

Seizing Life, episode 122
From Hiding Diagnosis to Advocating for Awareness: A Young Woman's Epilepsy Journey
Guest: Mariah Mayhugh
(Transcript)

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

This week, I'm thrilled to welcome Mariah Mayhugh to the podcast. Mariah was diagnosed with epilepsy at seven years old and experienced both absence and tonic-clonic seizures for most of her childhood and adolescents. During that time, Mariah hid her diagnosis from peers, friends, and teachers. But at the age of 17, a school assignment sparked Mariah's desire to go public with her diagnosis and become a vigorous and creative advocate for epilepsy awareness and education. Now 22, Mariah is here today to share her epilepsy journey and her numerous advocacy efforts. Mariah, thank you so much for joining us today. I wonder if you can start by sharing with us, I know you were seven when your seizures first presented, and so I don't imagine that you remember a whole lot, but anything that you can remember, what they looked like and how those early days played out?

Mariah Mayhugh: Yeah, I mean, obviously as you've said, I was seven, so I was really young. I honestly don't really remember a life before epilepsy, but I can remember sitting in my pediatrician's office because that's where we went first and my pediatrician saying to my parents, she said, "I think you need to take Mariah to Children's Hospital because I think this is epilepsy." And I just burst into tears because the hospital just seemed so big and so scary, and I honestly thought like, oh my gosh, I'm going to die.

Kelly Cervantes: Yeah, I can totally commiserate with that. I remember when my brother was born and going to visit my mom in the hospital and just being terrified. It's scary places when you're little and then when you're given a word like epilepsy, that what was explained to you about your diagnosis?

Mariah Mayhugh: So honestly not much, which looking back to me is a little bit strange as an advocate and as someone that works with children with epilepsy, I don't remember a time that anyone actually sat me down and explained to me what epilepsy was. I had this vague idea of what a seizure was because it was happening to me. When my parents just called my absence seizures space outs. So I just knew I have space outs and I'm different than everyone else, and that's pretty much all I knew.

Kelly Cervantes: So how frequently were you having your absence seizures, and did you experience any other type of seizure?

Mariah Mayhugh: Yeah, so I had absence seizures multiple times a day, at least 10 to 20 if not more. And then I also experienced tonic-clonic seizures, which started a little bit later, and I didn't have those as frequently, but they would show up every couple months.

Kelly Cervantes: Now I know that eventually you were able to gain control, but it was a journey. Can you talk to us about what you remember from that, all of the treatments and trials that you went through to get to where you are today?

Mariah Mayhugh: Yeah, the trials and tribulations. So basically from seven to age 12, I was on just a complete slew of different medications and hospital stays, tests, the whole shebang. And then when I was 12, we finally gained seizure control, and then after a year of having seizure control, my doctor wanted to try to wean me off the meds to see if I'd outgrown it through puberty. So we did that and it worked for a little bit. I think it was just under a year, but then my seizures came back and so then we had to start all over again, which was super frustrating. But thankfully it was around, I think it was December of 2015 or 2016 when I finally gained seizure control again, and I've been seizure-free ever since.

Kelly Cervantes: Which is amazing. And congratulations. Are you still on medication?

Mariah Mayhugh: I am on medication, but it's a lot lower dose than what I was on when I was little, so I'm very grateful for that.

Kelly Cervantes: That's incredible. And seven to 12, you're talking about experiencing regular seizures. That has to have an impact on you educationally and mentally. What did that look like for you in childhood?

Mariah Mayhugh: So it definitely had a really big impact on me. Thankfully it didn't have as big of an impact educationally as it could have because my parents made the decision to homeschool me. And so I was really able to be set up for success thanks to them, and especially thanks to my mom who was my primary teacher during those years. But socially, emotionally, it had a great impact in that I felt very isolated. I felt very alone. I remember writing in my diary that I felt like my epilepsy was a dark mark against me and I was terrified that anyone would ever find out about it. So that was really hard to deal with growing up.

Kelly Cervantes: So it sounds like you did not tell anyone about your epilepsy when you were younger.

Mariah Mayhugh: I did not. It was my dark secret that we protected at all costs, and I really felt like if anyone found out about it, I was going to be judged or I was going to be viewed as the sick kid or the weird one or things like that. And so I kept it completely under wraps. No one outside my immediate family knew.

Kelly Cervantes: That had to be so hard to carry that knowledge with you and be so worried about someone finding out about it. I want to go back a little bit and you mentioned that you were homeschooled and how much that helped you educationally. Can you explain why being homeschooled was so beneficial for you?

Mariah Mayhugh: Absolutely. Well, it was helpful for a lot of different reasons, honestly. So first reason is that I would have absence seizures throughout the day and that would cause things like memory loss. It would cause me to become frustrated. It would cause me to not be able to absorb lessons quite as quickly as maybe someone my age that's neurotypical would've been able to. And so I was able to revisit lessons and redo them as many times as I needed to. I was also able to take naps throughout the day well beyond the age that kids normally stop taking naps, and that really helped me to be well rested and to be able to function and be able to attend school. So that was really cool and I'm really grateful for all of that. Another reason it was helpful is I was at the hospital a lot. I remember being in the hospital and my mom whipping out the books and the laptops and be like, "We're going to do school." And I was like, "Darn it."

