Seizing Life, episode 78
A Family's Epilepsy Journey: From Diagnosis to Surgery
Guests: Daniel Allbeck, Paula Allbeck, David Allbeck

Kelly Cervantes:	00:00	Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
Kelly Cervantes:	00:17	Today I'm happy to welcome to the podcast, Paula and David Allbeck and their son, Daniel. Daniel experienced his first seizure at the age of 22. Medications offered Daniel some seizure control while he completed his education, earning an undergraduate and a master's degree and a teaching certificate. Despite an increase in seizure activity, Daniel was reluctant to pursue the option of surgery, but when his parents volunteered at a CURE Epilepsy Day of Science, the information they were given led Daniel to reconsider epilepsy surgery. Now six months after undergoing the surgery, Daniel and his parents are here to talk about their epilepsy journey, what led them to reconsider surgery and how Daniel is doing today. Daniel, Paula, David, thank you so much for joining us today. Daniel, why don't you kick us off by sharing how epilepsy first entered your life?
Daniel Allbeck:	01:13	When I was 22, I had my first seizure. I was in college. In the middle of the night I had a seizure and I didn't know what was going on. I was really out of it and at the time knew nothing about epilepsy. But now I see that that makes sense that I don't remember it very well, but... The way I remember it is I woke up in the middle of the night and I stumbled into my closet doors, which were made out of glass and the glass kind of all broke. And then I was making such noise that my parents came and found me. That's really how I remember it, but that's not the whole story. I think my mom knows more about it because when you're having a seizure, you don't remember a whole lot.
Kelly Cervantes:	01:54	So Paula, why don't you fill in the blanks for us?
Paula Allbeck:	01:57	Sure. As is the case with anyone who's having a seizure or has had a seizure, they're not going to remember it. And Daniel's actually confusing a later seizure with that first one. So on that day, and it was May of 2005, he had been asleep. First of all, he'd been out with friends quite late the night before, and he had to get up and go to work that day. And I knew he had to get up and go to work. We had a two story house at the time and his room was right above the garage. And his dad and I were both in the garage doing things. But I'd heard some noises coming from his room, but I thought he was stomping on the floor because the dogs were barking. So I didn't do anything for a few hours.

Paula Allbeck:	02:47	And then it got closer and closer for him needing to get up to go to work. And I finally decided that I needed to go up and say something. And I knocked on his door, no answer. I yelled into his room, no answer. I pounded on his door, no answer. And I finally went in and he was semi-conscious at that point, but not cognizant of what was going on at all. His lips were blue. There blackened, dried blood on his lips. He had knocked over the water glass that was by his bed. And I just said, "Daniel, what happened to you? What happened to you?" And after saying that about five times, he said, "I don't know." And we called 911. They came and got him and, long story short, he ended up being in the hospital in intensive care for the next six days.
Kelly Cervantes:	03:47	Now, did he have additional seizures in the hospital?
Paula Allbeck:	03:51	Yes, he did. So we were at a trauma center hospital. And so we were in the emergency room for 13 hours before they could get a bed for him. He went to his room late in the evening and they told us that the neurologist who served that hospital did his rounds at 11:00 PM every day. So Dave and I stayed until 11:00 and talked to the neurologist who said, this is a first seizure for him. We are not going to diagnose epilepsy yet. My nurse will call you and make an appointment. So Daniel had really come around and was aware of what was happening. He still was having difficulty with muscle control from those seizures, but he was much more himself. And so Dave and I went home to go to bed and we slept that night.
Paula Allbeck:	04:44	Dave came the next morning because Daniel was supposed to go home. He got to the hospital and he'd found that in the middle of the night, Daniel had another cascade of seizures, even worse than the first ones. And they had given him intravenous Valium. They had restrained him because, as many people who are having tonic chronic seizures do, when folks were trying to help him, he thought that he was being restrained for other reasons. He didn't understand. So they tied him to the bed. And that's how Dave found him when he got to the hospital. And Dave called me and I came right down. And Daniel was moved to intensive care. And we did not leave him alone again for the next five days. One or the other of us was there with him.
Kelly Cervantes:	05:36	So, clearly now he's had more seizures. You have an epilepsy diagnosis. What did they tell you? What was your understanding of epilepsy at that time?
Paula Allbeck:	05:45	I knew nothing about epilepsy prior to that. And to be very honest with you, that neurologist and even subsequent

