

Seizing Life, episode 79
Post-Traumatic Epilepsy and Our Veterans: Impact, Research, and Hope
Guests: Dr. Lauren Harte-Hargrove, Patty & Patrick Horan,
Alec Beauseigneur-Jimenez & Katie Beauseigneur
(Transcript)

Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.

Kelly Cervantes: 00:18 This week, in honor of Veterans Day, we're focusing on post-traumatic epilepsy by revisiting two previous conversations with veterans impacted by PTE. But first, I'm happy to welcome Dr. Lauren Harte-Hargrove to the podcast to provide us with a basic understanding of post-traumatic epilepsy and an overview of some of the research currently being done in this area. Dr. Harte-Hargrove is the associate director of research at CURE Epilepsy, where she is responsible for providing oversight of CURE Epilepsy's research portfolio and initiatives. She also acts as the project manager of the CURE Epilepsy Post-Traumatic Epilepsy Initiative, a team science program created with the help of a \$10 million grant from the Department of Defense.

Kelly Cervantes: 01:03 Lauren, thank you so much for joining us today. I'm super excited to share with everyone, this major project that CURE has been working on for years now, but I think it's important that we start off with basic definitions of some words, because as you know, science loves to use acronyms, and as they should, because no one should have to use words like electroencephalogram on the regular. So to help our listeners out, can you tell us what exactly is TBI and PTE?

Lauren Harte-Hargrove: 01:36 Of course, that's a great place to start. So PTE stands for post-traumatic epilepsy and is a type of epilepsy that can occur after a traumatic brain injury, or TBI.

Kelly Cervantes: 01:49 Great. And so, what are some examples of a traumatic brain injury?

Lauren Harte-Hargrove: 01:53 Well, there are a number of ways to sustain a traumatic brain injury, and it could be someone who just has an accidental fall and bumps their head. It could be a TBI that happens during a car accident or during a sports-related incident. For our military service members, they may sustain a TBI during the line of duty, so for example, it could be a blast or a penetrating brain injury. And in fact, all of these different types of traumatic brain injuries put a person at risk for developing post-traumatic epilepsy, or PTE.

Kelly Cervantes: 02:28 So let's dive into that relationship a little bit more. When you say that anyone who experiences a TBI is more likely to develop

post-traumatic epilepsy, what is the relationship between the two?

- Lauren Harte-Hargrove: 02:40 Well, there's a lot that we know about the relationship between TBI and PTE, but there's a lot that we don't know, that we're still working on understanding. So we understand that post-traumatic epilepsy can develop in as little as weeks after a traumatic brain injury. It could be months, it could be even years. Most people will develop PTE within the first two years after a traumatic brain injury, but again, it can be past two years, many years after that original traumatic brain injury.
- Lauren Harte-Hargrove: 03:13 We understand that a person who sustains a severe TBI is more likely to develop post-traumatic epilepsy, but there's still a lot that we don't understand about what puts a person at risk for developing PTE after TBI. And that's what we're working to understand right now, what puts a person at risk and what are those mechanisms that are occurring in the brain after a traumatic brain injury that lead to post-traumatic epilepsy?
- Kelly Cervantes: 03:40 What does post-traumatic epilepsy look like? Is it similar to just your generic run-of-the-mill, popped up out of nowhere, don't know why it's happening epilepsy?
- Lauren Harte-Hargrove: 03:53 Well, PTE happens after this period of time that is called the epileptogenic period. So epileptogenesis is the development of epilepsy, and so there is a period of time after TBI, before PTE happens, and so there's actually a period in which we could intervene if we understood more about PTE. But it is a recurrent seizure disorder, and so people who have sustained a traumatic brain injury and then develop PTE are having recurring seizures.
- Lauren Harte-Hargrove: 04:25 Now, we do have some medications that could treat this, but the medications that we have, many of them do not work on everyone and there can be unwanted side effects, and so there can be really a great burden on not only the person who develops PTE and who is having these recurring seizures, but also their caregivers and their loved ones and their family members. And so, it could be things that occur, such as cognitive decline, or comorbidities like depression can be associated with PTE, and so it really can have a profound impact on the lives of those who have sustained a TBI and developed PTE.
- Kelly Cervantes: 05:08 So it's a lot more than just unwanted seizures. There is a greater impact on someone who is potentially in therapies and recovering and just trying to get back and make progress after that TBI.

