

Getting Curious with Jonathan Van Ness & Elizabeth Pfiester

JVN [00:00:02] Welcome to "Getting Curious". I'm Jonathan Van Ness. And every week I sit down for a 40 minute conversation, sometimes it's more because I can't stop talking, with a brilliant expert to learn all about something that makes me curious. On today's episode, I'm joined by Elizabeth Pfiester, the founder and executive director of T1 International, a nonprofit led by patients that does not accept funding from the pharmaceutical industry and is fighting to put an end to the insulin price crisis. Today, we discuss what it's like to live with Type 1 diabetes and the current crisis surrounding insulin and pharmaceutical prices and what can be done to fix it. Welcome.

ELIZABETH PFIESTER [00:00:35] Hi. Thanks for having me.

JVN [00:00:36] Thank you so much for coming. So you have an interesting cross-Atlantic like origin story. Share, if you don't mind.

ELIZABETH PFIESTER [00:00:44] Yes, of course. So I was born and raised in the U.S. in a small town and was diagnosed with Type 1 diabetes when I was four years old. So that was pretty scary, kind of traumatic. But I had access to what I needed to live and survive. And-

JVN [00:00:59] Can I ask you, like, what, do you remember, like you were four? Like, what happened with, like, the like what happened?

ELIZABETH PFIESTER [00:01:05] Yeah. So I, I remember bits and pieces, but I had what they thought was the flu. I was kind of, you know, the typical symptoms of Type 1 are kind of flu like, you're drinking a lot. You're going to the bathroom a lot. You're eating a lot. And so doctors just kept saying, oh, it's the flu. It's the flu. And eventually, finally, my mom pushed and pushed. And by then I was in what they called DKA, Diabetic Ketoacidosis, which is where your body is basically putting acid into your blood and it's extremely dangerous. So I was in the hospital for two weeks and yeah, I just remember being really scared. My family was really scared. So that was that was tough. Yeah.

JVN [00:01:42] So you get diagnosed with Type 1 diabetes. And just quickly, do you know the, what's the difference in Type 1 and Type 2? 'Cause I've heard both.

ELIZABETH PFIESTER [00:01:51] Yes, so Type 1 is an autoimmune condition and that means your body stops producing insulin pretty much all together. The cells in your pancreas stop working and you need to take it with an injection or an insulin pump. Some way you have to get that insulin into your body, 24/7. Type 2 is more, it can be linked towards lifestyle and genetics and is often about the insulin not being used properly in your body. Or maybe you're not making enough of it. So you need to supplement. So with Type 1, there's this urgency for insulin. You must have it. With Type 2, it's a little bit less urgent, still serious, still a condition that needs to be managed and treated. But there's a lot of stigma and stereotypes around both. And often the two get really lumped together. And for people with Type 1, that's tough because we didn't, you know, it's nonpreventable.

JVN [00:02:37] Is Type 1, does it usually come on early in life? Or can it come on at any time? Or?

ELIZABETH PFIESTER [00:02:41] It used to be called juvenile diabetes. But now they're getting away from that because my husband, who's actually here, he was diagnosed with Type 1 diabetes when he was 23 and many people were diagnosed in their 40s, 50s. But often, you know, it gets this focal point on young people with Type 1.

JVN [00:02:57] So can you have Type 1 and just be like 40 in your body just like, like, like, like it, you were always going to have it, it just like didn't kind of turn on on you until?

ELIZABETH PFIESTER [00:03:07] Kind of. Yeah. They're, they're not really sure what causes diabetes. That's another part of it. Why they haven't found a cure yet. But it's something that, yeah, in a sense turns where your body decides some part is going to attack these cells in the pancreas and that can happen.

JVN [00:03:20] Because when you were 1-3, like your body, was your body making it?

ELIZABETH PFIESTER [00:03:24] Yeah, exactly. And so they really there can sometimes be this weird stage where it's slowly stopping making it.

JVN [00:03:31] Declining.

ELIZABETH PFIESTER [00:03:32] Yeah, but they're it's tough to say what triggers that immune response. So it can happen in your 40s. It can even happen when you're 50 or 60. And oftentimes doctors get confused and try to diagnose people with Type 2 instead of Type 1 because it is a little bit more rare.

JVN [00:03:46] So then you're four when you find out. And then can you just, I mean, what was that like for you growing up in Illinois, like living as a Type 1 diabetic? I mean, I remember, I feel like I remember the kids that had it at school, like with their, with the little blood test, which actually kind of made me jelly because, like, I wanted to do that and I thought it was kind of fierce.

ELIZABETH PFIESTER [00:04:04] We can do that if you want.

JVN [00:04:05] I was also jealous of the deaf kids because I loved the, I like lived for a hearing aid, I really wanted to speak sign language. I was like obsessed with the accessory of it all. Also totally didn't understand anything. Also, we had to make a note on that because I don't know if that's a controversial of me to say, but honey, I'm just saying. When I was little in elementary school, I just thought that, like, those little accessories were everything.

ELIZABETH PFIESTER [00:04:22] Yeah, well, that's great when the school is supportive of that too, because I remember in school, kids would count down. So I'd test my blood sugar on the meter and the meter. It was an old meter. Thanks, technology has come further now, but it would start at, I don't know, 20 and then everyone would count down. 19, 18. And it was like, you know, this team. So I think kids were similar and oftentimes kids are saying, "Oh, she gets a snack early, I want to snack". And, and it's, you know, I think that all comes from a good place. But for, for having to live with it, you have to be quite strict, especially when I was younger and I was on older insulins, which we might get to a bit later, but I had to be really careful about eating at specific times. And oftentimes, if you have to have an emergency snack, it's because your blood sugar is

low and you're feeling really bad. So, you know, there's perks to it, but there's a lot of difficulties and stress. I know for my family, it was just really, really hard and stressful because I had some very scary low blood sugars where I'd have to get an emergency glucagon shot, is what they call it, to shoot up glucose into your body to make sure that you're safe.

JVN [00:05:22] So, I mean, if it's not, like, traumatizing for you to share that with us, like, what does that look like? So, like, you wake up one morning and you're just, like, thriving, not thriving, like what happens?