		neurologists didn't tell me anything about epilepsy, except we're going to give him this medicine. We're going to try that medicine. What I've learned, I've learned primarily through CURE Epilepsy and other research that I've personally done.
Kelly Cervantes:	06:11	Now, Daniel had you had any knowledge of seizures or epilepsy prior to that first hospitalization?
Daniel Allbeck:	06:19	I didn't really know anything about epilepsy. I knew what a seizure was, well, I thought I did. And now I realize that I didn't. But I'd heard of them and stuff. But I didn't really know what epilepsy was. But looking back, I realize that I was having small little signs that I had epilepsy for several years leading up to my first actual grand mal.
Daniel Allbeck:	06:41	The biggest thing that was happening to me were confusion episodes. So I remember one time I was walking home and I just approached a corner, it was the corner right before my house, and I was confused. And I thought, wait, where am I? Which way to go? And didn't even remember what I was doing. I was like, well, why am I even here? And I looked up at the street sign and I recognized it as the name of my street, but did not know which direction to turn or where my house was or how to get home. And it was just pure confusion. And that happened to me several times. Everything else that happened, even to this day, it's hard to say if it was related to the epilepsy, if it was just some random thing. But it'd be like muscle contractions. But not nearly as noticeable, not as strange as the confusion episodes. Those ones were weird. And that's when I started thinking there's something going on. So that was about a couple years coming up to my actual first seizures when I was 22.
Kelly Cervantes:	07:39	So you get your epilepsy diagnosis and they start putting you on medications. Did the medications help? Were you able to get some seizure control from the medications?
Daniel Allbeck:	07:52	They helped. I was able to get some control. As many people with epilepsy know, you kind of have to experiment with the medication. You'd be very lucky if the first one you got solved all your problems. So they did at first, but then they didn't completely solve the problems. And so we've been tinkering with the medicine, especially in the early days we tinkered a lot.
Kelly Cervantes:	08:13	So you're 22 years old. You are wrapping up your senior year of undergrad. How did this diagnosis and the seizures and the side effects from the medications, how did that affect you in your social life and school?

Daniel Allbeck:	08:33	It was really bad timing. Like you said, it was my senior year of my undergraduate. And it was in the spring, so my finals were coming up and I had my seizures when I was studying and writing my papers.
Kelly Cervantes:	08:47	Maybe a little stress and sleep deprivation at play?
Daniel Allbeck:	08:52	Yes. So it wasn't until later that I learned that stress was my number one trigger. And I was under extreme stress that year, my finals of my final year of college and all that. Well, I went to the hospital for a week during finals and I failed all those finals because I wasn't there. And I wasn't able to tell teachers or professors what was going on because I was in the hospital. And so I failed them all. I mean, I didn't fail the classes. I failed the finals, but did get some pretty bad grades. In regards to your question about it affecting my social life, it didn't in the beginning. I really wanted to not believe that I had epilepsy. So I still did all my social life stuff. And that didn't really change for a long time. I still tried to act like everything was the same.
Kelly Cervantes:	09:40	Now were you public with your epilepsy at that time? Did you tell your professors when you were in graduate school? Did you tell your friends and other family?
Daniel Allbeck:	09:49	I'm not generally private about it. I'm happy to tell people, especially my friends and family. I told all of them. But I didn't tell professors because it wasn't happening frequently enough that I was hoping that it wouldn't affect any of my master's degree classes. But I also believed at that time that if something did happen, that I could go talk to them and they would be understanding. But if it was necessary, I would tell somebody.
Brandon:	10:18	Hi, this is Brandon from CURE Epilepsy. Did you know that one in 26 Americans will develop epilepsy in their lifetime? For more than 20 years, CURE Epilepsy has funded cutting-edge, patient-focused research. Learn more about our mission to end epilepsy at cureepilepsy.org. Now back to Seizing Life.
Kelly Cervantes:	10:38	Paula and David, how did this epilepsy diagnosis for your son affect you as parents?
Paula Allbeck:	10:45	I would say that it affected virtually every aspect of our lives. And like Daniel, I think I can speak for Dave when I say we simply wanted to have it not be true. We knew about epilepsy beforehand, but we really did not know how cruel and completely damaging it is to one's life. And it is that to the lives of the people who support the person who suffers with epilepsy

