190: Resiliency Radio with Dr. Jill: Manifestations of Mast Cell Activation (MCAS) in the Gut!

Dr. Jill 00:12
Welcome to *Resiliency Radio* with me, Dr. Jill, your go-to podcast for the most cutting-edge insights in functional and integrative medicine. I'm your host, and in each episode, we dive deep into the heart of healing and personal transformation. Join us as we connect with renowned experts, thought leaders, and innovators who are at the forefront of medical research and practice. We want to empower you with knowledge and inspiration, aiding you in your journey to optimal health. Today, I have a very special guest, Dr. Leonhard Weinstock, on the topic of mast cell activation disorders and the gut specifically. It's becoming an epidemic, and I can't wait to dive into this topic. But first, let me introduce our guest, Dr. Weinstok.

Dr. Jill 00:52
He is a Board-Certified Gastroenterologist in internal medicine. He is an Associate Professor of Clinical Medicine and Surgery at the Washington University School of Medicine. He received his medical degree from the University of Rochester School of Medicine and completed his postgraduate training and was chief resident in internal medicine at Rochester General Hospital. His gastroenterology fellowship was performed at the Washington University School of Medicine.

Dr. Jill 01:18
He is an active lecturer and has published over 140 articles, abstracts, editorials, and book chapters. He's given lectures throughout the world. He's currently researching our topic, mast cell activation syndrome, as well as small intestinal bacterial overgrowth, restless leg syndrome, mold toxicity, and rosacea. Dr. Weinstok, you and I might be the only ones who know how all those things are connected, right? [laughs]
Dr. Leonhard Weinstock 01:43
Yes, they're connected for sure.

Dr. Jill 01:46
Welcome to the show! It is absolutely an honor and delight to have you here.

Dr. Leonhard Weinstock 01:50
Jill, thank you so much for inviting me. I'm honored.

Dr. Jill 01:53
Oh, thank you. We got to talking because you guys are producing a documentary in the future. At the end, stay tuned because this topic is so important. Dr. Weinstok and his team are trying to raise funds to bring awareness, and we will be sure to give you all the information [you need] if you want to donate or support the cause. I want to be the first to say that I think this is so critical.

Dr. Jill 02:14
Before we go there, let's talk about you. How did you get into medicine? What drew you to medicine? And then what drew you into gastroenterology? Tell us a little bit about your journey.

Dr. Leonhard Weinstock 02:25
A lot of the people in my family saw me as a caring person, an individual, not a businessman, and always encouraged me to be a professional. My dad was a dentist, and my uncle was a pediatrician. I had models, so I always knew I was going to do that.

Dr. Leonhard Weinstock 02:51
I was a little bit of a renegade. I did pre-veterinary medicine for a little bit in Vermont. But then, after I worked on some dairy farms and worked with a family where one of them had cancer, I saw a different side. I thought: "I could get into this. I like the people-to-people more than the people-to-cow contact." So that's the way I went, and it did work out.

Dr. Leonhard Weinstock 03:22
The specialty of GI was something that I saw during my residency—mystery cases and mystery symptoms and people going years and years with abdominal pain where nobody ever figured out what was wrong. I thought: "This is interesting. Maybe I could get into that, learn more, get into the depth of it, and then come up with answers." Also, you could look with endoscopes and colonoscopes and do a surgical side of things, so GI had a lot to offer.

Dr. Jill 04:02
Wow. And what I see there is something I always see in some of the best physicians that I know, and that's curiosity—the idea that you could solve problems. I think

whenever we go into medicine and think we stop learning when we graduate, we lose that curiosity. With what you're doing and even your openness to mast cell activation and how this affects the gut, our topic today, it does take a curious person to keep searching and looking. As you well know, the complexity of the gut, the body, and our environment are exponentially increasing.

Dr. Jill 04:37
First of all, many of my patients and listeners have heard of mast cell activation syndrome. But for those who haven't, let's do an overview of: What is this issue? And why are we seeing more of it than we used to 20 years ago?

