Introduction to Mast Cell Activation

Though the one, area that a lot of people may have heard of mass cells is in the area of allergy. Marcel's are also involved in allergy because allergy like allergens, like pollen and, nuts and lots of things that people are potentially allergic to or things that the cells will recognize as bad and again, releases histamine and causes a downstream effect.

But mast cell activation syndrome, doesn't necessarily, mean that you have an allergy, but you could have an allergy or allergic responses. That's what makes the syndrome a little bit complicated.

So everybody has mast cells. Everybody's mast cells will they'll fight whatever they come in contact with. You know, the the example I like to give is Covid.

Okay. So let me just it just because a lot of people I give that example all the time, it's it's yeah it's unfortunate to be honest. It's really unfortunate that we have to use this example.

But you know, a lot of people know people or themselves who have had Covid. Welcome to Doctor Talks, the podcast where every episode leads to a healthier you.

Join us as we navigate the world of optimal health, uncovering groundbreaking strategies to conquer chronic disease. In each episode, we'll bring you the latest insights from leading health experts, medical innovators, and wellness warriors.

If you're seeking to transform your health journey, or if you're looking for answers to burning questions, you've come to the right place. Get ready to unlock the secrets of lifelong health and vitality.

This is Doctor Talks, real talk from real doctors. Only issues that matter to you most. Hi, everybody. Doctor Nancy O'Hara and I am thrilled to welcome Tanya Dempsey, to the podcast on demystifying patterns and Pandas.

Tanya is an expert in mass cell mediated disorders. Mast cell activation has taught me so much in that field, and I'm just thrilled to have her with us today. So Tanya, thanks for joining us.

Oh, thanks for having me, Nancy. I'm always happy to talk about all these mass cells. Well, I it's so important and so misunderstood. But but first, just tell our listeners or viewers a little bit about how you got to, to this part of your career or life.

Yeah. Well, you know, it's been an interesting journey, as many of us have had, you know. When I started, you know, I, I come from a very traditional, background.

And, you know, I was doing internal medicine and, you know, conventional practice for, for number of years before I realized, you know, this is this is really not working.

I need to have time to speak with patients. I recognized early on that that we were missing things when we were dealing with this, with our patients, that they're there.

That five minutes, is not enough. You need to day. You need to have a history. So I was always sort of thinking about, you know, root cause medicine before I even understood what would cause medicine was.

And and so, you know, eventually that sort of made my way into integrative medicine. And then once you're in integrative medicine and you have time to talk to patients, to think about the cases, to research, right?

Inevitably you're going to learn a lot. Right? And I learned something every day from my patients. And I have one patient in particular who I think really taught me about mast cell activation syndrome.

And she she's the one who really, you know, got me sort of launched me into this world because, she had this was probably back in 2015. She had, you know, these very complex, multisystem, inflammatory symptoms that I just could not put together.

You know, there were missing pieces that I just didn't I just didn't understand. And I was determined to figure it out. And and and one day on Pub Med, I came across, this thing, this disorder called mast cell activation syndrome.

And, and I was sort of thinking, you know, there are some features that she has that, that kind of sound like this, but like, what are the chances she has this?

Doctor Tanya Dempseyu2019s Path to Mast Cell Medicine

I, I've never heard of it before. I mentioned it to her. And it just so happened that she had a family member who was, at the NIH, and she mentioned it to him that I had mentioned this disease.

And then he said, oh, well, you know, the expert in this disease is Doctor Larry Afrin. And she said, would you mind talking to him? And I said, I'll try.

You know, he was in an academic center. My impression of people in academia was like, all right, they're really going to talk to me. I'm in private practice.

And I called his practice, you know, and I called. I spoke to his assistant. I said, I want to I have a case I want to discuss. And, and he said, they said, yeah, yeah, no problem.

You know, you want to talk next week. And they set up an appointment. And I was thinking, who is this guy who's taking this call from a random person to talk about this?

And, and I, he spent at least an hour, if not longer, probably an hour and a half, just giving me a brain dump. I still had to finish the job, right. And after that, I mean, I was sort of hooked and I was sort of thinking, this is I think this is the answer to so many things that I was seeing that I couldn't understand.

