

Seizing Life, episode 107
Unleashing Your Inner Mama Bear
Guest: Kate Neale Cooper
(Transcript)

Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy.

00:18 This week on Seizing Life, we present a special episode recorded live this past November at Epilepsy Awareness Day at Disneyland. Epilepsy advocate, mother and previous podcast guest, Kate Neale Cooper joined me for a discussion on advocating for your child's epilepsy care, an area in which unfortunately Kate and I have a great deal of personal experience. We spoke about our challenges in navigating our respective daughter's care and treatment. We offered advice in several areas including finding the right physician, doing research, asking for support, and dealing with schools and insurance companies. So with acknowledgement and respect to all of the papa bears out there who also advocate for their children here is unleashing your inner mama bear.

01:08 Thank you all for coming out today. I am sure, I know, I see mama bears and papa bears in the room too, for that matter. Having a child with a complex diagnosis brings something out of us that I don't think any of us knew existed within us. And all of a sudden we are thrust into this world and having to learn an entirely new vocabulary. And it can feel, I know I felt in the beginning, very isolated and alone and confused. And actually, my daughter was diagnosed with epilepsy the exact same week that my husband landed the role of Hamilton. He did it for a month or so on Broadway and then we transferred to Chicago. And I was like Chicago, Adelaide had just been diagnosed with epilepsy. I worked at a restaurant selling and coordinating events and I had done an event for this organization called Cure Epilepsy, and I remembered that they were in Chicago and one of my coworkers was like, "You should reach out to them. You're moving to Chicago. They're based in Chicago." And so I did.

02:22 I was like, "I don't know what I'm doing. I'm terrified. Can you please connect me with a mom who knows what they're doing?" And the folks at Cure actually connected me with Kate. So we have sort of had back and forth email exchanges for, well, Adelaide would've just turned seven, so probably going on six years now. Kate was my mama bear teacher.

Kate Neale Cooper: 02:50 I forgot that I was the first, I forgotten that I was the first person you talked to. I hope I said helpful things.

Kelly Cervantes: 02:55 You did. I feel like I went back to that email so many times. What advice do you have in those early days? I imagine that quite a few of you have gotten through some of those early days, but what is the advice that you give to sort of the newly diagnosed family? And when I say newly diagnosed, I think within the first few years because I think it's long learning curve, you think after maybe six months that you've got this figured out, but it's like it takes a few years to really get your ducks in a row.

Kate Neale Cooper: 03:32 For sure. I think in the very beginning, the most important thing is finding a clinician who can be your partner. And so for us, what that came down to is who treats us like a partner? Who's talking to us like we're their equal? Who's listening to our concerns? Who's pointing us in a direction with constructive ideas we hadn't thought about? So I think from the very start, it's identifying that medical partner and that's somebody who treats you like their equal.

Kelly Cervantes: 04:04 And I think that can take a few years. I know we went through at least three doctors, epileptologists before we found the one where I was like, okay. I mean we were over a year into the journey before I was like, okay, this is our guy. And I took Adelaide all over the country to try and find that doctor. We ended up finding him in Chicago where we lived, which was great. But it is, it's tough. And I think we were talking earlier and I don't know how many times I have mom and dads reach out to me, grandparents, and they're like, "My kid had a seizure and now it's going to take three months to get in to see the doctor," or six or nine. And I always say, "Make the appointment with that doctor, but hopefully there's more than one doctor, more than one hospital, more than one care center."

05:00 I will always want to give that advice, epileptologists, try and get in somewhere else. Even if you think that this is the best place, try somewhere else just to get in somewhere and keep that other appointment because get second and third and fourth and fifth and sixth appointments. Talk about they all tell you something different. But hopefully eventually one of them says something that fits. But I also found that to be true... Unfortunately, epilepsy doesn't like to come alone. It likes to tag along with other issues, be them mental health issues or my daughter had mass cell issues and pulmonary issues.