Kelly Cervantes: 05:23 So CURE Epilepsy has partnered with the Department of Defense on a rather large research project, which is super exciting. And you touched on it before, but can you explain a little more in depth, why the DoD is so interested in post-traumatic epilepsy?

Lauren Harte-Hargrove: 05:39 Right, so people who serve in the military may be more exposed to having a traumatic brain injury, just because of the nature of the work. In fact, from 2000 to 2020, over 400,000 active service members sustained a traumatic brain injury, and so that's a huge population who is then at risk for developing PTE. Now, even though we know that they may be at risk, we can't identify who will develop PTE, and so this is a really big unmet need that was identified by the Department of Defense.

Lauren Harte-Hargrove: 06:17 By and large, if a person has a diagnosis of epilepsy, they are unable to serve actively within the military, and so beyond that personal burden that we just talked about, the recurring seizures, the potential comorbidities, these individuals also are not able to serve any longer in the military. And so, this need was identified to be able to identify who is at risk for PTE following a traumatic brain injury, what's happening in the brain after a TBI that leads to PTE. And if we can understand that, we can develop a way to prevent the development of PTE altogether.

Kelly Cervantes: 06:55 Love, love, love the sound of that. How does this relationship between CURE Epilepsy and the DoD work? How is this grant set up?

Lauren Harte-Hargrove: 07:05 Yeah, so this is a partnership. We received a \$10 million grant and the work began in 2015. We were granted this funding by a certain section of the DoD, and it's a mouthful, but it's called the CDMRP, or Congressionally Directed Medical Research Program Traumatic Brain Injury and Psychological Health Research Program.

Kelly Cervantes: 07:27 Ooh.

Lauren Harte-Hargrove: 07:28 Yes, it's a lot to say. But we have this partnership now that was intended to develop this team science approach to studying post-traumatic epilepsy. and that is CURE Epilepsy's Post-Traumatic Epilepsy Initiative.

Kelly Cervantes: 07:42 Okay. Talk to us about team science, because I know this is something that CURE Epilepsy is very passionate about and something we've done before.

- Lauren Harte-Hargrove: 07:49 That's right. So CURE Epilepsy really brought this concept of team science to the field of epilepsy with its Infantile Spasms Initiative, and that was a team science approach to studying infantile spasms. So building on the success of that initiative, we are now using team science to study post-traumatic epilepsy. And you can think of it as, we have a multidisciplinary project, many different investigators, in fact, over 80 senior investigators, junior investigators, post-docs, graduate students, all working together as parts of the puzzle, lending their different expertise.
- Lauren Harte-Hargrove: 08:30 So we have six main teams, but we're meeting frequently so that our teams can learn from one another, so that they can share data in real time. And what we've heard from the feedback of our investigators working on the PTE Initiative is that it's just so great to have this wide variety and this huge number of scientists coming together to understand this problem and to tackle PTE. And we have also a panel of advisors that helps to guide us, and so this is really quite bigger than the normal way that science is conducted.
- Kelly Cervantes: 09:04 Can you give us a broad overview of some of the specific aspects that are being studied in this PTE Initiative?
- Lauren Harte-Hargrove: 09:12 Yes. So again, we have six teams, really teams of teams, that are working on this, and we have several investigators that are researching better ways to study post-traumatic epilepsy in a laboratory setting. So they're developing what's called an animal model, something that can mimic PTE in a human, but in an animal. And we need this so that we can be able to understand better, what are those mechanisms that are occurring in the brain after a traumatic brain injury that lead to PTE?
- Lauren Harte-Hargrove: 09:41 We also have several investigators that are looking at clinical populations, so humans who have been affected by traumatic brain injury and are at risk for developing PTE. And the goal of those projects is really to follow these individuals, understand who is at risk, who develops PDE, what puts them at risk? Is it something in the person's genetics that we can say, "Well, that puts them at greater risk"? Or maybe there's something that we can measure in the person's blood, like a protein, that would give an indication that that person is at greater risk.
- Lauren Harte-Hargrove: 10:14 What we're trying to do really is develop what's called a biomarkers, so something that we can measure in a person who has had a traumatic brain injury that would let us know that that person is at risk for developing post-traumatic epilepsy,

