Seizing Life, episode 72
Funding Epilepsy Research: How CURE Epilepsy advances science to find a cure
Guest: Beth Dean

Kelly Cervantes:	00:01	Hi, I'm Kelly Cervantes, and this is Seizing Life, a bi-weekly podcast produced by CURE Epilepsy.
Kelly Cervantes:	00:18	This week, I'm thrilled to welcome Beth Dean to the podcast. Beth is the CEO of CURE Epilepsy. She joined the organization in 2019 after working on the pharmaceutical side of epilepsy treatment for many years. Beth is here today to provide us with a better understanding of the organization, how CURE epilepsy raises funds and selects the research it supports and what she sees as the most promising areas of epilepsy research today. Beth will also answer questions submitted by podcast listeners, so if you've ever wanted to know exactly what CURE Epilepsy does and how research gets done, this is the show for you.
Kelly Cervantes:	00:58	Beth, thank you so much for joining us today. This is so long overdue, and I'm just thrilled to introduce the Seizing Life audience to you and you to them. To begin, why don't you tell us a little bit about your background and what you were doing prior to joining CURE Epilepsy?
Beth Dean:	01:16	Sure, Kelly, and thank you for having me. I'm excited to be here.
Beth Dean:	01:20	So I joined CURE Epilepsy about two and a half years ago. And prior to that, I actually worked in the pharma industry. I worked on the commercialization of new drugs and bringing them to market. I got my MBA, and then I started at Eli Lilly working on insulins. But shortly thereafter, I went to Abbott Laboratories and worked on a drug called DEPAKOTE. And DEPAKOTE is indicated by the FDA for several things, but one of its primary uses is as an anti-epileptic, and so that was my entrée into the epilepsy community.
Beth Dean:	01:57	And from there, I went to a company called Ovation and worked on some drugs like vigabatrin and clobazam and then did some consulting and worked at some other firms, but I've spent the bulk of my professional career working on anti-epileptics. So that connection into epilepsy is how I got connected with CURE.
Kelly Cervantes:	02:21	I think it has provided such a rich background for you coming into CURE to have that base knowledge and to sort of understand the workings from the pharmaceutical side.
Kelly Cervantes:	02:35	What did you know about CURE Epilepsy prior to joining us, and what attracted you to the organization?

Beth Dean:	02:42	Sure. So I was familiar with CURE as it was known then, back since 2003, 2004. In fact, I think I actually attended some of the earliest benefits a long, long time ago, totally dating myself, but back the 2004, 2005 timeframe.
Beth Dean:	03:01	So I was aware of CURE. I knew that Susan Axelrod, along with some other mothers, had founded the organization, and they were devoted to funding research towards a cure. Epilepsy research was, at that time and continues to be, underfunded. And this was a group of people doing grassroots work, raising money to fund important science towards a cure. So I knew that aspect.
Beth Dean:	03:29	And then I also knew that CURE had a sterling reputation with researchers and clinicians within the epilepsy space. Everyone thought incredibly highly of CURE.
Kelly Cervantes:	03:43	So CURE Epilepsy, we fund patient-focused research. And we tout that, it's all over the website on all of our documentation, but what exactly does that mean, the patient-focused research piece of that?
Beth Dean:	03:59	So we have a very focused mission, right? We are funding research to get us towards a cure. And I think back from the founding with Susan and the other mothers who started, they wanted to make sure that the patient community, whether that's a parent, a caregiver, or a person with epilepsy, that their feedback, their opinions, their desires, their needs were all incorporated into the research.
Beth Dean:	04:29	So when we fund projects, we have members from the community weigh in on the grant proposals and the science we're going to fund. It is... we take many, many perspectives into account when we choose the research we're going to fund. But the patient focus is an important part of that.
Kelly Cervantes:	04:50	So I know that we have the lay reviewers, which essentially means the yous and mes of the world, looking over these grants who don't have PhD or MD after our name, but then we do have the scientists also looking at it and giving their feedback. But I think you're right. It is that patient focus side, that getting the patient and caregiver input that sort of sets the organization apart.
Kelly Cervantes:	05:15	So CURE funds grants which go to fund research, but what is a grant? What constitutes a grant?

