

Seizing Life, episode 63
Raising A Child with Both Autism and Epilepsy
(Transcript)

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and this is Seizing Life, a bi-weekly podcast produced by CURE Epilepsy.
- Kelly Cervantes: 00:17 Today, I'm excited to welcome Liane Kupferberg Carter to the podcast. Liane is a journalist whose articles and essays have appeared in numerous publications, including The New York Times Parenting section, The Washington Post, The Chicago Tribune, The Huffington Post, and Parents. She is also the author of the memoir *Ketchup is My Favorite Vegetable: A Family Grows Up with Autism*. Liane's son Mickey was diagnosed with autism when he was five years old and several years later received an additional diagnosis of epilepsy. Liane is here today to talk about her family's journey with autism and epilepsy and the connection between these two often comorbid conditions.
- Kelly Cervantes: 00:56 Liane, thank you so much for joining us today to talk about this incredibly valuable topic. I think this is going to be a really interesting conversation for so many of our listeners. I want to start by finding out how epilepsy first entered your and Mickey's life.
- Liane Kupferberg Carter: 01:16 Well, we didn't see it early on with him, but he was already in early intervention for other issues, and around the time he was five, he was at his play therapist's office and just just started to stare, became unresponsive, and then sort of slumped backwards and looked like he was passing out. Skin went gray. We weren't sure he was breathing. It was really terrifying. We called 911. By the time they got there, he was breathing and beginning to come out of it, but we got in the ambulance, we went to the emergency room where he dozed.
- Liane Kupferberg Carter: 01:51 At that point, they didn't know what it was, so they recommended we speak to a neurologist, which we did, and he hospitalized us for 48 hours for a video EEG. At that point, he said that he couldn't make a diagnosis of epilepsy, although from the activity he saw that perhaps Mickey was more prone to seizures. Then, we didn't see anything again until he was seven and something similar happened. We called the pediatrician, ran over to the doctor's office. By the time we got there, he was already coming out of it and the doctor said, "Oh, I think it was just syncope, you know, he fainted," but this looked different than fainting.
- Liane Kupferberg Carter: 02:36 We didn't really see anything until he reached adolescence. Around the age of 12, again, he was working with a tutor at

home one night and she came in and said to me, "You know, he's playing this funny game. He won't talk to me." My heart sank. I just knew something was going on. I ran in there and I found him eyes locked to the side, rigid, not moving. Called to my older son to run next door to get my neighbor who happens not only to be a physician, but has a child with seizures. She came over. Even by the time she got there, he was still locked in that rigidity with the eyes to one side. Then, he heaved this huge sigh and it was like a puppet being let loose. Just suddenly the strings dropped and he collapsed. Then, at that point, he came back to himself.

Liane Kupferberg Carter: 03:28

Again, reached out, found a different neurologist at NYU. We hospitalized him for about a week for video EEG, and at that point we finally did get a diagnosis that he had epilepsy in addition to autism. Looking back when he was little, I think we were seeing Absol seizures. At the time he would just go blank for a few seconds and not answer if you called him. When I brought that up to therapists they would say, "Oh, that's just autism," but looking back now, I don't think it was.

Kelly Cervantes: 04:04

Give us a little background on Mickey's autism and how you came to that diagnosis as we sort of move into talking about this comorbidity.

Liane Kupferberg Carter: 04:14

Well, I'll try to condense it and give you the Reader's Digest version. Again, did not get a diagnosis on that one until fairly late. I, as a Mom and not a first-time Mom knew something was amiss. By the time he was nine or 10 months old, he wasn't hitting certain developmental milestones, things like, how big is the baby? He didn't point. He wasn't imitating, but that seemed to be all it was at that point because he was engaged, he was funny, lovable, he smiled a lot, but something just felt amiss.

Liane Kupferberg Carter: 04:53

It was a qualitative thing rather than quantitative, and every month when we would have our monthly checkup at the pediatrician, I'd bring it up and he would tell me, "No, no. He's fine. He's still within normal parameters. Don't compare him to your older son. Boys talk later." It wasn't until he was 18 months old and still not speaking and I said the doctor again for his 18 months checkup and he said, "Okay, now maybe it's time to go for a speech evaluation."

Liane Kupferberg Carter: 05:24

We did that. Yes, there was a speech delay. We started to address that. Nursery school suggested we explore a little further. We got a referral to a very well-known medical center here in New York. We went for what they call a comprehensive interview. They put him through all of the paces, psychological,

physical therapy, occupational therapy, speech. Ran the gamut, exhausted him, and at the end of that, and it was pretty brutal, the head of the team sat us down and said, "Don't expect higher education for your child." It was like peering into the abyss. We didn't know what that meant. We brought this sparkly, happy, loving child in and then to be told something like that... I should add this was the early '90s. I think not a great deal was known about autism at that point and they did not diagnose him with autism. They just said, "Communication disorder."