and also understand the mechanisms at the same time of what's happening in the brain after a traumatic brain injury. And in that way, we can really reach our ultimate goals. We're laying the foundation here for what we need to do, which is take those individuals that are at risk for developing post-traumatic epilepsy, and then develop a trial where we can find a way to prevent the development of post-traumatic epilepsy after a traumatic brain injury.

- Kelly Cervantes: 10:57 This particular study is focused more on our servicemen and women, but you think about it in terms of the mom who was in a car accident and suffered a brain injury. And just being able to imagine that while they're in the hospital, being able to have a blood test done, or an MRI, and immediately know what their risk level is, and to be able to start them on some medication, you just see so much potential and so many possibilities across the epilepsy spectrum.
- Kelly Cervantes: 11:29 Lauren, thank you so much for talking with us. Thank you so much for everything that you do for CURE Epilepsy and heading up this program. We absolutely adore you and value you, and so just thank you so much.
- Lauren Harte-Hargrove: 11:41 Well, thank you. I mean, it's been great being able to talk about it. And really, I just want to say, it's a team effort, and so I would just like to thank all of our researchers that are out there, hard at work.
- Brandon: 11:54 Hi, this is Brandon from CURE Epilepsy. Did you know that one in 26 Americans will develop epilepsy in their lifetime? For more than 20 years, CURE Epilepsy has funded cutting-edge, patient-focused research. Learn more about our mission to end epilepsy at cureepilepsy.org. Now, back to Seizing Life.
- Kelly Cervantes: 12:14 In November of 2020, we spoke with retired army captain, Patrick Horan, and his wife, Patty, about the traumatic brain injury that he suffered while serving in Iraq in 2007 and the resulting post-traumatic epilepsy that impacted his recovery process.
- Patrick Horan: 12:31 I'd been in the army for almost 10 years. In 2007, that's when I had been in Iraq for a year, and then one night, we were going at night to do a recon across the street, I guess. I'm not sure why, but I got... Two Iraqis shot at us, and I got a shot right through my night vision that I was wearing, and so it exploded. And then from there, it all just went into my-

Patty Horan: 13:13 Helmet?

Patrick Horan: 13:16 My helmet, yeah. Or my brain, also. And I-

Patty Horan: 13:19 Well, there's a small flap in the helmet, so the bullet actually snuck inside the helmet.

Patrick Horan: 13:27 And I passed out. I don't remember any of that. There's about two months... But one of my soldiers, he was trying to call me on the radio, and then he ran back upstairs. Two of my soldiers had come over to see what I was doing, and my soldier, he took off my helmet and just saw that half of my brain was just gone. It was destroyed.

Patty Horan: 14:00 Yeah, they couldn't tell where the injury was, so they took off the helmet, which probably wasn't the best idea, and half his skull came off with it.

Patrick Horan: 14:08 Yeah. It was incredible. From there, it was about 10, 15 minutes away, we went to Baghdad, and then less than 10 minutes later, I was in a helicopter, going to Balad. And I landed there 45 minutes later and they did the surgery right away, took off 40% of my skull, and then-

Patty Horan: 14:37 Yeah, Pat was really lucky too because that night, he was the only one injured and they had a clear road to get to the local field hospital. You hear about the golden hour, which he did get medical within an hour, so he was very lucky that night.

Patrick Horan: 14:53 Yeah. When I got shot [inaudible 00:14:57], I was in Bethesda, Maryland. It only took 36 hours.

Kelly Cervantes: 15:02 It sounds like it's a miracle that you're talking with us today. I mean, I can't even imagine, nor do I want to. Did anyone mention post-traumatic epilepsy to you at this point?