Beth Dean:	05:24	Sure. So a grant is the vehicle by which we provide money to a researcher to conduct research. So a couple times of year, we have a call for proposals, and this is the way we fund grants. We reach out to the epilepsy community, to researchers and clinicians, and we essentially say, "Hey, we're interested and giving out some grants for epilepsy research. Send us your really great ideas," and they do that in what's called a letter of intent and then we review those. And there's a whole bunch of stuff that happens in between scientists' review, community reviews. But then we ultimately pare it down to the ones that we think are the best science, and we award grants. And this is the amount of money that we give them to conduct that research. So a grant is the vehicle by which we provide the money to a researcher to conduct research.
Kelly Cervantes:	06:25	I don't know that many people understand how involved that process is or how long it actually takes. It's not that someone just comes to us and says that they have a great idea. Can we fund it? It is this rather long process.
Kelly Cervantes:	06:39	How long does it take, and how many people are involved?
Beth Dean:	06:43	So it takes probably about six months from start to finish. Like I mentioned, it starts with kind of that call for proposals, and then, we have to give the researchers and scientists time to get their paperwork together and submit it to us. And then we do an initial review and the scientists review.
Beth Dean:	07:03	And then we go back to the ones that we think have the most potential, and we say, "Loved the high-level summary you gave us. Now give us all the details," right? "Tell us everything you're going to do and tell us how much money you need. Tell us what you need the money for." And so we have to give them a month or two to get that together and send it back to us. And then we review them again in detail, and we score them.
Beth Dean:	07:26	And by the time we get through this whole process, and then ultimately the board of directors approves the recommended grants that we want to fund, it's about six months. And then we have to go through a contracting process which is all the legalese. So it's a substantial amount of time.
Kelly Cervantes:	07:44	So it's this crazy long process and all of the money that CURE raises really goes toward this research. This is the primary recipient of the money that CURE raises.

Kelly Cervantes: 07:56 And this is a question that I get a lot from people who really want to help. They're passionate about research, about finding a cure for themselves, for a loved one, but perhaps they don't have the financial capacity to donate and make a difference in that way. In what other ways can people help CURE Epilepsy and help push science forward?

Beth Dean: 08:21 I mean, there are really a lot of ways that people can help. And first, let me say that even small donations are important to the organization because if you give 25, 50, $100, when you multiply that with thousands of people, it adds up. So I do want to say the small donations are important as much as the larger ones.

Beth Dean: 08:44 But there are other ways that people can support the organization and help us raise funds to fund research. So a lot of people choose to hold events. They may do a walk or a run within their community. We have things like people will do yoga fundraisers or dressage. I mean, it runs the gamut. So whatever your passion is, you can take that and turn that into a fundraising opportunity for the organization, and we have kind of fundraising in a box. We have information to help you out with that. So those CURE Champion events, that is what we call them, are really important.

Beth Dean: 09:26 I also think helping raise awareness of CURE Epilepsy is important. So if you see a post on Facebook or Instagram and you share it with your community, helping people know that we exist, and we have this awesome mission that we're trying to cure epilepsy through research, broadening our reach, that way is really helpful. There are 3.4 million people in the US with epilepsy, and I would love it if all of them knew that we were here and doing this amazing work. So that's another way. It doesn't cost anything, but just sharing information, talking to loved ones or other people impacted and letting them know about CURE Epilepsy would be great.

Beth Dean: 10:06 And then we do have some other opportunities. We do have some individuals who help us review grants, people who aren't MDs or PhDs, but love science. We have an advisory council where people provide us feedback when we need assistance.

Beth Dean: 10:21 So there are a lot of different ways to support the organization, and we are grateful for everyone who gives their time and/or their money to help us with our mission.

Kelly Cervantes: 10:30 I think you bring up such a great point about sharing a social media post. 1 in 26 people will be diagnosed in their lifetime.

