

Seizing Life, episode 32 – Debbie Flader
What's Your Plan? Seizure Clusters and Rescue Medications

- Kelly Cervantes: [00:00](#) Hi, I'm Kelly Cervantes and this is Seizing Life, a weekly podcast produced by Citizens United for Research in Epilepsy (CURE). This week, I'm excited to welcome Debbie Flader to the podcast. Debbie is an original Co-founder of CURE, and has worked and advocated in the epilepsy community for more than 20 years. She is currently the Director of Clinical Outreach at the Epilepsy Foundation of Greater Chicago and is also the Founder and Board Chair of the Angel Wings Foundation, which is dedicated to enhancing the lives of adults with epilepsy through independent community living.
- Kelly Cervantes: [00:45](#) Debbie's daughter, Noel, was diagnosed at eight years old with Rasmussen's encephalitis, a catastrophic form of epilepsy that produces hundreds of seizures per day and does not respond well to treatment. Part of Noel's care included action plan. Debbie is here today to talk to us about creating an executing and action plan and the benefits of several new rescue medications beginning to hit the market soon. Debbie, thank you so much for joining us today. I'm so thrilled to have you here and your years of expertise.
- Debbie Flader: [01:18](#) Thank you for having me.
- Kelly Cervantes: [01:19](#) Absolutely. So, you have been in this epilepsy world for decades now, unfortunately. Tell us about your daughter Noel and when she was first diagnosed and your history with this wretched condition.
- Debbie Flader: [01:38](#) February 12th, 1992, Noel had her first seizure. It wasn't a clinical seizure, as many people would recognize as a seizure. She complained about her hands falling. That was her first symptom. But she complained about it for three or four days. So we took her to our primary care physician who thought nothing of it. He said, "Well, she's maybe got a little virus or something. So go back home." A few days later, we noticed that she was having some mouth movement, her mouth was pulling to the side and twitching. We now recognize at this point that those were focal seizures, but we weren't familiar with epilepsy. She was born healthy. She was eight years old and he had no health issues until February 12th, 1992.
- Debbie Flader: [02:28](#) For weeks and weeks, she complained about pain in her teeth. She complained about not being able to sleep. And the twitching was pretty relentless. It was continuing. It was building steam. During the night, she would sit on the couch and the twitching would go constantly. So I took her back to the primary care physician and said there's something definitely not

right here. He sent us for our first of many CT scans, came out negative. Nothing that they could see. Totally normal. He suggested we go to a general neurologist, pediatric neurologist, which we did. She had an EEG that looked pretty normal. And he told us that our daughter had middle child syndrome. That was her initial diagnosis. So we went home-

- Kelly Cervantes: [03:16](#) I'm sorry, I have to stop you there for just a minute. You had a general neurologist diagnose your twitching child. with middle child-
- Debbie Flader: [03:25](#) Middle child syndrome. Yes. Because she is the middle child and she's always had that really rambunctious personality, and he thought she was attention seeking.
- Kelly Cervantes: [03:36](#) Okay, go on. It just sends something up and down my spine that this is going.
- Debbie Flader: [03:44](#) Because you're a young parent. I was young at the time and had no health issues with any of my children, and this is the information I had gotten. So I'm trying to treat her behaviorally a little bit different in the home. Thinking, what are you lacking here, Honey? What do you need? Are you not getting enough tension because you feel like you're in the middle? While the twitching continued and my husband I said, no, let's just go down to Children's Memorial, it was back in 1992. Let's just take our through emergency room. So we did that. And of course we got there and she wouldn't seize there. Well, she's tended to have seizures between sleeping awake. When she was trying to doze, that period between sleeping awake. I said, "Noel, you're going to lay on this [journey 00:04:32], and we're going to get you to go to sleep."
- Debbie Flader: [04:33](#) So I tried to get her to doze off, tried to soothe her a little bit, made her comfortable, cover her up with a blanket. She sure enough started to have the seizures. So general neurology came back in and they said, we better admit her. I said, "Thank you." So she spent two weeks at Children's Memorial. EEG, spinal tap, MRI, extended ... I don't even think they had extended video monitoring at that time. It was just the old fashioned paper EEG. They did notice abnormality on her EEG. So they discharged us thinking possibly it could be Rasmussen's encephalitis, which is actually her diagnosis. But we didn't get that definitively because the only definitive way to provide that diagnosis to the parents is to have a brain biopsy.
- Kelly Cervantes: [05:19](#) I'm going to stop you for a second. I do want to find out what are the characteristics of Rasmussen's?

