

Kelly Cervantes:	<u>00:00</u>	I'm Kelly Cervantes, and this is Seizing Life , a weekly podcast produced by Citizens United for Research in Epilepsy , CURE.
Kelly Cervantes:	<u>00:18</u>	Our guest today is Meg Busing, a TEDx speaker and the founder of the Midwest YouCan Foundation. She started the foundation in 2011 with her husband after she had brain surgery to stop her out-of-control seizures. The mission of Midwest YouCan is to empower children with epilepsy by focusing on all the amazing things that they can achieve. Today, Meg shares with us how her summer camp helps children with epilepsy build self-confidence, develop meaningful relationships, and discover a world of dreams they can achieve. Thank you, Meg, so much for joining us today.
Meg Busing:	<u>00:52</u>	Thank you for having me.
Kelly Cervantes:	<u>00:53</u>	Before we start talking about your incredible summer camp for children with epilepsy, I want to talk about you and your journey. Give us a brief overview of how you got here.
Meg Busing:	<u>01:06</u>	It all started on March 6, 1998. I was a freshman in high school when, on a car ride home with some girlfriends, the car spun around and hit a tree. That kind of the start of all this. I had a traumatic brain injury. My head went through the window and hit the tree. I was unconscious and ended up in the emergency room. For the next six days, I was in a coma on a ventilator. They weren't really sure how I was going to come out of that, but I did finally wake up and was told that I had a traumatic brain injury. I went on to the local rehab hospital, and it was there where I saw what the effects of a traumatic brain injury actually were.
Kelly Cervantes:	<u>01:58</u>	What were those effects for you?
Meg Busing:	<u>02:00</u>	The physical therapy part of rehab went great. I could still walk and ride the bike, but it was in speech therapy where I was trying to think of words and having trouble. They would point to a pen, and I couldn't remember what the word was. They asked me to put a 10-piece puzzle together, one that my five-year-old could do. I wasn't able to put it together. It was at that point when I realized, okay, this is what a traumatic brain injury is.
Kelly Cervantes:	<u>02:35</u>	How long was it from the car accident until you had your first seizure?
Meg Busing:	<u>02:42</u>	I was able to finish high school and got into college. It was about five years after the traumatic brain injury that seizures started.

Kelly Cervantes:	<u>02:52</u>	Which is just insane to think about, that you went through all of that therapy.
Meg Busing:	<u>02:57</u>	Yes.
Kelly Cervantes:	<u>02:59</u>	You've mentioned in other videos that I've seen that you still worked with some short-term memory loss and things like that. You're going on and you're living our life, and then five years later, relatively out of the blue, you're battling post-traumatic epilepsy.
Meg Busing:	<u>03:15</u>	Right. I made it into nursing school, which was always a huge goal of mine because my mom is a nurse, grandma is a nurse, and a lot of aunts are nurses, so that was always my dream. I made it into nursing school and, during my second semester there, I was giving a presentation in front of class and noticed my heart started racing really fast. I thought, "Well, maybe this is nerves." But I don't get super nervous. Then I was having trouble breathing, or taking deep breaths, and I kind of started to stare off into space, unable to look away from the left side of the room. I could feel my lips smacking, and my hand was starting to raise in the air, so I tried to gather myself. It seemed like forever, but really it was probably only five seconds long. I tried to gather myself and then was able to finish my presentation.
Kelly Cervantes:	<u>04:12</u>	Oh my word.
Meg Busing:	<u>04:12</u>	Yeah. It was after that, and thank goodness it was a nursing school, that my instructor came up to me and said, "You know what Meg, I don't know if that was anxiety. You might want to get this checked out because I could foresee this maybe being a seizure."
Kelly Cervantes:	<u>04:28</u>	How fortunate that you were in nursing school.
Meg Busing:	<u>04:30</u>	Yeah, in nursing school really.
Kelly Cervantes:	<u>04:30</u>	There was someone who could recognize that in you and not just write it off. So you were able to address it rather quickly.
Meg Busing:	<u>04:39</u>	I was able to get in to a neurologist, but I had no idea what a seizure was, what epilepsy was. I had never heard of it, and that's when he told me, "Meg, you've had two or more seizures, so therefore you have epilepsy." So that was kind of a shock hearing that. It was just this short five- to 10-second thing that happened to me, and it had happened about three more times

before I went into the doctor. So, it was a shock to hear that I could actually have epilepsy and be automatically put on medication. Something about an epilepsy diagnosis is it's like your life has changed in a second. Where you always thought you were going to go, it's kind of turned right back around.

Kelly Cervantes: 05:28

How did the seizures impact your life?

Meg Busing: 05:31

In a lot of ways. It started affecting me in nursing school. I was having seizures, and, after a seizure in the postictal state, I just got so tired and wanted to lay down and go to sleep. Therefore, I was falling behind in nursing school, so I had to slow down my program. The seizures persisted, so I was put on three additional seizure medications.

