Introduction and welcome

Through. Welcome, everyone, to the mast cell summit. I'm doctor Christine Schaffner, and I'm thrilled to have my dear friend and colleague, Doctor Diane Driscoll, on summit with us.

And we are going to talk all things, parts of the vagus nerve. And really the relationship of mast cell in this constellation of symptoms. So welcome, doctor, doctor school, it's really an honor to speak with you.

It's an honor to be here. It is so great to catch up. Yeah, it's been a while, so I just am always I always have learned so much from you. And I'm excited to pick your brain.

And, you know, I always love starting these interviews with sharing your story, I think. And many people who are listening out there haven't found answers, haven't found the right treatment.

And when you're in the throes of this illness, it can be really a range of emotions. And you don't always see the light at the end of the tunnel. So I would love for you to take your journey.

And, you know, look at, you know, obviously you're thriving in life. And I just want people to have a moment of hope here. Excellent. I think that's such a great message, too, because I remember the many years I was 12 years or so of disability.

I went through that. You do feel ultimately like it's hopeless. And, there is always an answer for illness. There's always a reason for it.

Diane Driscollu2019s illness journey

Just because doctors may not have found it yet, or even the patients haven't found it yet, doesn't mean it's not out there. So it could just be right around the corner.

So as everyone's working hard to figure out some of these, quote, invisible illnesses, I think it's really important to just remember to hold on to. That means can flip around quickly when you least expect it right?

As you know, I, developed, pots secondary to a virus, and it was on a mission trip in Costa Rica. But I can't blame the virus. I can't blame Costa Rica.

Is everybody else got the same virus, and they did. Okay. And, but I was the one who started to develop these weird symptoms afterwards. Heart racing was triggering.

My, blood pressure was going up and down and digestion was affected. Horrible insomnia. It was it was so dramatic that I was shocked that the doctors were not only unable to, but in some cases, I'm willing to try to dig deep to figure it out.

So and then my kids got sick and my son was disabled. And it's just a horrible, horrible journey. But a few years into it, I recognized that, okay, this is all new.

They don't get this. You know, we're on our own here. So set up a research company, genetic disease, investigate. Or is that maybe I'm in position to get answers.

You know, I'm an eye doctor, at the medical background. But maybe even more importantly, I'm in the body of the patient, and I'm willing to donate that body to science to figure it out.

And, I had no idea it would take so long. There's revealed, but ultimately, I was able to recover and my cancer recovered, and now we're helping other parts.

Yeah, it's an incredible journey. And again, your story is you're not alone out there, right? There are people out there that it breaks my heart. You know, a decade of just struggling until they really, turn the corner and get back to life.

And again, in your research, you had to be your own advocate, in your own area. And, you know, you were really, you know, these illnesses have been ahead of our time and our understanding, right?

So the patient suffers. But, you know, then we look back and put the pieces together, and we're seeing this more and more, even with long Covid and things like this.

But I, you know, I would love for you to share kind of how did you connect the dots and really, how did you put, your symptoms together and, and understanding of what was going on?

I wish it was a straight line, like just connecting the dots. And there you go. You know, there's all over the place. Yeah, it'd be all over. Yeah, I took that and through.

Remember me? It was hard. And, I remember one day, a couple of years into it, I guess, and I was just writing down symptoms, and they were always changing, which my doctor said they were just, like, chasing moving target.

And that's when they start to wonder if it's maybe up there in the brain, you know? But I thought, I can't have, like, when I had an 80 different symptom.

I can't have 80 different disease processes going on. They've got it all together, at least some of them, you know, and started to look at different systems of the body and for example, the digestive system, you know, when you tie in there or how many would tie into, the brain, central nervous system, how many would be peripheral nervous system and just started to cluster them and started to see some patterns.

Finding symptom patterns and autonomic dysfunction

And, the patterns are pointing to, the autonomic nervous system to some degree. But there were so many, sections I had of symptoms that just didn't make any sense at all.

I had no idea what those were, and that took a while to peel back some of those. And then my kids, because I was working on all three of us, you know, at when they were different, we had some commonalities that there were, vast differences, too.

So it was years of just dealing with a gazillion doctors, gazillion tests, trying to put this medical puzzle together. And it was, very, very, very hard.

But when answers started to come and I could start to peel it back, they were, oh, years in between each layer. It wasn't like I was like, oh, I know what this is, blah, blah, blah.

