Seizing Life, episode 43
Growing Up and Gaining Independence with Epilepsy
Guests: Ashleigh Henrichs and Caroline Pratt
(Transcript)

Kelly Cervantes: 00:00

Hi, I'm Kelly Cervantes and this is Seizing Life a biweekly podcast produced by Citizens United for Research in Epilepsy, CURE. Today while we are still in social distancing mode we want to present an episode that we recorded prior to the COVID-19 pandemic. Back when we could still share a kitchen table with our guests we invited longtime supporters of CURE Ashleigh Henrichs and her daughter Caroline to speak with us about the journey from child with epilepsy to young adult with epilepsy and how the transformation can affect the parent child relationship. As high school graduation season comes to an end even in this time of pandemic we hope those of you with children entering college and those of you heading to college next fall will find value on Caroline and Ashleigh's story and advice. Thank you.

I'm delighted to have close friends of CURE Ashleigh Henrichs and her daughter Caroline Pratt on the podcast today. Caroline was diagnosed with epilepsy at the age of eight. She is now 17 years old and a freshman at Carthage College pursuing a double major in education and English. Ashleigh is the busy mother of three teenagers and an active volunteer serving on several local boards. Both Ashleigh and Caroline are passionate advocates for epilepsy awareness and research and have been dedicated CURE volunteers for years.

Ashleigh, Caroline, thank you so much for chatting with us today. So thrilled to have you here. So, we're talking today about the parenting journey of parenting a child with epilepsy and growing up and how you go through puberty and teenage years and relinquishing some control over that child as they head off to college as they have this tendency to do sometimes. But I want to start at the beginning of your journey tell me about when Caroline was diagnosed with epilepsy.

Caroline Pratt: 02:11

I was first diagnosed when I was three to four but then it went dormant for a few years so much that I didn't even know I had epilepsy. And then when I was eight I remember going up to my dad and saying like, "Hey dad, I'm shaking and I'm not cold and I don't know why." But according to mother that is not what happened.

Kelly Cervantes: 02:40

Alternating versions. Ashleigh what is your version of events?

Ashleigh Henrichs: 02:46

So, she had four grand mals when she was four but wasn't really officially diagnosed at the time. We did not put her on

		traditional medication and she the seizures went dormant for about four years. And she was getting new glasses and was looking in the viewfinder at the eye doctor and I was sitting next to her and she started shaking and obviously scared me and I called a friend who is a pediatrician and told her what had happened. And she referred us to a neurologist right away. And then she was officially diagnosed, had EEGs, they were all abnormal. So, that's how the bulk of the journey started at age eight so.
Kelly Cervantes:	03:34	And what type of epilepsy were you diagnosed with and do you know a genetic cause?
Caroline Pratt:	03:42	I believe the first epilepsy I was diagnosed with was at absence epilepsy.
Ashleigh Henrichs:	03:49	Absence and juvenile yeah.
Caroline Pratt:	03:53	And we don't have any genetic history because mom did some research and so did dad and I'm just special I guess.
Kelly Cervantes:	04:04	That you are very much so. So, receiving that diagnosis she's eight years old. Did the doctor tell both of you, did the epileptologist just tell you and then you told Caroline, how did that happen?
Ashleigh Henrichs:	04:23	So Caroline is our oldest so we had no experience with any major medical issue so this was the first for her dad and he and I received the news together and shared it with her and we really tried to frame it as that her brain didn't work the same as other kids. That there was some extra activity going on and at the time we had a treatment plan with medication. And so, that's just how we looked at it is that or told Caroline since she was fairly young that her brain was just misfiring and it wasn't quite working the same as her friends so.
Kelly Cervantes:	05:14	And how old were you when you started to understand? Because I imagine at eight, epilepsy is a complex condition for an adult to understand so it's hard to imagine that an eight year old is really going to be able to grasp what that means. At what age do you feel like you started to understand what epilepsy was going to mean for your life?
Caroline Pratt:	05:37	I am not actually sure. I think each year I learned a little bit more about it. And some of the major moments there was this doctor at Mayo Clinic and he asked me if I always talked stuttering a little bit and I just looked at him and I was like,

"What?" And everybody I knew said I didn't really talk that abnormal but and then I started thinking about I've missed at least a year of my life thanks to my seizures. And I don't know I think I've just always felt like I was different and for most of my youth that was okay. Then I entered high school and of course everything changed.

