AT Banter Podcast Episode 281 - Accessible Insulin Pumps

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SPEAKERS

Steve Barclay, Lis Malone, Rob Mineault, Kat Hamilton, Ryan Hooey, Ryan Fleury

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R **Rob Mineault** 01:46

Hey and welcome to another episode of AT Banter.

S **Steve Barclay** 01:51

Banter, banter.

R **Rob Mineault** 01:54

This is of course - that was really loud. This is of course the podcast where we talk with advocates and members of the disability community to educate and inspire better conversation about disability. My name is RobMineault. Joining me today, the cantankerous Ryan Fleury.

R **Ryan Fleury** 02:13

Hello again.

R **Rob Mineault** 02:15

The cheerful Steve Barclay. And the candid Lis Malone.

L **Lis Malone** 02:24

Greetings everyone.

R Rob Mineault 02:26

See, I know I left out the adjectives last week, so I was made sure that I came with came up with some this week because I didn't want to get called out on it.

S Steve Barclay 02:35

Those are some pretty fancy adjectives.

R Rob Mineault 02:38

Today's theme was C. Hey, how is everybody?

S Steve Barclay 02:50

Fantastic.

R Rob Mineault 02:51

You're supposed to say cheerful. You fail. See, I've already caught you not paying attention. Well, hey, listen, before we go sideways. Ryan, I'm really excited about today's episode. I want you to tell everybody why we're here and who we're talking to.

R Ryan Fleury 03:19

Sure. So why we're here is because one of our listeners - and I'm not naming names, but yes, I am. Bev sent us an email asking us to talk about being blind having diabetes and the accessibility or lack thereof of insulin pumps and apps. So we have two guests joining us from the CNIB. First we have Kat Hamilton, who is the Senior Manager of Advocacy and Public Education. And she is also leading the work on accessible insulin pumps. So we're glad to have you with us Kat.

K Kat Hamilton 03:49

Thanks for having me today.

R Ryan Fleury 03:53

Perfect. Thanks. And also joining us from the CLB is Ryan Hooey, who is a blind diabetic who has contributed to many podcasts about diabetes, and has also done advocacy work with diabetes Canada. Ryan, thanks for joining us.

R Ryan Hooey 04:08

Hey, guys, thanks so much for having me. Pleasure to be here. And I can't wait to tell you what I know or what I think I know.

R Ryan Fleury 04:16

Well, you definitely know more than we do.

R Rob Mineault 04:17

Why don't we just start with maybe Ryan and Kat, maybe you could just start out by telling us a little bit about yourself, and just how you guys got involved in this.

R Ryan Hooey 04:32

Sure it's Ryan here so I can kick things off. I am a 35 year old type one diabetic. And I've had diabetes since the age of seven. I'm currently living with diabetes retinopathy, which I have very, very limited eyesight and that sort of happened 10 years ago, went to bed one night I was completely fine. were reading glasses drove home and woke up the next morning and was completely blind. My retinas had just detached overnight. I currently use a Medtronic pump. And I also use the Libre sensor on my I guess, tricep to test my blood sugar. I'm very, very into the accessibility and keeping good care of my diabetes. And I just love chatting about it, I could chat all day about it, and some of the things that we're trying to accomplish within the CNIB nationally and internationally. But as far as we're aware, and as far as we've kind of done some research and stuff, there is not an accessible insulin pump, on the market for those with any type of vision loss. So we're looking to change that we're looking to get something on the market, whether it's an app, whether it's a pump, whether it's some sort of additional device that would give me the freedom to, to use my pump myself independently, and does not depend on people through FaceTime or sighted people to have to be around kind of thing.

R Rob Mineault 06:01

And so So what about you, kat? How did you sort of get involved in this?

K Kat Hamilton 06:09

I'm from the UK originally, and I used to work for RNIB. So for those who don't know, the Royal National Institute for Blind People in the original London. I was working there, as I said, about 10 years ago, and even back then we would have people call into our advocacy hotline to say, it was more of an inquiry at that point, like, you know, hey, I live with diabetes and sight loss. Can you tell me what pumps are out there that are accessible. And when we looked into it, there wasn't an accessible pump for people. And it was, it was kind of like, we didn't really have

anything to advise people of at the time and just said, you know, unfortunately, good luck. And we'll support any advocacy efforts. And then obviously, fast forward a few years, to about two or three years ago now, where we were starting to get calls from people coming into us, you know, very similar questions. And so, you know, it's been 10 plus years. I mean, it's been many years really, since the what, what would you say, like, 20 years since insulin pumps were originally introduced, and this is still an issue that we're dealing with. And, and as Ryan mentioned, you know, in the US, it's the leading cause of sight loss, I believe in in working age adults, is diabetes. So there's such a huge connection between the two communities. And it just It blows my mind that in this day and age, we're still having this discussion. So I don't have lived experience of diabetes. But I do have diabetes in my family. So it's something that's very near and dear to my heart as well, as well as being an advocate for these kinds of issues in the disability world.

R Rob Mineault 08:12

So I just want to take a step back from it just for people who maybe aren't familiar with, with what we mean, when we talk about an insulin pump. Could someone sort of walk us through exactly what we're talking about, like, what are they and how do they work?