05:38 And so that works across the board, I think find your team, find the right doctor, find the doctors who can work together because oh my God, it's exhausting being a quarterback and having to manage all those specialists. If you can find specialists

who are willing to work together outside of you and to loop you in, that to me was... When we found an allergist and an epileptologist that could work together on a treatment plan that elongated my daughter's life by at least a year.

06:13 So you found your doctor, you found your team. It could have taken years and years. I've heard so many horror stories over the year, but hopefully you find that person that you can trust that responds to you and a response time should be within 24 hours. I know that maybe is not the way that it is across the board, but if you call and you shouldn't be afraid to call, Kate was saying that she, we were talking earlier and she was saying that she can still has the phone number memorized.

Kate Neale Cooper: 06:53 The on call. I haven't called it in years, but their job is to answer my call. And so if I need it, I call it.

Kelly Cervantes: 06:59 And so never be afraid to call, never be afraid to ask those questions. There is no such thing as a stupid question. And sort of along with that goes, unfortunately, we like to place a lot of trust and hope in these medical practitioners and clinicians and when we say that you found the right doctor and they feel like the right person and it's the right team, that doesn't mean that they have all the answers. And unfortunately, in order to get our children or ourselves the best care, there's a lot of education that we have to do for ourselves. I've found over the years, we can't rely on the medical professionals. Kate, what kind of research did you do to try and what didn't we do?

Kate Neale Cooper: 08:00 There were so many different adventures in research in the Cooper household. One of the things that I found that I just want to recognize because I'm sure a lot of people in this room feel this, is I tackled epilepsy in the 17 years that my daughter had seizures. And in that time she had about 15,000 seizures by our account, on medication the whole time, which just never could get full control. But I found that I would throw myself into something like, yes, we're doing the ketogenic diet and she has to be hospitalized. I have to learn this, I have to do this. We try that for three months that didn't work and I was so emotionally exhausted that I would have to take a break and maybe for six months I did nothing. I mean, we were just doing whatever medication they were giving us.

08:45 It wasn't working and I was just recovering from that effort. And so I really want to recognize this is exhausting work. And do not beat yourself up when you think I need a little timeout after that big effort and then I'm going to feel better and then I'm going to come back and I'm going to try the next thing. But you

cannot do this 24 hours a day for a lifetime. It's just exhausting. So take a break, take a breather, and then go back out there. So I mentioned the ketogenic diet. That was one where I did a lot of research, found the Charlie Foundation that I saw as here today, was a game changer to have their help, just did a ton of research about how that food situation would work. And again, we had a great relationship with our epileptologist at the time, but when I called him, he had always said, "No, no, you don't want to do that, it's so much work. It's so much work."

09:34 And I kept listening and finally I remember calling him and I remember exactly where I was sitting and I said, "I want to do the ketogenic diet and you're going to tell me it's too much work. And when you say that to me, what I hear is I don't understand what you're going through." And I said, "So you can tell me where you would like me to consider admitting her and we're admitting her." And he was like, "Fair enough, here are the two places I'd like you to look at."

09:56 But I just needed him to know, you have no idea what it's like to be me. I get that you're a doctor, I get that. You see this. The very first time Virginia was in the hospital, she was having seizures every seven minutes out of the blue, just this perfectly healthy baby started having seizures.

10:12 And I was waiting and waiting for the doctor to come and he came and she was thrashing around in the crib having a seizure. And he just kept talking. And I said, "Excuse me, excuse me, will you please stop for a second? I mean her head's hitting the metal bars." And he said, "Oh, don't worry, I live in this world." And I said, "No you don't. You are visiting. I now live in this world and I need you to stop talking for a minute." Granted, I mean, needless to say, we were not with him for very long. We were not friends. We did not see eye to eye. But the point of that, we're the ones who live in this world and we're the ones who have to do the research at least to get started. I'm not saying I know what an epileptologist knows, but I also don't like being spoken down to.

