Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and welcome to Seizing Life. My guest today is Stacey Pigott. Her experience as the current research chair for Citizens United for Research in Epilepsy, CURE, gives her the unique ability to help make epilepsy research more accessible, which is our topic for today. Stacey is the mother of Evan, Henry, and Ava. Additionally, she is the chair elect for CURE. Stacey, thanks so much for coming back and chatting with us again.

Stacey Pigott: 00:38 Glad to be here.

Kelly Cervantes: 00:40 Tell us about your role on the research committee with CURE.

Stacey Pigott: 00:46 I'm currently the research chair, the research committee. It's a group of board members, non-board members, past board members, thought leaders that usually have some kind of personal connection to epilepsy, and they help guide and give us feedback on our research programs and helping provide us with a consistent patient perspective in the research.

Kelly Cervantes: 01:12 Which I think is important to know because while CURE is very focused on research, it's patient-focused research, patient-centered research. That is really the goal and the mission of CURE's research. Your background is in education. How did you find a passion for the research side of this disease?

Stacey Pigott: 01:39 It was really nurtured at about 2:00 a.m. Like a lot of other epilepsy parents, when you get that diagnosis, and you not only get the diagnosis, but in most cases it's, "Well, we don't know why your child has epilepsy," and you get that first medication, which so many of us unfortunately have experienced with our child failing on that medication, and you take out the pamphlet and you see, "We don't know why this medication may or may not work," or, "Here are all the side effects that may or may not happen."

Stacey Pigott: 02:12 As a parent and especially as busy as, understandably busy as all of the clinicians are, your access to the doctors and the nurses usually come in with so many questions, and a lot of them are so heavy that you find yourself in the middle of the night unable to sleep and trolling the Internet trying to find any answer you possibly can. That's how it started for me of just seeking out answers and realizing that, in that research, sometimes I could get answers, but usually, it just caused more questions and just continue to drive that process.

Kelly Cervantes:	02:56	What advice do you give to the parents out there who themselves scanning these research papers at 2:00 a.m. and not really being able to make heads or tails of it?
Stacey Pigott:	03:06	For myself, I was very lucky to have some mentors within CURE who really answered some of those basic questions like that you're asking me right now. For starters, you have to have a healthy acknowledgement that you are not a neuroscientist. You will never be a neuroscientist, and there are just some things you need to let fall away, that you are not going to be able to compete in understanding with someone with a scientific background.
Stacey Pigott:	03:37	From there, I think it usually starts to with what's your motivation, what are you looking for? I always find if I'm targeted in what I'm looking for, I read the research better. If I'm looking up a specific medication and what interactions may be with other medications or what the mechanism of that medication is working, whatever it may be, if I'm looking at mechanisms of epilepsy, if I'm looking at something specific on, say, genetics that it just really helps.
Stacey Pigott:	04:07	I always start with looking at the abstract. That introduction to the grant is usually kind of a lay summary of what that research proposal is about. Lean onto that heavily and really dig deep into that. That kind of abstract as well as the conclusion are where I'll focus my energies. I also, one thing I've also learned from a lot of other mentors was look at the model. Is it a mouse model, for example? Well, mice epilepsy and human epilepsy are not always the same thing, so you also-
Kelly Cervantes:	04:46	Interesting.
Stacey Pigott:	04:46	... have to recognize that some studies can be impacted by the model that they're using. Anytime you have a study that's using, that's a clinical study or is using human tissue, you can have a little more of an insurance that it's a applicable study to the patient.
Kelly Cervantes:	05:11	Right. Explain what a model is to [crosstalk 00:05:13]-
Stacey Pigott:	05:13	The model is just in the lab, what the scientists are using to study whatever it may be that they're studying specifically. For example, what has historically always been done are rats and mice. The only problem is, is that they have to often create epilepsy in a mouse, and that doesn't always mimic what

