Seizing Life, episode 100
Celebrating 100 episodes: Community, Impact, and Hope
Guest: David Axelrod
(Transcript)

David Axelrod:	00:11	Hello, I'm David Axelrod, a member of the CURE Epilepsy family, and this is the hundredth episode of Seizing Life, so we're going to do something a little different today. We're going to turn the microphone around on Kelly and talk to her about the lessons she's learned as host of this podcast, as an advocate in the epilepsy community, and about the important mission of CURE Epilepsy. Kelly, it's great to see you. Congratulations on this milestone.
Kelly Cervantes:	00:41	Thank you so much, and thank you for joining us today.
David Axelrod:	00:44	Well, it's always a pleasure, because you're such a good and old friend, and I actually remember exactly when you came into our lives. My wife, Susan, the founder of CURE, got a call. You were across the street in a hospital, but you knew about CURE Epilepsy long before you entered the epilepsy world.
Kelly Cervantes:	01:05	Yeah, that's true. I, in two lifetimes ago, worked at a restaurant where CURE was reaching out to host a New York City benefit. And I knew nothing about epilepsy, I knew nothing about CURE, but these people were really nice. They were from Chicago. I was like, "All right, let's-
David Axelrod:	01:25	We're all nice in Chicago.
Kelly Cervantes:	01:26	Right, aren't you Midwest nice? It's a real thing. I was like, "Okay, let's make this happen for them," And what I didn't realize is that two years later, I would have a daughter who was diagnosed with epilepsy the exact same week that my family found out we were moving to Chicago. And it was actually a fellow coworker of mine who was like, "Wait a minute, do you remember that organization? I think they were out of Chicago. They dealt with epilepsy. Maybe you should reach out to them and see if they can't help you." And so, I feel like my family's connection to CURE is kismet. It's just meant to be.
David Axelrod:	02:03	Well, I remember this because Susan told me about going to see you and Adelaide in the hospital, and how she walked around the block several times to steel herself for this conversation because she knew what a difficult road was out in front of you, and she knew more than you knew at that time. And it strikes me that you are now her on this podcast and elsewhere. You are talking to parents who are just starting this journey. How have you made that adjustment? How is that role for you?

Kelly Cervantes:	02:42	Well, first of all, if I could even dream to fill Susan's shoes, that would be an epic achievement. But it's a crazy turn. I'll never forget that visit with Susan in the hospital and she just sharing her wisdom and listening to me, and that's when I fully understood the kind of family that CURE Epilepsy could provide for me, and that is always what I hope to give to other families who are walking into this club.
Kelly Cervantes:	03:16	As you actually said to my husband, Miguel, one of the first times that you met him, you said, "Welcome to this club, I'm so sorry that you're a member, but we're so glad that you're here," and I'll never forget that either. It is, it's this club that you don't want to be a part of, but we don't have a choice in that, so let's welcome you, let's give you a hug, and let's do everything we can to make sure that you're as loved and at peace and prepared as you possibly can be, because epilepsy, it's a beast.
David Axelrod:	03:47	It is a beast. But you've taken this another step, because through this podcast, you're reaching not just one parent at a time, but many parents and others who are impacted by epilepsy at a time. What did you hope to achieve when you started this podcast years ago now?
Kelly Cervantes:	04:10	Yeah. When the marketing team came to me and said, "Okay, we have this grant, and it is to go toward awareness, and we want to create a podcast, will you be the host," it was a resounding, "Yes." I was like, "This sounds amazing." And the goal was to raise more awareness. It was to maybe lift CURE's profile, but it was also to be an educational tool, to be a resource for those families, and maybe even to reach beyond the epilepsy fold a little bit. Maybe we could find some topics that might interest people outside of the community, that might draw them in, that might help widen that net so that...
Kelly Cervantes:	04:53	It's an interesting thing. We spoke with Miles Levin a few weeks ago on an episode, and he talked to us about, so much of the epilepsy community is, we're singing to the choir, right, preaching to the choir, and the trick is to get outside of that. And I think one of the hopes is, yes, we can be a source of empathy, we can be a source of education for people within the community, but maybe we can also peak some interest from people outside of it too.
David Axelrod:	05:21	Because epilepsy is so misunderstood by people who haven't dealt with it, the pervasiveness of it, three million Americans grapple with it, the fact that a third of them have intractable cases of epilepsy that can't be easily controlled, and the impact

that has on people's lives, and yet, it doesn't get the attention that it deserves.

