

Kelly Cervantes: 00:00 I'm Kelly Cervantes, and this is *Seizing Life*, a weekly podcast produced by Citizens United for Research in Epilepsy, (CURE).

Kelly Cervantes: 00:18 My guest today is one of my favorite people in the world, and my life is so much better for knowing him. Miguel Cervantes stars in the Chicago production of HAMILTON as Alexander Hamilton himself and is a fabulous father to two amazing children. He is also my husband, and that is why he is the perfect guest to talk about being married with children with epilepsy. Thanks for joining me today, babe.

Miguel Cervantes: 00:42 Thank you for having me.

Kelly Cervantes: 00:45 I don't think that anyone would disagree that having children changes a relationship. Then throw a child with special needs or epilepsy into the mix and that turns it all on its head. What do you think the biggest change in our relationship has been since Adelaide was diagnosed?

Miguel Cervantes: 01:08 In remembering how it was with Jackson, with our son - anybody who has kids can attest to how selfishness becomes a secondary thought. You're now 100% focused on taking care of this new person. When Adelaide came along, I thought, "It's going to be that again." I thought the hard part of our relationship would be to say, "Okay, here's another baby. Now that we've finally got this other one into a good rhythm, we can figure out how we live our lives around his schedule."

Miguel Cervantes: 01:45 This new baby comes in and we have to go back to that other version of parenting, saying "Okay, new baby, you're up at night," and all the things becoming a parent changes. And then as we're learning about what her situation was going to be and how it was going to be different than Jackson's, there's a new parenting stress. The stress of figuring out how we stay positive with each other, not just because, "Oh, she doesn't have time for me because she has to take care of the kid," or, "We don't have time to do this because the babies need us."

But now it's, "We don't have time to do this because we're going to the hospital," or, "We don't have time to do this because we're worried about what is going to happen to her." There's such a different mental place you're in when the stress isn't about just regular life things, and it becomes about the health and livelihood of this child. The carefree moments we had when our child finally went to sleep, or the carefree moments we could find when someone, like a babysitter, watched our child weren't as carefree anymore.

- Miguel Cervantes: 03:19 I think it made it a little less easy to drop our parenting guard. Now, even in our carefree moments, in the back of our minds, we have this baby who is clearly sick. That doesn't go away.
- Kelly Cervantes: 03:39 You mentioned something that really struck me: there are different stages of parenting in terms of how you parent with a newborn and the amount of attention you need to give to that newborn, and then how your relationship changes as this child gets older. But Adelaide has never really gotten much past that newborn phase, so on top of her requiring all of these additional medical needs, or her family being separated because she's in the hospital, we have been in a newborn phase for three years. Waking up in the middle of the night and needing to tend to her and make sure she's okay adds another challenging element. We don't ever get to grow out of that.
- Miguel Cervantes: 04:24 When was Jackson was a baby, we would wake up and someone would have to get out of bed. He'd be crying, he'd be screaming, we go put him down, and all of those things. And now our wake-ups are an alarm going off because she's not breathing correctly, or us asking, "is she having a seizure right now?"
- Miguel Cervantes: 04:42 I remember being so frustrated with Jackson, "Just go to sleep! Please just -." And then that was our stress. We always had to wake up. We always got up and had to worry about what he was doing. But now it's a different version.
- Kelly Cervantes: 04:58 The life and death version. It's just so amped to another level. It's not just the annoyance of wanting to get a full night sleep or spend time together. It is the fear and anxiety that goes along with hearing those alarms or hearing her cry out and wondering if she's crying because she just had a seizure.
- Kelly Cervantes: 05:20 I think that our lives have also been incredibly enriched by having Adelaide and being exposed to this world and community, as well as by seeing parenting through eyes we had never imagined. In what ways, do you feel our marriage has grown as a result of Adelaide and her epilepsy?
- Miguel Cervantes: 05:43 I think we are staring adversity in the face every day, and we are a team. The teamwork aspect of our marriage, while never was a problem, I think-
- Kelly Cervantes: 05:54 It's certainly been tested.
- Miguel Cervantes: 05:56 Yeah, but I think you see-

