Seizing Life, episode 83
Personal Epilepsy Experience Inspires International Epilepsy Advocacy
Guest: Julianna Shinnick
(Transcript)

Kelly Cervantes:	00:00	Hi. I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by CURE Epilepsy.
Kelly Cervantes:	00:17	This week on Seizing Life, in honor of International Epilepsy Day on February 14th, we speak with Julianna Shinnick, whose personal experience with epilepsy inspired her to make a difference in the lives of those with epilepsy in East Africa. Since 2014, Julianna has regularly traveled to Tanzania, where she's been part of a number of projects aimed at improving the lives of those with epilepsy in the Mahenge region. She's here today to provide insight to what life is like for those with epilepsy in Tanzania and discuss what is being done to improve care, reduce stigma, and provide opportunity for those diagnosed in Mahenge.
Kelly Cervantes:	00:57	Julianna, thank you so much for joining us today. I have been looking forward to this conversation because I have a personal vested interest in Tanzania. I visited Tanzania also shortly after college and absolutely fell in love with the country, the community, the culture, some of the kindest, warm-hearted people I have ever met. I'm fascinated to hear, you started working with epilepsy patients in Tanzania in 2014, but you also have a very personal connection to epilepsy. I'm wondering how you got involved with the epilepsy community in Tanzania and how your personal story drove your interest in that region of the world.
Julianna Shinnick:	01:46	Yeah, I do have a very personal connection to epilepsy. I have epilepsy. I had temporal lobe seizures from the time I was a very small kid, as long as I can remember. Probably like a lot of people, I tried a ton of different medications, the low glycemic diet, nothing was really working for my seizures. I was having two or three seizures a week, all through my childhood, all through my teenage years.
Julianna Shinnick:	02:22	When I was in my freshman year of college, I decided to have epilepsy surgery. I had a right temporal lobe resection after my freshman year in college. I mean, it completely, completely changed things for me. I went to Mass General, I had my surgery. I woke up and I haven't had any seizures since then. That was 10 years ago.
Kelly Cervantes:	02:49	Amazing. I love those stories, they're my favorite.

Julianna Shinnick: 02:52 I felt after my surgery, it was like you know when you go to the eye doctor and they put the little lenses down and they're like, "Is that better?" and you're like, "Oh my gosh, I can see all the little individual leaves." You don't realize that you aren't seeing well, but then they're like, "Is this better?" and you're like, "Wow, I can see so clearly." That's sort of how I felt, except for my whole entire consciousness after I woke up from surgery.

Kelly Cervantes: 03:16 I don't think I've ever heard it explained that way before, but that is absolutely fascinating and such a great way for those of us who do not have seizures to understand.

Kelly Cervantes: 03:29 You have the surgery, you wake up with a brand new brain. You're in college. When do you first learn about this particular community in Tanzania?

Julianna Shinnick: 03:47 I think if my memory serves me right, it was a few years later. I was a junior now in college. I was, I think, still riding a pretty serious high from the surgery. I was doing a project for a sociology class about human rights and epilepsy. This one community kept coming up in my research, and it was the town of Mahenge. It's this little community tucked in the Wapagoro mountains in Central Tanzania. The reason that it was so well studied was this woman named Louise Jilek-Aall, this neurologist, had been there in the '60s and realized that there was this huge, huge proportion of people there that were having epilepsy. She ended up establishing an epilepsy clinic there, so there's been a lot of research about that community.

Julianna Shinnick: 04:46 The more I read, the more I was just captivated by this place, because here I was, so grateful and so privileged really to have had this surgery, and I realized that I'd been born in the right place at the right time. I could go to Boston and have this super high-tech imagery and super specialized doctors and everything I could possibly need to treat my epilepsy, and there, there's one tiny clinic with one doctor and a team of nurses that are spread thin to try and help people who are really not only struggling with epilepsy, but also with real, real social stigma surrounding epilepsy.

Julianna Shinnick: 05:38 I just got sucked into this thing. I kept reading about it and finally I decided to email Dr. Jilek-Aall. I emailed her and she didn't respond, so I was like, "Ugh, I guess that ship sailed." Then I finally saw her phone number on another thing, and I was like, "I'm just going to give it a shot." I give her a call, she picks up the phone and she's like, "Oh, hi. Yeah, you read about Mahenge? Yeah, let's talk about Mahenge." She chats my ear off for like an hour. I was like, "Yeah, I did email you," and she's