Kelly Cervantes: 05:50 And I think that that is largely because it affects so many people so differently. There isn't one situation. I mean, even both of us have daughters who are affected by it, but Adelaide was affected in a much different way than Lauren was, and it was still incredibly impactful on their lives. But that's entirely different from someone who is still able to have a professional life, to have a family. For them, it's more of this invisible illness. And so, it's such a wide-ranging experience for all of those that are affected, and it's really difficult to communicate that. But I think through this podcast, that's something that we've tried to do, is show this wide variety of ways that it does affect people.

David Axelrod: 06:40 How has this podcast affected you? We lived through this with you, the beautiful Adelaide, from almost the beginning to the end. Is it hard to talk about epilepsy? Is it cathartic to be with others who understand? Tell me how you think about that and how you feel about it.

Kelly Cervantes: 07:13 It is incredibly cathartic. It's interesting. I was talking to a friend last night whose daughter has epilepsy, and I was asking her how her daughter was doing, and she was like, "Oh my goodness, I'm so sorry. Is this hard for you to talk about this?" And I was like, "No, this gives me life. This is my purpose." And in some ways, over the course of Adelaide's life, you bring in all of this knowledge. I know so much about the brain and seizures and all of these terms. And then, after she died, they're just swimming around in my brain, not tethered to anything, but being able to use that knowledge, to direct it somewhere, be it through a conversation with a friend, or a patient, or through the podcast. It gives me a sense of focus, it gives me a sense of purpose, and I'm grateful for this community every day. My daughter may not be here anymore, but I will forever be an epilepsy parent and caregiver.

David Axelrod: 08:19 How do you balance your story with the need to give people hope?

Kelly Cervantes: 08:27 Yeah, that is a tough one. And I'll have parents who are newly diagnosed... their child is newly diagnosed with infantile spasms, reach out to me, and I'm like, "We are the worst case scenario. This is not how it always turns out." And it's hard, but what I can show them is that even in that worst case scenario, that I still have hope for the community as a whole, that I am still fighting, that there are organizations like CURE Epilepsy who, decades into this, are not going to give up. And that, I

		think, is the hope, is that really, really crappy things can come of epilepsy, and we can't deny that, and to deny it is a disservice to us all. But there is hope to be had through research, and I think it's redirecting the focus.
David Axelrod:	09:23	You say there are organizations like CURE Epilepsy, but I'd argue that there aren't, that CURE Epilepsy is unique because of the focus on research and the unwillingness to accept the status quo, and there is hope in that.
Brandon:	09:45	Hi, this is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over $85 million to fund more than 270 epilepsy research projects in 17 countries. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.
David Axelrod:	10:06	Now you are a past master on all of this stuff, tell me what you've learned that gives you hope about the research that's going on and some of the work that CURE Epilepsy is doing.
Kelly Cervantes:	10:20	Oh my goodness. I feel like we are at such an exciting moment in epilepsy research, where there is some incredible studies that CURE has been in part of, initiatives like the Infantile Spasms Initiative, for example. So just as I was coming into CURE, they were wrapping that initiative up. And I feel like so much of science is this push, push, push, and then you have to wait forever, and it can be really frustrating. But we are now seeing some of the results that came out of that study. Those scientists are getting these larger NIH grants and they are making real progress. It is not out of the foreseeable future that we could have a new treatment for infantile spasms, and how freaking exciting is that? We haven't had a new treatment for IS in years, decades, even. And now, we could, potentially, because of science, that CURE Epilepsy initiated.
David Axelrod:	11:18	Yeah. And what was unique about that particular initiative was, it brought scientists from many different disciplines together who often are in their silo, and it brought them together to share ideas and approaches, which is really an innovative approach to research.
David Axelrod:	11:37	Well, if those advances come, what a tribute to Adelaide, because your efforts will have made a big difference. So I think about that all the time, about our daughter, Lauren, and Susan's work, and the best thing we can do to honor her is to spare others from what she's been through, which leads me to the question about the podcast. You've done now, these hundred episodes, and you must have heard some incredibly moving

stories. What were some of the most memorable exchanges that you had or people that stand out in your mind?

