Dr. Jill

Your Functional Medicine Expert®

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Podcast:

#103: Dr. Jill interviews Dr. Tania Dempsey, MD, on MCAS

Text:

Dr. Jill 0:13

Hello, everybody! Good afternoon and welcome to another episode of Dr. Jill live. I'm so glad to have another special guest here today. I have the best job in the world when it comes to this because I get to talk to my friends and colleagues. What's really cool—the secret about these interviews—is that I always learn something just like you. I'm sure that from Dr. Dempsey today we'll learn some great things about MCAS.

Dr. Jill 0:37

Before we start and before I introduce her formally, just a little bit of background. You can find me and all kinds of blog [pages] and information from the last 10 years at jillcarnahan.com. If you need any products or services, you can find them at drjillhealth.com. You can find this episode, which is 103, and all the other ones on my YouTube channel, which is just under my name. You can also listen in your car as you're walking or hiking or wherever you're doing activities. [You can find us] anywhere you listen to podcasts. So find us on Stitcher or iTunes or wherever.

Dr. Jill 1:10

Today I am just absolutely honored to have a guest that I highly respect who's been publishing some amazing work. Today we're going to talk about some of those papers. She has been putting out incredible information. We were just talking right before we got on here about how important now more than ever the message of functional integrative medicine [is]. Sometimes I call it "medical mystery solving" because so many of you listening and so many of our patients, [also] if you're a practitioner listening, you know these are people who are coming to your clinic with very, very complex chronic issues that are mysteries to the most conventional doctors.

Dr. Jill 1:44

We're both trained in conventional medicine. However, what we realize is that sometimes there's more. There's more than just what we're taught. I always feel like the foundation I have in my medical training is critical to making good diagnoses and treatment, and changing medicine and shifting it. However, there's more. And today we're going to talk about more, especially in the realm of MCAS, which many doctors know a little bit about—mastocytosis—which we were taught in medical school. And today we'll go into all the differences between the different types. How do we diagnose it? How do we treat it?—and everything you wanted to know about MCAS.

Dr. Jill 2:19

But before I start, I want to introduce my guest, Dr. Tania Dempsey, a medical doctor. She's board certified by the Holistic Medical Association as well. She received her MD degree from Johns Hopkins University School of Medicine and her bachelor of science [degree] from Cornell University. She completed her Internal Medicine Residency at New York University Medical Center and she's currently a community staff member at Greenwich Hospital in Greenwich, Connecticut. So, it's Lyme country, right?—which we'll probably talk about infections too.

Dr. Tania Dempsey 2:49

Oh yes. We can cover it all.

Dr. Jill 2:54

In 2011, she founded Armonk Integrative Medicine, which has evolved into the AIM Center for Personalized Medicine, a destination practice in Purchase, New York, which focuses, as we just said, on complex multi-system diseases. And again, we were both just talking about how we need more doctors and we're both passionate about training and teaching because this is an epidemic and patients are getting sicker and sicker. She's been an international speaker, writer, and keynote [speaker] for the International Congress on Natural Medicine in Melbourne, Australia, [and has been] featured on Fox, The New York Times news, Reader's Digest, Huffington Post, The Observer, The New York Post, and countless other media outlets. I won't read all of the publications, but she is a well-published author. We are going to specifically talk about some of the recent papers that you've published because I think the data is going to be fascinating and interesting to our listeners. First of all, welcome, welcome! I'm so glad to have you here.

Dr. Tania Dempsey 3:58

Thank you for having me.

Dr. Jill 4:01

You're welcome. Where I want to start is with your story. How did you get into functional medicine? We're both MDs; [we're] very conventionally trained. I, like you, love our background. It's a great foundation, but we've gone broader, right? We've gone wider, we've gone deeper. How did you get to where you're at now in the integrative realm of medicine?

Dr. Tania Dempsey 4:21

Like all of us in the functional medicine world, we've all had our own journeys. Actually, I have always been interested in a more holistic view of health. I was sort of raised that way. I remember [when] I was a teenager and I had a pimple. My mother consulted her little vitamin bible and said, "You need zinc," and I would take zinc or whatever it was. It would work. But I grew up in that mindset: maybe there's a natural way; maybe it was the food; maybe it was something else. So I had that part of me going into medical school.

Dr. Tania Dempsey 4:59

What happened was that I found that I had to really split, kind of dichotomize my existence. So I was living this life where I was thinking about my body and what I was putting in it, the environment, and the nutrients. And then I was studying science and medicine, and there wasn't a lot of overlap. There wasn't an ability to really overlap. But I would walk around with this vitamin book in medical school and everyone would be like, "So what do we take?" I'm simplifying functional medicine, of course. It's not just about vitamins. But this was a secret, the way I had to think about health and lifestyle and then what we did in medical school and then training.

Dr. Tania Dempsey 5:42

So when I went into training, it was all about: people have high blood pressure, you put them on blood pressure medicine. I wanted to talk to them about what else was going on. I wanted to understand the links between the rest of their lives, not just their lifestyle and stressors, which are obviously very important, but also other things that were connected. Maybe they had stomach pains, or maybe they had other conditions. I always understood that there had to be a connection, but our training was that you treat that—isolation. [For example,] if they have stomach pain, you send them to the GI doctor. You know, you send them to all the [respective]

specialists. It started to get more and more difficult to confine my practice to doing that.

