Seizing Life, episode 38
NINDS and Its Role in Epilepsy Research
Guest: Vicky Whittemore
Transcript

Stacey Pigott:	00:00	Hi, I'm Stacey Pigott and this is Seizing Life, podcast produced by Citizens United for Research in Epilepsy, or CURE.
Stacey Pigott:	00:18	This week, I'm excited to host Dr. Vicky Whittmore, who's not only the Epilepsy Program Director with the National Institute of Neurological Disorders and Stroke, NINDS, but also a member of the CURE Scientific Advisory Council. She's with me today to share an overview of how the government supports and invests in the critical area of epilepsy research. Even before Vicky was with the NINDS, she was an integral part of the epilepsy research and nonprofit community. Over the course of 20-plus years, she has worked at the Tuberous Sclerosis Alliance, Genetic Alliance, CURE, and the National Coalition for Health Professional Education in Genetics. She also served a four year term with NINDS Council. Dr. Whittmore, Thank you so much for being with us here today. We've known each other many, many years through our work in the field of epilepsy and I'd like to maybe get us started if you could share with us how you got involved in epilepsy research.
Vicky Whittemore:	01:18	I got involved in epilepsy research really through a personal connection and I can come back to that, but I was working with the Tuberous Sclerosis Alliance and really interested in better understanding the epilepsy associated with that genetic disorder and started working with CURE and really supporting CURE's mission because I believed in what CURE was doing.
Stacey Pigott:	01:41	And you mentioned that you had a personal connection to epilepsy. Could you share a little bit about what that was and how that impacted your decision to get involved in epilepsy research?
Vicky Whittemore:	01:53	Sure. So my nephew, Clint, was diagnosed with infantile spasms and tuberous sclerosis complex when he was three months old. And so that really changed my life at the time I was a postdoctoral fellow in Sweden and came back to the United States, I took a faculty position and I was doing research on spinal cord injury and teaching and really felt as if that was not fulfilling me entirely. So I joined the board of directors of the Tuberous Sclerosis Alliance, and really began to drive their research agenda to the point where in 1994 I was offered a position to come and serve as the first Medical Director or Chief Scientific Officer of the Tuberous Sclerosis Alliance. So that was really my entry into understanding epilepsy and the devastating impact it can have on an individual.

Stacey Pigott:	02:50	So for your nephew, do you feel that as you watched the devastation of infantile spasms and the impact that that can have on an individual's development and their family, what did you feel you could contribute? You were in a unique position where through your field of study, you could do something that a lot of other family members are not able to do?
Vicky Whittemore:	03:20	Right, so it was actually quite frustrating because he was born in 1984 and at that time, the only medication that was available specifically for infantile spasms was ACTH. And the neurologist that he had, had just had a child with tuberous sclerosis with infantile spasms on ACTH die. And so my sister was faced with the decision, do we do that, use that medication or not? And they opted not to. And so he was then put on a whole cocktail of medications, none of which ever really controlled the infantile spasms and he would have 100 of seizures a day. And the impact that had is that now he is nonverbal, autistic, very intellectually disabled. And so that kind of impact that I saw on him personally and the challenges it really placed on my sister's family were pretty devastating.
Vicky Whittemore:	04:23	So at the time, I felt that the difference I could make was really to help push the research forward. At that time, there was very little research on tuberous sclerosis happening. We knew very little about infantile spasms. Obviously, the treatments were not there, not just for my nephew, but for other children and infants with infantile spasms. So I felt that that was the way I could make a difference was to really get involved in the organization, help to drive the research forward.
Stacey Pigott:	04:53	And is that common that a lot of kids impacted by TS have infantile spasms?
Vicky Whittemore:	04:59	Yes. A significant number of children with tumor sclerosis. We'll start by having infantile spasms.
Stacey Pigott:	05:07	You've had such an amazing career and continue to have such an amazing career in the epilepsy field and for a lot of us who are getting involved in this space as parent volunteers and advocates and whatnot, we always come across, we hear about NIH, we hear about NINDS, we hear about Center Without Walls, Benchmarks for Epilepsy, all of these different programs and organizations within the government, but I think it's oftentimes lost. What exactly all of these groups or committees do? Could you shed a little light for the average epilepsy family, what is NINDS? What is the Center Without Walls, things like that?

