Seizing Life, episode 51
Speaking Up About SUDEP: Two Mothers’ Stories
Guests: Libby Boyce and Jessica Brandes
(Transcript)

Kelly Cervantes:	00:00	Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
Kelly Cervantes:	00:18	Today, I'm joined by two mothers who have experienced the most devastating consequence that epilepsy can have for a family. Each tragically lost a son to SUDEP, Sudden Unexpected death in Epilepsy. Sadly and alarmingly, the incidence of SUDEP maybe more common than once thought. Recent evidence suggests that it occurs in approximately one in 1000 children and adults with epilepsy. Libby Boyce's son, Cameron, passed away from SUDEP in July 2019. He was only 20 years old. A month later in August of 2019, Jessica Brandes lost her eight-year-old son, Wiley, to SUDEP.
Kelly Cervantes:	01:01	They are here today to tell their stories and discuss what needs to be done to build awareness of SUDEP in both the epilepsy and medical communities. Libby, Jessica, thank you so much for coming here today to share and discuss this incredibly difficult topic. It really means so much to me personally and to our community to be able to share your stories and to share your sons' stories. And I think that's really where I'd like to start is just getting to know who your sons were, epilepsy seizures aside, what made them Wiley and Cameron?
Libby Boyce:	01:46	Cameron was a public figure and obviously people know he was a young actor. But for us, he was our son and he is our son, and he was born a very special human. He just had some pixie dust. We always used to say he was very much an old soul. He really understood on a very intimate and deep level so many things that were so beyond his years. And really, really felt very strongly from day one about helping others, and kindness, and not bullying, and finding creative outlets. He found dance at a very, very young age and he did that for, I don't know, 10 years almost, four to eight hours a day, and just absolutely thrived there. But for the family, he was a goofball. He was our rock. He was our glue. He was our cheerleader. He was just an amazing, amazing human. With his public reach, was actually able to do a lot with his philanthropic nature.
Libby Boyce:	03:07	And obviously, epilepsy hit us from left field when he was 16 years old. He did not have many seizures. We were not enmeshed or entrenched in the epilepsy community whatsoever. And so when he passed away from a seizure in his sleep, it didn't take us very long to decide and commit to the fact that we have to use his voice, which is now our voice, to do

		something in this community because everybody knows somebody who has epilepsy and yet it's the least known disease. It's just not acceptable. And so it has brought us to CURE. It has brought us to really thinking about and wanting to do something, with any power that we have to do something with, to end epilepsy and to end SUDEP, in particular.
Kelly Cervantes:	04:18	I feel your passion in my core of my being. Jessica, introduce us to Wiley.
Jessica Brandes:	04:26	Wiley and Cameron feel similar to me in that what really resonates for me is this old soul characterization. My child was only eight when he died, so hadn't quite had time to really put his passions to good use. But he was so artistic from a drawing standpoint, really loved art and drawing and creating comics and cartoons, and was just so funny and charismatic, and super entrepreneurial. He was so clear that he wanted to have a business and operate that business. And that ultimately, my husband and I would be his staff. That was a really well-decided thing.
Jessica Brandes:	05:09	I agree with Libby that we did not feel connected to the epilepsy community. I saw one seizure in my child nine months before he died. And the next time that I'm aware that it occurred, he was gone. I think what's most staggering to me about epilepsy is that the dangers of it and the consequences are so understated. There is this notion that like, "Oh, it's just a seizure. It's just a febrile seizure," which is not technically epilepsy, or it's just a benign condition. My son, literally the word benign is in my child's diagnosis. And when you die from it, it is not benign. That's the opposite of benign.
Jessica Brandes:	05:55	The dangers of it are just so misrepresented, and I know that it's scary to represent them differently. Because particularly in the case of SUDEP, if you can't prevent it, you can't predict it and you can't stop it once it starts, what really is the point of terrifying a family over this situation? And I think the point is that we're just caught less off guard. It's so, so devastating to get a phone call that your child is dead or to walk into their room and find them, which was my situation. It is the worst feeling in the world knowing how helpless and hopeless that scenario is.
Jessica Brandes:	06:37	Some level of like research and clear communication with parents and with patients really needs to start happening. It's not something that we were made aware of. I'm a practicing physician and it was not something that we'd ever really learned about, and it certainly wasn't taught to me in school. That being

said, I am not a neurologist, I am not an epidemiologist, so there's a difference there. It just was so incredibly shocking, and it's just so grossly understated and under communicated, in my opinion.