Kelly Cervantes: 07:11 For the best of us it changes and then you add in some complex medical stuff and that throws a giant wrench in the works. How do you parent through that? And especially Caroline being your oldest. So, you didn't have another frame of reference. You are parenting through puberty and teenage girl drama and craziness and at the same time navigating a disability. What would you tell her and what would you tell other parents who are walking down that path right now?

Ashleigh Henrichs: 07:55 For a lot of her, after she was diagnosed for several years Caroline did not want to talk about it with friends or people who didn't know her very well and we respected that. And then when she started high school she started having grand mals during school which up until that time she'd been fortunate enough to not have any outside of the home or any place like that so that really changed the game for us. And obviously her teachers and counselors were aware prior to that but then the students were surprised, were startled. So we talked with them, she went to a private high school so the classes were smaller.

And so, she chose to have me give most of the presentation but she was there. And I have to say that my greatest fear after giving it was that I would stand up there and there would be crickets. But I said, "Does anyone have any questions? I'm happy to answer." And several of her classmates had good questions and were trying to understand what it was and what happened to her brain when the seizures were occurring, what they should do. And that was really positive for me that they were responding and asking questions. And then she had other seizures after that discussion so the students knew just what to do and...

Kelly Cervantes: 09:29 Knowledge is power and it makes watching a seizure let alone experiencing one but watching it is a scary thing to witness. So, the more that we can educate people the less weird it is, the less scary it is for those witnessing it which is imperative in the peer pressure life of high school. Did you find that that helped your high school experience the more that your classmates understood epilepsy and seizures and what was happening?

Caroline Pratt:	10:03	I was really lucky because the reason I'd been, so I had been absolutely terrified of anybody that I hadn't made the decision to tell finding out I was absolutely terrified. And then, mom gave the presentation and I had always expected if it ever were to get out, I had always expected everybody being like, "Oh my gosh, she's such a freak." And that was probably mostly due to the many high school movies. But nobody treated me any different, nobody acted like I was somehow different than I had been before and nobody really even seemed to care and I was just eternally grateful for them.
Kelly Cervantes:	11:15	That probably had to give you a good amount of confidence and trust in this community that you could still be Caroline and you weren't Caroline with epilepsy you were just you that also had this, that wore glasses and had seizures sometimes. And you still got to be you and that's a pretty incredible gift I think from your classmates. And I imagine that a lot of that comes from the presentation that you were able to give Ashleigh just in educating and bringing awareness can do so much social good in those situations.
Brandon:	12:00	Hi, this is Brandon from Citizens United for Research in Epilepsy, or CURE. For the 65 million people worldwide living with epilepsy progress is unacceptably slow. At CURE our mission is to find a cure for epilepsy by promoting and funding patient focused research. Learn more at cureepilepsy.org. Now back to this episode of Seizing Life.
Kelly Cervantes:	12:20	So now you've gone through high school, you've had this positive environment. Your seizures are still not under control but it's time to start thinking about college. What is going through your mind when it's time to send in those college applications?
Caroline Pratt:	12:43	Well, for starters I did not want to go to a college so close to home. I didn't want to go too far away but I wanted to go maybe a couple of hours away. Then I started having more big seizures and closer together and of course I don't have a trigger so that wasn't really great. And on top of that I got a scholarship to Carthage and mom was basically like, "If you get a scholarship you're going. I'm sorry, you're going."
Kelly Cervantes:	13:28	I think a lot of parents feel that way so that's a pretty normal parent response
Caroline Pratt:	13:34	They were able to give me the accommodations that I needed.

Kelly Cervantes:	13:40	And what were some of those accommodations that you requested?
Caroline Pratt:	13:43	Well for one, I get to live in a dormitory that is typically only for seniors or people who request accommodations just because it's really great. You don't share a bedroom with six people.
Kelly Cervantes:	14:04	Which is important because you need your sleep. Lack of sleep and stresses can be a huge seizure trigger. So making sure that you can get a good night's sleep which can be very challenging to do in college if I remember correctly so I mean that's incredibly important.
Ashleigh Henrichs:	14:21	She also has academic accommodations and like her high school they were very open to that and she has extra time on testing. And it was interesting we had two very different experiences on college interviews and Carthage as I said was very open to whatever she needed to be successful. And another college said, "I don't think we've ever had anyone with a seizure disorder on campus." And I was thinking it's one in 26 so...
Kelly Cervantes:	14:55	You have.
Ashleigh Henrichs:	14:55	You have. But so again, she's been very fortunate to have the support system that she has and as her health is still a question mark we really are thankful that her dad and I are both nearby and that we can get to her if needed but that she can live on campus also.
Kelly Cervantes:	15:17	Yeah. And experience that level of independence and responsibility. And so, what is going through your mind as mom and your oldest but still your baby and I just, I can't even imagine the anxiety that you have around letting her go and explore this independent world and wanting to cocoon her. I think all of us want to cocoon our children even the healthiest of ones and now you're sending one out into the world that it's a little scarier. What are you thinking? What have you learned or what advice do you have to get parents through this?
Ashleigh Henrichs:	16:04	Well, there's a picture that Caroline loves to make fun of because we took a lot of pictures on move in day and there was one where I'm hugging her and I'm just a wreck, I'm just a wreck. And people who didn't know us that well thought, "She's going to college in your town that you live in so okay. I know you're a little nervous but..." But I think my advice again, the communication has to be there with wherever your child is

