

Shout from the Rooftops: Your Voice Can Help Find a CURE Seizing Life, episode 24 – Transcript

- Stacey Pigott: [00:00](#) Hello, I'm Stacey Pigott and this is Seizing Life.
- Stacey Pigott: [00:14](#) Today we're flipping the script to interview our very own Kelly Cervantes. Cure board member and regular host of Seizing Life. Kelly shares how she with her husband Miguel raise funds for epilepsy research. Among other things, the Cervantes family has partnered with Fairgrounds Coffee to sell Adelaide's Blend Coffee available in all Chicago area Mariano's grocery stores. Kelly, thanks so much for letting us turn the tables and interview you for a change.
- Kelly Cervantes: [00:39](#) Well, thank you for taking my job for a day.
- Stacey Pigott: [00:42](#) Happy to. I know you've spoken a lot on past episodes as well as just through all your many different activities that you do around the area about Adelaide's epilepsy, but could you give us all a little review and background on Adelaide's journey with epilepsy?
- Kelly Cervantes: [01:01](#) Absolutely. So the cliff notes version is, she was born normal, happy, healthy delivery, but we quickly realized that there were a handful of issues. She was losing a lot of weight. She was having trouble eating and at the time we didn't realize it, but now we know it was because she had really low muscle tone and it always felt like, there would be an issue, but she would get over it. It took her a little longer to get there, but she got there. It took her a little longer to smile a little longer to ... Those very, very early newborn milestones that you look for.
- Kelly Cervantes: [01:42](#) And then she stopped meeting milestones altogether. So by the time she was two months old, we had gone in for her pediatric checkup and the doctor was like, "Okay, she's not holding her head. She's not trying to roll over. I think it's time to see a neurologist." It took us two months to get in to see a pediatric neurologist and we start on this crazy testing journey.
- Kelly Cervantes: [02:07](#) Every test under the sun, MRIs, ultrasounds, every blood test you can imagine. We start doing genetic testing and then the very next test on our list was an EEG. Three days before she was supposed to get that EEG. She had her first seizure at seven months old and we took her in for the EEG three days later and we get the call from the neurologist saying, "Okay, you have to come in." And we had done an ambulatory EEG the first time. You have to come into the hospital, do an inpatient EEG. It was abnormal and we just, we need to check this out.

Kelly Cervantes: [02:43](#) So we go in and do the 48 hour EEG and come out of that with a generalized epilepsy diagnosis. Start her on a med and she starts thriving. And we think to ourselves, "Okay, we've got this under control. We don't have to worry about these seizures. Let's just figure out, you know, she's in therapy. We need to get her up to get her up to speed. Everything's going to be okay." At nine months old, I was actually ... My husband Miguel had booked Hamilton in Chicago and we were getting ready to move from our home in New Jersey to Chicago. And I had flown out to find us a home and a preschool for my son and I get a call from Miguel being like, "She's acting really funny. I don't know what's going on. Her head keeps bobbing. It could just be had control, but it looks funny to me." And we both agreed like, just take her to the ER.

Stacey Pigott: [03:35](#) Yeah,

Kelly Cervantes: [03:36](#) We're not playing around. Take her in. I get a call that evening from Miguel and the neurologist saying that they're diagnosing her with infantile spasms. Adelaide developmentally been around a four month old. At that time, she was nine months. She was developmentally around a four month but physically a little further behind, but cognitively she was there. She was with us. She was laughing, she was smiling. She made tons of noises. We used to joke that she was singing. She was so noisy.

Kelly Cervantes: [04:11](#) By the time I was able to make it back to New Jersey from Chicago, that child was gone. I held a shell of the little girl that I had left behind and we've never gotten that little girl back. It's always been one step forward, two steps back. We eventually got her smile back. She eventually started making physical progress, but then the infantile spasms came back and we just sort of kept going on that journey until about a year and a half ago. We lost her smiles altogether.

Kelly Cervantes: [04:48](#) Since then, we've also lost consistent eye contact and we just sort of continue to watch as the seizures keep taking her away and there's just no treatment available out there that seems to work. So that has absolutely motivated our fight for her. And also the platform that we have. Hamilton came into our lives at the exact same time that Adelaide's epilepsy did. For us, that journey is so parallel. So to have that platform and to have this sick daughter and to be able to, you know, that there's only so much that we can do for Adelaide. I say this all the time, but I often feel at a loss for her, but we can use that platform. We can help get the word out there. And it almost feels selfish to me to not be out there and to not be shouting. The word epilepsy just from the rooftops. Just getting it in people's minds

and getting, you know, so that, that it's something that they're familiar with and trying to make them care.