Dr. Leonhard Weinstock 04:51
Oh, yes. The mast cell is one of our white blood cells that lives mainly in the bone marrow. But when there's inflammation, a burn, or an injury, they come out of the bone marrow and go to the site. They orchestrate how much inflammation should be going on and how many new blood vessels should be created to help heal. But if one of these guys has a mutation on the gene that controls them, then it allows for these chemicals to come out of the cells and create a lot of damage and symptoms, both near and far.

Dr. Leonhard Weinstock 05:32
The fact is, it's incredibly common. It's been estimated that 15–20% of the country has some degree of mast cell activation syndrome. Sometimes people say, "It's more mast cell activation with symptoms and systemic syndromes." But those in the know know that you have to keep your mind open. Not only does it come alone, but it also comes in with Ehlers-Danlos syndrome and POTS, postural orthostatic tachycardia syndrome, thus forming the evil triad.

Dr. Jill 06:12
This has been of particular interest because, at least in my clinical practice, it is rising, especially since the pandemic. Let's talk about triggers, though, because that may pull it together.

Dr. Leonhard Weinstock 06:22
Absolutely. First of all, there are temporary triggers and then there are permanent triggers. As is often the case, kids are sick with a variety of conditions at birth or in childhood. They have headaches, asthma, eczema, food allergies, or GI problems.

Then, in the teenage years, young women have severe periods. Young men can have psychological problems, panic attacks, ADHD, and so forth. But they get worse along the years. If they get infectious mononucleosis, that can set off a permanent change and more damage to the genes, making them more uncontrolled.

Dr. Leonhard Weinstock 07:22
During adulthood, things also occur. Unfortunately, during the pandemic, COVID occurred. COVID also puts patients with a genetic aberration and activation of the mast cell on a regular basis, whether we can get out of this virus that lives in our body or not. And therefore, it's affecting the mast cells. But that's what you're talking about in terms of what's happened since 2020.

Dr. Jill 07:57
Or it weakens the immune system. It's almost like two ends of the spectrum: We have more autoimmune, more activation of mast cells. I always think of it like poking the sleeping bear. There are these cells that are supposed to protect us, but there are all these things in our environment that are irritating our systems more than ever before. Environmental toxicity: I deal a lot with mold. Do you see things in the environment affecting this as well?

Dr. Leonhard Weinstock 08:21
Oh, yes. We're getting ready to submit a paper on mold. This individual in the case report would go to different houses. He was a home inspector and worked for a company that dealt with selling homes, knocking down bad homes, and so forth. Every time he'd go into a moldy home, he'd have to run out of the house and he'd vomit. He'd have severe pain and diarrhea. Just imagine that happening on a regular basis. But some of these times it was so severe that he went to the hospital and his gut was paralyzed. It turns out that he did have mast cell activation syndrome from years and years back. Treating that and keeping him out of those homes led to a significant improvement in his status.

Dr. Leonhard Weinstock 09:24
Mold is incredible. It can activate good mast cells as well, and you can get the chemicals that we see in mast cell activation syndrome. But it can certainly activate mast cell activation syndrome. Patients can suffer until they get out of the

environment and do healthy things for their bodies that everybody who listens to your show knows about.

Dr. Jill 09:50
Yes. I love that you talk about that too, because what happens, I feel, is that the load on our bodies—whether it's infections, toxins, or inflammation—is getting worse. And I think that's why we're seeing more.

Dr. Jill 10:02
I want to go back to something you said that I think was really important. There's something that we were taught in medical school called mastocytosis. This is a proliferative disorder. That was the old thing that we were told to look for, even though mast cell activation is more prevalent, I think—you can correct me if I'm wrong—than mastocytosis. From the old school of medical education, we weren't taught a lot about mast cell activation, but it's becoming a bigger issue. Do you want to differentiate that just a little bit?

Dr. Leonhard Weinstock 10:30
Absolutely. First of all, it's something that people could diagnose relatively easily if they thought about it. But it was like 0.3 per 100,000 people per year [who would] get it, so that's an extremely rare disease. It seems like in medical school, they love the rare things like gigantism with growth hormone excess and mastocytosis. But the fact is that mast cell activation syndrome was not described in the literature until 2006.

