Kelly Cervantes:	00:10	Susan Axelrod is the founder of Citizens United for Research in Epilepsy, my mentor, and a dear friend. She's going to roll her eyes at me saying this, but in the epilepsy world, Susan Axelrod is a living legend. Around the kitchen table much like this one, Susan created CURE with other epilepsy moms. This grassroots organization blossomed over the next 20 years into the leading organization for epilepsy research. During that time, CURE has raised over $60 million and funded more than 220 research grants in 15 countries around the world. Talk about being a supermom. CURE has also been responsible for shining a light on SUDEP and infantile spasms, which were sorely ignored prior to CURE's efforts.
Kelly Cervantes:	00:55	Susan and I first met during one of Adelaide's hospital stays when she came to visit us. I will never forget the compassion and emotion in her eyes as she saw my infant daughter all hooked up, just as her daughter, Lauren, had been 36 years earlier. Susan, thank you so much for joining me today.
Susan Axelrod:	01:13	Thanks for having me Kelly. As I've said to you before and to so many other new moms, I've loved getting to know you. I love what you're doing, your energy, and your passion, but I so wish we weren't in this club together.
Kelly Cervantes:	01:31	Amen.
Susan Axelrod:	01:32	Yeah.
Kelly Cervantes:	01:35	I know you have told this story a thousand times and I'm going to make you tell it a thousand and one. Your Lauren was diagnosed at seven months old, which coincidentally is the exact same age Adelaide was when she was diagnosed. Take us back to that day.
Susan Axelrod:	01:56	Lauren was our firstborn child. Everything was going according to plan. Talk about “seizing life” - we had dates, we had expectations, I was in graduate school, I was going to complete my education. I had a baby, took three months off, started back to school. As you said, when she was seven months old ... She was perfect. By all measurements I could make, she was developing fine. She was beautiful, she was happy, she was friendly. All those great things.
Kelly Cervantes:	02:30	All of which she still is, I might add.
Susan Axelrod:	02:32	True, true, true. But she ... One night, I put her to bed. She actually had a cold and she had not slept for a couple nights. My

		pediatrician said to give her a quarter of an adult dose of a cold medication and maybe she'll sleep. I had an exam the next day, and all I needed to do was sleep. I put her to bed and she slept through the night, which was actually unusual for her, because she was usually still getting up once or twice a night. So, in the morning, I had to get going. I had to get to class. I go in the room and I see that she's lying on the bed. She's gray. I swoop her up, and I think that she's passed away. She is totally limp and then goes into a seizure. Well, I, like many of us, have never actually witnessed a seizure before, and didn't know what was going on. I knew it was not normal, but again, she's my firstborn and I'm thinking, “well, maybe I don't know.” One arm went up, her eyes rolled back in her head, she frothed at the mouth.
Susan Axelrod:	03:46	So I actually called my mom. I said this is what she's doing, and she said, “Emergency room.” I went, “Okay.” I get into gear, take my baby to the emergency room. I'm sitting, waiting to be seen, and she has another one of these episodes. They then inform me that this is a seizure. They whisked her off and do untold things like spinal taps and all sorts of things. I'm sitting there and I'm waiting. They come back in and they say, “We need to hospitalize her.” She continued to have seizures. I think it was very clear at that point she had seizures all throughout that first night. That first hospitalization, it was January, it was super cold. My husband will talk about walking back and forth to the hospital every day after work. I stayed with her. As you know, you don't ever leave a baby unattended in a hospital. She had just seized relentlessly. We were hospitalized for a month, and when they sent us home, she was still having about six seizures a day.
Kelly Cervantes:	04:50	Which is crazy to think about because the same thing happened with Adelaide. We never got seizure controlled. They sent us home and she's still having seizures. This is your first introduction to this and you'd think, “But how can you send us home? This isn't fixed.” You realize there's just no answers.
Susan Axelrod:	05:07	Yeah, and in my day and age, this was ... The epilepsy word, the E word, the big bad E word, was never brought up.
Kelly Cervantes:	05:15	You had mentioned that to me before. So, what did they tell you and when did you first realize that it was epilepsy?
Susan Axelrod:	05:22	She was diagnosed with an idiopathic seizure disorder, and I literally did not know for the first three years that I was dealing with epilepsy. Again, pre-internet, a long time ago.
Kelly Cervantes:	05:34	Right.