- Brandon: [06:10](#) Hi, this is Brandon from Citizens United for Research and Epilepsy or Cure. Epilepsy affects 3.4 million Americans. Learn more about cutting edge epilepsy treatments and research at cureepilepsy.org now back to this episode of Seizing Life.
- Stacey Pigott: [06:26](#) You made a choice. You decided to, as you said, start screaming from the rooftops about epilepsy. What drew you to Cure?
- Kelly Cervantes: [06:35](#) In my former life prior to Chicago, prior to epilepsy, I worked for a restaurant group coordinating and selling events. I ran a department and it was such a rush and I really enjoyed that. Interestingly, one of the events that I helped coordinate was Cures New York city benefit. Prior to epilepsy ever entering our lives. I had no idea what this was, but I was like, "Wow, those people from Chicago sure are nice. I really enjoyed working with them." Fast forward, I believe two years later and I'm shooting off emails. I'm like, "Okay, we're moving to Chicago. My daughter has epilepsy Cure." My immediate thought, I was like, "I've got to get in touch with these people." I have to like ... Maybe they can help with recommendations or they can put me in touch with other families or what is there ... I just, I knew that I needed to get in touch with them and we were embraced by the organization.
- Kelly Cervantes: [07:41](#) I got to sit down with several of the people who worked there and hear about Cures mission for research, which just spoke so deeply to me after having just recently sat across from a doctor who said, "We don't have a cure. We don't have any answers. We don't know why this is happening." And it's just mind blowing because you live in this day and age and you're like, well, we can cure cancer. Why can't you tell me how we're going to stop the seizures? Like it just ... So to sit across from these people who were just as exasperated, but we're doing something about it.
- Stacey Pigott: [08:23](#) Yeah.
- Kelly Cervantes: [08:24](#) It gave me hope in a way that I had not experienced prior to Adelaide's first seizure. And I was so moved by that feeling and that hope that I needed to be a part of this.
- Stacey Pigott: [08:40](#) Well, so what activities or have you been able to pursue through Cure?

Kelly Cervantes: [08:46](#) The very first fundraising campaign that we did for Cure was, it was the original, My Shot At Epilepsy Campaign and it was really simple in its function where it was just an online fundraiser. It was a raffle of sorts. And people just got to buy raffle tickets for different items but we started, got to use our platform to push it out. And in that very first campaign, we did it in November of 2016. So we had just moved to Chicago in September, a month and a half later we're doing a major fundraising campaign and we raised \$100,000.

Kelly Cervantes: [09:31](#) And I was like, "Wow."

Stacey Pigott: [09:33](#) Yeah.

Kelly Cervantes: [09:35](#) Like we can really do something here.

Stacey Pigott: [09:38](#) Mm-hmm (affirmative)

Kelly Cervantes: [09:39](#) And it was really exciting. And then connecting with these other families and being able to use our voice, being able to speak publicly at events to share our story, to move people. And the more that I spoke about it, the more opportunities started to come in. Like Adelaide's Blend, which was super exciting. That was really just through ... It was friends making connections with other friends. Introduced us to Michael Schultz who is the CEO, founder of Fairgrounds Coffee and Tea. And he came to us and as a dad, was moved by our story and was like, "My shot at epilepsy. Well you could have a shot at a cure, you could have a shot of espresso." And he sort of spinned it. And all of a sudden, before we could blink, he had graphic design people designing a bag with Adelaide's picture on it and our story raising money for Cure.

Kelly Cervantes: [10:39](#) And it's really all happened organically just because we're public with our story because we're speaking out and I do want to preface and say it is much easier for us to speak out about our story because Adelaide cognitively is unaware. She's not trying to get into college. She's never going to hold a job.

Kelly Cervantes: [11:05](#) So there is no risk in her future in us speaking out. Stigma and epilepsy is absolutely real and I do not downplay that in any way, shape or form, which only makes me feel that much more responsible for us to share our story because we can. But I do, I do understand that it is not something that everyone can do, but I do think it is incredibly important that we all try.

Stacey Pigott: [11:30](#) It's a really valid point too because that's something that advocates always need to weigh in and think about because as a parent advocate you are wanting to scream from the rooftops, you're wanting to kind of put it out there, but you do have decisions to make for your family and for your child impacted and make sure that you're doing right by them in the telling of the story and that you're telling the story as they would want it to be told.