		You have no idea who among your internet friends who are seeing your posts pop up on their feed every day, you have no idea which of them has a spouse that maybe has been diagnosed or a child that maybe, two weeks later, will be diagnosed and that having that information and sharing that name recognition of the organization CURE Epilepsy, it really does go a long way and is such a simple action to take.
Brandon:	11:11	Hi, this is Brandon from CURE Epilepsy.
Brandon:	11:13	Since 1998, CURE Epilepsy has raised over $78 million to fund more than 260 epilepsy research projects in 16 countries around the world. Learn what you can do to support epilepsy research by going to cureepilepsy.org.
Brandon:	11:28	Now, back to Seizing Life.
Kelly Cervantes:	11:32	I know that the government is doing research. Clearly, the NIH is doing epilepsy research. So if they're doing the research, why is it so important that CURE is also funding this research?
Beth Dean:	11:45	So I think there are a couple of reasons. I would say first, epilepsy is the fourth most common neurological disease, but we receive much less funding in epilepsy than other neurological diseases such as Parkinson's or Alzheimer's. The government has, for a variety of reasons, funds those diseases at a higher rate. So the additional research that we fund is important.
Beth Dean:	12:11	The other two things I would say is that it's important to build a pipeline of researchers, right? We need to attract young talent, people who are just getting their PhDs or their post-docs and they're choosing where they want to focus their areas of interest, and we want them in epilepsy. We want the best and the brightest helping us solve this puzzle. And by providing the smaller grants that we do, it attracts them into epilepsy and then, hopefully, they build a career here. So that's really important.
Beth Dean:	12:42	Additionally, one of the things that CURE does that's unique is that we are willing to fund riskier, innovative, groundbreaking research. So a lot of times, researchers will have an idea, but they don't have a proof of concept or supporting data to move it forward. And we're willing to take a chance on some of those things and give a researcher money to perform the experiments so they can generate data, prove their concept, and then hopefully, go to organizations like the NIH and get larger grants

		to do bigger scale funding. So we provide this kind of seed opportunity that gives scientists a chance to generate data and go on and do bigger and better things.
Kelly Cervantes:	13:30	I think it's so cool. I spoke to someone who worked for the NIH at some point, and she told me that they often look in... if someone is applying for an NIH grant in the field of epilepsy, they will look to see if they've received a CURE grant in the past which is such a cool thing that we get to be the organization that gives that initial stamp of approval for a young budding researcher's work to then go on and do this amazing work for the rest of their careers.
Kelly Cervantes:	14:08	I've read these statistics and some of them just really blow your mind that epilepsy affects more people than MS, Parkinson's, and ALS combined, yet receives less federal dollars per person, per patient than each of these. And I think that statistics like that just sort of blow your mind. Is there a reason that those diagnoses are getting those federal dollars when there's actually more patients affected with epilepsy? Not that those diseases don't deserve that money. They certainly do. But I think we'd all love to see some of that money go toward epilepsy also.
Beth Dean:	14:53	Right, right. And you hate... it's not a competition, right? We want all diseases to get funded and to move towards cure, so that is absolutely true.
Beth Dean:	15:02	I think to a large degree, epilepsy is still in the shadows. People don't talk about it the way they do, for example, with Parkinson's and the Michael J. Fox Foundation, right? They have somebody with a large public presence who's out there advocating and has really made a lot of great strides in terms of noise and awareness that have resulted in dollars for funding. And we don't have that in epilepsy.
Beth Dean:	15:29	A lot of people, there's still stigma to some degree. People don't talk about it. If they can take their medications and be controlled and not telling when they have epilepsy, I think many people prefer to do that. And so, as a result, epilepsy is not at the forefront of conversations. The grassroots activity, the advocating is probably not at the same level as some of those other disease states, so I think that has something to do with it, for sure.
Beth Dean:	15:58	I mean, we've made strides over the past decade or so, and we're definitely getting more funding than we used to, but still not at the level of other disease states.

Kelly Cervantes:	16:07	So what has CURE Epilepsy contributed to research? Are there any big successes that you can share with us?
Beth Dean:	16:16	Yeah, I think there are a couple places where we've made some really strong inroads. We have funded two initiatives. One was in SUDEP, Sudden Unexplained Death in Epilepsy, and one was in infantile spasms. And through those concerted efforts, we drove science forward. So for example, within SUDEP, we were funding this research back in the, oh, early 2000s, mid 2000s. And through the research, we now have a much better understanding of the cardiac and respiratory aspects of SUDEP which helps us understand what we need to look at to potentially prevent it going forward, but also, to identify who's at risk so that we can say, "You know what? You're having tonic-clonic seizures. You're having them at nighttime. You're at a higher risk, so perhaps wearing a watch or some kind of device will be beneficial for you." So those understandings have translated into our ability to identify those with risk and take some actions, and I think that's fantastic.
Beth Dean:	17:28	The same is true with infantile spasms. We've made progress. We brought together a team of scientists to work on the task. In fact, we recently just published a paper on the research, and there are some compounds and things in development which they haven't crossed the finish line yet, but I think because of our work and our efforts, we may get there.
Beth Dean:	17:52	So CURE's approach has been really instrumental in some very specific areas, in addition to the broader understandings of the brain and seizure activity and other things like that.
Kelly Cervantes:	18:04	Absolutely. We get to kick the ball and get it rolling and then the NIH sort of picks it up and makes something happen with it. But that ball doesn't start rolling. It doesn't make it into the NIH without CURE Epilepsy getting it going.
Kelly Cervantes:	18:21	So what is CURE Epilepsy's position on medical marijuana? We hear so much about it and now with EPIDIOLEX on the market, does CURE Epilepsy have a position? Do we fund research around cannabis?
Beth Dean:	18:41	So we are a science and data driven organization. That's just... it's in our DNA. It's who we are. So we are fully supportive of EPIDIOLEX and all of the clinical studies that occurred, the data that was generated and understanding the compound and what is in it and the purity of it. So we are thrilled that it was approved and that people have access to it.