Right? Yes. And, and then eventually, you know, he came and joined my practice, you know, because we had kept in contact, he saw the work that I wanted to do and, the center that I wanted to create, he was done with academia, and he's like, I'm like, all right, let's do it together.

And so, he's in my practice now. We learn, we, you know, we research. And, you know, the goal is really to continue to try to figure out how to get patients better.

I mean, that's the bottom line, you know? Yeah. For all of us. And, you know, our our although, you know, mine took me in a slightly different path. There's so many similarities.

I mean, really wanting to listen to the patients and spend more time and figure this out. Be the detective and you do that so well in, in, in your patients.

So but I think, you know, on this podcast we have hopefully a lot of parents, but we also have some practitioners. But there may be a lot of people who really don't understand what.

Marcella. So can you start there for us? Do you mind? Yeah. Yeah, absolutely. And and actually, even before I say that, I do that, I think it's just important to know that while I, you know, focusing on Marcel activation syndrome in a lot of patients, I treat the whole patient.

So a lot of these patients have other things that are either making this condition worse or this condition is making

that condition worse. Right? So I treat Lyme and mold and pans and pandas and all those things too, because they're all interconnected.

Right? And absolutely, I see it through the lens of a lot of these things, through the lens of the immune system. And so the mast cells or a, there's cell in the immune system, they're part of the primitive immune system.

We call it the innate immune system. And so they're our first line of defense against our environment. And so, you know, they're the ones that are sort of sitting in our, in our bodies and, and, watching for invaders, whether they're viruses, bacteria, fungi, whether it's, toxins in the, you know, in the air, wildfires.

Right. Smoke, whether it's, plastics, you know, so whatever, whatever toxin or foreign substance, is they're coming in contact with our body. The mast cells are ready to attack.

What are the ways they attack? Is they, they make granules of, of mediators, chemicals, a chemical that that some listeners may have heard of is histamine is one of the many, many, mediators that mast cells make, actually makes those make over 1200 different mediators.

And, and some mast cells don't make histamine at all. But since people know about histamine, the mast cells will make these granules of these different chemicals.

It sees the thing that, that, that it needs to fight. It explodes into granules, it releases those chemicals and the, the, the, you know, the goal is for those chemicals to kill.

Right. And and damage whatever that, you know, foreign surfaces or infection. And but the problem is that when the mast cells explode and release these chemicals, it's not only, affecting that that foreign body, that infection or whatever else.

It's also it's in our tissues. Right. And and it's causing local and systemic inflammation. Those are those chemicals are also not great for our, our own cells and tissue, mast cells or in every organ in the body, they're white blood cells, but they're not in the bloodstream like a lot of other white blood cells.

They're in all the areas of the body that are in contact with the environment. So they're in the skin tones of their cells in the skin, the respiratory tract, the GI tract, the nervous system.

Lots, and the nervous system, which, which kind of will bring us to the pants of pansies. Right. Turns in the brain. And again, they're they're ready to fight.

They do. They have other ways of fighting. They talk to other parts of the immune system. They send signals for certain cells to make antibodies to fight in that way.

Right. So there's there's lots of things going on. It's very, very complicated. Though the one, area that a lot of people may have heard of, mast cells is in the area of allergy.

Mast cells are also involved in allergy because allergy like allergens like pollen and, nuts and lots of things that people are potentially allergic to or things that the cells will recognize as bad and again, releases histamine and causes a downstream effect.

But mast cell activation syndrome, doesn't necessarily mean that you have an allergy, but you could have an allergy or allergic responses. That's what makes the syndrome a little bit complicated.

So everybody has mast cells. Everybody's mast cells will they'll fight whatever they come in contact with. You know, the the example I like to give is Covid.

Okay. So let me just it just because I give that example all the time, it's it's yeah, it's unfortunate to be honest. It's really unfortunate that we have to use this example.

But you know, a lot of people know people or themselves who have had Covid and and we know that Covid is a type of virus that activates the immune system, it particularly mast cells, but other white blood cells as well.