ELIZABETH PFIESTER [00:05:31] Yeah. So it can happen at any time a day. So I, I can show you my kid at some point if you'd like, but I monitor my blood sugar. I have to test it. Between 6 and 10 times a day. And yeah, you can wake up and your blood sugar is normal. But if you're stressed, if you're anxious, if you've been exercising, there's a million factors that can cause your blood sugar to go up or to plummet, especially for, I tend to have especially difficult blood sugars. And yeah, when it gets really scary, if you go low enough, you can pass out. You can have a seizure, which has happened to me before. And if you don't get this emergency injection, you're, you're in big, big trouble. And, you know, it's that kind of you're, you're out of control as much as you try to control the condition and monitor it, even if you do everything right. Sometimes unpredictable things happen because, because diabetes is not fun.

JVN [00:06:23] So, like, you could just be like at school and have like. And so do you know that like an attack is, what is it called if, if the blood sugar? Is it called an attack?

ELIZABETH PFIESTER [00:06:30] You would say probably just like a low blood sugar.

JVN [00:06:33] Like event?

ELIZABETH PFIESTER [00:06:34] Yeah, yeah. That's a good question. Episode, maybe. Maybe event. But yeah, I mean, I have, you know, a couple low blood sugars regularly and that happens without it being like a massive issue at times.

JVN [00:06:48] So any day, you might just like, when you test yourself, it might come back low.

ELIZABETH PFIESTER [00:06:51] Yeah, it could. It could. And then so you have to have some kind of glucose, sugar, juice, something. But if, yeah. If, if it gets severe enough you would maybe call it an event or something where you know, where it could get to that seizure point, where you're passing out.

JVN [00:07:05] So, like why do I not need insulin? Like, like, like what is my body? Like, like how does that work?

ELIZABETH PFIESTER [00:07:12] Your body makes insulin on its own beautifully.

JVN [00:07:15] In my baby pancreas.

ELIZABETH PFIESTER [00:07:15] Exactly. Your baby pancreas is doing its thing.

JVN [00:07:18] It's like if I have 17 coffees today and don't eat till 7:00 tonight or something, which I'm not doing, I swear, it's not my diet, I swear. I am being more balanced than that. But like, so my little baby pancreas just kind of chugging along.

ELIZABETH PFIESTER [00:07:30] It's just doing its thing. You wouldn't even know.

JVN [00:07:32] And for you, you might get up, like test the. What I'm trying to ask is like when you're doing everything right. Like, so like you just you wake up, you test your blood sugar, you have breakfast?

ELIZABETH PFIESTER [00:07:43] Yeah. Yeah. Test.

JVN [00:07:44] And then you go to work.

ELIZABETH PFIESTER [00:07:45] Yeah. Yeah, basically. And so I've got this insulin pump which is connected to me and it's ticking off insulin in my body regularly, consistently like your body's doing on its own. But this machine is having to, or if you were on shots you would be injecting. It's giving that background.

JVN [00:08:01] Oh, the machine just tells like a little thing to like put some in?

ELIZABETH PFIESTER [00:08:04] Yeah. So again. Well-.

JVN [00:08:06] Oh my god. Let's do it on Instagram for our post content, if you're into it. If you're not, if you're, if you're into it.

ELIZABETH PFIESTER [00:08:10] Yeah, we can do whatever.

JVN [00:08:11] That's content you can't even buy.

ELIZABETH PFIESTER [00:08:13] Yeah.

JVN [00:08:13] I'm obsessed with that.

ELIZABETH PFIESTER [00:08:14] I was thinking we could do an insulin for all cheer, but we could do.

JVN [00:08:18] Oh my god, I love. We can do all that.

ELIZABETH PFIESTER [00:08:18] Awesome.

JVN [00:08:18] I'm obsessed with the both of them.

ELIZABETH PFIESTER [00:08:20] OK, perfect. We can do it all.

JVN [00:08:21] So basically, you might be at-, but so you actually maybe don't get so much like low blood sugars because that's always making sure that it's regulated.

ELIZABETH PFIESTER [00:08:27] I have to say, this is a great piece of technology, but I have to manage this. It doesn't just do it all for me. So I tell it. I tell it, I need this much every hour and then I have to adjust it and every time I eat. So I have my breakfast, like you said, and then I have to tell it, I ate, now give me insulin. So it's not like it's, they're working on the technology to where it does it all for you. But right now it's still me 24/7 having to think about what did I eat? Am I going to be anxious, excited today on this? I have to make sure I'm getting more insulin or less insulin to adjust.

JVN [00:09:00] So like on your wedding day, you had to like, you know, that your blood sugar is gonna be, like, weirder when you're stressed and anxious.

ELIZABETH PFIESTER [00:09:05] And it's so hard to predict, though, as well, 'cause sometimes stress and anxiety makes it go up. Sometimes it makes it go down. And so some people are more fine tuned with their bodies. And even though I've had this for 26, 27 years now, it can still be tough to predict. And again, you can, can do it right. And then you can still have a plummet or a spike. So it's, it's 24/7. And, and, you know, I'm so lucky to have this technology and to have access, which, again, we'll talk about when it, when, when it comes to living in the UK. I-.

JVN [00:09:32] I'm really excited by that. So, OK, so you're, so like you go to junior high, you go to high school, like little do we know we're literally going to junior high and high school like three hours away from each other. Like who knew? Could we have been any cuter, like minding our own business, like just in Illinois, like running around the soybeans, the corn fields and the cows and the pigs.

ELIZABETH PFIESTER [00:09:48] I know.

JVN [00:09:48] And just like, what's that smell? It's the farm. So then it's like, so then you're minding your own business when, like, you move to London? What happened?

ELIZABETH PFIESTER [00:09:56] So I, I studied international studies in college.

JVN [00:10:01] Which was where? Where do you go?

ELIZABETH PFIESTER [00:10:02] At Bradley University in Peoria.

JVN [00:10:04] You're smarty mcsmartly fucking pants. That's a smart school. It's hard-, he's shaking it. Yeah, I tried out for their cheer squad, but they were like really good cheer squad. I was like I could not, like they're tumbling, I was like I cannot. It was, I couldn't.

ELIZABETH PFIESTER [00:10:15] OMG.

JVN [00:10:15] It was just completely like way too close to my house.

ELIZABETH PFIESTER [00:10:19] Yeah. Well, that's fair.

JVN [00:10:20] I needed to get like. I needed to get where there was more dick-a that I could experiment with.