Brandon: 07:10 Hello, this is Brandon from CURE Epilepsy. Based on recent studies, the prevalence of SUDEP or Sudden Unexpected Death in Epilepsy, is estimated to be one in 1000 epilepsy cases for both adults and children. CURE Epilepsy is committed to unraveling the mysteries of SUDEP. We are a leader in epilepsy research, awarding more than $4.5 million in SUDEP grants to date and supporting over 35 research projects. Learn more about SUDEP at cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: 07:42 I think the epilepsy community for such a long time has walked this tight rope of, we don't want to terrify these families for this rare thing that could happen. But at the same time, if you're aware, if you know what signs to look out for, if you know that this could typically happen in sleep, if there are precautions that could be taken, could we save lives? Could we bring more awareness? Are there times, is there research that we can do that will end SUDEP? And I think it has to start with talking about it.

Kelly Cervantes: 08:21 Jessica, you mentioned that SUDEP was not mentioned to you, either as a practicing physician, or in your son's case. Libby, was SUDEP ever brought up for you with Cameron?

Libby Boyce: 08:36 It was never brought up. There was a cavalierness to his diagnosis from his neurologist of just, "It's not a big deal. Just take your medicine." There wasn't a sense of any panic whatsoever, and I use panic loosely. I mean, it was just such a "no big deal" kind of conversation. That there was nothing that gave us any concern.

Libby Boyce: 09:04 Honestly, there's a couple of points I want to make. Honestly, for me, I was more concerned that he was going to choke if he had a seizure, and that's what I stressed about, but I had no idea that you could just lights out in a seizure. I'd also like to say that I believe very strongly that SUDEP is under-reported, so I believe it's more than one in 1000. Number one, because a lot of coroners, either people don't end up getting an autopsy or the coroner does not report it as SUDEP. I, in my little bit of research that I've done over the last year and a few months, have come to believe that it is much more common than one in 1000.

Jessica Brandes: 09:55 I totally agree with you, Libby. I'm sorry for jumping on you, Kelly, but it's like, "Oh, I have to say... "

Kelly Cervantes: 09:59 Yeah.

Jessica Brandes: 10:00 We, definitely because we have a minor, so our situation was not an adult, someone's child, but a minor, so an autopsy or post-mortem evaluation almost always occurs in that setting. An unexpected death of a minor prompts investigation, as it should. I think it's very difficult for coroners or MEs, medical examiners, and this is all state by state and county by county, so in some situations you have a medical examiner and in other situations you have a coroner who is announcing cause of death, and that's based on funding and who they can hire.

Jessica Brandes: 10:37 But in our situation, it was very hard for my medical examiner to basically throw his hands up and say, "I don't know what caused this, and so my only conclusion is SUDEP." The issue with SUDEP is that epilepsy is a functional disorder. If the brain is not working, there is no way to monitor or to determine cause of death, because you're talking about it only works when it's functioning, right? You can only see it when it's functioning. That's what sort of EEG is for.

Jessica Brandes: 11:09 The problem in this situation is that because there are no hard physical signs of this having taken place, that you look to any other possibility to describe a way that someone could have died. It was a long haul, months of work, for me to go back and forth with our ME. And I know a lot of children get classified as cardiac dysfunction or sudden mechanism of SUDEP, but I don't necessarily think that's the right way to describe it. And so I totally agree that the number may very well be much higher, and it was one of the reasons I fought for it. Is if we don't show the true representation of rates that it is occurring then we don't get the NIH funding to work for research for a cure, for treatment or prevention, et cetera.

Jessica Brandes: 11:59 I also think for me, if my child had an epilepsy that was specific to nighttime seizures, so they only occurred in his sleep, and if I had known at the time that that was an increased risk factor for SUDEP, I would have monitored him There's monitoring techniques and tools out there. I would have used one, whether it would have saved my child's life or not, I don't know. I chose not to. Because as a physician I thought, "I can handle a seizure. I can handle a sort of two-minute long seizure, no problem." I didn't realize that it could be terminal so quickly, and so I regret not having an option to advocate for my child or for myself, and really investing in time and looking into those monitoring devices.

