

**Seizing Life, episode 119**  
***Love, Marriage, and Epilepsy***  
**Guests: Tiffany and Chris Kairos**  
**(Transcript)**

- Kelly Cervantes: Today, I'm happy to welcome Tiffany and Chris Kairos to the podcast. Tiffany was diagnosed with epilepsy at the age of 22. The onset of Tiffany's epilepsy occurred only months after she and Chris were married, and plunged them into a serious health crisis that would deeply impact the first several years of their marriage and professional lives. They're here today to discuss Tiffany's epilepsy journey, its repercussions on their lives, and how they have navigated these challenges as a couple. Tiffany, Chris, thank you so much for joining us today. First off, I cannot believe that it has been five years since I saw you guys in person. You both look amazing. And I'm just so thrilled to be able to share your journey today, because I think that you have so much experience and knowledge to share with this community, and you're both just lovely people. So, welcome. And just to kick things off, can you tell us about the first time that you had a seizure, Tiffany?
- Tiffany Kairos: Yeah, absolutely. Let me begin by saying thank you so much for having us on your program. It's an honor. But yes, I was 16, it was 2002. I was asleep and I had had a grand mal seizure while I was asleep. I woke up to being carried down on a gurney with a paramedic on either side of me, dazed and confused, unsure of what was going on. And they took me into the ambulance and took me to the hospital, ran tests and let me know that it was a seizure.
- Kelly Cervantes: But you were not diagnosed with epilepsy at that time. I understand there was a pretty large gap in between your first seizure and your second seizure. What happened after that first seizure? And then tell us about that second one.
- Tiffany Kairos: Sure. So, after the first seizure happened, I was placed on medication. It was Dilantin. And I was on that medication for about six months, and I had no other seizures within that time span. So, they took me off of that medication and I just continued on life after that, just a normal girl, finishing out my teenage years. And fast-forward to 2008, Chris and I had only been married for four months. It was December 2008. I was driving and I crashed my car. While I was driving, my muscles had gone limp and my vision just became like tunnel vision. It started to go black. So, when I woke up from the car crash, I had only suffered whiplash, thank God. They loaded me up into the ambulance again, and I was dazed and confused. And they asked me who should they call. So, they called Chris.
- Chris Kairos: That was not a fun call.
- Kelly Cervantes: No, I can't imagine it was. What did they tell you?
- Chris Kairos: They said, "Your wife was in an accident." I said, "How's she doing?" And they said, "Well, she's still breathing." So, to me, I was just like-
- Kelly Cervantes: Oh, my gosh.

Chris Kairos: ... "What does that mean?"

Tiffany Kairos: I felt so bad.

Chris Kairos: So, thankfully, they were able to pass me on to somebody else who knew a little bit more. And they said, "Well, your wife was driving. She had an accident. She drove off the side of the road. She's okay, but we're taking her to the hospital." They told me where they were taking her, and obviously I dropped everything. I was at work at the time, dropped everything and took that white-knuckle drive over to the hospital.

Tiffany Kairos: So, again, they ran a lot of tests, the same tests that they did when I was 16. And it being my second seizure, I was diagnosed as having epilepsy at that point.

Kelly Cervantes: And what were you told about epilepsy at that time? I mean, what did you guys even know about epilepsy?

Tiffany Kairos: I knew nothing. I didn't even know what that word meant.

Chris Kairos: Yeah, same here. I mean, I knew the word generally, but I didn't know what it really was. I've heard the word, but that was about it.

Kelly Cervantes: Yeah. And so, what were you told at that time? You were like, okay, well, you've had two unprovoked seizures, so now you have epilepsy, were you given any education materials? Obviously, you were put on a medication.

Tiffany Kairos: I was put back on Dilantin, the same medication when I was 16. They gave me the standard packet that they do, but I was given very little information. They told me what I wouldn't be able to do, what I shouldn't do. And they told me that there were support groups in my area. And that was pretty much the extent of it.

Chris Kairos: And they wanted to do a follow-up where they could get her hooked up with a neurologist, things like that. So, it was very basic information and just procedure at that point.

