Seizing Life, episode 102
A Marine Explains the Value of Receiving An Accurate Epilepsy Diagnosis A Decade Late
Guest: Jack Somers
(Transcript)

Kelly Cervantes:	00:00	Hi, I'm Kelly Cervantes and this is Seizing Life. A biweekly podcast produced by Cure epilepsy. Today I'm happy to welcome Jack Somers to the podcast. He's a former United States Marine who has served in Africa and Afghanistan. Jack's military career was cut short when he began experiencing seizures while training at Camp Pendleton. The diagnosis he received sent Jack on a long and often frustrating journey of treatment that greatly impacted his professional and personal life for more than a decade. He is here today to share that journey with us. Jack, thank you so much for joining us today. By way, a little background, can you tell us a bit about your military experience?
Jack Somers:	00:59	Yeah, so I was commissioned in 2007 out here in Chicago as a second lieutenant, and then I was in the Marine Corps for about six years. And during that time I spent most of the time out in California at Camp Pendleton and twice deployed. First deployment was on a ship. We went kind of all around the world, different places, which was a lot of fun. Then the second deployment was to Afghanistan, a slightly different vibe, if you will. So in a nutshell, that was most of my time in the Marine Corps.
Kelly Cervantes:	01:32	Well, thank you so much for your service. I know that we all appreciate that. Switching gears slightly, how did epilepsy first enter your life?
Jack Somers:	01:46	After my deployment to Afghanistan, I came back and about a month and a half later I was running the local turkey trot during Thanksgiving. And as I passed the finish line, a bunch of people that are local that I'm very good friends with, they started asking me about a deployment that I had recently gone on and I had no idea what they were talking about. I really didn't know where I was, what I was doing. I didn't know who the people were that were asking me these questions. And these are lifelong friends. These are folks that not only do I know them, they're friends with my parents, but their sons and daughters are some of my best friends too. And it was a really surreal experience. I didn't necessarily know that it was a seizure at the time, but I was so uncomfortable because I didn't know what they were talking about.
	02:39	And they were very kind of, it felt like serious questions, but I didn't know why they were serious questions. And so I just kind of walked away and just tried to leave the whole area where

everybody was congregating. And as I started walking home, I just started picking up on, Oh, I recognize that house. Oh, I recognize this ball field. And things started coming back to me. And as I finally arrived home after about 20 minutes I knew that something had happened that was not normal, but I didn't know what it was. And that was kind of my first seizure experience.

Kelly Cervantes: 03:23 And then I understand you had two seizure, two more seizures after that one. Tell us about that.

Jack Somers: 03:33 Yeah, my next seizure was actually a drop seizure, which was the first of many that I ended up having and that I just dropped in my kitchen. I was cooking and just kind of dropped a sack of potatoes. And then I had another of my absent seizures where I called one of my roommates into the room. And during my absent seizures, I always remember one name, there's like one name that sticks out that is like, Oh my gosh, I got to talk to Travis, I've got to talk to Ryan, I've got to talk to Brett, whatever it might be, I've got to talk to my mom. And it's just that, that's all I remember.

04:18 And that was my first absence or was my second absence seizure. And then they just kind of started rolling in one, two a month. And most of those were absence seizures. Several of them were when I was working out or in the morning often they would happen. And so that was kind of like this, you don't know what happened, it was a seizure. And then all of a sudden it's just this kind of wave of, at least I experienced this big wave of more and more of them. And they started getting more severe and they started changing in form to all the way to then two grand mal seizures, which is why I was separated from the Marine Corps.

Kelly Cervantes: 05:08 Is that, and I want to get to that. Your story I feel is all too common where it just starts with one and then maybe a couple months later there's another, and then it's like the floodgates open and seizures are occurring regularly. So when and how were you diagnosed with epilepsy?

Jack Somers: 05:28 That's a really good question. I wasn't actually, I didn't know that I had epilepsy until about a month ago.

Kelly Cervantes: 05:38 Wait, I'm sorry. You started having your seizures when? How many years ago?

Jack Somers: 05:47 2010.