ELIZABETH PFIESTER [00:10:25] Yeah.

JVN [00:10:26] You know, that was not readily accessible, I feel like-. Because was there any gays for you? I mean, you're a lady so you probably weren't paying attention, but like, I feel like there's not a ton of gays in Peoria.

ELIZABETH PFIESTER [00:10:34] No, I mean, no.

JVN [00:10:35] No.

ELIZABETH PFIESTER [00:10:36] They're, at least not-.

JVN [00:10:39] Honey, Tuscan didn't have the most but it did have more than Peoria. Loved me a Tuscan.

ELIZABETH PFIESTER [00:10:42] Yeah.

JVN [00:10:43] Anyway back to diabetes and insulin.

ELIZABETH PFIESTER [00:10:45] Yes.

JVN [00:10:45] Yes. See how my brain just wants to go to gay stuff. She just wants to fly away to gay stuff. So anyway. So but you studied at Bradley.

ELIZABETH PFIESTER [00:10:54] I studied at Bradley and then I knew that I wanted to do something to do with, well, there's a lot of problems in the world and I wanted to try to do something to improve those, which it's massive and overwhelming the amount of problems around on the world. But I then got into the London School of Economics in the United Kingdom, in London. So I went to study there and studied kind of, again, international development, humanitarian emergencies, and still felt overwhelmed, but finally realized, OK, I know a lot about Type 1 diabetes. I started learning about global issues and access to insulin issues and realizing that people in many parts of the world who have what I have just by luck of where they were born, can't survive with the condition, which pretty much made me really angry because why was I lucky enough? I mean, it's already stressful and awful to live with the condition, but then to not even get a chance.

JVN [00:11:49] I'm really moved by people who take something in their, in their life that was difficult and use it to provide, like, hope and purpose for not only their lives, but the, I'm going to cry, but for people around them.

ELIZABETH PFIESTER [00:12:03] Yeah.

JVN [00:12:03] So I just like I think that people, you know, will say to me, like, you know, how did you get through like-? And it's like, I think using my pain to, like, give myself purpose to help other people. I don't know what that's called. I don't know if there is like a word for that in English. I don't know if there's a word for it in-.

ELIZABETH PFIESTER [00:12:21] We need to make one.

JVN [00:12:21] In any language. But I think that that is like, that gives my life hope and meaning. And ever since I was a small child getting like bullied as fuck in Quincy, I used to think, like, when I grow up, I want to do something that will like, help other kids that have this. So I just. If you're struggling with, like, your purpose in life and like you were just saying, you know, you were studying international stuff, but you like, you're like I wasn't quite sure. It's like you used what fueled your life and gave-, and use that to make you-. And I think for anyone listening is like I think that is so helpful to be able to take some that you have dealt with in your life and use that to give you fuel for purpose.

ELIZABETH PFIESTER [00:12:55] Yeah, totally. And I think it also, that times 100. And then also helped me see, like, what I can be grateful for, even though it's, it's an awful condition to live with. I am so, I'm 10 times luckier than people in other situations, even though, you know, it's all relative, of course. But being able to say, I have a lot. I need to, to use that to make it better for people that just weren't as lucky as I was.

JVN [00:13:24] We're not making a joke about that, but I am a comedian. So for people that don't have a lot, but if you like, want to have more, we're gonna do some advertisements really quick. So if you want to buy any of the stuff that were about to talk about for just two seconds, we're gonna do two ads and then we'll be right back with more "Getting Curious". Welcome back to "Getting Curious". This is Jonathan Van Ness. We have Elizabeth Pfeister, and that was not a joke I was making at the end of the break because we're talking about serious fucking shit. So basically, when you started studying the issues that people that were living with diabetes face across the world, you know, because in the United States, health care is a for profit industry and the United Kingdom it is not. It is a, it is a human right. Like, you get access to health care because you're British. Same thing in Canada. Like, if you're Canadian, they are taking care of you, period. It's not a for profit enterprise. Which is why in America, there's so much drama and, you know, issues around health care, because there are people that are getting, you know, 72 billion dollars over the last, what did Elizabeth Warren say? Like four years, three years like of, since the Affordable Care Act was enacted. The insurance business is still gotten 72 billion dollars of profit since then. So that is a fucking ruckus. That is a ruckus. So when we talk about the insulin crisis, I think that we don't really understand. And so this is like 18 questions in one. And I guess I'm actually going to differ a little bit to you because you can be guest host of "Getting Curious" for a little bit. It's like, how did T1 International come into play as you were learning about these? Like what? How do all this coalesce? Because you finish at Bradley and then like is, is your gorgeous man, is he British? Like, how do we get over there?

ELIZABETH PFIESTER [00:15:20] He is. Yeah.

JVN [00:15:21] He is?

ELIZABETH PFIESTER [00:15:22] He is.

JVN [00:15:21] Hashtag LondonBoy. Hashtag TaylorSwift. You're loving her new album. Have you heard that London boy album?

ELIZABETH PFIESTER [00:15:26] Yeah.

JVN [00:15:27] Do you feel like that's the story of your life? Because you're like listening to, like, stories about university in the-, you know, from a uni in the afternoon. Have you heard that song?

ELIZABETH PFIESTER [00:15:33] In some ways. Yes. Although.

JVN [00:15:34] It's cute, right?

ELIZABETH PFIESTER [00:15:34] Yeah, it's super cute. We met actually. It's even maybe cuter or cheesier because we both have Type 1 diabetes.

JVN [00:15:43] Ah.

ELIZABETH PFIESTER [00:15:44] So, yeah. So I went to study at LSC, London School of Economics. And ever since I went to study there, I was looking for my people with diabetes because I went to diabetes camp as a kid. And it's huge. It helps you take responsibility. It makes you feel like you're not alone.

JVN [00:16:00] Oh my god, you're going to make me cry. That's too good. It's too good. So you would go to a little beeby diabetes camp when you were a little baby girl?

ELIZABETH PFIESTER [00:16:06] I did. I know. It was amazing. It really changed my life. It was incredible.

JVN [00:16:10] 'Cause it gave you like community and connection with people that were going through the same thing.

ELIZABETH PFIESTER [00:16:12] 100 percent. 100 percent. And so we met and he was running-.

JVN [00:16:17] At camp?

