

Cathy: [00:00:00] I am shocked and appalled that the third leading cause of death in America has this little research and and true statistics behind it that it has.

Peter: [00:00:20] Welcome to Improv is no Joke podcast, where it's all about becoming a more effective communicator by embracing the principles of improvisation. I'm your host Peter Margarita's the self-proclaimed chief edutainment officer of my business, the accidental account. My goal is to provide you with thought provoking interviews with business leaders so you can become an effective improviser which will lead to building stronger relationships with clients customers colleagues and even your family. So let's start to show. Welcome to episode 53 of improv is no joke podcast. And today's guest is Cathy Paessun, who's the executive director for the central Ohio Diabetes Association and former executive director of the Juvenile Diabetes Research Foundation here in Columbus, Ohio, about the warning signs of type 1 diabetes and the latest research on finding a cure. Now I'm a type 1 diabetic who was diagnosed over 10 years ago. However on January 1st of this year my 16 year old son was diagnosed with Type 1 diabetes. That event has changed my focus on diabetes because we were lucky that I recognized the early warning signs, saw them, and reacted quickly to get my son to the emergency room. Unfortunately, a lot of parents do not know the signs and their child could die from high blood sugar if not caught quickly. The purpose of this podcast is to help raise awareness of the warning signs of type 1 diabetes so parents can react quickly. I would like to request that you point your friends, family, coworkers, etc. to this episode because it could save a child's life. With that said, let's get to this all important interview with Cathy Paessun.

Peter: [00:02:14] Cathy thank you for taking time out of your extremely busy work day to spend some time with me on my podcast discussing this very important issue of type 1 diabetes.

Cathy: [00:02:28] Pete I can't thank you enough for helping us spread the word.

Peter: [00:02:31] And you're currently the executive director of the central Ohio Diabetes Association.

Cathy: [00:02:37] Yes, exactly.

Peter: [00:02:38] And we met when you are the executive director of the Juvenile Diabetes Research Association here in Columbus. And we had this conversation, as I've said in my intro, about my son coming down with type 1 diabetes. Now it's no you didn't do that to my family. So I'm on this passionate journey of helping to raise awareness of this in everybody because I was in my 40s when I was diagnosed... But especially in children. If you could give the audience just a little bit of background about it and some of the warning signs and things that you've seen and things that you've heard over your tenure in both of these wonderful institutions.

Cathy: [00:03:26] Well, as you know, the problem is the warning sign of diabetes are that it can be perceived as "Well, they're a growing child. Of course they're incredibly thirsty. It's maybe this summer and they're playing sports and so they're drinking a lot more than usual and they're going to the bathroom more. Well of course they're going to the bathroom more because they're drinking more because you know they're so busy in sports. They're losing weight. Well of course they're losing weight. You know it's the summer, they're busier," all that sort of thing. And it just takes someone really saying, "You know what, this wasn't my kid before and this seems really

different. And I need to know what's going on." A lot of times it really is that parents - and I'll be a little bit biased and say the mom - but you know really either parent looking at the child and saying this isn't normal. You know I get that they're growing but but this isn't normal. And then just kind of insisting. You know going and sometimes unfortunately depending upon the awareness of the child's pediatrician, autoimmune illnesses like Type 1 diabetes... they may or may not be looking for that, you know, and we have certainly heard stories of parents being told "oh they're just growing, go back home," and then going back and insisting on a blood test or something like that, and the blood is up in the three hundreds or six hundreds or - God forbid - higher than that, and really up in some dangerous zones before before everyone really starts to realize oh my gosh... here is a fit, young, healthy, thin child and they're being diagnosed with diabetes. That's kind of blowing my mind because that's not what the public thinks diabetes is.

Peter: [00:05:25] Right. Can you help the audience understand what's the difference between type 1 and Type 2 diabetes? Because I see a lot of people having confusion with that.

