

Kelly Cervantes:	00:00	I'm Kelly Cervantes and this is <i>Seizing Life</i> .
Kelly Cervantes:	00:02	(Music Playing)
Kelly Cervantes:	00:13	I'm very excited to welcome my special guest for today's episode, Kurt Eichenwald. Kurt is a New York Times bestselling author, two-time Pulitzer Finalist, and a former Senior Writer with the New York Times and Newsweek. His latest book is <i>A Mind Unraveled</i> , a memoir of living intractable epilepsy. It is so riveting that I devoured it in one weekend (which is quite a feat considering, you know, well, I have kids). I have to admit that, even coming from within the epilepsy world, I was taken aback by the medical and personal treatment he received over the years.
Kelly Cervantes:	00:46	Kurt is joining me today to discuss his book and his journey battling epilepsy. So, thanks for sitting with me, Kurt. I have so many questions and things that I would love to get to, so we're just going to dive right in.
Kelly Cervantes:	00:59	Many of the epilepsy stories out there revolve around children, like my daughter, who are disabled as a result of their seizures. But what so many people don't understand is that one in 26 people will be diagnosed with epilepsy in their lifetime and that means they likely already know someone who has epilepsy. They just aren't public with their seizures.
Kelly Cervantes:	01:19	So your story is so effective in part because of how personal you are with the details. Why did you decide to share your history in this way?
Kurt Eichenwald:	01:27	You know, there was a point in 2010 when a bunch of epilepsy organizations got together, and they said, if we're going to bring epilepsy out of the shadows, people of some prominence have to stop hiding.
Kurt Eichenwald:	01:44	And they weren't particularly successful. Athletes come out, but not a lot of people are going to be professional athletes.
Kurt Eichenwald:	01:56	In my circumstance, I've got some level of fame, but I'm certainly not a professional athlete and so-
Kelly Cervantes:	02:09	You're relatable.
Kurt Eichenwald:	02:10	Yeah. Basically when I was first diagnosed, the first instructions I got from my neurologist was, "Don't tell anybody, keep it

secret. If you don't keep it secret horrible things will happen.” That got burned into my mind and it was a very, very horrible series of instructions. As I thought about this, I realized young people are getting that instruction from doctors and from family to this day. The point of the book is to say, no, this is destructive, and you can be open. And, more importantly, I've had some success in life and want to say even if you are really sick, even if you have a significant number of seizures, you still can achieve what you want.

Kelly Cervantes: 03:14 You start your book, *A Mind Unraveled*, with a real-life experience. You have had a seizure and, weak from that seizure, become aware that you are covered in snow. It's a terrifying moment to think about. Why did you choose to start your book with that experience?

Kurt Eichenwald: 03:36 That night has been the source of the nightmares for much of my life. I mean, I had made a very serious mistake. I was living the way I wanted to live, and I guess this is another message. I was living the way I wanted to live at Swarthmore. I had gotten back into school and I guess I grew arrogant because I took a shortcut. I got off the main path. At least this is what I think happened. I don't really have a memory of how I got there, but clearly, I was off the main path.

I had a seizure and afterwards there was a blizzard. By the time I woke up, I was buried in the snow, my clothes were frozen, I couldn't tell where I was, and I wasn't able to stand up. I crawled through the snow, and when I started falling asleep, I found a way to stop it. I had hurt my hand, so I started scraping my hand across the ground to cause pain to wake me up. I mean I was nightmarish, but I wasn't going to let myself die that night. I had more stuff I wanted to accomplish.

Kurt Eichenwald: 05:17 But I learned something very, very important. One of my roommates once said, "Stop trying to be super human." And that really was an important lesson. Just because I wanted to live a normal life with epilepsy didn't mean I had the luxury of being stupid. Getting off the main path when I knew I had convulsions and knew they could strike at any time was stupid. Just like it would be stupid for me to have gone swimming. Just like it would have been stupid for me to drive a car. It was stupid and there's a difference between deciding to live your life, deciding not to let epilepsy interfere, and being in denial about the possible consequences of a stupid decision.