Dr. Tania Dempsey 6:22

I started spending more time with patients, and then I would get reprimanded. My bosses [would tell me]: "You're spending too much time"; "You're not billing enough"; "You're not writing enough statins"; "You're not writing enough Lipitor." True story: at one point, first they were docking us $1 per patient and then $10 if the patient had [a] cholesterol [level of] over 200. They were docking our pay if our patients had [a] cholesterol [level of] over 200.

Dr. Jill 6:55

Unbelievable!

Dr. Tania Dempsey 6:58

I'm not making it up. That's a true story. So that was the last straw. I said: "Wait a second. You're going to pay me to put people on cholesterol medications? I don't even know if these people need cholesterol medication." There's so much more beyond medication. That was the point where I was like, "Okay, I've just about had it." And then more and more, I was seeing this there. I was also seeing it in my own life.

Dr. Tania Dempsey 7:25

I was dealing with an issue with my son who developed vitamin D deficiency—a really severe vitamin D deficiency—because his pediatrician told us, "Don't give him vitamin D." And I was trying to be this good mother who was like, "I've got to listen to the doctor." The pediatrician used to say to me, "Don't be the doctor, you're the mother." [So I said,] "Okay, I won't put him on vitamins." And [as a result], "Oh my gosh!" He was really very sick. So it was like: "Okay, now I get that the vitamin D thing is really important! This is very important." I started learning through my kids, myself, and my patients. And then I really had to go on my own. I said: "You know what? I'm going to take a risk and I'm going to start my own practice." I did it at a time when—at least in my area—every doctor was joining those big conglomerate—

Dr. Jill 8:14

You were going the opposite way!

Dr. Tania Dempsey 8:15

I went the opposite way. I said: "You know what? I have to do what's right. I opened my practice and said: "I don't know how many people are really going to come to me." But this is what I believe in. This is the way that I'm going to treat people. I'm going to spend time with them. I'm going to dig. I'm going to understand the connections for them. I'm going to help unravel their health. And if I see five people, okay." But obviously, it grew.

Dr. Jill 8:42

It grew and you're known in our world so well and so respected. I love that story and I can relate. Same thing—I grew up with organic vegetables and we'd go to the homeopathic stuff or those kinds of things in our home before we'd go to antibiotics or medication. So I kind of lived that. And then I went to the medical school environment, and there's also this very masculine [mentality]. You have to fit in and be this strong, tough [doctor]—not intuitive, not sensitive. So I kind of put aside my feminine intuitive nature—not that it's [about] male or female. But the feminine nature is more intuitive, wiser, more feeling, and more gut instinct versus just science. I think the best world is when we blend them both. But our conventional training is so masculine-analytical-driven like you've discovered.

Dr. Jill 9:31

I remember a little story that relates to you being paid for cholesterol in the hospital. I was the Integrative Medical Director at the center, and so I sat on a board with the GI director and the rheumatology director, and we were all sitting in the boardroom, and the medical CEO of the hospital was doing charts of beds filled by each department. [He would say]: "How many beds are you filling as a department in our hospital? How many patients are you sending to the hospital?" And of course, the gastroenterologists were filling them and the cardiologists were filling them, and then there was me with integrative medicine and it was like zero. I'm like, "Wait a second.... " Same thing. That intuitive sense was like, "This doesn't feel right because I want to keep people out of the hospital and I'm doing really well if I'm [at] zero [beds filled]." But I was actually docked as a department for not getting people to fill beds in the hospital because that's what they were tracking.

Dr. Jill 10:17

Both you and I kind of came up against the system that we knew. The beautiful thing about your story and mine is that this intuition in our hearts was like: "This is not right and I'm going to risk my life to do what's right and I'm going to take that change." I did the same thing; I started my own practice. I moved to Colorado. The

same thing, I'm like, "Will anybody come? Can I do this?" I love your story because it's so [similar]. Here we are now. We are making a difference, not only in our clinics but in the world [and] in our small little sector. It's so powerful when we follow [our intuitive sense].

Dr. Jill 10:47

As you're listening, you might not be a doctor but you might be a mother or you might be a nurse or you might be in some [other] profession, and I encourage you: one of the important things out of this moment in the conversation is that you need to follow that intuitive part of what's good and right for you and not feel like what you're told is always the right thing because we both had these times where we bumped up against something that felt wrong and we changed. We took a huge risk, and here we are, right?

Dr. Tania Dempsey 11:13

Exactly, yes. I think that's a powerful message. If you know something is wrong, whether it's your career or your health or whatever, you have to start listening. That was the point where I started listening.