Kelly Cervantes: [11:55](#) Exactly.

Stacey Pigott: [11:56](#) And everyone's hope is that their child will progress to the point where they could have the ownership and responsibility to be able to tell that. You hope that that can happen. But if that can't happen, you still want to be respectful of-

Kelly Cervantes: [12:10](#) Absolutely.

Stacey Pigott: [12:10](#) How you tell that story.

Kelly Cervantes: [12:11](#) And to that point as well, I think it's important to acknowledge that you don't have to have a man bun and be rapping on stage every night to be an advocate. You don't have to have that platform necessarily. It can be anyone and everyone can be out there sharing their story or it doesn't have to be that big. It can be as much as hosting a run in your area or a bake sale or having someone come in and speak in your child's classroom.

Kelly Cervantes: [12:47](#) I've sort of developed my own little mind frame of advocacy over the last couple of years and sort of these different branches of different ways that people can advocate and I really try, and stress to everyone that, you know, we can't advocate in all ways but to try, and find a way that you can because no one is going to care about epilepsy, the research, the advocacy, all of it as much as we will, the ones who are affected by it. So it is up to us to make people care. No one is going to care as much as we do.

Kelly Cervantes: [13:18](#) So we have to impress on them why we're doing this, why it matters. So there is advocacy through politics. If there is legislation that needs to be passed that you don't agree with people who aren't following specific ADA rules. Getting in front of your legislators, getting in front of your city counsel, making them aware that these are issues that need to be addressed. Letting them know who is in the community and it's not this isn't right or left Republican or Democrat, this is just getting out there and making sure that there is awareness from your

elected officials as to what is important to you and what needs to happen.

- Kelly Cervantes: [14:07](#) I would also say there's advocacy within education and that can be both advocating for your child in the school system. We spoke about IEPs on an earlier episode, but I also think that can be education perhaps within your workplace. Making sure that you know, okay you are high-functioning, you are working in your job, but there's a chance you could have a seizure there. What is your seizure protocol? Making sure that your employer understands, making sure that your colleagues understand and educating them about the condition as well.
- Kelly Cervantes: [14:44](#) Advocacy within, and this is probably one of the most important ones to me, and I think the most easily attainable is advocacy within your social world. So I always try, and use the word epilepsy as much as I possibly can. Someone will comment, "Oh your daughter looks so sleepy."
- Kelly Cervantes: [15:01](#) And I'm like, "Well actually she has epilepsy, and she had a seizure this morning so, she's tired after having that seizure." So just trying to use that word, getting it into people's knowledge in the same way that Alzheimer's or Parkinson's is. People just don't understand.
- Kelly Cervantes: [15:20](#) The fourth one is sort of a no brainer medical advocacy. This is advocating for yourself as the patient, advocating for your child as the patient. No one knows what is going on for your child or for yourself more than you do. So making sure that you are speaking up, whether that's getting nursing care in the home or advocating with the doctor. Trying to make sure that you're getting the best possible care that you can. And I cannot stress that enough. Having the fight.
- Stacey Pigott: [15:52](#) Mm-hmm (affirmative)
- Kelly Cervantes: [15:54](#) With the doctors and making sure that everyone is on the same page, and it's just such a necessity. And then finally, the one that our family has sort of latched onto immensely is advocacy through fundraising. And it's a challenging one I think for a lot of people to wrap their heads around and going out and asking people for money can be uncomfortable, right? Like everyone has their own cause everyone has their thing. So why do they want to help you? Which is one of the ways that we got so excited about Adelaide's Blend because it's so simple. So many people drink coffee.

Stacey Pigott: [16:37](#) Yeah.

Kelly Cervantes: [16:37](#) So I'm not asking you to donate, 5, 10, \$100, whatever. I'm asking you to buy, not that bag of coffee, but this, this bag of coffee. And then some of that will go toward epilepsy research. And so that was just such a beautiful way for us to sort of merge that together. And then don't get me wrong, I have no shame. So I also asked people for money all the time constantly as well. Because I care. Because I have to, because I need hope, because I need a cure for my daughter and I think, if anyone was faced with this situation, like both of us have been. You fight like hell for your child and the only answers out there right now are through research. So that's where our fight has to be.

Kelly Cervantes: [17:25](#) And so, yeah, I'm going to ask people for money because we need it. My baby needs it.

Stacey Pigott: [17:32](#) You like your point when you did your first fundraiser the My Shot and you're kind of thinking fundraising, fundraising, just you know, you're never sure what that is going to look like and then you hit 100,000 and I'm sure it just washes over you immediately of that's a year of research.

