

Kevin Kroeker

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Katie: Hey Kevin, thank you so much for joining the show to talk about your story with Loeys Dietz syndrome. Do you want to go ahead and introduce yourself to anybody that doesn't know you yet?

Kevin: Oh yes, so I'm Kevin Kroeker.

I was diagnosed with Loeys–Dietz in 2018. I I live with my wife on Victoria. and, uh, story kind of starts in 2017, it was late August and all of a sudden I, uh, uh, started having a heart attack, and that was totally out of the, out of the blue. cause there was really no, kind of warning signs or anything like that. and, that evening I had to do one of the hardest things, uh, that I've ever had to do in my life, and that was, to ask, ask my wife, uh, Jenna if, she could call 911, because I was having a heart attack, and [00:01:00] I honestly never want to have to do that ever again, uh, we've, I've lived in a,

an apartment building, and it's one thing to, , hear the,, first responders, , coming,, where it's like a fire truck and they're coming because the fire alarm's going off. Uh, it's a, it's a totally, , different kind of experience, , when you can hear the, . Ambulance coming and,, you know what's coming for you.

Katie: Yeah.

Kevin: that was a totally different, uh, , kind of experience.

Katie: How old were you when this happened?

Kevin: uh, I was 40, almost 48.

Katie: Almost 48. And prior to this, your medical history was pretty benign?

Kevin: Um, It wasn't, [00:02:00] benign. , uh, , but I'll I'm going to get into that in a little, bit here where I were, uh, kind of where I think it'll fit in.

Katie: Okay.

Kevin: uh, but I, I did have, uh, , some other other issues. uh, But I'll, uh, cause what I'll start with

is how I was, uh, , diagnosed,, , with Loeys Dietz in the first place. , cause, after I, after I had the heart attack and I was, in the ER,, , the cardiologist, told me the next morning that I had

something called, uh, SCAD, which was, uh, spontaneous coronary, artery dissection. Uh, the reason I all of a sudden had a heart attack the night before was, Uh, one of my coronary arteries all of a sudden decided to tear, , causing the heart attack.

And then I was referred to a geneticist, uh, one a [00:03:00] Dr. Stein. And, , we met with her and, kind of, uh, , relayed, a part of my medical history part of, also, also what had happened to my brother. about two and a half, Uh, here's earlier, , when he had died, , during an, an operation to , repair, uh, further repair, uh, , his aorta.

And, uh, he,

uh, he was, , during the operation, he was, , declared, uh, , a brain, uh, , dead off. A after it, uh, there was some complications, uh, when he had the, had that operation. He didn't, know that, uh, he had any, anything like that. Uh, uh, my geneticist,, when she heard that, uh, she was, uh, , she was [00:04:00] almost, certain that he had, Loeys-Dietz, which is what I ended up ha. Uh, having,

and,

also, also, as we were talking with our geneticist, , I kind of got the impression that

even though I was going to, uh, , get, genetic testing done, uh, it was kind of the way, , that she, , would, kind of look at me. I kind of got the impression that she Already, already kind of knew that I probably had Loeys Dietz. Uh, there was enough, features, like the almond shaped eyes and, and other kind of features, then I, after I got the, uh, the blood test done, that came back as being positive for, Loeys-Dietz, , syndrome.

And , [00:05:00] that, , pretty much if,

and then, uh, there's a,

because a type that I had, , is the cardiovascular, kind of,, version of it. There's a number of different, , types. , but I, I pretty much have the cardiovascular one. , so it's not just the aorta, it's, , , the smaller vessels all throughout the body. And, , and that's, , where

I'll go into, what you were asking earlier, if I had had any other, kind of things happen, because., The Loeys-Dietz, , diagnosis, explained a lot of other, , previous things, that had happened. Uh, I'd had two, hernias, , when I was younger. , the one, , was , when I was eight or nine when I was in grade three.

And the other one was, I'm not exactly, , sure. , how [00:06:00] old I was, but my mom, uh, , basically said I was, I was a baby. So, , it's kind of odd for a baby to get a, hernia. Like that doesn't seem like, uh, , like a normal thing to me, but,

Katie: Yeah, for sure.

Kevin: um, but it also, , helped explain, uh, , that around 20, , so years ago, I ended up, , having, I was working at the Calgary Zoo at the time, in the summer and ,

I was, I was Getting, , things,

kind of sorted out, out for when I was, , gonna, , start the nursing, program, and I was, I was taking one of, the, , CPR classes, And I was, I was totally fine when I was doing that. And then, when I came back to my apartment, it was the weirdest [00:07:00] thing that I, I can still remember vividly. I put my hand on the doorknob to open the door.