Patty Horan: 15:17 Well, yeah. I arrived at the naval hospital in Bethesda, but you arrived there late Sunday night. I took a red eye from Seattle, Washington, and I arrived in DC Monday morning, first thing, and was escorted to the hospital and got a medical briefing right away. So he was in the ICU. His head was so swollen, it looked normal, even though they had taken off probably 40% of the skull, or had been fractured because of the bullet wound, so one of the things on the list of probably 30 things that could go wrong with seizures. So they did say, "If Pat has a seizure within the first three weeks," that he would most likely pass away, so that was my first introduction to epilepsy, for post-traumatic-

Kelly Cervantes: 16:06 And did they say anything to you about what happens if he has a seizure after three weeks, or to be on the lookout for that?

Patty Horan: 16:13 No. So I mean, that really stuck in my mind, and he did not have a seizure. And prophylactic, I believe they gave him Keppra in the ICU for the first couple of weeks. So thankfully, at that point, no epilepsy occurred.

Patrick Horan: 16:31 After six weeks, then I went to RIC in Chicago and I was wearing a helmet-

Patty Horan: 16:38 For rehabilitation, right?

Patrick Horan: 16:40 Yeah.

Patty Horan: 16:40 So we were-

Patrick Horan: 16:41 [crosstalk 00:16:41]-

Patty Horan: 16:41 ... in Chicago. He did a lot of intense rehab and they did give me this really great book on brain injury recovery, and there was a section on epilepsy. No one really spoke to me much about it in Chicago, just gave me the book. And I remember seeing the page on it and thinking that it was a possibility, but I just felt like, oh, maybe that's not going to happen to us.

Kelly Cervantes: 17:06 But it did, unfortunately.

Patty Horan: 17:08 And it did.

Kelly Cervantes: 17:09 And can you tell us what happened when that first seizure occurred?

Patrick Horan: 17:13 I don't know anything, to me, happened, but Patty said she woke up around two o'clock in the morning, and just all of a sudden, I was having a grand mal seizure and Patty had no idea what a grand mal seizure was, so [crosstalk 00:17:32]-

Patty Horan: 17:32 No. It was probably the scariest moment in my entire life, honestly. I thought he was dying. It was four and a half months into recovery, and I thought, what in the world? He came back alive from this gunshot wound. We've worked really hard, and now he's going to die tonight. That's...

Patrick Horan: 17:50 So she ran outside when I... in the other room to look for a nurse, and it took a couple minutes to find a nurse. And then the nurse went with Patty to my room and the nurse was like,

"Oh, he'll be okay, he'll be okay. He'll stop. He's just having a seizure."

- Patty Horan: 18:11 Yeah, she identified it as kind of normal for the brain injury that he had, but it was a full body, very violent, convulsive seizure. But at least when it did surface, he was in bed, we were in a hospital, we could get medical quickly. It was pretty amazing that night too because it stopped and the nurse went away, and then 10 minutes later, it started again, so it was this rolling seizure situation, which was extremely dangerous.
- Patty Horan: 18:40 They call the paramedics from Northwestern, throw him on a gurney. We're running at two in the morning through all these hallways because there's these secret passageways from RIC to Northwestern. So they had to get him on a Dilantin drip as soon as possible because it could cause more brain damage, so it was an exciting evening, to say the least. But he did okay, but all the rehab that we'd worked on for months was just gone in a blank. [crosstalk 00:19:10].
- Kelly Cervantes: 19:10 Yeah, that was going to be my very next question, is just how did the appearance of seizures impact Pat's recovery?
- Patty Horan: 19:21 It was hard. I mean, most of his seizures were in the first couple of years and that's when we were working the hardest and the brain was putting itself back together. He was making the most gains, but then we'd get these horrible grand mals, and we were doing all sorts of different medication regimens, trying to figure this out. So it really got in the way of recovery and it was very deflating, and many times.
- Kelly Cervantes: 19:47 In July of 2020, we spoke with former Marine, Alec Beauseigneur-Jimenezur-Jimenez, and his mother, Katie, about the military training injury that he incurred in 2015 and his long journey to a diagnosis of post-traumatic epilepsy nearly two years after the initial injury.
- Alec Beauseigneur-Jimenez: 20:05 My whole life, I always have been interested in the military, and so I joined the Marine Corps infantry. And in the infantry, they have sections. You have a rifleman, assaultman, a machine gunner. I went the mortarman, and essentially, there's just a tube that shoots a rocket up and down. And on that day, we were out on a training accident and we just had a bad round. So as a mortarman, you load around in the tube, you drop it, and you duck your head below the muzzle so you get away from any explosives that happen above the muzzle. Unfortunately, I sat the round in the tube and I was waiting for the command to fire, but it prematurely went off, it cooked off in the tube, is