10:56 So between the ketogenic diet, I did a ton of research. That did not work, but we all just want to be able to say, at the end of the day, I did everything I could. That's our job. I just did everything, that whatever my child's potential is. I did everything I could to help them live up to that potential. When we eventually went the brain surgery route, I mean we tried when she was eight and we couldn't localize a focal point, so we couldn't do it. We revisited it in her teenage years and the first level four epilepsy center we went to said, it's just not possible.

They did an SEEG and everything, which is an invasive diagnostic surgery. They said, "We can't find it." But they were very dismissive of my follow-up questions and I just really felt like you are missing something. Like these seizures look the same every time, doesn't that mean they're coming from the same place? Sure enough, we went to another place a few months later and a few months after that she had brain surgery and never had another seizure.

11:52 I mean, it's not all sweetness and light. There are a lot of problems after you have 16 years of seizures. But I would not have known to push that hard if I had not been doing the research.

Brandon: 12:07 Hi, this is Brandon from Cure Epilepsy. Did you know that 30% of those diagnosed with epilepsy do not respond to current medications? That is why for over 20 years, Cure Epilepsy has been dedicated to funding patient-focused research to find a cure for epilepsy. Learn more about our mission and our research by visiting cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: 12:33 To that angle, it takes a moment to find your feet and your confidence in those rooms with the doctors. And you'll hear, I mean, if I had a dime for every time someone told me, well, your child best. And I think there's a lot of pressure in that statement. It's true. No one knew Adelaide better than I did. However, the pressure that comes with that, with knowing that you're the one who knows them best, it's heavy. It's work, it's heavy, it's a lot. And I think it's important to recognize that and cut ourselves some slack.

13:17 We have to have the fight and we have to go toe to toe. And I think one of the ways that I found it was easier to be able to do that was when I spoke in their lingo. When I talked the medical legalese, the medicalese if you will, all of those words, febrile instead of fever or secretions instead of spit, it's silly, but you listen to the terminology you use and when you spit that back out at them, they respect you more because you're talking their language.

Kate Neale Cooper: 13:56 Sort of circling back as I'm thinking about it, I wanted to touch on the research piece and knowing all there is to know, I mean obviously everyone is here and that is huge, but doing, you don't know what you don't know.

14:14 I'm thinking about the M-E-G that Virginia had and that was how they figured out. But there's only 17 of these machines in the country. So not this isn't an MRI, not every hospital has one.

So you don't even know what tools are out there that you can request unless you're doing the research to figure that piece out. So whether that is joining the Facebook mom groups, sometimes they can be a little dramatic and challenging, but there can be some good information in there. But finding the podcast, Seizing Life, find the sources of information where you can go because sometimes you do have to advocate. If your child isn't seen at a hospital that has that equipment, then your specialist is not going to potentially order it.

15:19 A lot of us have had genetic testing done, but do you know how frequently you can get it done? You've had whole exome sequencing, but have you had whole genome sequencing? And there's all of these different levels and layers to all of these tests and you have to ask for a lot of it. And if you don't know what to ask for, then you're taking a step back.

15:45 And then not only do you have to ask for it, you have to fight for it because you may get dismissed and told that that is not necessary, in which case go find someone else who will give it to you, ala the ketogenic diet or the surgery or whatever it is.

Kelly Cervantes: 16:02 Exactly.

Kate Neale Cooper: 16:04 We can't take no for an answer and that is exhausting and that is exhausting. Virginia, so we ended up with the MEG through a research study we were pursuing yet another hospital, yet another expert. And they said, we have these various studies going on that she might benefit from. And I'm just a huge believer in participating in research because it benefits all of us. And so we said yes to it and that's ultimately how they were able to figure out where her seizures were coming from. And then eventually to operate.

