

SEIZING LIFE – episode 39
Parenting, Epilepsy and COVID19
Guests: Jessica Rosini & Beth Scolis

- Kelly Cervantes: [00:00](#) Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Citizens United for Research in Epilepsy, CURE.
- Kelly Cervantes: [00:19](#) Today, with the current situation amid the Coronavirus pandemic, we are bringing you Seizing Life in a slightly different way. Instead of our usual setting, we are observing stay-at-home orders and social distancing by recording our episode remotely. In these unprecedented times, we are all challenged to adapt to a new normal, but for those with epilepsy or other medical conditions that put them in high risk categories, there are additional challenges and concerns.
- Kelly Cervantes: [00:43](#) Today, we're talking to Jessica Rosini and her mother Beth Scolis, who care for Jessica's five-year-old son, Dominic, who suffers from a rare form of epilepsy. Additionally, Jessica has two other children, all of whom are at home during the pandemic. They are Zooming with us today to talk about navigating these difficult times with a special needs child. Jessica, Beth, thank you for taking the time to connect with us today. And we are here today, we're talking about your son, Dominic, and your grandson, and some of may be work that you've been doing, and basically about how COVID is affecting your family at this time. So, to get things going, though, I'd love to just get your original story. How did epilepsy come into your life?
- Jessica Rosini: [01:33](#) Sure. So, my husband Chris and I have three children. Francesca is six, Dominic is five, and Christian is four. So, our Dominic was a happy, healthy, neuro-typical little boy, and then right before his third birthday, he had his first seizure. And in a two month period, he went from completely fine to developing four different seizure types, being placed on four different antiepileptic medications, and having up to a thousand seizures a day. So, needless to say it, he had an extremely explosive onset.
- Jessica Rosini: [02:18](#) So, that first year of his diagnosis, he was ambulated nine times, hospitalized 11 times, had to be an emergency helicoptered at one point. So, he was eventually diagnosed with Doose syndrome, or myoclonic astatic epilepsy, which I don't know if you're familiar with it, but it's one of those rare types of pediatric epilepsies that presents with multiple seizure types and is notoriously resistant to medication, which we've experienced.

Jessica Rosini:	02:49	So, he was eventually placed on a medical version of the ketogenic diet, which has helped tremendously. It's really saved his life. We just celebrated one year daytime seizure free, so that was a huge-
Kelly Cervantes:	03:03	[inaudible 00:03:03].
Jessica Rosini:	03:04	Yeah. It was a huge-
Kelly Cervantes:	03:06	Congratulations. That's huge.
Jessica Rosini:	03:08	... it was. Like I said, he was having seizures every 30 seconds at one point throughout the day. So, yeah, so we're still working on the nighttime stuff, but we are so grateful to have clocked that time a whole year without anything while he's awake during the day. So ,yeah, huge accomplishment.
Kelly Cervantes:	03:29	Now, how have the seizures affected his cognitive and physical development?
Jessica Rosini:	03:36	Yeah. Like I said, he was a totally happy, healthy, neuro-typical kid before all of this started.
Beth Scolis:	03:42	He was smart.
Jessica Rosini:	03:43	Yeah, yeah. He was doing like 48 piece jigsaw puzzles independently at two. It was almost freaky. We were like [inaudible 00:03:51] he-
Beth Scolis:	03:51	[inaudible 00:03:53].
Jessica Rosini:	03:51	Yeah. Yeah, so now he receives OT, PT, and speech, so that seems to be... His muscle tone has where he's been affected the most. Cognitively, we just had him re-evaluated for his IEP, and cognitively, he still is on track. He's age appropriate. He was in pre-K this year until, obviously, this happened and school stopped. But yeah, he was on track as far as his cognitive abilities, which is, again, kind of a miracle considering the tens of thousands of seizures that he suffered.
Kelly Cervantes:	04:36	It's really amazing. I mean, I can't even imagine. I mean, having your brain reset. We had an epileptologist one time that explained it to us, because our daughter was having very frequent seizures as well, and he was like, "It's as if someone is flipping the light switch on and off. When they flip it back on, you're a little disoriented." So, having that happen through those formative developmental years, I mean really remarkable

and so amazing that he's able to still start kindergarten on schedule, which I'm sure... Yeah.