Dr. Jill 11:06
Oh, no wonder, then. It was after I graduated. [laughs]

Dr. Leonhard Weinstock 11:09
Right. Exactly. After I graduated. And they don't teach it now, and that's part of our problem. That's what we're trying to do with this documentary—increase awareness amongst physicians and people in general so that they can get help for decades' worth of problems. And it is decades worth.

Dr. Leonhard Weinstock 11:31

But the thing about mastocytosis is that it is a malignant disease. It can be indolent or very slow, and then you get all the symptoms of mast cell activation: Diarrhea, hives, itching, rash, abdominal pain, brain fog, etc. They're very similar in terms of symptoms. But if you do a bone marrow, you'll see many mast cells because it starts there as a malignant disease. Whereas with mast cell activation syndrome, you see some in the periphery—in the gut, lungs, or bladder—but you don't see any in the bone marrow. It's very, very different.

Dr. Jill 12:17
And we're seeing much more MCAS than mastocytosis.

Dr. Leonhard Weinstock 12:20
Right. If we're thinking mast cell activation disease, that's really three things: MCAS (that's up to 17% of the population), systemic mastocytosis (which is less than one out of a hundred thousand), and mast cell leukemia, (which is one out of 500,000). That's the mast cell activation disease. They're very different but also similar with respect to symptoms.

Dr. Jill 12:59
Okay. So MCAD is the umbrella over MCAS, mastocytosis and mastocytosis leukemia. That makes perfect sense. We do have doctors who listen, so I want to make sure we're educating everyone because it's so important.

Dr. Jill 13:14
You work with the gut. This is a disease that absolutely affects the gut, but it affects so many other systems. Do you know anything about percentages?—because you can do a biopsy in the gut. Let's talk just a little bit about diagnosis. What would you do to diagnose mast cell activation syndrome?

Dr. Leonhard Weinstock 13:32
It's by doing the main seven chemical tests—four blood tests and three urine tests. The problem with the biopsies is that it's very common to find 20 or more per high power field. And there's some argument about that by the pathologists and others, especially the allergists. When you're diagnosing mast cell activation syndrome, you have to have two or more systems involved with typical symptoms, whether they be hives, gut symptoms, itchy eyes, or ringing of the ears and other problems. Two or

more systems are involved. Fatigue is a big one. Fatigue, brain fog, and muscle aching are very common.

Dr. Jill 14:26
I think I read that the top symptom was the brain. Maybe I'm wrong, but one of the biggest ones is generalized fatigue and brain fog.

Dr. Leonhard Weinstock 14:33
Absolutely. And then you add the third most common symptom, muscle aching, and that's the same thing as fibromyalgia. So you've got to say: How many fibromyalgia patients are really MCAS? Chronic fatigue syndrome patients—how many of them are really MCAS? And so forth. GI symptoms are very common. As a gastroenterologist, I see them being very, very common.

Dr. Leonhard Weinstock 15:00
Dr. Affron saw patients as a hematologist with a wide array of symptoms, and 50% or more had GI symptoms that were predominant and significant. The gut is affected in part because the gut is one of the main interfaces where you've got the mast cells living underneath the lining of the gut. For many patients, eating some gluten or dairy activates the mast cells, setting off the chemicals. It's the chemicals that we measure, and that includes prostaglandin, histamine, chromogranin—and we do measure tryptase because if it's high, you want to look for mastocytosis.

Dr. Leonhard Weinstock 15:47
There are two camps: One camp feels like tryptase is very specific to mast cells, which is true. But in fact, it's not very commonly elevated in mast cell activation syndrome. The problem is when a person with multisystemic disease sees an allergist with hives and asthma and they say, "I think I have MCAS." They get a blood test and the tryptase is normal and the allergist says, "No, you don't have it." That's a real problem in terms of management. The allergist also thinks it's very common to have anaphylaxis, but our group doesn't think so. Then there are three urine tests that are done, prostaglandin, histamine, and leukotriene E4.

Dr. Leonhard Weinstock 16:34
With those seven tests, about 70% of my patients who I think have MCAS are positive for one or more. And then the other group of, let's say, the 30% that have

negative markers, if they respond to basic mast cell therapies like antihystamines, vitamins, or flavonoids and they get better, then they're allowed to have the label of mast cell activation syndrome.