		happens to a human, so depending on what the study is looking at, it may not always apply as clearly as it should.
Kelly Cervantes:	05:49	They have to create the model, they have to create the epilepsy in the animal before they can then proceed with their study about that specific epilepsy-
Stacey Pigott:	05:59	Correct. Correct.
Kelly Cervantes:	05:59	... which is a whole other step in this research-
Stacey Pigott:	06:02	Whole-
Kelly Cervantes:	06:02	... process. Yeah.
Stacey Pigott:	06:03	Huge. It's a huge challenge for the field to be able to come up with an accurate model. It's always very exciting when a group of scientists are able to find some kind of animal model that has an epilepsy that matches up with a human epilepsy. That's very, very tricky. Luckily, there's some great progress being made. One CURE researcher, Scott Baraban, started with zebrafish, and that's been a fantastic model and has been really exciting to kind of... He still continues to use that model, and that's really taken off. That's something to always think about.
Brandon:	06:46	Hi, this is Brandon from Citizens United for Research in Epilepsy, or CURE. Since 1998, CURE has raised more than $60 million to help fund over 220 cutting edge epilepsy research projects in 15 countries around the world. Learn more at cureepilepsy.org. Now back to this episode of Seizing Life.
Kelly Cervantes:	07:03	What have you taken from your interactions with the scientists because not everyone gets to meet the people who are doing the research that are out there trying to find the answers for our loved ones. What is that experience like to be able to communicate with them and also to be the one who tells them that we're going to fund their research? I mean, you're in a really cool position.
Stacey Pigott:	07:26	It's been really fun. That has been probably the best day at CURE that we have that I know you've been in on as well as to be able to call a scientist and congratulate them that they have received funding for their research. That is always really exciting. It also is really exciting to always give them that patient perspective. Just as we approach the research with a patient perspective, when I'm communicating with the scientists, it's very easy to just thank them for what they're doing for our kids

		and our loved ones. Likewise, they're really happy to have that feedback, to have a face go with that research. It helps focus them as well. It's always a really great interaction, mutual admiration for what one another is going through in supporting. That's been great.
Kelly Cervantes:	08:24	I think for many people, they're aware very macro-level, CURE's mission is to raise money for research, but a lot goes into that, so the money is there, and now we're funding the research. How does CURE take it from that donation to a research grant?
Stacey Pigott:	08:45	CURE has always had a very singular focus on the research answering those questions that are plaguing us at 2:00 a.m. That's what draws I think a lot of our supporters, and I know it drew us to the organization. Once we're able to get a donation and we're able to use that money for research, the process starts with... we have a couple of different grant cycles. We get letters of intent from the scientists who send that our way with an intent to submit a proposal. If that letter of intent seems to fit within our mission of no seizures, no side effects, if we feel that it scientifically has potential and fits within our specific grant cycle, we then ask that a select number of grantees write or send in their proposals.
Stacey Pigott:	09:43	Once we get their full proposal, we have a process where we have a group of scientific reviewers who are friends of CURE in the field who have perhaps received grant money from us in the past or just have a longstanding relationship with the organization, and they so generously donate their time to read all of these different applications, every cycle. We have multiple scientists reading each application. We also have lay reviewers. We have a healthy cadre of lay reviewers who are just families impacted by epilepsy, and we ask them to look at the proposals through a different lens. We ask them to really focus on the CURE mission of no seizures, no side effects, and the patient perspective. That's what they analyze the proposals for.
Kelly Cervantes:	10:35	Once again, they're not expected to be the neuroscientist.
Stacey Pigott:	10:37	No.
Kelly Cervantes:	10:37	You have the neuroscientists doing that, but that patient focus comes through those lay reviewers.
Stacey Pigott:	10:45	Exactly, so we try to have that, both sides looking at a proposal. The lay reviewers and the scientists approach to the grants from two different angles, and we get them together on a conference

call for several hours and go through all of the grants with the scientists they've gotten to read and all the lay review reviews. The lay reviewers have gotten to read the scientific reviews, and they all kind of have a discussion about each grant and have the ability to change their scoring if they end up convincing one to a different score. We then take those averages, and we then take the highest scoring grants, and then we present it to our research committee. Our research committee goes over, reads through the grants, reads through the scores, and provides feedback to our research team led by Dr. Laura Lubbers, who is our chief scientific officer.

