## Seizing Life, episode 46 *The "Invisible" Consequences of Traumatic Brain Injury* Guests: Alec Beauseigneur-Jimenez and Katie Jimenez Transcript

Kelly Cervantes:	<u>00:00</u>	Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by Citizens United for Research in Epilepsy, CURE.
Kelly Cervantes:	<u>00:19</u>	Today, we continue our series of remotely recorded episodes during the COVID-19 pandemic by welcoming Alec Beauseigneur-Jimenez and his mother, Katie Beauseigneur to the podcast.
Kelly Cervantes:	<u>00:30</u>	Alec is a former Marine who sustained injuries in a training accident in 2015. Following the accident, Alec underwent a series of operations to repair and regain use of his right hand. However, it wasn't until several months after the accident that Alec experienced the first indication that he had also sustained a traumatic brain injury resulting in PTE, or post-traumatic epilepsy. Alec and his mother are here today to talk about his injury, diagnosis and living with PTE.
Kelly Cervantes:	<u>01:01</u>	Alec, Katie, thank you so much for joining us today and discussing your experiences with post-traumatic epilepsy and traumatic brain injuries. I have to admit personally that this was not a form of epilepsy that I knew much about until a couple years ago when CURE was awarded a grant from the Department of Defense to study post-traumatic epilepsy.
Kelly Cervantes:	<u>01:25</u>	I want to hear about how this all began for you, the training accident that caused your injury. Take us back to that day.
Alec Beauseigneur-Jimenez:	01:35	My whole life, I always have been interested in the military and so I joined the Marine Corps Infantry. In the infantry, they have sections. You have a rifleman, assaultman, and machine gunner. I went the mortarman, and essentially it was 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 muscle. So you get away from any explosives that happen above the muzzle. Unfortunately, I sat around 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 only way for the pressure to release is up at the top. So I was still looking directly at the top of the muscle and my fingers were there. So it knocked off my fingers and I got a huge round of concussive to my head. Concussion.

Kelly Cervantes:	<u>02:44</u>	Ooh, that's a little terrifying I can imagine. So what were the next hours and days like? I assume they rush you to the hospital and what are you told about your injuries?
Alec Beauseigneur-Jimenez:	<u>02:58</u>	So I'll tell you, initially when it happened, we were on the big island of the Hawaii where our biggest mortar range happened. So I just remember sitting there, it was a nighttime operation. And again, I didn't hear the command of fire and the round went off, so I thought something bad happened. 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 a get an EVAC up to our site.
Alec Beauseigneur-Jimenez:	<u>03:33</u>	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 Kane'ohe Bay where Tripler the Army base, 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 it's 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:	<u>04:14</u>	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 Alex said, a lot of surgeries, a lot of debridement, a lot of saving fingers, saving his thumb, but I think kind of what you're after is there was no real test and no real discussion about any brain head trauma.
Kelly Cervantes:	<u>04:42</u>	Was there an MRI done? Did they discuss concussions, traumatic brain injury, post-traumatic epilepsy with you?
Alec Beauseigneur-Jimenez:	<u>04:54</u>	I definitely think because again, my unit was still a lot of young guys. Just 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 ducked below the muzzle. And again, no real attention was directed towards my head.
Katie Beauseigneur:	<u>05:32</u>	And I think that the immediate concern was his hand. It was really saving his hand. The extent of the damage, that, that was the mission. That was the goal when they got there and the
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		medical staff. But you would still think something like that, they know. They know all possibilities that let's check everything. 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 hands. That was it.
Kelly Cervantes:	<u>06:12</u>	Which was the visible injury. I mean, you can see the logic in it that is that's the visible one that's there. Unfortunately, there's a track record of it is difficult for people to understand epilepsy. It is difficult to treat because it isn't visible because we can't see this incredible injury. When did you have your first seizure?
Alec Beauseigneur-Jimenez:	<u>06:37</u>	It was a few months after the accident. 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, kind of treated, and then sent back to the battalion that I was with.
Kelly Cervantes:	<u>06:59</u>	Did they give you any explanation as to why you might have had the seizure?
Alec Beauseigneur-Jimenez:	<u>07:05</u>	Again, 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 was where they relocated me to, just the stress of being in that battalion. I think they saw it more as we were causing trouble drinking away from the staff and something went bad and I just got directed to the hospital. It was more they saw it as me doing something wrong instead of relating it back to my injury.
Katie Beauseigneur:	<u>07:43</u>	And he went by ambulance. Because his friends saw him, what we know now, is it 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 a system" and they released him and that was it.
Kelly Cervantes:	<u>08:29</u>	They drug tested him, but they didn't do an MRI.
Katie Beauseigneur:	<u>08:32</u>	They didn't. And that was our first-