Kelly Cervantes: [17:48](#) Yeah.

Stacey Pigott: [17:48](#) That's a grant. That could be the grant. We don't know. Cure gives a great platform of being able to translate that fundraising dollars into something really, understandable, manageable, tangible.

Kelly Cervantes: [18:04](#) Yes.

Stacey Pigott: [18:04](#) That you just know exactly where that's going. What is your experience partnering with a local company? What has that been like and what advice do you have for other people to find a similar kind of partnership?

Kelly Cervantes: [18:18](#) So what I always try, and tell people is, reach out within your own network. So if you don't have sports connections, don't try, and reach out to your local sports team to host an epilepsy night at the basketball court. Where do your connections lie? Are they in the food industry? Then try, and host an event at a restaurant. Ask your friend who owns a restaurant if they'll do a give back night and then publicize that. Look at your contacts, look who your friends with, look who understands what your day to day life actually looks like. And use those connections to try, and build that fundraising support system.

Kelly Cervantes: [19:03](#) That's how you're going to be the most successful. And start small. There is absolutely no reason whatsoever that ... Allow, if it's an event, if it is a fundraiser, if it is a school program, allow it to start small in one classroom with 20 people. And then let it grow and expand. You don't have to shoot for the stars the first time because there is absolutely a learning curve.

Stacey Pigott: [19:32](#) Yeah.

Kelly Cervantes: [19:33](#) And you're probably in the beginning doing it on your own. Although I will say that Cure has the program, Cure Champions, where they have someone in the office who will sort of help and guide you through the process and sort of be a sounding board and send you materials that you need and that sort of thing. So you are working hand in hand with someone in the office, but you're the person on the ground and it is a lot of work and so start small. Let it be organic and let it be something that is in your wheelhouse.

Stacey Pigott: [20:07](#) Yeah, that's great advice. And I think too that what surprised me in my own experiences with fundraising is that, big or small, just have the event, just do it.

Kelly Cervantes: [20:17](#) Yeah.

Stacey Pigott: [20:18](#) Just take a risk, do it. And it's amazing watching that network of people come in to support too. The number of families who are also impacted, kind of come out of the woodwork and before you know it that one event pretty quickly and easily becomes a second and a third event.

Kelly Cervantes: [20:38](#) Yeah.

Stacey Pigott: [20:38](#) When you are able to tap into their network and their wheelhouse and it really can grow exponentially from there. So it's like just get out there and do it. Is great advice. So let's just say someone is stumbling upon this podcast, newly diagnosed, surfing the web as we both did, looking for answers, looking for some kind of outlet for their grief, their anger, their frustration. They stumble upon this podcast. What advice or message would you give to them to start finding their own way in the space of advocacy?

Kelly Cervantes: [21:15](#) I would say find your community.

Stacey Pigott: [21:17](#) Yeah.

- Kelly Cervantes: [21:18](#) Be it local or online. I am a member of, I don't know how many Facebook groups. All revolving around epilepsy and that ... Because I live in Chicago, which is great, I was able to meet so many families who are affected, but not everyone lives in a major city or knows other people. So that online community finding that so that you don't feel alone I think is step one, that comradery. And then find your local organization or reach out to Cure and make those connections and they can connect you with other families as well.
- Kelly Cervantes: [22:00](#) And then just start talking about it. Talk about it in your regular life with the people who are close to you. Get comfortable talking about it because that will make all the difference in the world. And by no means do you have to get out there and start raising money tomorrow, but just start small. Just chat about it and get comfortable and that'll make a huge difference. And the rest of it will follow.
- Stacey Pigott: [22:27](#) I think one of your best pieces of your many great pieces of advice is to just talk about it, chat about it, and we're just so thankful for your openness and your friendship and your support in helping to organize all of this and giving back to the community. It's making such a great impact. So thank you so much for doing the podcast and of course for talking with us today.
- Kelly Cervantes: [22:50](#) So happy to be here.
- Stacey Pigott: [22:54](#) Thank you so much Kelly, for sharing your journey from mom to advocate who chose to help your daughter and countless other children who suffer from epilepsy. If you want to contribute to epilepsy research, please consider purchasing a bag of Adelaide's Blend. You can find Adelaide's blend online at [cureepilepsy.org\adelaidesblend](http://cureepilepsy.org/adelaidesblend) or in Chicago, you can visit Fairgrounds Coffee or Mariano's grocery stores.
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