Cathy: [00:05:34] Right. Type 1 diabetes is an autoimmune disease. There is absolutely nothing that people who have type 1 diabetes did to get the disease. And there is literally absolutely nothing they can do to get rid of it. When someone, at any age, receives a diagnosis of type 1 diabetes, they will have this disease for life until JDRF and our research partners find a cure. Type 1 diabetes presents like diabetes but it's so different from type 2 diabetes. Type 2 diabetes, what it has in common with Type 1 is the suppression of the effectiveness of insulin in the body's system. So, in both situations of diabetes, the insulin produced by the body simply is not either effective or it's not enough or whatever to meet the insulin needs of the body. And so some sort of dose of external insulin for Type 1 is necessary. For type 2, what they can do is there are various medications that folks with type 2 diabetes can do to just sort of boost the effectiveness of the insulin that their body is making. So it winds up causing the same sort of reaction in the body, but the reasons are entirely different. Again type 1 is an autoimmune disease. There typically is some sort of trigger that creates an autoimmune response in the body, where the body attacks its own insulin and it is an autoimmune response. In type 2, it is the overabundance of fat cells in the body that can suppress the effectiveness of the insulin. And that's why, fortunately - yay for the type 2's - with appropriate diet and exercise changes, they can really manage that and keep it under control - maybe even not even have to do medications and you know... just really tight control can help them live with the insulin produced by their own body.

Peter: [00:07:47] Thank you for that clarification between type 1 and type 2 because I hear so many people get them confused and that was very articulate, but you also said something in there - you said something triggers. Can you talk a little bit about the triggering effect?

Cathy: [00:08:05] Well... what I'm going to say is that research is ongoing, especially in the type 1 world. A I'm going to digress for a minute: I am shocked and appalled that the third leading cause of death in America has as little research and true statistics behind it that it has. I'm just getting into the type 2 world but I can tell you, even with type 1 - thank God for JDRF; thank God they've been carrying the banner for 47 years to say we're going to understand this and we're going to find a cure because you know every day, all day long, 24/7, 365... if you get type 1 diabetes, that's never off your mind. That said, it does appear, you know, for the longest time everyone thought Type 1 was "juvenile diabetes" quote unquote. Well this is just in kids. If kids are diagnosed, then it's type 1 but it's basically the same thing. And we know now that that could

not be more incorrect. It was probably 100 years ago, if you were diagnosed with diabetes, you died because insulin was not discovered until approximately 1920, I believe it was. So let's say even 50 years ago you know you did not live to be an adult with type 1 diabetes if it was not diagnosed because it is a disease that will kill you. If you have too much sugar - too much blood glucose - in your system for too long, it simply cooks the organs and all the working systems of your bodies and you die young. And we assume that 50-75 years ago that's exactly what happened. People just were probably not feeling real great and then died young. Well thank God they finally started realizing that, hey, you can be young and thin and still have a very serious form of diabetes, and we need to do something about that. So, for the longest time, they thought... I love this: even in some of the materials they'll say it comes on suddenly. It truly doesn't. It's sudden to the family, but I have yet to meet a family who says Oh no he was fine one day and the next day his blood sugar was over 300 and he was diabetic. It just doesn't happen that way. It really is some sort of gradual diminishing of effectiveness of the body to use its own insulin, which becomes more and more obvious over time via the symptoms that we talked about earlier. And what they think, and what a lot of people will say anecdotally now, is there can be a triggering event. So many people have said you know what? About six months before I got diagnosed I had a really bad virus, or you know a year before I got diagnosed I was really sick and we didn't know what it was and then you know about six months later I started just really feeling horrible, and then another six months later we figured out it was type 1. So it does seem to have, in certain situations, and there are absolutely no absolutes when it comes to life one, and so it does appear to have a triggering event. And that is something where then it becomes interesting - the family history of it. And is it hereditary? They're not using that word anymore. It's not so much that it's hereditary, but maybe there's some sort of genetic predisposition where, if he has type 1 and your son maybe has a virus at some point, then maybe he has a predisposition in his body to have some sort of auto immune response to that and maybe it's going to present as type 1 diabetes as well.