ELIZABETH PFIESTER [00:16:18] No. So we met in London at a Type 1 social meet up group.

JVN [00:16:22] Got it.

ELIZABETH PFIESTER [00:16:22] Yeah. And so he was, he ran the group and-.

JVN [00:16:25] In London?

ELIZABETH PFIESTER [00:16:25] Yeah.

JVN [00:16:27] I wish we could-. Come in here. Come in here. Come, come, come. Just come say hi. Because the husband is in the other room, you guys, and I want to hear his little baby British accent. Not to sexualize British accents. British people are going through a lot.

ELIZABETH PFIESTER [00:16:40] They are nice.

JVN [00:16:41] But they are so cute. Hi. I didn't know who you were before. Nice to meet you. Just say "Hi" into the microphone.

ELIZABETH PFIESTER [00:16:50] John.

JOHN PFIESTER [00:16:50] Hello.

ELIZABETH PFIESTER [00:16:50] And you're in you're from London?

JOHN PFIESTER [00:16:53] Well, I, we met in London. That's where we were living.

JVN [00:16:56] But where are you from from?

JOHN PFIESTER [00:16:57] I'm from the northeast of the country, near Newcastle.

JVN [00:16:59] Is that Doncaster where Tan's from?

JOHN PFIESTER [00:17:01] It's a bit north of from there, but not-.

JVN [00:17:03] Oh, even more north.

JOHN PFIESTER [00:17:04] Even more. Yeah. Almost Scotland.

ELIZABETH PFIESTER [00:17:05] Yeah. So when I met him I thought he sounded Scottish, but now his accent is quite neutral.

JOHN PFIESTER [00:17:09] I know, I've kind of bit American actually.

JVN [00:17:11] OK. Get out of here. We love you so much. You're so cute. Bye bye bye. You stay here. We love you so much, John. Ah, you bagged a good one, honey. He's gorgeous.

ELIZABETH PFIESTER [00:17:19] Thank you.

JVN [00:17:20] And smart and involved. We love him.

ELIZABETH PFIESTER [00:17:23] Yeah.

JVN [00:17:23] Oh, my God. OK. So anyway, so he was running this gorgeous social meetup group for people with diabetes in London.

ELIZABETH PFIESTER [00:17:28] Exactly. And so, yeah, we-.

JVN [00:17:29] And you're a little baby girl who just got done with college.

ELIZABETH PFIESTER [00:17:31] Yeah. And I was doing my masters and we just hit it off. He baked some baked goods and-.

JVN [00:17:37] Do you love "Greatest British Baking Challenge"?

ELIZABETH PFIESTER [00:17:39] Yeah. Oh yeah.

JVN [00:17:41] How-?

ELIZABETH PFIESTER [00:17:41] We love it.

JVN [00:17:42] Sidebar. Like do we have to like deal with anything, when we want to have baked goods, when we have diabetes? Like what happens?

ELIZABETH PFIESTER [00:17:48] So that's, that's an interesting one because again, a lot of the myths out there are like no sugar or sugar causes diabetes and all these things. And of course, when it comes to Type 2 and lifestyle choices, that can impact it. But for people with Type 1, of course, you have to be careful. But for us, it's all about counting the carbohydrates. So if we are, it's really carbs. So pasta, any of that stuff you really have to count.

JVN [00:18:09] Oh, because it turns into sugar.

ELIZABETH PFIESTER [00:18:11] Yeah. Yeah. And so then you have to calculate and give a lot more insulin. So if you're having baked goods, it's fine as long as you give the appropriate amount of insulin. And then for each individual person like me, my body just doesn't handle carbs very well. So I try to avoid, but you also got to live your life.

JVN [00:18:26] So you have to give yourself, the insulin has to correspond for how many carbs.

ELIZABETH PFIESTER [00:18:30] Exactly.

JVN [00:18:30] Interesting. So you finish Bradley, you go there. You're doing your Masters and as you're studying at the London School of Economics. That was kind of when you were coming into your passion purpose of T1 International.

ELIZABETH PFIESTER [00:18:41] Yeah. Towards the end of that, it was kind of thinking, what am I going to do with this? I know that I want to probably work in nonprofits, do global work, and then eventually it sort of came to, I was, I was writing a blog about just my London experiences. And I was like, I should do a blog about these issues that I'm learning about. I started learning that there weren't any organizations that existed that were trying to change the insulin crisis globally, that we're having patients representing themselves. Oftentimes it's big corporate interests that are representing patients and humans, which is problematic, I think. And so, started just putting all the information that I was learning together in this blog, which then blossomed into eventually as I connected with more people and learn more about the issues. I realized, OK, nobody's doing this. Nobody is doing an organization that's focused on advocacy, focused on long term solutions. I'm going to have to do it. And so we registered as a charity in the U.K. I got a board of trustees and have had so many incredible volunteers that built and grew the organization into what it is now.

JVN [00:19:44] So just rewinding a little teeny tiny bit. So like when you were growing up in America and like going, like going to Bradley, like, were you just like on your parents' insurance, like they would give you the insulin that you needed? And-.

ELIZABETH PFIESTER [00:19:56] Yes.

JVN [00:19:57] And you didn't have to totally worry, or, and you had to worry about them, you're responsible for it. But you knew where you were getting your insulin.

ELIZABETH PFIESTER [00:20:01] Yes, exactly. My, my dad's job. Thankfully, I had pretty decent insurance, but I graduated before Obamacare. The Affordable Care Act came, came into play. So the day that I graduated from college, I was kicked off my parent's insurance. And so I was, it's a long story. But to cut a long story short, I ended up working two jobs to kind of equate to full time, but none, neither of them offered insurance coverage. So we had to pay, I think it was just around 600 dollars a month just to be added back onto my parents insurance, plus all the co-pays, deductibles, all those things. So that experience also really kind of opened my eyes to this is what I'm going to have to worry about and contend with-.

JVN [00:20:45] Is insulin sold is like a medicine in the U.S.? So like if, like, like 'cause I would assume everyone with Type 1 diabetes, do you need like a-? You may need like 500 grams, but someone else, maybe need like 200 grams.

ELIZABETH PFIESTER [00:20:56] Exactly. Exactly.

JVN [00:20:57] So anyone needs like a different amount a month.

ELIZABETH PFIESTER [00:20:58] Exactly. It could be one to four vials or even more, each month.