Kelly Cervantes: If I went to traditional school, we wouldn't be doing this right now.

Mariah Mayhugh: Exactly. But looking back, I'm like, I am so grateful for that because I didn't fall behind. I was able to stay on par with my schoolwork. Whereas if I'd been in traditional school, I mean maybe nowadays it's different because COVID really changed that landscape with remote learning. But 12, 15 years ago, it was not that way. And so I probably would've just wound up falling behind and it would've been hard to catch up.

Kelly Cervantes: Yeah, absolutely. Now, when you did get better control of your seizures or you had that brief reprieve of seizure freedom, you did end up doing a blended learning.

Mariah Mayhugh: Yes.

Kelly Cervantes: What was that?

Mariah Mayhugh: So when I was in eighth grade, which was the year that we had that reprieve of seizure freedom, I enrolled in a blended program, which was very similar to what a lot of schools did during COVID where it was three days a week, you did school at home, and then two days a week you went into school and you had classes and you had teachers and all the normal things. So I stayed with them throughout high school. I graduated from that high school and it was the best experience. I absolutely loved it. And again, I feel like it just set me up for so much success, especially with the relapse that I wound up having.

Kelly Cervantes: Now I understand that this experience led to your coming out, if you will, I believe is how you have referred to it in some situations where you started to be comfortable sharing your diagnosis. What spurred that change?

Mariah Mayhugh: So honestly, it is so interesting because if I hadn't been set up educationally as I was, I wouldn't be sitting here talking to you because I wound up enrolling in college classes when I was 15 because I was smart, I knew how to do it, and that's based off of the educational groundwork that was set. So I started

attending college classes. 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. And in the CNA class, we were on the unit learning about epilepsy and seizure care. And that's one of the first times I'd ever really heard epilepsy discussed outside the hospital. And it was starting to make me curious about my own condition.

So 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. And the point was to teach us how to research things. So I was like, I'm going to research childhood epilepsy because I am 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.

But 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. And 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. And 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. So it was making me so upset, why isn't anyone doing anything about this? And then I kind of 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.

Brandon: Hi, this is Brandon from Cure Epilepsy. Since 1998, Cure Epilepsy has raised over \$90 million to fund more than 280 epilepsy research grants in 17 countries. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: So 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 because my whole life she'd known me as like, oh my gosh, don't tell anybody. And 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. And I wound up infusing some of my own story into it. And 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." And that was a perfect segue for me to be, I think I really want to start sharing my story more

and start being more public about my journey. And 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." And it was really cool.

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

Mariah Mayhugh: So my friends took it really well. I remember I would just tell them one on one and I would just be like, "Hey, I've got something that I need to share with you and it's really personal." And 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. And it also just came at a really nice time with high school graduation and whatnot. So I wound up not staying in touch with a lot of people anyway, and just kind of transitioning into that new life, that new chapter of adulthood and also advocacy.

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

Mariah Mayhugh: So I was like, I don't know what I'm doing. And I had no idea. I had this very vague vision of I want to be an advocate, but I just didn't know how to get from point A to point B at first. So I just started Googling stuff and I found this epilepsy 5K that was being held in Colorado Springs from the Epilepsy Foundation of Colorado. And 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?" And they were like, of course. And so 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. And 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. I often say when I meet someone new who's newly diagnosed, "Welcome to the club. I am so sorry that you are a member of the club, but its members are some of the most incredible people you will ever meet." But your advocacy efforts just began with that 5K, and then you 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. So 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. And I

came up with this idea of doing 26 things, one thing a day every day in March up until March 26th. And one thing to spread epilepsy awareness. So I made a bunch of little purple ribbons and I passed them out to businesses and I hosted a little babysitting event where parents could come drop off their kids, donate like 50 bucks for the evening. I'd watch their kids and then the money would go to the foundation, stuff like that. And so 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 because I had learned so much at the library growing up.

I was like, this is a perfect opportunity to educate children. But when I was preparing for this event, I was looking it up on our library's database, children's books about epilepsy, and there was none. So I was like, okay, I'm not surprised, but mildly frustrating. So I hop over to Amazon, Barnes and Noble, all the big ones, and I look up children's books about epilepsy. And the only ones I could find were about little boy protagonists that had tonic-clonic seizures. And 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. So why is there no educational resources on this? And 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. And so I decided to write my own children's book about epilepsy featuring a little girl with absence seizures.