		too. Dave and I were, at that time, both professional educators. I was a school principal and Dave was a school counselor. Fortunately we had been at our jobs a long time and our school district was extremely supportive because we just stopped going to work. I'm a school principal and I simply did not go back to work until I could, which was about three weeks. Everyone was fine, but emotionally it was huge.
Kelly Cervantes:	11:55	David, how about you?
David Allbeck:	11:57	Mostly, I think that I was worried. I didn't really know anything about epilepsy at that time. Like Daniel, I knew about seizures and what seizures were, but I really had no idea of what epilepsy entailed. And so I was worried and scared. Didn't really know what Daniel was going to have to deal with and how we were going to deal with it. I just figured that we would just go one day at a time and figure it out as we went.
Kelly Cervantes:	12:27	Daniel, I know that you started the medication, but your seizures were unfortunately relentless. Sort of take us through that part of this journey. You go to graduate school and now you're working, but the seizures become a big problem. It's a bit of an understatement, I think, but...
Daniel Allbeck:	12:56	Yeah. So in the beginning they put me on some medicines. If I remember correctly, it was Depakote and Dilantin. And they did effectively stop the seizures, at least for a while. But they had some really bad side effects. And my doctor said, well, you know, they didn't completely stop the seizures and these side effects are not very good. So let's try a new medicine. And so we did, and I got the same results. The seizures weren't as frequent or as severe, but they still happened.
Daniel Allbeck:	13:26	And so between when I graduated college and when I started my master's degree, I actually applied to the Peace Corps. And the Peace Corps said, well, if we're going to send you, because I was going to go to Africa, they said, if we send you there, we can't get you medicine. So you have to go two years without a seizure for us to send you. And of course, what one year and nine months in, three months before I was to ship out, I had a seizure. And so I wasn't able to go.
Daniel Allbeck:	13:57	And so, because that happened, I thought, well now what am I going to do with my life? So I started a graduate degree program. And during that time I visited a new neurologist who was actually an epileptologist who specialized in epilepsy. And he started me on a new medicine. It was the first one that really made a big difference. And that medicine was Keppra. So when

that neurologist gave me Keppra, that changed a lot. But the seizures kept coming. The frequency stayed about the same, like one or two grand mals a year. But the smaller episodes that I get, the absence seizures and stuff like that, they were still very frequent, like once a day. And that was it up until I got a full-time job as a teacher, when my seizures really started happening, that led to my eventual surgery.

Kelly Cervantes: 14:54 I know that surgery had been presented to you as an option earlier on, but it was not something that you had been comfortable with. Why not?

Daniel Allbeck: 15:03 Oh, it's so scary to have brain surgery, right? Like there are so many questions. Will it change my personality? Will I be cognitively impaired? Will I lose muscle coordination or the ability to talk, who knows? Or see, like vision? Part of my epilepsy comes from my vision center. If they had to remove that during the surgery, I would be blind. So there were a lot of concerns, but my number one concern was will I be a different person? My personality, what if I come out and I'm eternally depressed or something.

Kelly Cervantes: 15:37 Now, Paula and David, what motivated you to continue to fight and look for more answers? And tell us about your journey in finding more information about the surgery.