Vicky Whittemore:	05:50	Sure, sure. It all becomes alphabets.
Stacey Pigott:	05:53	Yeah, exactly. Exactly.
Vicky Whittemore:	05:54	Right. So the National Institutes of Health is one federal agency that falls under the umbrella of Health and Human Services. So within the National Institutes of Health or NIH, there are 27 different institutes or centers. So NINDS or the Neurological Institute is just one of those 27 units that make up NIH. So within NINDS then our mission is to support and fund research on all neurological disorders as well as just really understanding the basics of how the brain works. So there's a large amount of federal funding that's going towards just understanding basic neuroscience, how does the brain work. And now with the new brain initiative, really pushing that forward in terms of really being able to develop new technologies to better explore the brain, which will lead to better treatments in the long run. So within NINDS a majority of research we fund on epilepsy are what we call investigator initiated grants.
Vicky Whittemore:	07:06	So it's a researcher at an institution who has an idea, who has plans to do research, submits a grant application that gets reviewed and if scored well, gets funded. We often have some special initiatives for epilepsy and for other areas of research, one of which being the whole Center Without Walls Program. So through that we have been able to typically the way we have functioned is we hold a workshop to really focus in on a specific topic in epilepsy research and then say what do we need to do to really advance that research area.
Vicky Whittemore:	07:45	So the first we did was on the genetics of the epilepsies. The second was on sudden unexpected death in epilepsy or SUDEP. The third was on post-traumatic epilepsy. The fourth center was on functional genomics and we're going to fund a second center on functional genomics. Those applications have just come in the door. And then the fourth we have, or the last actually fifth center, we have yet to be determined what that topic will be. But there are really ways to bring number of enough investigators from multiple institutions, multiple backgrounds to really focus and hone in on how can we solve this problem, how can we really push forward in that research area.
Brandon:	08:29	Hi, this is Brandon from Citizens United for Research in Epilepsy or CURE. Since 1998 CURE has raised more than $70 million to help fund more than 235 research grants in 15 countries around the world. Learn more at cureepilepsy.org now back to this episode of Seizing Life.

Stacey Pigott:	08:47	How has the landscape changed in your tenure at NINDS, what was the status of epilepsy research before you came and what changes have you seen?
Vicky Whittemore:	08:58	So I think the biggest change I've seen is we've gone, and a lot of this I think has also been driven by CURE, to be honest. I've seen the change from epilepsy being lumped into one bucket to really understanding that it's the epilepsies. That there are different kinds of epilepsies, different causes of epilepsy that they're not all the same, we can't treat them all the same and we've really shifted to really beginning to understand that the way to move things forward is sort of in targeted ways to understand, okay, with this cause of epilepsy, here's how we need to target a treatment. Rather than, again, just sort of lumping them all together in one thing because they're not.
Stacey Pigott:	09:45	Right, and you've referenced how CURES involvement with trying to move the field forward and collaborate and work with and support the great work that's happening at NINDS but CURE was involved with helping establish the benchmarks for epilepsy, I believe. Is that correct?
Vicky Whittemore:	10:07	That's correct.
Stacey Pigott:	10:07	And how did that, what exactly is that, and how did that, see change, kind of, you know, develop?
Vicky Whittemore:	10:14	Right. So CURE was instrumental in establishing the first Curing the Epilepsy Conference during the Clinton administration. And that conference resulted in what we now call the benchmarks for epilepsy research. And what the benchmarks are, our milestones and goals for the community to meet, to really push forward in understanding the epilepsies. So there are ways in which the community prioritizes research and it's not top down. It's not us saying, here are the research areas that are important. It's the community, all the stakeholders, individuals with epilepsy, the patient advocacy groups, clinicians and investigators all coming together to say, "Here's the progress we've made, but here's what we don't know," and how can we set these milestones and goals to really move forward and in understanding that the different kinds of epilepsy and getting closer to cures and better treatments.
Stacey Pigott:	11:13	Right. Since there is a sensitivity to the patient perspective and what the community is looking for and needs in epilepsy research, what are ways that the average family, parent, advocate, maybe even, some of the more the private organizations can have an impact upon the programs that

NINDS, for example, are instituting? What's the opportunity for collaboration, feedback, whatever it may be?

Vicky Whittemore: 11:46 NIH is always seeking input from the community and in many different ways. So at the beginning of each session we have someone either who has epilepsy or who has a loved one with epilepsy, tell their story to bring home to the community and the researchers and clinicians at the conference that this is something that affects people and families. And this year the epilepsy leadership council has been very involved in helping us to organize the conference, identify speakers, and would play a very active role in that conference as well as in the development of the benchmarks that will carry us forward over the course of the next many years.

