

- Kelly Cervantes: 00:00 I'm Kelly Cervantes, and this is *Seizing Life*. This weekly podcast, produced by Citizens United for Research in Epilepsy, CURE, aims to inspire hope and offer resources to the epilepsy community. Today we're joined by Eva and Michelle Wadzinski to talk about how to flourish in college as a student with epilepsy.
- Eva has accomplished a lot in her life. She is a psychology major at DePaul University, on the junior associate's board for the Epilepsy Foundation of Greater Chicago, and volunteers at the child life program at Lurie Children's Hospital. Prior to her collegiate career, she was a professional model and actress in Los Angeles and Chicago. She is here today with her mother, Michelle, who is a community outreach educator for the Epilepsy Foundation of Greater Chicago, and a member of the ParentWISE support team at Lurie Children's Hospital. Eva, Michelle, thank you so much for coming on to chat with us today. We met briefly at an event, probably a year or so ago. I've just been so excited to finally be able to chat about your journey and your experiences.
- Eva, tell us a little bit about yourself, and how epilepsy entered your life.
- Eva Wadzinski: 01:24 I was diagnosed at 13 years old when I was just getting ready to be a freshman in high school, which didn't really happen. I've had to transfer in and out of three high schools just because of accommodations, and I was having to miss class a lot. Now I've just started at DePaul University to major in psychology and, one day, get my doctorate in clinical psychology.
- Kelly Cervantes: 01:50 Congratulations. Do you know what is causing your seizures?
- Eva Wadzinski: 01:57 We don't know yet; we're getting genetic testing done soon. But they haven't come from relatives or from an accident. They just appeared.
- Kelly Cervantes: 02:06 What kind of seizures do you have?
- Eva Wadzinski: 02:10 Eight different kinds, some of which are myoclonic, partial seizures, seizures awareness that I can kind of tell that I'm having. Also, gelastic seizures and dialeptic seizures. That's a lot.
- Kelly Cervantes: 02:28 You know, you run the gamut.
- Eva Wadzinski: 02:29 Yeah.

Kelly Cervantes:	02:31	Throw some variety in there. Do you have seizure control?
Eva Wadzinski:	02:36	No, I do not have seizure control; I've never had seizure control.
Kelly Cervantes:	02:39	That's tough.
Eva Wadzinski:	02:40	Yes.
Kelly Cervantes:	02:42	So Michelle, Eva's diagnosed at 13, going into high school. What is going through your mind at this sort of critical juncture in her life?
Michelle Wadzinski:	02:56	When she was first diagnosed, I think there was a period of not accepting the diagnosis, for me. I had worked in mental health, and some of the medications they were suggesting that she go on, I was familiar with. The thought of my child having to be on those medications was overwhelming. So there was a lack of acceptance. It took a few weeks and many tearful phone calls with the nurse at the epileptologist office. Then, having finally accepted it, she started taking her meds. For the first three months, she wasn't having side effects, and had seizure control. I thought, "This is a piece of cake! This is not a big deal."
Michelle Wadzinski:	03:46	Then, come fall, the bottom fell out. She started having more and more seizures every single day. More and more meds were added on. It was always hard to tell, is this the aftermath of the seizures? Is this the medication? What's causing this general sort of flatness and foginess? And you ... It was a confusing time. I mean, she was home from school a lot. A lot, a lot, a lot. At that point, where you're entering your freshman year, and there's all those exciting things going on, she wasn't a part of those.
Kelly Cervantes:	04:24	High school can be such a challenging time for anybody, and you're walking into high school, but having to spend a lot of time at home. What was that experience like for you?
Eva Wadzinski:	04:35	That experience was very new for me because I had some seizure control, and then it just fell apart. I had to leave high school early and redo my freshman year, but, since I wasn't in school a lot, many, many friends left and disappeared basically.
Michelle Wadzinski:	04:53	She had to leave high school at the end of her sophomore year and switch to an online school because there were so many absences. The community, the teacher community, was super supportive. But there's only so much they can do; there are 30

other students in the class. When you're gone for a week or two every other month or every month, they can't go over everything with you and catch you up. So we went with the decision that online school would be best for her because she could learn everything she needed to learn to get what she needed, but on her own timeline. When she finished high school, there was a big discussion at her epileptologist's office convincing her that she needed to take a year off to get seizure control before starting college. Eva was really reluctant. She was ... I think so many things had been pushed back, so many things had been taken away, that now the thought of spending a year dealing with seizure control was too much.