Kelly Cervantes: 16:34 There is a ton of amazing research going on and there are studies and trials being done. If you go to the Cure Epilepsy website, there is a link where you can go and see all the different medical trials, medication trials that are going on, different things that are coming down the pipeline. The research is amazing, but once it gets to the patient phase, they need patients to test it. So look into that, seek that out, find out what's going on. And those can be incredible resources and it helps push science forward for all of our families, which is inspiring and incredible and I would also say, if you looked at something three to five years ago, look at it again. Bring it up again. Find out what's going on. Have things changed And now like you were talking about with the surgery.

Kate Neale Cooper: 17:30 We were told on multiple occasions that our daughter was not a candidate for surgery or that the surgery was going to involve a craniotomy, it was going to be incredibly invasive. And Kelly and I have laughed about this before, but when my daughter finally had her surgery, she had two tiny holes drilled right here. And I was telling Kelly, we've had more stitches at a birthday party. It was nothing. I mean, again, not everyone qualifies, but it was so different than what we had been told for so long. I mean, two tiny little stitches. I mean I could not stop staring at them when she came out and that was it. And again, it was 16 years, that was not it. I'm oversimplifying, but it was not the surgery that had been described to us when we started going down that path. Everything had changed in just a matter of a few years.

Kelly Cervantes: 18:16 Switching gears a little bit to sort of more personal social educational, my daughter passed away at four, so we did not reach school age, but I've spoken to so many parents over the years who have been through this and I'll speak to it a little later in regards to my son who was around for all of it. But what was your experience with Virginia in school, in managing her epilepsy in an educational environment?

Kate Neale Cooper: 18:49 Yeah, it was really interesting. We all know epilepsy is this tragically underfunded disease and teachers know almost nothing about it. And so what I ended up doing as a parent was educating teachers. So I built a presentation deck, it's in Keynote, but I can export it to any format, anyone who needs it, I will send it to you. And the whole first half is just educating them about epilepsy in general. They don't understand that it's a spectrum disease. They don't understand all the different ways that seizures can physically manifest. They don't understand how underfunded it is. So what I would do is basically kindergarten through six, she's got one teacher. I would meet with that one teacher and explain, although I say that actually we would get the music teacher, the gym teacher, and I would go there during the first week or so of school, after school, I would present it, answer questions.

19:41 So the first half was epilepsy in general, and then the second half was my daughter specifically, here's what Virginia's seizures looks like. She has them every night between 3:00 AM and 6:00 AM. She may be very tired, we're not asking for special treatment, but we want you to know where we're coming from. You do not need to call 911, please don't call an ambulance. You don't even really need to call me. But just educating them about what to expect, showing them videos of people having seizures, that went a really long way.

20:10 First of all, they realized how little they knew, but I also felt like after that I would have teachers call me and say, there's this kid in my class that we thought had ADHD and now I'm realizing I think he's having those absence seizures. Or I met a woman at a cocktail party the other day and her kid's having seizures and they can't get a doctor's appointment, can she call you?

20:30 So doing that outreach to the teachers proactively really, really helped. And we also always did the seizure plan. It's all on one page, here's what to do. Because generally we find that people don't know what to do when someone has a seizure and they either do something wrong and stick something in their mouth or they call an ambulance when you don't need an ambulance. So educating them about what the steps really are. And then in terms of socially, I had to bring a few parents into our confidences. When she was little, I just told everybody whatever I wanted. But once she was 13, it was her story to tell. And with her permission I would say, you need this person as your ally and can I tell this mom or this dad that you're spending the night with what's going to happen? But it gets really hard in the teenage years. I mean really hard.

Kelly Cervantes: 21:21 What I can speak to in terms of the educational and the social, we did a lot of education in my son's class because siblings are drastically affected by this. Right? Unfortunately, for four years of my son's life, he had to sort of take the backseat to his sister's life because it was emergency after emergency, hospitalization after hospitalization. And it would be very difficult for him to have friends come over to the house. There was medical equipment or if she was having a seizure. And so what we found, the best way that we could support him is I would have a conversation with his teacher, just request to have the phone call. I would have a phone call or go in person, it's too long to email. And I would give them a heads-up that I needed their phone number because I would text them and let them know if someone else was going to be picking Jackson up from school that day, if Adelaide was rushed to the hospital and I needed to have someone else step in.