R Ryan Hooey 08:31

Absolutely, I have no problem doing that. So I'm currently connected to one right now. And it's about the size of a 1994 Pager. And about every three days you have to refill an insulin tube in it with insulin and then change your spot. What the pump does is it's a mini computer, and it has a small screen on it. And there's about mine has 6 buttons on it. And none are labeled. They make noises when you when you touch them. But I can inject myself with insulin based on how many carbohydrates I'm eating. And that's at each meal. The great thing about a pump is that it continually pumps insulin into you. So through your diabetes team with your nurse educators and your endocrinologist, they come up with this ratio, it's called a basal ratio. And they determine how many units of insulin you need in a 24 hour period. Mine is really easy. I need 24 units of insulin in a 24 hour period. So my pump knows to pump me full of one unit per hour. Most people's aren't that complicated, or that easy, I guess I should say. And what happens with the insulin pump is that if you're excited and you can read the screen, you don't have to figure out anything. So I have what's called the carb ratio. Every seven grams of carb I eat at breakfast, I have to inject one unit of insulin. So pretty easy math. I have to do that in my head. But for younger children or people that just don't like math, you can type in the amount of carbs into your pump, and it will figure it out for you. I can't do that because I can't see the screen. And there's no audio and there's there's no beeps or anything to do that. Another thing that the pump does is the newer ones, you can actually hook a continuous blood glucose monitor up to it, and you can have it send your sugars to the pump. So it knows if you ate a whole bag of sour patch kids, it needs to work overtime kind of thing. Whereas I have to test and then just do it on my own kind of thing. Pretty much if you want to break it down my insulin pump right now for a person living with diabetic retinopathy that can't see is a fancy insulin syringe. It just pumps me full of insulin all the time, and I can't use any of the features.

R Ryan Fleury 10:49

So I guess my ignorance not having anyone who is a type one diabetic in the family. With your

insulin pump, you still then have to monitor the amount of carbs that you're you're taking in like you can't just go have three sausage, egg McMuffins at McDonald's and let the pump do its job, you still have to kind of figure that out on your own?

R Ryan Hooey 11:11

Yeah, that's correct. So the way that I was taught with my endocrinologist, he said, you can go have a piece of cake, you can't eat the whole cake. If you look at diabetes as a teeter totter, on the left hand side, we have sugar and carbs and food. On the right hand side we have insulin, you have to keep them equal. So the more food you eat, the left hand of the teeter totter goes up, then you have to counteract that by upping your insulin. So your right hand goes up, then vice versa, right. If you take too much insulin, you might have to sometimes add sugar. So it's kind of a very simplistic approach to diabetes. But when I was a young child, that's how they kind of taught me what I needed to do.

R Ryan Fleury 11:50

So I can still have pizza if I get diabetes.

R Ryan Hooey 11:54

Absolutely

R Ryan Fleury 11:55

Excellent.

R Ryan Hooey 11:56

Everything in moderation.

R Rob Mineault 11:58

So what talk to us a little bit about the pumps themselves. Are there a lot of different ones on the market that have a variety of different bells and whistles? Are there a variety of different price ranges, or are they pretty much all sort of the same?

R Ryan Hooey 12:25

An insulin pump is lavishly expensive. The one I'm currently wearing, I've had for about eight years, and eight years ago, it was (thank goodness covered by a provincial program here in Ontario), but it was $17,000. So I can only imagine what a pump costs now. I know different

countries have even different provinces within Canada, where I live have different coverages whether it's covered, it's not that sort of thing. And it's, it's disheartening, because I think there should be a national landscape within Canada and within the US where people shouldn't have to one pay for insulin or pay for the device that's actually giving it to you, there has to be some sort of coverage there or there has to be some sort of something that could offset the cost. There are a few different pump manufacturing companies out there. And for the most part, I would say the pumps have really the same features on it. Some differ a little bit, but it's pretty much like your choice of cell phone, they all do text messaging, they all do calls, you can all search, you know Facebook and do stuff like that. So it's just it depends on what you kind of want some attached to your arm some attached to your abdomen. But for the most part, a pump as a pump, it just does a little bit of the different features kind of thing.

R Rob Mineault 13:46

So now what's your what's your sort of sense of how hard would it be to make these devices accessible? You know, whether that's haptics or at least tactile buttons, or even it sounds like even like the different beeps, and sounds and alarms that it makes if they could differentiate those.

R Ryan Hooey 14:09

My dream device wouldn't even be an insulin pump. If I'm being honest, it would be an app on my phone that I could just do everything from. I mean, we can do banking, we can do some pretty sensitive stuff on our phone, but we can't administer insulin. I can track my blood sugar's on my phone, I can test my blood sugar with my phone, but I can't administer insulin. I think it's really easy. And I think we're almost there. Because you know, with VoiceOver and with some other features that are already added into Apple devices, that heavy lifting is done. It's just make the app and connected Bluetooth to my pump. A lot of the pushback that we have gotten from pump manufacturers is that they thought we wanted to retrofit an entire pump and they'd have to add the voice and do this and do that and take this off the market. And with health care it's a little different because there is a lot Big time. So even if you put a headphone jack on my pump, or change something that doesn't even matter about the medication administration, it's a two year waiting period to get it back on the market. So I think that's where part of the, I guess angst comes in amongst these companies. And I mean, it would be very easy to even just, you know, like some have tactile buttons, but now, everything is touchscreen. Now all the phones, even your microwave doesn't have tactile buttons on it. Right? There's, there's a lot of different things that that don't anymore. And I think that's another push is that, you know, it's not so much just the pump itself, it's even doing the administration part for me to change the insulin for me to change the the, it's like an IV, so we call it the, the infusion kit and the infusion site, I have to go back and forth left to right about every three to four days, depending on how poorly I eat, you know, and get that pizza going, you might have to change your pump a little bit more often because you're taking more insulin, but there's just a lot of things that you have almost have to depend on someone with vision.

R Rob Mineault 16:11

Now I want to talk a little bit about about the work that CNIB is doing. Because you guys have sort of been involved in this advocacy work for a few years. What kind of response have you

got?