Kelly Cervantes: 12:50 So much can be done with a simple conversation by the clinician just coming out and saying that this is a possibility, "I don't want to terrify you; however, you do need to know that this could happen." I think because there is so confusion in the medical community about how to treat them and what is causing them and all of these things that there is this inclination to throw their hands up. And by no means, do I want to throw epileptologists and neurologists under the bus, because I do believe that they are doing the best with what they have in most situations. But I agree with you both wholeheartedly that there has to be fundamental changes in the conversations that are happening in those clinicians offices with patients, with their parents.

Kelly Cervantes: 13:50 One thing that I have found through speaking with you both that struck me is that neither of you felt a part of the epilepsy community. It was not a significant enough part of your lives to sort of dive into this community. And I also wonder if there is something to that as well that, I don't know, harms our ability to be able to get the word out there about epilepsy, about SUDEP, because there isn't this sense of awareness even from those who are suffering from seizures to know that this is part of a larger scale issue. I'd just sort of love to hear your thoughts about that, and also where you sort of see yourself in the picture now? Do you, after the fact, feel more a part of this community, and how has that affected your outlook on epilepsy?

Libby Boyce: 14:52 I think part of it, and I won't speak for Jessica, but I do think that we're both similar in the sense that our children did not have active seizures a lot. If Cameron was having seizures every week or every day or every month, I think we would have dove in more, if you will. But he only ever had five seizures, and the fifth was the one that he passed away from. We had very, very full lives, all of us. And we were sort of taking Cameron's lead. He was an adult, he was a very mature adult.

Libby Boyce: 15:37 Maybe six months before he passed away, we had a conversation about it because I was thinking about changing his neurologist and he was like, "Mom, I'm good. I have a sense if I sometimes feel like maybe I'm going to have a seizure and here's what I do. And I'm hydrating and I'm taking my meds." I didn't go beyond that. And do I kick myself? Yes. Do I think if I had done something at that time it would have changed the outcome? Probably not. Because they don't change your medicine if you're not having seizures. They don't change anything if you're not having seizures. It's a catch-22 for people in our situation.

Libby Boyce: 16:22 Since he passed, we have had a lot of people embrace us from the epilepsy community and certainly in our desire to learn more about it and to get involved, to be his voice. That has been something that has been illuminating, has been depressing just to know that so many other people are living with this disease and sort of up in the air in terms of their future.

Libby Boyce: 16:57 And so for us, it's given us fuel to work for those people who have epilepsy, to do something for them. And that's what Cameron would want us to do. We've had a lot of people reach out to us to say they have a child who has epilepsy and they have needs and so on, because obviously the Cameron Boyce Foundation, we do take donations and we are committing to epilepsy research. There's a lot of different angles that we're sort of having to work through. And we wish we weren't in this situation, but we are. And we're really just trying to make the most of it and use Cameron's voice on his behalf.

Kelly Cervantes: 17:44 And you're doing amazing, amazing work. Thank you. Jessica, where's your head at in all of this?

Jessica Brandes: 17:54 Yeah. Again, like I mentioned, we saw one seizure. I believe that there had likely been others that I hadn't seen up until that point just based on the way that I found him in the seizure. I believe there may have been others. But I think if we had been connected with an epilepsy group... And this is not to say that I necessarily would have joined had I been offered it at that time, because it was so underplayed. And I did sort of think, "Okay, we're going to do some research. I'm going to look into it. We're going to manage this. It's going to be okay," because that's kind of my personality, like take the scary thing and find a path through it.

Jessica Brandes: 18:33 And I don't necessarily lean towards group support. That's not necessarily my place, but I might've joined a Facebook group. There's a possibility I would have seen SUDEP come up. And maybe I would have said, "Oh, hang on. I'm sorry, what now?" And gone back and had a different conversation that I didn't get the benefit of having because it just simply didn't come up in the articles that I read that correlated his specific diagnosis. Which if you're curious, and maybe I should just say, was benign rolandic epilepsy, so there's that component.