Peter: [00:12:06] OK. One, thank you for the background around diabetes being the third leading cause of death, as well as that trigger because I do remember when one of the first questions they asked us at children's hospital when they got him down there was, "Has he been sick lately?" And, in my son's case, he wasn't. We can't trace it back to that, and being a diabetic for 10 years - this is kind of funny - when he was told that he had diabetes my son did not miss a beat. He just turned and looked at me and said "Hey, thanks dad."

Cathy: [00:12:45] [laughs] Well, the little bit I know you, I'm not surprised you son said something like that.

Peter: [00:12:49] Yeah. But it's just those symptoms of excessive thirst, of urination - Another one... that "you know he's a teenager, of course he's going to sleep a lot, of course they're going to be lethargic." That's another one.

Cathy: [00:13:08] And eating a lot.

Peter: [00:13:08] Classic sign - and losing weight. Right. And those are really I think the big five that, if you even sense anything, take action on it. In fact, to your point, the gut feel that something doesn't seem to be right here. It just doesn't feel right. I remember you sharing with me, in our first meeting, that by not knowing some parents their children might be thirsty so

they're giving them cokes and milkshakes, which is the last thing because all you're doing is adding on to it.

Cathy: [00:13:45] Absolutely. Absolutely. Yes it's scary. It can lead to then - gosh, there's just a whole huge topic around the emotions of diabetes in general, but type 1 diabetes in particular... because everyone puts on a bold face, but if you can get them alone then the parents will say I feel horrible, I feel like I caused this, I feel guilty, I feel like I should've seen sooner. You know just all the emotions you can imagine; beating themselves up when it's still... you know think about it: type 1 diabetes is only 5 percent of the diabetes population. We have approximately 30 million people diagnosed with diabetes in America today, and only about 1.5 million of them have type 1 diabetes. It's still very... and you don't look at a young, thin child and think diabetes. You just simply don't. So it's just so interesting and certainly you know the important thing to remember - and for me this is true of type 1 and Type 2, but especially type 1 - you can't go into it thinking "oh I can never have a milkshake again. Oh I can never have birthday cake again." Yes you can, just in a very controlled way and you just have to really manage that. You have to get to know your body in a way that you know in some ways is much more intense, much more detailed, and yeah more of a pain than those of us who don't have an autoimmune disease. But for the people who understand hey it's this or a really ugly alternative of being sick a big part of my life and maybe you know not living a long healthy life like I said. In some people it makes them so much more disciplined, and I'd be curious, especially you being diagnosed as an adult, the changes that you had to make. Did you wind up just finding yourself being more disciplined?

Peter: [00:15:49] Oh very much so. The accountant in me. When I first diagnosed, I had a spreadsheet and I had what my blood sugar was, what I ate, a carb count. I was almost obsessive at that point. And then, as I made my way to the pump, I became less obsessive. But I still, 90 percent of the time, I'm diligent. And there's that 10 percent of the time - there's some days, because it is a 24/7/365, I'm like hell with it.

Cathy: [00:16:20] Uh huh.

Peter: [00:16:20] But that's you know very few and far between. And about the diet: What kind of blew me away when we were at Children's Hospital and the dietician came in to talk to Steven... she was kind of going through the list of things that he was eating - and maple syrup and he was drinking Coke - and she said the only two suggestions I'm going to tell you is get rid of those too. Everything else you can manage. Just learn how to carb count, learn how to make the adjustments. You can really eat or drink anything.

Cathy: [00:16:53] It's true.

Peter: [00:16:53] But you have to manage it. And I think it's that managing part that you know... I heard somewhere that two hours out of every day, like for a type 1 diabetic, is focused on managing their diabetes. From pricking your finger to blood to the whole recording aspect of it. But I want to take a step back to talk about the emotion because the few families that I've talked with, Yes. How could I do this? They were feeling bad. Like I said they didn't know the symptoms. And even in my case I was beating myself up for about 10 minutes. How could I have done this to this kid? And then I just rationalized. Well wait a minute. I'm living with. I've been an example for him that you can do anything you want to. You just have to manage it. But you know those emotions, and even after the fact, with he and I, because you can validate... at

16 years old, his body... It's different. It seems like every single day. There's no real consistency right now. Maybe he's in that honeymoon period. So I ask him what do you think? He'll check his blood and I'll go What do you think we should do? And I help him. I try to get him to give me the rationalization around it and understand it, and I know that I've heard stories of a lot of parents who tend to over manage it for their children, and become a little bit of a micromanager. And it's... I don't know. I don't like working with micro-managers as bosses so there's a lot of friction there.