Kelly Cervantes:	05:47	You got your first epilepsy diagnosis 12 years after your first seizure?
Jack Somers:	05:52	Yeah, that's correct.
Kelly Cervantes:	05:53	So what were you diagnosed with when you had your first seizure, when you got your first diagnosis I should say.
Jack Somers:	06:02	Actually, yeah, after my second grand mal seizure, I was diagnosed with generalized seizure disorder and I thought that was totally different than epilepsy. That's what I didn't know. And that's what really blew me away about a month ago when I asked doctors, because they kept saying, "Oh, we're going to find out what kind of epilepsy you have and we're going to keep monitoring you for five or six days." And because we're a little, we're looking at two different kinds of epilepsy. And I was laying on the bed with all these things all over my head that are figuring out what's going on with my brain and neurologically. And I just stopped and I said, "Do I have epilepsy?" And they said, "Well yes, you've had epilepsy for a long time. We're just trying to figure out if it's two different forms of epilepsy." And I couldn't believe it. I have just always thought that generalized seizure disorder was what I had. I was never told that I had epilepsy.
Kelly Cervantes:	07:12	Or that a generalized seizure disorder is the exact same thing as epilepsy.
Jack Somers:	07:18	It's the same exact thing.
Kelly Cervantes:	07:21	And I do want to get to that in a little bit because I do think it's so incredibly important that we use the word epilepsy because there are so many treatments and services out there that are tied to the word epilepsy and not to seizure disorder. And so I do want to get to that in a moment, but I want to dive a little bit further into your story first.
	07:45	So you are, it's 12 years before you get an epilepsy diagnosis, you have the generalized seizure disorder diagnosis, which in the grand scheme of the medical world doesn't necessarily do you a lot of good, but were you put on medication? What did your treatment look like over those dozen years?
Jack Somers:	08:05	Yeah, I'm probably, I would say 40 to 50 different treatment plans over 12 years of maybe probably 10 to 12 different medications. But the dosages, the, you're going to take more of this, less of that, you're going to take more of these two, you're

going to take less of this one, you've got to take this one at this time, we're going to up your dose here. It was excruciatingly painful to go through this with all these different treatment plans. Nothing seemed to work, but it was all about generalized seizure disorder. So to a point I'm like, I don't know. I don't know what that really means. I don't know what it is. I don't know how hard I have to work to help my doctors.

09:00 How much are my doctors supposed to help me? And when you're going through all these different treatment plans, which I would venture to guess is very common, especially with anyone who has generalized seizure disorder, you're kind of in this purgatory space, you're like, "Are you supposed to help me? Am I supposed to help you? What is help? What is the goal here? Am I supposed to get to no seizures? Am I supposed to get to some seizures? How long?"

Kelly Cervantes: 09:29 There's a huge learning curve that comes with entering the world of chronic illness and needing to understand how much you have to advocate for yourself. And I'm just thinking, especially when all of this is happening in your early to mid twenties, and those are skills that you don't necessarily have yet that especially medical advocacy for yourself. And because the doctors don't know everything. And that's something that you have to learn.

Jack Somers: 09:59 Yeah and if for anyone who takes a similar approach or has a similar route to mine, I moved. I physically relocated to multiple areas throughout the last 12 years, most of them in Southern California, which I've loved. But when you go from one neuro, if it's one neurologist and then all a sudden you go to another neurologist, which I would just be aware of because you're kind of starting over each time and it's so dangerous, especially if you're young and you're single and you want to go out and you want to drive around and meet new people and have fun. And there's certain kind of social expectations, professional expectations that you have for yourself and that maybe others have for you too.

10:50 And if you're dealing with starting over every two to four years, personally and professionally with new neurologists, Kelly, it was remarkably difficult and I just hid most of it. I mean, hiding everything that you could from other people. While pretty much trusting your doctors to do what's best for you and take care of you. That is a space that, once again, I don't think I'm alone. I think a lot of people do it. And I think a lot of veterans are in that space too.