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Alec Beauseigneur-Jimenez:	<u>08:36</u>	On top of that too, I had a huge fat swollen lip because my face slammed in the ground. Again, no attention to any head injuries.
Katie Beauseigneur:	<u>08:47</u>	I know that the people describe it as a seizure, the people that he was with. I just don't understand that piece. Looking back, I mean, I'm hindsight 2020. Knowing what I know now, but we can't go back. We can't go back because that doesn't exist. That day doesn't exist, but it definitely was unfortunate. But that was seizure number one, that was that 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 kind of 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.
Brandon:	<u>09:36</u>	Hi, this is Brandon from Citizens United for Research in Epilepsy or CURE. Epilepsy affects 3.4 million Americans learn more about cutting edge, epilepsy, treatments, and research at cureepilepsy.org. Now back to this episode of Seizing Life.
Kelly Cervantes:	<u>09:50</u>	And then the next seizure happened, but it was quite a bit later. Tell us about that.
Alec Beauseigneur-Jimenez:	<u>09:58</u>	Okay. So that one, I was medically retired from the military, just kind of now again, restarting life, essentially. It was definitely-
Kelly Cervantes:	<u>10:09</u>	How many years have gone by at this point, or how much time?
Alec Beauseigneur-Jimenez:	<u>10:12</u>	About a year and a half.
Katie Beauseigneur:	<u>10:14</u>	Yeah, I think a close to two years.
Kelly Cervantes:	<u>10:16</u>	Okay.
Alec Beauseigneur-Jimenez:	<u>10:17</u>	And really just starting, getting a groove. 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 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 that the load of stress that was happening

at the time, the transition in life still really kind of a grinding my

		gears, a long drive. Mom says a lack of oxygen in the caves could have sparked it. But it was, it was in the Cave of the Winds during a cave tour.
Katie Beauseigneur:	<u>11:22</u>	But again, it 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 known what to look for, I know that he's he had was having more than just these big ones. These big events for 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:	<u>12:00</u>	Yeah, absolutely. And so you have this second seizure a year and a half or so later, the second tonic-clonic, we'll say, because there could have been likely seizures happening in between and you just didn't know that that's what they were. At that point, an MRI is done and you are diagnosed, is that correct?
Alec Beauseigneur-Jimenez:	<u>12:23</u>	At that point, they referred me to a neurologist out in Colorado. So that was the first time I got a 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:	<u>13:16</u>	Unfortunately, there's all of these studies that have been done that show that sort of, once those floodgates open, it is very difficult to regain some semblance of control. It's much easier to plateau or maintain the control or lack thereof that you have, but regaining that is that much more difficult. Do you have seizure control today?
Alec Beauseigneur-Jimenez:	<u>13:42</u>	Seizure control's hard to say yes I do in various points, but you just never know when one of those puppies sneak up and wants to mess up your day. I do, for the most part, have seizure control with the medication I'm on. I did just get the deep brain stimulator surgery.
Kelly Cervantes:	<u>14:04</u>	Tell us about that a little bit.