Susan Axelrod:	05:36	I saw a report on an EEG and it said something about epileptiform activity in the background, and I panicked. I called her neurologist. I thought we now had a dual diagnosis. Idiopathic seizure disorder and epilepsy. He sort of chuckled at me - we were friends at the time. He said, “No, they're the same. We just didn't use that word before.”
Kelly Cervantes:	06:03	It's mind blowing-
Susan Axelrod:	06:05	I know.
Kelly Cervantes:	06:05	... to think Lauren was three before you realized that-
Susan Axelrod:	06:10	Yes, yeah. And, you know, I didn't have an internet to sort of look up idiopathic seizure disorder, find out that it's one and the same with epilepsy, and that ... So, at any rate, we brought her home. She had been crawling, babbling a bit. She was always a little bit quiet, but babbling a bit, and now, she could barely sit up in her high chair. Medications, the impact of by then, I don't know how many seizures - thousands of seizures.
Kelly Cervantes:	06:44	Sure.
Susan Axelrod:	06:45	When we were outpatient, they'd suggested we try using Valium, benzodiazepine, so we introduced that to her regimen. We'd put her on the Valium and the seizures stopped. We were like, “Oh my god, we're done, we've cured her.” She wasn't in great shape. Her motor skills had deteriorated. But three months later, the seizures returned, and they returned with a vengeance. That's sort of was the pattern that we got into for the next 18 years.
Kelly Cervantes:	07:22	I've heard of that - sort of a honeymoon period where the drug will work, and then it just stops.
Susan Axelrod:	07:27	And then they get resistance.
Kelly Cervantes:	07:28	The brain finds a way to work around it.
Susan Axelrod:	07:31	Yeah, the seizures - damn seizures - they're pretty persistent. We'd started calendaring it. We'd get three months of control, it was about as much as we ever got. One time, we got 11 months and thought, “Oh my God, this is amazing.” And then she broke through again. So, for the first many years of her life, we were

hospitalized every single time. Again, I would go in, or my husband could spell me a little bit, but we never left her alone.

Susan Axelrod: 08:04 First of all, for her emotional well-being. But secondly, every time we did, something happened. Wrong medications, whatever, it was just too scary to leave her. So consequently, her two younger brothers were left at home with caregivers, with neighbors, whoever we could sort of drum up. Because the one thing we all know about epilepsy is it's not predictable, so you don't know what day you're going to have to rush off to the hospital.

Kelly Cervantes: 08:31 So you are in and out of the hospital trying to figure this out, trying to find control, and you finally did get control when Lauren was 18 years old. How?

Susan Axelrod: 08:45 She was in really, really bad shape, and she had been put on a number of different medications. Again, we were treating her at home, but at this point, her doctor who knew her well said, “I think you’ve got to bring her in. We've got to get an IV going.” It was the only time I think he has ever looked at me and I just looked at his eyes, and he said, “I'm not sure what else we can do.” I thought, “This is it,” because she was just seizing, seizing, seizing. He'd added everything he felt was safe to add. But Keppra had just come on the market. Now, I had just started CURE, and so knew that this was something in the pipeline. I'd just become acquainted with some of the people at UCB who manufacture the drug, and that had been our lives. Whatever new drug was available, whatever study drug we could get on, stick her on that.

Susan Axelrod: 09:46 So I called somebody I had come to know at UCB and I said, “When can I get it?” She said, “Oh my God, I'm FedExing you some samples tonight.” Got them, gave them to Lauren, and those were her last seizures.

Kelly Cervantes: 10:06 Wow.

Susan Axelrod: 10:06 Amazing. So those seizures that brought her into the hospital were the last seizures we've witnessed, and that was now 18 years ago. I mean, I don't know how or why. I wish we knew why that drug worked. That's one of the goals of research, just to be able to-

Kelly Cervantes: 10:27 And you don't have a diagnosis for her.

Susan Axelrod: 10:27 We don't have a diagnosis.

