Kelly Cervantes:	00:00	I'm Kelly Cervantes and this is Seizing Life, a weekly podcast produced by Citizens United for research in epilepsy care.
Kelly Cervantes:	00:07	I want to welcome back our guest today, Meg Busing. She is a TEDx speaker and the founder of the Midwest You Can Foundation. She started her foundation in 2011 with her husband to empower people with epilepsy. While raising her first child, Meg was taking upwards of 20 pills every day in an attempt to control her seizures. After several years of fighting through medication side effects and still experiencing seizures in spite of the meds, she opted for surgery. Due to the success of the surgery, she has been seizure free for the past eight years and has since given birth to two more children.
Kelly Cervantes:	00:53	Today, Meg shares with us what it's like to be a mother with epilepsy. Thank you so much for coming back and chatting with us again.
Meg Busing:	01:02	Yes, thank you for having me.
Kelly Cervantes:	01:03	Of course. As a refresher to those who may not remember your story from our previous episode about your incredible summer camp, Camp You Can, I want to dive back in and probably a little more in depth about you and your personal story and how epilepsy entered your life. Let's start with that fateful day in high school.
Meg Busing:	01:27	Yes, it was March 6th, 1998 on the way home from school with four of my girlfriends. I was in a car accident as this car spun around and hit a tree. I was left with a traumatic brain injury.
Kelly Cervantes:	01:45	You wake up in the hospital. How long has gone by and what are you told about this injury and your prognosis?
Meg Busing:	01:53	Yeah, I was on a ventilator for about six days, woke up from a coma and my parents explained to me that I was in a car accident with four other girls and gave me a mirror to see myself and I thought I looked the exact same Meg that I was, so this isn't going to impact my future and all is good. But then, I went on to rehabilitation and found out that boy, like a lot of other traumatic brain injuries, this is something that's going to stick around.
Kelly Cervantes:	02:27	We sort of talked about it before, but it's really tough because you don't have the outward physical, you're not walking around in a wheelchair with crutches after that initial rehab, but there's still long lasting neurological effects. What did the doctors tell

		you to watch out for? Did they ever mention seizures to you as something that could happen?
Meg Busing:	02:51	They didn't really mention it that I can remember. It was trying so hard through physical therapy, occupational therapy, speech therapy. Let's just get you back to where you were, Meg. And so, the longterm effects weren't discussed as much including seizures, that they can develop as a result of a traumatic brain injury.
Kelly Cervantes:	03:14	Something that CURE is actually doing a lot of research on right now as a part with a grant from the Department of Defense is on post-traumatic epilepsy, which is epilepsy that originates from a traumatic brain injuries, and trying to figure out those causes and prepare patients for that experience to come down the road.
Kelly Cervantes:	03:35	Your seizures didn't start right after your accident? It was years later.
Meg Busing:	03:40	It was years later that they started and just from that leftover scar tissue on my brain, it just started firing incorrectly the doctors say, and that's why the seizures started about five years later.
Kelly Cervantes:	03:53	I just can't get over that, that five years goes by. You have gone through all of the physical therapy, but you did still have some effects from the TBI. What were you seeing in addition to the seizures?
Meg Busing:	04:12	Some short term memory difficulties, word finding difficulties. Just multitasking is another difficulty and it all depends on what part of the brain is damaged in a traumatic brain injury, but that's kind of the temporal lobe controls a lot of that short term memory.
Kelly Cervantes:	04:35	And so, you are in school. You all of a sudden now have this diagnosis of epilepsy. How did you handle that? Did you tell your peers? How did you talk about that in school and then in the workplace?
Meg Busing:	04:53	I didn't really tell anyone. The stigma, as you probably know, the stigma that comes along with epilepsy I thought could really affect my professional career. So, I told teachers. They were so supportive and got accommodations that helped me pass nursing school, but then getting into the professional field, no in job interviews I would never say, "I have epilepsy" or "you might

