Is Mast Cell Activation Syndrome (MCAS) the root cause of chronic illness? Transcript

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Introduction to Mast Cell Activation Syndrome

Welcome everyone to the Mycotoxins and Chronic Illness Summit. I'm doctor Christine Schaffner, and today my guest is Doctor Tanya Dempsey. We're going to be talking about is mast cell activation syndrome the root cause of chronic illness?

Please check out Doctor Dempsey's bio in the notes. She's an expert and very well versed in this condition. She's a clinic in New York. And she has many publications on this topic.

So I hope you enjoy this insightful interview with Doctor Dempsey. Welcome, everyone, to the Mycotoxins and Chronic Illness Summit. I'm Doctor Christine Schaffner, and I'm thrilled and honored to interview today, Doctor Tanya Dempsey.

She has shared so much about mast cell activation syndrome. And really we're going to dive in and really try to understand, could this be at the root cause of the chronic illness that either you're struggling with or if you're treating patients with.

So welcome, Doctor Dempsey, it's really an honor to interview you today. Thank you. It's an honor to be here. I'm happy to to spread the word and educate so absolutely.

Well, you live in this world, right? This is what you see every day. And I know I've only been practicing about 11 years. And I think during that time, you know, we've always seen sensitive patients.

But I feel like this, you know, increased sensitivity. I don't know if it's just our awareness or a new phenomenon with all of the environmental stressors and the pathogens that our patients are dealing with.

But, you know, physicians like yourself and your colleagues are putting the language around, really what is going on biochemically and physically with these patients.

And so, we'll just start with, you know, an overview. And, please share with us, you know, what really are mast cells and how can they tie in to the sensitivity, that we've seen in the office?

Yeah. And you know what? I'll just I'll just address your earlier comment about, you know, are we seeing more or are we just more in tune to it? Because I, I agree that over time, over the 20 ish years of my career, you know, I had these patients back when, now that I understand more about it, I would love to call those patients up and tell them, I think I know what you have.

I didn't know it back then. I mean, we we sort of empirically treated and got people better, but like, now this, this, this sort of just opens up into that.

But but I think that it's a combination of factors. Again, it's awareness but it really is that they are environment is very, very toxic. And that's I think the point of your summit it there's no question about it.

So, so I think that, you know, I think I'll start then just to understand, you know, our bodies, our, our, need to really, interact with the environment, right?

We, you know, as human beings, we need to know. And animals are like this. I mean, any living being has to have some communication with the environment, and and it's a protective mechanism.

Right. So we have mast cells if we get down to like the nitty gritty there, they're white blood cells and they're part of the ancient immune system. So that there are other animals that have mast cells as well.

And they are, a part of what we call the innate immune system. So they're, it's primitive. It's sort of like it's a fast, you know, kind of reaction. It's a fast interaction with the environment.

And mast cells are even though they're white blood cells, there are we have lots of white blood cells flowing through our, our our circulation in our in our bloodstream.

But mast cells live actually in our tissue and they live in their, our organs, the skin, the GI tract, the the lungs, the heart. Right. So they're everywhere where there's tissue and they are there to protect us from the world around us.

Infections, all infections, chemicals, pesticides, all everything that could be potentially dangerous to us. The mast cells are there to, to protect us.

And so I think about it, you know, when we think about, before we even talk about chronic disease, let's just talk about in every single person, whether they're sick or not, but they have mast cells and they have mast cells that will react under certain circumstances.

I like to use Covid 19 as an example because there are healthy people who have gone sick with Covid and they and and their mast cells will activate. It's an infection, right?

Whether they had a prior issue with mast cell activation syndrome or not, we're going to talk about what that means. Doesn't matter. Mast cell C virus.

They're going to go off and they're going to to try to combat it.

What Mast Cells Do and Why They React

And the mast cells have a couple of different ways that they they try to protect us. So they have one of the easiest things or one of the fastest things that they do is they they do granulated.

We say they basically I like to use the term explode. So they release these chemicals that they make these chemicals are known as mediators. They're lots of mediators that they make.

We we now have identified over a thousand mediators that mast cells can make. Not all mast cells are going to make a thousand mediators. But but the point is there's a lot of mediators that can do a lot of things.

And so when the mast cell sees a virus, whatever, right. It's going okay and it's exploding. And it could be histamine could be one of the mediators. That's a common one that a lot of people have heard of.

But again, there are others. And those mediators are inflammatory. They're they're they are in a sense trying to help. Right. So they're they're going to maybe fight that virus.

But you know, really at the end of the day, what they're doing is actually releasing these chemicals that are actually toxic to us. So if there's too much of that going on, wherever those chemicals are being released, they're causing inflammation.

So if if that reaction is happening at the level of, of the lungs, then you're going to you could cough, you can have shortness of breath. So it really depends on where the muscles are reacting to that, that that thing that trigger okay.

So that's that's where in normal circumstances and what should happen is if you have normal mast cells that are reacting to something, they should be able, if they're normal to reset, they just sort of like go back to normal and then they're waiting for the next event to happen, which may never happen or may now in cell activation syndrome, what we're talking about is these are this is a condition where the mast cells themselves are inappropriate.

They are I'll use the term mutated event. Right. They do carry mutations that cause them to to react more than normal. They don't reset. So they may react to the virus, but they don't go back to, to normal.

They're they send the person into this sort of spiral of continued activity and an initial activation syndrome. Most of the time it's something could be genetic or something that that is sort of presenting early in, in childhood.