K Kat Hamilton 16:27

Yeah, so it's, it's really varied. Like, I often feel like from the community perspective, whatever issue we take up, there's normally people that think it's an important issue and people that think that, you know, why CNIB is wasting their time on this. And I know we're on the right track when everyone in the community is like, yes, this is an issue. And please deal with this. So I would say from the community perspective, it's been 100% support, and we're always looking for people to come and join us on this venture and see, you know, how we can change things. From, you know, the government side of the house has been more challenging, especially during COVID trying to navigate conversations with Health Canada and and health ministries. That's, that's been trickier. And, you know, understandably, we haven't been top of the the invitation list to meet with politicians, but we have had some good conversations around, perhaps even advocating for having, you know, when these devices come to market in Canada, that there is a checklist somewhere that they assess if there's accessibility in these devices. And and if not, then, you know, I'm not saying it doesn't get approved, but the manufacturer has to make some commitments there to to improve that. And then I guess, you know, as Ryan was saying, with, with the manufacturers, they're not thinking what's happening this year, they're thinking what's happening five years down the line in their, in their product lines and, and what the next big thing is, so they they've been supportive, I must say, I don't think any manufacturers are out there that that don't want to make their product better. Especially, you know, if they can have a, an edge on their competitors in the market, then then why wouldn't you do that. But I think it's more trying to steer a really big ship that's moving really slowly to see how we can make those improvements further down the line.

R Ryan Hooey 18:51

And just to add to that, you can we've had a few Townhall meetings where even by the pump companies and things like that, and you can really tell a lot by who the pump company sends, a lot of times we get marketing people when we need the engineers, we need the people that are behind the scenes, and and can invoke change, not to take anything away from the marketing people, but they don't really have anything to do with the design. And it's really telling when you get a series of you know, maybe three or four pump companies, but they're all marketing people.

R Rob Mineault 19:27

Yeah, it's it seems interesting, because you kind of are attacking this with two different prongs, you know, you're sort of talking to the manufacturers as well as trying to change policy with with Health Canada. And it seems to me that that's sort of the one that's that's the big fix, if they lay down the law and say, Look, in order to for these devices to be approved, they need to have at least x amount of accessible components to so that somebody can can navigate this without assistance. That's going to solve problems right across the board. But it's true, I can see that going after the manufacturers could be really beneficial to because you're absolutely

right. like, all it's going to take is one manufacturer to to, to say take up this issue and make those changes. And then all of a sudden, they have a leg up on their competitors. And that can be really powerful to, to a company.

K Kat Hamilton 20:27

Well, I think the real kicker as well, for us, and our partners in the US have also faced this that a lot of the pumps have what's called a contraindication, through Health Canada. So what that means is that they deem it's not safe for certain patient groups to use, I think, you know, so, so people don't get sued if someone uses that product who's on their contraindication list. And, and then something bad happens to them. But the problem is a lot of the pump manufacturers who put down that their pumps are not recommended for use for people that are blind. So that that is just something that I just don't understand that in this day and age that we kind of say that it's not safe for people, instead of thinking outside the box with a design mindset, like how can we improve this?

R Rob Mineault 21:23

Yeah, well, especially because it's not like these pumps are new technology. They've been around for years and years. And there's been plenty of time to, you know, to come up with new generations of devices that maybe do have some sort of accessibility component. It's not like, you know, blindness and diabetes is a newly formed connection, the the this is all been around for years and years and years. So I, you know, I'm kind of with Steve, I'm really shocked that we're sort of fighting this battle in 2022.

R Ryan Hooey 21:57

And just to put this into perspective for you guys, so with me, this is my personal experience with the pump. We just had daylight savings, not too long ago, my pump is still an hour behind, because I can't set the time by myself, I can't see the time, I don't have that option available to me. So okay, fine, an hour isn't a big deal. But if I traveled to Europe, where it's, let's say six hours ahead, that's a big deal. If I can't change my pump time, I can't even tell you how much battery life is left in my pump right now. It could be ready to die. Or it could be you know, fully charged. There's, there's so many different things just accessibility wise that aren't being met. And then my endocrinologist have a great team, my diabetes, educating nurses that helped me out, they've done a lot of studies with me. And we found out that I can only use 11% of the functions on my pump. Like could you imagine if I handed you a cell phone and be like, Okay, well, you can make telephone calls with this. And that's it. But here's a brand new smartphone. That's pretty much what the pump companies are saying to someone like me, you know, I'm here use our pump, but 11% of it, that's it.

R Ryan Fleury 23:05

So is there any way to interface it with a computer or your smartphone and change date and time by using an app or a computer interface or can administrator remote into it? Sort of like a CPAP machines that can monitor and make studies changes that type of thing.

R Ryan Hooey 23:22

So to the best of my knowledge there, there's not. But there are some for mine, mine, my pumps, a little bit old, but for some of the newer ones, that is something that is not regulated through any health company or any health, you know, like Health Canada or anything like that. But people have hacked into some some pumps and they're able to control some with the with their phone. But the scary thing about that is it's not tested, it's kind of you're taking a chance would have fit conks out that sort of thing would have to change the security. So there are people that do do that in Canada and the US, but it shouldn't have to come to that kind of thing.

R Rob Mineault 24:02

Yeah. So I mean, what kind of response have you got from some of the manufacturers? Because it seems to me that that an app would sort of solve a bunch of different problems. Like there are apps where you can you can connect your fridge... everything has an app associated with these days these days. So I'm kind of surprised that that they aren't more excited about that. But why are they kind of lukewarm or are they lukewarm on the whole app idea or just slow to slow to develop something?

S Steve Barclay 24:02

Yeah.

R Ryan Hooey 24:43

So great questions and some companies are and some companies aren't. We've had some discussions with some and I personally had to sign a nondisclosure agreement. So I have to be careful what I what I say and don't say because this is like their patents and things like that. But there are a couple of companies that are are working seriously on an app right now. It's just not there yet. And there are some apps out there that do connect to pumps, but you cannot administer insulin from it's more. So oh, you can just enter your your blood sugar and the amount of food you're gonna eat. And it will tell you how much insulin you're supposed to give yourself. But you still have to use the inaccessible portion of the pump to pump that insulin. It's more just for tracking purposes, I guess.