Dr. Jill 11:27

It's such a great foundation, even as we start talking about MCAS and stuff. One of the things I think is so important for us in our practices with patients—and again, if you're listening—patients know when something's not right in their body, right? The more we can listen to and empower them to know that they can actually trust that feeling that something's not right, [the better it is]. So often they go to the doctor, they get a basic lab panel on their liver and kidneys—a metabolic panel—and then they get blood counts or they get thyroid, everything's normal, and they're told: "You're fine. Go home. There's nothing wrong." And listeners, comment here if you've ever heard that, because I bet you that many of you listening have heard, "You're fine; you're normal," [yet] you know inside something's not right. Again, part of our message is listening to the patients. That's a great segue because we deal with patients who have these medical mystery conditions that many doctors haven't been able to figure out or they've been to other places, I'm sure, by the time they get to you. Let's start with: How do you start when you're seeing a patient? What kinds of questions do you ask? Where do you go? What are you seeing change in the last few years? Give us a little snapshot of the complexity and what we're seeing now in clinical practice.

Dr. Tania Dempsey 12:39

Well, I spend three hours or more with patients for an initial visit. So [there are] things that you need to find out to really start to understand how their condition got to the point that it got to, and [it's important to know] what the triggers and the drivers of their condition are. I start at their mother's pregnancy if they know anything about that. I go back even further to if their mother was sick before she got pregnant—if they know that. Some don't [know]—[for example, those that are] adopted, etc. But [we look for] whatever we could find out about what may have impacted them, maybe genetically or directly, whether it's toxin exposure, their mother lived on a farm where they used pesticides or whatever. I'm looking at everything in the environment. I'm looking at stressors.

Dr. Tania Dempsey 13:31

I'm looking at traumas of various kinds—what we perceive as trauma. What one person perceives as trauma, another person may not, so it's really [about] understanding how things impact the patient and all kinds of exposures to infections. I live and practice in a part of the country where it's an endemic area for ticks and tick-borne infections and vector-borne infections. So that always comes up and that's something that I always look for. We're looking at all the environmental issues. We're looking at stressors, traumas, things that have affected them that they may not have realized impacted them, even things like head traumas, concussions, and things like that, the area of the country where they live or the area of the world where they live.

Dr. Tania Dempsey 14:30

I would argue, and I think there's some evidence to support that there are tick-borne infections or vector-borne infections everywhere in the world. Maybe Lyme is more prevalent in my area of the country. That's Lyme—Borrelia burgdorferi—and there are other strains, and they're all over the country and all over the world. I'm looking for exposures: Is it a tick bite? Is it a spider bite? Have they been bitten? Have they had fleas, lice, and other things?—because we know Bartonella can be transmitted by many of these. Have they been bitten by animals?

Dr. Jill 15:04

I love that you're saying that, by the way. I just want to pause because I have seen so many [cases of] Bartonella [caused by] spider bites or other types of things that are not ticks and that maybe don't leave a rash. I love that you mentioned that. Vector-borne infections—which is another great thing that you said—are not just ticks. In Colorado, we're supposed to be non-endemic. We have tick-borne relapsing fever, we have soft ticks, we have the lone star tick, and we have all kinds

of ticks that do carry infections. And we're seeing [cases] as long as we're testing the right way, which we can talk about in a few minutes. But I love that you're asking that question because it's so important.

Dr. Tania Dempsey 15:37

Yes, I think we've become short-sighted by focusing on the deer tick transmitting Borrelia burgdorferi—that particular strain—when we know that the other strains of Lyme or tick-borne relapsing fever are transmitted by different ticks and different species. And then a lot of these other insects or arthropods are transmitting Bartonella. Maybe mosquitoes are transmitting Babesia or maybe even Bartonella. I don't know if we have research yet to support that. So we need to know that and then we need to know about their pets when they were growing up.

Dr. Tania Dempsey 16:14

We need to know: Did they live on a farm? Do they have exposure to being bitten by wild animals? You'd be surprised at how sometimes they don't realize it until you start asking. "Oh yes, I was scratched by a cat when I was five! Then I had a lymph node that was swollen." And then the patient that comes in and says, "Oh yes, I had cat-scratch fever when I was younger," you have to jog the memory a little bit because sometimes people go on and don't realize the relevance of what has happened. The doctors they've seen and the practitioners they've seen have not really paid attention to it. So it's really, really comprehensive.

Dr. Tania Dempsey 17:04

We have to look at heavy metal exposures and mold exposures. I ask about where they work and where they live—even [where they worked and lived] in the past. They may not be living in mold now, but maybe they grew up in a moldy place. [We evaluate] how that impacted their health over time.

Dr. Jill 17:19

I love this because you're really laying the groundwork for what's so important. That clinical history is so powerful, right? Often—probably like you—I'll know in that clinical history very clearly what direction we need to go, and I'll prove it with the labs. But often, if a good history is taken, you will almost have your diagnosis before you do the testing—if you're really listening for those clues.

Dr. Tania Dempsey 17:42

Correct, exactly.

Dr. Jill 17:46

I feel like with the pandemic, an already shaky system has been revealed to be even shakier and less robust for these complex chronic conditions like you and I see. What are you seeing?—like environmental toxicity, an increase in these ticks in areas that are more populated. What things are you seeing in our world that are making this more complex and [causing] more cases of chronic illness? Are there any ideas about what might be causing some of this?