JVN [00:21:02] And that has a price on it. Like they put a price on it.

ELIZABETH PFIESTER [00:21:06] Oh yeah.

JVN [00:21:07] And you will die if you don't have insulin.

ELIZABETH PFIESTER [00:21:09] 100 percent within days or hours. I've, yeah, as I've said, I've experienced diabetic ketosis-, ketoacidosis myself. And it's, it's very painful and very scary. And it definitely will lead to death in a short period of time. And so even, that was back in 2011. The cost was still very high. And now, you know, almost a decade later, the costs have just skyrocketed over 1200 percent.

JVN [00:21:36] So once you. OK. Fuck me. I need to write that down. So we can come back to that. Wow. 1000 percent?

ELIZABETH PFIESTER [00:21:45] Yeah.

JVN [00:21:46] Gee, I don't even know what that is.

ELIZABETH PFIESTER [00:21:46] 1200 percent. Yeah.

JVN [00:21:49] 1200, Jesus fuck.

ELIZABETH PFIESTER [00:21:49] Yeah.

JVN [00:21:50] Sorry, Mom. So. Well, how did your relationship with obtaining insulin change like once you moved to the United Kingdom.

ELIZABETH PFIESTER [00:21:57] Oh my gosh. So-

JVN [00:21:59] 'Cause did you get to take on like the NHS once you went there for school?

ELIZABETH PFIESTER [00:22:01] As a student. As a student who's studying for more than six months, I was able to access the national healthcare system, which is incredible. I will, I honestly will never forget the first time I went to the pharmacy to pick up my prescription, my insulin, my test strips, all of these things that you stress about and have to battle with insurance. I went into the pharmacy, picked it up, they handed it to me. I walked out and I was just like, no co-pays, no nothing. And I, I don't remember if I did cry at the time or just was kind of in shock, I think, of the fact that this is how the system works here. There's so few less middlemen and stresses. And I still just have such gratitude every time I walk out of the pharmacy.

JVN [00:22:40] So once you could prove, like as someone that was going to go to school for more than six months, you didn't even have to wait the six months? Like you just had to show that you were going to be there for more than six months.

ELIZABETH PFIESTER [00:22:47] Exactly. That I was part of a yearlong program. And then I went to the doctor who gave me my prescriptions.

JVN [00:22:52] And did you get a bill? Did you get like, did you have to, did you have to pay British taxes or something? Like?

ELIZABETH PFIESTER [00:22:57] As a student, no. But, but then when I was no longer a student, once I-

JVN [00:23:03] And you had met that gorgeous man.

ELIZABETH PFIESTER [00:23:06] I met that gorgeous man, And then we eventually decided to get, to get married. And once I was a resident and could sort of prove that I was a resident and paying taxes, then I was also eligible for the NHS.

JVN [00:23:19] But basically, you didn't have to worry like where your insulin was coming through that transitional time.

ELIZABETH PFIESTER [00:23:23] No, I mean, yeah. As long as you kind of know that you have a right to live in the country, they don't, at least in my experience. Obviously, people have different experiences. But overall, there wasn't, there wasn't a worry. I mean, I've worried so much less about where my medication is coming from, how I'm going to get it. The cost. I mean, just so much less than in the States. And I would love to move back to the U.S., to be quite honest with you. But with two, two of us with Type 1 diabetes, it would be the dumbest financial decision we would ever make.

JVN [00:23:56] So when we have a for profit health care system like the United States does. But then there's one like, you know, Canada, United Kingdom. I think Japan is more, actually I don't

know what Japan's is so I won't name that. I won't. Yeah. So, I mean, what are the things that people with with Type 1 diabetes are facing in countries that have for profit or no health care system?

ELIZABETH PFIESTER [00:24:20] Yeah, it really does vary. So even like you were saying, I think the UK is a good example. There's other countries like Scandinavian countries which have very good health care coverage for their people. Canada's slightly more in between. They definitely cover on a base level, but there's a bit more out-of-pocket costs that people have. And then in some countries that I work in Ghana, Uganda, Tanzania, there, the health care infrastructure varies, but it can be a lot more difficult. They also often have insurance and many hoops to jump through. And just the the costs that the companies are charging for insulin. We do a survey at T1 International every two years that looks at what the out-of-pocket cost is for people. And some people in certain countries are paying, for example, 10 dollars a vial, but that may be more than 50 percent of their monthly income. So the companies are charging whatever they can get away with no matter where they are in the world.

JVN [00:25:15] And that 10 dollars is, how much of that person's?

ELIZABETH PFIESTER [00:25:17] It could be 50 percent, 60 percent, even 80 percent of-.

JVN [00:25:20] If you're in a developing place and you have to have it to live.

ELIZABETH PFIESTER [00:25:22] Exactly.

JVN [00:25:23] Are the rates of Type 1 diabetes in those countries, like similar to what they are here?

ELIZABETH PFIESTER [00:25:27] Great question. Actually, there is not good data on this. So part of what T1 International does is tries to look into and collect more data because there are some countries where they don't even know the rates. They claim that they're lower, but they haven't had anyone actually go and study and look at the rates. And there's also slightly different presentations of diabetes where there maybe kind of in between Type 1 and Type 2. So there's a lot of interesting stuff that people aren't putting money in research time into which they should be, I think.

JVN [00:25:53] How to pharma-, well. Oh, right on an interesting moment. We're going to be right back with more Elizabeth Pfiester right after the break. Welcome back to "Getting Curious", this is Jonathan Van Ness. We have Elizabeth Pfiester, founder of T1 International. So basically, how is insulin made? Like from, like how do these pharmaceutical companies, like, make the insulin that gets sold?

ELIZABETH PFIESTER [00:26:25] Yes. So it used to be, so insulin has had progression over a long period of time. It used to be animal insulin that was made from animals. Now it's made in big vats, basically, chemically produced to mimic human insulin. But it does work better in the body than animal insulin, for example. But it is made in these giant vats and then put into these small vials or pens and estimates are it costs around 6 dollars maximum for one vial. Yet the companies are charging around 300 dollars, list price, for one vial.

JVN [00:27:00] So in America. It's \$300.

ELIZABETH PFIESTER [00:27:02] Yeah. We're talking about America. But, but in other places, again, they will charge whatever they can.