Beth Dean:	19:11	I would say that we also know that not everyone has access to EPIDIOLEX for a variety of reasons. And so we want to support the epilepsy community and patients with what they need. We would, I think, say that in consultation with your physician, if you feel that medical marijuana is appropriate for you or your physician does and you're working with them, we would support that as well.
Beth Dean:	19:38	But we do encourage the study and understanding of all those other types of medicinal marijuana.
Kelly Cervantes:	19:49	I think that makes perfect sense. I think it is... we can treat medical marijuana the same way that we treat any other drug. We're not going to go out and promote DEPAKOTE or TRILEPTAL over any other medication. It is another treatment. It is another medication.
Kelly Cervantes:	20:10	But more importantly, I think for our purposes, it is not a cure. It is another treatment, and CURE Epilepsy's focus is always going to be finding that cure or cures which kind of brings me to my next question which is do you think that we will ever find a cure for epilepsy?
Beth Dean:	20:36	I absolutely do think that we will find a cure, but it will be cures, right? There are many types of epilepsy, so there are going to be many cures, and I think some will come faster than others. I think for some of the monogenomic epilepsies in individuals where a specific gene has been identified, we'll probably get to cures fairly quickly for those, and that's super exciting.
Beth Dean:	21:02	But at the same time, I think it's important to recognize that for a lot of people who have intractable epilepsy, we know it's much more complicated. We don't fully understand the biology behind what's going on, and it's going to take longer to get to a cure.
Beth Dean:	21:17	So there will be a continuum where we will get to some and some will be further out, but it reinforces the importance of our mission, that we need to continue to fund this research to understand the brain, to understand seizure activity so that we can get to cures for all. But I am hopeful.
Kelly Cervantes:	21:38	I had a recent conversation with Dr. Steve White, and he left me with so much hope where he was like, "I really..." it is cures. He completely agrees with you that it's not just a single cure that we're looking for. But once that first cure is found that it will be like dominoes, and that cure will help us find the next cure for

		the next genetic syndrome, and it'll just move quicker and faster, and that's such an exciting thing to think that that's entirely feasible, that we can see something within our lifetime where we are actually curing epilepsies.
Kelly Cervantes:	22:20	What part of research that is being conducted right now excites you the most?
Beth Dean:	22:25	I think it is the genomics, the work on the genetic epilepsies. We're finding genes practically every day, understanding the impacts that they're having on individuals. And they are... once you've kind of identified the cause, you can find the solution. And so this is relatively new in the past 5, 10 years. It's exciting. And again, it's hopeful because we understand it, we have the ability to fix it.
Kelly Cervantes:	23:00	Well, I am super thrilled to end this conversation on this note of hope. We don't always get to do that, but I'm going to take this one and run with it.
Kelly Cervantes:	23:12	Beth, thank you so much for chatting with us, for educating us on CURE's grant review process and where CURE Epilepsy really fits into our community. Thank you so much for the work that you do, being the CEO and leading the CURE Epilepsy team. I think I speak on behalf of all of us when I say we are just so lucky and fortunate to have you leading the way.
Beth Dean:	23:38	Well, thank you, Kelly. And let me just reciprocate and thank you for all the work you have done as an ambassador for CURE Epilepsy and for families who are impacted by epilepsy and with the podcast because it's awesome. And I'm glad to be here.
Kelly Cervantes:	23:56	Thanks.
Kelly Cervantes:	24:03	Thank you, Beth, for explaining how CURE Epilepsy finds and funds the research it supports and for sharing your insights about patient advocacy and the promising areas of epilepsy research in which CURE Epilepsy is engaged.
Kelly Cervantes:	24:17	If you would like to help CURE Epilepsy in its mission to support patient-focused research, please visit cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
Brandon:	24:36	The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. 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.
Brandon:	24:58	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.