Brandon:	11:31	Hi, this is Brandon from Cure Epilepsy. Did you know that 30% of those diagnosed with epilepsy do not respond to current medications? That is why for over 20 years, cure epilepsy has been dedicated to funding patient focused research to find a cure for epilepsy. Learn more about our mission and our research by visiting cureepilepsy.org. Now back to Seizing Life.
Kelly Cervantes:	11:56	You sort of touched on it a little bit, but I want to dive a touch deeper. How did having seizures, not knowing you had epilepsy, but at the time you were having seizures and how did that affect your personal life and your career? Obviously you were forced to retire from the Marines because of this, and so I can only imagine the emotional and social implications.
Jack Somers:	12:28	And so I guess on the personal side, it can be extremely isolating. It was at times really isolating because you can't drive, which sounds like a small thing, but in the grand scheme of things, especially if you're younger, if you're single, being able to drive somewhere, just having that independence taken away is tough to handle. And especially when you don't really want to tell the whole world and all your friends and everybody that you have seizure disorder or epilepsy. You don't want to say that. So you find yourself just, what I did was I lived really close to vibrant areas where I could ride my bike, I could ride a bird scooter, I could take an Uber, I could do all of this, I could just walk. Because that was one of the best ways to get past the fact that I was having these seizures, that I didn't have a way, I didn't have a driver's license.
	13:33	Professionally, yeah. I loved being in the Marine Corps. It was so much fun for me. I felt like I was a pretty strong Marine and I was fortunate and so blessed to be what I thought was a really solid leader. To not have that opportunity, it was confusing because I didn't know where to go. I'd left the Marine Corps and it was pretty much take a bunch of pills and go on with life. I was like, but I can't drive. I'm having these seizures which knock you out for at least a day, sometimes more. I didn't know if employers were going to be very cool with that. I didn't think they would be.
Kelly Cervantes:	14:21	So did you tell people or did you keep it quiet that you had epilepsy?
Jack Somers:	14:27	I kept it extremely quiet. Yeah. I was convinced that I could overcome it. I was convinced that it was not impacting me the way that it would impact others. But that was obviously not the case. And if I could do it over, I would do many things over and not be so stubborn, not be so hard on myself. But I think that's

all too common in the community is to think, no, I can get past this, I can do it. And it just keeps punching back.

Kelly Cervantes: 15:06 Yeah, I think it's hard, especially with anything neurological, be it epilepsy, be it mental health, be it any of these things, it feels like something that we should just be able to think ourselves out of. But it's a physical ailment, just like anything else. You're not going to be like, "Well, I'm going to think myself out of high blood pressure." It doesn't work that way. But because it's in our brain, I think so often we're like, "Well, it's just something that we can think our way out of." How were your employers? So clearly you were able to get a job. Do you ever have seizures at work?

Jack Somers: 15:48 Yeah, getting a nine to five, I found that to be extremely difficult. I've always kind of had more of an entrepreneurial interest and that's been a little bit more in my blood. And so I stuck to that for many years and I was really fortunate to have some success on that end.

16:08 But as I started having more seizures, I realized that once again, not having a driver's license, and this is 2015, '16, '17, it was a little bit before a lot of Zoom meetings were really popular. Before the virtual meetings were, I would say, really accepted. It was still a lot of one on one. If you got to drive 45 minutes or an hour to meet with someone, that was the culture. And getting my license taken away for six months or a year at a time and basically just going flip flopping, having three months with the driver's license, a year without, two months with the driver's license, a year without, it was like, man, I don't think I can be a very good entrepreneur if I can't visit any of my clients or any of my partners or any of my mentors.

17:05 All of a sudden you kind of felt like the walls were starting to collapse or certainly getting closer and closer. And so that made it difficult. To follow up with that last part was when I did get a nine to five, I studied computer science in 2017 and then got a nine to five. It was not long before I knew. I mean, I was having seizures, not just, I mean I was having seizures when I came home or before I went to work. And it impacted my abilities and that's no excuse. That's just like, I don't want them to know that I had seizure, that I had epilepsy, even though I didn't know. But it was like a knock on my confidence. It was a real humbling experience. And unfortunately I was then terminated from that job, which was the first time that I was fired. And it was so unlike me. I think that I hope other people understand that for me was kind of like the whoa, things are happening that are