Cathy: [00:18:29] Well. So... So first of all, I want to go back and add in something that I didn't say earlier. So especially in type 1, because I am more familiar with that, but I have to wonder how true this is in type 2. There can be a virus there that can trigger some sort of immune response within the body to start attacking the insulin that the body makes, but it doesn't mean that it's a full-on assault from day one. So a lot of times - I think that's what people mean by the honeymoon period, and honeymoon is kind of an odd way of thinking about that because what it means is we know that you have a form of diabetes and that the insulin your body creates is becoming less and less effective. But it's not completely ineffective. So especially in the case of your son, he's growing. So is that his pancreas is pumping out no insulin? You know probably not. And what they're finding is, especially when women go on and get pregnant, they have a lower need for insulin during the time that they're pregnant. Well what the heck's going on there? You know I used to work with a woman who had been type 1 since she was 15 years old. She had three children. God bless her. And with all of them, she noticed the decrease need for more insulin during the course of the pregnancy. Well, hmm, we thought her pancreas was dead. Obviously not. And what they're finding is - and I think the latest research I saw, as you know someone who was looked at maybe 30 years into a diagnosis, and when they really got down into it and looked into the pancreas, that pancreas was still pumping out just the barest amounts of insulin, but it wanted to. And so of course there's research around how do you reactivate the pancreas, while at the same time suppressing that autoimmune response to then attack the insulin that's created. So I did want to add that: that it's really just such a much more complex disease than anyone ever dreamed it was. But, so more importantly, so then that very much leads into the emotions because you think you have this thing down. Oh well you know I was on the internet, I read five articles. OK I got this. And the information about diabetes is just changing on such a rapid basis because of all the wonderful research going on - definitely in the type 1 world. And so I think the first thing, as I said, that parents feel is guilty. Did they do anything and/or why didn't they see the symptoms sooner? Why didn't they get their child help sooner? But unfortunately, as you know from personal experience, the real emotion that comes out over time is... we can politely call it burnout. Some people are willing to just you know go ahead and say it's depression. It's actual, honest to god clinical depression that I have to spend you know literally every day of my life thinking about this situation, and if I don't the worst could happen, in the case of folks with type 1. And so just the depression that the parents feel for their children, the depression that people with type 1 can feel... I have heard of people - and I'm not on any of the diabetes blogs; you might be - but some people just say you know what I'm just not going to have diabetes today. I'm going to get up. I'm not going to check my sugar. I'm going to eat what I want. And I'm just not going to have diabetes today. And so of course they have to do is notify everyone they know hey I'm doing this you know. And if you if you notice anything or anything like that, but they just need that break. They just need to feel like they have that. Well now thank God we have the artificial pancreas coming out. And with Medtronic you know virtually closed loop system that's available. People can almost have that kind of break from Type 1 diabetes, where it is not a constant pressure on them. And I feel certain, over the course

of time, we will hear that a lot of the emotions around, again, type one in particular: people are able to lift some of that depression and some of that sadness and burden that they may feel from having having a chronic disease like that.

Peter: [00:23:14] Yes. That's something that they talked to us at the Children's hospital about. Keep an eye because if he starts getting depressed or whatever, but this potential closed loop and the artificial pancreas... the one blessing that I think my son has is there will be some cure in his lifetime. And he's turning 17 soon... so hopefully by the time he's 25. The way technology is going and the potential pump that is a closed loop system, which means that it will have a sensor in place on your body... it sends your blood sugar to your pump. And then the pump itself will automatically make the adjustments of the amount of insulin that you receive, as a pancreas would do. A lot of people thought that's what the pump already does and it doesn't. And through my endocrinologist I've already heard that there's two artificial... I don't how you refer to it, but the implant of an artificial pancreas into the body. You'll never have to pick your finger again.