22:33 So I always had a rapport with his teachers in regards to that. And then I would also request that we could come in to the classroom and we would bring Adelaide with us and we would talk to the kids in his classes. We did this in kindergarten, first and second grade. And we would talk to them about epilepsy and about seizures and her various equipment. She had a G-tube and she eventually got a VNS. We'd talked to them about what an EEG was all in very kid-friendly terms. But the amazing thing about it is then when my son's friends saw Adelaide at

pickup, they would come over and they would say hi to her and they understood that she wasn't verbal, they understood that she wasn't mobile and they accepted her for who she was, and because they accepted her, my son then felt more accepted also because no one was whispering or saying anything negative to him about his sister or behind his back about his sister.

23:33 They had been informed, and that's all children need. They need to be taught empathy and they need to be informed on what is going on in the world around them. And I had so many parents outside of come and thank me for doing that, but it was all for Jackson. And that was just so incredibly beneficial. And the cool thing is now is that even after his sister has passed away, he always, on one of the many epilepsy awareness days in a year, he asks to talk to his teacher and will do a little presentation still about epilepsy.

Kate Neale Cooper: 24:09 That's awesome.

Kelly Cervantes: 24:09 Because he wants people to still know about it. And this is still a huge part of his life and he's still a part of this community. And so I think that recognizing that we have a lot of times we have more than one child in our family and there may be the one child that has the epilepsy, but the entire family is impacted. Another thing that I did for my son is that he has been in therapy since he was six years old. Just having that person to talk to who's not my husband or I, was incredibly beneficial for him because he did, he got angry that we weren't always around and that he never knew who was going to pick him up from school, and so having that outlet for him was incredibly beneficial as well.

25:07 So I think that all of that, there can be a lot of pressure that we put on ourselves when we're caring for our child with epilepsy, but there are all of these other moving pieces in our lives as well. And taking a breath and stepping back and seeing what we can do for the grander picture is going to help us down the road, it's going to help. I feel like my son is more emotionally balanced now than he probably would've been had we not had him in therapy earlier. He was able to handle his sister's passing and all of those things. I mean, it still sucked, but a little smoother and a little healthier because we don't get to just be the parent to a child with epilepsy.

Kate Neale Cooper: 26:00 Yeah, that's great.

Kelly Cervantes: 26:01 It's a whole family thing. All right, what do we have next? Insurance. Everybody's favorite fight. Do you have any fun insurance stories, Kate?

Kate Neale Cooper: 26:18 We didn't have too many nightmares. Just a couple of thoughts on insurance in general. Don't assume that something isn't covered. I mean, again, for our daughter's ultimate brain surgery that was three separate, well sort of three separate out-of-state trips. And I had no idea. I thought, is this even possible? I was shocked to learn, oh, they're in network, we're in Virginia, they're in Texas, but somehow they're in network. So don't assume, don't give up before you even check. It might be covered. Then the second thing is when something gets denied, don't ever take no for an answer. Just resubmit that puppy. There's never like, oh, that's nice. Okay, do it again. Yeah, and you could change nothing and the next time they accept it. And again, I'm not advocating anything illegal, just sometimes it isn't coded correctly. Sometimes they're not looking at it. So if the doctor forgot some weird piece of documentation, find out why it was denied, talk to your clinical coordinator and find out what they can do to resubmit. We can't ignore the reality of the limitations of insurance, but make sure they're real before you assume that they exist.

Kelly Cervantes: 27:35 Request that doctor to doctor call. A lot of insurance companies, they may deny you the first time and then if you call the insurance company, you can request to talk to one of their medical professionals and your doctor can talk to one of the insurance company doctors and they can have the verbal conversation explaining why this is necessary, and a lot of times you can get a lot further going that route also.