Kelly Cervantes: I mean, you're 22 years old. You guys, you're newlyweds. I mean, the first year of anyone's marriage they say is the hardest, but you guys picked it up an extra notch here, I think. I mean, it's just that's such a young age where you are expect... I mean, you are an adult legally and in all other senses, but these are incredibly challenging skills to learn and develop, to be an advocate for yourself, Chris to be an advocate for Tiffany, to learn the medical system and how to function and operate in it. What did those early days, weeks, months feel like for you guys? And were you able to get control of the seizures? You said you started on Dilantin, and did it work, or were you having more seizures?

Tiffany Kairos: It didn't work. It really didn't work. They were having a difficult time trying to manage my seizures, because they were acting very-

Chris Kairos: Unpredictable.

Tiffany Kairos: ... unpredictable.

Chris Kairos: Erratic.

Tiffany Kairos: And I was having to navigate my emotions because this was all new to me. I didn't understand what was happening, and I felt alone. I didn't know anybody else that had epilepsy.

Chris Kairos: Yeah. And I could say the same, as far as like she was saying, everything was new and it was different. So, it was like, it's just things that we hadn't dealt with before. We always say, yeah, we got our vows tested right out the gate. Our wedding vows were tested right out the gate. We always say it was a journey. It was a day by day thing, a minute by minute thing at certain points, as I'm sure you have experienced and many others have as well, where you really do have to take it one step at a time. And that's really all we could do, and that's what we did.

Kelly Cervantes: Tiffany, you had to quit your job because of this. I mean, this wasn't you go on living your life. I mean, your life was entirely upended. And in turn, Chris, yours was too, right?

Tiffany Kairos: Yeah.

Chris Kairos: Oh, yeah.

Tiffany Kairos: I'm not a quitter. I really tried to continue working despite having the seizures, but the seizures just wouldn't allow me to work because I would have them on the job, which made it very dangerous. So, I just had to make the decision that I couldn't work. It just wasn't the smart move.

Chris Kairos: And they were grand mal seizures that were happening often, and in the beginning a lot there. So, if I was at work, there was no one there with her. And then on top of that, we had all these doctor's appointments and things like that. So, it just became really hard for me to stay consistent at work too, to where I actually had to quit my job as well. And ultimately, we ended up losing our first town home. And actually, the dreaded thing that I'm sure nobody who is newlyweds wants to think about is we had to move back home. We had to move in with my mom, which we're thankful for her and for having a place to go. But it definitely rocked our world, that for sure.

Kelly Cervantes: I mean, it's so much change in such a short period of time. How did you educate yourselves on epilepsy and where did you turn to for support?

Tiffany Kairos: Well, both of us, we were given very little information to go on, as far as understanding what epilepsy and seizures were. So, I think the both of us can say that we went to Dr. Google.

Chris Kairos: Yeah, I know I really spent a lot of time just Googling everything. I looked at all the medical types of websites. I looked at holistic websites, I looked at forums, things like that, where I was just trying to find as much information as I could. At the time back then, I was typing in, how do you cure epilepsy, because it was still so new. I didn't know that at that point there is no cure. So, it was just management, but it was definitely a lot of Googling. I would say that was the bulk of what we did. We had contact with her doctors and things like that, but you're limited to appointment times or to the things that you think of while you're in the room. At the time, we didn't know to prepare for appointments ahead of time.

Kelly Cervantes: There's a learning curve in those early days of just you have to learn how to communicate with doctors and how to function within the system. And there is no guidebook for that, you just have to really figure it out on your own.

Brandon: 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 25 years, CURE Epilepsy has been committed to inspiring hope and delivering impact by funding patient-focused research to find a cure for epilepsy. Learn more about our mission and our research by visiting [cureepilepsy.org](http://cureepilepsy.org). Now, back to Seizing Life.

Kelly Cervantes: Tiffany, you talked about how lonely it was in the beginning. And so, how did you find the support to lift you up to the person you are today?

Tiffany Kairos: I found a group on Facebook with a bunch of patients and caregivers. And I was just amazed at the amount of support that was being shown with one another, and that was given to me. That was so inspiring and encouraging.

Chris Kairos: Being with family and that closely with them too, at the time, I mean, they were super supportive.

Tiffany Kairos: Oh, yes.