Dr. Tania Dempsey 18:21

On a basic level, this has been a really stressful time, right? [There are] economic issues. Obviously, now there's war and people are dying. People were in isolation for a long time with COVID. We have that part of it. There was a lot of depression and a lot of eating for comfort. People in general need other humans. We may be introverts or extroverts, but in general, there's something to be said about the socialization of humans. In isolation, I think that a lot of people noticed a shift. I think that promoted the wrong [type of] eating [habits], a lot of excessive alcohol use, and increased drug use. We saw a range of things happen during this pandemic.

Dr. Tania Dempsey 19:16

But I think that a lot of people also got sick with COVID, some of whom were aware that they got it—they had a diagnosis. But early on in the pandemic when we didn't have testing yet or we had testing but maybe people weren't able to get it. I have patients who really feel that they got sick in February of 2020, before the lockdown in March. We can't prove that they had COVID, but they feel that that was essentially the straw that broke the camel's back, that their health declined at that point. I would argue that much of what we're seeing in terms of the increase in chronic diseases is linked to mast cell activation syndrome on some level. Of course, it's hard because that's the lens that I see things through, but there's no question that infections like COVID will trigger mast cells to activate even in normal people who don't have mast cell activation syndrome. So I think a lot of people had some underlying dysfunction that they didn't know about, at least in my population.

Dr. Jill 20:27

I agree with you 100% on this because I've seen that. I think that this virus, because it was so prevalent and so virulent as far as contagiousness, a lot of people that maybe haven't been exposed to tickborne or vector-borne infections were exposed to COVID. Let's go to the basics because you wrote a paper on how to diagnose

mast cell activation syndrome. For listeners who aren't super familiar—my listeners probably have heard of this—what is it? Why is it different from mastocytosis? How do you present? Tell us a little bit about the basics of mast cell activation.

Dr. Tania Dempsey 21:01

The paper is called "Diagnosis of mast cell activation syndrome: A global consensus-2." It's consensus-2 because there are papers that refer to a slightly different way of diagnosing mast cell activation syndrome, and so we call them consensus-1, [consensus-2, etc.] Really, what we understand is that mastocytosis is rare. It's a cancer essentially of the mast cell. There are a lot of mast cells growing, and they're also activated. So patients with mastocytosis can still have the symptoms of the activation. But mast cell activation syndrome is basically [when] people have a normal number of mast cells, but they're not normal. They're very very reactive. Why does that happen? There are lots of theories to that, but what I would say is that there are some people who are born with completely normal mast cells, and those mast cells—when [people] get COVID or if they get another virus or Lyme disease or whatever—they all activate, but then when the infection, the trigger is taken care of, they go back to baseline. Patients with mast cell activation syndrome have abnormal mast cells that develop [when they're] pretty young. Usually, patients with MCAS have signs of it in childhood—generally speaking. Usually, before they're 21. Usually, there's already evidence. But they may not be that sick and maybe their symptoms wax and wane, so they're fine. They don't think about it. Then, over time, there are these additional triggers that bring it out.

Dr. Tania Dempsey 22:47

When mast cells are dysfunctional, they're reacting even when there's nothing to react to. They are releasing chemicals. Part of how mast cells work is that they release these chemicals that are supposed to fight the environment, but in fighting and releasing these chemicals, they're also damaging wherever they are in our own body. That backfire is very inflammatory. Over time, people who have mast cell activation syndrome can have these triggers that could bring it out. I would argue that some patients with COVID had MCAS [but] they didn't know it. They got COVID and then it was the trigger that brought it out completely.

Dr. Tania Dempsey 23:36

So anyway. Back to the paper. The reason we published this paper is that there's really so much uncertainty or differences in terms of how to diagnose patients who have these symptoms. It is a multi-system disorder; it can affect every organ in the body. That's the thing about mast cells; they are everywhere, in every organ, but

they're not in the blood, generally. They are produced in the bone marrow. They're white blood cells, and they go from the bone marrow and they go into the tissues. They go into the lungs, into the skin, and everywhere they're supposed to go, and that's where they develop. Symptoms can range—basically in every part of their body. So if you have patients who have multi-system symptoms and they have what looks like a release of these chemicals, which we're going to talk about, then you can look towards making this diagnosis. The reason we published this paper is that this other group, which I have a lot of respect for, put a lot of stock into measuring one particular mediator that mast cells produce, and that is tryptase.

Dr. Jill 24:56

Yes, okay. I love where you're going because I couldn't agree more, which is why it's so important.

Dr. Tania Dempsey 25:00

I get asked this all the time. Even for doctors who are studying this, it's hard to understand. I think that the easiest way to think about it is this: mast cells make tryptase; all mast cells make tryptase. If you have mastocytosis, you have a lot of mast cells. [As a result], you'll have a lot of tryptase because, again, if all mast cells make them and there are a lot of them, there's going to be a lot of tryptase. In mast cell activation syndrome, it's the same number of mast cells—they're normal numbers—but they're activated. Activation doesn't necessarily make more tryptase. There's a small subset of patients who will have a mast cell reaction and will see an elevation of tryptase and they'll meet the criteria that were put forth by this consensus-1 group. You have to have a specific rise in tryptase and then you can say, "You had a reaction and so you have mast cell activation syndrome." But the vast majority of patients will not see a rise in tryptase. They will have a normal tryptase [level] at baseline. So many people then will be misdiagnosed or underdiagnosed if we just rely on tryptase.