Dr. Jill (pre-recording) 17:15
Hey, everybody. I just stopped by to let you know that my new book, *Unexpected: Finding Resilience through Functional Medicine, Science, and Faith*, is now available for order wherever you purchase books. In this book, I share my own journey of overcoming a life-threatening illness and the tools, tips, tricks, hope, and resilience I found along the way. This book includes practical advice for things like cancer and Crohn's disease and other autoimmune conditions, infections like Lyme or Epstein-Barr, and mold- and biotoxin-related illnesses. What I really hope is that as you read this book, you find transformational wisdom for health and healing. If you want to get your own copy, stop by ReadUnexpected.com. There, you can also collect your free bonuses. So grab your copy today and begin your own transformational journey through functional medicine and finding resilience.

Dr. Jill 18:11
And we'll put that paper because I know the consensus statement that you have been an author on is one of the things that, at least for me as a physician, has been a game-changer because you list all the criteria in that paper and kind of say: Let's shift from just tryptase as the only thing that we look at. Is it true that histamine and tryptase are going to go up and down based on their acute exposures so that if you caught it during an acute flare, you might get it? But because it can go up and down... And they're also very volatile in the blood and urine. Is that correct?

Dr. Leonhard Weinstock 18:39
Correct, yes. To address that, ideally, when I do the blood and urine tests, I say: "Are you feeling poorly today?" Many people are feeling poorly. Most of my statistics of 70% positive are because they're at baseline and many people simply have fatigue or flushing when they see me, so I'll do it. But if they're totally asymptomatic, which is rare, I'll tell them: "Take a trigger. Do a trigger. Eat it or go out in the heat and come in and be off. But don't overdo it so you're set back for a week. And then come in for the test."

Dr. Leonhard Weinstock 19:26

And the tests—you have to have somebody who knows what they're doing because spinning the plasma heats the plasma up. Two of our blood tests have to be spun cold. That can be done with little jackets that keep the blood cold in the centrifuge or by going to the hospital.

Dr. Jill 19:44
Which two are those?

Dr. Leonhard Weinstock 19:46
Histamine and prostaglandin are the plasma. And then the urine has to be collected cold, kept cold and then frozen when you bring it in so that it can be mailed to the reference lab that looks at those levels.

Dr. Jill 20:05
And some of the details are in your article, I know—the consensus statement. But that's really important if you're a physician or even a patient listening. If these things aren't kept cold from the collection, especially the urine, it's very likely to give a false negative result, correct?

Dr. Leonhard Weinstock 20:18
Yes, absolutely.

Dr. Jill 20:20
The other thing you mentioned early on was genetics. I'll just tell you about myself, for example. I grew up on a farm. I had severe eczema, severe allergies, Crohn's disease, gut issues, and all this. I am sure I have all kinds of mast cell issues, genetically. Do you see that the majority of patients have genetics that are positive? Do you even test those?

Dr. Leonhard Weinstock 20:45
The testing for the KIT genes that are positive requires a lot of blood and research labs. There is one gene that's commonly tested for patients who have mastocytosis and that's available, but that's really never positive for MCAS. Dr. Molderings has described many different mutations of the genes.

Dr. Leonhard Weinstock 21:12

And you ask, why are we seeing it more? Is it because we're more aware and a little bit smarter? Or is it the epigenetics and all the toxins in our environment that are changing our genes after we are born and then it trips the mast cell gene controller, the KIT gene, so that we lose control? Then we have a hyperimmune state, but we also have a state where the mast cells don't know what they're doing in terms of controlling infections, so people tend to heal poorly on their skin. They tend to go from a simple viral bronchitis to a bacterial bronchitis. And the same thing for the nose and sinus problems. It's kind of a yin-yang there.

Dr. Jill 22:10
Yes. I've seen that because there's autoimmune, innate immune activation, and all the cytokines, which we saw in COVID and we see in mold. It's very similar. But then, on the other hand, they're very susceptible to not being able to fight out intercellular bacteria, infections, or things. It's this very bizarre immune system dysfunction—kind of the worst of both worlds.