You know, it wasn't one thing. And, each layer ended up being important. And then when I was ultimately on the other side of that, we looked at, okay, we're all different to some degree.

We have some commonalities. Let's start with those. But what are the differences? And how could people end up in the same place or get worse, or have, secondary issues that could, make them present differently, etc.

and really try to expand out? Or because I thought I might be in position to help a lot of people and not just me and my kids, you know, so that we spent a lot of time doing so.

Yeah, again, I, I hear you in that. And this is not often a linear experience. That was wise of you to just start, you

know, seeing these patterns right, in these clusters.

And, I guess when you look at that, at that point where you started to feel like you were making progress in your how do you feel like potentially, started to click or shift within you?

Any like understanding or any strategies you were starting to implement? Again, I know it's not that black or white, but I can learn from it. I mean, when you start to, you know, get an understanding more and more of an understanding, the deeper you went, you know, like better care now.

So just walking through that, I will try, the first thing and I cannot believe, looking back, that it took me this long to figure it out, but, the first thing I, I figured out and both my kids and I was that we had high intracranial pressure.

And no one at that time, not a single solitary cell was looking at that in any of the invisible illnesses. And this is one thing I did get lucky on being an eye doctor.

We were trained in that, we didn't present typical. So it was easy to miss that some of the symptoms were so persistent. And one time I remember I was looking down at my car radio and it looked like it was moving away from me.

And I knew as an eye doctor, okay, it's not moving. I could do a quick test on my eyes and realized which ocular muscle was not working right, and I thought, what's the number one cause of that eye and cranial pressure there on Abby?

Weird. You know? Oh, no, that's what it was. So figuring out something objective that gave us some immediate relief helped. But then trying to figure out, okay, that's not the primary problem.

It's a secondary issue. What is that secondary to what happened then moving on to the next layer. But that was a significant step. Yeah. You know, there's no accidents, right?

I think, equally in this position as an eye doctor, right, to be able to, you know, pick up on that sign or you could have missed that, right, is oh, I absolutely could have.

I even like I used to play the flute when I was sick. That was like the only thing I had left. And after I played the flute, I was tremor. I thought, okay, what caused that?

You know, I need cranial pressure. It was it was subtle. And again, we didn't present. It's like we would think of this typical patients. But indeed, that was said.

So I absolutely I did get that. Yeah. My background was perfect for that.

High intracranial pressure and early clues

And then you said, you know, again, these are layers, right? And so what they say was, next layer that really kind of started to make this make a little bit more sense.

I remember it well. And this also is a process, right. There's nothing simple but clustering. Some of the symptoms I saw, they affected the central nervous system peripheral.

And so autonomic. And I sent out over 500 symptom checklists to patients with pods, chronic fatigue syndrome, PTSD study. Interestingly, and looked at patterns in these symptoms.

And in those symptoms, I tucked in 38 symptoms of anticholinergic syndrome. That's a syndrome where if you and just like a poison and it breaks down and neurotransmitter acetylcholine it affects all those systems at the body.

And I had a suspicion that was effective because of the patterns again. And, and the majority of those patient

patients, so the majority of those symptoms, they would come and go and they wouldn't be so bad.

Like if you were poisoned, you go into coma, seizures and death, you know, not to that point, but they were symptoms. That is, chronically ill patients.

We we don't go to the emergency room with saying, you know, I'm light sensitive and constipated. We go in with, I feel like I'm dying, you know? So those are ones we just try to ignore.

We push through as much as we can. And, but those turned out to be important. It looked like at first blush, it was a vagus nerve, because the organs of the vagus nerve were not working well, like my gallbladder shut down, for example, and they said, well, your ejection fraction is better for let's remove that.

We're again, I remember saying, well yeah, it's it infected like an appendix or so I was going to blow and I was like, okay, it's okay. Is the opening where the bio comes out.

Is it like stuck closed or something? And now I thought, well, if it's not urgent to me this sounds neurological. It sounds like the organ is just sitting there waiting and, and says, you know, let me know when you need me and I'll kick out some bio.

And it wasn't doing it. And, that turned out to be really important. So the organs could function. Again, it wasn't an vagus nerve problem. It was a neurotransmitter problem.

So it was more of a global issue. That is, you know, the vagus nerves, anti-inflammatory nerve of the body. So working through some of the illness, when that wasn't working well, we got worse in many ways.

Yeah. And getting that back going, among the other systems of the body was significant. And that was an important second.

