Growing Pains: Living with a Sibling with Epilepsy
Seizing Life, episode 022 – Transcript

Kelly Cervantes:	00:10	Our guests today, Michael Axelrod and Marilynn Gardner are not only remarkable people, but they also have remarkable siblings. They will share what it was like to grow up with siblings who had epilepsy and how it affected their lives. Mike is the founder and principal of GPG Strategies, a Chicago based government affairs and business development firm. He is the son of CURE founder Susan Axelrod and a member of CURE's board. His sister Lauren, suffers from epilepsy. Marilynn is the president and CEO of Navy Pier. During her 20 plus year tenure, she made a significant impact establishing Navy Pier as a world-class cultural destination. She is the daughter of one of CURE's founding members and now a board member herself. Her brother Marty has epilepsy. Thank you guys so much for joining us today. I have to admit that when we first sat down in the conference room to try and plan out the episodes, this was immediately one that I was looking forward to, to have you both as guests obviously, but the topic is near and dear to my heart as well. Having my neuro-typical son in addition to our daughter and just sort of being very aware of how all of this is affecting him. So I really do appreciate you guys being here today.
Kelly Cervantes:	01:29	With that in mind, what is your earliest memory of epilepsy coming into your life?
Marilynn Gardner:	01:37	Well, for me it was... I am 10 years older than my brother Marty, and I was then 11 years old when he had his first, they called it a convulsion, but many years later we learned that it was epilepsy, that it was a seizure. But that is truly my first memory of him sitting in the highchair, babysitter in the house, and then all of a sudden the babysitter is gone. My mother comes home from the hospital with Marty who had had the convulsion. Unexplained.
Kelly Cervantes:	02:16	It's terrifying I'm sure.
Marilynn G.:	02:17	Yes, very scary.
Kelly Cervantes:	02:18	You were old enough to be aware that something was wrong and something was scary.
Marilynn G.:	02:22	Right. And that there was nothing that could be done to help him in the moment, but then also we didn't hear an explanation.
Kelly Cervantes:	02:32	Yeah. What about you?

Mike Axelrod:	02:34	Lauren and I are about the same age. She's slightly older than me. I'd like to say have a a specific time that I remember. I've blocked out most of my childhood, I think predominantly as a result of that. So I'd say probably my first memories are in the junior high level and her having significant seizures, significant and long and intense enough that my mom would have to administer Ativan to sedate her. That's probably my first memory. Like I said, I think everything before that's been blacked out, not just involving that, but everything in general.
Kelly Cervantes:	03:32	So you could say the impact on epilepsy in your life was fairly significant.
Mike Axelrod:	03:40	Yeah. I don't think that's an understatement.
Kelly Cervantes:	03:47	Do you remember when you fully understood the impact that epilepsy had had on your siblings life?
Marilynn G.:	03:58	I think the most impactful thing for me, and I'll get emotional, is Marty is fully functioning, drives his car to work every day and works in a bank. He's worked in the same bank for some 15 years now probably. He went away to high school, he went away to college. All very normal things like the rest of me and my siblings, but periodically there would be a seizure that would set him back. Again, so very different than what your daughter and what Lauren goes through, but still as impactful. And then to be a young man driving to work and have a seizure behind the wheel and have a license taken away and fully understand that this is happening. So it's more in the adult stages of life where as an adult and a sibling you see the dramatic impact because he's not able to have the independence that the rest of us have been able to have. And there's probably always that fear in the back of his head, like in the back of all of ours, when is it going to happen again?
Kelly Cervantes:	05:24	And so where is he at now? Does he live independently? Is he-
Marilynn G.:	05:28	No, he lives at home with my mother who is in her 80s. And she still does take care of him though he does have much more independence than so many others who are affected by epilepsy. But again, there's always this fear and whenever there is a seizure, there's a setback. So he could live independently, but I think there is always the fear of the what if, when you're alone.