Jessica Rosini: [05:13](#)

Right.

Kelly Cervantes: [05:16](#)

You can imagine that's got to be so terrifying for you, especially given you didn't get to finish this school year in a school, and now he's going to be going to a new school, I imagine. Talk to us about that and how your fears and anxiety and how COVID has affected that.

Jessica Rosini: [05:35](#)

Yeah. So, that's definitely one of the biggest hurdles that we're dealing with right now, because you're right, he is going to a new school. Right now, he goes to a private pre-K that's basically around the block from our house for two and a half hours. And in our district, kindergarten a full day, so he's going to be going to a new school, a full day kindergarten, and our school district is so wonderful. My mom actually teaches in the school district, so that's definitely a leg up for me because she's a special education teacher. So, I have some inside scoop on what to do.

Beth Scolis: [06:15](#)

[inaudible 00:06:15].

Jessica Rosini: [06:17](#)

Yeah. Yeah. So, the district is so wonderful, and they were allowing me... I've already had a couple of meetings prepping them for Dominic's arrival next year, and they were allowing me to come in, and at the end of the school year, seizure train the entire staff, educate them about the diet, and just give a picture overall about him because... Yeah. And obviously that's not happening anymore, so we're trying to find ways around that and how we're going to proceed with making sure that they're ready for him.

Kelly Cervantes: [06:51](#)

That has to be terrifying, but has there some comfort... And Beth, are you in the school that he will be going to?

Beth Scolis: [06:59](#)

I am not. I'm in the middle school, but in my background, I have the early intervention experience. And the people in our district that are doing it, when Jessica and I met with them, there were familiar faces there, and we know that they're going to look out for him just like they do everybody else.

Kelly Cervantes: [07:21](#)

Of course. Of course. And you mentioned he gets PT and OT and speech therapy. How are you maintaining, are you maintaining, those therapies? It's not as if he can get them at school or he can go to a clinic or you can have people come into-

Beth Scolis:	07:43	People come in the home. Mm-hmm (affirmative).
Jessica Rosini:	07:44	We just are so fortunate to work with such wonderful people. All of his therapists are just amazing. So, we've switched over to teletherapy, so through Zoom, meeting with his therapists and just trying to come up with the best way to still access the services that he needs because he was just making such wonderful progress. We want to make sure that we're maintaining that. And it's very different being home as opposed to it being a more structured school setting, and the expectations are there that this is what he needs to be doing and things like that in that routine. So, it's kind of just the trial and error thing right now. It is going well as far as the teletherapy so far. We have to see if the novelty wears off with that.
Jessica Rosini:	08:36	And I know that other parents of special needs or medically complex kids are feeling the same way, but now it's just a little bit more on our shoulders than we already have. So, we're having to step up a little bit more. We have all these hats that we wear as parents of special needs children or medically complex children, so now, we just put a PT hat on sometimes, now an OT hat, speech, all of that. So, we're just doing-
Kelly Cervantes:	09:07	You still have two other children, one who's doing homeschooling, and one, I assume, is just sort of-
Beth Scolis:	09:15	Glued to your hip.
Kelly Cervantes:	09:19	That sounds age appropriate.
Jessica Rosini:	09:20	Yeah.
Kelly Cervantes:	09:21	How are you doing? Because when everything shut down, I have to say that was one of my very first thoughts was thinking of all of the special needs and medically complex parents out there and seeing all of the parents of neuro-typical kids get overwhelmed with homeschooling, and I was like, "Yeah, it is overwhelming." But you add on to that the PT and the OT and the speech. You add onto that having to do telehealth with the doctors or having to ask for additional months of prescriptions with your insurance, and I could feel the weight and the anxiety. And so, first I want to say you're both superheroes and superstars and super moms, and I think that-
Jessica Rosini:	10:18	[inaudible 00:10:18] yeah.