Liane Kupferberg Carter: 06:27 Then, we found our way to an expert down in Bethesda, Stanley Greenspan, who was at the time the preeminent psychiatrist for treating these kinds of disorders. He spent four hours with us. Videotaped us playing, which was a little uncomfortable. Made me feel like we were flunking play 101, and then at the end of that he gave us several diagnoses, none of which were autism. He called it static encephalopathy, multisystem developmental delay, but he did outline a very ambitious program of therapy and said, "You don't know how high he's going to go until he reaches his ceiling, and that's true of any child, so don't compare him to your other child."

Liane Kupferberg Carter: 07:13 Really, it was a wonderful visit because he kind of gave me back my hope, but again, no firm diagnosis and it wasn't until Mickey had that seizure in the therapist's office when he was five. At that point, the neurologist said that he had PDD NOS, Pervasive Developmental Disorder Not Otherwise Specified, which is a form of autism. That was really late in the game and, again, I have to stress it was the '90s. Not as much was known and I don't know that that would happen today. I think they'd be a lot quicker out of the gate to diagnose.

Kelly Cervantes: 07:51 Well, we know that one-third of people with autism are at a much higher risk for developing seizures and epilepsy. When Mickey received his ASD diagnosis, was epilepsy mentioned to you as something that you should be on the lookout for?

Liane Kupferberg Carter: 08:08 Never. Nobody ever mentioned it to us, which is shocking looking back. I will say that, again, it was the '90s and not as much was known about autism. What most people knew at that point was the movie Rain Man or there was a character on that TV show St. Elsewhere, but nobody knew people with autism, at least not in my extended circles. I don't know, maybe they had not really correlated the prevalence at that point. That's the only reason I can think of because, no, nobody ever, ever mentioned it to us. I wish they had.

Kelly Cervantes: 08:49 Do you know if that has changed? Is there any push within the autism community for there to be more discussion or more warning to parents to be on the lookout for seizures and epilepsy?

Liane Kupferberg Carter: 09:04 That's a great question. I don't know if there is officially. Certainly, I see it because I get phone calls frequently from parents of much younger children who are diagnosed and looking for advice. I am asked about that now, so I think there is a general awareness in the autism community about the prevalence, but as to whether the clinicians are really sitting with families down and saying, "Hey, look, this is what you have to be on the lookout for," I couldn't answer that. I hope so.

Kelly Cervantes: 09:35 I hope so, too.

Brandon: 09:40 Hi, this is Brandon from CURE Epilepsy. An estimated 3.4 million Americans and 65 million people worldwide currently live with epilepsy. For more than 20 years, CURE Epilepsy has funded cutting-edge, patient-focused research. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.

Kelly Cervantes: 10:04 It's not until adolescence, he's 12 years old when he officially gets that epilepsy diagnosis. What treatments did you try? Did they work? Have you found a successful treatment?

Liane Kupferberg Carter: 10:17 That's still a work in progress. We've found that medication is more of an art than a science. We started him on Lamictal. It seemed okay for a few weeks. Then, it was actually his 13th birthday. We went to the movies. We went to see Willy Wonka & The Chocolate Factory. We were perhaps sitting maybe a little too close to the screen and there was a lot of flickering and a lot of colored action going on. Just towards the last five minutes of the movie, suddenly he pulled to the side and had a tonic-clonic with me holding him.

Liane Kupferberg Carter: 10:54 It was horrifying. It was the first time I'd seen that. Lasted perhaps two minutes, although it felt like an eternity, and then when he came back to himself, one side of his face looked paralyzed. He was talking out of the other side and we waited until that passed. Interestingly, nobody in the movie theater around us noticed or looked, which I felt like my life had been splayed open and nobody noticed.

Liane Kupferberg Carter: 11:26 Eventually, we got him out of there. We got him home. Spoke to the doctor who then added Keppra to the mix. That didn't work

very well. We had side effects with that, agitation, anger, so again, back to the hospital. We spent another week at NYU. They weaned him from that medication, added another medication. Long story short, we cycled through several meds at this point. He's currently on three and he still has breakthrough seizures. They're partial complex. He has not had a tonic-clonic... Well, actually a year ago he did have one. He spiked a fever of 103, which is why they believe that happened. Now, they come maybe every four to six weeks. We will see a cluster, and then he's fine again until the next one.