going as far as every housing, academics, counseling everybody has to be on the same page.

But Caroline has not been healthy since she started at Carthage even move in day. We got a call right after we left but she's making her way and she wants to make her way. And we have one of the things we started was an app, a medication app, so that we get notified, her dad and I do if she's not taking her meds and so that's pieces like that. But we can't hold her close that wouldn't be good for her, it wouldn't be good for us. She does need to have that level of independence. We prefer that she have a cleaner room but that's on her but this is... And the other part that was a little different is that she skipped a grade so she's only 17 at college but again she's making her way and it's important to her that she does that with limited interference from mom and dad so.

Kelly Cervantes: 17:59 Caroline, what advice would you give to other teens and kids getting ready to go off to college in what they should be looking for both in a school but also navigating that parent relationship?

Caroline Pratt: 18:19 Well, I would say just be sure to stay close with your family I found that's what helps me. They're always there to support me. And honestly the best advice would just be to be yourself, epilepsy is what you have it's not who you are and just be you and most of the time people won't even really notice you have it.

Kelly Cervantes: 18:57 Right. Absolutely. Ashleigh, what advice would you give to parents as they are navigating this new found freedom for their children? You can't go into the classroom anymore and give the presentation about epilepsy that's something that Caroline has to do on her own in a way that she's comfortable. So, how do you best navigate this next stage of your life?

Ashleigh Henrichs: 19:29 I think one of the things that I was very happy and impressed with was that each of her professors emailed her and said, "We're aware that you have accommodations. We need you to schedule a time with each of us to discuss exactly what we can do to help you." And so that was big for me as a parent because I'm out of that, I'm not involved with that, and that's Caroline's responsibility now and which was important. So that role changed with that email. And I've never been a helicopter parent. I mean it's certainly epilepsy changes things but my children need to solve problems on their own. And of course this thing's progressive, if nothing was happening then mom would get involved but college is again there's a lot more responsibility on the student and there really needs to be.

So, just again communication is key. I had to be comfortable with what I was hearing and seeing before we committed to Carthage and I think that's true. Whether your child's going to a large school or a small school they have to want to be there and you have to be comfortable with that investment, with the resources available. And then you have to trust, you have to place a lot of trust in the faculty and the staff and your child. Certainly I don't remove myself from the equation entirely but it's a different stage in her life absolutely and in my life and it's hard, it's hard. It's wonderful.

Kelly Cervantes: 21:27 Do you get notified with every seizure?

Ashleigh Henrichs: 21:30 No. Caroline typically will let me know with the larger ones. She had one in class yesterday and that's just a struggle. It's one thing if you're in your dorm room and it happens privately but it's hard to be in a new environment, have a fresh start, which is what we told her college was and then but still you have to deal with it.

Kelly Cervantes: 21:59 You're still taking your baggage along with you unfortunately though so. Well, I am so grateful to both of you for coming and speaking with me today and sharing your journey. Parenting is the most challenging and difficult job I think any of us could ever have but my goodness do our kids make it worth it.

Ashleigh Henrichs: 21:59 That they do.

Kelly Cervantes: 22:22 So, thank you for sharing your experiences on both sides and I so appreciate both of you.

Ashleigh Henrichs: 22:31 Thank you for having us.

Caroline Pratt: 22:33 Yeah. Thanks.

Kelly Cervantes: 22:38 Thank you again Caroline and Ashleigh for sharing your journey and experiences living and growing up with epilepsy. Part of parenting is knowing when to allow your child freedom and part of growing up is knowing how to deal with that freedom. The choices and consequences for a growing child with epilepsy can have a serious impact on their health, wellbeing, and future that's why it's so important for parents and children with epilepsy to establish open lines of communication and trust. CURE invests in patient focused research to create new therapies that promote seizure reduction and freedom for epilepsy patients and their families to. Help further CURE's research please visit cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.