Anticholinergic patterns and vagus nerve testing

So for people who obviously are medically minded, the symptoms that you were talking about are related to settle Colleen. And then people, potentially who don't have they're having basically not that neurotransmitter is not able to communicate or work in the body and leading to all these symptoms that you, you are experiencing a we summarize in that correctly for people. Yes.

I really wanted to pick it apart carefully, okay. To get this right. So I wasn't sure if something was breaking it down, making noise and what I wasn't sure if the receptors were starting to shut down.

In fact, you know, I guess for the people out there that, PhD PhDs here, right, have to get so deep into this, and that can be eye numbing, to go into this, that when you stimulate a nerve, the transmission goes down the nerve and it releases the chemical, the neurotransmitter, and that jumps across a gap across the synapse and lands on a receptor, and then the receptor triggers the organ to work.

So I didn't know. Is something wrong with receptors? Or is something breaking down that neurotransmitter? And I was able to figure out how to test the receptor and all the research to date.

Then was that part was an autoimmune condition affecting the receptors. And they been looking for years for why can't we figure this out? You know, why is all the testing negative?

And what I did was use, a replacement for the neurotransmitter to test the receptor used in case the vagus nerve, it was nicotine were great. So I knew then that it wasn't an autoimmune condition affecting the receptors.

The receptors were fine. It was the neurotransmitter, and I wasn't getting anywhere with trying to figure out if something was break, I just was I just kept banging my head against the wall and that.

And then one day I thought, wait a minute, could something be blocking its release? Could something prevent the release of the neurotransmitter when that nerve is stimulated?

And whenever you have an idea like that, or a new idea of any sort, you first want to go to existing literature to see if somebody has already figured it out.

Right. And sure enough, that's already been done. So that, okay, that's the most likely scenario. And if that's the case of patients either have, the inability to release that neurotransmitter effectively or if the nerve is damaged for any reason, to very easy to damage.

The vagus nerve is so long. Could we just use those receptors? Yeah, but no one had ever tried to do that orally. We can't use nicotine because it is, so, inflammatory.

It releases chemicals like last days and college and things that we do with tissue and actually worsen information. So it was a real double edged sword. It wasn't a treatment.

It was a good diagnostic test but not a treatment. So I sent we're trying to come up with something orally that would come into place and treat basically acetylcholine, any genetic issue with the pseudo and wanted to have a workaround for that.

I used my ancient organic chemistry to try and figure some of this out, and then I looked at the pathway and tried to put together everything that, if something were low and say, a nutrient, for example, that would limit our ability to, to produce acetylcholine.

Put that in. I put everything in and then had to work on the dosing for about three and a half years. I didn't want the receptors to become numb, if you will.

And if you if you're too heavy handed with this, they start to shut down. And you have to be careful with that. You develop what's called tolerance. And then I was especially proud of the work in the genetics seven no one had ever figured out how to work around that.

I didn't want people to have to know what their genes were to get help. And then I wanted it to cross the blood brain. So, at the time when I was sick, I got so bad I couldn't even stay away.

I was asleep of it like three hours and I couldn't even do that consecutively. I'd be awake maybe an hour and a half in the morning, an hour and a half in the evening. And that was a struggle.

So I don't have to get ill as I did, to appreciate the benefits of that. Crossing the blood brain barrier to being able to stay awake was one of so. Yeah.

So it when that person class, back when I was putting it together and giving it to my kids and taking it, I was patient zero. They were patient wanting to, you know, and they helped me work through this.

I called it ventures.

Developing a neurotransmitter replacement approach

I found an old, sheet of paper stuck under the drawer with the in and written out for the kids with the ingredients is vagus nerve neurotransmitter replacements.

It's interesting history. Before I figured out it wasn't a vagus nerve problem. And when you started taking, what is now today person class. And I love it.

I use it a lot with my patients. You know, was that one of the turning points for you when you started using that? Did your. Yes really shift? Yes it did.

I wasn't totally done yet. There was no one magic bullet. But. Yes, absolutely. And and importantly to I was getting again these new symptoms would come on just getting sicker and sicker.

And I got to the point I had neurological symptoms, I was hallucinating and my doctors couldn't figure it out. A lot of that was the malabsorption. And when that vagus nerve is not working, well, we can't break down our food properly, absorb the nutrients from it.

And my son got so bad, he developed osteoporosis. He broke his arm. Just throwing a ball. Just putting on his coat. Broke his arm. He missed over three years of school.

