POTS: A Personal Path To Autonomic Solutions Transcript

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Introduction and guest background

Hello and welcome back to our reversing mast cell activation syndrome and histamine Intolerance Summit. I'm your host, Dr. Meg Mill And today I'm joined by my esteemed colleague, Dr. Diana Driscoll.

She is an optometrist and an authority on the autonomic nervous system, plus an expert on pots And a lot of people that suffer from mast cell activation syndrome can also suffer from pots So I'm excited to bring this to you and really get into some of the dynamics behind it and how she treats this.

Hi, Dr. Driscoll, thank you so much for joining us today. Thank you for having me, Dr. Mill and I appreciate it so much. I'm very honored to be here. Well, I am so excited to get into this.

And we're going to start here by talking about the nerves and Marcel. And I think this is going to be really exciting. We're going to get into some new things that we haven't heard yet in the summit.

So let's just start by talking about actually before we dive in, I'd love to hear just your story and how you really got into this work and where you are today, right?

I wish I could say, you know, I've always, always wanted to get an answer for this, but that is not true. I got thrown into this. I mean, I was an optometrist by trade and got a virus when I went overseas at a mission trip, and a couple weeks after that, I started to show weird symptoms and went downhill and started with weird heart rate.

Blood pressure was out of control. My digestion started to be affected. I felt like I was hot and cold and my moods were totally going haywire and my blood pressure was out of control, up, down, all over the place.

And that started a long journey to a diagnosis of Pots postural orthostatic tachycardia syndrome. And then my kids were sick about a year later and no one could help.

That traditional treatment for that was not helping. We were getting worse. Every year. I was disabled by it. My son was disabled. He, missed over three years of school and then his growth start to start wasting away.

Developed severe osteoporosis. He broke an arm. Just throwing a ball, just putting on his coat is so fragile and no one could help that. So it was one of the most frustrating learnings.

And I put, our case into the hands of the experts. We were in clinical trials for Pots for three years, and their conclusion was that our Pots patients are perfectly normal.

They're just more aware of their own body that you've got to be kidding me.

What POTS is and why the label falls short

So I had well, we're in we're on our own here. Let's go ahead and dive in that if anybody has a chance to figure it out, it could be a doctor. He's in the body of a patient and I had kids affected.

Let's get to work on this. It was extraordinarily long journey, but I was thrown into it against my will, fortunately got answers. And now I'm helping others. So.

Yeah. Yes. Well, isn't that often the case with so many of us? It's often our own personal journeys that. Give us a. Passion really, to do the research and find out the answers.

Because we know, and I hear that too. Like so often, people come to me after they've been told, oh, you're fine, I'm

going to use air quotes, you're fine.

And you're like, no, I know I'm not fine. I'm reacting to everything. There's so many things going on and and it's frustrating. So we're so thankful. Yeah.

Yeah. Looking and giving us some answers here. Now before we dive into some of these other connections, can you actually just tell us what pots. It's because maybe not everyone knows.

Yeah, absolutely. There's a little bit more information out there now because that 10 to 14% is what they're saying and because Covid patients are developing it.

So now we're hearing a little bit more in the news, etc.. But Pots stands for postural orthostatic tachycardia syndrome, meaning when the patient's vertical their heart starts to race.

And to me that label is a bit of a problem because it implies in most people's minds it's a heart problem. And patients are sent to cardiologist because their hearts are acting up.

And then the cardiologist check out the patient saying the heart looks okay. Structurally everything's great. You know, it just goes really fast when you're vertical.

But Pots doesn't say anything about why that's happening in each case. So I think it's really set us back. both practitioners and patients in getting the answers we need.

And cardiologists don't know what to do. So a very, very difficult situation. Yes. So you are some one of the ways that you work on this is through the nervous system.

So if we could dive into that a little bit. Yeah. It's interesting because if you look at Pots so there's a fair amount of information out there that says it's a disorder involving the autonomic nervous system, the system of the body that you don't have to think about.

It works all by itself, right? Your blood pressure, your heart rate tier production, etc.. Digestion. You don't have to make yourself digest.

Inflammation, the autonomic nervous system, and mast cell activation

You don't have to make yourself create tears. Instead, we found that's probably incorrect. Okay, it can appear that way because those systems fail, but they're failing for other reasons.

And until we identify that and if if thoughts persist that it's an autonomic nervous system disorder, we're never going to have these patients. So again, very frustrating where we're stuck with that diagnosis and stuck with that belief.

But instead we found that the majority of patients we see once we screen out for quite a few things, like heart problems, for example, is that they're inflammatory patients of some sort or other, and that inflammation is causing damage and the immune systems are affected.