Stacey Pigott: 11:47 The research committee is able to provide another layer of feedback, and from there, Laura is able to make a recommendation on what we fund, taking into account all the scores, all the reviews, and then makes a recommendation to our board of directors. Then our board of directors, who also have access to looking at the grants and whatnot, then vote to approve those grants. It's a big process.

Kelly Cervantes: 12:18 Stacey, there's so many people involved just to get from point A to point B, and this is happening in multiple cycles a year. I mean, it's just... But it's incredible to me that that many people are involved in the decision that the process is that thorough and that through this, CURE funds some of the more out-there research, I would say, not necessarily your standard NIH grant, shall we say, the research that may be a little more difficult to find funding, but is still really exciting.

Stacey Pigott: 12:57 We have always sought to fund what we would call gaps in the field and look at things that other people are not, certainly maybe wanting to look at but just don't have the funds and ability to do so. Very early on, funding research into SUDEP was huge, absolutely huge. Through some really strong leadership by people like Jeanne Donalty, Gardiner Lapham, we were able to really address SUDEP within the field. I think that one of the first things that we did that usually CURE funds a lot of studies dealing with epileptogenesis, which is the mechanisms of how epilepsy starts in the brain.

Stacey Pigott: 13:48 But one of the early things that we funded was a big SUDEP registry in Canada. Canada was just given their healthcare system. They had a better mechanism for tracking patient data, and while we usually go a little more scientific on our grants, because there was such a lack of information about SUDEP, just being able to track patients who had sadly succumbed to SUDEP was really desperately needed in the field, and CURE was able to fund that, the great scientist Elizabeth Donner in Canada.

That's one example where we've found an early impact and did something that other groups were not doing.

Stacey Pigott: 14:38 As I had mentioned before about funding zebrafish as a new model, tons of examples where CURE has looked for gaps and funded things that at the time were a gap but have ended up becoming a major part of the field that is able to be taken up for example by NIH. A lot of times, we take a lot of pride when we're able to fund a group that almost seed, a group that can come up with the pilot data so that they then are able to apply to NIH and get even more funds and really let the research takeoff.

Kelly Cervantes: 15:19 To our supporters who are interested in learning more about the research or educating themselves or getting involved, what ways can they do that?

Stacey Pigott: 15:29 I always found that there's really couple of different ways that you can have an impact for myself in having all these questions around epilepsy. I found... and we all know the total loss of control you have when you have a loved one with epilepsy. It is happening at any time. It just overtakes your entire family, your entire life. Having an outlet where you can contribute, where you can make a difference helps to give you a little bit of control in an uncontrollable situation.

Kelly Cervantes: 16:11 I couldn't agree more.

Stacey Pigott: 16:14 To really make an impact, it's not just about reading the grants and educating yourself and learning about it. It's using that research to also make yourself a better advocate for your loved one, ask better questions of the clinicians when you're talking to them. You can... and that's why it's so critical too, when you have a clinician, you want to be an equal partner in that process and be able to advocate equally for your loved one of what medications they're on and so forth.

Stacey Pigott: 16:48 There is that piece to that, in order to do such great research, we desperately need money to do it, and fundraising is a piece of that. That's another way that you can really get involved, that if you want to see the research move forward and you want to have an impact, if someone wanted to be a lay reviewer for CURE, that's fantastic. We're always welcome to inviting new lay reviewers-