K Kat Hamilton 25:30

Yeah, and correct me if I'm wrong, Ryan, but I think some of the apps that are either in development or are out there in the market is still very kind of visual base. You can look at the details on the app, but it's still in like a graph format. And it can be challenging, I think, for people. And I think in some of the conversations that we've had around the question, you know,

is the app accessible? They don't always know the answer straight away. If, if they say, you know, we hope so. And, you know, I'm sure we keep to the guidelines out there. But it's, it's not always the band aid solution that we hope it will be.

R Ryan Hooey 26:16

Yeah, you're absolutely right. And I sometimes forget that, because I can't see the graphs on there, I just, I have tried a couple of the apps and there was graphs everywhere. Even some of the blood sugar testing apps are the I mean, the buttons are accessible. And you can actually test the blood sugar, but it pops up in a graph. And I don't know what that means, unless you turn on the the feature that some of them have built in sort of voiceover features, which is great, because it'll say, Oh, your blood sugar is, you know, 5.4, or whatever it might be. And that really, really is helpful. But there's a lot of graphs and data that I would love to have access to. But I just don't know how they would make that accessible. Right, I guess it's more for my endocrinologist and pump team, because I would say all of them have sight. And I would I don't want to be remissed here, but I don't I don't I think most teams across the country probably are similar to that.

L Lis Malone 27:14

How big is the actual landscape for the manufacturers for these pump devices? Because I honestly, I mean, this is a new new area for me, like most of us on the show, but so I'm just curious, I have no idea how many manufacturers are and how many different models there are floating out there right now.

R Ryan Hooey 27:36

So it's kind of a difficult question to answer because some are covered, and some aren't. So in Ontario, where I live, you have about four manufacturing companies where you can get coverage for your pump. But there's only about four choices there. But that's not the only pumps that they offer. Those are just the ones that have been covered under a provincial health program. There's obviously more variety in the US, there's a few pumps on the market there that aren't in Canada, that by but I, I would say the biggest pump manufacturing company to this date is Medtronic in worldwide. And they are billions out there. But with especially with the, with the pump, it's they've really been doing a lot. And they've been putting out pumps for 15, 20 years. So there's quite a lot of models, but a lot of them don't work. Now there's maybe mine is about as old as you can kind of go back. But just picture like, could you actually picture using a cell phone that's five years old? Probably not, right? Or you'd have some struggles. So it's, it's it's kind of one of those questions. It's just keep getting better with more features, and more this and more glitz and more glamour, but they're just missing the accessibility and the Universal Design mark.

L Lis Malone 28:53

Do any of them have in the interim as they're hopefully developing a more accessible type of pump? Do any of them have accessibility helplines, at least so that you have someone within the company that can maybe walk you through or guide you, at least as kind of putting a

the company that can maybe walk you through or guide you, at least as kind of putting a crappy BandAid on a big laceration, but at least some sort of support in any way?

R Ryan Hooey 29:19

They do. Unfortunately, it's not like FaceTime or anything. It's more so over the telephone, right? So I would still have to have someone with vision here with me. Because I mean, it only takes, you know, I'm supposed to press down four times I press it five, and I don't know where I am. And then there's no help there. And the last thing I wanted to do is be changing how much insulin I'm getting at three in the morning when I'm sleeping kind of thing instead of me just changing the time. But it's been very helpful. Like I said, I'm with Medtronic, and their helpline has been very, very helpful. It's just unfortunately, you still have to have sort of a sighted person present.

R Rob Mineault 29:57

So I mean, it sounds like like I mean, these pumps sound like they're, they're amazing technology. And it's really improved a lot of people's lives who live with diabetes, except for the fact that like, I'd be terrified. Like, if you have this device strapped to you that you really, you can't see. And you're just you're kind of, I mean, does that affect you? Like, are you ever like terrified or just hitting the wrong button or hitting it too many times or, and then you're just, you know, you're screwed?

R Ryan Hooey 30:29

I am. The thing that terrifies me most though, is that all of the, for my particular pump all of the tones are the same. So it could be telling me oh, you have low insulin, or your battery's low, or the temperature is too cold outside, you're walking around, you need to get inside your pumps too cold, all of them sound the same. So it's a guessing game. You know, like, you can kind of make an educated guess, oh, it's about day two and a half, I probably need to change my insulin. Whereas I haven't changed my battery in a month, because it's literally old school, you put in a double A battery. And that's, that's how you you, you kind of do it right? But it's just, I've had some close calls, there's been times where no one's available on FaceTime. I was traveling for work one time and I was alone in a hotel room and my pump started making noise. I'm like, Oh, my goodness, what? What's going on? I have no idea. Am I getting insulin? Am I not getting insulin? And that, you know, it's luckily I was okay. Fingers crossed, knock on wood. But you know, that wouldn't happen if there was just an app that could tell me or even the pump had some built in accessibility feature so that I knew what it was trying to tell me. Because it's not just going crazy for the fun of it, right? It's trying to tell me something.

R Rob Mineault 31:38

Well, and that's the really infuriating part is that I mean, that wouldn't even be a hard fix just making different chimes or alarms for different issues. Like that's, that's not at all are hard, designed feature to start building into the new generation.

R Ryan Hooey 31:55

No, absolutely. You're preaching to the choir, that's one of the strong recommendations we've made. Even if you make the app still give it an option of you know, hey, changing these features to even vibrate and vibrate and sound, so a person that is deaf would also be able to use the pump or hard of hearing.