Cathy: [00:24:24] Right. There are so many advances on their way, and you know a lot of people refuse to even refer to the system as the artificial pancreas because, clearly, the pancreas does more than pump out insulin. Just because the insulin part of it isn't working doesn't mean the pancreas isn't working - the pancreas is still doing a lot of other stuff. So just so much more information and so many more wonderful forms of technology, and especially with your numbers being able to be made available to your loved ones or caregivers via the phone. And I don't know if you are on that system but think about how you're going to feel when your son spends his first night at college.

Peter: [00:25:09] I'm not going to sleep.

Cathy: [00:25:12] Well won't it be wonderful - if he is willing - you know won't it be wonderful for him to be on a system where you will have, on your phone, exactly what his numbers are as of... I think it's every five minutes, I believe, and just be able to know. And then of course you'll build your care system around him or whatever college he goes to. So that if you're ever concerned you're able to contact other people but. But what an advance. I mean just imagine sending your kid off to college with a disease that unfortunately you know one one or two wrong moves and unfortunately it can take their life. It's just unbelievable.

Peter: [00:25:54] Yeah. I actually have some literature on that on the Dexcom G5 Mobile where his numbers are uploaded and I could look on my phone and see how see how he's doing, which is incredible.

Cathy: [00:26:07] Yeah amazing amazing stuff is coming. You're absolutely right. I mean the experts in the field say, depending upon how you define a cure, we really will have a cure in... you know certainly in the lifetime of the people being diagnosed right now. I do want to say one more statistic. You know back in the day juvenile diabetes, type 1 diabetes, was diagnosed in children only. But these days there are 30000 diagnoses every year in the United States - of those, 15000 of them are children but fifteen thousand of them are adults.

Peter: [00:26:45] Wow.

Cathy: [00:26:45] And so it's just not juvenile diabetes anymore. It is type 1 diabetes. It is an autoimmune reaction in your body to, probably, some sort of trigger or event or illness or something like that.

Peter: [00:27:01] I didn't realize that statistic. That's absolutely amazing. As we begin to kind of wrap this up, prior to us recording this, you made a reference to I think it was called Reagan's law?

Cathy: [00:27:19] Reagan's Rule.

Peter: [00:27:21] Can you explain what Reagan's rule is?

Cathy: [00:27:25] Well I had the privilege of meeting a woman here in Ohio who is working to try to get something like Reagan's rule implemented in Ohio. What happened was a 16-month-old little girl in North Carolina was showing all the symptoms. Her mother, I believe it was, took her to the doctor I'm going to say more than once. The doctor did not recognize the symptoms and did not properly test Reagan. I think did not test Reagan at all for diabetes and Reagan passed away from high blood sugar somewhere around two years old. My impression was this was a rural doctor, a primary care doctor, who of course you know they can't even be expected to be experts in everything. But this was a situation where I believe the doctor was not necessarily in you know a big city area and just did not have the kind of continual education about all the different symptoms and putting them together and finding diseases they might not actually think about. So in North Carolina there is Reagan's Rule, and it is just a... I hate to say requirement, but it is just sort of like we as a state have agreed that we are going to provide continuing education to all of our doctors, especially those in the non urban areas, on the symptoms and signs of type 1 diabetes.

Peter: [00:29:11] Wow.

Cathy: [00:29:13] Again, I believe there is you know there is the attempt to get something like that in Ohio. I don't know where that stands. To my knowledge they haven't introduced legislation or anything like that. But even at that, you know this is where the network of parents and interested adults is so important to JDRF and to the central Ohio diabetes Association. We need everyone out there raising awareness about diabetes and raising awareness about what we need to do in order to make sure that all the right people have all the right information. Our schools, our churches, our (believe it or not) doctors offices. It takes a village.