Kelly Cervantes: 12:21 Oh my goodness. I have always loved speaking to people with epilepsy, those human interest stories, and especially, I think of Channing, who is still horseback riding and still skiing, and finding these ingenious ways to still live their life and understanding that their epilepsy is still a disability. It still puts these restrictions on their life, but finding ways to live full lives within those restrictions has always been just... I think it's such an important message to get out there, because I think whether it's parents, whether it's an adolescent, a teen who's been diagnosed, being able to show that, yes, this sucks, hands down, this is really, really crappy, but it doesn't have to ruin your life.

David Axelrod: 13:24 Yeah, and it must mean something to you, to talk to people who can describe their experience, because Adelaide couldn't. Even Lauren really can't articulate the experience of having epilepsy, so yeah, I can see where that would be really meaningful to you.

David Axelrod: 13:43 You mentioned earlier the fact that CURE Epilepsy provides grants, often to scientists who have very venturesome ideas about how to approach epilepsy, which is needed because the existing ideas haven't been adequate, but they can't get funding because they're not proven theories. Well, CURE Epilepsy provides the grants to allow them to prove their theories and go on to get grants from the National Institutes of Health and other funders.

Kelly Cervantes: 14:22 Yeah, it is one of the things I am most proud of CURE for doing. It is these young researchers, these researchers who are early in their career, they have these big ideas, these really interesting, but not proven ideas, and CURE always makes sure that the science is sound. It is a very rigorous process for our grant reviews. And in fact, there are other organizations out there who look to CURE to model their grant review process off of ours, and we act as a mentor in that way, so it is not as if we're just throwing money out there to whatever hare-brained idea comes across. It has to be founded in legitimate, scientific-backed research.

Kelly Cervantes: 15:09 But it is these ideas. We need those big ideas. I don't know, how many families have heard the horse and the zebra comparison where a doctor is like, "Don't look for the zebras, look for the horse," when they're talking about a diagnosis. But when you're dealing with something as wild as epilepsy, you have to look for those wild zebras, and the research has to be in those wild zebras. It has to be in these outside the box thinking, and that is what CURE is funding. And if we don't fund it, no one else is, and it's a huge responsibility. But then, we do. You fund something, and it catches on, and there's this promise of something else there, and then it takes off. And it is the CURE Epilepsy seed money that is propelling this larger research, and it doesn't happen if we're not here.

David Axelrod: 16:06 It's funny that you should mention zebras because one of the earlier CURE grantees actually used zebrafish because they have a particular neurological system that was good for this kind of experimentation, to rapidly test the efficacy of epilepsy medications. That was a CURE grant.

David Axelrod: 16:28 Speaking of these researchers, we came through a very difficult period, and your podcast has as well, because of the virus and COVID. I want to ask you in a second how you navigated that with the podcast. CURE funds labs around the world. Many of them had to close down because of COVID, and some of the experiments were spoiled by that, and CURE played a role in keeping many of these researchers and many of these labs alive.

Kelly Cervantes: 17:12 Yeah, COVID had a real serious threat to set epilepsy research back years because these animal models were going to be lost. Because of proper COVID restrictions, people weren't able to get into their labs, and in some ways, money could be a bandaid there. And CURE was able to step in and provide the opportunity for grants, to just help keep the lights on in some of these labs, even when the institutions, because it was necessary, had to make these restrictions because of COVID, and CURE was able to help bridge that gap. And hopefully, a lot of research wasn't lost because we could step in and help. And that's a really cool thing about CURE Epilepsy, because we're not this monstrous organization, we can be nimble, and we can think on our feet, and if there is a need in the community, we can jump in and help.