- Kurt Eichenwald: 06:33 So I'm much more attentive now. Even though now I'm not having convulsions, I'm still attentive to what could happen if I did. Where am I? What am I surrounded by? It got burned into my head over 15 years – no, 11 years of having convulsions. And so that night, as horrible as it was, communicated two things in the book and the most important one is never give up, but don't be stupid.
- Kelly Cervantes: 07:22 That message to me speaks volumes - that idea of never giving up. As I read your book I kept getting reminded of the quote, "In life you don't get what you deserve, you get what you settle for." And when you were unfairly thrown out of college, you refused to settle. When unfairly treated in the workplace, you refused to settle. When given bad advice by your father and doctors, you eventually learned not to settle. You refused to settle for anything but a full and fulfilled life. How did you do that?
- Kurt Eichenwald: 08:02 I recognized that, as far as we know, we have one life. And I could have stood back and said, "This is hard. I can't keep doing this." Sometimes I did say that, but ultimately this was my only chance.
- There was a point where I was in the hospital, and I saw this elderly couple, and they were just loving and wonderful (he was my roommate). I thought that night, "Why am I fighting so hard? What do I want?" I realized that their life was a symbol of what I wanted and for the next hour I just visualized my life. I realized I wanted to be a newspaper reporter, I wanted to be married, I wanted to have children, I wanted to be a good dad and good husband. I mean it - very, very detailed. And once I visualized that life nothing was going to stop me from getting there. If you know your goal and things get in the way, you have to knock them back. You don't really have a choice unless you give up and giving up goes back to the "we only have one life" point.
- Kurt Eichenwald: 09:38 Why give up?
- Kelly Cervantes: 09:40 With that said, you did at times through all of that, once you were starting to get control, settle for partial seizure control due to the difficulties and risk of changing meds. What did you learn from that experience?

- Kurt Eichenwald: 10:00 Well there's a difference between having the life you want based on those things you can control and trying to get control of what you can't.
- Kurt Eichenwald: 10:14 Life is divided up between what we control and what we don't. Seizures is one of the things I do not control and so I go to the point where I achieve the medication balance and seizure balance that I am willing to live with. That is my balance.
- Kelly Cervantes: 10:37 To that extent I would say that your story could be a textbook on patient advocacy. What advice would you give to someone? How do they know when they've found the right doctor?
- Kurt Eichenwald: 10:50 The key to finding a good neurologist is that humility is the most important element. The ability for a doctor to stand back and say, "I don't know." Because the reality is this isn't like a broken bone. This is neurons somewhere in the brain that are damaged or malformed. They don't even know. They have theories, but they don't even know specifically why that happens. Why if you go through a clump of bad neurons, it sets the entire brain off.
- There is so much they don't know, and a lot of neurologists were the best in their class and saying, "I don't know," was sort of beaten out of them. Every neurologist I have had from Dr. Naarden forward has been one who said, "I don't know." And there's also the importance of a neurologist telling the patient, "You're in control in terms of when we stop."
- Kurt Eichenwald: 12:11 I had a neurologist who said, "The most important thing is we stop the seizures." And that's not true.
- Kurt Eichenwald: 12:18 The most important thing is that I have the life I want to live. If we stop the seizures and I have so many side effects – well, I don't want that. It's my balance and the doctors who recognize it's my balance and understand that they can't necessarily stop the seizures are the great ones.
- Kelly Cervantes: 12:41 Just currently in our life with our daughter, that balance between seizure control and quality of life is so key. We could have seizure control tomorrow if we wanted to, but she'd be in a coma because of all the meds that she would be on. It's finding that balance and finding the doctor who will respect that balance and what the patient or the families want. That balance is going to be different from person to person and from family to family. That partnership between the patient and the doctor - finding someone who's willing to treat together.