		really, really impacting me personally and professionally and I've got to figure out what's going on.
Kelly Cervantes:	18:36	Well going from being, considering yourself to be this very fit soldier and then you are back in the civilian world and you're in the civilian world with a disability. Although I doubt at the time that you had wrapped your head around the fact that it was a disability, that you were working with a disability and I can't even imagine without the correct terminology around it, how frustrating that must have been. Did you have a support network of family or soldier friends around you?
Jack Somers:	19:16	Yeah, I did. So I kept my world separate by perhaps living in California. And my friends out there knew what was going on. At times having three, four, or five drop seizures where I smashed my head on a sidewalk or on a concrete road or on a curb and have to go to the emergency room and get stitches and have a concussion. People could see this, people, my friends could see it. I always held back from letting my parents know and my family because I didn't want them to see me like that. So my support networks were very different. I had the ones who I couldn't hide it from and they supported me in certain ways. And then I had my other group mostly out here in Chicago and what have you, that they were my family but best friends in here. But they supported me in other ways. That was in much, it was due to me withholding information because I didn't want to be vulnerable like that.
Kelly Cervantes:	20:27	So when did you start telling people, What was the impetus for you to let your family know what was going on?
Jack Somers:	20:34	Yeah, it was about two years ago and I moved back to Chicago. When they saw how I was and having these episodes, having seizures and I couldn't hide it from them anymore. I wanted to, it was the worst feeling in the world. It was my two worlds colliding and my parents are my heroes and my brothers and sisters I love so much. And I never ever wanted them to see me like that. They'd always call me Captain Jack and I wanted to stay Captain Jack and serve and not feel like they had to help me.
Kelly Cervantes:	21:21	You can still be Captain Jack and need help. Ugh, you're breaking my heart. So I'm curious, I sort of want to get back a little bit to the difference between getting this generalized seizure disorder diagnosis and then finding out only last month that for the last 12 years what you've actually had is epilepsy. If you had known from the beginning that what you had was

epilepsy, how could that have changed the trajectory of your life and where you are now?

Jack Somers: 21:54 Yeah, I think look at how many generalized seizure help groups there are versus epilepsy help groups. I don't know where a generalized seizure help group is. I've never seen one before, but epilepsy help groups and communities, they're huge and they're there for a reason because it is so helpful to talk with other people who are going through or have gone through or will go through the same things as you. When you don't have that, you can just start right there. And I think that really captures the type of community that you have to work with. And when you just have generalized seizure disorder, I mean you feel about as alone or confused as one can feel because you're like, is this serious? Is it not serious? Do other people have this? Don't other people have this? Am I supposed to reach out and find people who have generalized seizure disorder?

22:59 Is this something that in the military community, is this a secret? Is this something I should share? I guess I'm just going to kind of have to do this alone. Whereas if I would've just been told, Hey Jack, it's okay, you have epilepsy now let's attack it. Let's figure out what you can do. Here's some community groups you can jump in on. Here's some folks, here's some other Marines that would be happy to connect with you. Here are organizations or groups that we have right here in the VA system that are designed to help you and support you. Here's the medication. This is epilepsy medication, we're going to take this on and we're going to start step by step, crawl, walk, run. And I feel like I could have better served the community had I just been told or diagnosed properly and said, "You have epilepsy Jack, now what are we going to do about it?"

Kelly Cervantes: 23:59 Yeah. Well and one of the first things that comes to my mind too that I often encourage people, especially when they have uncontrolled epilepsy, is that they need to go and see an epileptologist. But if you don't even know that you have epilepsy, how are you going to get to the right specialized doctor so that they can try and identify the kind of epilepsy you have? Because depending on what kind of epilepsy you have, they can target treatments better, you have a better chance of finding better seizure control, but you can't do any of that if you don't have the vocabulary, if you don't have the diagnosis to begin with. And it's just so hard. I'm so sorry that this has been your journey. So often we see, particularly in veterans who develop epilepsy, something that we call post-traumatic epilepsy. And it is often the result of a traumatic brain injury, which can happen when soldiers go to battle. Do you know if you had a TBI, a traumatic brain injury? Is your epilepsy actually post-traumatic epilepsy?

Jack Somers: 25:12 Well, hot off the press, just yesterday after 12 years of having seizures or epilepsy, just yesterday I went in and was diagnosed with a traumatic brain injury. And this goes back to what they think was combat related. A particular event with my platoon where we encountered a grenade blast that was very close and we continued to fight through that particular event and engagement, which I'm so proud of my Marines and the way that they acted and every action they took. As my doctor said yesterday, I didn't have seizures going in to Afghanistan. That particular event happened along with others, but that one was kind of sticks out. And then a month and a half after that combat event, I then had my first seizure. And I mean he kind of looked at me almost like, are you serious? Do you not see the chronological order here?

26:26 You're fine. No seizures. And then you had this event along with others, but then a month and a half you have your first seizure and then they start to snowball. It was amazing because as the doctor said, kind of looked at me and looked at my parents and we're like, doesn't this look at it? It makes a whole lot of sense. It doesn't seem like very hard to piece these together, these events, no seizures, combat event. Then you have seizures immediately following. And that was amazing. It was so relieving Kelly. I had the best night's sleep last night that I've had in years, I swear because I felt like for the first time I understood what was going on and that they gave me a whole community, a whole team with a case manager, a coordinator who she said, "If you have any questions, if you need to get in touch with anybody, call me. If you don't know who to call me and I'll figure it out."