Kelly Cervantes: 06:01

All with their own side effects, I'm sure.

Meg Busing: 06:01

Yeah, each one has their own side effect. Then you're on four of them at the maximum dose, about 20 pills a day.

Kelly Cervantes: 06:09

Oh my gosh.

Meg Busing: 06:09

And the seizures weren't stopping. They just kept coming. So I did make it through nursing school, luckily with the help of amazing teachers. I became a registered nurse and started my first nursing job. But I continued to have seizures.

Kelly Cervantes: 06:29

You have now been seizure-free for how many years?

Meg Busing: 06:32

About eight years.

Kelly Cervantes: 06:34

Congratulations.

Meg Busing: 06:35

Thank you. [crosstalk 00:06:36].

Kelly Cervantes: 06:35

That's very exciting, and it was all due to brain surgery?

Meg Busing: 06:38

To brain surgery. The doctor told me, "Meg, we don't have a lot more medications for you to try, and we think you're a very good surgical candidate. We'll just remove the part of your brain with the scar tissue from your 1998 traumatic brain injury in hopes that your seizures will stop."

Kelly Cervantes: 06:58

Sounds very similar to a gentleman, [Howard Zwirn](#), who I interviewed on a previous episode.

Meg Busing: 07:03

Yes.

Kelly Cervantes:	<u>07:03</u>	About the brain surgery ... it's so amazing for the people that it works for. It really works for those who are candidates.
Meg Busing:	<u>07:13</u>	Right.
Kelly Cervantes:	<u>07:14</u>	So, you come out on this other side, and I clearly understand your being inspired by your journey and the desire to want to help others, but why a summer camp?
Meg Busing:	<u>07:25</u>	I had volunteered at a camp for kids with cancer in California before nursing school started. I saw how truly valuable it was bringing a group of kids together who really understood each other's illness.
Kelly Cervantes:	<u>07:38</u>	So you have this idea, thinking, "You know what? I want to make a camp for kids with epilepsy." Then you do. But there was a lot of work that had to happen in the middle.
Meg Busing:	<u>07:50</u>	Yes.
Kelly Cervantes:	<u>07:51</u>	What did that look like? How did you get from point A to point B?
Meg Busing:	<u>07:55</u>	I just kind of looked for local resources and went ahead and found a supportive group of people who really helped me navigate the 501(c)(3) process. We started out under a different non-profit who really led and guided us on the way to build ourselves up so that we were able to brand off on our own. They were just amazing in helping us take in donations and getting the small stuff done. As a nurse, you know, I don't know what goes on behind the scenes of businesses and non-profits. So it's been a huge learning experience for me. Then, as we continued, in about the fourth year of camp, we branched off and started our own 501(c)(3).
Kelly Cervantes:	<u>08:47</u>	What is the age range of those who are attending the camp?
Meg Busing:	<u>08:51</u>	From 7 to 17.
Kelly Cervantes:	<u>08:52</u>	Are most of the children who attend mainstreamed in their schools, or are you working with some kids who also have learning or developmental disabilities as well?
Meg Busing:	<u>09:04</u>	Both, yeah, but most of them are mainstreamed in schools, but they do have assistance. Our criteria is that they are able to feed themselves and to shower or take a bath by themselves, to be able to meet activities and daily living.

Kelly Cervantes:	<u>09:27</u>	What does a day at camp look like for the YouCan campers?
Meg Busing:	<u>09:32</u>	They wake up and go to breakfast with their fellow campers. Then they just spend the day with amazing volunteer camp counselors who take them to all of their activities. Some of them will start out fishing or boating, or on the ropes course or the zip line. We have archery. We have arts and crafts, and we also have a teen discussion group where they can talk about what it's like to have epilepsy. Because, with epilepsy, it takes a physical toll on people, but it also takes an emotional toll, especially on kids.
Kelly Cervantes:	<u>10:13</u>	Which is something that you mention on your website, about the mental well-being of these kids and how being in camp can really help them. What are some of the things that you've seen and heard being around the kids while at camp?
Meg Busing:	<u>10:30</u>	Walking by a cabin or standing in a lunch line, you'll hear things like, "This is the only place where I can talk about my seizures without feeling embarrassed to." That's really what I'd like kids to get out of camp, to feel like they're not alone. I've walked by and also heard them say, "My brother and sister get to go to summer camp. I'm never able to go. Now I have Camp YouCan, and now I can go to camp."
Kelly Cervantes:	<u>11:00</u>	Yeah, absolutely.
Meg Busing:	<u>11:00</u>	It's just a great opportunity for the kids. And for the parents, it's great to know that they're leaving their child in a safe place.
Kelly Cervantes:	<u>11:08</u>	Which leads perfectly into my next question which is, how do you keep them safe? I mean, they are still doing all of the activities that a normal camper would, but that can be dangerous for some of these kids. What precautions do you take? How do you make sure that these kids can enjoy camp, but that you're sending them back to their parents whole, healthy, and happy?
Meg Busing:	<u>11:32</u>	The same.
Kelly Cervantes:	<u>11:32</u>	Yeah.
Meg Busing:	<u>11:33</u>	Yes. I always say that safety is our number one priority, closely followed by fun.
Kelly Cervantes:	<u>11:38</u>	Yeah.