S Steve Barclay 32:17

Yeah, and it's not like there aren't enough things that can go wrong in the system as it is like, you know, and when things go wrong, they can go wrong quickly. For my son's a type one diabetic, and you know, every now and then he'll he'll put on a pod, and it says it's operating. But it's not. So you've got to be, you've got to be very careful when you're using these things.

32:43

I've tried out the pod I'm curious, do you and uh, pardon me if I'm being too personal, but you fill a pod for him?

S Steve Barclay 32:52

No, no, he does it. He's sighted though.

R Ryan Hooey 32:54

So just watch him next time and picture someone without sight trying to stick the needle into that small little hole. It's impossible. Like I hate to say things are impossible. But it's impossible. I stabbed my fingers so many times, I couldn't even use it. I just I gave up. That's another design feature. Because that's not the only pump that has something similar to that where the hole is so tiny, that you can't use anything but a syringe like I even tried to use a, an insulin pen, but the needles weren't, I guess hard enough or, you know, strong enough to to make it through the rubber. So it's, it's, it's a really difficult thing to get in there.

R Rob Mineault 33:38

Are pumps sort of your only option? Like if you really didn't feel comfortable in using one of these pumps, and you're a diabetic could you just can you go the old school route school route these days and and just do needles?

R Ryan Hooey 33:53

Yes, absolutely, we should make that distinction because there are treatments out there where you can just take, you know, insulin injections, whether it's two, four or more times a day. Pumps are definitely not for everybody. But it's a continuous drip of insulin, just as in a non

diabetic, there's a continuous drip of insulin from their pay increase. So it's, it does for me, it's changed my life for the better. My sugars are not that they were out of control, but they're even in better control than they were before. The pump just makes it easy, right? And it gives you a little bit more freedom to eat what you want. You don't have to feel guilty about having that McDonald's once a week, whereas, you know, you kind of got to figure out some things when you're when you're doing the the insulin needle. So the way it kind of works is you usually do fast acting insulin when you're eating so let's say breakfast, I have to do insulin about maybe 20 minutes before I eat that only stays in my system for about three hours. So after that three hours let's see I get caught up in a workout and I don't eat lunch till three. There's no insulin in my system for almost five hours there, whereas the pump would be pumping me full of insulin and keeping, even though I'm not eating keeping me on a steady kind of less roller coaster ride for my sugars. So that's kind of the the benefit of a pump as opposed to just doing the the insulin injections. And I did them for years. Like I said, it's only been about 10 years that I've been on a pump. So I've been doing them for for years and years.

R Rob Mineault 35:31

And you're probably your body's not going through such a roller coaster ride with with a pump, because it's it's keeping everything level.

R Ryan Hooey 35:41

That's the idea. But like our discussion, right, you know, you can eat a piece of cake, you can eat the whole cake, there's some people that try to take advantage of it. And they think, you know, hey, I'm not a diabetic because I got a pump? Well, no, you're very much still a diabetic, you still gotta be a little bit careful as to what you're what you're ingesting.

R Rob Mineault 35:59

So could you talk to us a little bit about this idea of the hybrid closed loop system? And what what is that and what's the implications of of a pump like that?

R Ryan Hooey 36:12

Mine doesn't have it, right. So that's kind of a newer thing where I believe that's where you can have the continuous blood glucose monitor hooked up to your pump. So it says, oh, Ryan sugar is a little high, I need to automatically pump insulin to bring him down, there's the kind of called the correction factor. So for every, let's say, every point five that I'm over a certain sugar, it will pump me full of a little bit of insulin. Mine doesn't do that. Like I said, mine's a fancy insulin pen, I still have to test my blood sugar all the time and kind of adjust my my own insulin by myself kind of thing.

R Rob Mineault 36:53

So it sounds like it's it's a little more hands off in terms of it's just doing everything for the

person.

R Ryan Hooey 37:00

Yes and no, it's really great when you're you know, you're traveling, you might not have access to your pump, you're on a plane for you know, six hours or when you're asleep. I don't wake up at three in the morning just to randomly test my blood sugar. But if you have that closed loop system, it's continually doing it for you every, let's say five minutes or so. So it kind of keeps a much better I it's just the you know, the, the newer pumps are very expensive and very inaccessible. So it's, it's kind of I couldn't imagine trying to set that up by myself when I have a hard enough time setting this old school pump up by myself.

R Ryan Fleury 37:36

That was kind of my next question is, is that the reason you haven't upgraded to a newer technology or a newer pump because you're familiar with this one and you can kind of do what you need to do.

R Ryan Hooey 37:49

That's exactly it. So I have remembered how many buttons I need to press to get to sort of where I am right and if I feel uncomfortable with where I am I'll usually FaceTime someone and say hey, what does the what does my pump say? I mean not ideal but it's a pretty good backup plan if you need to, to know exactly what's on the screen of your pump. But that just having the to memorize everything and how to change my infusion said how to how to do that kind of thing. It's it's it took a long time that's for sure. I was very uncomfortable doing it for years but then I just had to take the reins one day and it has worked out for for better or for worse, knock on wood.

R Rob Mineault 38:33

Well and then you know even once we do you solve the accessibility issue with these pumps, it sounds like we still have the affordability factor to fight for as well. Because they obviously these devices just they need some funding behind them.

R Ryan Hooey 38:50

Yeah, and I really feel for those people that live outside of Ontario, where there might be lacking coverage or no coverage. And I know that it's different all around the world right? I don't want to say I've been told that I have to live in Ontario but if I were to move to a different province I would lose my funding for my pump and I don't think I could afford it. Right it's you're you're literally purchasing a used car at that price and it's you know, the I don't know if there's financing and stuff available but it's just they're really really expensive, great tool. It's just not a lot of people you know have $17,000 just laying around that yeah, let's go buy a pump today you know. impulse buy.

