

Seizing Life, episode 70
From Epilepsy Researcher to Epilepsy Patient: A New Perspective
Guest: Dr. Steve White

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a bi-weekly podcast produced by CURE Epilepsy.
- Kelly Cervantes: 00:18 Today I'm happy to welcome a long-time member of the CURE Epilepsy community, dr. Steve White. Dr. White has been involved in epilepsy research for more than 40 years. He is currently a professor and chair of the department of pharmacy at the University of Washington. Previously, Dr. White spent 30 years as a faculty member at the University of Utah, where he also led the epilepsy therapy screening program. Additionally, Dr. White was CURE Epilepsy's first research director and has served on several advisory groups, including the Infantile Spasms Initiative and the Post-Traumatic Epilepsy Initiative. He continues his long association with CURE Epilepsy as a member of our scientific advisory council.
- Kelly Cervantes: 01:00 He's here today to talk about how his perspective on epilepsy and epilepsy research has been shaped by his personal experience as an epilepsy patient. Dr. White, thank you so much for joining us today. I've been so looking forward to this conversation with you, one of the main reasons being that you have been involved in epilepsy and epilepsy research for 40 years. You are a trove of information. What initially got you interested in epilepsy and epilepsy research?
- Dr. Steve White: 01:33 Well, thank you, Kelly. Please, Steve is fine, okay?
- Kelly Cervantes: 01:40 Noted.
- Dr. Steve White: 01:41 Okay. Like many of us, I think my mentor had a huge role in defining my interest in epilepsy and getting me going there. I was honored to work with one of the greats in basic epilepsy research during my graduate studies, Dixon Woodbury, and he took me under his wings and introduced me to the community back in the 1980s, and got me motivated towards the underlying biology of epilepsy as well as basic mechanisms of anti-seizure drugs. The other thing, a notable thing I would say, is that one of my thesis committee members was a pediatric epileptologist in Salt Lake at the time, Jack Madsen, and I just saw how passionate he was for his patients and how much his patients and their families loved him as a caregiver. I just felt like this is a community that I'd like to be a part of.
- Kelly Cervantes: 02:57 I love that so much. We're so grateful to have had you. You are both a researcher and an educator. Can you tell us what your focus has been in both those areas?

Dr. Steve White: 03:10 Sure. In my early days, and during my graduate training and postdoc, it really was around the basic mechanisms of anti-seizure medicines, trying to understand how they work on neuronal cells, as well as in networks. Then as I transitioned into the what's now called the Epilepsy Therapy Screening Program, it was at the time called the Anti-convulsant Drug Development Program at Utah, I became very, very interested in animal seizure, and epilepsy models and how they could be used for identifying and characterizing new drugs that might ultimately be used for the treatment of epilepsy.

Kelly Cervantes: 04:03 I'm going to interrupt you right there just for a moment, just for the lay listener here. When you talk about an animal model and why that is important, what specifically does that mean, the model?

Dr. Steve White: 04:17 Well, we've been fortunate, really over the last 75 years, to have models that can help to model the human disease. For instance-

Kelly Cervantes: 04:31 It would be a mouse or a rat or something along those lines that models the disease, and then you can test your theories or these pharmacological substances on the animal model to see how they work.

Dr. Steve White: 04:50 Exactly. Most, if not all, of the anti-seizure drugs that have come on the market have been tested in one of these rodent seizure models or epilepsy models. That gives the proof of concept that a drug is getting into the brain and has an ability to block a seizure or stop a seizure. For most of the time it's very predictive of outcome when a drug goes into the clinic. Unfortunately, doesn't always predict efficacy in that highly refractory patient population. That's where we need new models. I've spent a lot of time over the course of my career trying to help develop new models and bring them into the testing protocol to see if we couldn't find better drugs for that particular population.

Kelly Cervantes: 05:50 What have you focused on in terms of an educator?

Dr. Steve White: 05:55 From an educating perspective, I think it's largely trying to get students interested in epilepsy and trying to help them really recognize the need that's out there, and the importance of understanding epilepsy at a level that you can take new therapies forward for the patient. It doesn't take much, once a person begins to identify with a patient or a caregiver, how important research is in epilepsy. From an education perspective, I like to try and make sure that that link is made

and the student has an opportunity to look into the lives a little bit of the patient with epilepsy and perhaps walk in their shoes, and just understand how important it is that the work they're doing may ultimately lead to better therapies.