Kelly Cervantes:	06:00	Did you take that year?
Eva Wadzinski:	06:02	I did not.
Michelle Wadzinski:	06:05	She went part-time.
Eva Wadzinski:	06:06	Yeah, I went part time because I get bored very easily. I could not fathom being out of school for a year and then having to jump back into it.
Kelly Cervantes:	06:17	I just have to imagine that the college application process was significantly different for you than for your peers. What was that like?
Eva Wadzinski:	06:28	The application was very easy. I just had to write an essay about hardships, and I have a lot of those.
Kelly Cervantes:	06:37	Check, check.
Eva Wadzinski:	06:39	So I got in, and then I started four classes. My grades kind of just fell down because of how many seizures I was having. I was also weening off one medication and putting a new medication on.
Kelly Cervantes:	06:52	This was not at DePaul? You started at ...
Eva Wadzinski:	06:55	Harold Washington City College. I started in a community college because I didn't think I was healthy enough to go to a four-year university. I also went through two brain surgeries in the process. Eventually, I started at DePaul with four classes. It was not working out well, so I went down to three, and it's been better.

Kelly Cervantes:	07:17	At some point, you decided that you could make that change from the city college to a four-year university. What inspired that change?
Eva Wadzinski:	07:29	I always have the notion and the mentality to think, if you want this hard enough, you'll be able to get it, regardless of your disease. So you kind of just have to push forward every day. You end up having to educate your professors and your classmates about your student accommodations because no one seems to know what epilepsy is.
Kelly Cervantes:	07:52	Which leads perfectly into my next question. What do you tell your professors, and how do they respond?
Eva Wadzinski:	08:01	It differs.
Michelle Wadzinski:	08:03	We have a letter that we've been giving to every teacher since, I don't know, freshman year. We've modified it, but it's the same letter going out, make the modifications, printed out, give it to them, trust that they'll actually read it. You know, and then ...
Eva Wadzinski:	08:18	And then I'll have one professor that's like, "Well, you were gone," which was because of seizures, but they think I just skipped class. Then I have to go to my doctor, my psychologist, my student accommodations, and get everyone to say, "No, that was not because I skipped class, but because it's unsafe for me to be in class." That's tough when that happens.
Kelly Cervantes:	08:40	It's creating more stress for you in an already stressful environment. I mean, college is hard, right? So that additional work has to be tough. What do you tell your peers, your fellow students?
Eva Wadzinski:	09:00	I don't usually tell them because it's more of a personal thing. Especially if I'm not close to them, or their friends of mine, then it's like, I'm just gonna [inaudible 00:09:10]. But I've had seizures during classes, and then it makes the professor more aware because I don't have tonic-clonics unless I'm off of my medications. I have all these other ones that may not be apparent, but I had a seizure in my math class where my arm convulsed, and it actually hit one of the other girls. She said, "Are you okay?" Like they thought I was probably on some drug.
Kelly Cervantes:	09:38	Which is just so frustrating that that's where the thought process goes because people are so uneducated about seizures.

Eva Wadzinski:	09:44	Yeah.
Michelle Wadzinski:	09:45	People feel afraid of what they don't understand. If they take the time to learn and understand, I think then they're more supportive.
Eva Wadzinski:	09:55	It's like teaching your siblings or your friends too. Both of my best friends, right when they found out I had epilepsy, they were on Google, looking it up, looking up my seizures. My siblings did projects in college about epilepsy. If people say that epilepsy's a mental illness, then they will say, "No, you're wrong," to the professors.
Kelly Cervantes:	10:17	Good!
Eva Wadzinski:	10:18	They'll stand up for me and everyone else. So you basically have to be the same to your professors, and hope they look up the information.
Kelly Cervantes:	10:27	If you think of it, before epilepsy touched your life, how much did you know about epilepsy?
Michelle Wadzinski:	10:32	I knew the tonic [crosstalk 00:10:36]
Kelly Cervantes:	10:38	Exactly, exactly.
Eva Wadzinski:	10:39	Me too. I didn't know anything about it, so I try to remind myself, unless there's a family member or a friend who has it, they don't understand. First, we try to go gently with education, and hopefully that resolves everything.
Kelly Cervantes:	10:59	You talk about student accommodations. What are some of the accommodations that you have requested from your schools?
Eva Wadzinski:	11:10	I have a longer time for tests, extended time. If I have doctor or medical appointments, that I will get passed for it. Sometimes that happens, sometimes it doesn't.
Michelle Wadzinski:	11:24	That's not an official accommodation; that's something that's not available through the accommodations department, and we fought for it to increase the awareness. If she's having a day where she's having 10, 15, 20 seizures in an hour, she needs to come home, take rescue medication, and that puts her out. She can't be in class. Then, with some of the epileptologist appointments, they are hard to schedule., You have to keep it because you might not get in for a little while, and you just need

to be there. So we fought for that accommodation. The extended time for tests is ...