R Ryan Fleury 39:35

So Kat is that something that CNIB has been addressing with Health Canada or manufacturers across the country when it comes to funding?

K Kat Hamilton 39:45

So we've definitely been supportive of that, you know, for obvious reasons, but thankfully, no the the diabetes organizations like JDRF and Diabetes Canada have really been kind of leading the charge on that. And they've also in turn been really supportive of the accessible insulin pump campaigns. So, for that one, we we let the Diabetes heavy hitters lead the way and we tend to support them on that, and especially as some legislation just went through, um, in the last year or so that was I think it's called something like a framework for a National Diabetes Act. And hopefully, that federal legislation is going to address some of these, you know, really big inequities that we have across Canada right now.

R Rob Mineault 40:39

So how is the campaign going?

R Ryan Hooey 40:41

It's definitely a marathon, not a sprint. I think we're are making good progress. But I mean, I say that as you know, what I'm hoping in my lifetime, we see some changes, right? Because it's something that I thought was easy, but there's a lot of red tape and behind the scenes stuff that I wasn't privy to, right, I thought it was a let's just make an app and do Okay, here you go, right. I mean, 14 year old make apps, right, and put them on the Google Play Store and stuff. So I thought it was a little bit easier. But I'm hoping that our voices are being heard. And I'm hoping that they see the need, because it's not I mean, as much as I'm griping about it, I'm not the only one. I know there's many, many people out there that would benefit, even people that don't classify as a CNIB clients or someone with vision loss. Maybe they're just a senior citizen, and they wear glasses. I mean, there's got to be some, you know, features that can help them to right, when you look at universally designing this, don't design it after with accessibility in the background, design it upfront with options that you know, that are available, like maybe they're just running in the background, and nobody ever knows. Like, people use my cell phone and they don't know that there's Voiceover that I can turn off and on until you have to go and use that right. Just as an example. I mean, let's let's get going with with that kind of stuff. And then we'll be talking.

K Kat Hamilton 42:06

I think back to like where we were even a couple of years ago, and I'm sure a lot of people listening to this, who are diabetics with sight loss who have been, you know, telling the companies for years, this is an issue. And even when CNIB first started on this, we were reaching out to the manufacturers and trying to even just get an initial meeting, and we

weren't really getting any response at all. And then fast forward to now, as Ryan was saying, working with different manufacturers, and even them reaching out to the community and asking people to sign an NDA and bringing them into the design process and consulting with people who are blind or partially sighted, like, to me that is, in itself already. Just, we've come so far, and I just really want to continue to build that pressure, and especially in the US that they're also doing a really great job with the FDA and different levels of the US government trying to fight this fight there as well. So, as Ryan said, it's definitely not one of those one and done quick campaigns. But I definitely feel optimistic for the future for this campaign, for sure.

R Ryan Hooey 43:30

Yeah, and it's interesting, because, you know, we're talking about, you know, this is a big step. And I think it is that the conversation is actually happening because at the start, we were sending emails and we were thought they were just getting lost in cyberspace, or, you know, we're being ignored, but now we're receiving the emails. So it's, it's kind of come full circle, and we just gotta hope that we can capitalize on this sort of growth and and hopefully just keep it going. Whether you know, any progress, you know, even if it's like point 1%, getting to that 100% accessibility, any little percentage point is favorable my books as we move closer.

R Rob Mineault 44:09

Well, where can people find out more information if they want to learn more about the campaign, or just about accessible insulin pumps in general?

K Kat Hamilton 44:16

Well, I would suggest just going to the CNIB website, or if you Google "CNIB accessible insulin pumps", then it will take you directly to our accessible insulin pump campaign webpage. It has videos of people's testimonials and explanation of the issue and, and ways that people can get involved. So it's all on the CNIB website. I just don't have a nifty URL that I can give people that is super memorable right now. So the best way is google it.

R Rob Mineault 44:52

We will link to the page for sure in our show notes as well. So people can just check the Show Notes.

K Kat Hamilton 44:57

Yeah, I guess the only thing just thinking a technology that we haven't maybe touched on, and it's really early days right now, but there is a company out in the US. And it's, it's actually owned by a blind entrepreneur who has diabetes. And he is working with different engineers across the world to develop the prototype for the first insulin pump that's accessible. I guess going back to the earlier conversation, you know, apps are great for many people, you know, who loves their phones and a tech savvy, but there's still a lot of people out there that don't

want to use a smartphone or can't afford to, or whatever the reason is, and I think that's also really exciting to see where that goes. They're in the process of, of getting FDA approval right now. But as we all know, what happens in the US Canada, hopefully isn't too far behind. So we might even see something like that in the near future, coming to Health Canada, which, which would be really cool.

R Rob Mineault 46:13

Yeah, well, absolutely. And you're absolutely right. I mean, apps, I think, I think going the app route would be the easy solution. But it's not necessarily the best one. Because at the end of the day, you're absolutely right. Some people, some seniors, you know, don't don't have a smartphone, or he can't afford a smartphone or their smartphone is older. And they might have trouble running the app. I mean, there's all kinds of issues. When you're relying on an app and same thing, you know, you lose your your internet connection on your phone. There's all kinds of things that can sort of go south on you, when you're relying on an app, especially when it's when it's about accessibility.

R Ryan Fleury 46:48

Keep in mind, too. It's only been in the last couple of years that Apple came out with all the health centers in their Apple Watch. Right? So how long was that in development before it was released to the public? And how long did the approvals take to, you know, meet the different restrictions around the world. So I can understand this taking some time. And now that Apple is shown that you can use sensors to do certain types of things. It shouldn't be much of a push. And it sounds like the conversation has been started. So sounds like there's hope.