- Kelly Cervantes: 12:25 It's a frustrating beast, indeed, the not knowing. Are there any considerations around treating epilepsy for someone who has autism that need to be taken into thought?
- Liane Kupferberg Carter: 12:42 That's a complicated question because there are no medications that are specific for autism except really to treat anxiety, which he certainly has a great deal of. I think perhaps the two feed on each other, that he's already gotten a heightened sensory system and more anxiety, and I think the unpredictability of the seizures is very hard on him and on us. I think that one sort of... it kind of scaffolds on each other and it does make it complicated. Sometimes we'll see a certain kind of behavior pattern before a seizure where he's a little belligerent, he's cranky, he's irritable, and people [inaudible 00:13:28], "Oh, that's autism," but it's not with him. It does really seem to be an indication, but it took us years to figure out that correlation.
- Kelly Cervantes: 13:37 Well, and to that point, some of the behavioral characteristics or communication patterns, intellectual disabilities, as a parent, how do you decipher what symptoms and side effects are a symptom of the autism or a symptom of the epilepsy? I imagine that a lot of them look the same, or does it matter?
- Liane Kupferberg Carter: 14:11 I think ultimately it doesn't matter because I respond the same way. Again, he's got that heightened sensory system. As a baby he had a lot of sensory issues and I think when there's some sort of discomfort in his body and he can't articulate it, he'll act on it. There's a very popular saying in the autism community, which is, "Behavior is communication," and sometimes when he can't access the words, it's really up to me to decipher what it is he's trying to tell us with the behavior.
- Kelly Cervantes: 14:45 That makes sense. We've talked a lot about stigma and epilepsy on this podcast. What are some of the pervasive stigmas that you see around autism?

- Liane Kupferberg Carter: 14:55 Probably the biggest one is this idea that people with autism have no empathy, that there's a flattening of affect. Now, there's also another popular saying in the autism community, which is, "Once you've met one person with autism, you've met one person with autism."
- Kelly Cervantes: 15:13 I [crosstalk 00:15:14] like that.
- Liane Kupferberg Carter: 15:16 I can only speak for my own child, my own life experience, and the empathy I would say is probably the biggest misconception out there. I think there's a lot of fear. I think naturally it's human nature to fear what we don't know, we're unfamiliar. Certainly, I saw after we got the epilepsy diagnosis where suddenly play dates that he would go on, the other parents became nervous, and one in particular wouldn't agree to play date unless it was either at my house, or if it was at her house, she wanted me to stay at her house. I understand that. My older son has a severe life-threatening food allergy and I know that when he used to go to friends' houses for play dates, there was a lot of conversation about what to feed him, what to do. Where was the EpiPen? I get it. I do. I get that fear aspect.
- Kelly Cervantes: 16:14 You've mentioned your son a couple of times. Having a sibling who requires a lot of additional attention can be difficult. In what ways have you and your husband changed perhaps your parenting styles or been there for your older son to make sure that he was getting what he needed as well and not feeling left out?
- Liane Kupferberg Carter: 16:42 Yeah. I think that's inevitable whenever one child has special needs. You have to make a very conscious effort to spend as much time and attention and energy as you can a not-affected sibling, and not affect is really a misnomer because, of course, he's affected by his brother's condition. The thing about siblings is I think they're kind of the unsung heroes of autism. They grow up in waiting rooms far too soon, but on the flip side of that, they do learn so much compassion and kindness. I think it was really... The hardest time I would say was probably the teenage years, which are hard no matter what, but what we found was our older son didn't want to bring friends home anymore.
- Liane Kupferberg Carter: 17:35 Prior to that, it had never been an issue and he was really his brother's fiercest champion, but in high school I think some embarrassment about being different had crept in. That was difficult and it was also difficult when he took high school biology and came home one day and said, "Well, how do you know that I won't have a child with these conditions?" The truth is we don't know. What I think I said at the time was something

like, "We Spit for Science. We give blood. We enter every possible test, every study, every protocol and we support these organizations and hope that by the time you are ready to have children of your own that maybe we will have better answers, maybe genetic answers."