Dr. Tania Dempsey 26:14

There's another condition that also causes an increased level of tryptase and it's called HAT, or hereditary alpha tryptasemia. It's very easy. It's a genetic test. You can check the number of copies of the gene that makes tryptase, and they could still have mast cell activation syndrome too. But what we did in this article is really outline things you should think about in terms of diagnosing patients, the general themes of mast cell activation syndrome, which are that you could have allergic disease, you could not, or some kind of allergic phenomena, inflammation generally, and abnormal growth and development. I think of things like increased cysts or

nodules or things like that; it's more complex than that, but I'm simplifying it. If you have this, then this is the way that we approach our patients who have mast cell activation syndrome [by] saying: test tryptase because sometimes it will give you information; if it's too high, you've got to rule out the hereditary issue and you've got to rule out mastocytosis; but let's look at all these other things that we can measure to help make the diagnosis. And that's what we looked at in this article. I think it's a helpful outline for people to either bring to their practitioners or their doctors and to say, "Can you read this and test me for this?" or for practitioners to actually read it and get some more clarity on what they can do to try to help make the diagnosis.

Dr. Jill 27:49

Yes, I love what you framed because, again, some of the stuff we talked about in medical school—we were taught in this very narrow box. The box is great, but there's often a spectrum of illnesses and these things that don't fit into a neat, tidy box, and yet our patients are still suffering and they still fit the general criteria. I've heard in clinical practice—and I'm assuming in your paper [as well]—often the clinical symptoms that they fit, and then if you intervene, they get better. Is that part of your diagnosis in this paper as well?

Dr. Tania Dempsey 28:14

[nodding]

Dr. Jill 28:15

Yes. Granted, I do the labs just like you do, and there are other markers too. Do you want to name some of the other markers that are commonly tested?

Dr. Tania Dempsey 28:24

Sure. Really, the number one—the most sensitive and specific marker is heparin. But it has to be measured in a specific lab. So heparin is a blood thinner, but it's made by mast cells in the body, in microscopic amounts. But if it can be measured correctly—we have a lab that we're using right now that I think is really good at picking it up. A lot of the labs will measure heparin because people are getting heparin as a drug, so they have to measure it in very, very small quantities. But heparin is by far one of the best [indicators]. You see elevated heparin [and] there's no other reason why they have elevated heparin unless they're taking it. You can imagine if they have elevated heparin, the types of symptoms that they may have. So if they're a woman and they're having heavy periods and excessive bleeding, you

can say, "Oh, maybe the mast cells in the uterus are producing an excess amount of heparin, causing more bleeding." So I think that's a really, really important marker.

Dr. Tania Dempsey 29:29

But then we measure something called N-methylhistamine—which is a metabolite of histamine—in the urine. We'll measure histamine in the urine. We'll measure leukotrienes and prostaglandins. So there are a number of things that can be done in the urine. There are some that can be in the blood. Sometimes we have to do a couple of rounds of it. I might get a heparin level, I might get a histamine level; I like to have two markers to make a diagnosis. But while I'm waiting and while we're still not sure, I'll do some simple things to start getting people better because sometimes it's going to be hard to make an official diagnosis.

Dr. Jill 30:07

Yes. Again, I am not the expert like you, but I have found in clinical practice that they need multiple things to get it controlled in general. Generally, one thing will not calm the system down enough. So this tends to be a multi-level [treatment] from herbs and supplements, quercetin, and meds. So we really go the gamut of getting these people controlled. Now one thing you mentioned that I have a curiosity about: you mentioned N-methylhistamine in the urine, which I measure as well; but is that a better marker than serum?—because it feels like [the levels tested in the] serum would go up and down and you'd miss it, whereas [with] urine you'd collect it and you'd see the [overall levels] body. Am I just making that up or is it true that you're getting a better measure over time of the histamine versus blood?

Dr. Tania Dempsey 30:48

It's a great question. The problem is that N-methylhistamine is a thermal labile, so it's very sensitive to heat. It quickly dissipates.

Dr. Jill 31:02

That's where the patient has to take their urine with ice to the lab, right? It's that important.

Dr. Tania Dempsey 31:07

That's right. But think about this: the patient has done everything properly [such as] refrigerating every sample—doing everything to keep it cold so that the mediators can be measured—but then it gets to the lab and it sits on the shelf in the lab. We had a patient who told us this. She did everything right. She handed it over to the

lab, and the lab took the container out and left it on the counter. That's it, it's gone! Yes, exactly. The problem is assuring that the sample was taken care of. What I find is that all of them are hard to see in the urine because it's hard to control all those variables.

Dr. Jill 31:52

It's exactly like you said. I totally get that. The other thing I thought about was: how does IgE play into this? Eosinophils, IgE—those aren't mast cells but they are related. Is there a relation to elevated IgE or elevated eosinophils in mast cells? Or are those two separate issues.

Dr. Tania Dempsey 32:13

I think there's a subset of patients who have more allergic diseases. To be clear though, there are patients who have allergic symptoms with mast cell activation syndrome, but they've been to the allergist and they're told that "you're not allergic to anything." You're like, "Yes, okay." You're not allergic but the mast cells are still reacting to those things but not through IgE, which is the allergy immunoglobulin. I do have a subset of MCAS patients who do have allergies as well. Allergy is a mast cell disorder. But they have allergy plus other systemic issues.