Dr. Jill 22:31
Let's talk about someone who does have this. What would you do as far as starting treatment? As a gastroenterologist, it sounds like you're doing tests, doing a great history, and then doing interventions. But they don't all necessarily require an endoscopy or biopsy. Is that correct?

Dr. Leonhard Weinstock 22:46
Correct. I've been dissuaded from doing that. Also, those people who are coming for their 45-year-old colonoscopy who have mast cell activation syndrome want to be pretreated with intravenous Benadryl, Pepcid, and, in some cases, Versed, and in some severe cases, Solu-Medrol. From the propofol, you don't want to get into a situation where you get activated. I've had some patients get into severe hives and it's been hard to get them out of that because they're very sensitive to chemicals.

Dr. Jill 23:29
Yes. Let's talk about that. We wanted to talk about treatment, but before we do: Triggers. You mentioned heat. What are the top seven or ten things that you see as triggers? And maybe there's [inaudible].

Dr. Leonhard Weinstock 23:40
I just put a table together and presented an article. I had a patient, a 53-year-old

man, with 30 years of attacks—abdominal pain, diarrhea, and vomiting. It turns out he was a paint salesman. Whenever he had long exposures to paint sales or conventions, all those volatile organic chemicals made him flare. That's a table that's going to hopefully be in an article that will be published soon. But basically, it's environmental, infectious, chemical, implants, and temperatures. A lot of the common ones are heat and cold. Dietary was another big one. The most common ones are gluten, dairy, yeast, and high-histamine foods. If you've got some implant, that can be a problem. Smells are a big thing.

Dr. Leonhard Weinstock 25:04
Patients of mine go into a Macy's and they encounter the terrible odor from perfume and bang—they're on the ground, passed out. Some people, like my first patient ever, said that the big box stores were her kryptonite. She had both POTS and MCAS. She would faint going in there. Part of it was the fluorescent bulbs.

Dr. Jill 25:33
Wow, amazing. It's almost like an unending list of things that could trigger. It's interesting because I was diagnosed with Crohn's at 26 and, looking back, I had mast cell activation probably from birth. But Crohn's was one of the biggest changes for me, and I didn't even know the commonality was a low-histamine diet. I just knew these certain foods were triggers for me. More than any other thing that I did as a dietary intervention were the low-histamine foods. I was like, "This thing fermented this" and these other things like aged meats and cheeses, bone broth, avocado and spinach. I had no idea back then. Now it's like, "It was histamine foods!" It made a huge difference in the activity of Crohn's, which probably was connected to the severity with the mast cells being activated. It's very interesting.

Dr. Jill 26:23
Let's talk about interventions first. What do you do as far as natural [remedies] and medications? Go through the list, because there's a long list of things we can do.

Dr. Leonhard Weinstock 26:32
Absolutely a three-week diet trial. And it's hard to go off gluten.

Dr. Jill 26:37
Low histamine—is that the main thing?

Dr. Leonhard Weinstock 26:39
Gluten, dairy, and yeast. And low histamine is kind of what I say. It's a little bit flippant to just say: "For three weeks, you've got to do this." But you've got to do it because you don't know how the medicines are going to work.

Dr. Leonhard Weinstock 26:56
Step one treatment for me—all but one are over the counter. What I do is H1 blocker and H2 blocker. In English, that's famotidine. We used to have Zantac, but now we have Pepsid (famotidine). And there are two others that are a little bit harder to get. But sometimes one person does better—one versus another. That's the same thing that could be said for the non-sedating antihistamines, Claritin, Zyrtec, Xyzal, Allegra, etc.—the trade names. Those two are the cornerstone. But then vitamins C and D are important. You want to get your vitamin D levels up to the ideal levels—70 or so. Usually, 1,000 [mg] or sometimes 500 [mg] of vitamin C works better than a higher dose. And then a flavonoid. If somebody really has terrible brain fog, then I'm going to go more with luteolin. If there's just more body systemic problems, then quercetin. The only prescription medication at this point, pretty much for all my step-one patients, is low-dose naltrexone.

Dr. Jill 28:32
Excellent. And you do that with ketotifen?—because that's a favorite.