Jessica Brandes:	19:07	I agree with Libby. We've also been embraced by the epilepsy community and this broader community of individuals who have lost children, which is a much, much, much broader than just epilepsy. But for this purpose, we have been approached by so many. We've shared our story very publicly, our grief very publicly, our regrets very publicly. I don't think as a parent when your job is to protect your kids and you're unable to do that, there's never a day that I live that I don't have massive regret for any possible choice I could have made differently at all to prevent that outcome. I just don't get the ability to go back and try differently, and that's such a tragic thing.
Jessica Brandes:	19:57	For me, we've participated in research, we've submitted samples to facilities and to programs that are attempting to identify components and risk factors and gene predispositions for SUDEP and things like that. I would say I'm less publicly sort of an advocate, partially because my own grief is so strong. And my son had a twin brother, has a twin brother, who's nine and who so desperately needs my love and help right now, particularly because he lost his only sibling. And then we had COVID come right on the back of it, and so his social world has changed so much over just a really short period of time. He really needs my, and I feel guilty giving it to someone else who is no longer there and who doesn't really need me anymore versus giving it to him, who's still very much tangibly needs my attention. I'm a little torn on it. I don't know, I'm working it out.
Kelly Cervantes:	21:10	It's interesting. I think Miguel and I have similar conversations. I am so ingrained in the epilepsy community and in CURE because I need to be, it helps me feel closer to these families and to Adelaide. But meanwhile, I think Miguel struggles with that a little bit. He's like, "Okay, she's gone and we still have this other child and he needs us too." And so I understand that so implicitly. And we all just have to find our own path and find our own way, and what makes sense to us.
Kelly Cervantes:	21:53	Clearly, I think you both wish that the doctors would have explained that this was a possibility. Is there anything from a clinician standpoint that you wish would have been done or would have been said? Is there anything that you want other families who have a child with epilepsy to know, a child who has had a seizure, two seizures, five seizures? What do you want to tell them?
Libby Boyce:	22:23	I think there should be a starter kit, and it sounds funny. But I feel as though when somebody gets an epilepsy diagnosis, they need to have an orientation to the disease. And I have told, I have actually gone back to Kaiser Permanente, the medical

center that was Cameron's neurologist, where he was, and spoken to them about this. Because I just think the cavalierness by which he got his diagnosis was just unacceptable. And that it is the responsibility of any doctor giving a person, nevermind a child or a young adult, a diagnosis of epilepsy, they need to be tooled and armed with everything that they can get.

Libby Boyce: 23:15 And so I really believe it takes more than a 10-minute visit to go through that. And there should be some kind of standardized way to give families tools that they need and an understanding of how it actually can be fatal. And here's what you need to do, and here's how you live with this, and here's the things you watch for, and here's how often you should come to the doctor. We weren't even told that. Here's where would change your medicine. Here's where we wouldn't. If we are in a situation where we change your medicine, there's these things that can happen. It's just, there needs to be more information. And I just feel that there is no excuse for not having some kind of standardized orientation or explanation of how to live with epilepsy.

Jessica Brandes: 24:12 I would say for me, when I think back on all of the choices that I made along our sort of very, very short diagnosis window, which is only nine months long, in some ways I think, would I really have changed anything even if I had the information? Particularly as it's conveyed as a statistic, it's incredibly unlikely, it's extraordinarily rare, right? We kind of filed those things away, and I don't know that I would've changed anything.

Jessica Brandes: 24:43 I would've hated to have had him live a life where he didn't have sleepovers, where he couldn't travel with us. We traveled to 13 countries before he died and he was only eight and a half. If he hadn't been able to do red eye flights and things like that because it would have disrupted his sleep schedule, would that have been a shame to have missed out on? Of course.

Jessica Brandes: 25:04 To speak to this notion of your idea of this sort of orientation, this gathering around... I'm working with a family now, not as a practicing physician but as a family friend, who's just had a new diagnosis of epilepsy. And I completely agree with you. This young woman is so like, "What is happening to me?" She's having absence seizures, which are very scary because you have no idea, you can't account for the time that you've lost, which is very frightening as a teenage girl. And so it's super striking to her that she doesn't understand and she's confused and there's anxiety. And there's very little conversation around how to connect with other people who are like you, how to handle these things. And particularly, what are the risks of this becoming increasingly a fatal? Which for these teenagers and young adults is, the risk of missing the dose of your medication could be very severe. There is a lack of that process.