Meg Busing:	<u>11:40</u>	That is a top priority we have. We actually are lucky enough to have an epileptologist. He flies in just for camp.
Kelly Cervantes:	<u>11:49</u>	Oh my gosh.
Meg Busing:	<u>11:50</u>	He stays in the cabins with the kids and is able to be in the same room. We can always contact him. We also have four registered nurses who come, so they're the ones who can dispense the medications to the kids. We go through a thorough medical history with them as they register for camp. So we have an idea before they even get there as to what they're going to be like, and the care that they're going to need. Gathering all that information and having those resources there, the nurses and the doctor, are really how we keep it safe so that kids can get out there and enjoy those activities. We're sensitive too. You know, some seizures can be started by heat. We have kids with heat sensitivity, or light sensitivity, so we're really careful to plan our activities around those kids and the needs that they have.
Kelly Cervantes:	<u>12:50</u>	It's such an incredible opportunity to be able to give them, to allow them to feel normal.
Meg Busing:	<u>12:56</u>	It's just awesome to see a kid come to camp and say, "Mom, I see that zip line, but I want you to know I'm not going on that. I'm not going to go on that, Mom." Then, the second day of camp, they're up there zooming across the zip line.
Kelly Cervantes:	<u>13:12</u>	Oh my goodness.
Meg Busing:	<u>13:13</u>	That's what we love to get out of camp, and what we love to see campers doing. We take pictures for mom and dad, and they can't believe it when they come and pick up their child.
Kelly Cervantes:	<u>13:23</u>	[crosstalk 00:13:23] So much.
Meg Busing:	<u>13:23</u>	They're like, "No way. That's not my kid going across the zip line." And yes it is because they actually are encouraged by all the other campers and camp counselors. It's just an awesome opportunity. I created it because I thought, "Man, I wish I would've had something like that when I was a teen."
Kelly Cervantes:	<u>13:41</u>	Right.
Meg Busing:	<u>13:42</u>	That's where the idea came from as well. Just to have that experience.

Kelly Cervantes:	<u>13:47</u>	And how rewarding for you now because the traumatic brain injury and the seizures did take some of your abilities away.
Meg Busing:	<u>13:57</u>	Yeah.
Kelly Cervantes:	<u>13:57</u>	In terms of being able to keep a nursing job, you still get to use that nursing degree that you worked so hard for.
Meg Busing:	<u>14:07</u>	Yeah.
Kelly Cervantes:	<u>14:08</u>	Talk about what this camp means to you.
Meg Busing:	<u>14:12</u>	It just means so much that I can still use my nursing knowledge and my ability to help others. That was always my goal as a nurse, to make a difference, but it's just doing it in a different way. It's not in the clinical setting, in the hospital setting, but I'm still able to make a difference and use my nursing knowledge to make safety our number one priority at camp. All around it's been a great opportunity to still use my skills, but in a different way, which a lot of people with a disability have to do. With brain injury, with seizures, they kind of just have to take the road less traveled and find that there are still things that they can do. That's where the name Camp YouCan came from.
Kelly Cervantes:	<u>14:59</u>	I love it. And you are now sort of exploring adult activities?
Meg Busing:	<u>15:06</u>	Yes.
Kelly Cervantes:	<u>15:06</u>	And family activities.
Meg Busing:	<u>15:09</u>	Yes.
Kelly Cervantes:	<u>15:09</u>	Sort of branching off into this new direction, what do those look like?
Meg Busing:	<u>15:14</u>	We do a monthly Young Adults With Epilepsy group, YAE is what we call it, for kids or young adults 18 and over to meet once a month. They have trouble relating to friends in different ways, but this is a time for them to get together, hang out, and see what they can do together. We also have our Family Camp that we're starting this year. This is an awesome opportunity for families to come together, for parents to have a discussion, for siblings to have a discussion, and for the kids with epilepsy to also have a discussion with each other, all while going on the ropes course, the zip line, or doing archery. I just foresee it as a change for families to come together and relate.