Kelly Cervantes:	<u>10:19</u>	[inaudible 00:10:19] eyes in this community all the time, every moment of every day. So, how are you holding up? How are you managing? Is there any tricks that you've learned that help you figure this out? Is your husband home? How are you making it work?
Jessica Rosini:	<u>10:41</u>	So, no, my husband is considered essential personnel, so he is still going to work. And like a lot of things-
Kelly Cervantes:	<u>10:49</u>	It's a blessing you have the income-
Jessica Rosini:	<u>10:51</u>	Absolutely.
Kelly Cervantes:	<u>10:51</u>	... but then you are by yourself.
Jessica Rosini:	<u>10:54</u>	Right, right. Yeah. So, yes, you're right about that. It is a blessing. But yeah, a lot of things that you said just with trying to access his medication and getting larger quantities of it to limit the amount of trips we have to make to the pharmacy and things like that, which means., I'm sure you know, those phone calls to insurance, which turn into hours and hours of trying to-
Kelly Cervantes:	<u>11:22</u>	You have so much extra time on your hands, don't you? [inaudible 00:11:27] want to spend your time.
Jessica Rosini:	<u>11:27</u>	[inaudible 00:11:27]. Yeah. Yeah, yeah. So, yeah, there's definitely that, and the therapies are different. And of course, the obvious worrying about him getting sick. The common cold has landed him in the ICU before to get supported breathing, so there's that worry there. And then, there's the worry that if I get sick because while my husband is wonderful, we're a great team, he's super hands-on, but all of the diet and the medications and the prescriptions, all of that, that's all up here. That's my thing. I do that. So, I'm trying to create a Google Doc with everything if, God forbid, I would get sick or be out of commission, things like that.
Jessica Rosini:	<u>12:19</u>	But it's funny because I started to realize that I'm doing better than most people I know, as far as handling this. And I was thinking about it a lot, like why is that? And I think it's because we've been here before. At the blink of an eye, our lives changed completely. We've done that before. Not being able to leave the house, like I said, the first year of his diagnosis, we couldn't leave the house. I had these three small children, and Dominic was seasoned constantly. We were stuck in the house for a year with that. So, I walked this path a little bit before in some sense, but I definitely see a parallel. And I found talking to

other parents who are in similar situations as us, kind of feel the same way. This is like old new, sister, like story of my life. So, I can see that. Not to say that we don't face additional challenges because of the medical complexity of Dominic and-

Kelly Cervantes: [13:29](#)

You're just better equipped to handle them. You have-

Jessica Rosini: [13:31](#)

I think-

Kelly Cervantes: [13:32](#)

... the mental tool's at the ready.

Jessica Rosini: [13:34](#)

That's what I said. I think I just am adapted to crisis mode. I think that I just am kind of like, "All right, this is what's happening. What can we do about it?" And just trying to make it and maintain everything the best way I can for my family. So, like I said, not to negate the challenges and the toll on... Everybody's dealing with things differently as far as this pandemic and the toll on mental health being stuck at home and things like that, but yeah, I just feel like I have some things in my tool belt that your average person or your average parent doesn't have, lucky for them.

Kelly Cervantes: [14:19](#)

Yeah. Beth, are you able to co-quarantine? Are you able to help? How are you-

Beth Scolis: [14:26](#)

I am blessed that I can. As a teacher who does remote learning, I have some flexibility there. I have quarantined myself. There are no more walks with friends. My husband's retired, so he is home too, so I go over and give a little support. I go nowhere else. I get my groceries picked up at curbside, so we're doing our part to stay quarantined. But it definitely does, I think, help that I'm able to go and support Jessica and Chris and those three angels. We're lucky.

Kelly Cervantes: [15:08](#)

Yeah, absolutely. And I have to imagine just as being a mother yourself and being able to help your own daughter, I mean you love those grand babies, but at the end of the day, that's your baby girl who's managing this crazy ship that is going through a hurricane of a storm.