Kate Neale Cooper: 28:05 And that goes for pharmaceutical coverage too.

Kelly Cervantes: 28:06 Absolutely.

Kate Neale Cooper: 28:07 Because they're like, "Oh, well this is also an epilepsy drug." And you're like, oh, that's, that ain't going to work. They think you can just change drugs or the generic may not be the same thing. That applies to pharmaceuticals, procedures, everything. And then also with these complicated cases where you have to travel out of state again, think about the fact that if the service you're looking for is not available in your network, they might have to cover it because it isn't available in your network. So again, that's another thing. And most of these hospitals have clinical, I mean many of you probably already know this, but they have clinical coordinators who can help you figure that out, how to present the case, how to explain it, and provide the

documentation you need to show we have this thing that your hospital and in fact no one in your network does, so you need to cover Adelaide or Virginia going to get this.

- Kelly Cervantes: 29:01 Well, and as you're talking about all of the... Find out what supports your hospital does have, because I think you'd be surprised how much support exists that you may not even be aware of. So we had become frequent flyer members at the hospital and the social worker came in and she was like, "Do you know that we can help you get home nursing?" And I was like, oh, well I full-time taking care of Adelaide at home. And I was like, "Well, we don't need home nursing." And she was like-
- Kate Neale Cooper: 29:36 I don't need a break.
- Kelly Cervantes: 29:38 She was like, "Yes, you do, Mama, you do." And I was like, "Well, I don't even know if we qualify." And she sat there and even though she was the social work in the hospital, she helped me even once we were discharged to help get home nursing in our home, walking me through, we were denied the first time, which was insanity. Or I think we were given 10 hours. And I was like, awesome. Then she helped us refile it and we ended up getting 40 hours of home nursing a week, which was life changing, you can take a shower. I got to shower.
- Kate Neale Cooper: 30:19 And have a meal.
- Kelly Cervantes: 30:20 40 hours away a week, I mean that's eight hours a day now that's still how many hours? It's still 16 hours that I'm on duty. And she had seizures round the clock, I mean, she did not care what time it was and with her breathing issue, so it was around the clock job, but for eight hours I could go to my son's baseball game or go to a parent teacher conference. And so those things make a huge difference.
- 30:49 So ask, what services are available, the care coordinators, the social workers can also help you fight for the drugs. My daughter needed a medication and our insurance had decided that only children under the age of two needed this particular medication and she was two and a half. And I was like, well... because the drug was for infantile spasms and she was no longer an infant. And I was like, "Well, guess what? She still has infantile spasms," she has hysarrhythmia, I don't care what you want to call it or how old she is. And they helped us fight to get it.

- 31:28 And so reach out to the hospital, call to epileptologist, find out what additional services are there, and maybe you don't need them now, but maybe you'll need them down the road. And just knowing that, having those phone numbers in your back pocket, those email addresses so that they are accessible to you, and thinking about what was your community and social supports?
- Kate Neale Cooper: 31:59 That's a great question and I haven't thought about that in a while. We live in a great little walkable neighborhood where all the kids kind of hung out together and we all went to the same park and we were friends with those people before Virginia was diagnosed, so we had a ton of support. And thinking about this, I'm going back to what you were saying about, you were talking about how hard this work is and how we have to admit that it's work. And one of the things that I've found along those lines is people tend to lionize like, "Oh, you're so amazing. Oh, you're so amazing." And it again, like you said, make it very hard to ask for help. And what we found really helpful is in the moments when we weren't in crisis, or as we felt a crisis approaching, we started making a list of the stuff that we needed help with.
- 32:47 So one point in time that was returning all these Netflix discs, which is not a thing anymore, so that's taken care of. Yay cloud. But it was also the dog has to be walked and if we're in the hospital who's walking the dog or we have these other children, Ned needs to be picked up, Gilbert needs to be picked up. So we started just making a list because in that moment when someone offered help, I was like, I can't think of anything.
- Kelly Cervantes: 33:10 No, in the moment you're in survival mode.
- Kate Neale Cooper: 33:13 So we just had lists and people want to help you. They feel so helpless. And so we kept a list that's and we actually changed our door so that it was a push code so we didn't have to hand out keys. There were a lot of people in Richmond, Virginia with a key to our house. So we finally just put the door code up and we would say, yeah, you know what? Actually we're still waiting for the neurologist on call. The dog hasn't been fed, can you please go feed her, walk her, the boys would love to go to a movie. Could you take him to a movie? So we just started keeping a list where we could ask for help. And it made it so much easier. The other thing we found was we never did a carrying a bridge or anything, but we would do a mass email at the beginning of a surgery situation.
- 33:59 So it would just sort of set people's expectations. So I wouldn't have to say the same thing to 25 different people. I would pick who the people were, who needed to know, here's an email.