Right. There's this cytokine storm that everybody sort of talks about. But there's a subset of people who get Covid, their immune system kicks in, they deal with the virus, and then everything sort of like resets.

I like to think of it as like, so the immune system just goes, okay, we're done. And their body goes back and and sort of, you know, fine. Right. So we know people who have had Covid and have had no sequelae after it.

Right. Everybody's right. They're fine. Then there are people who have had Covid where the immune system does not reset, the immune system continues to be activated.

And there are lots of reasons that could be we don't have to go into that part. Or we could, but but, there could be residual spike protein. There could be residual virus.

I mean, there's there are a lot of a lot of theories on this, right? Nonetheless, of the, mast cells and other mu cells continue to be activated and continue to cause a problem.

And that's mast cell activation syndrome, because, again, everybody has mast cells and activate. But if they reset, those people do not have mast cell activation syndrome.

What Mast Cells Are and How They Work

The syndrome is that even at baseline there's always a little bit of activity happening. There's always a little bit of inflammation. And then there's a big event like Covid that takes them over the edge, or they get exposed to mold, or they get Lyme disease, or they get exposure to some kind of trauma.

Yeah. Stress. I mean, there's like the the list is, you know, is very right. It then takes them into this, into this area where the mast cells can't stop and they continue to to fight.

And, and we see that all the time and, you know, trauma. But for, for us in their kids, the mold, the vector borne diseases, Covid certainly this mast cell activation syndrome is is what we see.

And I think it's fascinating. You know, you said so many things, you know, it's like, no, no, I, I it's wonderful. But I think number one, you know, it's not just histamine 1200 different mediators that are released when the mast cells do granulation.

And people need to realize that this isn't such a simple I want to get a histamine level to see if they have mass cell activation syndrome. I hear that all the time.

And you know, and so we'll get into that. But so many facets of that. And then to that, that although they can have allergic symptoms, they don't have to that there are mast cells in all the parts of the body and, and the brain.

You know, a lot of our kids, it's you know, it may just be anxiety and brain fog and they don't have a thing on. It's down their skin and it's still mast cell activation syndrome.

Exactly, exactly. And I think what's really, really important to understand is that this is a multisystem inflammatory disorder. Okay. But there could be systems or a system that is more vulnerable than in a particular patient.

And so for some patients, the, neuropsychiatric manifestations are much worse than any other problem in the, in the body. Although they might have some mild GI symptoms, they might have some, some joint pain, they might have headache, like, they may have other systems involved, but they, they can just have this predominant anxiety, OCD, depression or whatever.

And, and that's the problem is a lot of those patients, when the neuropsychiatric symptoms are the most

predominant, they, they get shipped off to the psychiatrist.

Yeah. Yeah. Without understanding that there's a medical reason right for that. Right? Right. And never treating or even looking at the immune system and, and this particular piece of it too.

Yeah. The other thing that I find fascinating is you have like a family living in mold, and you have several people that may be susceptible, but one has neuropsychiatric symptoms, another has respiratory symptoms, another has more classic symptoms.

But the baseline root cause the mold activating the mast cells is is the same. But they're presenting very differently. Yeah. Exactly. And and historically, I mean mast cells helped us to deal with toxins with parasites.

But but I think one of the reasons it's so much more prevalent is we live in such a toxic world, you know, the plastics and and all of that for sure. In our world, they kick it up.

And now we're getting it backfiring, so to speak, of that protection. Oh, 100%. And I think that, we're going to continue to see an increase in, in this, in this condition, you know, in 2017, I think it was 2017, the paper came out of Germany, where they estimated like 17% of the population of Germany, had a nasal disorder like nasal activation syndrome, 17% is a fairly large number.

That was already, you know, seven, eight years ago. And, and by my estimates, and in talking to colleagues, I think we're definitely closer to 20%. If not more.

And when you look at, how many people are suffering from, let's say, long Covid, you'll, you know, you'll see how those numbers are actually quite similar about 20% of people probably at this point have some features of long Covid or post Covid.