David Axelrod: 18:13 Yeah, and I think another element of this is that CURE Epilepsy has not only kept labs running, but it's kept young, very gifted researchers in the field. And I know that's a focus, to provide funding for some of these young, brilliant researchers who could be doing any number of other things, want to work on epilepsy, but weren't able to find funding to do it before CURE Epilepsy came along.

Kelly Cervantes: 18:42 Yeah, I mean, absolutely. If they can't find funding, then they're going to go somewhere else, and so, you have to give them the money to keep going, to keep their labs open, and CURE is there to help those young researchers, and to keep them invested in the disease, and it's incredibly important. They need money to run their labs and we can provide that.

David Axelrod: 19:04 Yeah, I do want to ask you about this podcast and COVID, because part of what makes this such a compelling podcast is the intimacy between you and the people you're talking to. How did you function, and how did you create that kind of connection when you couldn't be in the same room with people?

Kelly Cervantes: 19:31 Yeah, when we started the podcast, it was all done in Chicago, in our board member's kitchen, and that was great. I miss that. This is so amazing, to have you in front of me and to have that connection, but I think we all transitioned to this sort of Zoom life, and it's having those small conversations before the cameras start rolling. It is learning about someone and making those efforts, and technology is incredible. And in some ways, I think the force to go entirely digital with our interviews has also opened the doors. Now, we don't have to have someone in Chicago. I can talk to someone halfway across the world or in Texas or in California, and I now no longer live in Chicago. I'm in New Jersey, and so, it-

David Axelrod: 20:30 We regret that, but yeah.

Kelly Cervantes: 20:32 Yeah, well, me too, some days. But it's opened the doors, and I get to talk to so many more people, and share their stories, and talk to the researchers themselves in ways that we wouldn't have before. So yes, I do miss that intimacy, but I am so grateful for this push, because now, I've gotten to connect with and share the journeys of so many more people.

David Axelrod: 20:56 Now, you wear many hats. You're not just the host of this wonderful podcast, but you're the chair of the board now. I want to talk to you about one element of CURE Epilepsy that I think also makes it really distinctive, maybe not unique, but certainly distinctive, and that is, this isn't just a foundation, this is a movement that started-

Kelly Cervantes: 21:28 You quoting Hamilton on me?

David Axelrod: 21:30 Geez, maybe I am. I will be singing and dancing before the end of this podcast. But the fact that you, as someone who lost a child to epilepsy, and so many others who are involved are people who have suffered the pain and the devastation that epilepsy can create, I think adds a sense of mission that is so powerful. I would say the thing I learned most from this experience is that there's nothing more powerful than a love of a mother.

Kelly Cervantes: 22:17 No, there isn't. I never ever want anyone to have to go through what my family and what my daughter did. But it is, it's happening every day. There are families being diagnosed. I'm active on social media, and I connect with families, and I watch their children, and some of them pass away. I don't believe that things happen for a reason because I cannot figure that out, how what happened to Adelaide could have ever happened for a reason.

Kelly Cervantes: 22:59 However, I can make it mean something after the fact, and that is what CURE Epilepsy has provided me. Yes, I am the board chair, yes, I host this podcast, yes, we do fundraising, whatever we can, but anything that I have given to this organization is paltry compared to what the organization has given me and given my family in terms of purpose and drive and fulfillment. And it's that give and take. It's the community that I got. From the moment we stepped foot in Chicago, it is that community that carried me through Adelaide's illness and has lifted us up, even after her death. I don't have the words, and I'm usually pretty good with words, for what this organization has meant to me.

David Axelrod: 23:53 Well, that sense of community is something that we all cherish, all of us who have suffered through and watched our children in pain. But you are good with words and there are people who need to hear these stories beyond the epilepsy community, people in positions of power, people who have the ability to fund the kind of research on a large scale that's necessary. And so, these testimonials from people like you are really, really important and meaningful, and I think CURE Epilepsy has changed the dialogue and the discussion in the scientific community and the policy community about the urgency of epilepsy research.