		like, "I'm 75, I don't do email. There was no way I was going to respond to your email, but I'd love to talk to you." We kept talking and eventually she said, "You should really go to Mahenge. I think that you should work with the clinic there. Let's get you over there."
Julianna Shinnick:	06:33	After my senior year of college, I applied for the Davis Projects for Peace fellowship, which is a $10,000 grant. It's from this woman named Kathryn Davis. She had a large fortune, and when she turned 100, she decided to dedicate it to a hundred projects for peace. She gave out her entire fortune to young idealistic people with weird ideas. I wrote up a grant talking about helping people with epilepsy find jobs and find a place in their community, in Mahenge. I got the grant, and so I flew to Dar es Salaam after I graduated college and took the 15-hour drive up to the mountains, to Mahenge. That's how I ended up there.
Kelly Cervantes:	07:22	That's absolutely incredible how these two worlds converged for you.
Brandon:	07:32	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:	07:52	You mentioned a little bit the stigma, but what is day-to-day life like for people with epilepsy in this region of Tanzania?
Julianna Shinnick:	08:03	Yeah. First off, there's so many more people with epilepsy in Mahenge than there are here. When I was growing up-
Kelly Cervantes:	08:11	I'm going to stop you there for a minute, I'm sorry, because I'm so curious and I have to imagine everyone listening is. You're talking about such a significant more amount of people in this region of Tanzania that have epilepsy than the average statistics in the United States. Why is there such this high density of epilepsy patients in this one area?
Julianna Shinnick:	08:37	Yeah. We think it's about 10 times greater. It's still hard to know with statistics because it's hard to reach people in the same ways that we survey people here. But when I first went there, we weren't really sure at all why there were so many people with epilepsy, it was kind of a mystery. At that time they thought maybe vitamin B deficiency. They thought all of these people, all these different places, have had some level of a

		displacement over time, maybe that has something to do with it. They thought maybe it was long-lasting effects from measles. There were all of these different theories. In 2017, a paper came out in Science that brought us the closest to understanding why there's so much epilepsy that we've gotten. Still not a hundred percent sure, but we really think it has to do with onchocerciasis, which is river blindness.
Julianna Shinnick:	09:32	What happens is there's these little filarial worms in the rivers, and then people get infected with these worms. There's a little tiny protein on the filarial worms that looks a lot like a protein that's both in our neurons and in our muscles. They think what's happening is when people's immune systems are trying to fight off river blindness, they sort of friendly fire and end up attacking their own brains, which results in seizures. That gives us a little bit more to work with than what we had to work with even seven or eight years ago. Now we can start targeting epilepsy upstream, not just treating the epilepsy once people get it, but also trying to prevent river blindness infections.
Kelly Cervantes:	10:24	Absolutely. That is promising, that this paper came out. Hopefully, fingers crossed, there can be more and better treatments. Sorry, I interrupted you. Let's go back to your original question about what life is like. Like I said, you mentioned the stigma, what does daily life look like for epilepsy patients in this region of Tanzania?
Julianna Shinnick:	10:50	A paper came out in 2010 where Dr. Louise went to Tanzania. She speaks really beautiful Swahili, so she got a group of people together and started just asking them about epilepsy and their beliefs about epilepsy. She found out that 65% of people in Mahenge thought that people with epilepsy weren't fit to work or to go to school. People with epilepsy form their own kind of class there, where they're excluded from being productive members of society, really. Kids from a really young age who have epilepsy just don't see themselves as having any kind of future because they're often kicked out of school and they're often excluded from the workforce because nobody will hire somebody with epilepsy. They think people with epilepsy aren't capable of working, they're not good workers.
Kelly Cervantes:	11:46	That's absolutely heartbreaking to hear. Is the stigma based in some type of culture? What do they attribute the seizures to? I know in Latin and parts of South America, there is this idea that people with epilepsy are possessed or things like that. Is it something similar, culturally?