Kelly Cervantes: 27:37 Now you have this care team. But on top of that, I can also imagine sort of the peace of mind that now where this came from. You understand why this is happening to you. You now have a diagnosis, you have a treatment plan, you have a team of doctors and people who can help you with all of the various symptoms and side effects and seizures and everything else that goes around along with it. And it all started because you just needed to get the word epilepsy. I have to imagine that that's comforting to just, there's power in having knowledge.

Jack Somers: 28:21 My gosh, it's incredible. And the other part of this, to anybody who has epilepsy or post traumatic epilepsy, which he, it's doctors specifically used that yesterday. Is if it's a residual from a traumatic brain injury, which epilepsy can be a residual, if you have a moderate to severe traumatic brain injury, you're then so much more likely you're at high risk to develop posttraumatic epilepsy. And mine has been in the form of absent seizures, gran mal seizures, but then also drop seizures. And so anyone out there who has had or has posttraumatic epilepsy, or had a traumatic brain injury, just reach out before you start having those drop seizures. Because when you have a drop seizure, you don't know when it's going to happen. You, I mean you just smash your head on the ground and it creates another TBI and the more of these you have, and I had four or five of them in maybe 6, 7, 8 months, then it's just like, it's another TBI, another TBI, another TBI.

29:38 And you just add on to the issues and you add on to the kind of frustration that you have, which can cause anxiety, social interaction issues go as far as depression, anger, mood swings. And I've had to tell my parents like, "That's not me. I'm just working through this stuff." And for anyone who has had a traumatic brain injury, even if you haven't been diagnosed, I encourage you to please reach out, whether it's me personally, get in touch with me, reach out to the Cure Epilepsy Foundation so that you don't get to where I have been. It's not fun, it's not fair. And honestly, it just hurts so many people around you that you no longer feel like you're, you feel like a burden and no, nobody should feel like that.

Kelly Cervantes: 30:36 Jack, that is incredible advice. Is there anything else that you want to add to whether it is a fellow veteran who is out there or someone else who thinks maybe they have epilepsy or they've been diagnosed with a generalized seizure disorder, or maybe they're newly diagnosed with epilepsy or they've had it for years and they're just scared. What do you want to tell them?

Jack Somers: 31:04 Yeah. If you've been told that you have generalized seizure disorder, you have epilepsy and start there. Start there and just look up epilepsy treatment groups around you or look up different epilepsy help groups. Look up in the VA, what options they have for folks with epilepsy. Just don't do what I did and use generalized seizure disorder this whole time when life really could have gone a different direction had I just been using the word epilepsy. And so start there.

31:45 Just say epilepsy and do yourself a favor and do all, everyone the favor of being able to support you and do things for you faster than if you just use generalized seizure disorder so that you can do what you really want to do. You can go out and serve again and you can stop feeling like you're on the canvas

		boxing and you've got a blindfold on. Use epilepsy and you're blindfold. You can take it off and you can start to see what you're fighting.
Kelly Cervantes:	32:21	Captain Jack, I think that you are pretty amazing and I am so honored that you are willing to share your story with us. I truly believe that you are going to do amazing things for your community, for our epilepsy community through sharing your story. And I'm looking forward to seeing where your newfound knowledge and wisdom takes you and hopefully that includes a few less seizures down the road as well too. I'm just, I'm so appreciative. Thank you so very much.
Jack Somers:	32:55	It was a privilege and honor to serve and thank you for having me.
Kelly Cervantes:	33:01	Thank you, Jack, for your service and thank you for sharing your epilepsy journey with us. As Jack's story highlights, getting an accurate epilepsy diagnosis is vital to finding effective treatment, but we can't get an epilepsy diagnosis if we don't say the word epilepsy. A seizure disorder is epilepsy. If we don't say the word, we can't treat it and we can't find a cure for something we don't acknowledge. That is why cure epilepsy would like to invite you to take part in our, say the word hashtag, say epilepsy campaign. Share your epilepsy story on your social media using the hashtag say epilepsy, and then tag cure epilepsy in your post. Together we can raise awareness of epilepsy and together we can fund the research that will lead us to a cure. Through research, there is hope. Thank you.
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