Alec Beauseigneur-Jimenez:	<u>14:06</u>	Yeah. So ultimately I talked with my first neurologist, she had presented me the idea of the vagus nerve stimulator and the deep brain stimulator. I was more interested in the deep brain stimulator. So from then on to this point I've been kind of seeking that as my end goal, what's going to kind of help me out. Now that it's implanted, I don't have it turned on yet, so I don't have much information on that. Besides the surgery, they give you a sweet couple of haircuts, they implant the probes up here, and then they put the generator in your chest
Kelly Cervantes:	<u>14:44</u>	Similar to a VNS, but from my understanding, it is more directly implanted on the brain versus the vagus nerve.
Katie Beauseigneur:	<u>14:53</u>	And you don't get to a brain stimulator. Though, without going through the medication trial and errors. I think one of the goals was really to find that focal point and to possibly remove that part. And hopefully the goal was really to be seizure-free. I mean, that's what we all want, but all of the tests we did and just the rapid increase of seizures that really changed his life and debilitated him, we actually had got it over to the epilepsy center in Tampa and started doing inpatient EEG. That's where we found there were stuff coming from both sides. And then that led to the SEEG, which is the invasive where they drilled nine holes and put the probes in and he was in the hospital for 10 days, to really get a solid understanding of what was happening. And that's when we really learned that he wasn't a candidate for finding that focal point.
Katie Beauseigneur:	<u>15:52</u>	Because there's two of them, it's on both sides and the amount of seizures he was having. I think they got 60 in six days, but he was still on a heavy dose of medication because they slowly take him off. And that's when they decided that the deep brain stimulator at this time was the best therapy for him. In addition to his medication.
Kelly Cervantes:	<u>16:13</u>	Right. You mentioned that the seizures were coming from both sides of the brain at this point. Were they able to find or see some type of brain injury in the scans?
Alec Beauseigneur-Jimenez:	<u>16:28</u>	Yeah. With my epileptologist, when I got my first real big MRI focused on trying to find a problem in my brain, I do have a lesion that we believe came from the accident. It's up in my right hippocampus area and it did show signs of a lesion that was just never focused on that at the very beginning.
Katie Beauseigneur:	<u>16:55</u>	And that was one of the things that the target area, I guess they were really focusing on. Because when you saw that lesion, that's a hard thing to see in your brain, just a gap. They were
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		just hoping that that may have been the center of the source, but it proved not to be, which is kind of interesting. It just proved not to be, they weren't even coming from that area. Even though there's brain damage there, there's definitely some damage there around that area. And we'll never know where that came from, because I've always said this about Alec too, with all the seizures that he was having. I believe he could have even sustained more head traumas with the amount of times that he's gone down and not been seizure control. He has had some other injuries to his head, which are they're alarming and they're scary when you live a life with seizures.
Kelly Cervantes:	<u>17:52</u>	Yeah, absolutely. I think you touch on a really important piece here that I want to dig into a little bit more and that is how have the seizures affected your life? You talk about more seizures, bring more seizures, brings more damage, brings more negative effects and impacts on your life. For those that may not understand what that actually looks like, can you tell us, or give us some examples of how it has impacted your life?
Alec Beauseigneur-Jimenez:	<u>18:29</u>	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 medication out of frustration, when at the very beginning, when stuff was ramping up and I would just go off and try to be a way 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:	<u>19:37</u>	That we are beyond grateful that you are speaking with us today about your journey, but have you always been this open about your epilepsy and the seizures, or is this something that you have hidden in the past?
Alec Beauseigneur-Jimenez:	<u>19:54</u>	Oh, for sure. I've hidden from a lot of people, and still to this day. I was a server at Dave and Busters when I moved out to Colorado, just getting extra change and going to college. I would go wait tables after school and when something felt off, I would duck in the bathrooms, kind of have seizures in the bathrooms and then come back out and finish the shift because I didn't want people to see me struggling or even have a seizure out in front of everybody else.