Stacey Pigott: 12:33 From the perspective of the young investigator all of the wonderful scientists that were so incredibly so grateful for that scientific community and so grateful for new investigators to be coming into the field. They need the research dollars and obviously CURE does what it can to support that. Many other organizations do that as well. What's the role for NINDS and the nonprofit sector to help support the research and these grants?

Vicky Whittemore: 13:13 So organizations like CURE play a critical role there in that what cure does through the funding of their Taking Flight Awards, their Grant Awards is to provide that seed money to an investigator to get started with a new idea with new research. And then the preliminary data that they obtained with that funding from CURE or an organization like CURE allows them then to come in with a much stronger grant application to NIH that allows them then to get much larger grant dollars to carry their research forward. So organizations like CURE really see the research and really can help us to partner with us in that way to identify really good research ideas and new investigators coming into the field.

Stacey Pigott: 14:04 And it's certainly, it's so prestigious for when an investigator is able to get that, NIH grant and whatnot. And it's really kind of helps to establish them as their lab and whatnot. I know that's critically important to the field, right.

Stacey Pigott: 14:26 CURE as an organization is able, as a private nonprofit, is able to fund research all over the world globally and support labs in lots of different countries obviously. And NINDS can not do that. How does that impact some of when you're trying to look at what epilepsies that you're trying to look at and follow according to the benchmarks, how does that work on a global scale? And how does that interact with what other countries are

		doing and what the research that they're doing and perhaps what their benchmarks are?
Vicky Whittemore:	15:04	NIH does fund some research around the world. Typically, it's done either through our Fogarty International Center, which funds global health initiatives, or if there's a grant that's funded by say NINDS there may be a foreign component to that. So for example, our post-traumatic epilepsy Center Without Walls, that center is primarily made up of US investigators, but there's also investigators that are part of that from Finland and from Australia. So they're brought in because of their expertise to really help to expand the expertise in the research that's going on, say within an initiative like that.
Vicky Whittemore:	15:47	But foreign investigators can apply for funding from the National Institutes of Health. There's just a bit of a higher bar in that we have to make sure that those research dollars that are going outside the United States are going to fund research that either cannot be done in the United States or there's expertise in another country that we don't have here. Or, for example, some of the really critical epidemiology work on SUDEP has happened in Sweden and some of the Scandinavian countries that just have amazing databases that we don't have here because of their electronic medical records systems there. So you know, we try to take advantage of those kinds of avenues of research if the money is being spent in a foreign country to really bolster things that can be done here in the United States
Stacey Pigott:	16:43	CURE has been so fortunate to not only have you on our scientific advisory council and you've been a wonderful friend to the organization and we have such great respect for all the work that you're doing at NINDS it's a partnership that we just value so much. What do you feel, historically that partnership has been able to create? How have we been able to mutually help push the field forward towards a cure?
Vicky Whittemore:	17:17	I think that partnership has gone both ways. I think that NINDS has helped to strengthen CURE and CURES programs and really helped to work together as partners when there's an area of research need to really be able to work together to identify that need and address how to meet that research need. And I think also the CURE has really pushed NIH in different directions and said this is not enough. We need you to do more. Because it really was CURE pushing, working with Senator Kennedy's office many years ago that led to the whole Center Without Walls program. And without that push, I'm not sure that would have happened. And that came specifically from CURE wanting more and saying we need more, we need coordinated efforts. We

		need these large projects that are not going to be incremental but are really going to make a huge jump in our understanding of epilepsy.
Stacey Pigott:	[18:22]	We're so grateful that you are with us here today. And we were joking that you're like the ultimate epilepsy mom crush because you know you've had such an amazing career in publicly working with the government but also through the nonprofit sector. And then of course having that personal experience that provides the passion and motivation for doing what you do. And you've just had such an amazing career and we're just so grateful for your career in epilepsy. But of course for being with us today to share all of that with us. So thank you for coming today. Thank you for having me.
Stacey Pigott:	[18:57]	Thank you again to Dr. Vicki Whittemore for helping us understand the important role the government plays in epilepsy research and how it collaborates with others to progress research towards a cure. While the government has made epilepsy a priority, their efforts alone are not enough. This is why CURE and its mission to fund patient focused research is essential to help us find a cure. Epilepsy will impact one in 26 Americans in their lifetime and there is still so much we don't understand. To help further our ability to fund critically needed research, please visit cureepilepsy.org\donate. Your support and generosity are greatly appreciated.
Brandon:	[19:42]	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained here 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 specific health situation.