		need to give me some extra time" cause I just thought they're not going to hire me because of the stigma that goes along with epilepsy.
Kelly Cervantes:	05:31	And not understanding how it can be so different for each person and that it affects each person. You start taking meds to try and control the seizures. Did you ever find seizure control on meds?
Meg Busing:	05:44	No. I got up to four medications, 20 pills a day like you said with no seizure relief. Still experiencing the lasting effects of my traumatic brain injury, but also those side effects of the medications were really putting a halt on my life-
Kelly Cervantes:	06:02	Which sometimes those side effects are worse than the seizures themselves.
Meg Busing:	06:06	Yes, they are and trying to finish nursing school and get through college, it was a real difficulty once the seizures started in addition to the leftover side effects of the TBI.
Brandon:	06:19	Hi, this is Brandon from Citizens United for Research in Epilepsy or CURE epilepsy affects 3.4 million Americans. Learn more about cutting edge epilepsy treatments and research at cureepilepsy.org. Now back to this episode of Seizing Life.
Kelly Cervantes:	06:35	You make it through nursing school while experiencing seizures and you get out of nursing school and you are trying to hold down a nursing job. What was that experience like as you're battling the side effects, the seizures and short term memory loss?
Meg Busing:	06:56	Yeah. I had always dreamed of being a pediatric nurse and working hands on with patients and so that's where I started, but as the seizures persisted, I would be at work during the day and I would kind of feel an aura, like one was coming, so I'd have to step aside or I would start getting dizzy from my medications. I'd have to go lay down in the break room. It was really impacting my nursing career. I tried another job in community health. It was school nursing, another dream job, but the seizures got worse.
Kelly Cervantes:	07:33	What kind of seizures were you experiencing?
Meg Busing:	07:36	I was having the complex partial seizures.
Kelly Cervantes:	07:38	Okay, and what do those look like?

Meg Busing:	07:40	My complex partial, and they're always different from patient to patient, but mine would be where I'd be in the middle of a discussion like this and all of a sudden I'd kind of pause. People have told me I would stare off into space. I'd start smacking my lips. My arm would start to rise in the air and I wouldn't respond to people talking to me. I remember the post-seizure state too would almost be was difficult too because while I was seizing, people would be like, "Meg, Meg, Meg. Are you okay? Meg, Meg", and I wasn't responding, but then that almost made the seizure worse. I don't know how to describe it, but it almost made it and people would try to touch me. "Meg, it's okay", and that would almost make it worse too. Just such a stressful experience, a seizure, which I think a lot of people including yourself can relate to.
Kelly Cervantes:	08:39	Absolutely. You're having these complex partial seizures. They're spiraling out of control and in the middle of this you meet your husband.
Meg Busing:	08:50	Yes.
Kelly Cervantes:	08:51	How did you guys meet?
Meg Busing:	08:52	We met on a blind date. We met and I felt like that was something I had to get out of the way before I really got emotionally attached to it.
Kelly Cervantes:	09:04	How did you tell him?
Meg Busing:	09:05	It was on the first date and he's a counselor, so he already put off the persona of you can tell me stuff and I won't judge. And so, I just said, "I have epilepsy and this is what it looks like and it's a result from a traumatic brain injury", and just tried to get it out of the way so it wouldn't surprise him later.
Kelly Cervantes:	09:27	How did he respond?
Meg Busing:	09:28	He was so supportive and compassionate and wanted to know more about it and just very understanding, and that's kind of where we hit it off.
Kelly Cervantes:	09:40	You date, you get married and you decide you want to start a family, which is no easy task as we know from a previous episode that we did on being pregnant with epilepsy. How did that personal journey work for you in terms of managing medications and keeping yourself and your baby inside of you safe?