- Kelly Cervantes: 07:11 It's such an important point, and it's one I don't think I necessarily realized, is just how separated sometimes the research community is from the patient population. Unless there is an effort made by one party or the other, that the researchers may not have ever met someone that their research actually directly affects. I think that's so important for that connection to be made. That leads me perfectly into my next question about CURE Epilepsy, this organization that you became familiar with several years ago and which has brought us together today has a decades long history of bringing researchers and the patient population together. How did you first hear about CURE Epilepsy and what motivated you to start working with us?
- Dr. Steve White: 08:07 I first became aware of CURE Epilepsy back in 2000 at the White House initiated conference on curing the epilepsies. At that meeting, I heard Susan Axelrod speak for the very first time. I listened to her impassioned plea, her story and their journey with Lauren over the years, and their frustration, if you will, with not having answers and not being able to get those answers. I think she changed the dialogue in the epilepsy research community. We went from thinking about finding therapies for stopping seizures, which still remain a significant need, to beginning a conversation around how do we find a cure? How do we find a disease modifying therapy? I think she really, in a very impassioned way, called out the community, that we need to be looking beyond the symptomatic treatment. We need to be thinking cures and disease modification. That really has changed the landscape. I think CURE should be proud of themselves for taking that leadership position and changing the conversation.
- Kelly Cervantes: 09:53 Now we know how you first became aware of CURE Epilepsy, I would love to hear how you have contributed to the organization. You've been quite a resource to CURE Epilepsy over the years.
- Dr. Steve White: 10:05 Thank you, Kelly. I think my initial interaction was serving as a reviewer on some of the grants that came in or letters of intent, and advising on what looked like promising research. I was also fortunate to have received an early grant from CURE, so I've been a funded investigator. Then in 2010, early 2011, I was fortunate and honored to be invited to serve as a research

director for CURE as they were looking to transition their research a little bit. I served in that capacity from 2011 to 2015. Most recently, I joined the scientific advisory council. Again, I'm just honored to be a part of this.

- Brandon: 11:22 Hi, this is Brandon from CURE Epilepsy. 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. Now back to Seizing Life.
- Kelly Cervantes: 11:43 Now within the last few years, epilepsy has entered your life in a far more personal way. Can you share that journey with us?
- Dr. Steve White: 11:53 Yes, there's an awful lot of irony in the whole story, if you will. In 2010, May of 2010, I had a generalized tonic-clonic seizure after returning home from a trip on the east coast. Just a couple of days prior to that my wife and I had returned from Israel, so I was pretty sleep deprived, pretty stressed at the time. Got home from that trip back east with horrible headache. I laid down and a few minutes later had this generalized tonic clonic seizure. I woke up in a little community hospital not too far from our home in Salt Lake. I don't know, two or three hours later when I sort of... The lights were starting to come back on, I had been informed that I had had a seizure and that was the start of my journey.
- Dr. Steve White: 13:06 I was told a couple of times by the attending that night, "Don't worry, everybody gets their first seizure for free." I realized enough about epilepsy to realize that there probably wasn't a free seizure, regardless of your age, so I had an MRI done the next morning and that led to the identification of a benign brain tumor. Two weeks later that was being resected. It was about 18 months after the resection when I started having focal seizure events and started being treated for those. I'm very, very fortunate in that my seizures are well controlled by the medicine that I take. In that regard, I feel fortunate to have benefited from the miracles of modern science and drug discovery and to be seizure-free.
- Kelly Cervantes: 14:19 I also imagine that having a pharmacological degree and expertise helped significantly in your journey as well. I mean, I can only imagine how well you were able to advocate for yourself and how closely you were able to work with your doctor. How do you think that helped you?
- Dr. Steve White: 14:44 Oh, I think it was incredibly beneficial. I have to say that by virtue of my understanding of the disease and knowing the right

questions to ask and the right people to get access to, I probably had more access than a lot of people, and that's something that I feel guilty about in some regards, but I also feel overwhelmingly disappointed that not everybody has full access despite how good our healthcare is in this community and in this country. I think a lot of people lack access.

- Kelly Cervantes: 15:30 Yes. It's not a fair system, to be sure, especially when there's not enough doctors and entirely too many patients. I know that you were diagnosed in 2010, however, you did not choose to publicly share your diagnosis until about 2019, in fact, at an American Epilepsy Society Conference. Go big or go home, I guess. Talk to us about why... A, why you didn't share your diagnosis earlier and what motivated you to finally share it and in such a big way at the AES Conference.
- Dr. Steve White: 16:08 It's an interesting question, Kelly, and one that I've thought about a lot, and I thought about certainly a lot before I made the announcement in 2019. I'm not proud of the fact that it took me so long to have this conversation with the community, particularly knowing how important it is for people to talk about their journey and to be willing to share their journey. Years before I had overheard a conversation with Susan Axelrod and Dan Lowenstein talking about the importance of people, if you will, sharing their story and taking ownership of their epilepsy. I kept saying to myself, after that, for probably four years, I need to do this. I need to be able to come out and talk about this.
- Dr. Steve White: 17:17 What drove me to that night was I went with another faculty member and a couple of dozen pharmacy students as part of a Global Brigades medical mission to Ghana two years in a row. On those two trips, I spent my time with students interviewing patients and caregivers and really learning about their struggle there and the treatment gap that exists in Ghana. There was a moment of, if you will, feeling of hypocrisy, if you will, knowing that I had a secret I wasn't willing to share, but I was willing to ask other people to share their journey. I think it was that moment that really said, I've got to talk about this. I've got to free myself of this burden.
- Kelly Cervantes: 18:25 Did you experience any stigma or bias from anyone afterwards?
- Dr. Steve White: 18:33 No. I had absolute full support. Both my wife and I were really taken aback by that, the support of people that came up at the reception, but even subsequently to that, and it was just... I can't think of a better place and a better community to have had the conversation with, initially. I will say, as an aside, when I had that conversation with the CURE community in 2019, there

was a huge relief taken off of me. The ability to talk openly and freely about something that I've kept secret for a decade was freeing, if you will. I control it now, it doesn't control me, and if in some small way that helps others, mission accomplished.

