don't see as many seizures. Educate yourself anyways. We were forced to educate ourselves. We were, because seizures were happening and we had no choice but to educate ourselves, so you have to educate yourself, understand that doctors don't know everything. You are the true doctor, the parent, because you're seeing how your child's reacting to whatever you're giving them. You're seeing

how your child's behaving. You see all that stuff, versus the doctor that just sees her for 10, 15, 20 minutes. You have to relate that to the doctor, make sure you find a doctor that that's going to listen to you and not just say, "Hey, you go by what I tell you and that's it," because again, the doctor, the neurologist has to listen to you and work with you to make sure that you're working together to get to a solution.

They don't know everything, obviously, and I'm not saying anything to make them look bad, but they know enough to at least guide us as parents. At the same time, you have to make sure that you're there to communicate with them and be patient, and follow your gut, so if something doesn't look right, don't force it. Just don't force it. If it doesn't look right, it's probably not right, and just be patient and it could be a long journey as well.

Kelly Cervantes: That is excellent advice. Christy, anything you want to add?

Christy Tsane:

Yeah, join support groups. I mean, honestly, join support groups. Find friends that your child can relate to and try to figure out a new normal for your family.

Don't just stop, because I think there were years where we just kind of stopped living our lives. We were chasing the cure, so we just kind of stopped, because our life, our mantra became, "Well, when we find a cure and when she's okay, then we'll start living our lives," and that doesn't work. You've got to live your

lives through it. Find your bliss through the struggle. Just kind of try to figure out

what's good for your family.

Kelly Cervantes: I think you hit on something. There's one person in the family that is diagnosed

with epilepsy, but that diagnosis affects the entire family, and sort of keying into that and recognizing that is a huge step that needs to be acknowledged,

especially when there's other children in the family. Christiane, I wonder, I want to ask you, what advice would you give to another kid who's been diagnosed

with epilepsy?

Christiane Tsane: I would tell them, don't let epilepsy stop you from doing the things that you like

to do.

Kelly Cervantes: That is excellent, excellent advice, and you are the perfect poster child to be

delivering that message. I also want to know, when or what is the next race that

you're looking forward to?

Christiane Tsane: The next race I'm looking forward to is participating in the Junior Olympics in

Iowa in July of this year. I need to be practicing with my dad to not only qualify for that competition, but to also compete with the best 12-year-old girls in the

country.

Kelly Cervantes: I love it, and I cannot wait to cheer you on from a distance. I am so excited for

you, and we wish you all the best. I just want to say thank you so much to all

three of you for sharing with us today. You are incredible, and I just appreciate so much your openness and advocacy. Thank you so, so much.

Christiane Tsane: Thank you.

Lawrence Tsane: Yeah, thank you so much for having us, and thank you for providing this

platform as well, because once again, when we first started, we didn't have things like this to learn from. Being able to share our stories, what she's gone through, we're hoping that it's also going to help another parent somewhere

around the world, so we really appreciate it.

Kelly Cervantes: Thank you Christiane, Christy, and Lawrence for sharing your epilepsy story with

us. We wish Christiane the best of luck in her future competitions. As the Tsanes' story makes clear, people with epilepsy often struggle to find an acceptable balance between seizures, medication side effects, and quality of life. For too many people with epilepsy, the side effects of medication can be just as challenging and debilitating as the seizures themselves. That is why CURE Epilepsy was founded 25 years ago by mothers who could no longer accept the status quo of epilepsy treatments. Our goal is to find a cure for epilepsy. You can help us achieve that goal by visiting cureepilepsy.org/donate. CURE

Epilepsy, inspiring hope and delivering impact. Thank you.

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professionals who are familiar with the individual's specific health situation.