Kelly Cervantes:	06:07	And I imagine that’s something that you can relate to probably more so because he was leading this-
Marilynn G.:	06:18	Independent life, yes.
Kelly Cervantes:	06:18	... normal life, an independent normal life. And so you can sort of imagine yourself in those shoes having pieces of that stripped away.
Marilynn G.:	06:25	And it just keeps getting taken away from him over and over and over again. And that's where it's, how do we make this stop for him, and others like him, but then even more so for those who can't live any semblance of a life that we deem as normal and independent.
Kelly Cervantes:	06:45	Right.
Brandon:	06:48	Hi, this is Brandon from Citizens United for Research in 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.
Kelly Cervantes:	07:03	Mike, when did you first understand the scope of your sister's illness?
Mike Axelrod:	07:10	I remember the incident, I don't remember the exact... when it exactly was. I believe high school. Like I said, we're very similar age. And it's when she had a brain surgery to try to see if they could localize where it was coming from and perhaps even remove that part of the brain. And I remember first they took her off her medicines to force her to have seizures. This was still at a time when she was having sometimes numerous seizures a day. And then they did the surgery. I saw her afterwards, her eyes were swollen shut and bandages around her head and small wires, but accumulated, about this big coming out of her brain, while they forced her to have seizures. The disappointing thing was that they weren't able to localize it.
Mike Axelrod:	08:21	So I'm not saying it was all for naught, but there was no tangible outcome from that for her. But I'd say that was probably the first time.
Kelly Cervantes:	08:35	And how is Lauren doing today?
Mike Axelrod:	08:38	That's a complicated question I suppose. Cognitively, she's at a low level just because of what she's been through growing up.

		Her seizures through probably hundreds of different combinations and therapies have been controllable, which is great. And she's in a position where she is with other people, where she can feel normal for lack of a better term. And that's really great. But cognitively there's not going to be much improvement.
Kelly Cervantes:	09:13	Cognitively, what age would you say Lauren is at?
Mike Axelrod:	09:17	I would probably say, 10 maybe.
Kelly Cervantes:	09:23	My understanding is, and talking with your mom, I mean you grew up in hospitals, in and out of hospitals as your sister was going in. How do you think that your sister and epilepsy and all of that shaped who you are today?
Mike Axelrod:	09:39	Oh, I think it shaped about 95% of who I am today, for better and worse. On the better side, I think having a sibling that has significant or any health related issues just makes you more empathetic to people in general. And I think I am for the most part. But on the other side of things, there's a certain part of you that's robbed of your youth. Because it's very hard, I think, for a parent to give the attention that is needed medically to one sibling and still give the attention that is needed, not medically, but emotionally to another child. And I don't think that makes anyone a bad parent. I think it just is the situation you're dealt. I think it also is... To this day, if I don't hear from somebody right away or if I don't... If I contact my wife or something and I don't hear right back, or a friend or something like that, I automatically go to the worst and think something bad has happened or that type of thing.
Mike Axelrod:	11:02	I have no doubt that that relates directly back to the fact that, according to my mom, we'd have to get up in the middle of the night and she would go to the hospital and we'd have to go to a neighbor's house, or we'd have to go to the hospital with them and that type of thing. And anytime you didn't hear something, it was not a good thing. And so I know that that's still at the core of who I am. I'm not sure that will ever change, but decades later, at least I've I think started to understand how it impacts me.
Kelly Cervantes:	11:39	What about you, Marilynn? You sort of mentioned, I think that a lot of your brother's issues really started to erupt a little later in life, but how does that give you perspective as a mom?

Marilynn G.:	11:54	Well as a mom and also when Michael was talking, I was thinking too from my role in my job, and I certainly have the empathy but also am able to literally drop everything to deal with crisis situations and keep my cool. Which is something that, there's some of it that may be an aid, but also it's just the way that you have to operate.
Kelly Cervantes:	12:32	One thing I know that Miguel and I have tried to do is have separate time with Jackson, where he gets just us or one of us. So we're not like lugging all of Adelaide’s medical equipment around or things aren't subject to her health and how things are going. Is there anything else along those lines that either of you would recommend that might help the neurotypical sibling?
Marilynn G.:	12:59	I think that's commendable and it's something too that I try to do with my three children regardless of their abilities. So I think it is important anyway, but just continue to try to make things as normal as possible. I know there are always, you're going to get sidetracked just like we were, whether you were home or away, but it's the experiences as a family that kids will remember and we were fortunate to have that. My parents made a point to always bring the family together on holidays, and we'd travel as much as possible, and it's just that time as a family, but then the one-on-one time too is critical for any child.
Kelly Cervantes:	13:59	Yeah. What about you Mike? Is there anything that you would... Any specific things that you would recommend to the parent?
Mike Axelrod:	14:09	The one thing I would say that I think is pretty important from my experiences to mothers, to parents in general, is that it doesn’t…. that having a child with significant challenges does also significantly impact the other children.
Kelly Cervantes:	14:31	Of course, and not to minimize it.
Mike Axelrod:	14:31	I think just that recognition is one thing. Another is to listen to them because I think kids, if they feel that it is appropriate or okay… and welcoming, may be a better term. I think that they want to share their feelings with their parents. But I think a lot of times getting back to the empathetic part of siblings, they feel like they don't want to burden their parents or their parents have too much with the other kids.
Kelly Cervantes:	15:07	Yeah, I see that in our son.
Marilynn G.:	15:08	That is a good point.