Chris Kairos: They were very supportive. So, I think our family was huge.

Tiffany Kairos: Oh, my goodness, yes.

Kelly Cervantes: As a newlywed couple, I'm sure you had thoughts and plans for what your future would look like. And I'm not sure if that had included children, but how did the epilepsy diagnosis affect your future planning?

Tiffany Kairos: Well, before the seizure happened in 2008, I, of course, had this beautiful thought in my mind of children, and flowers and making dinner, all those things that one would after you get married. But that was quickly changed, because health comes first.

Kelly Cervantes: Yes, 100%. Is that something that you spoke to your doctors about?

Tiffany Kairos: Yeah. A couple years, later we talked to the doctor about that. And he let me know that there could be a risk. I have a type of epilepsy, it's called refractory epilepsy, which means it's difficult to manage with medication. So, they were trying all different types of medication to try and stop the seizures or at least lessen them. And I was having difficult seizures. So, the combination of that would be very risky to both the fetus and myself.

Chris Kairos: Especially, the side effects of the medication when she was on probably three different medications at that time. And the fact of if seizures were to happen, especially grand mal seizures, if they were to happen while she was pregnant, I mean, it's literally one seizure happening could be devastating. And at that time, again, like she was saying, there was really no seizure control at all. So, it was very risky. And not only would it have been dangerous potentially for a baby, but also for her. So, there was a lot to consider.

Tiffany Kairos: There was, yeah.

Kelly Cervantes: It never ceases to shock me just how many different aspects of our life epilepsy can affect, from your professional life to family planning, to obviously your health. But its ramifications on our life are so grand and so wide. Now, I do understand while you do not have total seizure control, you have been able to make some progress with medications. When did you finally see that shift, where in particular the tonic-clonic seizures weren't happening regularly?

Tiffany Kairos: Well, I do have two types of seizures. I have the complex partial seizures, and I have the tonic-clonic seizures. Those typically happen, what would you say, every three?

Chris Kairos: Tonic clinics, yeah. About 3 to 4 months. The complex partials, more often.

Tiffany Kairos: More often.

Chris Kairos: A lot more often.

Tiffany Kairos: Yeah, a lot more often. So, I'll take that over the tonic-clonic seizures.

Chris Kairos: When she went to Cleveland Clinic for the first time and got her current neurologist who she's with now, maybe around 2017-ish, somewhere in there, he put her on a certain cocktail, I guess you could say, of medications. That was really a turning point of when the grand mal seizures started to-

Tiffany Kairos: Lessen.

Chris Kairos: ... space out further.

Kelly Cervantes: I mean, you're talking about, so you had that second seizure in 2008, you said?

Tiffany Kairos: Yeah.

Kelly Cervantes: And it took until 2007. So, you're talking almost 10 years before you could get significantly improved control.

Chris Kairos: Yeah. A lot of trial and error of medications and learning triggers.

Tiffany Kairos: And switching doctors as well, though.

Kelly Cervantes: I mean, we were talking about that before we started recording, just how important it is to find that doctor that you finally trust, and listens to you, and you can communicate with and whatever all those pieces are, all those boxes to check. But at a certain point, Tiffany, you found a way to accept epilepsy as a part of your life and began to figure out a way to move forward with epilepsy. And you and Chris started The Epilepsy Network. Tell us about that, and what motivated you to become an advocate?

Tiffany Kairos: When I found that group on Facebook and I saw that support that was being shown with everybody else and that I was receiving, that was a light bulb moment for me. That was something that really stuck with me. I wanted to be able to create a community also that could help others and help them not feel alone like I had felt alone in the beginning. So, I thought to myself, well, I'm not sure exactly where to go from here. I don't know what to do. I've never advocated before. But I thought, well, I think I might try and make a video. I'm scared. I've never been in front of the camera, but I'm scared. But I really want to advocate, because I want to help people. And so, I grabbed my little Fuji camera.

Kelly Cervantes: I love it.

Chris Kairos: You held onto it.

Tiffany Kairos: I kept it. And I don't know if you remember the index cards, and I wrote on them. And I propped this up, and I recorded and I shared my story and I put it on YouTube. And the amount of support and the impact that it had was just beyond my understanding. I was amazed, over 10,000 people saw that video.