Dr. Leonhard Weinstock 28:34
Ketotifen is definitely the next step after that. Part of step one does include ketotifen, cromolyn, and Singulair. But the problems are A) cost and B) you have to do cromolyn very, very slowly. Otherwise, it can react and activate the mast cells. And then you've got montelukast (Singulair), of which I'm not quite sure, but probably 5–10%, especially in mast cell women, get psychological disturbances.

Dr. Jill 29:12
I would agree. I feel like that one's a wild card. It doesn't always work as well as it should—according to the mechanism.

Dr. Leonhard Weinstock 29:18
Right. Especially if LTE4 is elevated. Ketotifen is very good. Especially if there's insomnia, it can be helpful.

Dr. Jill 29:33
Excellent. And there are some big players, like immune modulator steroids. In my book that I wrote last year, the preface is about a young woman who passed away. She had mast cell activation disorder, and she was so sick. I'm sure it was the triad. I saw her late in the game. But I wanted to bring to the public the severity of these kinds of things. I'm sure you've seen that too. When you have someone who's maybe bedbound—in a moment we'll talk about the triad because that maybe fits in more with the triad and the dysoternomy—or in these really severe cases, how do you stabilize them? What are the bigger guns that, if needed, could be used?

Dr. Leonhard Weinstock 30:11
You mentioned steroids. We do want to keep them off. If I have somebody with severe diarrhea, though, budesonide is a nice one because it doesn't get absorbed from the gut. And then steroids. If they have severe pain, they're in the hospital, then I'll give them the IV protocol created by Andy in California. He came up with the idea of IV Benadryl, IV Pepsid, IV Versaid, or Ativan, and IV ketorolac (Toradol), which I'm not thrilled with because it can produce ulcers and a fluid challenge. He gives those to his patients who have POTS but also MCAS. It can be very helpful. I have some patients who are getting intravenous fluids and the three medications intravenously to keep them out of the hospital. Or if they're in the hospital, I'll give that. The steroids can be given with that complex as well. But the more and more steroids, the more risk.

Dr. Jill 31:39
Yes, I couldn't agree more. And I wait for those at the very end. But for those really severe cases, it can be lifesaving. You mentioned Versed and Lorazepam (Ativan). Benzodasapenes—even though we don't love those, they're very habit-forming orally—have an effect on mast cell activation. Is that correct?

Dr. Leonhard Weinstock 32:01
They stabilize it. There's an animal study that proves that. And there's empirical data just from managing patients that it's a very good drug. It's step two. Step three would be Xolair. If you've got hives and asthma that's refractory to therapy, seeing an allergist to get that drug—it's a shot once a month—anti-IgE can be very helpful.

Dr. Jill 32:38
Excellent. I don't usually prescribe that. Like you said, I usually refer out to an

immunologist or allergist. But in Xolair, in my small clinical experience, maybe 30% of people react to it too. Do you have people who react to it?

Dr. Leonhard Weinstock 32:53
Yes, for sure. It's immunogenic, so that's the problem. But there's one good article about it that looked at multiple things [along with] GI symptoms, and there was a 30–40% improvement in GI symptoms. It even improved neuropsychiatric things. And I wanted to talk about that if we have a moment.

Dr. Jill 33:18
Yes, let's go into that because it's huge. Let's just frame this because you wouldn't necessarily think mast cells are in the brain, but obviously, it has a huge, huge impact on these things. Dive into that and tell us how that could present with mast cells.

Dr. Leonhard Weinstock 33:32
One of the questions I have always asked once I knew about some of the manifestations is: Did you have panic attacks as a kid? So many people did. And then depression—I started taking a history, delving deep into depression, bipolar [disorder], and ADHD. Dr. Afrin did a whole article on different reports. There are many neuropsychiatric disorders associated with mast cell activation.

Dr. Leonhard Weinstock 34:10
We just published a paper; it was a case series of eight people who had a variety of psychological problems that were made worse by psychiatric medications. They didn't tolerate it or it made it worse, and/or they were suicidal—some of them all their lives. Diagnosing MCAS and treating them for MCAS got all their psychological problems better. We're now going to do more of an epidemiological study to see how often it is and how people have responded once they're diagnosed with MCAS. For me, this is one of the most exciting things that we've done because so many people tell you they react terribly to SSRIs and other things.