The immune system does affect the autonomic nervous system. So to be treated as a nervous system, probably you don't get there. If you can back up and figure out where that's coming from, you have a chance to normalize that.

Yeah. Yeah. That's so powerful. Now, we know that a lot of people with mast cell activation will develop Pots. There can be a common connection between the two of them.

So I know you've talked about different nerves. So that helps different things. So what nerve helps control abnormal or creates this abnormal mast cell activation. Yes.

And I think that's such a good point that you mentioned Dr. Mill because mast cell activation syndrome something is activating those mast cells. So even when you have that diagnosis you don't have your underlying problem unnecessarily.

Right. The problem is still what is activating the mast cells. And that's likely where your answers are in the body set up supposedly perfectly. Of course we know there's no perfect, right?

Unfortunately. But the body is set up to help control abnormal inflammation. And the nerve that does that is the vagus nerve. And that was figured out, gosh, in the early 90s or so, which is great.

but when something goes wrong with that system, if you're prone to abnormal inflammation, let's say you have a genetic disorder that you can't regulate it properly.

You see a fair number of those, or you have some autoimmune condition that fails in certain areas of inflammation, what have you. There can be a lot of reasons that inflammation can take off and do damage, and then that damage causes more inflammation.

The vagus nerve would normally help with that. Sometimes it can get overridden by those issues, and it has to be identified and then triggered and make sure that nerve is still working and patients can recover.

That's okay. So how do you begin to identify abnormal neurology when it comes to your patients with Pots or MCAS. Right. And we're really careful here because we see everything here okay.

But when a patient or a doctor suspects pots and they call us, the first thing we do is make sure it's not a heart problem. Right? A cardiologist does need to rule that out.

And assuming the structure of the heart is good, we also want to make sure it's not a neurodegenerative condition, okay? Because those patients can also display as pots.

And then it quickly morphs into other things like mast cell control goes wacky.

Vagus nerve dysfunction and receptor-based treatment

And but you can't afford to miss says we had one patient who, the doctor said it looked like pots. Her heart rate would go up when she was vertical, but she didn't fit this pattern that we we usually see. And, instead, it was an autoimmune condition that initially affected neurology, but it ultimately caused and supplied as they killed her.

So had that gotten messed? and she'd gone down a routine past treatment, it would have just been something I could not have lived with. So it's important to screen that screen this out.

But inflammation does affect the immune system, right? And then the immune system does tie into, nervous system. So for example, one big thing we discovered was certain aspects of inflammation certain cytokines and chemokines can block the release of acetylcholine at the side of the vagus nerve and other parasympathetic nervous, nerves, and ultimately causes organs to start to fail when that's identified properly.

If it's treated as a neurological condition, you can't get it going. You've got to treat the inflammation that's keeping that nerve from working, and it can come back. So, And you and I were talking before we actually got online and we I am so interested to share this.

So you are saying that patients actually, that don't need to stimulate their vagus nerve. So let's talk because I know we have a lot of people talking about vagus nerve stimulation, and I. Think I've seen it.

yeah. Yeah. And this goes back many years. So, did the research has been almost ten years ago or about ten years ago, I guess. And it just happened. And I was a patient. Right.

And got to the point that it looked like the vagus nerve wasn't working. When I did have runaway inflammation, we could do blood work and see that. But to my GI tracts shut down and my gallbladder stopped working.

They said, we want to take it out. And I said, well, is it infected? You know, an appendix or something? And I said, no, okay. Is it, fibrotic? Is it scarred?

Is it brown and shriveled up, or is that opening blocked? And that. No, it looks okay under imaging, but the ejection fraction was something like 8%. Because it is it's not working.

So, you know, that sounds like the organ itself is okay. I said, if I can figure this out, if it's neurological, is it possible that the organ is just sitting there just waiting for, a signal?

You know, tell me when you need me. I'm right here. Yeah, and it's not getting that signal. And if I could figure that out, maybe I could say that organ.

So I ended up testing the receptor of the vagus nerve for both my son and I. I couldn't have a bowel movement. It'd been two weeks. I couldn't do it. They tried everything with me.

I was in the emergency room. I saw surgeons, everything. And I used the agonist or substitute for the neurotransmitter to see if it would land on the receptor and stimulate a bowel movement.

So the agonist for acetylcholine at the side of the vagus nerve. And I was thinking this there, that oh that's easy. That's nicotine. The vagus nerve is the only nicotinic acetylcholine nerve in the body.