He was so sick. And some of those traumatic symptoms were from severe nutrient absorption. And it was something it was like this invisible problem because without Crohn's or celiac or being an alcoholic or something, doctors don't really think of that.

Even my neurologist, I had all these neurological symptoms and it never occurred to him that, oh, maybe you're not absorbing nutrients. Not even a chance.

Because we have vitamins and everything like that just doesn't happen unless you have some illness. And I didn't have any unknown illness. So that was important.

You created your own medicine? Yeah, yeah, I know, I love that in music. And so, you know, so we established straight the role of the vagus nerve. We've talked about, and, you know, some of the symptoms, so obviously the communication in the neurological system that has been, really illegal terms.

And then I want to, I want to tie this into mast cell in a moment, but I want to, you know, just, stay on. This is something you said because I think it's a great point to educate that parts is not a vagus nerve issue, you know?

So when I think about hearts, there's a lot of still, you know, trying to figure out underlying causes, what, you know, what people are, challenged with and where to start.

And so can you tell us what you mean by parts is not a vagus nerve issue? Because I think sometimes that gets misunderstood. Yeah. I think and I if there's patients out there, they'll know what I'm saying.

It's so much worse than that. Okay. You can have vagus nerve problems. Patients do. They have injury and things like that. They can develop constipation since like a stent test when I was sick from head to toe and it was so miserable.

It's hard to describe the suffering. Because it wasn't just organ dysfunction. Right? Sometimes it felt like I was on fire from the inside out and, trying to tell a doctor I felt like I've been poisoned.

Electrocuted, and like, my blood is on fire. They don't. That means what are they going to do with that? You know, but it was just so much suffering. If all it was was the vagus nerve.

I think it'd be easy. Right? But now it was so much more than that. And that's kind of what tied in to, the is some aspect of inflammation interfering with this neurotransmitter.

What type of inflammation is it, what cells are getting activated. And that's where Marcel's came up. And mast cells are under control. The vagus nerve, a lot of inflammatory cells are under control.

Vagus nerve. So if we don't keep that working, some, chronic inflammation like that takes off running, and it has very little ability to get rain down.

And that's where some of those chemicals released from inflammatory cells, from the mast cells and the inflammatory cells that track was causing some of that, you know, on fire kind of feeling.

Yeah, I think about, you know, like burning symptoms or, you know, that that can present in lots of different ways in our community, rates of extremities, the brain, skin, you know, these, you know, different symptoms.

So would you say it's the mast cells plus the recruitment of the other inflammatory cells? Yes. That's at the root of that symptom for you. And that's right there.

Mast cells may or may not be primary. Right. But they get caught up in most any chronic inflammation. So when it starts to cause those symptoms for your skin or for that feeling, they do have to be considered.

And we do see it.

Why POTS is more than a vagus nerve issue

Parts scare true mast cell patients. And those patients are trip place is always always. You can't get a measurement. But in the ones where the trip is normal, I think we have to keep our thinking caps on.

We can still help those people, but we don't want to necessarily jump to masses. The only problem are we can cut short some of the help we can. We can provide for them.

So they're they're horrible cells. When you talked about the burning, it was I don't even know that burning is quite the right word, but it felt like there was heat rising up in my body.

And then it felt like my brain was on fire, which I do realize no one knows. And, and and then the heart rate would take off. This is like a major, I would say panic attack, but it wasn't a panic attack.

I would tell the doctors, it's like my body's panicking without me, okay? And my body was just taken off racing and I couldn't bring it in. And then when that those horrible episodes occurred, just one after the other.

After the other, there's the suffering is so intense. Yeah. So it is. If you say it's burning to a doctor, I think it limits again how bad it is. But we don't have good words for it, right?

Yeah. Oh, we don't have a misery scale. We have a pain scale, which is great, you know. But it wasn't that I was in so much pain. It was that I was so miserable.

Like a differentiator. And I want to agree with you there in to the. The language is limited. And it is, you know, a lot of the symptomology with what people are going through.

And I think that makes it challenging, especially, still in the conventional world, to really kind of honor and try to go as deep as probably they need to when they hear these symptoms, they kind of, you know, they go to these like, anxiety.

Exactly. Okay. So but I, I think the language is, is limited to describe the suffering. Yeah. So then, how did you approach that layer? We can, I would love to get more of your thoughts on mass on the moment, but I would love to hear your thoughts on that layer of the illness.