And then often when we were doing big things like surgery, I had a chief of communications, it was my brother. And so I would communicate with just him and then he would communicate with the rest of the family. Because again, you talk about how it affects Jackson, it's also my parents. If I had to call my parents after surgery and say, "Well, she has a brain bleed, we're going to ICU," well then they were freaking out, then I was caring for them when I really needed to be focused on me and my kid.

34:41 My brother was a lot more even keeled. I mean, it wasn't that he wasn't concerned, but I would let him have that uncomfortable conversation with my parents, I had enough to deal with. So I had this appointed little chief of staff situation and I would just send him one text and I instructed everybody, "Jim will be communicating with you. I will not be able to answer your messages. I appreciate the love and concern, but we are going to be 100% focused on Virginia." Yeah, because you can't. It's exhausting. That worked really well for us. That was really helpful.

Kelly Cervantes: 35:13 I had a list of moms in the community that I could reach out to, and then there was sort of one who would rally the troop so I could reach out to her when we needed something, and then she would disseminate, she would send out a text to the mom, text chat and say, okay, they need X, Y, and Z. And someone would be like, okay, I can take Jackson here or there. We can take care of the dog.

Kate Neale Cooper: 35:42 You need a bat signal.

Kelly Cervantes: 35:45 But we cannot do this alone and I didn't have family around, so we didn't have a family support, so we had to make friends quick. And I was like really sexy and cool to be friends with Hamilton, but guess what? We're going to ask you for a crap load of favors and we are not going to pay them back.

36:06 I will get you tickets to see Hamilton and that is about all I can offer you. No, but you have to just ask for help and know that people love you and they're willing to help you and you have to suck up your pride. And that was really hard for me because I've always been sort of headstrong and independent and I can do this and I learned very quickly that I couldn't by myself. That just wasn't going to be an option. And so you have to ask for help. You just do.

36:33 This can feel isolating, but you are unfortunately, fortunately, not alone. There's an entire conference of us who are going

through something similar and take hope in that, take heart in that there is someone else who has gone through this before and there are people that you can reach out to, there are organizations that can help you. Go on social media, find those advocates, reach out to them.

37:01 I respond to DMs, find the people who can help and ask the questions and it's a pretty fabulous community. I will never forget. So Susan Axelrod founded Cure Epilepsy. Her husband is David. And one of the very first times that we met him, he came up to my husband and he said, "I am so terribly sorry that you are a part of this club, but we are so happy to have you here." And I will never forget that because it is a really crappy club to be a part of, but I have never met more amazing people than I have as came with my membership card. So thank you guys so much for coming and listening and wishing you all the best.

37:48 Thank you to Kate Neale Cooper for sharing her experiences and advice. And thank you to all who attended our podcast recording at Epilepsy Awareness Day at Disneyland. For 25 years, Cure Epilepsy has been dedicated to funding patient-focused research with the goal of finding a cure for epilepsy. If you would like to help us achieve that goal, please visit cureepilepsy.org/donate. Cure Epilepsy, inspiring hope and delivering impact. Thank you.

Legal Disclaimer: 38:29 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.