Kelly Cervantes:	10:27	You don't know what was ever causing her seizures, so there's just no way to know.
Susan Axelrod:	10:33	Yeah.
Kelly Cervantes:	10:34	It's no wonder you started CURE. But you are the mother of three children, you have a special needs child, your husband is traveling a ton. How in the midst of all of that are you like, “Okay, I'm going to start my own non-profit”? And not just “I'm going to fundraise.” You're funding research. This is a lot of work. This isn't just going out and throwing fundraisers. You're raising money and then you're finding research projects and grants. I mean, this is no small feat in the midst of all of this. Where was it born from?
Susan Axelrod:	11:17	You know, it was born from the desperation that we all feel, those of us whose kids had not responded to medications and whose lives are being just destroyed, if not lost. It came from slowly (again, talking about my age and how long ago this was) meeting other moms. The power of moms. One of the physicians who was on our board when we first started used to say, “There's nothing like an angry mom.” And I used to say, “We're not angry, we are desperate.” To me, there's a difference.
Kelly Cervantes:	11:55	There's a big difference, I agree.
Susan Axelrod:	11:57	I started to meet these other moms, and we started to do some fundraising for support groups and things like that. Then we really started talking and learning. I thought Lauren was the only one out there who didn't respond to medications, I honestly did. I thought epilepsy had certainly been cured and solved by now and I just had this flukey child. Fast forward to meeting some moms and I'm like, no, there's a lot of us. There's a lot of us. It's a spectrum. There are some who lose their lives, there are some who can function fairly well, there are some Laurens sort of maybe in the middle there. I mean, so the impact is very variable, but we're all struggling, and we all want more for our kids.
Kelly Cervantes:	12:52	So how do you get from moms around the kitchen table to actually funding research? There's a lot of work that has to be done in between. You were not scientists. You can fundraise, but there's a big difference between fundraising and choosing grants, and getting the grants submitted.
Susan Axelrod:	13:11	Absolutely.

Kelly Cervantes:	13:11	So how did you get from point A to point B?
Susan Axelrod:	13:13	I have been known to say - people would say, “What was your business plan?” I said, “There wasn't one.” We started and I think one of the most remarkable things that's happened is we had so many friends who watched our lives, watched our lives with Lauren, and wanted to do something. Friends that had skills, talents, and expertise in certain areas. Not in science, not in epilepsy certainly, but were just absolutely ... They just felt so frustrated because there was nothing they could do. So initially, one of those friends connected us with our attorney, who drew up our first incorporation papers.
Kelly Cervantes:	14:02	And all pro bono?
Susan Axelrod:	14:03	All pro bono. So that was a tremendous step.
Kelly Cervantes:	14:07	Wow.
Susan Axelrod:	14:07	So she was doing that, getting us registered as a non-profit. Subsequently, we've had all sorts of people just donate strategic planning, donate marketing research, donate event planning, you name it. It is a way for people - and I would encourage everybody out there. We all know somebody who can help. It's not always about dollars, but those gifts have enabled us to put the dollars we raised-
Kelly Cervantes:	14:40	Gifts of service.
Susan Axelrod:	14:40	... more directly into research.
Kelly Cervantes:	14:42	Right.
Susan Axelrod:	14:43	Of course we hoped it would help our own children. But the hope was it would lead toward better understanding of the disease and better treatments, preventions, and cures.
Kelly Cervantes:	14:55	I think that's sort of my next question. What were those early goals? You wanted the move the ball forward, but what did you think was going to come out of it? Where did you see it going?
Susan Axelrod:	15:07	I'm sure all of us who were involved in the initial founding of the organization had different expectations. But mine really were ... I had maybe given up hope for Lauren. Here, maybe I was a little pissed off that nobody was looking at this disease and what caused it. It was just sort of this acceptance.