Jessica Brandes: 26:01 I do speak with neurologists now and say, "No, no, no, this is my story. This is not just a statistic. You are looking at someone who has had this happen." Which I think is very, very different, right? We tell people before they get behind the wheel of the car, you don't wear your seatbelt, you could die. That's a statistic. It would be unfortunate and unlikely, but it could happen. We still drive, right? These families, they still have to deal with epilepsy, but there is a need to tell them and to convey really all of the options for what goes down.

Jessica Brandes: 26:31 And the single thing that I regret the most is sitting in that neurologist office and not saying, "Okay, I hear you. This sounds benign, and okay, and we're going to outgrow it. But what's the worst case scenario?" That's the question I didn't ask, and maybe it's because I just didn't want to know. But I didn't ask it. And I'm so sad for myself, for my son, for his brother, for my family that I never thought to say, "What is the absolute worst-case scenario here? And what do I do about that?"

Libby Boyce: 27:03 Yeah. And just, I mean, Jessica and I have talked about this. I cannot live with myself thinking that if I had done something differently, the outcome would be different. That's just, I can't. I do it in my head sometimes and it's-

Jessica Brandes: 27:21 A bad path. It's very bad.

Libby Boyce: 27:23 ... It's a really bad path. And the reality is, I've had many conversations with many people in the medical field who have told me there was nothing else I could do. Nonetheless, I just want to impress that, especially with what Jessica is saying is, a person misses one dose of their medicine and they're at risk. Just that alone is very, very important information. The fact that the medicine may or may not work, or may need to be changed, just information about the future, anything about what it is to live with epilepsy. And we didn't get that. And I don't think Jessica got that, and I don't think a lot of families get that.

Libby Boyce: 28:13 And so that's part of our passion for this is to say to doctors, you can do better. You have this information, and if you don't go get it, because you shouldn't be a neurologist and not have this information. And that's kind of more along the lines of where we're pushing. We're not trying to throw anybody under the bus. But if you have a child or you have a young adult, you should understand how important it is to know these nuances.

Kelly Cervantes:	28:46	Yeah. I completely agree. And Jessica, I think your analogy of putting on a seatbelt behind the wheel, I mean that is it exactly. You need to take your medicine, you need to get enough sleep. There are these known risk factors. And then beyond that, there is incredible research being done to understand the mechanisms behind SUDEP. There is 100% the possibility that a cure for epilepsy may be years down the road, but we could stop SUDEP much sooner than that. If we can understand the mechanism that causes that, it is possible that science can prevent SUDEP from ever occurring to another person with epilepsy. These are our real achievable goals that are out there. But if the awareness isn't out there, if people don't realize that this is a possibility, if you know the medical examiners aren't recognizing the cause of death as SUDEP, then we don't get to that point.
Kelly Cervantes:	30:01	I know it's of no consolation, but I know the strength that it takes to be able to share your personal story and to be able to open up and share your sons. And for that, I am eternally grateful, as I am for your friendship. I just think that you two are amazing and I'm so appreciative to you for chatting with us today.
Libby Boyce:	30:30	Thank you, and thank you for your friendship. And I love you and I love Jessica. And yes, I couldn't do it without you guys.
Jessica Brandes:	30:38	I love you both. Thank you so much for having us on this chat, and I look forward to seeing you both in person very soon.
Kelly Cervantes:	30:49	Thank you, Libby and Jessica, for sharing your stories and for raising awareness of this scary and difficult topic.
Kelly Cervantes:	30:57	We in the epilepsy community cannot shy away from uncomfortable conversations about epilepsy and the risks of SUDEP. Only by frankly discussing SUDEP can we raise awareness and help patients, families, and physicians reduce the risk. And only by funding research, can we learn about the mechanisms behind SUDEP and make progress towards eliminating this devastating outcome.
Kelly Cervantes:	31:23	In 2004, CURE Epilepsy launched the first-ever private US SUDEP research program. Since then, CURE Epilepsy has awarded more than $4.5 million in SUDEP grants, supporting 35 research projects. We've made significant progress and learned how to better mitigate risk, but we need to eliminate SUDEP completely. Please, help us continue towards that goal by going to cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.

Brandon: 32:09 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. 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 specific health situation.