Dr. Jill 32:55

It's kind of like allergy is the umbrella and the mast cells are one thing under the umbrella, but there are other things under that umbrella of allergies that can be—

Dr. Tania Dempsey 33:04

I actually think the opposite. I think mast cells [are at the top] and I think allergy is one, and I think there's MCAS being under, which can include allergy but doesn't have to include allergy. That's kind of how I think about it. There are going to be patients who have elevated IgE. They really do have allergies to certain things, but they also have dysfunctional mast cells that are also reacting to other things.

Dr. Jill 33:33

This is a great conversation, by the way. Thank you for clarifying.

Dr. Tania Dempsey 33:41

Good. I think this is confusing and I have to say that I've talked to allergists who [may not] understand this. So you can definitely have high IgE levels and MCAS, but

you can also have low IgE levels. Now mast cells also have a few jobs. They release mediators; they also have conversations with other cells in the body, and one of the cells that they often interact with are the eosinophils. So there's a subset of patients who are more prone to an increased level of eosinophils. They can have eosinophilic esophagitis, so EoE in the esophagus. They may have it in their blood. They may have other manifestations. No one studied it precisely to say that EoE is MCAS or eosinophilia is MCAS, but I would argue clinically that many of those patients who have eosinophilic problems often have, when diagnosed, underlying mast cell dysfunction. So I have patients who have EoE who have done an incredible amount of work with their GI doctor. They take the proton pump inhibitors. Sometimes they change their diet, but sometimes they don't. Then I see them and they're not getting better. Sometimes they've done steroids. I said, "All right, let's figure out why these eosinophils are still reacting like this." There must be a trigger for the eosinophils. One trigger is mast cells, so we work on their diet, we work on the diagnosis, and we work on the mast cell trigger therapy.

Dr. Jill 35:27

Are you putting them on a low histamine diet or any other things that would be common? Probably gluten-free, dairy-free, low histamine—is that the basic [regimen] there?

Dr. Tania Dempsey 35:36

Basic. Not always low histamine. That's a whole other thing to talk about because I think there are some discrepancies in different low-histamine diets. I think that is not always the issue for a lot of people. Mast cells make over a thousand mediators; histamine is one. But that may be. I think it's very individualized. But from an eosinophil perspective, I may be targeting the mast cells. And I certainly have patients who I have found the right MCAS protocol for and their EoE disappears. It's amazing. The GI doctor thinks it's something they did; really, it's the work with the MCAS. But of course, with eosinophils, you always have to think about parasites and there are other things that—

Dr. Jill 36:23

Exactly. I love that you're saying that. That's why I want to ask you what your experiences are [in this regard]. There are people with zero IgE. There's a new paper on an immune deficiency that's considered just IgE, right? And I was like, 'ah!' because we know about IgG and IgA, but that's actually a new category of immune deficiency. But they still have mast cell issues, right? So what you said could be true because the IgE is zero and yet they still present with mast cell issues. My own

personal experience was after the mold exposure. I got so sick and then when I started taking binders I had hives and all kinds of mast cell symptoms head to toe because I was going too quickly. So I totally get this.

Dr. Jill 37:07

What are the triggers? We talked about [how] usually there's this genetic predisposition where people are born more prone to this because you could have someone with mast cell triggers and not get it because their mast cells are more stable. This goes back to infection and stuff. What would you say are the most common—maybe top five or six or ten or whatever—things that you see most commonly triggering mast cell activation?—like infections or toxins.

Dr. Tania Dempsey 37:29

Yes, absolutely. I would say mold is number one.

Dr. Jill 37:32

Yes, I totally agree with you there.

Dr. Tania Dempsey 37:34

I've had my own mold exposure and issues, so I can say that there's no question that there's a mold problem in this world in this country. There's not a lot of understanding [about it]. Too many people are living in conditions that are really, really disease-promoting; [they're] really, really sick. Mold, for sure. We say mold—it's not an infection, but it can be. So some patients who are exposed to mold are sick because of the mycotoxins. But I've certainly had patients who are sick with the actual mold [where they have an] infestation of aspergillus, let's say. They get aspergillosis. So it could be both. So mold is a big trigger, let's just say.

Dr. Tania Dempsey 38:20

I would say from an infection perspective—and again, it may be because I have a very skewed view, and maybe it's the patients I'm seeing—Bartonella is number one, two, three, four, and five, along with mold. I think that the issue with Bartonella is that because it's transmitted by so many different things, it's not like Lyme that has to come from a tick. I think it is very pervasive. The map of where bartonella is found is everywhere, like sub-Saharan Africa, you know, everywhere. So you imagine that that's going to lead to a lot of cases—a lot of cases that we're going to see of chronically ill patients. Many of those Bartonella patients also have co-infections, so it's interesting. In the Lyme world, they talk about Lyme and

co-infections. I talk about Bartonella and Bartonella's co-infections. So sometimes there's Lyme there, sometimes there's something else.