And I think that that that sort of makes sense because that's about what we're seeing with mass observation syndrome. And I think it's going to get worse the, the more, exposure and toxins and, and the like our, you know, that we're exposed to I think it's inevitable, which is, which is sad.

Great. I agree. So you have a patient where you're suspecting this from history. Do you always do testing? And if you do or when you do, what do you do?

Yeah. So, you know, because because I like to publish and, and because I work with doctor, you know, Afrin, you know, we do try to, to do as much testing as possible to determine, the diagnosis because then, then it first off, the patient, has a diagnosis which then really validates them.

And allows other doctors to recognize that they have a true disorder. So I think it's so important to get the answers for the patient to prove that that's what they have.

It also does help, you know, when we do research and we publish and things like that. But but most importantly, it's always the patient. So so I do try to test if I have a suspicion, we try to do the testing now that there's, there are, there are you know, there are issues that come up.

The testing may be, negative. Maybe we have to do a second round of testing. Some of the testing can be costly. So then we have to, you know, sometimes maybe make some concessions and try to figure out, how to get the most bang for our buck, you know, when, when doing it.

But but generally, if I can, what I want to do is I want to I want to do some blood work on the patient. And I do want to measure histamine. I want to measure plasma histamine.

I can measure a whole blood histamine because there's a chance that the histamine will will, you know, be picked up and, and and that that, again, is a helpful marker.

Then, you know, we also test for another marker called, chroma green and a chroma grind and a can be produced by mast cells. Unfortunately, it's not specific for mast cells because there are other cells that make it the same with histamine.

There are other cells that produce histamine. So they're not specific markers. But if you have enough of them, it kind of supports that that, you know, we're dealing with this particular disorder.

And in the blood we can also check crypts, which is another potential marker there are some downsides and and some issues with triptans. And then heparin is a very sensitive and specific marker of mast cell activation syndrome.

Because mast cells are the only cell of the body that actually makes heparin. Heparin is a blood thinner. You know, some people may have heard of it because they give it in the hospital if you have a blood clot.

But it turns out that that mast cells are the cell that, that manufactures minuscule amounts when, when they're activated. And if you can find, the right lab to do the right assay, and which we're very fortunate to have, you can detect those minuscule amounts of heparin, and, and that can help with the diagnosis, because if someone has an elevated heparin, there's nothing else that causes an elevated heparin but circulation syndrome.

So it's a very specific, you know, fascinating. Ideally, I'd like to get two, markers or points of laboratory evidence to support the diagnosis of nasal activation syndrome.

But, but if you have a heparin level, you know, it's pretty convincing. And then you, you sort of see if you can get something else. So that's that's primarily the blood work.

There are other markers that I will, look at because I think it's helpful, but those are, you know, the primary ones. And then, we do urine testing, which is, random urine and 24 hour urine to look at the metabolites.

Some of these mediators at mast cells produce. The problem with those mediators is that they are very thermal labial, and including the ones we do in the blood to very thermal labor, meaning that they're very heat sensitive.

Yeah. And they get destroyed very quickly. So when patients do this test, they have to control the, the temperature. They have to be sure that the urine is kept cold at all times.

They they have to make sure that it's part of the lab cold, that the lab keeps it cold. Once it gets there, does it leave it on the counter, which we have been?

You know, I've had patients who have done this test, let's say locally at their, at their, like local lab core or whatever. And they will say, you know, I gave it to the, to the lab tech and she just left it sitting on the counter.

I have a feeling my, you know, the results will be negative. And sure enough they're negative. So every step of the way has to be controlled, in order to detect those, those various mediators.

And we can measure things like prostaglandin, D2, we can measure leukotrienes, metabolite of histamine, histamine. So there are bunch of them. And then one way, one other way that that works for a lot of my patients, especially adult patients, are harder in kids.

If they've had an endoscopy or colonoscopy. Often there are biopsies, you know, you know, kids who have, let's say, eosinophilic esophagitis or they have swallowing issues or whatever.