Meg Busing:	10:09	Yeah. Well, I didn't know going into it that I would be a high risk pregnancy and with my nursing background I knew kind of the process of pregnancy and stuff, but never high risk and what that entailed. And so, we just had to keep a closer eye on my pregnancy and I had no idea that the medications I took could have an impact on baby with any sort of birth defect or cleft lip and palate. They told me all the risks, and so the real goal during pregnancy was preventing seizures.
Meg Busing:	10:48	I had heard all the side effects of keeping medication going while pregnant, but found out too that it was safer for mom and baby to stay on the medications and try to prevent seizures. No messing with seizures while you're pregnant. Stay on the meds that you're already on. And so, they kept a really good eye on me and baby, but the seizures did persist through pregnancy and actually got worse-
Kelly Cervantes:	11:20	Which is terrifying.
Meg Busing:	11:21	Yeah.
Kelly Cervantes:	11:21	I'm sure as you are leading up to this big moment when you're going to be a mom for the first time and your seizures are getting worse. Not to mention that lack of sleep and stress are huge seizure triggers.
Meg Busing:	11:38	Huge trigger. Yeah.
Kelly Cervantes:	11:41	They're kind of unavoidable with a newborn baby. Good luck to any parent who can sleep and have a stress free life with a newborn child in the home. What precautions did you take?
Meg Busing:	11:53	Again, marrying my husband, very supportive and understanding and luckily pregnancy is nine months, so you can prepare for what's ahead, but yeah, just had to keep real tabs on how I was resting and he had to take over with the baby sometimes. Always and I would feel like an aura coming. I thought, I need to put baby down. I need to not be holding Brody. And so, it just took a real toll and knowing that I needed sleep and where I would be laying down in our bedroom with the side effects of medications and post-partum. Yeah, and postictal. It was just not what I ever envisioned pregnancy looking like and just bonding with baby and not being able to hold them as much as I wanted to.
Kelly Cervantes:	12:49	Sure. You had to make the choice not to breastfeed as well as a result of the medications, which a decision that every woman

		makes, whether to or not, but that decision was sort of taken away from you.
Meg Busing:	13:05	Right. A lot of women get to decide what works best for them and their family and baby, but yeah, kind of being told another you can't with epilepsy just in a different way. That was kind of a shock and a real bummer that I wouldn't be able to do that with my son.
Kelly Cervantes:	13:26	But better that you get to stay on your medications and have a happy and healthy baby as a result.
Meg Busing:	13:32	Exactly.
Kelly Cervantes:	13:34	How old was Brody when you made the decision to have epilepsy brain surgery?
Meg Busing:	13:42	He was about one and a half, and I had always said whenever I heard the option of surgery, I would just automatically be like, nope, let's try another medication. Nope, just increase my meds.
Kelly Cervantes:	13:55	Say imagine you were told that because of the traumatic brain injury, they know exactly where the seizures were originally.
Meg Busing:	14:02	Yeah. That's what they're saying.
Kelly Cervantes:	14:04	You were a candidate probably pretty early on. What in the end made you decide to go for the surgery?
Meg Busing:	14:11	It was all having a child and having a baby and just wanting to bond and be there and the seizures were just putting a halt and getting in the way of what I always envisioned motherhood being like. It was as Brody was almost one year, one year old, I thought, no, I need to be here as a mom, and that's what really got me thinking about, okay, maybe surgery should be something to be looked into because I have a baby I've always dreamed of and I want to be the best mom I can be.
Kelly Cervantes:	14:46	Let's give this a shot.
Meg Busing:	14:47	Let's give it a shot and see what happens.
Kelly Cervantes:	14:49	That had to be terrifying for your entire family to be going in and having brain surgery, meanwhile you're leaving a young child in the waiting room, but you came out amazingly and you've been seizure free for eight years.