And over time it does tend to worsen and sort of escalate during a person's life when they're exposed to a lot of things in the environment that are potentially toxic.

I mentioned infection, but but mold is a fungus, right? That is an infection. But then those that fungus, let's say, produces micro toxins. So it could be anything. Right.

But in Marcel activation syndrome it's really the cells themselves have probably been abnormal before the trigger. And the trigger makes it worse. And then it sort of then sets them up for the next event.

And they never I can't say never. I mean, that's my job is to get them back to, you know, back to normal. But but often they just continue to escalate.

So mast cell activation syndrome just to to just even to clarify even more, you know, there are different ways to look at it. There's something called primary mast cell activation syndrome.

And there's something called a secondary. And then there's idiopathic. And so in primary mast cell activation syndrome those are people who that is actually the root of their condition.

That's starting from childhood. They've had triggers. They've had infections. They've had mold exposures. But the real root you have to eliminate triggers.

But the real root is the mast cell in secondary mast cell activation syndrome I have I have a handful of patients like this. They are completely normal.

They never had any immune dysfunction whatsoever. They have a major event. I have a patient, for instance. She's well until the age of 40. Right. Like lived up really, you know, very productive life and then got Lyme disease.

Right. And then is is now in a state of mast cell activation syndrome secondary to infection. And in some of those cases, you treat the underlying trigger infection, you eliminate the toxin, whatever it is.

And they do reset. And the mast cell activation syndrome sort of gets reversed. In some cases it just continues unfortunately, and becomes there becomes the problem.

And idiopathic is sort of like probably a combination of all the above. We have yet to figure that one out. Right? You know, it's probably all of the above. Yeah.

No thank you. That was excellent overview. One of the things two, as you're describing this, you know, is there in some of, what I've tried to understand clinically, do you feel like there's a spectrum, like there's kind of this, you know, there's a primary and secondary and there's, you know, the diagnosis of mast cell activation syndrome.

But do you defining your practice of there's, like a spectrum, like maybe people are not that extreme, but they have more irritable or excitable or, you know, just mast cells that just don't reset as well.

But it's not completely in that expression of a diagnosis. Have you been seeing that as well? Oh, oh. For sure. Yeah. There's really a broad spectrum of disease.

And I would argue that there are a lot of people walking around with mast cell activation syndrome who don't know that they have it because they're relatively healthy, because, you know, they might have had a few weird things pop up, but no one's ever put it together for them, and then they just continue being okay.

Right. But then there's, you know, the other there's another set of patients who have some issues or coming to a doctor. They're they're looking to get, you know, some information.

They know something's wrong, but they're still highly functional. Right? They're still in a state where, yes, their immune system is more reactive, but but they, Or their bodies compensating, right.

There's some way that they're still controlling it. And then, you know, obviously at the end of the spectrum is very severe disease where it's, you know, basically the body is almost shutting down because of this level of inflammation and reactivity.

And I think what's really even important to understand is in this, in the spectrum, there are people who have more allergic like phenomena. And those are those are the patients that are a little easier to diagnose.

Spectrum and Types of Mast Cell Activation

Right? Because they, they, you know, they just it comes to mind, right? They, they have some seasonal allergies. They have some food allergies. They may not even have allergies.

They've been to the allergist. They've been told they don't have allergies, but they have that sort of allergic like phenomena. They have some hives or they're itchy. Right.

And those are the patients that are a little bit easier. They're on our radar. But there's but you don't actually need to have any allergic like phenomena at all and still have nasal activation syndrome.

And this is like a take home message. Like I want to make sure that people listening understand that they don't need you don't need, to be that person.

You could be someone who has inflammation as your primary issue that, you know, you have, joint issues, you have pain, you have neuropathy. You know, again, you could have decided, no. Me, you know, dysfunction in the autonomic nervous system, you could have dysfunction in the GI system with gastroparesis.

You could have and not have one allergic symptom whatsoever. I can still have. And that is muscle activation syndrome. Really. It's not proven otherwise.

And then and then you could also you could have a combination of those. And then lastly, you could have because I think they're really the way to think about is are like three themes of mast cell activation syndrome.

So you have the allergic like you have the inflammation, and then you have destro ism, which is sort of like abnormal growth. And development. So those are the patients.

They have lumps, bumps, nodules, cysts, you know, in various places. And they and they can be, very disruptive. They can be they could be very mild. That can be more severe.

That so that and that could be their main issue or it could be combined with those other things. So if you start to think of it that way, you start to understand how many patients really are affected by this.

And according to some research out of Germany, a number of years ago, they published that 17% of the population, at least 17% of their population. And if we assume their population is similar to our population in the United States, we would say 17% of people have cell activation syndrome.

So now you understand, like the reason that can be is because it could be such a wide variety of manifestations. Yeah. That's again an incredible number.

You know when you think about it with the general population and I think as we put our attention to this, we, you know, have the opportunity to diagnose our patients.

And you know, of course that sets us up for the appropriate treatment and for them to get their lives back. But, I guess where we could go now, I think people are probably like, well, maybe this is me, you know, maybe I've had this, like, where do we start with, you know, tests and how can we really, hone in if this is really the thing that needs to be treated, to get as well?

Well, I think, look, I think you need to take a very comprehensive history. So if, if people are, you know, they need to they need to make sure if they're the ones so that they're the patients that are listening, you know, they need to find a practitioner who's willing to listen to them.