what we call it, and the amount of... The only way for the pressure to release is up at the top, so I was still looking directly at the top of the muzzle. And my fingers were there, so I knocked out my fingers and I got a huge round of concussive to my head, concussion.

Alec Beauseigneur-Jimenez: 21:13 I just remember everybody scattering, looking confused, don't know what was happening. I got the corpsman down. He threw a tourniquet on me pretty quickly, but we had to get everybody... an evac up to our site. And then once the evac brought me back to the main camp that we established, I had to hop on a helicopter over to the Kaneohe Bay where Tripler... the medical base was. And I just remember being confused, scattered around, not sure really what was going on. I remember looking down at my hand and just seeing red, so I thought the whole hand got knocked off. Thank God just a couple of my digits shortened a little bit. The next few days, I was surgery, so I was under a lot of anesthesia. I couldn't tell you what happened after the next few days. She can tell you on that one.

Katie Beauseigneur: 22:08 Well, and what happened, quite quickly, Alec, actually, is even the one that phoned me. So I was in Florida, so within 24 hours, I was on the plane there, so I got to him pretty quickly. And like Alec said, a lot of surgeries, a lot of debridement, a lot of saving fingers, saving his thumb. There was no real test and no real discussion about any brain, head trauma.

Kelly Cervantes: 22:34 Was there an MRI done, any sort of brain scan? Did they discuss concussions, traumatic brain injury, post-traumatic epilepsy with you?

Alec Beauseigneur-Jimenez: 22:46 Because it was so visual, my hand was the issue. There was no attention really directed towards my head. I don't think that the story out on the field got well written down because essentially, you're supposed to duck below the muzzle, where all the explosion comes from, so I think they thought I'd ducked below the muzzle. And again, no real attention was paid directed towards my head.

Katie Beauseigneur: 23:16 Right, I think that the immediate concern was his hand. It was really saving his hand. The extent of the damage, that was the mission. That was the goal when they got there, and the medical staff... So I don't recall ever, them saying anything about an MRI. If they did one in the beginning, they didn't find anything because I was with him for the next 20 days in the hospital. There was no MRI. There was no discussion about head trauma. It was really his hand.

Kelly Cervantes: 23:45 Which was the visible injury. I mean, you can see the logic in it. That's the visible one that's there. When did you have your first seizure?

Alec Beauseigneur-Jimenez: 23:55 The accident happened in May and my first seizure happened in December, so pretty quickly after. But again, it really didn't show much attention. I just was driven to the hospital, treated, and then sent back to the battalion that I was with.].

Kelly Cervantes: 24:13 Did they give you any explanation as to why you might have had the seizure?

Alec Beauseigneur-Jimenez: 24:18 I was out at one of my friends at my battalion's house. We were having a few beers, just kicking back, away from... The wounded warrior battalion is where they relocated me to. I think they saw it more as, we were causing trouble, drinking, away from the staff, and they saw it as me doing something wrong instead of relating it back to my injury.

Katie Beauseigneur: 24:44 And he went by ambulance because his friend saw him... what we know now was a tonic-clonic seizure. He fell over, he had facial injuries, and I got the phone call from him in the emergency room. I even remember speaking to the nurse. They had him handcuffed to the gurney because he was angry, and we know that when people have seizures, they get angry, they get confused. That's typical for Alec. We know that now. And it was described by the friends he was with. It was two people. They described that it looked like he had a seizure. They drug tested him, they did all these things, and said, "We don't see anything in his system," and they released him, and that was it.