Kelly Cervantes: 24:42 Oh, there's no question about it. I mean, before Susan founded CURE Epilepsy, no one was talking about curing the disease. No one thought that that was possible. It wasn't even on the table. And Susan comes in and says, "Excuse me, no, the treatment is not good enough, we need more research, we need to find a cure, there has to be a cure," and she completely changed the way we communicate about this. Prior to CURE Epilepsy coming in, SUDEP wasn't a conversation. It was hidden in the shadows. No one wanted to acknowledge that it existed. There certainly wasn't research specifically looking at SUDEP and-

David Axelrod:	25:24	Explain what SUDEP is.
Kelly Cervantes:	25:25	Sudden Unexpected Death in Epilepsy. So it just wasn't talked about, and then CURE comes in, funds some research, and now you see it as a platform in multiple epilepsy organizations. There is significant more research. There has been larger grant funding research in the SUDEP space, and it was CURE that raised that. It's CURE's ability to shine this spotlight on a specific part of the disease state and then have that lifted up by the community, and people pay attention in this epilepsy space. When CURE focuses on something, everyone looks to see what we're focusing on.
David Axelrod:	26:09	Yeah, yes, absolutely. But I do think it is the passion of people for whom this is a personal mission, a personal cause, that has helped make that so.
David Axelrod:	26:21	Other disease groups have benefited from high-profile celebrities who stand up and identify themselves with a cause. I mean, the Michael J. Fox Foundation is the most obvious example of that, but there are many others. Epilepsy really hasn't had that. We were blessed by Miguel's presence here when he was in the production of Hamilton here, and he was quite the local celebrity, and obviously, an incredibly gifted performer, and his participation helped lift us up. But I guess it's because of the stigma that we have to defeat, that epilepsy is somehow some sort of character deficiency or whatever it is. How do we attract more prominent people to this cause, to help lift it up further?
Kelly Cervantes:	27:21	Yeah, and how do we get more of them here prior to something tragic happening? I think of the amazing work that the Cameron Boyce Foundation has done, and Libby and Victor Boyce have done an amazing job, but it is-
David Axelrod:	27:37	Cameron died-
Kelly Cervantes:	27:37	Cameron passed away from SUDEP-
David Axelrod:	27:39	... [inaudible 00:27:39].
Kelly Cervantes:	27:40	... just a few months before Adelaide passed away, and it is unbelievably tragic that it took his death for that to... I hope that we can come to a place through advocacy, through people sharing their stories. And Miguel has a platform, you, sir, have quite the platform. It does. It takes these people with these

		larger platforms to share their experiences, but it doesn't have to be the celebrity. It can be the everyday person-
David Axelrod:	28:20	Well, we've seen that.
Kelly Cervantes:	28:21	... who is open and willing to talk about it, to not hide it, and whether it's sharing it on social media, being comfortable to share it in their social circle. But we have to support them and give them the information so that they do feel confident and comfortable. And yes, we can rely on the people at the top with the platforms, but I think that this is a grassroots effort and it really has to start with the people who are affected every day.
David Axelrod:	28:49	Hence, Seizing Life, which is a part of that effort. And you're taking to the written word as well. You're writing a book, and that will be another important lever to get people to focus on this issue.
Kelly Cervantes:	29:04	Yeah, so Normal Broken will come out little ways away, November of 2023, so I'm in the final stages of writing it, due to my publisher soon. But it's about grief and the grief journey. And my grief journey of losing my daughter started long before we said goodbye to her physical body. Epilepsy can force you to grieve some normalcy and these typical life moments that you just sort of expect, and so, I was grieving her long before.
Kelly Cervantes:	29:42	In fact, I remember, it was probably a couple days before she died, and I turned to my mother and I asked her, "Do you think all of this time that I've been grieving, will that count as time served toward my future grief sentence?" And she was like, "Yeah, Kelly, I don't think it works that way," and it doesn't. But I'm hoping that this book can be a companion of sorts to meet people wherever they are in the grief process, because it is not linear. It is a deranged chicken dance.
David Axelrod:	30:15	Well, and in fact, the darkest place for a parent who has a child, who is going through really severe epilepsy is the what might have been place, the dreams that never will be place. You try and avoid it at all cost and be grateful for every good minute in every good day that you can find.
Kelly Cervantes:	30:41	But it's hard not to. I call it being lost in the hads, lost in what you had, in the dreams that you had for your child or for yourself, if it's affecting you personally. And it does, grief came into my life with epilepsy, and it has not left, and it never will. But I do, I hope that this book can help people, whether they are grieving an idealized life, whether they are grieving the loss

of a spouse or a parent or a child, and just be that friend that they need.