Kelly Cervantes: Which I think goes to show how many people are out there looking for community. They're looking to find someone else that they can connect with, so that they don't feel so isolated and alone. I'm always curious, because I'm in awe of people who have epilepsy who become advocates. I think it is

significantly easier for people like myself who are a parent caregiver, particularly in my situation with Adelaide, because she was unaware of what was going on. So, all of my advocacy, it was for her and for the community, but it was never going to negatively impact her. But it can be scary to go out there, and to talk about your diagnosis, and to talk about how it affects you. So, Tiffany, was there a moment where you just decided that you wanted to step into that advocate role, that you were ready to share your story?

Tiffany Kairos: I just really looked at Chris and I said, "Let's do this. Let's create a community and let's help out other people, patients, caregivers. And let's raise awareness." Well, both of us created a Facebook page and we called it The Epilepsy Network.

Kelly Cervantes: It helps to have a graphic designer in the house.

Chris Kairos: I was going to say, at the time, we had moved into our first apartment since everything happened. We had a nine by nine room where we both had our home offices.

Tiffany Kairos: Him on one side and one the other.

Chris Kairos: Our back's facing each other, but we both had our computers. So, we came up with the name and it started simply with the Facebook group for The Epilepsy Network, and then a simple website at the time.

Kelly Cervantes: And what are your goals for the group?

Tiffany Kairos: Well, the aim is to really build community, help people not to feel alone, have a place to come together and raise awareness and crush stigmas.

Kelly Cervantes: Yes.

Chris Kairos: Well, definitely.

Kelly Cervantes: Yes. I hear all of that.

Chris Kairos: And make more advocates.

Tiffany Kairos: Exactly.

Kelly Cervantes: Yes. I love advocates.

Chris Kairos: Making advocates.

Tiffany Kairos: Exactly.

Kelly Cervantes: Yes, 100%. Now, Tiffany, have they ever been able to localize your seizures? And you said it's refractory, but can they figure out if surgery is an option for you?

Tiffany Kairos: From the time that I was diagnosed, they ran a whole lot of tests, a bunch of tests. And there came a time, a day, I think it was 2018, October 2018, I made the decision that I wanted to do an SEEG procedure. That's the biggest one you can do. And so, in doing that, one of the things that I needed to do was shave my head.

Kelly Cervantes: I mean, that's a big deal. I remember seeing your posts about doing all of that and just thinking how brave you were. And you really documented this journey so, so beautifully. For anyone who is curious about this process, I highly recommend that you go back and you look at Tiffany's posts on an SEEG, because you really were just so brave, and strong, and detailed and informative. What were the results of that? I know you were in the hospital, it felt like forever.

Tiffany Kairos: Well, yeah, it was a 21 long day process. A lot of people, they aren't in the hospital as long as I was. They just couldn't get me to have a seizure. It just wouldn't happen. But they did find out where my seizures were coming from. But unfortunately, where my seizures were coming from, it was too big a risk to perform surgery. Because if they were to do so, it would damage my vision, my memory, and my speech. So, they didn't want to touch that.

Kelly Cervantes: I mean, we talk about it all the time, but your quality of life, at the end of the day, you have to make some pretty heavy decisions. Although, that one sounds pretty straightforward.

Tiffany Kairos: Yeah, I know.

Chris Kairos: That's what it was about. Absolutely, it was the quality of life. And even her neurologist and the other neurologists were saying, "Yes, you have seizures now, but your quality of life is so much better right now compared to what it potentially could be if we tried to perform the surgery."

Tiffany Kairos: Yeah.

Kelly Cervantes: Well, it's amazing to know that you have that information though, that you know where they are, because who knows what scientific advancements will come along in the future that could potentially open that door? Now, in terms of managing your epilepsy today, you said that you have the two different types of seizures, the tonic-clonics and the complex partials. Do you have any auras or ways that you can know that one is coming and you can prepare?

Tiffany Kairos: So, they're tricky. Sometimes I do, sometimes I don't. Sometimes it'll just yank the rug out from underneath me and I'll just black out. But when I do have those auras, I'll get a funny smell in my nose, kind of like burning wires or soapy bubbles, and that drop feeling. It's almost as if you're going down a hill.