R Ryan Hooey 47:18

There's also we're hoping for Yeah, and like you said, Apple with their sensors. I mean, everybody, nobody wants to be first everybody wants to be a quick second in the technology game kind of thing. Right? So it's, it's just a matter of time, like we've been touched on before. Oh, there's going to be a pump company that does this with an app or this or that. And you know what, everybody will follow suit, kind of thing.

R Rob Mineault 47:41

Well, listen, Ryan and Kat, thank you so much for joining us today and talking about this. I hope to have you guys back to discuss the world's first accessible insulin pump.

R Ryan Hooey 47:55

Thanks so much for having us. And thanks for giving us the platform. I hope all of your listeners enjoy. And special thanks to I believe you said her name was bad for recommending us. I had a great time chatting with you guys.

S Steve Barclay 48:07

Excellent. Well, you know, if you have other stuff that comes up in your in your careers here that needs to be shared. Do keep us in mind. We have at least four or five people listening.

R Rob Mineault 48:21

Alright guys, well, listen, have a great night. And like I said, we'll stay in touch. Have a good evening. Thanks.

L Lis Malone 48:29

Thank you.

R Rob Mineault 48:31

I tell you guys, I'm really, really shocked at this. I'm with Steve, I just cannot believe that that this has not been addressed. After how many years have these pumps been around?

S Steve Barclay 48:45

Yeah, yeah. It's it's bizarre, particularly given that stat that, you know, it's the leading cause of vision loss for working age adults in the States. You think there's a huge market there that would be demanding it, but apparently not,

L Lis Malone 49:00

it really stinks because it's going to take somebody who, who lives with diabetes, who's a prominent figure, who's going to have to put some PR muscle behind the cause? That that's usually what it takes to get some real widespread attention. Unfortunately, yeah.

R Rob Mineault 49:24

Oh, absolutely. Although I think that CNIB is doing, doing it, right. Because, you know, having these campaigns and gaining visibility and educating people about these issues, is, I think half the battle. I mean, hey, just look at us. I mean, we're pretty dialed into accessibility issues, and, you know, the disability community. And I had no idea that this was this was a thing. You know, and I don't think any of us did, it took a listener to email us and ask us to cover this, to really, to really learn about it. So I think that that's really one of the big keys here is that, you know, there just needs to be a real, a real hard education campaign learn about what the lived experience is like for these people who are, are living, you know, trying to deal with these insulin pumps when they're blind or partially sighted.

L Lis Malone 50:15

Well, and also, the point that was made during during the interview about how it's unfortunate that it's just the marketing people that seem to come to these meetings, and it's not the end of the design engineers. And it's the truth be told, it's the marketing people, the salespeople who are going to have to kind of create a dollars and cents justification on how much it's going to cost. And, you know, what the development will be? And how many more pumps will they sell, and, you know, blah, blah, blah. So, I mean, it really does come down to the that marketing and business side to really constitute some sort of corporate change, or, you know, manufacturing change.

R Rob Mineault 51:00

Yeah, well, I mean, and that's why it can be challenging, I'm sure going after the manufacturers, because at the end of the day, as much as we'd like to think they want to do the right thing, really, they want to do the thing that is gonna make them money or continue to make some money. So it's, you know, those are hard sells, you know, nobody's going to completely redesign their device in order to make it accessible, and take, you know, two or three years of development in order to do that and cost their company, how many 1000s of dollars to do that, just because it's the right thing. I think at the end of the day, really what what needs to happen is that it they need to be mandated. In order to be approved, there has to be a certain level of accessibility built into these devices, or they just don't get approved,

L Lis Malone 51:52

Ryan Fleury is all depressed now he doesn't he doesn't even want to eat any McDonald's.

R Ryan Fleury 51:56

No

S Steve Barclay 51:57

I don't think he can get that depressed

R Ryan Fleury 52:01

No, it would take a lot to drive me that far down.

R Rob Mineault 52:05

I listen, if I was McDonald's, I would just make like, once you just make cheeseburgers like with insulin in them. So the insulin burger or something? Like I don't know, can that be a thing? Self-regulating burger? Yeah, there you go. That low carb burger. Yeah, I want my pizza with

regulating burger? Yeah, there you go. That low carb burger. Yeah. I want my pizza with pepperoni, mushrooms, green peppers and insulin, please.

L Lis Malone 52:31

I want my my insulin like a dipping sauce. Yeah, you know, and it's again, I know, we're we're kind of saying the same thing over and over again. But it what, what pisses me off about this is that I feel like they they would not want to make this improvement to help those in the blind and low vision community. I think that if they realize that, well, this would be a really snazzy thing for everybody else to use, kind of like how, you know, we've talked about this on the on the program, how things that were designed for accessibility are now becoming mainstream features that able bodied people love and, you know, like the, you know, voice commands and things, things, things of that nature. So, yeah, I think if people if people who, who use the device, whether they're, you know, just like we were talking about the universal design, say, Yeah, you know, I want to be able, I, this has to have Bluetooth, or this has to have, you know, this functionality, or I don't want to have to keep looking down it because I'm multitasking, I want to just be able to, like, you know, feel the haptics going off and, and whatnot. So it almost has to be a demand of the the actual device and technology being better for lives in general, and not just the low vision community.

R Rob Mineault 53:58

Yeah, it's very true. It's sad, but true. But I often also wonder, like, I feel like maybe sort of the push back against the idea of an app. I wonder if that has a lot to do with them being a little bit nervous about an app driving something like and I think that that's that's why Ryan was saying that, you know, you can you can do a lot of monitoring with an app, but you can't actually deliver insulin using the app. And I'm sure that that's because there's just there's there's too many there's security concerns. There's if the app glitches out like they don't want to be responsible for for actually injuring somebody fairly badly, by like, you know, a mistake or the app that you wrote, or somebody hacking into their to an app like it just it seems to me like there's just too many variables there.