Paula Allbeck: 15:49 When Daniel was first in the hospital, as I mentioned, we would take turns staying there. And our daughter was away at college, so the house was empty. And I would come home and research online. And that was my first learning experience about epilepsy. And it was so bleak and so dire that I would literally scream into the empty house. And then I would cry a lot. And then I would go back and research some more. And that's how I first found CURE Epilepsy. And it was Lauren Axelrod's story via Susan and David Axelrod on CURE Epilepsy that first brought Keppra to our attention. And we actually talked to Daniel's first epileptologist about Keppra, and that's why he started it. And that was the first measure of relief Daniel ever really had. And at that moment, I think I can speak again for Dave and say, we determined that this, aside from supporting our family, finding a cure and doing what was at our disposal to help would be our sole focus.

Kelly Cervantes: 17:12 David, do you have anything that you want to add to that?

David Allbeck: 17:16 For me, one of the biggest issues was when Daniel had a seizure, they took away his license. And every time he'd have a seizure, especially if he's out in public, he'd have a seizure and people would call 911, and the ambulance would come. And we knew that that wasn't going to help him at all, that if he were to go to the hospital, they weren't going to be able to tell us anything, because we'd been through all of that so many times where they run all these tests and they can't really tell you anything. So it was kind of frustrating. He'd be out doing something, he'd have a seizure and then we'd get a phone call. The paramedics would come and we'd be like tell the paramedics don't transport him because they can't do anything. We'll just come and get him.

David Allbeck: 18:02 And so we had a lot to learn. But every time he lost his license that made it more difficult for him to be able to go to work or to get where he needed to get. And you don't realize how much your life is impacted by something like that until you're stuck at home and you can't go out and do those things you need to do. The whole process that we went through just from knowing very little to everything that we learned really opened our eyes as far as what we needed to do to get our son to the point where he could be self-sufficient.

David Allbeck: 18:42 Paula and I volunteered at a CURE Epilepsy conference. And I think it was there that we heard some things that really changed some of our decisions. One of the doctors that was talking said to us, if you'd been having seizures and it had been going on for a year and you don't have it under control with medication, then you should be considering getting the surgery done. And after that was over, I said to Paula, look what this guy said. Daniel's been having seizures for over 10 years and that's way past a year. We should be considering getting the surgery. And that's when we started looking into it. So I went on the internet for once and I dug around and I found this program at UCI and they had a quote that said, we take the problems that no one else can figure out and we can solve them. And that's how we got this started. And that's how Paula got in touch with the doctor, neurologist there at UCI. But that's what got everything rolling.

Kelly Cervantes: 19:45 I love A, that you got that information at a CURE Epilepsy event. And also thank you for volunteering. Daniel, I want to ask, what was it about this particular epileptologist and brain surgeon that convinced you that surgery was the way to go? And is there anything that happened in in your personal life that really motivated this change?

Daniel Allbeck: 20:10 Yes. There's definitely something that motivated it and it was the dramatic increase in grand mal seizures that I was having when I got my teaching job. I hadn't had such a such bad cases, such frequent seizures since I was in my early twenties or mid-twenties, when I first was diagnosed. So that was the personal motivation was, wow, my so seizures are getting really bad. What else can I do?

Kelly Cervantes: 20:35 Was it affecting your ability to work?

Daniel Allbeck: 20:37 Oh yeah, I got fired. I mean, they didn't say that's why, but that's why, because I was having poor attendance because I was having so many seizures. But then, still, all my concerns surrounding brain surgery were still there. So I talked to my neurologist and she talked to me about my medicine. We adjusted it slightly. It really didn't make any difference. And so, she said, what about brain surgery? And I was under the impression that I was not a candidate. And so she led me to, I don't know what the word is. She...

Kelly Cervantes: 21:17 Referred?

Daniel Allbeck: 21:17 Yes. Thank you. She referred me to the surgeon and it was him that finally gave me the confidence to do it. Not only did he say you're a candidate, he said, you're a good candidate. And then I said, well, I'm scared. What would you do if you were me? And he said, I wouldn't do it if it was anybody but me, but since it's me, I would do it. And I thought, wow, that was pretty, that was some extra confidence right there.