The history has to be from the beginning of their life, and I would argue even earlier than that. Right. So the history of the mother, some people don't know that history.

They're adopted. They don't. Right? We do just sometimes the history is not available. But if it is available to try to understand what what the person was exposed to, all these triggers need to be evaluated first.

Before you even go to testing. You need that history. You need to understand, right? Because if there is mast cell activation syndrome and you and you find it, you're not going to get the better unless you've identified the potential triggers that are making them worse. Right?

So the history is imperative, right? So I take a very, very thorough, you know, two three hour history. And then and then you start to sort of unravel where you figure out what you need to test for.

And if you've determined that the story really kind of is consistent with potentially mast cell activation syndrome, then we send them on that path for testing. The testing is is a little complex.

And unfortunately, we really are struggling to find labs that can do the testing correctly. The testing, some of the things that we do, a lot of the testing relies on trying to find those mediators that the mast cells produced.

A lot of those mediators are very sensitive to heat temperature changes. They they degrade very, very quickly. So they were only around for a short period of time.

So if you're trying to collect it in blood or urine, it's sometimes you can't find it. It's so sometimes it's a lot of salt and sometimes it's just because that's just what happens.

So the process of testing relies you need to we need to have a reliable lab. So what we've done is we've we've we've created our mast cell collection lab.

We don't do the actual, you know, testing of the specimens, but we've, we've arranged we have a lab that we work with. We we process the specimens properly with a refrigerated centrifuge.

Everything is kept cold and and and, avoiding heat. So we prevent the breakdown. And so we, you know, we do. Some of the testing is done in the blood.

Some of the testing is done in urine. Sometimes it's a 24 hour urine collection. And I would argue you probably need to do all these things, to get to really understand, because sometimes it's hard to get the answer.

But, you have blood, urine. And really the third way you can, the third piece of data that you can use for the diagnosis is, with a biopsy sample. So lot of the patients that I see, they've, they have GI symptoms.

So they've had an endoscopy or a colon. Skippy, they've had some kind of scoping and and often they've had biopsies done. And if we can get those biopsies and we can have them stained in a certain way to light up the mast cells, and that's the type of stain that most pathologists won't do.

They just they're looking for other things. Like most people are not thinking about mast cells. But we go back and we we have them stained. And if you see more than a certain number of mast cells on a, on a specimen that's, that

is supportive of the diagnosis.

And I like to have two, pieces of data, it could be a blood test or a urine test or, and, or, you know, a biopsy, but you'd like to see two mediators, ideally, or two sources of that, that there's a mass cell activation process going on.

And that combined with the clinical history allows you to make the diagnosis.

How Mast Cell Activation Is Diagnosed

No thank you. And I know that because you do this day in and day out, you've perfected a lot. And the the process and it's complex, as you said, you know, in this realm, as we're talking to patients and clinicians who treat mycotoxins, illness and chronic illness, there's a lot of, you know, a lot of this is a, you know, the reliance on clinical history and, you know, just therapeutic trials based on, you know, that data because we're yeah, I mean, we're doing this in 2021, right?

We're recording this. And it's if we just use lab work alone, we would probably miss a lot of opportunities to treat our patients empirically. So it's it's great.

It sounds like we're getting there, but still, you know, it's still it's complicated. Right. And, you know, I was trying to, you know, but I, I was just saying, are there, you know, in the basic blood work, you know, that people have more access to do you see, certain patterns or trends, like some of us will look at, like eosinophilia or total IgG or like, you know, things, you know, again, that won't catch every bucket that you've shared.

But do you see, like some of that, kind of like patterning in some of the basic work that makes you think that we should go down this direction? Yeah.

And you brought up two very, you know, important findings and, and very easily accessible by most practitioners. Draw it, draw that. And any lab can do it.

But definitely you see an elevated IgG. There's a there's a flavor of allergy. You see 80% cinephiles. There's a flavor of allergy, of course with eosinophils you also have to make sure they don't have parasites or something else.

Right. So it's not specific but it does. It does kind of give you an impression. I would say that it's not uncommon to see. And again, you can't you can't just assume it's national activation syndrome.

But sometimes we see Polly CIC Mia. We'll see an elevated hemoglobin. You know those patients that you're not you're not sure they don't have hemochromatosis.

They don't have a reason to have like elevated, you know, red cells. But they they have those elevated red cell indexes. And so you think why why is that.

You know, maybe driven by by mast cell activation. I'll sometimes see elevated platelets again, not specific for mass activation syndrome. Sometimes we see white cells just the total number low or high.

You know. So you start to see especially if you see a pattern. I would never use one blood test alone. But if I've gone there but you know, their blood count a bunch of times and I see that there's like sort of this consistent pattern and I've ruled out other bad things that it could be.

Right. The whole point about about diagnosing mass activation syndrome is that you really want to make sure that the symptoms and the signs and the clinical data and the, and, and the other, you know, all the in the laboratory data support that nothing else explains that this condition, that muscle activation syndrome can explain, you know, the entirety of of the patients, situation.

But if you're, you know, you're doing a workup and the white count is high and you find out they have an infection,

right? You can't just say, that's mast cell activation syndrome. Right?

So it's a little bit it is again, a lot of, reliance on you. You know, you need to know this stuff. But I do think for people who don't have access to, like, really complex testing, they can, you know, you can tell some things from from blood.

I see very often metabolic issues in mast cell activation syndrome. So they might have an elevated hemoglobin A1. See, they're not diabetic yet, but they might have some insulin resistance very commonly seen not 100%.