Kelly Cervantes: That's incredible. And 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. I know. And 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. So 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. So I decided to run for Miss El Paso County because I heard that there's a lot of stigma around pageants and around, oh, it's literally just based off of your looks. It's a beauty pageant. But the Miss America Organization, particularly post 2018, really has been working hard to change that narrative. And 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. So 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: That's incredible. And 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.
- Kelly Cervantes: I love that. So which sort of pulls into the way that you want to direct your epilepsy advocacy moving forward through media. You've done the book, you've done the pageant. What is next for you in terms of raising that awareness in media?
- Mariah Mayhugh: So there's definitely a lot that is next. One thing is that when I wrote this children's book, it actually caught the attention of some pretty big organizations and it won the 2020 Reading is Fundamental Children's Book of the year. And then from that there is an organization called The Storyteller Foundation that contacted me and they said, "Hey, we love your book. We love where you're going with this. Why don't you come out and we're going to all go on basically this big cruise networking event thing. So why don't you come out to Florida and do that with us?" This was two weeks before COVID, by the way.
- Kelly Cervantes: Oh, my God.
- Mariah Mayhugh: So I had just started hearing about COVID on the news, but I was like, oh, whatever the news flavor of the week, it'll be gone by the time I get back. So I go on this cruise and come back and the world is shutting down.
- Kelly Cervantes: Thank goodness you were able to get off the boat.
- Mariah Mayhugh: That's what my mom said. She went with me. She was like, "I am stunned we didn't get stuck." But anyway, it was so cool. I got to meet so many amazing people. The writer of *Sleepless in Seattle* became one of my mentors, former president of Paramount Pictures and Walt Disney Studios, just all these really, really incredible people were reading my book and really telling me, "Hey, I think that this is something that really needs to be shared with the world on a bigger scale." So I'm still working with them. And we are in the talks of getting an agent attached to my next book, which is a novel that I've written for young adults, and it's like a dystopian thriller novel. It's not like the children's book, which primary goal was to educate. This is fun. It's just for people to read, but the main protagonist has epilepsy, and that's what I wanted from it. I wanted it to be a story anyone can just enjoy on its own, but also showcase a disabled character at the forefront.
- Kelly Cervantes: Absolutely. It's about that awareness and about normalizing and bringing that attention through traditional media forms I think is going to make such a strong impact, and I am so grateful that someone like you has taken that task on. So Mariah, tell us what your life looks like now.
- Mariah Mayhugh: So my life now is a combination of things being pretty normal and also some really exciting things. I'm living on my own, which is super exciting, especially as

a person with epilepsy. I know I'm so blessed to be able to live independently. I work a full-time job in social media management and I also run a freelancing business for social media management. My days are just full of lessons for singing, songwriting, dancing, and also advocacy events. So I live a pretty packed life, but I'm very grateful for it.

Kelly Cervantes: It sounds like you're just a little bit busy, which I love. As someone who lived with epilepsy for most of her childhood, what would you want to tell other children out there and their parents?

Mariah Mayhugh: I want to tell them that it does not have to define who you are and you can literally do anything that you want to do. Something that I am aiming to do is genuinely spread that message to children with epilepsy and their parents and adults with epilepsy because I'm a singer songwriter and I have plans and goals to audition for American Idol this year, and I'm really hoping to get to share my epilepsy story on this national televised stage because I want to show people, hey, yeah, I have epilepsy, but that does not mean that literally anything is off limits. I can do anything I want. Sometimes that means I do things differently, but that doesn't matter.

Kelly Cervantes: You are so confident and comfortable talking about your diagnosis now, and I wonder if you can give some advice to other teens to be able to have that same confidence and comfortability that you do.

Mariah Mayhugh: Yeah, absolutely. So for me, I realized that once I stopped hiding who I am, it's like a complete weight got lifted off my shoulders. And so if you're a teen or a young adult with epilepsy, I know that there is really only one thing that kind of matters during like that period in your life. You just want to fit in. And the important thing to realize is that we all have something, like we all have something that makes us different, unique. We all have struggles, we all have things that we're carrying, and when we start talking about those things that we're carrying and we share that with others, they suddenly feel less alone. And we can build this amazing community that can uplift each other. And so now all of a sudden, instead of all of us shouldering this alone, we feel lighter and we're together. So it's like a win-win.

Kelly Cervantes: Amazing. Mariah, you are a delight to talk to, and I cannot wait to see where life takes you and to follow you along wherever you end up next. We're wishing you all the best luck, and thank you so much for chatting with us today.

Mariah Mayhugh: Thank you so much for having me. It was an absolute pleasure.

Kelly Cervantes: Thank you, Mariah, for sharing your story and for all of the advocacy work you've done and continue to do to raise awareness and knowledge around epilepsy. We'll keep an eye out for your novel and can't wait to see what other great things are in your future. Cure Epilepsy has been funding cutting edge, patient-focused epilepsy research for 25 years. Our goal is a world without

epilepsy. If you would like to help us achieve that goal, please visit cureepilepsy.org/donate. Cure Epilepsy, inspiring hope and delivery impact. Thank you.

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