And I got instant headache. And I thought, well, that's kind of odd. Like I'm. I Used to get headaches, often, but I never had one where, one second I, I didn't have a headache, the next second, it was like a bad headache.

Katie: Mhm.

Kevin: And that carried on, , for a week, , non stop, like I never, I could take Tylenol.

, all day long, and it wouldn't do anything. And then after, after I'd had that going on, like I wasn't, that great, and then there was, my brother came to check on me, and I wasn't doing well at all, and he, uh, he took me to the, ER at the Rocky View in Calgary, and, uh, my doctor.

Uh, he [00:08:00] Scheduled an MRI and when he was, uh, , looking at the results

of that, one of the neurologists in the hospital happened to be with him at the same time and, and he looked at my, , results and, and, and then all of a sudden in the span of about a couple of hours after that, I was, , being transported to the ICU ,

at the Foothills Hospital. And,, he basically told me there that the, uh, the reason for my headaches was that, , one of my carotid arteries feeding, , blood to my brain was 90 percent blocked.

Katie: Mhm.

Kevin: And, , the reason for the headaches was, , one of my Uh, smaller blood vessels,, directly behind my, [00:09:00] my eyes was, , trying to compensate, as well as it could, but because it was, it was behind the eyes, uh, it was putting pressure, on that eye, which was, , causing the, uh, headaches that I went on, on for that whole week.

Uh, so then I ended up, in the, uh, the stroke rehab, uh, unit for about, I think about four or five days or so.

Katie: And you were how old?

Kevin: I would have been, at that point, I would have been in my early thirties, maybe like 32 or so.

Katie: And at that time, did they have any kind of suspicion of why you had had that happen to you?

Kevin: well,

Katie: they look into that?

Kevin: uh, they, after, I was discharged, they had, , someone was looking into, uh, uh, , see if it was [00:10:00] Marfans,, because that was the only, only thing on their, uh, radar at that time, cause Loeyes-Dietz wasn't, , discovered until like 2005,

And this was, About three, years or so before that,, the results of that was negative. So, I was basically in the dark at that point, I didn't exactly know, what was actually going on. the only, only thing was, from that point on I've been taking a low dose aspirin, every day since then.

, but then it wasn't until, all this other stuff happened, over 20 years later that I, I finally figured out, , because it explained, All of, all of those issues because it was, uh, smaller, [00:11:00] vessels. uh, so then I've been getting, uh, like, MRIs,, once a, a year pretty much. And that, , pretty much, , scans, uh, my whole Aorta from the top all the way down and, uh, I'll make sure that things

are aren't kind of progressing. And then I also have a,, uh, scan, , done on my head as well. , cause I have, I have like a tiny little,, uh, like aneurysm in there and they're keeping track of that too. So,

Katie: Yeah. , I'd love to know what you were told about Loeyes Dietz Syndrome when you were given that diagnosis a few years ago, and what it felt like for you.

Kevin: um. I was told , that I, uh, shouldn't lift, , more than like

25 pounds, uh, , [00:12:00] which pretty much, because I had, uh, right before that, like the, uh, the, uh, the morning before I had the heart attack was, I was working at, as a care aide at a nursing home, and that was basically it. the last time I worked as a care aid, uh, because of the, the weight, um, issues because of, the physical demands of doing that kind of a job, I was, I was no longer

able to do that anymore,

so it was a bit of a, uh, of a shock at first and, um, and not. , kind of knowing, uh, how things would go, after that. So, , the next, uh, five or six years were a bit of, a journey of discovery, of, learning as much as we could about Loeys-Dietz and, getting, , support , from, uh, people.

Uh, [00:13:00] people. And, a couple years ago there was, uh, like in the middle of the pandemic, there was a virtual, walk, walk thing that was, done through, , through the Marfan,

, foundation in the, on the states. And, I was, I was made the team leader for the Loeys-Dietz, group. And so that was, kind of neat and, there was

all kinds of support, , from that. Like, I was basically told if you, if you ever need

any, anything, like, we're here for you. And that was, that was like a, a huge, kind of thing for me. And, I was also, able to, um, email Dr. Dietz, , with certain things. If I. Uh, needed to, like I didn't, uh, uh, uh, make it, uh, like any, uh, very complicated kind of [00:14:00] thing. I just, uh, just, uh, very, and he was always, uh, very generous with his, time and stuff. And I never had someone , like that, who was,, so, , knowledgeable and, and,

uh, someone who was, , that high up who had discovered Loeys-Dietz, I never expected that I would be able to, email him and he would actually write me back. Like, that was a huge, , kind of thing for me. Like,,

Katie: Yeah, that's wonderful. And Hal, I've met Hal too. He's fantastic.