But it is not an uncommon thing. We see hormonal imbalances. So you know, in general I think, women with polycystic ovarian syndrome are at higher risk for having mast cell activation syndrome.

And I would I would say actually that it's mass activation syndrome. That probably puts them at risk for polycystic ovarian syndrome. But there are all of these syndromes.

And so they those women have high testosterone. They they may have acne, they may have increased hair. They may have weight issues or not. They may fertility issues, women who have, abnormal periods, heavy bleeding.

So you're doing this hormonal workup and you start seeing there's something off that can be, you know, again, supportive of the diagnosis, but not diagnostic.

You know, yeah, that's, some interesting connections I had to put together. And, you know, when you're talking to my colleague, you know, because, you know, for women also who might be, going through infertility or trying to get pregnant, sometimes that andro is prescribed right around those, you know, you know, situations to, you know, help, with fertility.

So it's like, of course, you know, but, you know, you, I, you know, you hear things differently. So that that's interesting because in a lot of our chronic illness community.

Right. A lot of women, you know, they have PCOS and they have, endometriosis and they have, you know, fibroids and these, you know, these, you know, these conditions.

So sometimes we just think are, you know, related to estrogen dominance or microbiome issues or so forth. But this is another lens to look at that. That's really interesting.

So, you know, I can pick your brain all day long. So I'm trying to, well, you know, so so, you know, when I think of mast cell activation and this is where I'm learning from you today, you know, there's, you know, again, the buckets that you shared and, you know, I'm a natural pad.

So I'm always like, thinking about, like, the trigger, right? Like, okay, what's causing this. Right. You know, so I'm thinking, you know, there's often this pattern that I've seen at least that my patients teach me that often patients with Lyme and co-infections, especially Bartonella, they kind of could have this piece of the puzzle going on at the same time.

Also, we'll talk about, of course, mycotoxins and how that can kick things up. And then parasitic infections too, because of, you know, just how the immune system shifted with parasitic infection.

So there can be more kind of histamine type, reactions. You know, when you treat, parasites, sometimes people get these skin rashes and, you know, these types of things.

So how do we, you know, make sense of this? So again, you've shared this.

Basic Lab Clues and Related Patterns

I don't want to reiterate, but should we be thinking of like these infections trigger the mast cells. You gotta figure out

the infection piece and then, you know, reset the mast cells or like, hey, we're on the planet.

We're exposed to these things all the time. You know, it's the terrain that's dysfunctional and the mast cells that are probably, you know, for that person.

Could it be more, triggered by these things that people are exposed to and that creates the illness? Does that make sense? How I answer yes. Yeah, yeah.

Yeah. No, it makes a lot of sense and actually is a conversation that I had with almost all my patients, mainly because, you know, we get we get this data right.

We've we've tested for mycotoxins and we find out that they are living in a, in a moldy home. We've done some tick-borne testing because they've had some exposures that we're worried about.

You know, maybe they they've had a cat and they've been bitten a bunch of times. Maybe they've had, you know, maybe they've had a tick bite or they've they've grown up in a endemic area.

So we do the same line testing, tick borne testing. Right. Maybe they have a spagnola positive test. That makes me concern and you know, and then I've done I've done some work looking at their gut because they have a lot of gut issues.

So I see dysbiosis and I see, you know, you know, an abnormal maybe leaky gut or whatever. Right? So I see all these things and, and I also have this history that supports mast cell activation.

And I might have some data to support the diagnosis. And you sort of you look at and I say to the patients all the time like I can't tell right at this moment what the real root cause is, right?

But I suspect as we kind of go down this path, it's going to be very clear. And and that's the truth. Over time, the things clear up. But I would say that one of the things that has really changed in my practice the last few years is that in the past I would focus more on these issues.

The mycotoxins, the infections, hoping that that would sort of reset the mast cell part of it. And and then a lot of those patients, you know, they would they would have these perks, time or reactions or detox reactions or they just wouldn't tolerate things.

And you would be spinning, you know, you're spinning your wheels and thinking like, how am I going to get these patients back? And these are the patients that I now do the opposite for.

And I would say that I do that for almost all my patients. Now you have to go after the mast cells. You have to you have to think about if they have high histamine levels in the blood, then you, you know, you think about different antihistamines, whether they're drugs, whether they're naturally antihistamines.

You might need muscle stabilizers, you might need to run through a lot of things. But the point is that any treatment will not be tolerated very well by a lot of these patients, at least the patients that I've seen, they've been so chronically ill.

And if I try to like unravel all the stuff in their environment that they've been exposed to, I think I, you know, they they don't get they don't respond.

Right. But when we start to calm down the mast cells, we start to calm down, reduce the mediators, reduce some of the inflammation. You know, and we're sort of working on the other stuff.

It becomes clear, okay. The mycotoxins not good for them. It's not good for anybody. And at some point, you know, they have to get out of that house. But, you know, it's fascinating.

I have patients that are still living in their moldy home, but I'm treating them for their mast cell activation syndrome. And they've said to me, I can't, I can't I don't have money to remediate.

There's nothing I can do, you know, and I need to get them better. Right. And I know that I'm not going to be able to detox them. I'm not going to be able to do I'm going to work on their mast cells, because if I can at least help stabilize them and they're not so reactive to the environment, they're going to they're going to get better.

And I have a patient today who emailed me. He he what he can move out of his house. He can't afford to to to do the remediation. His micro toxin levels are off the chart.