Beth Scolis: [15:28](#)

Agreed. Watching their struggles has definitely put a different layer on this for my husband and I, but we could not be more proud of them. They arise to every occasion. I have never seen a more talented and just stronger advocate for Dominic than watching those two go to bat for him. The research that they have to do for everything, because he is so rare, is... And now, Dominic's getting ready to wean another med, there isn't a

whole lot out there for them, so watching them just delve into that and really look for the answers that they need is impressive, to say the least. But we are so blessed. We really have the three F's. We have our faith, we have a super supportive family, and we have the best friends that we'll send TikToks to make you laugh or... They come when needed.

Kelly Cervantes: [16:41](#)

So, I want to dive a little deeper into how your life has changed on a more micro level with COVID coming into the picture and needing to quarantine. You have all three of your children are at home, they are spending more time together, but they're probably also seeing another side of their brother's epilepsy. Have they said anything to you? Do they notice things? Has it affected them at all?

Jessica Rosini: [17:17](#)

Yeah. I mean, definitely Francesca. Like I said, my daughter's six, and she's in first grade. And she remembers before epilepsy came into the picture, so she's very aware of that Dominic was fine and now these are the struggles that he has. And school was just always an escape for her. Like I said, he's been daytime seizure free. He's running, he's playing, he's a lot of ways a very typical five-year-old, but the diet's very difficult for him. He suffers a lot of GI symptoms. He vomits a lot. He recently in November had a G tube placed because he just... He was already picky eater before all of this, and now having mayonnaise based foods, 90% of his calories are coming from mayonnaise butter, heavy whipping cream, and oil. So, it's not very palatable for an already picky eater.

Jessica Rosini: [18:27](#)

So, yes, so he has a G tube now. So, she's just home more, and she's very sensitive and she's very in tune with my energy and my stress level. So, I really have to make sure that I am taking care of myself, too, because she can sense if I've been up all night... He's having a little bit of a rough patch. He had six seizures the other night, so I was up and threw up twice in an overnight period. So, obviously, I didn't get a whole lot of sleep. But then, she's not going to school, she's there all day to see the ramifications of a sick brother, a tired mom. So, she doesn't always verbalize it, but she senses it and she can definitely pick up on those things.

Kelly Cervantes: [19:24](#)

Yeah. Those older siblings, we learned very quickly that Jackson could understand and heard a lot more than we thought he did. And then [crosstalk 00:19:37].

Beth Scolis: [19:37](#)

He hears everything.

- Kelly Cervantes: [19:39](#) They do, they see it all, and they're processing it in their own six-year-old way.
- Jessica Rosini: [19:45](#) Yeah. She did ask me the other day, she said, "Mommy, what if Dominic gets the Coronavirus?" And I don't know if she heard me talking about my worry about that. I try and be aware and conscientious of what I'm saying in front of her because, like you said, they really do pick up on everything. You got to really watch it. And we've always just tried to be very honest as well and equip her with information so she's not left to guess or wonder, and tell her all of the things that we're doing to make sure that that doesn't happen, things like that, and reassure her that we're being safe and that's why we're staying home and those kinds of things.
- Kelly Cervantes: [20:32](#) That's so smart. So, you mentioned that Dominic is on the ketogenic diet, he is also on some other medications. What is your medication process right now? You mentioned having some difficulty with the pharmaceuticals. Are you going into the doctor's office still? How are you managing all of that?
- Jessica Rosini: [21:01](#) We are not. We had a slew of appointments scheduled that were all canceled because some of them were... Like the neuro genetic clinic, to catch up on, because that research is advancing so quickly and he hasn't had genetic testing done in awhile, so we were planning on doing that. A DEXA scan that would test his bone density being on the ketogenic diet for two years, that was canceled. We have our keto and neurology appointment coming up next month and there hasn't been anything said about that, so I don't know. I think it just depends on what's happening as far as restrictions. I would imagine that we could do a video appointment for that, but he also gets frequent blood work, which is honestly my biggest concern just based on the meds that he's on and the diet. We do have to monitor a lot of things. So, he's due for those next month, so that's just a conversation that has to be had with his doctors and weighing the risk versus benefit.
- Kelly Cervantes: [22:23](#) I can imagine how difficult that decision is going to be, to have to make balancing COVID and just regular care of your son.
- Jessica Rosini: [22:33](#) Mm-hmm (affirmative).
- Kelly Cervantes: [22:35](#) Now, I have also been made aware that you guys are pretty phenomenal advocates on your own. Talk to me about Dominate Epilepsy.