Kevin: yeah.

Katie: so glad you got that support.

Kevin: Yeah. So, uh, yeah. , that's been a, a big, a big, a part of, of, um,

, getting through. Uh, this the past, uh, years,, plus I've, uh, also,

also had a great cardiologist, Dr. Franco, over [00:15:00] in Victoria here, and, , getting all the, um,

uh, the MRI, uh, scans arranged, , cause in Canada, it's, that's a whole different system than in the, , States. Like, you. You have to, , you need, uh, like, to have, um, an actual, , kind of diagnosis, so that, you can justify having, All of these yearly, kind of MRIs. Uh, so that at once I, after it was confirmed that I had Loeys-Dietz, then it was, it was easier to do that because

I guess he had the proof, uh, that uh, he has, this and he needs to have, , his aorta, uh,, checked like, , once a year and, , so yeah, that was

Katie: Oh, that's great. , I know that since your [00:16:00] diagnosis too, you've had kind of like this extensive family history of Loeys-Dietz uncovered. Is that, is that fair to say?,

Kevin: oh,

oh. Yeah. Oh, uh, yes. Like, uh, like it's, because I've, because my geneticist, she was certain that my brother who died,, had it. She was also, , quite, , assured also that, uh, dad, also would have had it. Even though he's never had any kind of symptoms or signs of it, , ear, ear early on that were, , that would've been, uh, noticeable like with, , the, uh, the vessels and stuff.

But then he had, all of his life, I think he's, uh, had a, a low heart rate and a. And low blood, uh, low blood pressure. So, , that I pretty much would've mimicked, uh, someone [00:17:00] taking,

, like a beta blocker. You would basically do the same, , same thing. I'm convinced, uh, one other brother,, for certain I'm, , sure, uh, that he. has it as well. and then, , other, other members, of his family. I'm, I'm pretty, I'm pretty sure, , also,, and then, also, also extended, extended family, , going, , into some aunts and some uncles.

So there's at least One, one aunt and one uncle, and there's, at least, , two cousins, , from the, , the one family, , where, I like, it's confirm, it's confirmed with the same kind of, of genetic testing that I had done, and the exact same result. So, all I guess. Uh, [00:18:00] totally confirmed. And then one other cousin on the, on a different family is also con, also confirmed there too. Uh, so there's, out of a family of, of like 11 or 12, , kids, at least, at least, , three of them, including my dad, , would have had it. Uh, plus I, , there was other. Other aunts who, , who had, , apparently had, , other kinds of, of like heart, heart issues, , that, uh, may have also been, part of it too, maybe, I don't, I'm not, I'm not sure,

Katie: Yeah, but this diagnosis then really helped to kind of bring some answers to the family, it

Kevin: yeah, oh, oh, yes, yes, and there was also one other thing I just wanted to, clarify, like, [00:19:00] uh, there's often a misconception that, , Loeys, uh, Loeys-Dietz and Marfan's only affects, , taller people, which, uh, , which isn't always the case. There are, , some people who have Marfan's who are, are shorter and also Also, the same, , thing applies with Loeys-Dietz, uh, because my one cousin who,, is confirmed, is, is a, a lot shorter than I am, and still, and still has Loeys-Dietz.

So, uh, like if you're if you're a, a, a shorter, uh, uh, uh person don't, I don't just assume that, that it's not possible that you, uh, have, , Loeys-Dietz, , cause especially if it's,, something that's within your [00:20:00] family already, and, and you happen to be, , shorter, and, and one of your siblings has it and they're tall, don't.

I don't make the mistake of thinking that it's not possible. I get the genetic testing done.

Katie: Yeah, that's such a great reminder, too, in general, that for Loeys-Dietz and for Marfan and for VEDS, too, like, there are signs and symptoms that they say could point to it, but not everybody has every single feature. Some people don't have hardly any outward features at all and It's not like this uniform.

Everybody with Marfan looks the same. Everybody with Loeys-Dietz looks the same. Everybody with VEDS looks the same like there's a lot of variation in our communities And it's such a great reminder to get tested if you're, if you have it in the family or Or have a medical history that's potentially concerning for it[00:21:00]

Kevin: yeah, yeah.

Katie: Yeah What is it like, I know you're in your 50s now, what is it like being in your 50s with Loeys-Dietz?