- Kelly Cervantes: 19:47 That's so important, owning it, and just... We're so grateful to you for sharing that because now you come to epilepsy research and your studies and your education understanding both sides of the coin. How has being an epilepsy patient affected your work?
- Dr. Steve White: 20:09 Oh, it certainly impacts everything I do on a daily basis. There's more passion. Again, I feel very fortunate with my epilepsy to be well controlled, but that being said, there isn't a day that goes by I don't think about it. I don't think about how unstable the situation could become, overnight. I hear the stories. I talk to the people and and I say we've got to do better for them. We need to continue the push forward and not let the pressure off.
- Kelly Cervantes: 20:55 Getting back to your history within the epilepsy community, in your 40 plus years of time, what do you think that the epilepsy community has done incredibly well? What are some of the things that you've been a part of that you're particularly proud of?
- Dr. Steve White: 21:17 I look back over the course of my time in Utah and now in Washington and the time that I spent with CURE and as it relates to particular projects, I'm incredibly proud of the advances that we were able to make in the screening program at Utah through a committed staff and our colleagues there that continue today.
- Dr. Steve White: 21:44 My time with CURE, I have to say having the opportunity to launch the Infantile Spasms Initiative and bring together a group of eight very talented investigative teams to try and tackle a problem in a new way through team science and collaborative team science and letting the science really drive the direction of the research, and then that parlayed into the Post-Traumatic Epilepsy Initiative, which I'm delighted to see continues today. Some strong teams of investigators there that are advancing our understanding of post-traumatic epilepsy and potentially identifying treatments and cures for them.
- Kelly Cervantes: 22:43 Conversely, what should we be focusing on and working on?
- Dr. Steve White: 22:48 What we have done really well as a community is advance the science around the basic understanding of how seizures begin,

they stop, the pharmacology of the treatments we have available, but also innovative new treatments. We've done really well at bringing younger investigators into the community to advance our scientific understanding. In some ways I think our science is outpacing our ability to translate these findings to the patient community. I wish there were a way to advance, in a more timely way, some of the findings at the bench to new therapies at the bedside.

Dr. Steve White: 23:46 I guess what I mean by that is, at least in preclinical models and rodent models, we have a number of therapies that show significant promise as disease modifying drugs and curative treatments, but the ability to translate that at the clinical trials and get those trials running quickly and efficiently in the right patient population, I think is an area we could use some help with. I realize that these are not inexpensive studies to do. It takes a lot of resources to do, but that I think is my biggest frustration is seeing all of this great science that someday will make its way to the clinic. I guess I'm just a little eager for it to happen faster.

Kelly Cervantes: 24:42 I think that we all are, but it's... I take from that great hope and promise that there is the basic science there, and then all we need is that money to fund this translational research, which is actually something that I know that CURE Epilepsy is starting to fund a little bit more of this type of research so that hopefully we can speed up those treatments and find potential cures. I guess, along those lines, is it one cure that we're looking for or is it more accurate to say cures?

Dr. Steve White: 25:17 No, I think it's more accurate to say cures, multiple cures, but it may be too early to make a judgment on that, too. I think once we have that very first successful, and a highly successful, therapy that cures or modifies or halts the progression of a particular epilepsy, that is going to provide us incredible insight into how to do the next study and how to tackle the next one. Now it may very well be that that therapy, because of similar underlying mechanisms and other epilepsies, is more generalizable to different epilepsies. I think a cure for a genetic epilepsy is going to be different than a cure for post-traumatic epilepsy or tumor induced epilepsy or infection induced epilepsy. We need that first one because that's going to be our roadmap to more success.

Kelly Cervantes: 26:31 We cannot wait to celebrate that, for sure. Thank you so, so much for speaking with us today. Thank you for your four decades of commitment to the epilepsy community and for

your help in all that you've done in the many hats you've worn with CURE Epilepsy. We're just so grateful for your contribution.

- Dr. Steve White: 26:53 Kelly, thank you so much. It's been my honor, and I look forward to many, many more years together. It's been a real honor to work with CURE and all of my colleagues over the years.
- Kelly Cervantes: 27:08 Thank you, Dr. White, for sharing your knowledge, insights, and personal epilepsy story. As Dr. White's journey makes clear, epilepsy research has made significant progress during the past four decades. We have greatly enhanced our knowledge of epilepsy and the mechanisms behind seizures, and discovered new treatments that have improved the lives of people with epilepsy. With nearly one third of patients unable to gain seizure control, we still have a long way to go to unlock the mysteries of epilepsy and discover new treatments. Those discoveries will only come through research. We ask you to help CURE Epilepsy fund this vital research by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.
- Brandon: 28:01 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. CURE Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with the patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.