- Eva Wadzinski: 12:01 It's very helpful because I might have seizures during classes, and it takes me 10 to 15 minutes to be aware, so it's very helpful in those situations. I'll have classes where I have seizures, and then I can't really get back to the lecture right away. Then you lose that 15 minutes of class, so what are you going to do? Ask them to repeat all this stuff? And I have short-term memory loss sometimes, and sometimes I don't retain everything. So I always have loads of notes written out so I can remember it.
- Kelly Cervantes: 12:35 Are there specific things that you would recommend to schools, different ways that they can better accommodate students with epilepsy?
- Eva Wadzinski: 12:45 You know, one thing that I try to give people who are around my age or going to high school or college, more information about is that they don't give you a menu of how many student accommodations you can get. You have no idea what's out there for you, and you have no idea if it's actually going to apply to your disease, whatever it is. So I think that's not okay? What if this one's going to very much help you, but they're not going to say, "Oh, you can have this, or you can not have this."
- Kelly Cervantes: 13:14 To even know what the possibilities are, to know what you can even ask for.
- Michelle Wadzinski: 13:19 It's a law that students are protected through primary and secondary school. That law does not extend to college students. That it as the decision of the university and the instructors. If the university has a good center for students with disabilities, and whoever's in charge of it is really passionate and deeply connected, then you have a good advocate. We've had an amazing experience with the person she has presently. But we've had an experience where I don't even know why that person was in that department because the fit was really bad. But you're still at their mercy in many cases. The law does not protect you at university-level. It does not protect students with disabilities.
- Kelly Cervantes: 14:13 I had no idea.

Michelle Wadzinski:	14:15	It was shocking to me too when she started down this road at the university, and, all of a sudden, I learned that the same protections ...
Kelly Cervantes:	14:23	...Like the ADA protections...
Michelle Wadzinski:	14:26	Educational things, yeah.
Kelly Cervantes:	14:29	Wow.
Michelle Wadzinski:	14:30	So it's an individual experience at each individual learning institution.
Kelly Cervantes:	14:35	Huh. So going on this journey through high school, going to college, now being in college, what tips, recommendations, or advice do you have for teenagers who are walking the same path as you?
Eva Wadzinski:	14:56	I would connect with people who are already in school who have epilepsy because they're able to give you a lot more tips. And you have to be an advocate for yourself. Also, just research a lot about your university because some have good student accommodations, but some have horrible ones. You really have to look further than a person who doesn't have a disability. And it's ...
Kelly Cervantes:	15:22	It needs to be part of your college selection. Not just who has the prettiest campus and the best food, but you're really looking at, you know, that's a major decision factor.
Eva Wadzinski:	15:34	A lot of times, if you have epilepsy or any other disease, your doctors are in one place. For me, I had to find a university in Chicago, or Illinois, because I didn't want to change and restate my story every single time.
Kelly Cervantes:	15:50	I understand that.
Eva Wadzinski:	15:51	I would just give them that realization that it might not work for you, but you also have to work at it at the same time.
Kelly Cervantes:	16:01	You can still get out there, you can still get that college degree, but you also have to respect your limitations.
Michelle Wadzinski:	16:09	Yeah.

- Eva Wadzinski: 16:09 You should always go back to your student accommodations and update them of what's going on because they can change things for you. It's an ever-changing disease. I think it's important being resilient about going to these people, going to your professors, because then they'll start understanding a bit more.
- Kelly Cervantes: 16:27 It all boils down to communication.
- Eva Wadzinski: 16:29 Also, I think people need to be aware that you're not going to get judged if you have to do five years of high school instead. If you have to take limited classes each quarter or semester. And it's more normal to be in school for five years.
- Eva Wadzinski: 16:45 At university, yeah. And people aren't going to judge you for it because it's college. No one really cares that you've been ...
- Kelly Cervantes: 16:53 No one is looking at your, when you're applying to jobs, no one is looking at your resume, thinking, "Oh, it took you seven years to graduate?" No one is paying attention to that!
- Michelle Wadzinski: 17:05 If they are, I kind of think if you bring up why, you'll get major points for tenacity, right? And with her situation, I think depending upon whether or not your seizures are controlled has a big impact on your overall energy level, and your ability to just juggle things. Since she doesn't have seizure control, between classes, going to class, doing her studies, that kind of taps her out with her energy level there. Living at home has been good, at least I think it has been, because I handle the minutiae of life. The food, the laundry, the this, the that. My thought is, I know she's got so much on her plate. I'm just going to take care of everything else that I can so she can use the energy she has on school.
- Eva Wadzinski: 17:57 I have three classes a day, and I make my schedule a certain way just so I have time, if my epilepsy goes awry. So after all three classes, right when I get home, I'm asleep at eight o'clock, nine o'clock.
- Michelle Wadzinski: 18:12 It's not just the physical. The emotional can be exhausting too. So rest is a good thing. The bed is a good place.
- Kelly Cervantes: 18:22 Yes. Absolutely. Absolutely.