Well,

Kevin: I kind of view it, , view it like, , where, knowledge is power, where, , the more you, know about it, and the, and the,

and the more you are able to, , get support through like, like either Facebook groups or, whatever,, happens to be out, out there. That,, has made it a lot, a lot easier, just, knowing, uh, knowing what, to, uh, expect, knowing that,

, that I'm getting the, , necessary, , scans done. Like I'm a, [00:22:00] huge, uh, Star Trek, , fan, so I kind of consider them

like,

, those tricordered, that kind of scans that they do on Star Trek. I, I kind of think of it that way, that I'm, I'm being, , kind of scanned like that, , cause I know, As some people get claustrophobic in, , in the MRIs, I just try to,

, kind of visualize myself being somewhere else, and,, so it's not really a big deal for me, but, , but yeah, it's,

uh, Knowing, uh, that

also, also having the support of my wife has been, uh, absolutely, absolutely fantastic,

Katie: That's wonderful. I'm very interested in your experience with Loeys-Dietz and Like the medical system or any medical providers or anything like that or lack of knowledge like have you encountered any Lack of knowledge about Loeys-Dietz or is there anything that you'd want medical [00:23:00] professionals to know based on your experiences? Anything like that that has come up since your diagnosis

Kevin: I've been, , really fortunate, Dr. Franco was, , he's been fantastic as a cardiologist. I do think, I think I was the, uh, first, , patient he ever had who had, , Loeys-Dietz. So, uh, so I think he, he himself was probably a bit on, on a, on a learning curve himself. , which he has, , done, , well.

I would, uh, what I would say, , to other medical professionals, if, if you're, not knowledgeable about Loeys-Dietz and you, uh, you have someone who comes across their way and, um, that I would highly recommend would [00:24:00] be the LoeysDietz. org site in the States and the LoeysDietzCanada.

org site in Canada. cause I was looking at the Canadian one last night and, , there is a huge amount of information there. of information that, uh, you can access, on the, on the menu part of the Canadian website. , there's a clinician's, , thing. And,

it gives you links to, so many different, , things that, uh, you can,, Access information on, like, it, like it gives you the, the current guidelines for, , when you need to intervene,, surgically, with the aorta or, or, there's like a, a head to toe, , kind of thing that.

Uh, shows you, all of the [00:25:00] different things,, that can go on, on someone's body. It gives you, , so many, , different things that you could, learn more about Loeys-Dietz so you can properly, , treat the, , the patient. , patient and, and the, uh,

, the American site is, , has pretty much the, uh, the same, , kind



of, of information on it. , it's organized a little bit differently, but it's pretty much, provides the same amount of information.

Um, And the best part of the American one is, is that Hal Dietz is, is all over the place.

Katie: I'll put a link to those in the episode show notes too. So if you're listening to this right now and you're like, I didn't catch those URLs, uh, check out the episode show notes and I will put them in there for sure. , Another question for you I have is [00:26:00] if somebody's listening to this show and listening to you share your experience with Loeyes Dietz and they either think that they have Loeyes Dietz or were just diagnosed with it and trying to kind of navigate those first few years of getting through that diagnosis period, what kind of advice would you give somebody?

Kevin: I, I would, I would say,, and I, uh, some people might, I think of this as a,

of a cliché, but, I think it's, I think it would be, important to take it like one day at a time, like, like try not to get, overwhelmed by it, and, like I said earlier, um,, knowledge is power, and, and the more, and the more you know about it, I think the less, freaky it becomes, and just, , [00:27:00] talk to, other people that, uh, you know. and,, there's, numerous, , support, , kind of groups that you can join where, where, like, everyone in the group,, has Loeyes, Loeyes-Dietz, or Marfans or VEDS, And you can share your, , stories with them and get their, uh, their support. And that, and that can, make a, make a huge difference. Yeah, that's, that's what I would, yeah.

Katie: That's great advice, and I'll put a link to those support groups. Or at least the websites where you can find those support groups and the episodes show notes as well. I I'm so glad you mentioned them like I 100 percent stand behind everything you said and the value of Talking to somebody else With a condition that you have or something like [00:28:00] it.

I think can really really help when you're really going through it

Especially at first, I mean, you read all this crazy stuff on the internet and then, you know, there's a different picture than when you talk to a person and I think it's so important to get that perspective

Kevin: Yeah. Yeah.

Katie: and build those relationships. Well thank you so much for coming on and sharing your experience with Loeyes-Dietz.

Kevin: It's been a pleasure, Katie. And, I also wanted to mention that, uh, that my wife is a, a huge fan of your, , show and a regular

listener, so.

Katie: Thank you. so much for listening. What was her name?

Kevin: Her name's Jenna.

Katie: Hi, Jenna. Thank you so much for listening. I really appreciate it.