Kelly Cervantes: 25:30 So they drug tested him, but they didn't do an MRI?

Katie Beauseigneur: 25:33 They didn't. I just don't understand that piece. Looking back, I mean, I'm hindsight 20/20, knowing what I know now, but we can't go back because that day doesn't exist, but it definitely was an unfortunate... But that was seizure number one that was the clinical signs that showed something major. I know, just by looking back at that time, the confusion, his memory, he remembers not a lot of that time. We had blamed it on the medication because he was on a lot of medication. I really do believe that he was already having some seizures. We just didn't see them.

Kelly Cervantes: 26:14 And then the next seizure happened. How many-

Alec Beauseigneur-Jimenez: 26:17 It was-

Kelly Cervantes: 26:17 ... years have gone by at this point, or how much time?

Alec Beauseigneur-Jimenez: 26:20 About a year and a half.

Katie Beauseigneur: 26:21 Yeah, I think close to two years.

Alec Beauseigneur-Jimenez: 26:24 I was medically retired from the military, just now again, restarting life, essentially. I selected a college back out in Colorado, moving away from Mom, after all this medical stuff, being released. That was a hard pill to swallow, being medically retired from the Marine Corps, because that's what I wanted to be in. So I've picked a new career path, I'm motivated to get to Colorado, move into my place. I just drove from Florida to Colorado with all my gear, moving into my apartment. My cousin came out to visit me and we were in what they call Cave of the Winds. It's an attraction out in the mountains. And I had a seizure when we were doing a cave tour, and I just think the load of stress that was happening at the time, the transition in life, still really grinding my gears, a long drive.

Katie Beauseigneur: 27:23 But again, that was a tonic-clonic. It was one of those big seizures that you can't avoid. You see them, you know they're happening. And I continue the position that, had I had known what to look for, I know that he was having more than just these big ones. These big events were just presenting, but I know what I know now about seizures, and specifically, Alec, there were other things present that I just didn't know. We didn't know what they were to even identify those things at the time.

Kelly Cervantes: 28:00 Yeah, absolutely. And at that point, an MRI is done and you are diagnosed, is that correct?

Alec Beauseigneur-Jimenez: 28:10 At that point, they referred me to a neurologist out in Colorado, so that was the first time I got, really, attention towards my head. I'm now in with the neurologist and she starts me on a light prescription of Keppra. So now, they're thinking I'm having seizures. I don't think I was diagnosed specifically at that point with epilepsy, but from then on, my epilepsy really started ramping up. I was having the tonic-clonics, grand mals. And we started gaining the knowledge of what we know now that, hey, this is a really big problem. We need to give it more of a focus and treat it as a bigger problem. So I started getting prescribed medication and we just started testing out a lot of different things.

Kelly Cervantes: 29:03 How have the seizures affected your life?

- Alec Beauseigneur-Jimenez: 29:06 One big thing that I do want to put out to whoever watches this is, I like to be a very independent person and I do have a support team, but I don't ever really want to lie into their hands too much. But there's been multiple times where I've come off of me out of frustration. At the very beginning, when stuff was ramping up, I would just go off and try to be away, thinking that moving or changing my locations is what's going to solve the issue. And I end up in a hospital, not knowing where I'm at, and my mom has to come. You can't do this alone. It does definitely bring on some dark days. You can't go after certain things that you thought you wanted to. You have to take a slower pace at things. but everything is achievable, just at the right speeds, and with the right support system, and relying on your team, essentially.
- Kelly Cervantes: 30:16 Thank you to all of our guests for sharing their insights and experiences. We want to take a moment to let our audience know that, sadly, Alec Beauseigneur-Jimenezur-Jimenez passed away in early 2021 from an accident unrelated to epilepsy. As you heard in the excerpt from our conversation, Alec was a young man with a great love for his country who was determined not to let epilepsy control the course of his life. We honor Alec's determination and spirit as we continue our mission to advance research and find a cure for epilepsy. Thank you.
- Brandon: 30:58 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 a patient's physician or other qualified healthcare professionals who are familiar with the individual's specific health situation.