Kelly Cervantes:	15:09	He just doesn't like... We try and keep a very open environment and try and get him to talk about it, but I think he is, I think he's afraid to burden us further or to make us sad.
Marilynn G.:	15:20	Right. And he sees the stress that you're under with it.
Kelly Cervantes:	15:24	It's such a tricky balance.
Marilynn G.:	15:27	And at such a young age you're able to recognize that.
Kelly Cervantes:	15:30	Mike, as you were growing up and your sister was having seizures, what was your friend's understanding? How did you communicate that experience with your friends? Were they aware?
Mike Axelrod:	15:41	Oh yeah. I mean, there was no misunderstanding about at least the fact that something was going on with her. I mean-
Kelly Cervantes:	15:52	Was that embarrassing to you?
Mike Axelrod:	15:53	Yeah, I think so and I feel guilty about that a little bit. I mean, it was embarrassing because you're so self-conscious as a teenager and hormones and everything else, and yes it was embarrassing. I feel bad saying that, but it is true. But friends can really... Real friends, true friends can really, really be lifesavers in some sense. And they can in some ways make up for some of the time and energy that's taken away from you by your parents. And it's not who are the cool people and all that kind of stuff, it's who are your real friends. And so I can say without a doubt that my good friends who I've carried and have carried me through that time, there's a 100% comfort level there. And so I can say without a doubt that that's one of the most important parts.
Kelly Cervantes:	17:12	What is your relationship like now with your siblings?
Marilynn G.:	17:17	Well mine, again, Marty is a fully functioning adult though who has epilepsy. He's funny, he's engaging, he's great to be around. But again, you always worry when, as you said, it will rear its ugly head again.
Kelly Cervantes:	17:38	And I imagine he is living with your mother, is there the main... The thought has to be in the back of your mind-
Marilynn G.:	17:49	What happens?

Kelly Cervantes:	17:50	What happens?
Marilynn G.:	17:51	Yes. And that is something that weighs on all of us. And it's neat to see Marty though, wanting to date and networking and things like that, then you hope that he's able to meet someone and be with somebody in the future and have a life much like the rest of us. But again, your mind always goes back to the what if?
Kelly Cervantes:	18:21	Yeah. And what about you and Lauren, Mike?
Mike Axelrod:	18:24	I mean, this is I consider a very good thing, but she's kind of got her own life now. You know what I mean?
Kelly Cervantes:	18:31	She does.
Marilynn G.:	18:31	She does. She sure does.
Mike Axelrod:	18:33	She has 500 friends, which she'll tell you about. She knows each of their birthdays and-
Kelly Cervantes:	18:38	Her boyfriends. [crosstalk 00:18:39].
Mike Axelrod:	18:38	... the boyfriends. I need a chart to keep up with that. And so she's got her own life going. I mean, it's great. I mean, I think that's the most gratifying to see is that she's created the life she has created for herself. But I think that her life... where she lives now, it really is what dictates my relationship and I think our family's relationship with her.
Kelly Cervantes:	19:11	Thank you both so, so much for joining me today and talking about your experiences. I really hope that it helps other families out there as they're navigating this all consuming world that epilepsy presents. Thank you.
Marilynn G.:	19:28	Thank you.
Kelly Cervantes:	19:32	There is no way children can fully understand the challenges their siblings with epilepsy face, but that doesn't diminish the impact epilepsy has on their lives. I'm grateful to Mike and Marilynn for sharing their stories. So that we can better understand their experience and learn how we can better support the siblings of our special needs children. For additional stories and strategies about how you can better manage epilepsy's presence in your family, please subscribe to Seizing

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Brandon:	20:10	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained here and it's 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 strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with the patient's physician, or other qualified healthcare professionals, who are familiar with the individual specific health situation.