Kelly Cervantes:	05:58	Gotten a work out.
Miguel Cervantes:	05:59	You see that when you really need to be a team, when you really need to come together, it's not just, "I'm so mad at you." It's, "We need to keep our daughter alive," or, "We need to keep our family together." That's when the real testament to the teamwork of the Cervantes' team really comes together. You don't get to test those things very often in a normal track when you have kids that are just living regular lives.
Miguel Cervantes:	06:31	I think we have been given the opportunity to really dig in and say, "Are we going to be strong enough to get through whatever is coming?" Clearly, so far, so good.
Kelly Cervantes:	06:43	One of the things I think we do very well to maintain our teamwork is communication., Sometimes it's just lying in bed at night and checking in with each other, making sure we're on the same page with both Adelaide's medical decisions or care, and things that are going on with Jackson.
Kelly Cervantes:	07:10	We don't talk about it every day certainly, but those weekly or bi-weekly talks we have just lying in bed at night - I don't know what I would do without those. It's just keeping that communication path open.
Miguel Cervantes:	07:26	In any relationship, I think there has to be communication, and in our relationship even more so because of the way that we have structured our day-to-day activities.
Kelly Cervantes:	07:39	And I would argue that there has to be incredible structure when you're dealing with a child who is on a lot of meds. I mean, goodness gracious, Adelaide's schedule with her therapies, and her doctor's appointments, and this, and that, and making sure the prescriptions refilled. That really has to be one person's responsibility. Otherwise you're going to end up with the child getting the same meds twice.
Miguel Cervantes:	07:59	Something we've done well - sometimes better than other times and sometimes less well - is understanding where each other's weaknesses are, accepting them, and saying, "That's okay because the larger picture is the most important one, and that's how we get through a day, or a week, or a month, and the next year, or whatever happens." Understanding that we are accepting of each other no matter what.

Kelly Cervantes: 08:31 I think that is such an incredibly valid point. I don't think I've heard you articulate that or thought of that myself, but I think it's incredibly true.

Miguel Cervantes: 08:42 I don't know if you remember - of course you remember - you were going to work every morning and I was not. I was taking care of the house and all these things, and I was going to these appointments and-

Kelly Cervantes: 08:54 This is right when Adelaide was first diagnosed.

Miguel Cervantes: 08:57 When Adelaide was diagnosed. I went to talk to this geneticist, and this little guy, was telling me all these things. He gave me these papers and he said all these words, and I said, "Yeah. Okay. Yeah." And then I came home, and you said, "Did you write it down? Did you bring the papers home? Where's the folder?" I said, "Argh!" Clearly, our roles in this situation... I had the wrong role.

Kelly Cervantes: 09:22 I think it's like you said. You have to be aware of your partner's strengths and weaknesses. I am neurotically organized, and you are not, so it makes more sense if... I remember that. I remember taking over Adelaide's medical care when you booked HAMTILON and you started going into rehearsals. I was like, "Okay, where are all of Adelaide's papers? Where are all the tests?" And you were like, "Oh, they're in the office."

Miguel Cervantes: 09:46 A pile of papers.

Kelly Cervantes: 09:47 I open up the door to the office, I look on the desk, and it was just papers everywhere. I had mild panic attack, and then I got in the car and picked up office supplies and got everything organized over the course of the next two days.

Kelly Cervantes: 10:04 I think it really goes back to that excellent point you made. You just have to be aware of what each of you does best and doesn't do well and not get mad at the other person for not being great at what you know is not their strong suit.

Kelly Cervantes: 10:33 Your family member with special needs, with epilepsy, is always in the back of your mind. We try and go out, go to events, have date nights. But how do you manage that without feeling distracted while we're out or feeling guilty for stepping away?