Kelly Cervantes: 17:20 And to be... that is not a Chicago-specific-

Stacey Pigott:	17:23	Correct.
Kelly Cervantes:	17:23	Our lay reviewers are all over the country.
Stacey Pigott:	17:25	All over.
Kelly Cervantes:	17:26	Yeah.
Stacey Pigott:	17:26	Right. Right. But likewise, the research isn't going to happen if we don't have the funds to do it, and organizing grassroots, from lemonade stands all the way through to big benefits, every dollar helps. That has a big impact as well.
Kelly Cervantes:	17:45	The average epilepsy parent/caregiver may not have all of the time in the world to be going out there and doing the research themselves. What resources does CURE provide that can help deliver the research to them?
Stacey Pigott:	18:02	I think, for starters, if people go on the CURE website, they can certainly go and look under Research and can see a lot of the different things that we're funding. You can also sign up by your email to get some of our research summaries, and those are fantastic where, daily, you can get an email summary of any new epilepsy research that has come out. It's not just our donors who are relying upon those updates, but we have a lot of our scientists who subscribe to those daily updates because they're using that as a way to get the latest news on epilepsy research as well. It's really become an awesome way to daily get just updated on what's going on. Then there's ways to dig deeper and read, but it is provided with the name of the research in a very quick lay summary of what that research accomplished or what their successes were. That's a really great way to go-
Kelly Cervantes:	19:07	Amazing.
Stacey Pigott:	19:07	... about it.
Kelly Cervantes:	19:08	We've talked about how exciting it can be to follow the research that's coming out. On the other side of that, have there been hard things that you've come across, if there've been challenges as you're watching the research come through maybe that you didn't expect?
Stacey Pigott:	19:25	I think the biggest challenge is that when you have these brilliant, brilliant dedicated scientists who are in the lab and in the universities collaborating with lots of other scientists and

whatnot, certain ideas, technologies, et cetera, obviously become incredibly intellectually stimulating to them. They're fascinating. As a lot of the scientists say, that's sexy science. They get just really drawn to it. I think it's really cool, and it is. It is amazing science.

Stacey Pigott: 20:03 However, sometimes that sexy science does not work for a patient, and having... There've been so many times when we read something, we say, "Okay, that idea is so cool, or that's fascinating," but yeah, I don't think I would use a laser in that way on my kid's brain. You, really, like, "I don't think you're going to convince a parent to sign their child up for that study," for example or whatnot. That's where sometimes that patient perspective that we're able to provide becomes a really critical voice because if... The science has to work hand in hand with that patient perspective. At the end of the day, it's to bring it out of the lab and to the bedside.

Kelly Cervantes: 20:56 Well, and just that, taking it out of the lab to the bedside, the process, CURE is funding the initial research, but then in order to get it to the bedside, there's probably several more rounds of research that needs to be funded, be it by CURE or by the NIH or by some other organization, before it can ever even get to the bedside, and that process, it can probably be, just the length of time can be a little discouraging.

Stacey Pigott: 21:27 Yeah. I think anything that we can do as an organization to push that timeline to go faster, we are certainly interested in doing that. I think there are some advances that are hopefully going to start doing that, the way genetics is exploding right now, and we're starting to find that precision medicine has some real opportunities for better diagnoses as well as better treatments. Hopefully, we can move that forward but in the past 30, 40, 50, years, it has not-

Kelly Cervantes: 22:02 Gosh.

Stacey Pigott: 22:02 ... moved quickly enough. I think patients as well as the scientists would agree.

Kelly Cervantes: 22:07 Yeah. Stacey, thank you so much for teaching us about the research that CURE is doing and sort of breaking it down for us in a easy-to-understand non-neurosciencey way, so-

Stacey Pigott: 22:22 Very non-neurosciencey way, but it's a process that I'm still going through and always happy to share.

Kelly Cervantes:	22:28	Well, we're greatly appreciative for all that you do for the-
Stacey Pigott:	22:30	Thank you.
Kelly Cervantes:	22:30	... organization. I want to thank Stacey again for her insights into how to make epilepsy research more accessible. If you want to learn more about epilepsy research, please check out the new CURE mobile app at the Apple app store, Google Play Store, or your preferred app provider. Thanks so much.
Brandon:	22:55	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained herein 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. CURE strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.