He has tremendous neuropathy. He has every chronic disease known to mankind diabetes, high blood pressure, kidney failure, you name it, he has it. Severe depression on a lot of medications.

And I'm, you know, and I'm thinking, how am I going to how am I going to get him better? Right. So he tests positive for Bartonella. He has about you know, he is my typical patient though.

And he's miserable and he's in pain. Right. So, you know, we we try these different things. Right. And then I and he was so resistant to doing, antihistamines.

There was no way he said that's not my problem. And I said it is your problem actually, because we've confirmed you have vessel activation syndrome. Let's just try it.

No, there's no way an antihistamine is going to help me. You've got to find another way. Right. And we went through this for, you know, a few weeks. And then finally I convinced him.

It's like, just do me a favor. Just get some Allegra. Let's just start, you know, because, again, I'm limited with what I could use for him. I'm limited, by a lot of things.

And so, Allegra, right over the counter, can you just go get some and just do me a favor? Just try one and try to. And then and then let me know. Right.

So I spoke to him two days ago. Two days ago. Right. He emailed me today, and for the first time in months, his neuropathy pain was controlled. He tried gabapentin, Lyrica, you know the neurologist through all these things the guy was screaming in pain.

Triggers, Infections, and Environmental Load

And Allegra one one pill a day for two days. He said wow the neuropathy pain is better. So my point is this. So I'm getting to the point where I feel like all those things are so important and I'm never going to I'm never going to ignore it.

And and here's a guy where I'm going to have to work on all these other issues that we found and all the environmental stuff, but wow, how powerful is that?

That just bringing down his histamine level a little bit gave the guy relief so that now he sees, okay, this is potentially the problem. So I'm I'm making am I making sense.

Oh yeah. That's perfect. That that makes a lot of sense. And no, I want a win right. For this patient and for you, of course. You know, to you know, see that, you know, clinically and, you know, I, you know, we think about, again, like, as a natural path, I'm thinking like, oh, support organs of elimination and lymphatics and as, as you're sharing as and I agree because of what I see as well that, you know, potentially for some patients like really starting with the mast cell piece and, you know, the reactivity piece, we, I have a clinic with a team of doctors, and we had a, a meeting this morning, and we were actually one of the cases that were presented is exactly, like different, but similar.

Right. But like really reactive. And, you know, this doctor had this patient and a lot of things, but we were still like you still we still are missing some pieces of the muscle piece to, you know, allow the patient to go through treatment.

But right, you know, and to start, you know, you know, really alleviate suffering. So, so you mentioned Allegra, right. And so and you mentioned already some categories, but I'm sure people who are listening are like, okay, how do you treat this?

Like, how do you even go about treatment? Like, so just maybe some, clinical, insight to treatment. Sure. I mean, I think, you know, I like to set some foundational support for the patients.

Most of these patients are vitamin D deficient. And and mast cells have vitamin D receptors on them. So if there's a deficiency that makes nerve cell activation worse.

So, you know, a simple tool I use is I treat the vitamin D deficiency and sometimes like, okay, you know, that may not solve the problem for some, but wow, some patients just a little extra vitamin D helps them.

So there's some simple things, you know, that I might do early on. Or I might just, you know, go right into the antihistamine. You know, category. And and in the antihistamine category we have the antihistamines that are over the counter.

We have Benadryl, which is a, which is an older, form of an antihistamine. And then we have sort of the newer generation Claritin, Zyrtec, seasonal and Allegro.

And then we have the generics of all those different formulations. And there's liquid and gel and rapid, dissolving. And there's so there's a lot of options over the counter.

We have there are prescription antihistamines that sometimes we, we have to go to. Sometimes we have to compound the histamines. And I would say compound anything.

And I would say the biggest challenge, you know, in treating is that, mast cells can react to medication, to vitamins, but more importantly, they can react to the fillers that the medications or the vitamins are mixed with.

So there could be a, the capsule was often made of like methyl cellulose. Some people react to that. Sometimes there's magnesium Stewart, sometimes there's, crossover Dom.

There's some of the, pharmaceutical stuff, though. There are ingredients that, you know, companies use to sort of fill things up or like to make a tablet stay together.

Sometimes they put dyes in it so they have like, colors. I don't know why. That's crazy. That's probably my biggest pet peeve is the dyes. Like, why would you put dye in an allergy medicine?

I, I to make sense. So, so sometimes it's, you know, we have people try one formula and maybe they don't do well, or they don't react. Well, we might have to try them on a different formula of the same drug, because maybe we're not sure is a drug is the problem or or if it's the stuff that the drug is with.

That's why sometimes compounding it and having a special pharmacy and make it without a lot of the other ingredients, sometimes that's helpful. But the point is that there are a lot of like, simple things that, that people could do.

So those antihistamines that I mentioned are in the category of each one blockers. So they block a histamine receptor, in the body called H1. And we have a lot of H1 receptors in your skin.

And the respiratory tract. So that's why when you take an antihistamine like for allergies or from cell activation syndrome, it goes in, it blocks the histamine.

So the histamine can't can't cause a problem. That's basically what it's just like blocking it from working because a histamine is the thing that's really inflammatory.

But we also have we have natural antihistamines vitamin C, quercetin. So there are a number of natural compounds that have some of that property. And then we have another class of drugs called H2 blockers.

And H2 blockers are histamine blockers that they block these H2 receptors that are mostly in the GI tract. They're often marketed for people with heartburn or acid reflux.