How did you have developed a deeper understanding of that? Right. Well, when I started to suspect it just from presentation, antihistamines are important and and, you know, mast cells and the cells, they recruit spit out histamines.

Well, I don't know that we know 60 maybe other chemicals a time, you know, but that's a significant chemical, especially when we're dealing in a lot of Pots cases.

Not all, but in a lot. The fast heart rate and blood pooling, etc. is a cardiovascular consequence. Some aspects of inflammation and histamine is bad on blood vessels.

It causes them to leak. The cells separate, which is, is there's a point to it because in an area of injury, like you sprain your ankle, it sends those healing elements right out of the blood, right into the tissue to start the healing process.

So it's important. But it does cause pain, and it, and the other chemicals do cause swelling, of course, because the fluid gets at redness because of the basal dilation.

But in a sprained ankle, there's an ending. There's healing in the vessels still. And we're good to go. But if you can imagine having a sprained ankle, a little bit all over your body all the time, you're kind of getting a hint of what we're dealing with, with inflammatory.

So histamine does need to be blocked for a while because they're histamine receptors right on the blood vessels. Let's not have a go there okay. We're trying to work on those levels.

And then we look at other, histamine receptors and see do we need to address that or not. And then of course those stabilizers get it to then chromium, depending on where we suspect these cells are getting activated.

And that helps to always get the vagus nerve working.

Mast cells, histamine, and inflammatory symptoms

Otherwise you're fighting an uphill battle. And that's usually a good start for most people. Usually when people get sick enough, they're so sensitive, incredibly sensitive.

I was one of those and I remember telling a doctor, if you give me a medicine, okay, first I'm going to take it to my forehead. That goes, well, you know, if you're doing well, I might like it.

And he said, what do you mean? I'm just so sensitive. And patients get sensitive to most any food, to chemicals to sense to, you know, stress anything, which is a ball of sensitivity.

And that's an inflammatory reaction. So it's great to just calm things down a little bit with a stabilizer or take a step back, let them take a chill pill, if you will.

And sometimes that takes that job, too. We've been has it been your experience that you've seen an increase in how sensitive people are that come to your office over the years?

They've always been sensitive. Oh, but what we did see was with Covid, more inflammatory. So, no surprise there, because so many patients are triggered by viruses or certain bacteria, other things that can trigger like stress, injury and seizure.

And sometimes we never can point to a trigger. We were pretty much prepared for that when Covid hit. I thought this virus could be significant enough to do it.

The virus I got in Costa Rica, the doctor suspected we all got some form of a SARS virus because it was so good in the lungs. We all were in the hospital at some point because we couldn't breathe.

And I thought, this is a serious virus, let's say. And indeed, that's what's happening. So it, as you know, in some patients are recognizing how it can kick off an abnormal inflammatory response in those predisposed.

And it's more the inflammation and it gets people than it is the virus itself. So it it did kind of open up more of an understanding of what patients with parts deal with, which is oddly good, I guess I would say that mean it's horrible.

We're going through a pandemic. It's horrible what's happened, but it has validated quite a bit of that presentation. Yeah. And your tools were ready, right.

To handle we were already seeing the patients. Right. Yeah. It was just it was seamless. Yeah. Mean I think our, community has, you know, a lot of the framework and tools to really support, you know, patients who have long haulers, long Covid because, yeah, you know, essentially we all are looking at, right, these post-infection syndromes and the inflammation that they ride.

And so so anything unique to long Covid that you see that's different from what has walked in the door before. You know, it's interesting because we're all still learning about it.

And typical of I guess, any virus. But there's more attention to Covid. You have to make sure the lungs are actually okay, you know, and the heart is actually okay.

I think post Covid patients get a fair amount of attention initially because they feel like I can't breathe a chest pain. My heart rates all over. My blood pressure is low and the focus goes to is their structural damage.

Right. And that's important to rule that out. So I encourage patients to go through that regular stuff, go through it, make sure everything's okay. But typical of inflammatory parts patients post viral.

Usually it's fine side right. It's fine. And then they go to okay, so let's start antidepressants or something. It's just the same horrible journey. Their validation goes out the window.

And, that's exactly what my family went through. And it was it was just beyond frustrating. It's really just wrong. I wish I known then what I know now.

There's no no way to do that. But I think the tendency is if we can't recognize it and identify it, it doesn't exist. I knew that wasn't true. There's plenty of things we don't measure yet.