Dr. Jill 35:04
Yes. And to know that there's something else out there. That makes so much sense. Years and years ago, I was studying just histamine, which is only one little thing out of the hundreds of chemicals that mast cells produce. There's a definite correlation

with focus, lack of focus, and even IQ. There are a couple of studies on IQ and histamine, which is crazy. But it interacts with the brain on a profound level.

Dr. Jill 35:25
You mentioned the triad. To me, this is one of the most fascinating things because, as I've understood the triad, and this is what your documentary is going to talk about, it pulls together some of the most complex cases that are mysterious as far as what's going on. You mentioned it before, but let's talk again about: What is it? And how do all these things connect in our common presentation?

Dr. Leonhard Weinstock 35:48
Absolutely. The evil triad is MCAS, Ehlers-Danlos syndrome, and POTS. Either they run together because they're common or it's more likely that there's an etiology involved. If you talk to any POTS expert who knows a lot about mast cells, they'll realize that about a third of POTS patients are caused by mast cell activation because the mast cells live in the nerve bundles of the parasympathetic and sympathetic chain. If you're constantly firing away chemicals—also, the blood vessels are there—that open up the blood vessels and allow the body to pool blood in their veins, their pulse is going to go up and their blood pressure may go down. And at least they may have syncope or be near syncope. If we say a third of POTS patients are due to MCAS, then we want to worry about hypermobile EDS.

Dr. Leonhard Weinstock 37:06
It was Dr. Afrin's idea that the MCAS patients not only have inflammatory and allergic mediators but also have growth mediators. Many of the patients can get subcutaneous nodules, fibromas, and increased rates of cancer. His idea was that the patients with mast cell [activation] who were secreting growth mediators would make the tendons and ligaments grow, which would therefore make somebody hypermobile. That's one way to connect it.

Dr. Leonhard Weinstock 37:55
I studied restless legs in 180 MCAS patients. How many percent had it? Forty percent. But twenty percent had EDS and twenty percent had POTS. It gives you an idea. This was just looking at patients who had GI disorders and came to see me. But I looked at whether they did or didn't have restless legs. The concordance rates were twenty percent POTS and EDS. They're very common together.

Dr. Jill 38:29
I have a question. You might be the author of the papers I'm referencing, but I've read some papers on rosacea and SIBO, as well as restless leg and SIBO. For me, it's been a big aha because, for so many of my patients, when we treat the SIBO, those things will improve. You've probably been the author of some of those papers.

Dr. Leonhard Weinstock 38:46
Yes.

Dr. Jill 38:46
Where does SIBO fit in? In my very humble clinical opinion, I feel like some of the microorganisms in our gut can produce excess histamine and trigger mast cells. Is there a connection between bacterial overgrowth or fungal overgrowth in the small bowel and the manifestation of mast cell activation?

Dr. Leonhard Weinstock 39:03
Yes, there is. I looked at 130 patients with MCAS and did breath tests on everybody. Most of them had bloating, abdominal pain, or bowel habit changes. Thirty percent had positive hydrogen and ten percent had positive methane curves. The inflammation that we get on the gut lining is something that's important because that is one of the triggers—that's on the trigger table, as is SIFO—that can make the mast cells indwelling in the gut lining worse. So that's really important.

Dr. Leonhard Weinstock 39:52
Restless leg syndrome. Likewise, I think it's a systemic inflammatory problem. We've been studying it for quite some time. Endorphins are low and inflammation is high in many of the secondary restless leg syndrome [cases] and MCAS throughout that forty percent. That's the highest positive concordance rate of secondary restless leg syndrome of forty different diseases. It's really big. For a lot of my patients that I treat with LDN for mast activation, their restless leg syndrome gets better when we're reducing the inflammation. And that just doesn't happen. So there is the SIBO connection. And maybe it's decreased parasympathetics, so you have decreased vagal tone and you're not flushing out the bacteria. And that's why you get SIBO in MCAS.

Dr. Jill 41:05
Maybe it's the migrating motor complex and that small bowel motility that's impaired as the thing that causes—

Dr. Leonhard Weinstock 41:12
I think you're one hundred percent right.