- Kurt Eichenwald: 13:19 Yeah. I mean that's the thing. Particularly for parents, if you look at your child and the child is all right, but when you up the medication or change the medication, they are zonked out, change who they are, or in any way are living a life that isn't happy, go back to where you were. Seizures themselves, they clearly are unpleasant. Having a miserable life is worse. And the medication can cause you to have a miserable life if you don't recognize this is all about a balance.
- Kelly Cervantes: 14:11 What would it have meant to you if research had advanced sooner to provide you with better treatments earlier? Are there drugs that you're on now that weren't available before or different tests that are available to patients now that weren't when you were initially diagnosed?
- Kurt Eichenwald: 14:32 Well the answer to those both are yes. The drug I'm on now, I don't even understand what this means, but my neurologist says that this affects a different channel.
- Kelly Cervantes: 14:45 We've heard that before, too.
- Kurt Eichenwald: 14:45 Yeah and it's like, okay, different. That means it does something that the others didn't and so this drug is relatively new. It did not exist when I was 18 and it's doing a really good job.
- But when I look back at what would've made a difference for me, the most important thing would be if people understood epilepsy. I could deal with the seizures, I could even sort of accept them, but no matter how well I could deal with that, I couldn't control how people reacted. I did get thrown out of school. I did get fired from a job and fired on my first day of work. They learned I had intractable epilepsy and within hours I was sent out of the office, supposedly never to return. Ultimately those were the things that were so difficult and back then there really weren't organizations of the scope of CURE. I felt very much alone. I felt very much like this is something that's me.
- Kurt Eichenwald: 16:23 Over time I met people who also had epilepsy, but the solitude and dealing with the horrible reactions people had - I needed a lawyer at one point when I was thrown out of school. Well, how do you find a lawyer? Now you go to the Epilepsy Foundation and you look at legal resources. In a way, I wish a lot of what exists now existed then. But I'm okay. As bad as everything was, I have achieved the life I wanted to live.

- Kelly Cervantes: 17:18 Which is amazing.
- Kurt Eichenwald: 17:19 I think one of the things that people get most surprised by when I say it is, if I could go back in time and push a button and make it so I never had epilepsy, and I never went through these experiences, which you know were pretty horrible, I wouldn't do it. There's something about having a chronic health problem, particularly one that for me was very serious for a long time. It reshapes your perception of life. It reshapes who do you want to be. You don't have the luxury of drifting through and just sort of making decisions out of convenience. When I think of my past, I think of my present. My children wouldn't exist if I hadn't had epilepsy. I wouldn't be married to the woman I am for complicated reasons. I wouldn't have the job I have. I wouldn't have the success in the job I have. Before I had epilepsy, I was thinking about becoming a lawyer simply because I couldn't think of what else to do. There's nothing wrong with being a lawyer, but I would not have been happy in that job.
- Kurt Eichenwald: 18:57 And so it's not a curse, it's just part of a life. And it can be - if you use it to learn about yourself - it can be part of a very good life.
- Kelly Cervantes: 19:19 On behalf of the community, I can't thank you enough for sharing your story. Is there one piece in particular you would like people to take away from this book?
- Kurt Eichenwald: 19:31 Epilepsy doesn't have to stop you. Epilepsy doesn't have to be the deciding factor of your life. I was extremely sick, and I didn't stop because I couldn't. Because I couldn't, because I only had one life. If your one life is about staying safe, if that's the focus of your life, don't drive in a car. And I don't mean if you have epilepsy. I mean don't ride in the passenger seat because lots of people die in car accidents.
- Sometimes we have to accept risks in our lives in order to live our lives. That has to be the goal for parents with children with epilepsy and for anyone with epilepsy - live your life. It will be really hard at times but other times it will be really glorious. Because when I was really sick I did visualize children, my kids say they feel so proud of the fact that I fought so hard for the purpose of them existing. They understand that. That is a testament to living a life. We have to live a life. We cannot make this the center of our lives. And particularly this message needs to be heard by parents because I know it's terrifying.

Kurt Eichenwald:	21:40	I know it can be overwhelming, but children have to live their lives, particularly when it's time for college. That's one important message that I hope the book communicates.
Kelly Cervantes:	22:05	Thank you so much.
Kurt Eichenwald:	22:07	Thank you.
Kelly Cervantes:	22:09	Again, Kurt Eichenwald's book is <i>A Mind Unraveled</i> . I cannot stress this enough: go out, buy this book, download this book, read this book, share this book. This is a story that you can relate to whether you have epilepsy or not. It is a testament to what we can achieve even when faced with the most dire of circumstances. What we can overcome and how they can shape us.
Kelly Cervantes:	22:34	(Music Playing)
Kelly Cervantes:	22:37	It has been almost 40 years since Kurt began chronicling the challenges he faced in <i>A Mind Unraveled</i> . Despite technological advances and progress towards identifying the causes of epilepsy, one third of people still live with uncontrolled seizures. We still have so much further to go before we find a cure for epilepsy. That is why I am on the board of Citizens United for Research in Epilepsy, CURE, which is the leading non-governmental agency fully committed to funding epilepsy research. To help us find a cure please donate to cureepilepsy.org/donate .
Kelly Cervantes:	23:09	(Music Playing)
Seizing Life Disclaimer:	23:16	The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained here and 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.