Julianna Shinnick:	12:11	Yeah. I mean, I think historically it was definitely a belief that maybe ancestral spirits or spirits in general, something was cursing the community that was resulting in these really scary seizures that they couldn't explain. Over time, now when you talk to most people in Mahenge, they're like, "No, people go to the clinic, they get medicines. It's a medical condition," but you can't wipe away that sort of history or that stigma over just a generation or two. I think still somewhere tucked in the DNA of the village is this idea that people were cursed.
Julianna Shinnick:	12:52	Then I think just having so many people with epilepsy, it makes it so that they form their own sort of class of people that are more systemically discriminated against.
Kelly Cervantes:	13:05	Now, it's incredible that there is this clinic there. However, I have to imagine that it does not compare with the epilepsy monitoring units that we see in a class four epilepsy center hospital in the United States. What does epilepsy care look like? Are there medications available? How are the neurologists there? How are they treating epilepsy?
Julianna Shinnick:	13:37	Yeah. Right now, there's a doctor and a nurse that run the clinic, Dr. Bhwana and Grace Kibiriti. They're incredible. They run around on their motorcycle, delivering medications, deep into the bush. They're so dedicated to the people with epilepsy, but like you say, they don't have the support and the infrastructure that we do here to provide that care.They have phenobarbital and they have Dilantin, are the two medications that they have at the clinic.
Kelly Cervantes:	14:12	Just those two.
Julianna Shinnick:	14:14	Just those two. As any of us who have taken any of those medications know, they're not going to be the best for everybody. That's the options they have. A few years ago we were able to partner with an organization called The ROW Foundation to get Lamictal, or [inaudible 00:14:31], because it's the generic, but we were able to get that medication to the clinic as well, which is really exciting, especially for pregnant people with epilepsy. But, I mean, there's nowhere near the medication options.
Julianna Shinnick:	14:50	Then in terms of diagnostically, I couldn't find any statistics about Tanzania, but in Uganda, which is right next door, there are like 15 MRI machines in the entire country. I live right down the street from Penn Medicine, that's in my backyard, and there are 12 MRI machines at Penn Medicine. I have a few patients in Mahenge that have had MRIs, but they've had to travel 15

hours by car to Dar es Salaam and that's a huge amount of money that most people don't have.

Julianna Shinnick: 15:26 Then even the medications that they do have, one of the real challenges is sometimes there'll be shortages of those medications because they come from the government, it's a government-run healthcare system. They'll get a certain amount of phenobarbital from the World Health Organization. It goes to Dar es Salaam, it gets distributed throughout the country, but somewhere along the way, sometimes there's floods, sometimes there's a greedy pharmacist who decides he's going to divert it to his own local pharmacy. Usually about once a year, I end up getting WhatsApp messages that are like, "We don't have any phenobarbital. It's all gone for the next three weeks," which is really awful for people who are already on the medication and then they're having breakthrough seizures because they can't get it for a period of weeks.

Kelly Cervantes: 16:16 Well, not even just breakthrough seizures. I'm thinking of going cold turkey off of some of these medications is dangerous.

Julianna Shinnick: 16:23 Right, exactly.

Kelly Cervantes: 16:23 In and of itself, especially depending on what kind of dose the people are on. I mean, that's sort of terrifying. Yes, breakthrough seizures, but also just having to stop and not be able to titrate down is really, really scary. Tell me about the projects and initiatives that you worked on and continue to work on personally in Mahenge.

Julianna Shinnick: 16:49 Way back in 2014, I didn't realize how much of the center of everything the river is, because water is really scarce there and whether it's the elephants going to the river to get their water or the people going to the river to get their water, everybody depends on this river to get what they need. I was asking people, "What do you know about epilepsy, and what do you think people with epilepsy need here?" Multiple people brought to my attention that there had been a few deaths the year before from women who were going to the river to get their water and they had fallen in the water because they had seizures.

Julianna Shinnick: 17:34 But I thought the other issue is that people in the community don't think that people with epilepsy can work, so what if we had them build a water tank close to the center of town so that people wouldn't have to go to the river to get water. Then that would be a useful amenity for the entire town and maybe they would see that people with epilepsy could work and could make

		something happen. I started talking to the doctor and the nurses. I was like, "I think we should hire a bunch of people with epilepsy to build a water tank, close to the clinic."
Julianna Shinnick:	18:06	The next morning I wake up, and I had this little balcony in my little room at the seminary, and I'm really sleepy, I'm not much of a morning person. I walk out and I'm about to get some coffee, and there's a line of people with epilepsy all just through the courtyard. They're like, "We heard you're trying to build a water tank. We're ready to work. When do we start?"
Kelly Cervantes:	18:31	That's amazing.
Julianna Shinnick:	18:33	And so we hired a bunch of people to build this water tank. I remember, when I saw the tank all finished and people from all over the village lined up with their buckets on their head, ready to get their water, and they're like, "Oh, who built this? This is awesome," and you hear people being like, "Yeah, it's the people with [foreign language 00:18:54], it's the people with epilepsy. This white lady hired them to build it." It was great to hear this hearsay in real time of like, "Yeah, people with epilepsy, they built this thing that's really useful for you, and they can do that work."
Kelly Cervantes:	19:11	That's incredible. I love that story so much, not only helping the community and preventing future deaths, but showing the community that people with epilepsy can, will and want to work. Have you noticed a difference in, you talked to the first time you went was in 2014, I know that you haven't been able to go back since COVID, but over the course of these years, have you been able to sense, I know that, like you said, this is going to take generations to work through this stigma, but have you at least seen progress in this regard?
Julianna Shinnick:	19:53	Yeah, I mean, I think I have. Another project that I have worked on is giving people vocational scholarships and educational scholarships, because so many people with epilepsy get kicked out of school at a really young age. If they can go back and continue an education, most of them will if they're given the money, but what I hear over and over again from people is, "I have five siblings. My parents couldn't afford to send all of us to school," and the kid with epilepsy is going to be the one that's left behind. If we can fund people to go back to school or to get a vocational degree, that's been one of my big goals.
Julianna Shinnick:	20:36	The first vocational program we started was tailoring, because there, any skirt or dress or tux or whatever you're going to get made, it has to be made right in the community. That was the