David Axelrod: 31:21 Well, I can tell you that we have returns that tell me that you sharing your stories and exploring other people's stories here on this podcast has had an impact on people's lives, and we asked people to sign a digital card for you, so-

Kelly Cervantes: 31:43 Shut the front door.

David Axelrod: 31:46 I never heard that. That's got to be an Omaha expression, but we say it differently in New York, but that's where I grew up. But among the comments that people sent were these. Kelly has brought so much visibility to epilepsy and to CURE Epilepsy. She took a horrible situation and used it as a gift to help others. Your generosity, curiosity, and warmth ensure that important information about epilepsy is shared broadly throughout the community. Thank you for your tremendous commitment to ensure that the important stories are told. You gave us the courage to become advocates when we felt so defeated by epilepsy and infantile spasms. You are bringing awareness and education to the world.

David Axelrod: 32:34 And then, finally, here's another one, although this is just a sampling. In you, the epilepsy community has found a formidable and tireless warrior who continues to educate, advocate, and inspire. Thanks for all you do. I only wish that that was my offering, because that's exactly how I feel about you. And just as we wrap up, I was lucky enough to know Adelaide, and I think she would be very proud of what you're doing.

Kelly Cervantes: 33:06 Thank you so much. That means so much to me, and it's, I mean, so much to hear that the podcast or the work, the advocacy, that it is touching people and it is reaching people. But I may be the face on this podcast, or the voice, but this is not my production in any way, shape, or form. There are all of these people standing around us right now who are the true drivers of this, who are out there, finding the topics and interviewing the people and sending me the notes so that I can look good and polished and like I know what I'm talking about, but they're the ones who are doing all of the work, and editing it together, and then getting all the social... I mean, this is-

David Axelrod: 33:53 And unplugging the refrigerator so it-

Kelly Cervantes: 33:54 Unplugging the refrigerator-

David Axelrod:	33:56	... doesn't make noise, yep.
Kelly Cervantes:	33:59	... so it doesn't make noise. I have so much admiration for CURE's MarCom team, specifically John Boston and Debby Hecht. This podcast would not exist without them. I am the face, I am the voice, and that is where my contribution to this ends. They are truly the players that make this happen.
David Axelrod:	34:18	Well, we are grateful to all of you, and I hope that you invite me back for the 200th anniversary.
Kelly Cervantes:	34:23	Yay. Will you, please?
David Axelrod:	34:26	Yes. I can't wait, I can't wait.
Kelly Cervantes:	34:28	Ah, I-
David Axelrod:	34:28	But I look forward to another hundred great episodes.
Kelly Cervantes:	34:31	I love chatting with you.
David Axelrod:	34:32	Thank you.
Kelly Cervantes:	34:37	Thank you, David, for joining me for the hundredth episode of Seizing Life, and a heartfelt thank you for all your support, and to Susan for her vision in creating CURE Epilepsy, which has led to groundbreaking research, built community, and provided hope to those living with epilepsy and their families. I also want to thank all the researchers, physicians, and community members who have shared their insights, expertise, and stories with us in our first 100 episodes.
Kelly Cervantes:	35:07	Hosting this podcast has expanded my knowledge of epilepsy and increased my admiration for the researchers seeking new discoveries and the doctors treating those with epilepsy. It has also deepened my feeling for this community, strengthened my resolve to advocate for epilepsy awareness, and inspired me to push for more research funding so that one day, we will have a cure for epilepsy. If you would like to support our mission to find a cure, please visit cureepilepsy.org/donate. Through research, there is hope. Thank you.
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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's specific health situation.