- Debbie Flader: [05:25](#) Well, so typically it affects girls 10 years and under, one side of the brain, and it tends to create brain atrophy or the brain starts to shrink in size in the hemisphere. The only treatment option at the time was hemispherectomy, where they remove the half of the brain, and it was her dominant side. So there was no option at all surgically for Noel at that time. So I joined a support group immediately. We had one in our community in Carol Stream where I live on the western suburbs, and they told me about a wonderful doctor at the Rush University in Chicago. Said, "You got to go him. He's great." So we did. And this physician was Noel's doctor in August of 1992 and he still treats her today. So we have a really great relationship with him and Noel simply adores him.
- Debbie Flader: [06:14](#) In 1992, any testing, there was no good way to look through the skull, the bone to see if she had a tumor on the inside. So he said we have to do an operation to open her up and take a look to make sure she doesn't have a brain tumor. We said okay. So we're preparing for that. We saw him in August, her surgery was November 4th of 1992. So she didn't have a tumor. And I thought, whatever else comes our way, we'll be okay. Because she's going to be okay. She's going to survive this. So she spent two weeks in the hospital, went back home and she continued to seize. That was in 1992. Fast forward 28 years, she's still continuing to seize. It's been rarely a day without a seizure in all these years.
- Kelly Cervantes: [07:01](#) So she's still having seizures-
- Debbie Flader: [07:02](#) She's still having seizures. The last year, we've had her on a CBD treatment regime and she's doing better. The seizures have decreased but because of the isolation and the ongoing uncontrolled epilepsy over the years, she's developed mental health stuff.
- Kelly Cervantes: [07:20](#) Which is a major comorbidity with epilepsy. And the two, especially, you see it in those who have not been terribly affected intellectually, that do grasp their situation, that those really do go hand in hand.
- Debbie Flader: [07:40](#) So it's challenging and she continues to be isolated, and she seems to want to withdraw more and more. She just prefers to be by herself at this point. So it's really heartbreaking. It's really heartbreaking as a parent to watch that.
- Brandon: [07:55](#) Hi, this is Brandon from Citizens United for Research in Epilepsy or CURE. For 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: [08:15](#) Through all of this, you are still out there advocating and you are supermom in my book. You were sort of talking about earlier how far we've come having an EEG readout on paper.
- Debbie Flader: [08:33](#) Things have changed.
- Kelly Cervantes: [08:34](#) It has changed. And there are some new exciting developments that are coming down the pipeline, specifically around seizure rescue meds. So can you tell us a little bit about what a seizure rescue med is? And what's out there now and what's coming down the-
- Debbie Flader: [08:53](#) So I'll tell you a little bit about Noel seizure clusters because they're frequent, I would say they occur three to four times a month, and that's for the last 15 years. And she'll have a seizure, and a minute later, she'll have a second seizure, and a minute later, she'll have a third seizure, and then I know we're in for trouble. So they will continue, and sometimes they escalate in intensity, and she can't get up or go to the bathroom or leave her bed because they happen every 60 seconds. And her head will drop and she'll twitch and she'll drool. And then she'll snort in a big breath of air, and then she'll have 60 seconds of peace and then another one will come. So it's a horrible, horrible situation.
- Kelly Cervantes: [09:41](#) How long will that that cluster last?
- Debbie Flader: [09:44](#) If we're lucky, two hours. If we're not, it can go 8, 10, 12 hours. And the only rescue med that is available that I know of right now is a rectal administration and she just outright refuses to do that. She's 35 years old and I feel that I have to respect her wishes. She does not want to take a rescue med rectally.
- Kelly Cervantes: [10:11](#) Which, personally that sounds awful. But there's also outside of modesty or uncomfotability, this has been a major issue within the epilepsy community, because what do you do for a child in school? So many schools, especially in urban areas don't have nurses anymore. So you're going to have that third grade teacher administer a rectal med to their student? No.
- Debbie Flader: [10:38](#) But you're the parent and you're worried about sending your child to school because what if that child goes into status and needs that rescue med desperately? So it's a point of