Kelly Cervantes:	15:27	There was no other organization like this out there doing this research.
Susan Axelrod:	15:33	That's right. There wasn't a voice out there saying my kid ... I mean, I really thought I was alone. There were no people. We know that a third, that's an estimate, but a third of patients are intractable. So where are those people, where are those voice? That's-
Kelly Cervantes:	15:47	And now we can find them on social media.
Susan Axelrod:	15:50	Right.
Kelly Cervantes:	15:53	There's this other connectivity. But you didn't have Google, you didn't have a Facebook social group to find those parents.
Susan Axelrod:	16:01	Yeah, and I will say one of the most amazing things to me, apart from the moms and the dads I've met, is relationships developed (I don't think we can speak enough about this) between parents, family members, researchers, and clinicians. That was a very unexpected benefit, but I think it has really sort of made a cohesive community. I think that for the doctors, they were sort of operating in this vacuum without their cheerleaders, without people saying this is the important work. You’re working on these rats, making them have seizures, trying to develop things. But nobody is saying, “Go, go, go.”
Kelly Cervantes:	16:49	Right. So that sort of kind of leads me into my next question. I know you fairly well at this point, and you are a bit of a perfectionist. I know the fact that you've been at this for 20 years and we still don't have a cure for epilepsy is heavy on you, that that's hard. But CURE has accomplished so much. The epilepsy community and awareness, the research being done is so much further along than it was 20 years ago. Where are those changes? Where do you see that growth? What has changed in our community over the 20 years?
Susan Axelrod:	17:24	First of all, I think it's very clear we've made progress in genetic discoveries.
Kelly Cervantes:	17:28	Absolutely.
Susan Axelrod:	17:30	I, again, that needs to take us to the next step of the being able to diagnose, and then tell-
Kelly Cervantes:	17:40	That sort of precision medicine.

Susan Axelrod:	17:41	What is that precision medicine, personalized medicine, what is going on, which is the core of what we want to accomplish in some ways. There are new discoveries all the time in the genetics of epilepsy, so I want that to start leading now to better treatments and answers for the kids. I mean, my heart is with the kids, but we really ... The research we do will hopefully help everybody, no matter what they're age or when the onset of epilepsy happens, because we know that can begin at any age. So, I think that's a scientific progress that can't be denied, that is definitely going forward. That really sort of reinforces my core belief, which is that we need to understand the why, to develop rational and more effective treatments that don't just obliterate our kids' brains.
Kelly Cervantes:	18:39	True.
Susan Axelrod:	18:39	And so I think that's really important. I think we have gotten the word out there a lot more that people are struggling, people are suffering. Epilepsy is not a sexy disease. It hasn't had the public persona of all these other diseases, and so we've really had to fight for our space. Within neurology, it's one of the most common diseases, and yet the budget certainly didn't reflect that. I think we've made progress in that, we've certainly opened up the field of sudden unexplained death in epilepsy.
Kelly Cervantes:	19:16	SUDEP.
Susan Axelrod:	19:16	Yes, SUDEP, which was never, ever even talked about. Doctors didn't talk to their patients about it, and really thanks to one of my personal heroes, Jeanne Donalty, whose son Christopher passed away from SUDEP - she called the NIH and they didn't know anything about it. She really spearheaded this whole program, which has now taken off. You know, I think as a relatively small research organization, I know we're the leading research organization-
Kelly Cervantes:	19:49	Which says something in and of itself.
Susan Axelrod:	19:50	Yeah, we've worked our tails off, and if you compare our budget to that for other diseases which affect even fewer people, and maybe affect them later in life, it's still paltry. We really need to do much better with that, but we have opened up a lot of fields. In addition to SUDEP, we have focused on infantile spasms, in part because that is, as you well know, a potentially really devastating diagnosis. But also, one of the things we've tried to do is carve new paths in the way research is done in epilepsy, and a lot of other fields, we're doing team science. With our infantile spasms program, we invested in a group of researchers