L Lis Malone 54:50

Because it's so much better for somebody to just click a button too many times and give themselves too much insulin that way. That's a much better way.

R Ryan Fleury 54:59

Early on in the conversationthey said that these manufacturers don't even suggest people who are blind use their devices, for liability sakes. That's ridiculous. That's what really got me to because of the fact that it's the leading cause of blindness in the US like that's, it's it's not like this is something that's not really connected to that community.

R Rob Mineault 55:24

It's literally connected like, it just it blows my mind.

R Ryan Fleury 55:31

Yeah, somebody's research is falling down somewhere. Yeah. The numbers are out there.

R Rob Mineault 55:37

Well, I can't imagine that the numbers are any surprised them. I think they know, I think that just for a long time, they've gotten a pass on this. And you know, what, the technology, the accessibility technology has gotten to a point where I'm sorry, but no digital device out there has the excuse of, oh, well, we can't really make it accessible because reasons. Like that just doesn't fly anymore. Yeah, you absolutely could make it accessible if if you design it from the ground up with that intent. So yep. So obviously, we just need to go mainstream. Like if we had like a whiskey pump that people could just like plug in and just delivers like little trace amounts of whiskey just keep them buzzed all day. Maybe then we could get some traction.

R Ryan Fleury 56:27

We could guess probably exists.

L Lis Malone 56:29

Need a couple extra pumps already.

R Ryan Fleury 56:32

Steve we know because you're on and off the wagon all the time.

L Lis Malone 56:37

We'd have to we have to set yours like a morphine drip. Or it doesn't matter how times clean it goes. Steve clicks it. It only is gonna give them so much whiskey.

R Rob Mineault 56:45

You know what, then Steve? You could hook that up to that siren that you have that goes off whenever the Canucks get a goal.

R Ryan Fleury 56:55

You get a shot when they score. He's thinking now

You get a shot when they score. He's thinking now.

R Rob Mineault 57:10

Do it yourself.

R Ryan Fleury 57:12

Mike, let me re re engineer your pump.

S Steve Barclay 57:19

Can I have the old one you're not using?

R Ryan Fleury 57:23

Where's the schematics for this thing?

R Rob Mineault 57:25

Whiskey right into the bloodstream. Bypass the stomach altogether. All right. Wow. All right. Well, let's get out of here. Yes. Oh, yes. Oh, hey, you know what, before we go, I wanted to bring up while Ryan actually wanted to bring this up. Ryan once you go ahead and and and talk about it.

R Ryan Fleury 57:47

So because this show is going to be dropped on April 13, I want to remind people about the fundraising concert that is happening for the persons with disabilities in the Ukraine happening on April 16. The We're With U concert. Check out all the information when it airs in your timezone and where you can hear it go to mushroomfm.com

R Rob Mineault 58:14

When is the when is the date of the concert?

R Ryan Fleury 58:17

Next Saturday, April 16th. Starting at 11am Pacific anyway. And they don't know exactly how long it's gonna go for. But currently they're saying some hours.

R Rob Mineault 58:28
That's so cool. Yeah, did you hear anything back? Because now you submitted a song did you?

R Ryan Fleury 58:34
Yeah, it's gonna be aired.

R Rob Mineault 58:36
Oh, really? Wow. Whoa, do you know a time? No. Oh, man. I gotta listen to everything.

L Lis Malone 58:43
Listen for some hours

R Ryan Fleury 58:46
Yeah, yeah, yeah. The deadline to submit. We'd have to check the date again. But there is a deadline to submit your musical performances if you want it aired for the concert. Certainly, we can link to that in the show notes. But yeah, all the details are on mushroomfm.com

R Rob Mineault 59:03
Excellent. All right. Hey, Lis.

L Lis Malone 59:09
Yes, Rob?

R Rob Mineault 59:12
Where can people find us

L Lis Malone 59:15
We can be found on the web at atbanter.com

S Steve Barclay 59:24
Random cowbell.com

R Rob Mineault 59:30
You're trying to start a new thing. Incidentally, I cannot wait for Lis's audiobook so stay tuned for that coming coming next year

R Ryan Fleury 59:45
Hairy Balls with Lis Malone.

S Steve Barclay 59:51
I really did miss something early on.

R Rob Mineault 59:55
You did

L Lis Malone 59:58
Ryan's already doing the book trailers Thank you.

R Rob Mineault 1:00:02
Seriously man

R Ryan Fleury 1:00:06
Itchy Balls by Lis Malone

R Rob Mineault 1:00:11
See this is what happens when you encourage us

R Ryan Fleury 1:00:19
Three different anifungual treatments for balls

L Lis Malone 1:00:25

Lis Malone 1:00:25
I gotta say, Ryan knows a lot about ball dysfunction

R Ryan Fleury 1:00:39
well that's book 4

R Rob Mineault 1:00:56
Ok

L Lis Malone 1:00:57
You started it Rob.

R Rob Mineault 1:00:58
I know. I know. I did. I did. I just I thought the sensitivity training would pay off but it clearly has not.

L Lis Malone 1:01:04
Apparently not.

R Ryan Fleury 1:01:06
Rob the instigator. Right?

S Steve Barclay 1:01:10
You got quite the Library going there, Ryan

R Rob Mineault 1:01:16
Where were we? Okay, what do we get? Oh, hey, they can also drop us an email if they so desire at cowbell@atbanter.com

S Steve Barclay 1:01:28
Or here and they can get us on social media. We are on Facebook and Twitter.

R Rob Mineault 1:01:34

All right. Beauty. All right. Is that it? Are we done? Yeah, we're done. Right. That's it. We're done. Thanks, everybody for listening in. Big thanks, of course to Ryan and Kat for joining us. And we will see everybody next week.