So I took a, nicotine patch and I put it over the side of where the valve was earlier. So now that we suspect it was closed and it worked almost immediately, I had a bowel movement.

An hour and a half later. I used it again the next day, bowel movement next day. The next day. But nicotine is very inflammatory and I couldn't stay with that after about four days.

But I knew the receptors were working fine no matter what was getting to the nerve, and figured that out. Yet, involved other patients and did some trials.

The receptors always were. So then I worked at okay, if this is more systemic than just the vagus nerve, is it affecting pupil size tear production? And both of those were affected.

Pupils tended to be bigger, eyes tended to be drier and cognition and wakefulness was going down. Thought I'd love to figure out an oral supplement that would come together just like nicotine did, and land on the receptors.

Make the nerve work and have no nicotine to activate inflammation. And that was years in the making. And that's where Parecen Plus came. And it's received right back together.

Our fifth patent now on it. And then the chronic dry eyes were resolving. pupils go smaller within a day or two, wakefulness improved etc.. So, we didn't have to stimulate the nerve.

That nerve is autonomic. You shouldn't have to make it work if it isn't working. There's a reason for that. And you kind of need to know the reason or just use the receptors.

So we didn't know the reason for every case. We didn't know if the nerve was damaged, which can happen. It's such a long nerve. It's very easy to damage it.

if, say, there was compression, I was looking at the neck. Is there compression at the brainstem? Is it nicked for any reason? It didn't matter. The receptors worked great.

So we can still use those receptors. And, unfortunately, we don't want to ever blame the patient for their illness.

And I've seen that before where someone would try to make their nerve were.

And it's not helping. And then I hear practitioners say you're just not trying hard enough, or maybe you're not doing it right. And it wasn't the problem.

So neurotransmitters not getting released. We use the receptors. It works great. Yeah. Wow. And were you able to save your gallbladder. I was yeah. Well good I was I mean it was immediate right.

And I remember the doctor saying well you can live without a gallbladder. Oh you're right, except I put cheese on everything. You know, I love cheese.

And I went through a time where I know you in the audience is very familiar with. I just got so incredibly sensitive. I was sensitive to anything. Food, spices, chemicals, scents, stress.

I'm just a ball of sensitivity. And I almost couldn't tolerate any food. So by the time I started to work through that, I wanted to expand my diet. I didn't want them to limit me if I was going to be able to get back to normal diet and put cheese on everything again.

So it was a great thing, Bill, save that organ. But it was even more important to move past red and become complete gastroparesis. nothing was working and the pancreas wasn't working.

Developed pancreatitis. At one time, stomach acid production went way down and eventually I started to lose weight. At first I wasn't losing weight, but I was showing neurological symptoms of malabsorption.

And then later I did start to lose weight. My son certainly did. It got so bad. At one point, Doctor Miller was hallucinating and the doctors had no idea what was going on.

That nerve wasn't working well, so not only did digestion suffer a great deal, malabsorption occurred, but I couldn't control any of this information.

Yeah, yeah. So getting that back to work was hugely helpful. Yes. Yeah. That's wonderful. So we're going to take a quick break here and then we'll get a little more into the pairs.

And plus and what you where we start with treatments and all of that. But I hope everyone is finding this interview helpful on their health journey. And if you are a summit purchaser, stay right here.

Because we're about to dive even deeper with Doctor Driscoll. And if you're not, you can actually push the button on this page to purchase this interview and the entire summit.

Hope you have a great day, and thank you for joining us.

Prescreening, diagnostics, and root-cause evaluation

If you're still watching this interview, then I thank you for being a valuable member of our community. So let's talk a little bit because you mentioned the pair of them.

So when is that something you I guess actually before I want to get into that. But before we get into that, let's even take one step back and someone comes in to your office.

They're a new person, they're listening, and they have pods. They've been diagnosed. I think they do. Where do they start? that we prescreen the patient.

So because it is easy to either misdiagnose or miss something that shouldn't be treated as typical pods. So and we look at the cardiology records, we make sure they move past that.

And then we start with over 200 signs and symptoms. Then we look at the previous records because something's going next. We want to figure out what has been determined, what has been ruled out and what hasn't been explored yet.

And then bloodwork is really important. We're going to dig deep and we look into many aspects of information, and that's us. One, it's not the only one, but certainly that's included.

And then we'd like to look at a brain MRI. And where I got started to get some answers initially was my very first study was to look into the eyes. So we did get fundus photos and visual fields.

And we've seen a propensity to get abnormal intracranial pressure, a propensity for certain types of cardiovascular inflammation. And looking in the eyes is oftentimes a clue.