JVN [00:27:07] Wherever they can.

ELIZABETH PFIESTER [00:27:08] And of course, they're still making a profit. Even if they charge 25 bucks, they're making a massive profit on something that costs around 6 dollars to produce.

JVN [00:27:16] How is that allowed to happen?

ELIZABETH PFIESTER [00:27:19] Well, there's a lot of reasons. So these pharma companies have a lot of power and influence. I'm sure, as you know, the lobbying dollars spent by these pharmaceutical companies, insurance companies, all of these big corporate players put so much money into our government that most, most people in government don't want to take a stand and hold these companies accountable. They just have so much power. Of course, here in the U.S. also, the system is way more complex than it is in most, most, in many other countries. So because we have all these middlemen, they can all just keep blaming each other and say, oh, well, it's the pharmacy benefit manager's fault, it's the insurance fault. And nobody ever really gets held accountable and they all keep profiting off of patient lives.

JVN [00:28:03] So when you started T1 International. I mean there is. I think for people that aren't living with diabetes, it's hard to even understand, like what, you know, you're up against and what you kind of have been facing. And just like what your mindset would be, just having, like, lived with it. So, but that's like on a personal, you know, like one-to-one level, like, what are the wider issues of this insulin crisis? And like, so what are the issues? And then what are being done with them from T1 International's perspective?

ELIZABETH PFIESTER [00:28:31] Yeah. So, I mean, on, on the most basic level, people are dying because they can't afford their insulin. And this is, this is horrific. In a country that constantly likes to brag that it has the best health care system in the world.

JVN [00:28:44] So right here in America. Right now. There is a crisis of people dying from lack of insulin.

ELIZABETH PFIESTER [00:28:49] Exactly. So even just this year, we know of 4 people who confirmed that it's because they were rationing their insulin because it was too expensive is why they passed away. And that's just for-

JVN [00:29:01] Let's break that down a little bit, because I think that is something that people are not hearing. I did not know about this until I discovered T1 International, until I discovered you. So there are people in America that are young people that are living with Type 1 diabetes that due to the, 'cause OK. So let's say that you're insured, right? So and let's say that you have like a silver plan and your prescription deductible is, let's say, 2,000. So until you pay 2,000 dollars in prescriptions, you don't get that copay.

ELIZABETH PFIESTER [00:29:31] Exactly.

JVN [00:29:31] Like so your insulin is not going to be 35 dollars until you've spent 2,000.

ELIZABETH PFIESTER [00:29:35] Exactly.

JVN [00:29:36] Let's say you're a young person and let's say that your parents aren't around anymore. Your parents don't have means. Like, you know? You don't have help. You're a single person. 20s, 30s, maybe have student debt. Maybe you and let's say maybe you lost your job. You don't have Cobra. Maybe you didn't sign up for the Affordable Care Act, you're like I'll just pay that one percent of whatever, like, you know, for being uninsured. And so those people would have to, because there's an uninsured issue or there is an insured but can't meet the copay issue.

ELIZABETH PFIESTER [00:30:05] Totally.

JVN [00:30:05] So there's both.

ELIZABETH PFIESTER [00:30:06] Totally.

JVN [00:30:06] So in these four confirmed cases in 2019. Do we know of any cases in '18 and '17? I'm sure there were.

ELIZABETH PFIESTER [00:30:13] Yep. Yep. So we have, we have kind of a running list of families we're in touch with over the past few years. We have 12 on that list right now. But many, many people's deaths get attributed to something else that was caused by their DKA. So we know that the number is much higher. We know that 26 percent of people who responded to our survey, which had nearly a thousand respondents, 26 percent of people are rationing their insulin due to cost. They have rationed at some point in the last year. So rationing is very dangerous and leads to these deaths.

JVN [00:30:43] What happens when we ration?

ELIZABETH PFIESTER [00:30:45] So it's like I was explaining to you earlier, diabetic ketoacidosis where acid builds up in your blood and it can kill you. It's, it's incredibly dangerous. And it presents like the flu. So a lot of young people who have never experienced DKA, diabetic ketoacidosis, before will start throwing up. They'll start being sick and thinking, gosh, I really have the flu and they don't connect it because also your brain function is not as strong when you're in DKA. Again, acid in your blood. So you're feeling poorly. You think you have the flu and you just kind of don't do anything about it. And, and this is what has led to the deaths.

JVN [00:31:23] And would that diabetic person, like, not have the gauge thing that's like attached to you that like has, like that tells you where you are or something, or?

ELIZABETH PFIESTER [00:31:30] So, again, it really depends. Even if you, probably not, because if you're struggling financially, if you don't have insurance, you don't, you can't afford the technology. You're not testing regularly. Also, if, I know-

JVN [00:31:42] So if you don't have the thing hooked into you, you're still have to like, would just be doing the blood point.

ELIZABETH PFIESTER [00:31:46] Which I do too. And this just gives me insulin so it doesn't tell me my blood sugar levels.

JVN [00:31:51] Oh. OK, so you're still having to do that. OK. OK.

ELIZABETH PFIESTER [00:31:52] There's a lot of different pieces of technology though. But yeah, more than likely, someone who also knows that their blood sugar is running higher than they want it to be. Isn't gonna want to test if they already know that they're high to see that number is pretty demoralizing. So not only are you probably not testing for that reason, you probably can't afford the test strips. So there's all these things than confound.

JVN [00:32:13] And you can't help if your blood sugar is high. I mean, what? Because, like, if the person, like, trying to eat healthy, trying to avoid carbs, like they're not, you know, they're doing all the best things, but maybe have stress because they don't have enough money for the insulin.

ELIZABETH PFIESTER [00:32:23] Exactly. And if you're taking less insulin, your blood sugar will be higher. So every time you inch back on that insulin, your blood sugars creep up and up and up.

JVN [00:32:32] So really, it's like if your body, if your meter is telling you that you need a certain amount of insulin, your blood test is telling you that you need to dose yourself a certain amount of insulin, that's the amount you need to dose.

ELIZABETH PFIESTER [00:32:41] Yes. And if you don't have that, then why would you test? Because then you're being told to do something that you literally cannot do. So it's this terrible cycle of all these things that are playing against people who, as you say, are already probably struggling with many things. People's stories that we know, some of them had insurance, some of them didn't. Many of them were working multiple jobs. You know, people are doing their best. And this is, this is what's happening. And it's incredibly outrageous. It. It makes me sad, it makes me angry. And so.