contention. The good news is there's some really good things coming in the pipeline, I think. Nayzilam has been recently approved and that is nasal administration of midazolam. And that will be life changing for my daughter, I hope, and for thousands and thousands like her that suffer from these seizure clusters. So we're really excited about that. I don't think it's hit the market yet, but it should be I hope by the end of the year. So that's really, really good news in the epilepsy community.

- Kelly Cervantes: [11:17](#) And I know that there is other research being done trying to find other avenues. So hopefully, this side of seizure medications, these rescue medications to stop these clusters, to stop the status epilepticus, we'll start to see more treatments hitting the market after only really having one drug.
- Debbie Flader: [11:38](#) One drug for all. So we're hitting year 28 in February, and that's all I've had all that time. And that is really a sad, sad situation.
- Kelly Cervantes: [11:49](#) It's unacceptable.
- Debbie Flader: [11:52](#) It is unacceptable. So we're excited. I'm really excited. We've got different administration procedures. Some will be in the mouth and some will be I think inhaled. I think it's going to be a good day for epilepsy when we get some of these options available for our kids.
- Kelly Cervantes: [12:12](#) Absolutely. Which sort of leads me into my next picking your brain of your decades of experience here. So often these rescue meds need to be incorporated into a Seizure Action Plan. I don't know that folks are aware of what a Seizure Action Plan should consist of, who should have one, who should not only like who in terms of like, who has an epilepsy patient should have one, but who should that then be disseminated to within that person's community? What are your recommendations for creating a Seizure Action Plan and what is it in the first place?
- Debbie Flader: [12:57](#) It's simply a plan every patient with epilepsy has their own seizure type, seizure duration is different for everybody. So it's simply a plan, and this is especially important for children who are in the schools. Because the nurses and the schools without nurses need to know what to do. The first thing we've got to address is, should we have the EMTs come in this case or not. And that's a decision that's made at the school. So the Seizure Action Plan is a plan that's developed with the physician and the school and the physician signs off on it with the parents perspective of what they would anticipate should occur if the seizure lasts more than 10 minutes. Some will allow seizure

clusters to go for a half an hour just depending on their own personal situation.

- Debbie Flader: [13:48](#) Moms and dads usually know what they need from the school. And the schools are very accommodating if you can get the doctor on board. In Chicago, we have full load of case managers that are willing to help. People develop their Seizure Action Plan with the Epilepsy Foundation case management team and the physician in the school, and they work together to create a plan that's unique for every single student with epilepsy in the schools.
- Kelly Cervantes: [14:12](#) That an incredible resource.
- Debbie Flader: [14:13](#) We talk about using an emergency med, is that needed in the school? Is it not needed in the school? Do you prefer we call an ambulance? Do we not call an ambulance? Do we call the doctor? Call mom and dad immediately and they can come to school. So it's just really a precise plan of what to do in an emergency. So it's really beneficial.
- Kelly Cervantes: [14:29](#) And what would be included in your daughter's Seizure Action Plan, for example, for an adult who perhaps is not in a school?
- Debbie Flader: [14:37](#) I think even if you don't have it written on paper, you still need to have. If people are caregiving, if I have somebody come into caregive if I'm out for the day, they need to know if a seizure cluster begins, what do we do? At what point do we give an emergency medication? So everybody should have this information available. Adults, kids, everybody.
- Kelly Cervantes: [14:59](#) We're calling right now a story of a young woman who was on a subway train and felt her aura. And she was about to have a seizure. And she had her Seizure Action Plan, it was a laminated piece of paper. And she looked around the train to try and find a face that she thought was friendly. And she handed the piece of paper to this stranger and told her that she was about to have a seizure, and could she help her. Not all of us have those amazing strangers sitting on the subway with us. But I think having that laminated piece of paper, having that medical ID bracelet, having whatever that is, can really help keep our family members and our epilepsy patients safe.
- Debbie Flader: [15:50](#) As safe as we can. I think there's always risks, seizures are risky, but I think we've got to do better. There's seizure detection watches and those kinds of things that will call an emergency number. Technology is really moving us forward here. And