		first program that we started and had a few tailors graduate from it. We gave them their own sewing machines, they both were able to open their own businesses from their homes.
Julianna Shinnick:	21:03	Then I went back about a year later, I had some more funding, I was like, "Let's start a carpentry program." I remember going to the carpentry teacher and he was like, "Yeah, no, what are you talking about? People with epilepsy can't work." I said, "Have you run into Margaret down by this street?" and he was like, "Oh yeah, she makes really great dresses. My wife really likes her stuff." I was like, "Oh yeah, she was part of our program last year," and he was like, "Oh, that was good product," and so he was like, "Okay, I guess I could do it if you're funding these people to learn carpentry. I'll give it a shot." You can see the domino effect of the first one was hard, the second one was less hard because there was already something to go by. I see people taking really tangible examples and realizing that maybe that they were wrong about what they thought.
Kelly Cervantes:	22:03	I love it so much. I know that you've not been able to travel back, for obvious reasons, over the last couple of years. I imagine if you're not able to get back, that other volunteers and people aren't able to travel in as well. How is the community doing? Are they still able to thrive, or even just status quo, get treatments and medicines?
Julianna Shinnick:	22:30	In terms of COVID in general, I mean, I think they're struggling in that there's such inequality with the way that vaccines have been distributed and they don't have the refrigeration that they need for the Pfizer and the Moderna vaccines. I did receive word that a month ago they got a big shipment of Johnson & Johnson vaccines, so I'm really grateful for that. So far I think they've been relatively okay, but I do worry for them.
Julianna Shinnick:	23:01	Then in terms of supply chain, it's usually around this time of the year, in the rainy season, that the drugs start getting backed up. When there are shortages, it's usually during the rainy season. I mean, I really worry in terms of if we can't get two-day delivery on Amazon, I'm guessing that it's the supply chain is going to be a problem for them as well. We have been doing a lot of WhatsApping, a lot of chatting about applying to grants and that kind of thing, so just trying to plan for the next thing, but I do worry for them.
Kelly Cervantes:	23:41	Now, when life settles into whatever our new normal is, what are your goals? What do you hope for the epilepsy patients in Mahenge? What do they need most?

Julianna Shinnick:	23:57	They need both the very basics, they need a constant supply of medication and they need to have greater access to different medications. I think so much of the disease there is the social aspect of it and being seen as an outsider, as somebody who's not going to work, not going to be productive. Seizures are one thing, but really being so held back from living your life is another. I'm really hoping to continue supporting people to go back to school, to get jobs and to live productive lives once they get their seizures under control too.
Julianna Shinnick:	24:45	I mean, our students are really thriving. There's this one student, [Winfreda 00:24:49], that we've been supporting for a long time. She got kicked out of elementary school when she had epilepsy. We funded her to go back to a private high school and she totally killed it, she did great. She got amazing grades and she wants to apply to nursing school, which is really, really exciting.
Kelly Cervantes:	25:08	Is that the best feeling in the world, to know that you had a hand in completely changing the trajectory of this young woman's life? I mean, that's just incredible. I love the work that you're doing there, and thank you so much for sharing it with us today.
Julianna Shinnick:	25:24	Thank you so much for having me.
Kelly Cervantes:	25:28	Thank you, Julianna, for your experience and insights. Those of us who have been touched by epilepsy know that there are no borders when it comes to seizures. Epilepsy can develop in anyone, at any age, anywhere in the world. An estimated 65 million people worldwide currently live with epilepsy. Unfortunately, one-third of those people do not respond to current medications, and as Julianna related, those in developing countries often encounter multiple challenges, from accessing medications to deep seated stigma that impacts educational and employment opportunities.
Kelly Cervantes:	26:05	For more than 20 years, CURE Epilepsy has understood the need to find a cure for epilepsy and has been dedicated to funding research that will lead us to those cures. We ask you to join us by visiting cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Through research, there is hope. Thank you.
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