- Liane Kupferberg Carter: 18:28 I think at the time that did seem to comfort him. I'm sure it's still on his mind. He's engaged to be married in a few months and, of course, it's got to be on his mind. How could it not be?
- Kelly Cervantes: 18:41 Now, have you done genetic testing for Mickey to see if you can find a genetic diagnosis?
- Liane Kupferberg Carter: 18:48 We have. We to date have found nothing. We've done Simons Simplex, CGI, several studies at NYU. Still happy to keep spitting and giving blood, but nothing has turned up yet. They found one chromosomal deletion or one spot on a chromosome and turned out my husband had the same deletion, and the doctor said it didn't seem to be a significant part of the genome. They didn't think it was anything, so we're still waiting.
- Kelly Cervantes: 19:24 I know that path all too well. You mentioned in the past about how you actually feel that Mickey as an adult now that the epilepsy is a slightly more challenging part of his life than the autism in some respects. Can you speak to that?
- Liane Kupferberg Carter: 19:47 We've put in a lot of time now with autism. I feel like we have a pretty good handle on what works for him and how to make him as productive and happy as possible, but the thing about seizures is it's like terrorism. You never know where or when it could strike. We've seen it at the beach, walking across a parking lot, at a Super Bowl party. There's no rhyme or reason that anyone who's ever been able to discern to the pattern, so it's hard to live with. It's stressful for all of us. We're hypervigilant. One ear is always cocked listening to make sure he's okay. If he's in the shower, someone is standing nearby just in case.
- Kelly Cervantes: 20:38 How is Mickey doing today? What does a typical day look like for him?
- Liane Kupferberg Carter: 20:44 He's doing great. The pandemic was challenging. He was home for seven months, but I think we were very lucky in that sense because now that he's not in school, we didn't have to deal with any of the hybrid learning issues. Now, he attends a wonderful day program that we're thrilled with. As of last week, he's going five days a week. It's called Spectrum Designs. It started in Port

Washington, Long Island, New York, 10 years ago. It was started by some moms, as so many of these programs are, and the company piece of it, which is Spectrum Designs, they do branded merchandise. Anything you can put a logo on, t-shirts, hats, coats, anything.

Liane Kupferberg Carter: 21:34 In addition to that, there's a second prong to that. It's kind of a hand-in-glove situation. They also created a social service agency called The Nicholas Center and, really, one enables the other. The thing is, after the age of 21, you kind of go over the cliff and there just aren't... It's not like school. There aren't programs for our kids anymore, but The Nicholas Center, in addition to providing all of the vocational or the pre-vocational training that he needs to work at Spectrum, they provide a whole range of wonderful services. They work on vital work skills, they provide job coaching when he's actually working at Spectrum. They do life skills, social skills, peer connections, recreation, community partnership.

Liane Kupferberg Carter: 22:27 He's out in the community and he comes home happy and engaged and so proud of the work that he's doing. It's meaningful and he's making new friends. The people who work there, they have wonderful dedication and high affect and they're warm. It's just this wonderful, wonderful experience. We could not be happier with it.

Kelly Cervantes: 22:57 I love that so much. We need more programs like that one out there. You are so well-spoken and you have so much experience in both the autism and epilepsy parenting worlds. What advice do you have for parents who are newly-diagnosed, who are starting on this journey? What should they be keeping in mind?

Liane Kupferberg Carter: 23:24 Oh, gosh, so much. I would say to remind yourself that it's a marathon, not a sprint, so you really need to pace yourself. Self-care is very important and when I say self-care, I'm not talking about going to a wonderful spa for a week. I'm talking about the basics, getting enough sleep, eating well, exercising. There was a study done several years ago that showed that autism moms had stress levels that were similar to combat soldiers and they did this by measuring cortisol levels. I don't know, I know at the time I knew a lot about autism moms who said, "I don't know why they bothered studying it. They could have just asked us." There's a lot of truth to that. I would say that that would be the biggest piece of advice.

Liane Kupferberg Carter: 24:15 I would also say you are the expert on your child, not the doctors, not the therapists, not the teachers. They're all wonderful, or most of them are, but they go home at night, you

don't. You're in this for the long haul, so I think you really need to trust yourself. Trust your gut when something feels wrong. Find your fellow travelers because they are the ones who really, truly get it and they will shore you up and make you laugh. If you need a 2 AM run to the emergency room with your kid, those are the people you call.

- Kelly Cervantes: 24:53 Absolutely. I couldn't agree with any of that more. Thank you so much for taking the time to speak with us today and sharing your years of knowledge and experience. I do think that this is a conversation topic, the comorbidity between autism and epilepsy, that really needs to be discussed more and brought into the light. I don't think as many people realize how common and how intertwined the two diagnoses can be, so we just greatly appreciate your knowledge and sharing it with us today.
- Liane Kupferberg Carter: 25:30 Well, thank you for having me. This was great.
- Kelly Cervantes: 25:33 Thanks so much.
- Kelly Cervantes: 25:37 Thank you, Liane, for sharing your journey and experiences with your son, Mickey, and for your advice to others parenting children with special needs. The comorbid relationship between autism and epilepsy is common, but we still don't understand how and why one-third of those diagnosed with autism also develop epilepsy. Understanding this connection may be a key to unlocking some of the mysteries of both autism and epilepsy, but we will only achieve that understanding through research. That is why CURE Epilepsy is committed to funding epilepsy research. We hope that you will help us in our efforts to advance epilepsy research by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
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