JVN [00:33:10] But, you know, if you did a thous-, well, first of all, thank you so much for all the good work that you're doing for people that are living with Type 1 diabetes. So thank you. Second of all, if you had a thousand respondents from this and you know that over a quarter, like 26 percent, I mean, obviously that is something that's going on in the wider Type 1 diabetes community. If that's so.

ELIZABETH PFIESTER [00:33:27] Totally.

JVN [00:33:27] So that is like a huge issue across the board. And it can lead to like, I'm sure it leads to other health issues for people with Type 1 diabetes, which would only put a bigger impact on the health care system. And this is one thing that really pisses me the fuck off. That thought of, you know, like I compare it to like drunk driving 'cause it's like, it makes sense in my mind. It's like when people are like, well, I don't want to spend money on a cab, so I'm going to, like, drive myself to and from. Well, now you've endangering people's lives. Plus, you've gotten a DUI and now you have like 15,000 dollars of court fees to pay off. So from a health care perspective, it's like this, when it's for profit, it's like and just, you know, a lot times like Republicans here in this country. It's like they don't want to spend money on, you know, health

care, for instance, because they're like, it's too expensive. But the cost of not caring for people in the first place ends up way superseding the costs that it would have been if you would have just helped people, if you would have just done, if you would have invested in people in the first place. It would have been less expensive in the grand scheme of things. It's, it's being so tight with your fuckin' money that makes it more expensive later on.

ELIZABETH PFIESTER [00:34:28] Yes. Preach. Yes, totally. And this is, this is where it just becomes, again, so difficult because we can see the power and influence from these companies. We also, you know, not, there's, there's great organizations out there doing great work. But most diabetes organizations take huge sums of money from the big three insulin manufacturers. Insulin manufacturing is dominated by three big companies only. They basically hold a monopoly and their prices have been going up in lockstep.

JVN [00:34:55] Who are they there?

ELIZABETH PFIESTER [00:34:56] They're Eli Lilly, Novo Nordisk and Sanofi. Eli Lilly is based in America. The other two are based in Europe. But they-

JVN [00:35:03] And if they're making vats that costs 6 dollars, but they charge 300.

ELIZABETH PFIESTER [00:35:06] Exactly. And they're the only ones. They kind of push other players out of the market. They have this huge power and influence. And they're also influencing many, many health organizations, which is why these organizations stay, well, we believe this is why they stay quiet and they don't speak out, because nobody wants to bite the hand that feeds them and they can't advocate as freely and speak about these deaths. And no one is talking about these deaths.

JVN [00:35:28] In America, do we get insulin from the ones that are in Europe?

ELIZABETH PFIESTER [00:35:32] So some, some, yes. So-

JVN [00:35:34] I wonder if that's something to do with, like, those, you know, how like Trump was all about like, you know, don't send the business to Ireland, but sometimes it's like-. I bet the ones that if we get insulin from the ones in Europe with like tax law things like I bet those ones are getting like really fucking rich. I bet the American ones too.

ELIZABETH PFIESTER [00:35:47] Yeah. They all, they all are. And then Brexit's a whole other thing too, because people are worried about insulin supply once Brexit happens. That's a whole other conversation.

JVN [00:35:56] Do you, are you concerned about that?

ELIZABETH PFIESTER [00:35:58] I mean anytime that I have to think about my insulin supply being compromised, it's terrifying. I don't imagine that the companies would, if anything, I'm just worried that the national health care system in the UK will get further ripped off because they'll find ways to charge more and say, well, now it's because of all the Brexit negotiations and because of the way things were.

JVN [00:36:20] Now we can charge you more.

ELIZABETH PFIESTER [00:36:20] We can charge you more. That's my concern. And I, and I would think that the government would know that we have to have our insulin. But again, it's, it's a battle I don't wanna have to fight and it scares me to have to fight that battle when there's big battles going on elsewhere.

JVN [00:36:35] Do you-? So speaking about battles. In America, you know, I think transparency around health care, I think is a really big deal. And I mean, until we make the health care system a right and not a for profit entity, I think that this is going to continue to be an issue for people just across the, across the country. But I do know that there are some things that T1 International has been advocating for, you know, to create, to help with the policy change. And I know that there has been some victories in the last few years with policy change. Give us a silver lining.

ELIZABETH PFIESTER [00:37:07] Yeah, of course. Well, to me, the biggest hope that I see in all of this, because it is kind of a dark outlook, is these successes that we've had. And these successes are because of patients, people like me and my colleagues and my volunteer friends realizing that we have a voice. And, you know, this is where change has happened historically with the HIV AIDS movement. It was led by patients and the people most impacted by what they were facing. We know what it's like and we know what needs to change. And this has led to, yeah, progress. We've seen transparency legislation passed in Nevada, which was the first of its kind, to try to bring more light, because as I mentioned before, about all the finger pointing, until we can see more of what's actually happening behind-the-scenes, it's really hard to make meaningful legislation to address it. We've also seen price caps.

JVN [00:37:53] Can you tell us, so that bill you're talking about, it's Nevada Senate Bill 539, which requires insulin manufacturers to report costs and profits and to notify the state before planned price increases.

ELIZABETH PFIESTER [00:38:06] That's right.

JVN [00:38:07] That's interesting.

ELIZABETH PFIESTER [00:38:08] Yeah. And this is what, the kind of things that we need. But the companies are kind of fighting that, of course, they have a lot of power. They have a lot of money. They're pushing back. So they don't have to do these reports.

JVN [00:38:17] Did you? Is that where you were able to get some of these prices from, from that bill of the 6 dollars to 300 dollars?

ELIZABETH PFIESTER [00:38:23] That was from a different study. And we're still kind of working on getting the results from this legislation that's passed. But this is where advocacy and what we do as an organization is such a long game, because this is, this is one step. But we have to make sure that we actually get the reporting and we act on that reporting. So there's other legislation that's coming forward, like putting a cap on the amount that people have to pay.

JVN [00:38:43] And that's the California one.

ELIZABETH PFIESTER [00:38:45] So there is some promising legislation in California, but Colorado recently passed a price cap.

JVN [00:38:50] Ooh, I don't have that one in my notes. Tell us, tell us, tell us.