Daniel Allbeck: 21:46 But if somebody is going to be doing brain surgery on me, I want them to know, to believe in themselves that confidently. And so he inspired confidence enough that I trusted him. And that was the final icing on the cake or whatever that made me finally do it. I was unable to work. My neurologist says, oh, I am a good candidate. And the surgeon says, oh, I can get this done. Definitely. Nobody else, just me. And I was like, oh, well found the right guy then.

Kelly Cervantes: 22:15 So you make the decision. You're going to have brain surgery. What were the next steps after that to get the surgery?

Daniel Allbeck: 22:28 So the first thing they had to do was they brought me into the hospital. I think it was a four-day stay. And they took me off my meds so that they could induce a seizure. And I think it was like a four day long EEG. So they had wires underneath, like a head cloth, just all glued in my head in different places. And the idea was when they induced a seizure to see where they're happening in my head. And that was pretty rough. You stay there for four days and you're having seizures a lot. But I guess

		they found enough information that we proceeded to the next step, which was to schedule the actual surgery.
Daniel Allbeck:	23:06	So when I went in for the surgery it was the two step process. The first process was they had to open up the skull and they put this chip, it looked like a computer chip, but they had to slide it under my skull so it was sitting on top of the area that they had previously decided was where the epilepsy was coming from. But then they needed to narrow it down more specifically. So this little chip they put in my head would register where the electrical disturbances were happening in my brain or abnormalities.
Daniel Allbeck:	23:37	And so once again, they took me off my meds and induced seizures so that this little computer chip could tell them, okay, this part definitely was part of the seizure. This part was not though, and so on. So that's how they determined exactly which part to resect. And so sometimes they found areas, they said, okay, this area is definitely having seizure activity, but we still can't remove it because we also noticed that when we electrically stimulated, it makes your arm move. So if we removed it, you wouldn't be able to use your arm. So they had to make decisions, some small sacrifices, is it worth it to lose a little motor coordination if it will help reduce the seizures. In the end, I didn't lose motor coordination, but they did resect some areas that were near that motor coordination area of my brain.
Kelly Cervantes:	24:29	So then what did the recovery process look like?
Daniel Allbeck:	24:33	The recovery process was basically at home. I was surprised how quickly they sent me home. They spent a week in the hospital prepping and leading up to the surgery. And then the day after the surgery, they were ready to let me go home. It was really just take pain reliever, was mostly Tylenol, keep hydrated and rest. I was tired all the time. And the doctor told me I would be. And that took about two weeks. But after two weeks I was feeling myself again. I was ready to go to work, do stuff. I was still very self conscious about the scar. But other than that, I really thought the recovery was not as bad as you would expect.
Kelly Cervantes:	25:14	That's incredible. So when did you actually go back to work?
Daniel Allbeck:	25:19	So I didn't get to go back to my full-time teaching job. So I was a substitute teacher and I think I was subbing again, about a month later, maybe six weeks later, somewhere around there.

Kelly Cervantes:	25:29	Did the surgery have any, did you notice any complications with your memory or cognition or mobility?
Daniel Allbeck:	25:36	So immediately after the, when I was still in the hospital, I really didn't have any problems. They even had me do some agility tests where I walked around and they made me like pirouette and walked back and I nailed that. And that was like the day after the surgery. But it wasn't until I got home, so maybe two days later that I realized I was having motor coordination problems in my left hand. I couldn't even pick up the cup off of my table to drink. My fingers just wouldn't do what I wanted them to do. But that went away after about two weeks. Now my hands are back to normal. So as of now I have no memory problems, no muscle coordination problems, no vision problems. I've been very fortunate and happy with the outcome.
Kelly Cervantes:	26:17	Do they know why or what was causing the seizures?
Daniel Allbeck:	26:19	That was always my question. It still is my question. They don't know. My newest neurologist, she said that the most likely thing is that I've had it my whole life and it just didn't manifest itself until I was 22. And so then that question is, well, what made it take that long to manifest? And they don't know.
Kelly Cervantes:	26:37	Paula, in all of the research that you've done and advocating for your son with his doctors, what advice do you give to other parents and to patients, as well, to best care for and advocate? What do you wish you would've known?
Paula Allbeck:	26:57	So there's so much that I would say, but I will tell you that the most important advice I think I can give to a patient or to one who supports an epilepsy sufferer is absolutely seek out an epileptologist, a neurologist who specializes in epilepsy. That has been of critical importance. And if at all possible seek out that epileptologist at a comprehensive epilepsy center. That's just been critically important to Daniel's improvement.
Kelly Cervantes:	27:37	Absolutely. David, do you have anything that you want to add to that?
David Allbeck:	27:44	Well, I think, Paula and I are pretty unified in this and I think what she said about looking for an epileptologist is important, because some of the neurologists, even though they're good at what they do, they don't really understand epilepsy the way that I think epileptologists do. And so I think that was huge.