But sometimes we use it for people who don't have those symptoms. But sometimes combining an H1 blocker, regular antihistamine with H2 blocker like Pepcid or Tagamet or something like that, Zantac was one we used before was taken off the market.

There's a prescription, one available as well. So sometimes combining those two, just dampening as many of those histamine receptors as we can is the key.

So one thing alone might not be enough. But together there's like a synergy. So we see that a lot in the mast cell world is that it seems like sometimes it's a combination, not any one thing alone.

So those are like the simple things that that people can do. And then, you know, if those don't work and I want to make a point that if those don't work, it doesn't mean you don't have mast cell activation syndrome.

Okay. Because I see this quite a bit where people get really frustrated and doctors get frustrated and they'll say, what we've tried all the antihistamines and they didn't get better, so that must not be the problem.

Well, maybe histamine is not their problem. Maybe. Maybe that's not the mediator that we need to be targeting. Maybe they're resistant to that. I don't you know, I don't know, but I have patients where the anti histamine is not going to solve the problem.

And or the, the, the long acting or newer ones don't work. But Benadryl is the thing that works sometimes and sometimes that does it. So so I think it's about persistence.

It's a lot of trial and error. And, you know, it sounds a lot like experimenting. And I kind of, you know, I hate to use that word because it's, you know, we're not experimenting on patients, but we but the point is that everyone's mast cells are different.

Every single mast cell, every single person has different mast cells. Even within families. You would think that there would be some genetic component.

Nope. So what one person reacts to or one one person's mast cells react to positively or negatively does not apply to the next person. So I present this case and I say, well, I will like to help this patient, right.

But for every patient that Allegra helps, I have, you know, ten other patients who can't take a like RA. Like, what's the worst thing for them? So, so the point is that the only way to know is to give a trial.

And I would say that realistically, I like to give 2 to 4 week trials. I would say that some things will be apparent very in a very quick you know, time period could be a week, could be two weeks.

But I usually tell patients, give it a couple of weeks if you're not having side effects, if you're having side effects. All right. Move on. That's not going to be a good one for you.

But you give it a couple of weeks, maybe a little longer, definitely by a month. If there's no response. It's not not the right, you know, intervention.

So so then you move on and you try something else. And this is this trialing does take time, right. And so it does

take a lot of patience. When patients are miserable.

They they, you know, feel crummy. It seems like a long time. But then when we hit it right then it's, it's great but it can but it can take time. And antihistamines are not for everyone so I might I want to make that point you know.

Yeah there are a lot of other things. There are stabilizers. And she taught often we sometimes use low dose naltrexone. And there again there's like a, a slew of other things that are a little bit more, you know, not like first line, but, you know, definitely can be helpful for some patients.

Thank you know, that, that really, gives us a picture, right, of, treatment options and then also, you know, like with everybody, right. It's that combination for that person at the right time.

And, but the goal is I like how you give a time limit, though, to trials because, you know, the goal is for this person to, you know, feel better. So, yeah, like, if it's not working, you know, come up with another combination with your provider.

Treatment Approaches and Antihistamines

So, you know, once we kind of get the mast cell situation stabilized and people, you know, feel like, okay, they have more quality of life, you know, they can have more resilience in their system.

Do you find that, like, okay, that's, you know, a big part of treatment and we settle there or do you feel more confident going like, you know, does this patient like the like our patient, do we need to treat all those things that we just listed and then do eventually when that burden or that, that total load in their system, is like gets to a tolerable level, do the mast cells, you know, become happier and just reset, or is this kind of like, this person just has mutated mast cells, you know, for life?

I mean, you know, I'm I'm an optimist. So I don't think anything's for life. But even with what we know now, you know, just curious about your experience, really, of what you see.

So, yeah. And I think that's an excellent question because, I guess that's the question that patients ask all the time. Are you going to get better? And then everything is going to be fine.

And and again, there are patients where taking the low down, reducing the burden, stabilizing their immune system and all that is going to bring them to a point where they may still have more reactive mast cells at the base of things.

But but they can. I have patients who go years without needing any intervention for whatever reason. Maybe maybe the mast cells are just yet. They're stable.

Maybe it's a different population of mast cells, and they they just are not as reactive. You know, basically I, I heard the statistic that the bone marrow puts out new mast cells, something like every 3 or 4 years.

So there can be like this, this like sort of life cycle of, you know, so maybe the next batch of mast cells that are produced are going to be better, you know.

So I'm an optimist to like you. And I always think, yes, there's got to be a way. But I also see patients who will always need some mast cell support for, for for their life.

And, you know, it might be that they always need to take an antihistamine, you know, and that's like, okay, it's not a big deal. Or, or they always have to take something up.

There may be that may be the case because they know that in the long run, they're just setting themselves up for a more sort of productive and, lower risk situation where they don't have to worry so much about what's going to happen.

So so, for example, right. I think about I use Covid 19 quite a bit because it really is such an interesting, horrible virus, but, but interesting in the sense that it's a virus.

We know it activates mast cells. So in our in my cell population, what's interesting is that I have patients who, have actually done quite well with the infection.

Surprisingly, these are some of these patients are more so reactive. And you think, oh, if they get, you know, if they get sick, it's going to be horrible.

Or if they get the vaccine, maybe that's going to be horrible for them. And they've done surprisingly well. And, and and for not. All right. But a lot of them. And the question is why.

And I look back in these, some of these patients or just well-controlled their mast cells are well controlled so that they are not as, as inflamed from the, from the, from the virus.