that's great. That's really great. Maybe we'll have better options.

Kelly Cervantes: [16:11](#) So I also want to take a moment to talk about the incredible organization that you have started here in the Chicago area, Angel Wings. What is it? Why is it important? Why should people care?

Debbie Flader: [16:24](#) Well, five years ago, my family and I had a discussion and said, including Noel, Mom and Dad are getting old and we're not going to be here forever to care for you. I want you to be in a place, Noel, that is beautiful. And you can experience life to the fullest with the necessary supports in place so that you're safe and you're taken care of. So Angel Wings was born. And we have been raising funds for the last five years. We're working with the partner agency in DuPage County, who is going to be responsible for the care. The funding for the care will come from the state of Illinois. We will buy the home, maintain it, buy the roofs, shovel the snow, and we will be the landlords. So we're actually starting to search for property this year. By the end of this year, we hope that this is fully funded.

Debbie Flader: [17:21](#) So the state of Illinois is a little bit tricky to get that pool of money to follow the person with the disability. There's 25,000 people on a waiting list for that pool of money. So we've been trying to work out a lot of scenarios to make this happen. But I think that we are going to go forward and hopefully by next summer, we will have four young women living together with epilepsy. They have to have epilepsy and living together in a home that will be fully staffed. They'll have 24-hour supervision. They will be able to access community supports, go to programs.

Kelly Cervantes: [17:54](#) That's amazing.

Debbie Flader: [17:55](#) And have enriched lives without their parents. Because we are not going to make it forever. Unfortunately, we have to pass that baton.

Kelly Cervantes: [18:04](#) Well, in sort of speaking to the comorbidity of mental health to still be living with your parents as a grown adult is also impacting that. So to have that independent freedom-

Debbie Flader: [18:20](#) It's person-centered, so that's the big buzzword, person-centered planning. So Noel can go to a home and say, I'd like to do this, but I don't want to play Bocce on Special Olympics. I want to learn to ride a bicycle in the sand. So it's supposed to be

based on what they want, just like you and I make choices. We want to live the life that we want to live. We want to have our choices.

- Kelly Cervantes: [18:49](#) That's amazing. And where can people find more information about Angel Wings?
- Debbie Flader: [18:52](#) www.angelwingsfoundation.net.
- Kelly Cervantes: [18:55](#) Perfect. Debbie, Thank you so much for sharing.
- Debbie Flader: [18:59](#) It was such a pleasure. Thank you.
- Kelly Cervantes: [18:59](#) Your story, Noel's story and for being an amazing epilepsy fighter for all these years.
- Debbie Flader: [19:05](#) Thank you. I appreciate it. Thank you for allowing me to come.
- Kelly Cervantes: [19:11](#) Thank you again to Debbie for sharing her family's journey with epilepsy and explaining the importance of having an action plan. Vital rescue medications which save lives and provide seizure relief for so many epilepsy patients can only be created through years of research and clinical trials. That is why care focuses on funding critical research for this condition that will affect 1 in 26 Americans and 65 million people worldwide. Only research can lead us to better understandings of epilepsy and more effective treatments to reduce and eliminate seizures. To help CURE fund this important research, please visit, cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
- Brandon: [20:01](#) The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained herein 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. 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.