That made a big difference in the treatment and the directions that we went.

Daniel Allbeck: 28:08 My dad and mother, absolutely right. It was the epileptologist, the specialist in epilepsy that made the difference. The first epileptologist I visited was the one that put me on Keppra. So he was the first one that I really saw any dramatic improvement. And then the second epileptologist that I started seeing was the one that recommended brain surgery. So they were the only ones that really took proactive steps to help me.

Kelly Cervantes: 28:39 What advice would you give to someone who was considering surgery?

Daniel Allbeck: 28:41 My advice would be seek out epileptologist, just like we said, because that's the person you're going to get the most useful information from. But then you really need to decide for yourself, weigh the risks and benefits. How bad is your epilepsy? Like I mentioned earlier, I was very, very skeptical and hesitant to do it. What drove me to do it was the increase in severity and plus all the information we gathered, especially my parents.

Daniel Allbeck: 29:14 And that would be something else that I want to say to people with epilepsy is be proactive in your own research to help yourself. My parents did a lot more work for me than I did for myself. So I would say if you're considering surgery, make sure you talk to multiple experts. And then after you hear what they have to say and the risks of the surgery, then you have to decide for yourself. Am I happy with my life? Am I content? Or am I struggling? Is it affecting my life? And if it is affecting your life in any negative way, I would say if your surgeon recommends it, then you should do it.

Kelly Cervantes: 29:54 Daniel, I have to ask, how is your seizure management now after brain surgery? You're six months post-op.

Daniel Allbeck: 30:02 So for those listeners that don't know, my surgeon said that if I go six months without having a grand mal seizure, that he will consider it a success. Because the surgery itself, they told me right off the bat, this is not going to get rid of all of your symptoms. The goal is to get rid of the grand mals. You're probably still going to have smaller episodes your whole life, which we'll have to use medication to treat.

Daniel Allbeck: 30:27 So I have not had a grand mal since the surgery. That's great news. I still do have some of the smaller, I'll get muscle twitches, sometimes I see flashing lights in my left eye, or I'll

		even lose left peripheral vision. But those only last a couple minutes max. And the grand mals haven't happened yet. Knock on wood because at six months they said, we're good. But I think that no matter what, I'll be worried about it or it'll be on my mind my whole life, the possibility exists. And the doctor even said, there's no 100% guarantee that you'll never have one again, but at six months we can be confident and call it a success. So I think that's tomorrow.
Kelly Cervantes:	31:07	Eek. All right, well, I am crossing my fingers, crossing toes, crossing everything that you continue to be tonic-clonic free and move forward in finding some stability in your life. I am just so grateful, Daniel, Paula, David, for chatting with us today, for sharing your experiences and walking us through your diagnostic and surgical journeys. Thank you so, so much.
Daniel Allbeck:	31:37	You're welcome.
Kelly Cervantes:	31:40	Thank you, Paula, David and Daniel, for sharing your epilepsy story experiences and insights with us. The surgery that Daniel underwent would not have been possible a decade earlier. Scientific advancements can vastly improve quality of life for those living with epilepsy. That is why CURE Epilepsy has been funding epilepsy research for more than 20 years. We know that the research being conducted today will lead to a better life tomorrow for those living with epilepsy. Please help us advance epilepsy research by visiting CUREEpilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
Brandon:	32:29	The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. 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 Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.