- Beth Scolis: [22:49](#) In a world where there's so little that I can actually do for Dominic, and there's so little control over epilepsy, we had to find something to give us and know that we were doing something to make a difference in the world. My state rep, Chris Quinn, is amazing. We have HB 1820, which on March 16th was to be voted on in the education committee at 10:30, that morning is when COVID shut down Harrisburg in Pennsylvania. It was heartbreaking, but... I know. It's for seizure smart schools. As a special education teacher, I was totally unaware of the number of different types of seizures kids could have. I was unprepared, and I have learned so much through Dominic. He has taught us enormously, but it also showed what a void there is in the public education system.
- Beth Scolis: [23:59](#) So, it is to ensure that school personnel are trained in seizure recognition and response so that our kids are safe. Just in my state alone, we have almost 17,000 kids who have epilepsy, and as a teacher, we're with them sometimes more waking hours than their parents so we want to make sure that everybody is prepared for that. And we had a rally scheduled for March 23rd, too. State rep Quinn also put through a resolution to recognize March 26 as Purple Day in our state, so we were rallying to do that. And we do a Dominate Epilepsy fundraiser for Purple Day, and such support comes out from family, friends, the vendors, donations come in. And we were disappointed that we are postponing. It will happen. CURE is our heart now. That's where our drive is. We need a cure for Dominic and for all the other warriors out there.
- Kelly Cervantes: [25:14](#) I could not agree with you more.
- Jessica Rosini: [25:16](#) I was going to say, Kelly, I'm sure you can relate to that, to being in a situation where you just have no control over what's happening to your child. And one of the most therapeutic things that I have found to do is to help somebody else or raise awareness or raise funds. It's so unbelievably therapeutic to just find something good in such a horrible situation. And now, that's gone with the things that we had to cancel, but then you came along and asked to talk to us.
- Kelly Cervantes: [25:55](#) Well, now you get to share your story here, and we're just so thrilled. You ladies bring up so many incredible points. You have such bright spirits. I think people, they hear of Doose or of infantile spasms or SCN1A, and these are rare disorders but epilepsy in and of itself is not rare. One in 26 will be diagnosed, and these are the things that we have to remember and we have to keep our kids safe in school. And that starts with educating the teachers and the professionals who are in those

buildings, and so I am crossing fingers for you that once we are on the other side of this and governments and schools can open their doors again, that I know that that we will see the Dominate Epilepsy bill get passed and that will all be in thanks to you two. So, thank you guys so much. Thank you for coming on and chatting with me today for being the warriors that you are. I'm sorry that you are a part of this crappy club, but goodness, are we happy to have you here.

Jessica Rosini: [27:13](#)

Thank you so much, Kelly.

Beth Scolis: [27:13](#)

Thank you so much.

Jessica Rosini: [27:15](#)

Thank you so much.

Kelly Cervantes: [27:19](#)

Thank you Jessica and Beth for sharing your story, insights, and advice on navigating these difficult days with a special needs child. At this moment, we are all trying to adapt to circumstances that none of us could have prepared for and remain hopeful in the face of the unknown. For those who have epilepsy or care for loved ones with epilepsy, this is their reality every day. Wondering and worrying when the next seizure will strike, where they will be, how it will affect them, hoping they will be okay. CURE knows the only way to alleviate these fears is by finding cures. During these challenging times, CURE remains focused on its mission, on funding research that will lead us to breakthroughs and understanding and treating epilepsy. The work being done in labs today will bring new treatments to hospitals in the future. We hope you will be a part of our mission by donating at cureepilepsy.org/donate. Your generosity is greatly appreciated. Thank you.