ELIZABETH PFIESTER [00:38:52] Yeah. So it's very recent and it's it's one hundred dollars for people with insurance, though. So this doesn't include people without insurance. And we're really trying to improve this, this legislation, but it's a first step. So for for one month, the maximum is \$100, which I feel is still too much. But again, it's a step in the right direction where it's stopping people from having to pay \$800 or \$1000.

JVN [00:39:12] I mean, so like, OK. So I am HIV positive. And I, this actually just happened to me like a month ago where I didn't have a bottle of my pills, like I'd left them in New York and I was in Philly and I didn't want to miss a night and it was like 10:00 o'clock at night. And for me to go buy like a month of my pills because I haven't needed to use my deductible yet because, like, I've just, you know, it just comes when-. So I haven't had a deductible. It was 3,000 dollars to get a bottle of pills, for 30 pills. So it's like and I have insurance.

ELIZABETH PFIESTER [00:39:46] Right.

JVN [00:39:46] So, and, and my deductible was I think my, my prescription deductible is really high. So like that didn't even meet it.

ELIZABETH PFIESTER [00:39:52] Yeah. Wow.

JVN [00:39:53] So it's like, or maybe it does now but I ended up paying like 3,000 plus dollars for.

ELIZABETH PFIESTER [00:39:56] Yeah, it's outrageous.

JVN [00:39:56] Yeah. So I mean I would much rather pay a hundred, you know?

ELIZABETH PFIESTER [00:40:00] Exactly.

JVN [00:40:00] To get my shit.

ELIZABETH PFIESTER [00:40:01] Exactly.

JVN [00:40:02] You know, so I just think that's crazy. I. Fuck it, I'm going to do it right now, so when this comes out, we can do it. I am supporting Elizabeth Warren for president because she wants to-. I, that is what sold me is like I am all about taking the money away from the insurance companies.

ELIZABETH PFIESTER [00:40:18] Yeah.

JVN [00:40:19] 72 motherfucking billion dollars is too mother fucking much. I've been working my ass off all day and night for my whole motherfucking life and get out of my face.

ELIZABETH PFIESTER [00:40:28] Yes.

JVN [00:40:28] With 72 billion motherfucking dollars.

ELIZABETH PFIESTER [00:40:31] Yes. Yes. Definitely.

JVN [00:40:31] Fucking get out of here.

ELIZABETH PFIESTER [00:40:33] It's outrageous.

JVN [00:40:35] That is who I'm endorsing for president. You did hear it here first. Senator Warren, get your ass in here. I know you're saving the world, but fuck. We want to hear what's going on. Elizabeth Pfeister, queen. So this that part in yoga class where, you know, you, you wanted to learn crow, but, you know, that teacher was just do an arm bands and all sorts of shoulder mobility and you're like, fuck, I'm never come back to this class again. What did we miss in class and with T1 International, how can? Well, one thing that you touched on that we, I actually, we actually have to talk about, you do not accept contributions from, from Big Pharma?

ELIZABETH PFIESTER [00:41:10] Correct. We don't. From day one. We, we wanted to be independent, uninfluenced. We don't accept from Big Pharma, from, we're really careful about thinking about the money that we do accept to make sure that it is not influencing us in-.

JVN [00:41:23] So small donor only.

ELIZABETH PFIESTER [00:41:24] We, yeah, we are, we're kind of getting to where we might be getting some bigger grants, but we're, we're really thoughtful and are considerate.

JVN [00:41:31] But they're not from Big Pharma.

ELIZABETH PFIESTER [00:41:31] Not from Pharma. Not, not in any way that, again, we try to be really cautious about where will, where might this influence us. And if it does in any way that we don't have complete control over our advocacy, we don't accept that fund.

JVN [00:41:45] I love that. So now is there any, is there any headstands that we missed?

ELIZABETH PFIESTER [00:41:50] Let me think.

JVN [00:41:51] Should people follow like T1 International on Instagram?

ELIZABETH PFIESTER [00:41:52] Please follow us on Instagram, Twitter, Facebook. We're on all the channels.

JVN [00:41:58] Does any one of those things interact more with, like some news policy, or is one more informative or uplifting? Like where do you think people should really get into?

ELIZABETH PFIESTER [00:42:05] Great question. The #Insulin4All hashtag is big on most channels, particularly Twitter. So there's a lot of discussion, stuff happening there. But I would say, yeah, Instagram is more uplifting, if you want some. It's a tough issue, but it's it's positive. We're also holding a vigil this weekend to honor lives lost. Nine families who have lost someone will be

speaking at this event. It's going to be outside of Eli Lilly, right in front of their headquarters. This is a difficult, tough issue. But as I said, nobody's really talking about it aside from us because we're independent. And although this is a massive issue, you won't see the bigger organizations talking about these deaths.

JVN [00:42:43] Because they're being paid off by the insulin companies? Essentially.

ELIZABETH PFIESTER [00:42:45] Yeah.

JVN [00:42:45] Well, you didn't say, but I did. So it's fine.

ELIZABETH PFIESTER [00:42:46] Yeah.

JVN [00:42:47] Elizabeth Warren for President. So great. I mean, I feel complete. Do you feel complete?

ELIZABETH PFIESTER [00:42:52] Yes. Thank you so much.

JVN [00:42:53] Elizabeth Pfiester, thank you so much for your tireless advocacy. And thank you for, we got to figure out the word and what language it exists in, but turning your pain and your, turning your pain into your purpose.

ELIZABETH PFIESTER [00:43:01] Yes.

JVN [00:43:01] And it's just incredible.

ELIZABETH PFIESTER [00:43:02] And thank you for using your power for good.

JVN [00:43:04] Yes. You've been listening to "Getting Curious" with me, Jonathan Van Ness. My guest this week was Elizabeth Pfiester. You'll find links to her work and T1 International in the episode description of whatever you're listening to the show on. Follow us on Instagram and Twitter @CuriousWithJVN. Our theme music is "Freak" by Quin. Thank you so much to her for letting us use it. If you enjoyed our show, introduce a friend. Show them how to subscribe. Honey, we're on Spotify, Apple podcasts. We're all over the damn place. "Getting Curious" is produced by Emily Bossak, Julie Carrillo, Rae Ellis, Harry Nelson and Colin Anderson. And me.