I can't predict that for everyone, but I but that's sort of the message I like to give to my patients that it's not a bad thing necessarily to need some support for a while, because maybe that just is better for you, right?

That that allows you to live your life and not worry. So much about, you know, my patients who are really, chemically sensitive or, you know, they, they react, they go to a hotel and it's a moldy hotel, and all of a sudden they're, you know, all their symptoms are back, right?

I have patients, though. That better? I've control their mast cells and their immune system and reduce the burden. And I've done all that stuff. They can go to a hotel and be close to mold and not and not, you know, really, really decline again.

Right. That's huge. Right. So I think about the work that I'm doing as preventative also, it's not just helping them now, it's helping them be less reactive to their environment because the reality is our environment is so toxic and we've got to have a defense mechanism against it.

This is just one way of looking at it. No, I love that. I, I often say like, well, if we lived in Utopia, this would be different, you know? But we're on planet Earth in modern times, and there are just a lot that, we're up against. Right?

And so again, I often say to, you know, health is resilience, right? That's our job. Like, we're not going to be able to control our environment and all the ways that we would like.

And so how can we be more resilient to those exposures and bounce back and not be taken down and out of life? You know, so I think, no, I, I think this is a really, yeah, important message, an important approach.

And that really makes a lot of sense of the, I didn't know the life cycle of NASA. So with with it being that long, you know, it makes sense that, you know, we do need, you know, this is like a through line for through treatment.

You know, many of us see patients for a year or two, especially to get them stable before they're, you know, in more of a maintenance and maintenance mode so that that makes a lot of, a lot of sense, Doctor Dempsey.

So, I mean, you've touched on so many things, so I, I just wanted to circle back just because a lot of people who are listening to, the summit are, you know, focused on Michael Jackson and Michael Jackson, you know, how is there anything that you want to add when you have, like, you know, that this, patient does have a high Michael Jackson bird?

And like any other strategies that you're thinking, that we haven't covered. Yeah. Well, I think I like to think about this Michael Jackson issue, on two levels.

One is the environmental exposure. So the more go in the water, damaged buildings or whatever they're being

exposed to from the outside. But I also see quite a bit of Michael toxin burden from, from the mold factory that they have inside, I call them, I call them mold factories.

And they have so much, you know, the, the, gut dysbiosis, they have abnormal, gut bacteria. They might have high levels of yeast, they might have high levels of of other types of fungus.

They make mycotoxins too. And so so then it's like the double whammy. You have stuff inside. You have stuff outside. The mast cells are going nuts. And and so the toxins themselves are going to be triggers from mast cells.

But I think what's really interesting is I had a colleague, use this sort of, example, because she's a, she's an expert in, in mold and mycotoxins. And so the way she described it to me is really, is really fascinating.

The high say, if you think about like the picture like the, the candida, yeast and they have these like, likes, we call them hyphae, but they like these long things.

Right. And they can touch a mast. So I the, the imagery that I it's just incredible what I think about as she said, it's sort of like the hyphae touches the mast cell and like pops, it's like a building.

It's like boom, boom, boom, boom. But so then you start seeing like you start thinking, right? You don't just have the toxins that are there are constantly making the mast cells reactive.

You're actually having like the physical force of yeast internally actually activating mast cells. Wow. Well, so you know again it's a it is a very comprehensive approach.

So I'm I'm looking at their mast cells. And I know that I have to give them some support there. If, if I you know, if I've proven that that's what they have.

So I'm working on that. Listen you have to remove them from the environment ultimately. Right. But they have to, you know, but there's so many factors that, that affect that their ability to do that sometimes it's not possible, but you hope that they could find a way to either remediate or move out or whatever.

But if they can't, you've got to work with what you work. You know, what you're dealing with. And if there's, internal yeast problem, we have to treat that.

So sometimes it's antifungal therapy, you know, could be with medication.

Long-Term Management and Mold Exposure

Sometimes it's with herbs. It's whatever. I, you know, we think we, they can handle, you know, that their body can handle their mast cells can handle.

So sometimes we have to sort of lower their, you know, kind of reduce their mold factory to reduce some of the mycotoxins. Sometimes we use binders. I find binders a little bit hit or miss in the mast cell population.

And you do have to be really careful with them. So I it's really a very gentle approach. You know, I might be doing a little binder and I do I make sure that their mast so you know support is on, on board and I'm, you know, we're kind of like it's like a dance.

I see kind of what we do is like it's a little bit of step this way and then we step this way, then we move that. Because we just don't know, right? Because every patient is different.

But at the end of the day, you're not going to get the patients better unless you've dealt with the triggers ultimately. Right. I can say like this one patient, yeah, a leg was helping, but is it going to solve all his problems?

I doubt that. So we're going to have to start peeling that onion. I use that analogy a lot. I see these layers, you

know, and mycotoxins are in one layer for, for a lot of my patients.

And, you know, you've got to strip that layer away and then kind of get what's underneath it. But I would I would argue that in the majority of patients who have micro toxin illness, there is a immune dysregulation that was there already.

And then the mycotoxins exasperate exacerbated it. And, and and then and we know that mycotoxins suppress the immune system. And then they activate the other part of the mixes with the mast cells.

So it's a mess. Like, you know, I see this I see this in Covid infections. I see this in my Lyme patients and Bartonella patients that many of them, not all in medicine.