Kelly Cervantes: Like on a rollercoaster or something?



Tiffany Kairos: And on a rollercoaster, yeah.

Kelly Cervantes: But at least that gives you a little bit of time, I suppose, to prepare to get yourself into a safer position.

Tiffany Kairos: Yeah. Usually, when that happens, I get down onto the floor. And if I have enough time, I will call out to Chris, either vocally. Or if my phone is nearby or in my hand, I'll shoot a quick text and say, "I'm not okay. Can you come here?"

Kelly Cervantes: Yeah. You have both lived with epilepsy now for quite some time. And I wonder what advice do you have for other couples who are navigating an epilepsy diagnosis or years of life with epilepsy? You're in such an incredible position and you've learned so much. I wonder what you can share with other people about being in a relationship with epilepsy?

Tiffany Kairos: You go right ahead.

Chris Kairos: Okay. I'll start with, well, there's a lot of things, we'll put it that way. But one of the biggest things is to be patient with the entire situation. And I know it's easier said than done, but when you're able to be patient with it, you're giving grace to whoever's experiencing the seizures, and you're giving grace to yourself, because you're going to need it. It's not easy in any sense. And unfortunately, through the communities that we've been involved with, we've heard a lot of marriages that fail pretty quickly, actually, when a epilepsy diagnosis comes on board. But it doesn't have to be the end. Really, like I think we were talking about, it really comes down to a choice. You can let it make you stronger or you can let it destroy you. And it is that choice every single day.

But as you continue to make the choice to be patient, have grace, and let it make you stronger and just keep faith in that, that you will get stronger over time, you do begin to see a change. You begin to adjust, start to understand things better, start to communicate about it better, because you're both getting more experience, more knowledge. And actually, it can really help your love grow stronger for one another too, because I mean, you're brought up to this different level. When you get married right away, if epilepsy's not a factor at that point, then you love each other the way that you ought to, hopefully. But then you really learn this whole side of what it's like to care for one another, to sacrifice for one another, to really go the extra mile with one another. You know what I mean? It's a lot. So, I would just say, just keep sticking it out. Don't get hopeless, stay hopeful, and have grace with yourself and with your significant other and with the situation.

Tiffany Kairos: I can't follow that up. That's perfect.

Chris Kairos: Well, and to not be afraid.

Tiffany Kairos: Yes, absolutely.

Chris Kairos: Because that's another thing. And that's easier said than done too, if you don't mind me going on just a smidge more. I was going to say, because in the beginning when she started having seizures, I was terrified. Every seizure she had, I thought I was going to lose her. I thought that was it. I mean, there were times where she'd have seizures at night that would wake me up in a sleep. And as a caregiver, there's nothing you can do. You can't stop a seizure. You can't. You can do your best to care for them. But after those things, I'd be so shocked and terrified. I actually had tremors afterwards for a little while. That did go away. Now, I'm acclimated to it. I'm adjusted to it in the sense of where it's not scary. And that's the thing is I wish I would've known that back then, is that it's nothing to be fearful of. Yes, you don't want anyone to experience a seizure. Yes, it's a terrible thing, but at the same time, to not be afraid in such a way that keeps you away.

Kelly Cervantes: That is great advice. Well, Tiffany, Chris, you are both just sunshine coming through my screen here. And I am just in awe of your positivity and your support, both for one another and for this community. You two are doing amazing work. And I just wish you both the best and so, so much happiness going forward.

Chris Kairos: Thank you.

Tiffany Kairos: Thank you.

Chris Kairos: Same for you too.

Kelly Cervantes: Thank you Tiffany and Chris for sharing your epilepsy journey, challenges, and insights about living with epilepsy as a couple. For 25 years, CURE Epilepsy has been the leading non-governmental supporter of epilepsy research. Our mission is to fund patient-focused epilepsy research that will lead us to a cure. If you would like to help us achieve our goal of a world without epilepsy, please visit [cureepilepsy.org/donate](https://cureepilepsy.org/donate). CURE Epilepsy, inspiring hope and delivering impact. Thank you.

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