Miguel Cervantes: 10:51 It's never not part of the way I view my life. If we get a chance to go somewhere else and it's not some event that's about epilepsy or special needs - don't get me wrong. They're all very

nice events, but if it's something that has nothing to do with that or has nothing to do with our daughter -

- Miguel Cervantes: 11:16 The other half of our life is not them. Even if she was running around like a regular kid, we would need to have the kind of nights where we don't worry about her, or them, or what's going to happen. What's going to happen is going to happen. It is what it is. We are not changing the course of her life one way or the other by going to see a movie.
- Kelly Cervantes: 11:43 It's true.
- Miguel Cervantes: 11:43 We're not going to affect how good or bad her next seizure is going to be by going to have dinner. I think maybe because I do that on stage all the time, I can compartmentalize what's happening.
- Kelly Cervantes: 12:01 That was going to be my next question. Six nights a week, seven shows a week you leave our house and you go off to the theater. Sometimes we're in the hospital and you're going off to work. Life doesn't stop. The show must go on, as they say. How do you do that? I'm with her all the time. I may run errands here or there when we have the nurse.
- Kelly Cervantes: 12:30 You leave, and you have to. We need you to. Is that a relief for you? Is it hard?
- Miguel Cervantes: 12:42 I think I would be lying if I didn't say it was absolutely a relief. Now, I don't go to the theater and be like, "Woo-hoo, I'm out of here!" It's not like that. I think it's more a relief of focus, a relief of the reminder-
- Kelly Cervantes: 13:00 For the first year or so of you doing that show, I resented you immensely because you got to escape, and I didn't.
- Miguel Cervantes: 13:08 I go to this building and I hang out with grown-ups who are doing other things, and life is happening all around. Just some sort of other stimuli that's not focused completely on our sick daughter is a relief. I go to work. It's going to my job. It's a very cool job. I get to do a lot of cool things. But, nonetheless, it's my job. I am surrounded by other folks, other ideas, and other sounds.
- Miguel Cervantes: 13:38 I think that is the benefit of what I get to do. You don't have that. You are in the house with her and with our other child, Jackson, who needs what he needs. He needs dinner, he needs

the stories, he needs a bath, and he needs homework. That's all happening as well.

- Miguel Cervantes: 14:00 The relief I have as the parent - my parenting duties are on hold for four hours a night while yours continue. That can make it easier for me to sort of back off when we're not with them because I'm not with them every night already. When you leave, it's during the rare occasions when someone else is doing what you do all the time. For you to be able to say, "They'll be fine," is probably not as easy for you as it is for me.
- Miguel Cervantes: 14:30 I think I am forced every single night to put everything that is happening in the back. That doesn't mean it's always gone. If something is happening, if the doctor said something, or if you said something, I'll be thinking about it and have to compartmentalize if I can't really focus-
- Kelly Cervantes: 14:56 I'm sure you use it during it's Quiet Uptown.
- Miguel Cervantes: 14:58 I use it sometimes in the weirdest places. It was during Yorktown or something, or some non-stop. It had nothing to do with my children and for some reason I thought of Jackson talking to Adelaide or cuddling with her, and I was tearing up like, "What are you doing here?" That's when it gets hard.
- Miguel Cervantes: 15:22 I should ask you a question. When I got to go out and I got to go do the show, and I ran off with all my actor friends to do the show at night, what did you do? How did you come to terms with that and not hate me every time I walked in the door?
- Kelly Cervantes: 15:52 Therapy. It took several months of therapy and maybe a prescription med thrown in there as well to help with the daily anxiety of all of it. But I had to work through what our new roles were and accept our situation. And just through talking about it with someone, through having an hour a week where I could just word vomit all of my frustrations, resentment, anger, and "life isn't fair, boo-hoo me."
- Kelly Cervantes: 16:32 Just having that one hour a week really helped until I could find my feet under me and figure out what my purpose was in all of this and how I fit into this new life and this new marriage where I wasn't the breadwinner anymore. I wasn't the one going off to the exciting events and meeting cool people. This turn as Miguel Cervantes' wife as opposed to having my own career and identity took time and a decent amount of therapy.