- Eva Wadzinski: 18:24 I would definitely get a psychologist. That is a big ... If somebody's having emotional times with going through school, or just life in general, to have a psychologist by your side ...
- Kelly Cervantes: 18:36 I am a huge proponent of mental health. I think it really, especially with a disease that's so stigmatized, disrupts your life so much. I really do think that those two pieces have to go hand-in-hand. You mentioned trying to reach out to other students, finding other students who have epilepsy. Is there a place where you recommend trying to find them?
- Eva Wadzinski: 19:04 I would go to the Epilepsy Foundation of Greater Chicago because they have support groups with teens and with kids who are in college too.
- Kelly Cervantes: 19:14 You're also very vocal about your epilepsy on social media. I imagine that's probably another place where you can find other teens. I think it's incredible how open you are and how brave you are ...
- Eva Wadzinski: 19:28 With my social media, I'm very frank about everything; I don't hide much. A lot of people sometimes don't get deep brain stimulators, so I gotta be a little different. I think when classmates find my Instagram, and they're like, "Oh, she actually goes through this," then people understand a little bit more. I've had direct messages from people who were in my last high school whose younger sister got diagnosed with epilepsy, and she wanted to make a coffee date, so she had somebody to connect with. Also, people who went through college already, they give me tips. Or just a flurry of people.
- Michelle Wadzinski: 20:12 It's a process, for sure. You know the first year of diagnosis, we couldn't say the E word in the house, not within earshot. Then we could say epilepsy. But we couldn't say it outside of the house. We certainly could never say it at school. I think it was a good three, four years before you got to that point of being sort of sick of hiding it.
- Kelly Cervantes: 20:38 I think that that's an important piece to acknowledge too. I think that level of acceptance can't be rushed. That has to be something that each individual person comes to on their own, however long that takes. And that's okay.
- Eva Wadzinski: 20:57 Learning that you have a chronic disease at 13 years old is a lot to handle at first, and the support of my friends group went away. So I had to find these new people. Since I'm on the

associate's board, all of us are younger, and a lot of us don't have controlled seizures. So we connect with each other all the time. Once I was having cluster seizures, and this girl was asking, "Can I bring you food? Can I bring you movies?" They get it more, yeah.

- Kelly Cervantes: 21:29 That's amazing.
- Kelly Cervantes: 21:31 It is crazy though how difficult it still is to talk about epilepsy. On all these different levels, even as an adult in a profession, how much do you share? If you share too much, are they going to doubt your ability to handle the workload? You know, if you're taking care of a child who has epilepsy. If you don't share anything, then how can you get the support you might need? I mean, it's a tight rope, that's for sure, and the general lack of understanding about the condition does not help matters in any way, shape, or form. I applaud both of you for being so open in public, and just knowing that, even with the 20 minutes that you've spent with us today, how many families have found comfort, and how many people you've helped with sharing your story with us today. So we thank you so, so much for being here, for chatting with me. You're both amazing humans, and I'm so pleased to have gotten to know you better.
- Eva Wadzinski: 22:35 Thank you.
- Kelly Cervantes: 22:40 It was a pleasure to speak with Eva and Michelle. Eva's experiences show how imperative it is for us to end epilepsy stigma and grant students equal access to curriculums and opportunities both inside and outside the classroom. That is why, in partnership with funding from Lundbeck, we offer education enrichment fund scholarships at CURE. The fund offers one-time, \$5,000 scholarships to those living with epilepsy, as well as their family members and caregivers who plan to advance their personal knowledge in epilepsy research, health education, advocacy, and/or awareness. Applications are open through April 15th; you can learn more and apply at CUREepilepsy.org/Scholarship. Finally, don't forget to visit @seizinglifepodcast on Facebook and Instagram and @seizinglifepod on Twitter. Thanks so much.
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qualified healthcare professionals who are familiar with individual medical conditions and needs. CURE strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.