We never say all. We never say 100%. I would say many patients have some susceptibility, the genetic genetic susceptibility or whatever. And then that mold exposure or micro toxin exposure is the straw that breaks the camel's back and then everything goes back.

So so it has to be dealt with. It is a major thing, but it may not be the root cause of their problem. The root cause is the immune dysregulation. Started the whole process problem in the beginning.

And yeah, does that make sense? Really? Well said. And really. Yeah. Comprehensive. And yeah, I agree. I mean, I think, it goes back to that idea of resilience and, you know, our immune system and, you know, we're just up against him, exposed to a lot.

Right? And why is someone in the same building fine. And the other person not, you know, there's all of these, you know, factors. And that's what we see a lot with mold illness, right?

The partner is totally fine and can understand their partner being, you know, so sick, you know, so we see that individualization and you know, just, you know, and I'm kind of jaded because I treat this all day long.

I'm like, we've all but a lot of us have been exposed to wine and viruses, you know, all of these things and why I'm always asking, why is this person sick and this person not, you know, so I think this gives a really, elegant explanation, you know, to that.

And so, so, as I said, Doctor Dempsey, I could talk to you all night long here. And I know, I know, we've covered a lot of ground and and an excellent, explanation of how mast cells and this immune dysregulation can be at the root of anyone who's suffering from a chronic illness.

Is there anything that's on your heart that we haven't touched on before? We wrap up? Yeah. Good question. I, you know, no, I think I like to just, you know, just emphasize the fact that, you know, there patients are people not feeling well if they're listening to this and they're not feeling well and they don't have the answers, the answers are there. Right?

I just you might not have found the person who can who can find the answers for you, but I just like to encourage people to just keep keep looking and trying and trust their body because, you know, doctors can tell you that there's nothing wrong, but, you know, there's something wrong, right?

So I say, forget what doctors tell you. You're the patient. It's your body. So you know. So keep keep figuring it out. And you know, if thinking about muscle activation syndrome resonates with you, right?

If it's something that kind of makes sense with your history, read about it. There's so many resources we we blog on it quite a bit on our on my website and Facebook and, and so, you know, and I and my partner here in the office, Doctor Lauren Safran, has, you know, has his book out.

Don't bet against the outcome if you really want to, you know, dig deep and into the world. You know, we have my, my website doctor Tanya dempsey.com and my new website, which is Aim center Time.com, because we just

created a new, our new institute, Aim center for Personalized Medicine.

So we're we're just trying to get the information. So I encourage people just read, not just my stuff. There's plenty of other stuff out there. And, and just, you know, continue to, to, to find to find the solutions.

I just, I think we just, patients don't, feel validated enough. It really breaks my heart. And I just want people to know that there's a reason something's wrong.

Just gotta find it. Yeah. No, I love that message. And I'm in full agreement. You know that? There's nothing that's random in the body, right? It's. Something's going on and just find the physicians who will work with you to uncover that.

And it's not just all in your head, right? You know? So, so, no, I I'm in full agreement. And you've done a great job, you know, sharing and educating our community.

So definitely have your websites and, people can, you know, what states can you see patients out? So people might want to, you know, work with your clinic.

How do you work with people either in person or via telemedicine? Could you share a little bit about that? Yeah. So, you know, definitely, the Tri-State area.

So I'm in New York, see, patients in Connecticut, new Jersey, Pennsylvania, sort of like I actually, I would say the it's not just the Tri-State. It's sort of like the northeast area generally.

We're good. Massachusetts. I do prefer it's possible to see patients in person if they're in states that I'm not licensed in. So we're working on that.

I'm working on my California license. I'm working on my Florida license. So I hope that once I'm licensed, it will be easier to do telemedicine. But right now we do require patients to be seen for at least the first visit so that I can examine them and see them in person.

There is something to be said about the about the physical exam.

Patient Advocacy and Closing Remarks

You know, it's one of those things that, you know, we sort of think, oh, we're never going to find anything. A lot of doctors sort of don't even take out their stethoscope.

But you'd be surprised what I find in the physical exam. And so I feel like that piece of information, although some of this can be done with telehealth, that first visit where I'm feeling their thyroid, you know, I found a thyroid nodule this week.

I found a large thyroid that's like I find things that no one else has found before because no one's actually, like, touch the patient. So, so, so the point being that we're working on some more licenses, state licenses so that I can do more telemedicine, sort of initially and then hope the patient can eventually get here.

But I really think it's important that, you know, if Covid restrictions are better and people feel like it's safer, I think coming in in person is still better.

And then we follow them, you know, you know, I patients I international patients, I do patients from wherever. And we see them you know, and we continue you know, monitoring them.

I think telemedicine has been you know, we've proven it during Covid times that it's you know, it's a great way to, to to interact with, with patients and reach them when you might not be able to.

But right now we are the point is we are a little bit limited because some of the states now. So like up until maybe this month, we had more freedom to do more telemedicine.

But we've been getting emails from various states telling us that as a because the Covid numbers are down, that they're taking away the emergency, services that they sort of they had in place that allowed outside doctors to treat patients in those states.

But it's getting a little tricky. Yeah, I know right. Always something to navigate. But now it sounds like you're doing a really great job to, you know, Castanet.

So you can see as many people, who can. So that's wonderful. So. Well, I can't thank you enough for this interview and you shared so much excellent information today for all of those who are listening.

And again, the message of hope and uncovering the, the root cause of whatever the chronic illness may be. So thank you so much for being part of the summit.

Oh, it's my pleasure. Thank you. Thank you for having.