Peter: [00:29:54] It does. And to that point of raising awareness, I was actually in Endicott, Nebraska, which is about about an hour and a half outside of Omaha, with a client and one of his managers said that his son was diagnosed at the age of 12 or 13 with type 1. It was really difficult on him because he was the only kid in school with type 1 diabetes. And they would go to Nebraska diabetes association whatever. And I know central Ohio Diabetes Associates has these camps. And his son was going to these camps to, in their terms, feel normal again; to be around people just like them versus... I guess fortunately... unfortunately in the school that my son goes to the nurse told me there's 15 to 16 diabetics at school.

Cathy: [00:30:53] We can't get over it. I believe in a kind of a very loose statistic but I think nationwide children's hospital gets probably 300 diagnoses a year. And doesn't that just blow

your mind. Now, Nationwide Children's Hospital covers a 26 or 27 County area. So they are covering you know from central Ohio down. But that number just blows my mind.

Peter: [00:31:19] I mean I can do the math on that: that's about one a day. The statistic that I have not asked, and you said you don't know it but you know that it has occurred, is how many children have gone in too late to be diagnosed and, unfortunately, don't come out the same way they go in.

Cathy: [00:31:40] You're right, and this is my final banner because we do not have a diabetes registry in the state of Ohio. So there is no requirement for doctors to report that they have diagnosed. There is no requirement to report complications that may have come from a diabetes diagnosis. And there's no requirement to report a death based on high blood sugar, or anything like that. And we need to change that. This is just too prevalent a disease. Type 1 and Type 2. it's too prevalent. We need to know more about it. We need to understand exactly where it's occurring, and in what numbers, and then begin to look. What's going on there? You know there can be obvious environmental factors. Let's look for the less obvious environmental factors. I mean we just need more information about this disease.

Peter: [00:32:32] Well, as you know, whatever I can do to help, and this is one way that I want to do this, is to get this you on this podcast to talk about it. And for those of you who are listening, pass this along. Have someone download it. You know any parent, any family member, coworker, or anybody. Just have them listen to this. And the reason to listen to it is to hear the signs and see it and just have that in in the back of your mind at all times. If you see something weird, act on it.

Cathy: [00:33:08] Yes absolutely. Yeah. You know it's funny - people can just appear to be kind of zoning out at work and they may be too high or too low. And it's worth possibly having that conversation.

Peter: [00:33:21] Exactly. And as a couple of diabetic friends of mine have said, "Diabetes: we're the ones who take drugs not to be high."

Cathy: [00:33:34] [laughs]

Peter: [00:33:36] And I asked them you know a lot of dealing with it - they're type 1 diabetic - a lot of dealing with that goes back to your attitude that you take. And you know I've written a little bit of comedy about being a type 1 diabetic. It's the only time in my life I've ever been number one.

Cathy: [00:33:56] [laughs]

Peter: [00:33:56] If you don't attack it with a positive attitude, it can really wear you down.

Cathy: [00:34:05] Oh I can't even imagine. No you are to be admired, Pete. You are an ambassador for the type 1 population and just a reminder that... it's not that the diabetes controls you - it's that you have to control the diabetes. And people like you are a good reminder of that and just you know that discipline that you take toward your diabetes you obviously have towards all areas of your life and that has led to the success that you have been able to

achieve. The podcast, the book, your speaking. I mean this is exactly what we want people with type 1 to think it's possible.

Peter: [00:34:47] Thank you. I greatly appreciate the kind words and you've got my contact information. You know if I can ever do anything for you - you need either somebody to speak at an event - just let me know and if I'm in town I'm right there.

Cathy: [00:35:03] Wonderful. That's great.

Peter: [00:35:05] Cathy, thank you again. A lot of great information. Go to central Ohio diabetes Association Web site. Go to the Juvenile Diabetes Research Foundation Web site.

Cathy: [00:35:16] There's a lot of information there, and be aware of Type 1 Diabetes. Thank you again.

Peter: [00:35:26] I can't thank Cathy enough for taking time to have this discussion on my podcast on helping to raise awareness of signs of type 1 diabetes and understanding the challenges of being a Type 1 diabetic. Now in Episode 54, I interview Alan Lloyd, who's the new CEO of the Montana Society of CPAs. Once again, I'd like to request that you point your friends, family, coworkers, etc. to this episode because it could save a child's life.

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