So I still enjoy that part of it too. And then we dig deep and figure out what's going on to drive some of this, and then what kind of dominance of ball.

And from it, how can we lay out a plan to start to crack some of that and get the patients online passports, which is certainly doable, but getting to the point of managing whatever it is that got them to this point so that they're not sick people again, and if something else came along and kicked up their inflammation, they don't have to start over.

Right. That was a really bad fear I had for a long time. I just felt real tentative with my own recovery and how would I know that the next virus that came along wouldn't set me up again for failure.

But you get comfortable with what you're doing and get your health back and very active, and then you no longer feel that fragility again. But that's what we do here is guide people through that in every case.

Yeah, that is a really good point because I think when you have something like pots, when you're having something like a mast cell activation, you feel your body is sometimes against you.

And so that idea of, okay, even as I'm the fear of trusting the healing process, one like that, you actually can get better when you haven't been feeling well for so long.

And then I know that you aren't going to go back down. So I do appreciate how you're saying, okay, what if you get the next virus? What if something else comes up that just puts you right back into this?

So education is key. Like empowerment, education is also a piece of this. You are exactly right. And I know when my kids were sick and they were in recovery and then they went on, they went to college and did great, by the way, totally healthy.

I wanted to make sure they had that education because I wanted them to feel empowered that they got it. They know what they're doing with their body. They don't have to rely on me or anybody else.

And that works so well. And we see patients from all over the world. I don't want them to feel like they're dependent upon us and figure things out. So education is really important.

And you had mentioned something. I think it's important to just put this out there that most inflammatory patients are highly anxious. we get that way because some of the oxidase syndrome, the inflammation in some of the the vascular problems affect the brain.

But we're afraid of our own shadow. And some patients can develop such high anxiety, they can be afraid of either the testing or the very medicine medicine that can pull them out of it.

And it's a horrifying place to be. But we've seen everything from agoraphobia, you know, where they're afraid to leave their homes. they're unable to speak on a phone call, something like that.

It's just highly anxious. And I think to many doctors or practitioners on the outside, seeing that it looks like a psychiatric condition, it is not. It is the effects of that inflammation.

Had I not gone through every single symptom like that, I would have never believed that was possible. And then I would have never believed to be possible.

Pull out of that. yeah. Yeah, I got to get rid of that stigma. when we're dealing with anxiety, depression, it's a psychiatry habit. It's oftentimes organic.

Yes, I agree, and when you're working on both finding those root causes, along with really calming the nervous system down and all of those things. Yeah.

Whether it's when I finally start to feel some relief and, you know, it's all tied in together. And getting that balance back again, I mean, it felt like for years I was just flooded with adrenaline.

I couldn't handle any stimulation. I couldn't handle any stress.

Anxiety, education, and recovery mindset

I was in a dark room and I carries I had earplugs. Anyone who came in the room had to whisper, you know, I remember hearing something slightly negative, like other even bad weather.

No, can't hear it. You know, I couldn't handle anything. I couldn't make a phone call. I couldn't call for a pizza. I just couldn't do it to be cripple like that into Back to Normal life is an amazing journey.

But I know the doctors kept saying it sounds like anxiety. That's what they were thinking. It sounds like a psychiatric note when it was it. And part of me was just as hard headed, didn't I?

Didn't I knew not that I had not to go there. I did not have psychiatric conditions suddenly brought on from a virus. You know, I was nearly 50 years old and I got sick.

That just wasn't it. Yeah. but I thought if I had been, like a 13 year old girl or something, going through that and being told that, would that have just gone so deep into my soul?

I think I'm just crazy person, you know? That's just me. I'm always going to be this way. Maybe I didn't, but I I'm afraid for this. People. Yes. And it's just good to listen to this and see that there's hope.

Because when you know that you can turn things around, you can feel better. You're not going to have to react to everything for, for your life. And, and I think that that is just having that knowledge and belief is part of the journey too.

Yeah. And we do that every day. But it is us. And not only to give the patients their lives back, but the family there lives there too, because as you know, and one person's deeply affected, everyone around them is affected and their lives revolve around the illness and that it doesn't have to be that way.

So I was given a second chance. I would have never dreamed that was possible in the thick of illness. and others should never lose hope that they may not have all of their answers yet, but their answers are out there.

I guess. Hang in. Don't give up that hope. I'm sick. Yes. Thank you. Well, let's talk a little bit about your your pair of them plus. So when do you and then kind of what does that do for the patient.

You know what we look at is we exaggerate it look at symptoms of anticholinergic syndrome or anticholinergic poisoning. And that's where you ingest a poison and it breaks down acetylcholine and certain symptoms evolve.