Dr. Jill 41:14
Okay. That would make so much sense. People who have a chronic viral load or a tick-borne infection often have some issues with small bowel motility and the vagal nerve, and it seems like it's all connected.

Dr. Jill 41:29
This is so fascinating. I'm so grateful that you're out there doing the research and publishing. Whether you know it or not, I've been quoting your work for years. You've been putting it out there and helping doctors like me really understand what's going on. I'm so grateful that you have been curious and keep looking for those answers.

Dr. Jill 41:48
Obviously, we want to talk about the documentary—where people can donate or help support that effort. But before we do, is there anything else on the horizon that you've been studying, looking at, or maybe seeing some correlation? What are the next steps in this area?

Dr. Leonhard Weinstock 42:04
The next step is definitely the psychological issues in MCAS patients. A number of us have large numbers of patients and we'll hopefully send out a bulk blind email. If you do or don't have psych problems, please just answer the questionnaire. And then we'll come up with an idea of the frequency of MCAS in patients who have refractory or difficult-to-manage psychiatric problems. Some of the people on our website discussion group feel that most of their patients who have had bipolar disease have mast cell [activation], which is really interesting.

Dr. Jill 42:56
In my small, little clinical experience, I would agree 100% that this is so connected. I wonder if maybe 95% of our mental illness is organic, whether it's inflammation,

immune dysfunction, mast cell activation, or other infections—you name it. I think there are so many times where it's an underlying cause versus just something that you were born with. And I'm sure you're seeing that too.

Where can people find your work and your research? And then we'll talk about where they can donate to the film.

Dr. Leonhard Weinstock 43:25
At GIDoctor.net under 'Resources', there are a number of little slideshows, PowerPoints, and articles that I've written.

With the documentary, we're trying to make it a learning experience for everybody, whether they be medical professionals or something to open the eyes of patients who have had to deal with symptoms for decades and are now finding answers. We explain what's going on in the movie about mast cell activation syndrome.

Dr. Leonhard Weinstock 44:08
We are doing something unique. We're tying it to an online library with papers and PowerPoint presentations. In that way, we help patients and potentially doctors who are interested. We have to get the doctors interested. We have to get this into the medical schools. It's just absurd that it's not.

Dr. Leonhard Weinstock 44:36
As far as where to go, it's MCASFund.org. No matter how little or how much you choose to donate, that will be great. It's a not-for-profit movie, so we're not making a dime. We're putting a lot of efforts in. We've filmed half of it, but now things have slowed down in fundraising. Anybody anywhere can [donate]. Even a bricklaying for $10 would be fantastic.

Dr. Jill 45:13
I am one of your biggest fans and I think this is so critical. And like you, I think that we need to educate our fellow physicians because it is an epidemic. The more doctors we have that can help us treat these patients, the better. I love that you're doing this. I'm your biggest supporter. I'll try to help you get the word out and be right there with the donations as well.

Dr. Jill 45:32
If you heard this and you're driving in your car, wherever you listen to your podcasts, in the show notes we'll have these links. So don't worry if you missed it. You can find that on my website or anywhere you've listened to this podcast.

Dr. Jill 45:44
Dr. Weinstock, thank you for your heart, curiosity, work in the world, and your ongoing efforts. I know this isn't easy because you also have a full clinical practice, but we are so grateful. And thanks for taking your time today to talk to us.

Dr. Jill 45:57
Well, that's a wrap. Thank you, guys, for joining me for this wonderful interview with Dr. Weinstock. I hope you will check out MCASFund.org and support this documentary. I think it's a critical effort—we need to educate the public and other physicians on the prevalence of mast cell activation disorders. I know many of you who suffer from that will appreciate it.

Dr. Jill 46:20
We hope you've enjoyed this show and I hope you'll stay tuned for more empowering episodes with new episodes I release every week. You can find them all on iTunes, Spotify, or wherever you listen to or watch podcasts. You can find the complete transcripts and more information and links on my page, JillCarnahan.com, or on YouTube. And if you want to have links to any of the products that were mentioned in this show or others, just go to DrJillHealth.com. Thanks so much and I'll see you next week!