But we can't identify things if we don't measure them. And our ability to measure certain things is getting better. So much like the discovery of bacteria, for example, you know, before a microscope, usually you wash your hands before surgery, you know, it was important, you know, brush off the dirt.

But when someone invented a microscope and they saw this little things crawling around, they said, this might be important. And then they started more sanitization and ultimately antibiotics, etc.

it changed medicine because they could see and that's what needs to happen, an invisible illness. We have to do better at measuring some of these things.

And when we do, there won't be, quote, invisible illness. It's not gonna be invisible. You can point to it. And then ultimately my goal is to identify the genetics of it.

So either we can change the genes, which I don't even know what to do with that ethically. Or patients can know from birth if they have some challenge there so that they have a way to attack that so they don't have to get sick.

So it's a lofty goal, but that's my personal list.

Long COVID, inflammation, and invisible illness

When I look at what you've accomplished so far, I have. Well thank you. Yeah, yeah, I know you're on your way to recovery. It was great, you know. Oh my gosh. Right. I talked to one patient.

She said that if I had recovered from this, I think I'd be on a beach in Hawaii. Is appealing as it sounds. This is my joy because that bond with patients is so special because they won't talk to someone else who's gone through it and they won't get there.

And, it brings me right back. Every patient brings me right back to how it was. And, you want to help? Yeah. So, yeah, with the knowledge you have. Right.

It's like, how can you not bring, you know. So exactly, exactly. Can't exit stage left and, you know, just release information. You guys are gonna be good to go because that's probably not the case.

It takes a long time for diagnostic and treatment protocols to shift long time in the patients like me. We're caught in that. In-between. The research is move beyond where practitioners are.

And it takes a long time for that to all catch up. So what do we do in the meantime? And that's hard. I want to, you know, I know some people might be curious.

You've alluded to that. There are a few different types of pots in your, you know, framework. And you mentioned inflammatory pot. And would you be able to kind of walk us through your, you know, is there a way I know you do a lot of thorough workup, with patients and you really, get a deep understanding of their biochemistry and, you know, their physical, exam and all of that.

But they're, you know, patterns that you kind of put people in, like pattern or patterns or buckets. And we're very careful with this. Yeah. I don't know what's good.

And I don't want to put you on the spot there, but it does anything that you feel comfortable sharing, you know, I do I think it's real easy to see a Pots patient and love them into the same group as everybody.

I so, so, so much a control freak for each case. And we really want to be very careful. We don't miss something important. So for example you don't want to miss a heart problem.

That would just be silly, right? So cardiologists need to rule that out. There are some neurological diseases that initially present with, like ALS or Parkinson's or Gehrig's disease.

You don't want to miss says. And the treatment for that would be completely different than nothing that we could handle. But they need to see a neurologist to work through that.

We had an interesting case. MedStar attic conditions sometimes come out with pots, and that's kind of important. But, we had a case, someone who was told she had pots, and she was, on treatment for cancer.

Okay, we need to slow down and let's evaluate this carefully. And went through some symptoms, as we do with all the patients, to be qualified, to see.

Did she have symptoms, like a heightened cranial pressure, vagus nerve problems, or, you know, growing issues or what have you at flushing on fire feeling, you know, anything that that suggested akin to abnormal inflammation said none of it but her orthostatic tolerance.

Ridiculously horrible. And I looked at that as I don't think this is, there is a very rare, autoimmune condition that affects autonomic receptors. And interestingly, some cancer medications can trigger that autoimmunity.

And indeed, that's what it was. And the way it was figured out, it was, she developed and satellite and was in the hospital. They called her husband, said she's going now.

And, and she was going nuts for five days before someone recognized it, that it was affecting the brain and they were able to get her on IVIg. This is a horrible case because then she has to go up the cancer, you know, dealing with that.

But I thought had we just taken her in like, yes, it looks like we would have done her such a disservice. So we really are very careful about, making sure we're seeing the patients we should be seeing.

And usually patients come very full, fully evaluated. They've gone everywhere, but they see us everywhere. So we look at all those records and just make sure nothing's getting missed.

I think that's one of the biggest fears it I have as a patient, I've seen in many of our patients that it feels like there's some it feels like you're being eaten alive by something.

And we have to make sure we're not. Yeah. No.

Careful POTS evaluation and avoiding missed diagnoses

I, always appreciate how thorough you are, and, yeah, it kind of makes people crazy, you know? But, I mean, it's it's great to be that really thorough investigator and detective for people, and, you know, that you can trust to your your approach in your treatments because you, you know, that you've uncovered all the stones you you need to.