Dr. Jill 39:14

I love that you're saying that because I could see that in clinical practice too. Sometimes I think we go in our own little spheres. We're like, "Is it just me that's seeing this?" But I would just say, over and over and over again, that Bartonella rises to the top as one of the biggest things [along] with mold and MCAS and these whole layered mixes that people get where they get really really sick. I would agree with you, I think it's more prevalent than Lyme. It really is a big deal by far.

Dr. Tania Dempsey 39:37

I think Babesia is next because the more we're testing, the more I'm understanding. If you think about where Bartonella goes when you get infected, it actually goes to the red blood cells. Babesia lives in red blood cells. They actually have a symbiotic relationship. So my understanding is that Babesia—I forget the word I'm looking for—basically forces the iron out of the red blood cells. And bartonella basically eats iron—uses iron for its metabolism. So what I'm finding is that the more Bartonella I find, the more Babesia I see with it as well. But I think the top layer, the thing that's really making them sick—it's both. You've got to deal with both. But I think Bartonella ultimately is the problem, but Babesia is complicating their illness, I think. I might change my mind later.

Dr. Jill 40:32

I totally agree. Again, it's fun to talk to you because I'm seeing this too and yet I'm always like, "Is this just me or… " Babesia and Bartonella are so common and so hard to treat. It's not an easy "get better in three months" kind of [thing]. Wow, this is such great information. What about your paper on chemicals and MCAS? Let's just transition a little bit because you wrote another paper. Give us the title of that one and let's talk about what the main findings were.

Dr. Tania Dempsey 41:03

This is it: "Mast cell activation may explain many cases of chemical intolerance." We published it with Dr. Lawrence Afrin and Claudia Miller, who is really a pioneer in the TILT—toxicant-induced loss of tolerance—world. That's her thing. For this paper, we had a hypothesis that chemical intolerance may be due to MCAS—that MCAS may be the driver. But no one's really published [anything] on it; no one has really looked at it. It's commonsensical to me. But you really need to publish it and get the information out there. So, hopefully you can go beyond and can improve it.

So what we did for this study is we had our patients fill out a questionnaire that's been validated. Claudia Miller has developed this questionnaire called the QEESI. It's a 50-question questionnaire. People can find it online. I think if they go to tiltresearch.org, they could take the test themselves. I actually encourage everyone to take the test.

Dr. Jill 42:10

If you're listening, I'm going to give these links; I will post them. Wherever you're listening, we'll be sure to include all these links, plus to your research and your website, so just don't worry. If you're listening in your car, you'll have access to whatever you need.

Dr. Tania Dempsey 42:24

There's a lot of information.

Dr. Jill 42:26

Yes, so repeat that website real quick, and then the QEESI test is the name of the questionnaire, right?

Dr. Tania Dempsey 42:32

Right. It's tiltresearch.org. QEESI might have their own website now too, I think. So anyway, QEESI is the questionnaire. There is an abbreviated questionnaire called the BREESI. The BREESI [test] has three [main] questions. It's a nice sort of overview. It's very clear if you take the BREESI tests and you answer at least one question with a yes—are you sensitive to paint fumes, tobacco, or gasoline?; there are a bunch of these questions—the recommendation is that you go on and do the QEESI. In our practice, we just said: "Look, our patients are already sick. We know that a lot of them are chemically sensitive, so let's just give them the QEESI and see what happens."

Dr. Tania Dempsey 43:22

What we did was we took their QEESIs and matched them up with their diagnosis. So if they had mast cell activation syndrome and they had a positive QEESI—a high score on the QEESI—we were looking at the numbers there. What is the correlation between a positive MCAS diagnosis and a positive QEESI? And we found, yes, a large percentage of our patients clearly had that. We don't know because we haven't proven this yet: could you have chemical intolerance and not have MCAS? I guess it's possible. I can't say that all of those patients have MCAS yet because we haven't

proven it. This was our hypothesis, and we have a theory. We're supporting our theory, but we don't know 100% yet.

Dr. Tania Dempsey 44:07

I would argue that you could have MCAS and not have chemical intolerance. And I have patients who may be sensitive to some things, but they really are not profoundly sensitive. I have MCAS patients who come in with perfume on and I think, "That's crazy!" but that doesn't bother them. But there are other things that obviously they're reacting to. But anyway, I think this paper goes one step further in [helping to] understand why patients get to the point that they get to. We know that some people are chemically intolerant and some people are sensitive to EMFs. Some people are sensitive to noise and sound. So we start to understand the mechanism. What we want to understand is why. We think it's mast cell driven. So what is that process that leads to that? So that's kind of what the paper covers.

Dr. Jill 44:58

This is so exciting because I am not a researcher but I have such an appreciation and admiration for you for putting out these papers because this is where we need to take medicine—just bring the data. What we start with is observation, which is what you're saying. [Essentially, you said]: we saw this and we thought maybe there's a connection, so let's start to look at the connection and write the papers and then continue to prove it out. So thank you for all that you're doing there. There is one other paper I want to mention before I let you go that you've talked about, which is the post-HPV vaccine and what you're finding. Do you want to share just a little bit about that?

Dr. Tania Dempsey 45:32

Yes. This was a case series based on our observations. Look, I'll say this: one of the things that was really important to me once I was in the functional medicine world and treating patients, it became very clear that we needed to publish. I feel really strongly about that and especially when Dr. Afrin joined my practice, because he's a researcher and because he's coming from that academic background. I think that the two of us saw this opportunity.