		who *had to*, we forced them to, come face to face and work together on this problem. So basic researchers and clinicians, we really tried to facilitate communication. This is working in your rat, how is this working in your babies? And really get that moving.
Kelly Cervantes:	20:56	It's mind boggling to me that science doesn't do that already - the researchers, how proprietary they are over their research, and how it's just not for the greater good. I think those are two aspects that CURE has found these needs and shined this bright spotlight so that other organizations kind of come in and take that, and CURE can move on to the next thing. But also, this idea of enforcing that team science, it's just ... I think CURE has done so much for our community, for science, and research in general. Is there anything in particular that you are the most proud of?
Susan Axelrod:	21:37	One of the things that we have really loved doing is funding young investigators.
Kelly Cervantes:	21:42	Right.
Susan Axelrod:	21:43	We rely on all the people who are established in the field, and they have done tremendous ... They've just been a tremendous support to us, helping to review grants and select the best work. But bringing these young people in, and then when you see some of the areas that they say ... Because we pride ourselves in being the risk takers, within reason, but we want to invest in new ideas.
Kelly Cervantes:	22:11	Right.
Susan Axelrod:	22:12	And simultaneously build the pipeline of researchers for the next generation. So, some of these individuals have just had tremendous success, and it's opened up just new fields and new ways of looking at epilepsy, which I think is critical, and they can't do that with government funds. This is a critical space.
Kelly Cervantes:	22:32	No, they want a more solid return on their money. CURE can take those risks.
Susan Axelrod:	22:37	And we have to sort of tell people we're willing to do that. Along with that, we also have to expect there could be failures. I mean, that adds to our body of knowledge.
Kelly Cervantes:	22:49	It's not lost on me how parallel our stories are, that I am one year younger than Lauren, and how that has impacted our

		friendship. I see the work that you have done and I am just always in awe of you. So, to that point, taking your lead, where do you want to see CURE go? Where do you want to see the epilepsy community push forward? Where do you want us to be 20 years from now?
Susan Axelrod:	23:35	Out of business.
Kelly Cervantes:	23:36	Yes.
Susan Axelrod:	23:38	Could we do that please?
Kelly Cervantes:	23:41	I'll second that.
Susan Axelrod:	23:42	Yeah, I think I'll still be on the planet at that point, and I'd like to just say, “Hey, I'll be there for the celebration.” I think that we are on the cusp, maybe another 5 to 10 years, of being able ... As we know, epilepsy is many, many diseases, so we can't say we're going to cure it all. But let's start tackling them, and that's what I'd like to see happening. That's one of the reasons we've sort of approached infantile spasms or SUDEP. Let's zero in on this. Or prevention of epilepsy after a head injury. This is a known risk factor, these are known things. Let's get smart here and sort of figure out how we can tackle this. Break it into pieces-
Kelly Cervantes:	24:26	Stop it before it happens.
Susan Axelrod:	24:27	Stop it, right. Exactly.
Kelly Cervantes:	24:28	Or know exactly what treatment is going to work for that specific epilepsy.
Susan Axelrod:	24:33	Exactly. More funds are desperately needed, and I don't want anybody to think that that's not the case. However, I do want to make sure that it's focused. I think our impact has been really significant and there are other people, and hopefully, pharmaceutical companies, etc, that will be interested in development of therapies. But if we can lay the groundwork for them and be really smart about what we're doing - I just want to get to the point ... On my way over here this morning, or actually before I left this morning to come here, I had opened up my email and there was another email from somebody asking: baby, just newly diagnosed. And as it was hard for me to walk over and see you and Adelaide that very first time, I just ... My heart breaks. You know, it's an infant. It just shouldn't be

happening. So, I want to see that number greatly diminished. It may be unrealistic-

Kelly Cervantes: 25:42 60 percent of patients who don't know why, I think, to your point. We've got to make a dent in that number.

Susan Axelrod: 25:48 Yeah, and I want to see - I think the community that you're building with this podcast and your work in bringing people who are, yes, younger than my daughter, into it as support. Because we didn't have that, so we found each other just by happenstance. But it's huge what can happen, the power.

Kelly Cervantes: 26:12 There's power in numbers. Susan, thank you so much for talking with me, for being a friend and a mentor, and we are all indebted to you.

Susan Axelrod: 26:22 I'm all in, so thank you for what you're doing. I appreciate it.

Kelly Cervantes: 26:26 I adore you.

Susan Axelrod: 26:27 Thank you.

Kelly Cervantes: 26:30 For the fundraising, advocacy, and research Susan has contributed over the last 20 years, a simple thank you fails to suffice. To me, she will always be a symbol of hope that through research, a cure can be found. But as Susan has stated, in spite of all of her efforts, so much more remains to be done. If, like me, you cling to hope for a cure, then we need your help, and that can be as simple as staying informed. You can learn more about the research by CURE, and our community, by visiting seizinglife.com/research. Finally, don't forget to visit and follow @SeizingLife podcast on Facebook and Instagram, and @SeizingLifePod on Twitter. Thank you so much for listening today.