And doctors in the E. R. eye doctors are trained to recognize that, like eye doctors, we prescribe anticholinergics.

They dilate the pupil. So we're trained to recognize that.

But what I did over about five years when I sent out symptom checklists for patients with, pod's EDS, Ehlers-Danlos syndrome, massive activation, fibro myalgia, and, interestingly, PTSD.

There's some autonomic signs there. And in these hundreds of symptoms, I tucked in 38 symptoms of anticholinergic poisoning. And the vast majority of patients showed the majority of symptoms they would come and go to some degree.

but you could clearly see there was a tendency for constipation, gastroparesis, gallbladder problems, poor digestion, malabsorption, fast heart rate flushing, dry eyes, large pupils, brain fog, cognition problems.

And that showed the picture. And then testing the receptors of the vagus nerve and nicotine. Tell me this was an acetylcholine problem.

Parasym Plus, ocular support, and where to find Dr. Driscoll

and the Pearson price that first came out almost ten years ago, again, just puts everything together, not only to increase the choline, but to retain it there at the nerve site, to cross the blood brain barrier to boost cognition for this.

So declining and it also importantly, it covers any genetic disorder in the acetylcholine pathway. When I was first researching this, I thought, okay, this is a genetic problem I'm in.

I'm affected. My kids are affected. What are the chances genes are not involved? And then is it a problem with acetylcholine? Now I don't want people to have to know their genes to know whether or not this will help.

Let me just examine all of this and put something in the supplement that'll cover for that. And there and then the amounts of the ingredients are important.

Two of the ingredients would work against each other if they weren't balanced out. Then one of the ingredients, very importantly, can actually start to shut down this cooling receptors.

it adapts, if you will. And we couldn't afford for that to happen. You'd need more and more. So it was years of work but delighted with the outcome. And even in patients with severe gastroparesis or on feeding tubes, we've had patients with half their intestines removed.

We'll just put it right into the feeding tube. Works great. Yeah. So get that nerve working again. It's not your fault that it's not working. It's likely an inflammatory state, but we don't have to get the information to zero in order to work around that.

Like, I'll always be an inflammatory patient. I'm not a sick person now, so there's differences and I'm not sensitive anymore. I think it's really important.

But I was for so long. Oh my goodness. But keep that nerve working. Get it working. Keep it working. You'll continue to feel better. It's important. Yes. And then you created a of some plus for the eyes too.

I did when I saw that the dry eyes were going away. I experienced that myself. That I really need to work on this Sunday. Okay, so much going on with pots care there.

But then finally I took a pause. I said, okay, how can I prove that this is affecting tear production? Like I was able to prove the receptors of this nerve work with nicotine and then what can I do to improve upon that?

what else could we do to help with the ocular component to it? So that took a few years to. But the big breakthrough really was in seeing when you, hit the correct receptor and into your production and pupil size.

It's not a nicotinic nerve. You can't use nicotine, okay? It's a muscarinic nerve. Totally different. And then I realized the muscarinic nerve for tear production is the same as the muscarinic nerve for pupil size.

So when I hit the muscarinic nerve, pupils got smaller, proving the tear production was improving. So that was a big moment for me. And, we knew it now that.

So we improved upon parasympathetic for people who are suffering more with the ocular component to it. Right. And I'm so proud of that too, and love to see some of the people that like when I was an eye doctor doing routine eye care, the people we couldn't really help, they we look and go, what are we missing?

They don't feel good. You know, their eyes are dry. They lean toward depression. They don't feel good. They forget their appointments. They're grumpy. What have you, yeah.

Their neurology is affected. It's a systemic disorder that's exhibiting with dry eyes. But if you ask the patient more symptoms, yes, they tend to like sluggish digestion or brain fog, more fatigue.

And if you can figure it out so well. Yes that's great. And you provided so much helpful information. Can you share where everyone can find you? Absolutely.

I'm at potscare.com parasym plus at TJ It's named for my kids. tjnutrition.com and we were about to release some more information soon here, so we're looking forward to that.

There's more coming. but these invisible illnesses in my lifetime, it is my passion to help change them from invisible to or just not looking in the right places.

And that's where I think your work doctor now, and some of the other people you're interviewing is so important. We've got to get word out to people that their answer is and more coming. And, hang in there because they don't have to stay stuck where they are.

Then thank you for helping to spread word and awareness for so many of these conditions. So, So yeah, well, thank you so much for joining us and the hope you've provided and the knowledge we really I appreciate it.

I'm so happy to do it. I appreciate you to thank you. Thank you. Have a great day everyone. Right.