Kelly Cervantes:	<u>20:31</u>	First of all, you are amazing and so incredibly strong and resilient, and that story gives me absolute chills, but it also makes me incredibly sad that you were in a bathroom stall at a restaurant having seizures while on your shift and then would go out and continue. And I just, I can't imagine being in that position and it makes me equally impressed and just so sad and frustrated at the same time.
Katie Beauseigneur:	<u>21:02</u>	And just to talk a little bit about the supports, I mean, there would be so many times he would call me. He was in Colorado, I was in Florida and he would call me from these stalls, "Mom in the bathroom again" and talking through and figuring out his calming mechanisms. He's had a lot of practice in calming his body to do those things, but there's been a lot of calls from bathrooms. More than I probably care to admit.
Kelly Cervantes:	<u>21:32</u>	What is your advice for other parents in your position where you're getting those calls and you're thousands of miles away and you seem so calm about it. I mean, I know it's terrifying watching your child or hearing about a seizure that your child had and feeling so helpless. How have you remained calm? How have you recognized and balanced independence versus wanting to take care of your baby?
Katie Beauseigneur:	<u>22:02</u>	Well-
Kelly Cervantes:	<u>22:03</u>	And meanwhile, I know that you are a grown man, but to a mother, you are always your mom's baby.
Katie Beauseigneur:	<u>22:09</u>	That's very true. Yeah. I think early on, I just didn't even really know. I think we were in such go mode, at the time it was, I feel like they were just crisis after crisis after crisis. Ambulance, then it was calls from the bathroom. Those were some of the dark, dark days and we had them with the hand accident, and fast forward two years, we're on a different crisis mode. I think we were just really in, go mode trying to really figure things out, especially me. But ultimately that led to him coming home. "Mom, I can't be here anymore." He couldn't live independently to where he had to come home, which was easier than being thousands of miles away, I'll tell you, but we're very new in this community. We've spent all of 2018 really just discovering his seizures. 2019 is where we've really just been doing all the testing and hospitalization to this point.
Katie Beauseigneur:	<u>23:05</u>	But as a parent, I've had to sit back and show up when he needed me in big ways. Big ways. And I think for any parent dealing with epilepsy is, it's helping them gauge this because I had to show up, but then I also have to step away, because
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		independence for him is huge. This is a 25, almost 26 year old guy that was in the military. And moving home with your mom is hard. So that's really, for me just watching that, engaging that, and helping him when I see things that he may not recognize too, is pointing them out here. "Are you feeling okay?" And just being really just supportive and knowing what my role is, to step up, step back. To allow him to grow and be independent as he can at this point in his life, which is important.
Alec Beauseigneur-Jimenez:	<u>23:58</u>	And that just goes back to, you have to be truthful with your support groups. Because I definitely would keep a lot of information away from my mom because it is. I just wanted her be proud of me independently. And I would have seizures call her after or call her before seizures. I could gauge what types were coming on at that point. But you just have to be open and truthful, because ultimately when you're unconscious and nobody's there around, doesn't know what's happening to you, they're going to get the call as my emergency contact number and she's got to be fed the whole story. Know what's happening, make sure people are timing it, places that I'm at and all that.
Kelly Cervantes:	<u>24:46</u>	Yeah. Communication is integral. Unless you have that support team, unless you have that seizure action plan in place, you're just putting yourself at greater risk. I think that's really incredible advice. And tell us about what you're doing now.
Alec Beauseigneur-Jimenez:	<u>25:05</u>	I still want to use my post 9/11 bill for school, but at this point in time, it's just not smart because my memory is horrible. And I don't want to waste that on a degree and not remember anything that I did. So again, we're leading up to this point where I have the deep brain stimulator implanted and see how that kind of affects me and then go on and achieve those goals.
Kelly Cervantes:	<u>25:32</u>	When you're able to start school, what is it that you would like to study?
Alec Beauseigneur-Jimenez:	<u>25:37</u>	The college that I was out in Colorado was aviation electronics. And then that's what I'll go back towards when I go back to school.
Kelly Cervantes:	<u>25:46</u>	Amazing. Well, we wish you the best of luck with that. Alec, Katie, thank you so much for sharing your story with us. Alec, thank you for your service I'm sorry that this was the crappy club that you had to enter following that one, but I hope that you know that you are in incredible company and we fully support you and hope that I get an email one day telling about
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your graduation and moving on into aviation. I can't wait to read all about it. Alec Beauseigneur-Jimenez: 26:31 Thank you for having me. Katie Beauseigneur: 26:32 Thank you, Kelly. **Kelly Cervantes:** 26:32 Thank you, Alec and Katie for sharing your experience battling post-traumatic epilepsy. CURE understands that epilepsy can strike anyone at any time without warning. One in 26 Americans will develop epilepsy in their lifetime and the cause can vary from genetics to illness to infection to traumatic brain injury, and some never know the cost for their epilepsy. That is why CURE is dedicated to funding patient focused research that will bring us new knowledge, therapies, and cures. Now more than ever, we need your help to pursue our mission. Please visit cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you. Brandon Laughlin: 27:15 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 individuals specific health situation.