- Kelly Cervantes: 16:05 Immediately, the first thing that comes to my mind is the siblings of kids with epilepsy. So often, it's the child with epilepsy who the family world sort of revolves around. So, to give these siblings the opportunity to come together and meet other siblings who are a part of this epilepsy world, and to be able to connect with them and realize that their family isn't the only one that stops the second their brother or sister has a seizure, is really important.
- Meg Busing: 16:38 Exactly. That's exactly what we like to get out of it. For a place where the siblings can relate too because some of them have said, "I feel like I've had to grow up faster than some of my friends because I help with my sibling."
- Kelly Cervantes: 16:51 ...the same with my son.
- Meg Busing: 16:51 That's what I was, yeah. That they are sort of a caretaker as well as Mom and Dad. I think it is a great opportunity for them to hear from other brothers and sisters that it's like that for them too.
- Kelly Cervantes: 17:05 And the parents. For the parents to come together.
- Meg Busing: 17:08 Yes.
- Kelly Cervantes: 17:08 And meet other families as well, and in this incredibly fun environment. I just think that's great. Where is the camp?
- Meg Busing: 17:18 The epilepsy camp is at the Eastern Nebraska 4-H Center.
- Kelly Cervantes: 17:23 Where can people learn more?
- Meg Busing: 17:26 We have all the camp information on our website at www.midwestyoucan.org. It has all the camp information and activities that we have planned. We do an epilepsy walk run. It's just a neat opportunity for families.
- Kelly Cervantes: 17:42 How do you pay for the camp? Is this entirely on the families, or is some of it subsidized with donations?
- Meg Busing: 17:49 Yes, it is subsidized with generous donations from the community.
- Kelly Cervantes: 17:54 It's incredible.
- Meg Busing: 17:54 What I tell parents and potential donors is that epilepsy is also an expensive disorder to have. So, we like to keep things as

cheap as possible for families. We don't want money to be an issue for them coming to camp. We also offer full scholarships for campers, partial scholarships, and we pick up the tab on the expenses that we don't charge for them. It's \$150 for a kid to come to camp.

Kelly Cervantes:	<u>18:27</u>	Oh my gosh.
Meg Busing:	<u>18:28</u>	Yeah.
Kelly Cervantes:	<u>18:28</u>	For a whole week?
Meg Busing:	<u>18:29</u>	For three nights, four days.
Kelly Cervantes:	<u>18:31</u>	That's unbelievable.
Meg Busing:	<u>18:32</u>	And the generous Epilepsy Foundation helps provide scholarships as well. They've been amazing to work with, to get these kids to camp because they see the true value.
Kelly Cervantes:	<u>18:43</u>	You know, camp is such a special experience for children.
Meg Busing:	<u>18:47</u>	Yes.
Kelly Cervantes:	<u>18:48</u>	The memories that I have from camp are special. You just don't think about these groups of children who, because of their seizures, aren't able to enjoy this very basic part of childhood that so many of us took for granted growing up.
Meg Busing:	<u>19:04</u>	One thing that I love is they make these friendships at camp. Again, it's only three nights and four days, but they go on to be friends for a lifetime. They go on to be friends who come back to camp as counselors. They go through this journey of camp together. That's what I love to see about camp too, the friendships that they make.
Kelly Cervantes:	<u>19:29</u>	It's more than just those three nights.
Meg Busing:	<u>19:32</u>	Right, for them ...
Kelly Cervantes:	<u>19:33</u>	It's a lifetime of friendship and understanding.
Meg Busing:	<u>19:35</u>	Yes.
Kelly Cervantes:	<u>19:38</u>	How do you want to see the organization grow even more? Where would you love for Camp YouCan to be 5 or 10 years from now?

Meg Busing: 19:46

I would love to just see us touch so many more lives and to really get that Family Camp going, and a Siblings Camp going. I think these are really great ways to continue to touch the community, so they can discover that they're not alone. We have campers from Iowa, Nebraska, Kansas, and Missouri. So the word is getting out, and we're continuing to grow in our number of campers.

Kelly Cervantes: 20:15

Meg, thank you so much for coming today, chatting with us about Camp YouCan, and for all of the amazing things that you're doing. Having taken your experience and turned it into something that can help children across the Midwest is really remarkable. Thank you so much.

Meg Busing: 20:31

Thank you for having me.

Kelly Cervantes: 20:36

Thank you again, Meg, for sharing how we can provide life-affirming experiences for children with epilepsy. It is so important that we focus on the amazing gifts and abilities that children with epilepsy have, instead of letting them feel isolated because of this horrible condition. To learn more about how to separate stigma from truth, watch our webinar on epilepsy stigma at CUREepilepsy.org/EpilepsyStigma. Please visit @seizinglifepodcast on [Facebook](#) and [Instagram](#) and @seizinglifepod on [Twitter](#). Finally, you can sign up for information about upcoming podcasts, or listen to past episodes by visiting seizinglife.org.

Disclosure: 21:19

The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained here 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 health care 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 the patient's physicians or other qualified health care professionals who are familiar with the individual's specific health situation.