Dr. Tania Dempsey 46:02

We have to get this information out there, otherwise, we're existing in our own worlds. You know that, right? We practice and do our things; we notice these things; we hear of other people noticing them, but we need to convince the greater medical community because we can't help all the patients. We need to treat others,

so I think publishing is a really great way. So that was my little segue. I'm really excited to be doing this. I didn't think I would be doing this, but I am. I'm so excited.

Dr. Tania Dempsey 46:31

Anyway, in this paper on the HPV vaccine, what we have found—there's some literature already to support this—[is] that there's an increased risk of POTS, postural orthostatic tachycardia syndrome, after the HPV vaccine. People are studying that and trying to understand that. So what we're starting to understand in our practice is that POTS is very much related to MCAS in a subset of patients. So can you have POTS and not MCAS? Yes, I think there are patients who really don't have MCAS and they have, let's say an autoimmune-driven POTS. But a fair number have an overlap of mast cell activation and postural orthostatic cardiac syndrome, and I'll say EDS may be the trifecta that closes the loop. So if our hypothesis is that many positive patients have MCAS and the HPV vaccine was causing POTS, what if what was really happening was that the HPV was actually exacerbating underlying MCAS? So the key is that it's not causing MCAS but that, like I mentioned with COVID, it's a trigger that brings that underlying susceptibility.

Dr. Tania Dempsey 47:53

What we found in our case series is that many of these patients who presented with POTS and then finally we diagnosed them with MCAS, if you go back in their history, it's very clear that they had signs of something early on. And they had the vaccine, and whether it was the first one or after the third one, they went on to develop POTS and significant disability, and then finally we were able to put it together and they had MCAS. So this is bringing to light the fact that there may be something specific about the HPV vaccine. Maybe we can generalize this to other vaccines. It's not anti-vax; it's very much pro-vaccine. But it's about trying to understand individuality in medicine. It's always about: "You need this." Right? And I would argue, yes, I think that to prevent HPV-related cancers, it's very very important.

Dr. Jill 48:50

I love that you're saying that because I agree. I've always told patients I completely believe vaccines have a place. I am 100% behind them, but if you take a very large population with any intervention, you're going to reveal—I always relate it to a cardiac stress test. You have a 65-year-old man walking around with no symptoms or problems. You put them on the treadmill and maximize their cardiac output and, all of a sudden, you reveal a deficit that they were walking around with [which was] underlying. You reveal something that was hidden that could have caused death to

that person. It's the same thing we're talking about here. You have this massive population and most people are totally fine. But when you stress them with an adjuvant or something else, all of a sudden you reveal: "Oh they had MCAS"; or "Oh they developed POTS." So I love that you're clarifying because we need this. We need to be able to do this in a way that's good for our populations and helpful and also know the few canaries that maybe would react to it, right?

Dr. Tania Dempsey 49:51

Right. So it's helping patients to recognize that these things happening to them are not because they're crazy or they're imagining things. The things some doctors say about their patients are mind-blowing. Also, I think that the way science has to go and medicine has to go is that we have to be able to start to identify the patients who should be getting the vaccine or shouldn't be. Or they need the vaccine and they have underlying MCAS. Can we stabilize their MCAS? Can we give them mast cell targeted therapy and get them ready for the vaccine?

Dr. Jill 50:27

I just love this and it's important work that's needed in all of these realms because we need the voices that are advocates for the canaries—the one in a million, one in a thousand, one in ten thousand—that are going to have reactions to these interventions. So thank you for your work. I'm just imagining too, as you were talking—as we end here—this big map. Ideally, we [would] have this map. I can see EDS, POTS, and MCAS. Someday we're going to have a map of how they all fit together and maybe the genetic predispositions. With your research, I thank you because you're making this map for us. You're actually helping to create a map for the new medicine, which is the medicine of personalization that goes to the individual because we're all so different. There's no one-size-fits-all. There's no N of 1 right. There's no real N of 1 as far as this perfect patient that fits the criteria. So this personalized idea of medicine is really where the future of medicine is going, I believe.

Dr. Tania Dempsey 51:27

Yes, I couldn't agree more.

Dr. Jill 51:29

I'm so delighted about this conversation. I've learned so much from it. Where can people find you? Where can people find more information on the papers you published? Tell us [about] any other links that would be helpful.

Dr. Tania Dempsey 51:42

Sure. So I have my practice. The website is aimcenterpm.com. [PM stands for] 'personalized medicine,' so we've abbreviated it. I have my own website, drtaniadempsey.com. Facebook is Dr. Tania Dempsey. On Instagram it's @drtaniadempseymd. So we're trying to update all those places with all the stuff that we're publishing. And of course, I don't have my own podcast, but I've done a lot of podcasts and we have those all available as well.

Dr. Jill 52:18

Very good. Thank you. Awesome! Like I said, I'll include all those links, and thank you for your tireless efforts. I'm just so appreciative of the work that you're doing, Dr. Dempsey!

Dr. Tania Dempsey 52:28

Thank you. Thanks so much!