Kelly Cervantes: 17:19 Then I found my purpose with CURE. I found a mission and a job to keep me going. Obviously, Adelaide gives me incredible purpose, but if I determine how successful or how happy I am based on how Adelaide is doing, that would be a pretty poor barometer seeing as we have very little control over her condition. That's certainly helped.

Kelly Cervantes: 17:49 I think if I hadn't been able work through it, I probably would have asked you to come with me to some sessions and requested we do some couples counseling to try and figure it out together. But I've powered through, and found my feet, and here we are.

Kelly Cervantes: 18:17 What advice would you give a family, the parents, or a couple who is just getting an epilepsy diagnosis, or have a special needs child? To keep their marriage strong, to keep their marriage healthy, what's the first tip you would give them?

Miguel Cervantes: 18:36 The first one is to not expect your partner to feel the same way you do all the time. The first one is to really allow space for differences of understanding. I think in a way, if you're not both allowed to digest what's happening in your own way, then you're always going to be at odds on how to deal with it, and then that's going to cause a problem.

Miguel Cervantes: 19:28 The next thing is once you're in it, don't be afraid to ask for help. Ask for help. Ask your family. This is such a hard thing for me to understand about our situation compared to other people's situations. For a long time, we did it in on our own, and by we, I mean you did most of it, and I tried to help when I could. We would be at odds because we didn't have a rhythm for both of us to be involved in an equal way.

Miguel Cervantes: 20:13 That was a hurdle we had to get over. The way we got over it was to hire a nurse. This nurse came in and says, "Wait, you've been doing this all on your own? I went to school for this. This is a person's full-time job." Then you realize how heavy it is.

Kelly Cervantes: 20:41 Even for those who maybe aren't quite as disabled as Adelaide, having a qualified caretaker, babysitter, or someone who knows what to do when a seizure happens and deliver nighttime meds, even if they're not an RN, like Adelaide needs.

Kelly Cervantes: 21:08 Having that qualified caretaker who maybe isn't a family member, so you're not always relying on grandma and grandpa to step in and help. Have a list if two or three strong people you can reach out to, so you can get away and get that time

together. If that support system isn't there, then how do you focus on the marriage?

- Miguel Cervantes: 21:42 People don't understand. They see a kid in wheelchair, with crutches, or with special needs don't realize that all around that child is a plan of care, this schedule. The timeline goes on and it doesn't stop. These things have to be done, and someone has to do it. If this is a child, then it's the parent's job to do it. That happens every single day.
- Kelly Cervantes: 22:24 Every minute of every day.
- Miguel Cervantes: 22:25 Every minute of every day.
- Kelly Cervantes: 22:26 We have to schedule a time to be married.
- Miguel Cervantes: 22:30 In that schedule of medicine, you have to schedule a time to say, "This is also equally as important, if not more important, because if this team is broken, then how do we take care of this child and keep that team and our son and the rest of our family in line?" I've heard it from so many people, "Make sure you guys are okay because sometimes sicknesses can rip a marriage apart."
- Kelly Cervantes: 23:02 In fact, Adelaide's doctor told us that. He was like, "Make sure you have date nights." Well, babe, I love you. Thank you for keeping our team in line with me.
- Miguel Cervantes: 23:13 Listen, thanks for keeping me around.
- Kelly Cervantes: 23:18 I hope you understand more about being married with special needs children but, more importantly, about what helps Miguel and I keep our relationship strong on this epilepsy journey. Giving up is not a choice for us both in our marriage and our search for a cure. We love our daughter too much to do anything less.
- Kelly Cervantes: 23:35 That is why we want to ask you to help us. Please share this podcast with friends and family who face a similar situation. Let them know that they are not alone.
- Speaker 3: 23:52 The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained here 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.

Speaker 3: 24:10

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