Meg Busing:	15:03	Yes.
Kelly Cervantes:	15:04	Congratulations.
Meg Busing:	15:05	Thank you. Yes. Not a lot of people understand that we're like, it's like a birthday.
Kelly Cervantes:	15:10	It is.
Meg Busing:	15:10	It's like celebrating seizure freedom is just-
Kelly Cervantes:	15:14	It's huge.
Meg Busing:	15:15	It's huge.
Kelly Cervantes:	15:17	But one thing I do want to take a moment and stress is that even though you have been seizure free for eight years, you are still battling epilepsy and the effects. You told me that you're still on medications, which means you still have the side effects from those medications.
Meg Busing:	15:34	Yes.
Kelly Cervantes:	15:35	And it doesn't erase the damage from the traumatic brain injury, the short term memory loss that you have. You're still parenting with these med side effects, as well as the results of the TBI. How has that impacted your parenting?
Meg Busing:	15:55	It's forgetfulness and I said my nine year old by nine years now is so used to having mom being forgetful that sometimes he'll tell a teacher, might need to remind my mom, write it in there today and yesterday that I need to bring certain book for show and tell.
Kelly Cervantes:	16:14	That's so amazing that he's come up with his own little tactics.
Meg Busing:	16:18	Yeah, to kind of get around his mom having a difficulty with short term memory. It's just neat how he's kind of picked up on it, but again is okay with it and kind of adapts to having a mom with-
Kelly Cervantes:	16:33	It's his normal.
Meg Busing:	16:34	Yeah, and can be there to explain to his younger siblings, hey, it might take a mom a little longer. Hey, let's go to dad for help with the homework, but it's neat how he can empathize and really understand that although short term memory and

		sometimes recall multitasking aren't my strengths, he also sees the positive things that I've been doing in the community. So, it's just-
Kelly Cervantes:	17:06	And just how much you love him too.
Meg Busing:	17:08	Yeah.
Kelly Cervantes:	17:10	Tell me again, how old are your three children?
Meg Busing:	17:12	Nine, five and three.
Kelly Cervantes:	17:15	Are there tips or tricks that you would give to other parents out there who are looking to start on this journey? They have epilepsy, they're having active seizures and they want to start a family or perhaps they're in a similar position to you and they already have a family and they're living with seizures or the after effects of seizures and epilepsy. What tips or words of encouragement do you have for people out there in your shoes?
Meg Busing:	17:46	I think just always being honest with your kids and letting them know that mom might have a difficult time, letting them know that yes, mom takes medication, but those are for her wellness. Not because she's sick, but to keep her healthy. Mom is taking these medications. My mom might need a little more sleep because seizures can happen if you don't have enough sleep. Just providing them the education about epilepsy I think has been really important with our kids, and not to shelter them, but to empower them and be open about it to talk about our strengths and weaknesses. I think overall just reflecting on it. I think it sort of has been a benefit to our family in that way for our kids to develop some empathy and understanding that not everybody's the same.
Kelly Cervantes:	18:41	Absolutely. You've spoken a bit about your husband and what an incredible partner he is in all of this. What are ways that someone's partner and in life and in parenting can be supportive to a parent with epilepsy?
Meg Busing:	19:02	I think just always being there to listen because we do have our difficulties and stresses and just being there as number one cheerleader. I know that gets tiring for them too, but just always being there for their spouse or significant other and taking a partnership in getting through this epilepsy and being a team and always staying involved in the latest treatments. I just

		think it's important for families to be involved in the overall care.
Kelly Cervantes:	19:39	Meg, thank you so, so much for coming and chatting and sharing your very personal experience. When an adult who is living a mainstream life tells their story, the impact is massive and there is risk for you in sharing something so personal. I'm so appreciative to you for sharing your story and especially something as personal as parenting and motherhood. You're an inspiration.
Meg Busing:	20:07	Well, thank you for this opportunity.
Kelly Cervantes:	20:12	Thank you again, Meg, for sharing your story. It's inspiring to see how you balanced searching for seizure control while raising a family. Meg's journey with epilepsy is a reminder that the fight to find a cure is about more than just the elimination of seizures. It is about the emotional and psychological toll epilepsy takes on patients and their families. If you want to support research into finding a cure for epilepsy, please consider donating to the organization which produces this podcast CURE, Citizens United for Research in Epilepsy.
Speaker 3:	20:48	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained here and is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs.
Speaker 3:	21:06	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.