So I am knowing that is that's really great that you can do that again. So it's early. So I have a great team. Yeah. Great team and doesn't happen without that you know.

So that's the jury's out. So so this is I always learn so much from you, Diana. And kind of as we kind of wrap our conversation, just bringing in a back to the Marcel community, that tuning in, you know, any other pearls that you want to share?

In your experience around Marcel and parts that you want to, make sure those out there might not have put together or might not have thought about in helping to approach their, you know, road to recovery. Right?

I think just staying in the science is important. And any invisible illness. So if the the testing premise is negative, keep your mind open to the possibility.

It's something that's mimicking. And there are lots of inflammatory conditions that mimic it. And I see that heartache, patients stopping with that diagnosis when maybe something else is getting messed.

But in many forms of chronic inflammation, histamine is an enemy. So antihistamines are usually your friend. And if you respond very positive, positively to that, there's something going on following likely some chronic inflammation.

You want to make sure the neurology is as good as it can get. This putting the the acetylcholine levels for not just the vagus nerve, but even the lacrimal nerves that produce tears.

We found those are affected. And patients were going on to chronic dry eye trying. Now they presented much like a Shogun syndrome patient. And that wasn't what it was.

And then the brain, the cognition. So when we're dealing with inflammatory parts and a cardiovascular response, it's a lot about the blood vessels. We want to take good care of them.

And as patients start to recover, ultimately getting back to exercise or movement, you know, just increased blood flow can be really helpful. And teaching people whatever is going on in their body to try to notice if there's a trigger for a worsening and, you know, with mast cell, it's very common, and it doesn't mean they'll never be able to go back to whatever that trigger us.

But as the inflammation improves, they oftentimes can. But during recovery, it's great to identify those and set those aside, to improve the the outlook there and calming inflammation like ketosis and or even Crumlin, for example, will help calm mast cells.

Also calms eosinophils base it builds you don't necessarily have to know your strict diagnosis to get some help with some of those things, because I know many of us flounder with the lack of a specific diagnosis.

We might know it's inflammatory. There's some things we can do right then. We don't have to have a label to start a treatment. So, I remember as an eye doctor and training, learning, okay, it's great to get a label on a condition of that.

Absolutely.

Recovery pearls and where to learn more

That before you figure that, treat what you see, if you see infection, treat infection. If you see inflammation, treat inflammation. And then just keep going after the label.

I think it's so many invisible illnesses. We don't have good labels. But we we can treat what we see. So control that inflammation. The vagus nerve is really important.

And person plus helps with that. But it's hitting some of those chemicals can help to and patients can start to improve and recover. Yeah really great points.

And no I, I love that as I doctors I agree. What you see that's great. That's great I know it's such a concept but you doctor they can see inflammation on the MRI and I said can you treat that.

She is. No, no without a label I go you can see it. You know, it just didn't make any sense to me. But someone could suffer that much and then weren't even willing to give it a whirl, you know, so we can be safe, cautious, and yet proactive.

Even without a label. There's a way to walk that line. And unless we we make that effort for our patients, they're going to suffer much more than they need to.

So yeah, well, great advice, and I'd love for people to know where they can find out more about Pat's care and Paris and plans and whatever information you want to share so people can go deeper with, some of the knowledge that is touch on your your knowledge is so deep.

And I know you ask a lot of, you know, broad strokes and sharing of some things for people to think about. So where can people find out more of you in your work?

Yeah. Person plus and new person plus eyes. Is that vagus nerve support.com? It's the company TJ nutrition that works off of the patents I've gotten for that is that was all new.

And then I'm at Pat's care.com, and other places too. But those are probably the best places to find some of that. And that'll take you other places. But you just can't be in the deeply into this for, you know, 15 years plus, without a lot of information getting discovered.

And it's been quite busy. Yeah. So I try to release everything I learn to help as many people as possible. And you're doing an incredible job. You are too kind. You are too.

You are doing the job of getting the word out. So, and helping your patients. Of course. So it does take a village, doesn't it? Yeah. No. I feel like we're a team effort.

Well, not all of us, but now I'd. I can just appreciate your passion and dedication and all the knowledge that you've uncovered for us. So thank you for being.

Yeah. Of course, part of the summit. It's always such a joy to connect with you. It was delightful. Thank you. Christine.