Sometimes they'll go down and they'll scope them right, and they'll take biopsies. You can request the biopsies to be stained, with a special stain called the CD 117 stain.

And that actually looks for mast cells in the biopsy sample. They don't routinely look for mast cells. That's the problem. Right. So there are some that the results often of these biopsies is normal.

And then you know, we you know, send it to our pathologist or their various pathologists all over the country that are willing to redo the staining on these samples.

And, and if you have more than 20 mast cells in a what's called a high powered field, right. That's a that's a, a very, very, you know, I sort of sort of, suspicious finding for mass observation syndrome and, and in line with the criteria we use for diagnosis.

Yeah. Now, obviously they're having an endoscopy for other reasons. So they have some amount of GI symptoms.

Mast Cells, Allergy, and Long COVID

But but would you see that in a, in someone who does not have GI symptoms in a, in someone who has another system that is very affected by mast cells.

Has that ever been to. Great question. It has been not it has not been published. Okay. I will tell you anecdotally that I have a patient who has more of the respiratory skin and, and brain stuff, brain fog primarily with, with almost no GI symptoms.

And she had a routine colonoscopy and, or she was going for a routine colonoscopy and I, you know, I asked the GI doctor, you know, look, if if everything is clean, what they'll do when they do a colonoscopy is unless there's a polyp, if it all looks normal, they won't biopsy like a routine over 50.

You know, patient. I asked them to take biopsies, which they kind of weren't thrilled with. I, I just because I really want to make the diagnosis and we were we were sort of on the fence still with a diagnosis.

But she definitely had a multisystem inflammatory disorder. And the biopsies were positive in the colon. She had no gi. Wow. Yeah, yeah. So it makes you think that that in a lot of these people, even if the brain is their main area of neuroinflammation or the skin, that they may well have over activation of these mast cells in other areas, but for other reasons, they're not showing the signs and symptoms.

Leading you'll have to let me know when that's published. So, but but one of the things I heard you say also is colic. You know, when we're talking about kids, colic can actually be a sign of mast cell activation.

Yeah, yeah. You know, so, so symptoms. Yeah. Yeah, absolutely. And I think that these are the kids, you know, when, when we take a history, you know, you know, my patients are a little older, right?

They're, you know, adolescents are older. But when you take that history and they say, and we ask them, you know, how were you when you were an infant?

Did you have colic? Did you have any issues? Right. If they had early colic, it's a very, again, suspicious symptom that makes me think that they had some, evidence of vessel activation syndrome early in life.

Yeah, that was, you know, relatively, manageable. Right? They usually they can go through the early years with, you know, a little bit of this and a little bit of that, a little bit of call like a little bit of an ear infection, a little bit of, you know, these, these somewhat, you know, normal quote unquote normal childhood things.

And then at some point in their, in their either early childhood life or later childhood life, there's, you know, a bigger event that then brings that out.

Yeah. Some kind of trigger as we're seeing so much with Covid reactivating so much of of underlying root causes. Yeah. So how maybe describe just a little bit more because this is a pandas, podcast, how the mast cells impact the neural inflammation, specifically.

So the way I think about it is that the, the nervous system, the brain, has, various cells, that are involved in keeping, the brain healthy. We have you have the well, you have the neurons that are sending the signals, in, you know, the

electrical signals in the brain and elsewhere in the body.

We know that all neurons are surrounded by mast cells. So I like to I like to draw for my patients, and I'll draw like, here's a neuron. And then I draw these little things around the neuron and here's the mast cells.

And so if you just look at the neuron itself you'll see that that if the mast. So it's a two way street. So the mast cells if they get active, if this is something not right and they start to release these, these mediators, they'll send the signal to the neuron.

And that causes a little inflammation at the at the level of the neuron. The neuron then releases a neurotransmitter, to tell the mast cell, you know, something.

And then the mast cell has to release more mediators. And then it sets up this really vicious cycle. So at that level, you it's almost like this. I think about it as if you think of a neuron like a wire, and you have the insulation around that wire, and it just starts to get frayed over time.

Right? So again, the signals are not being transmitted correctly. Right. There's like short circuiting that happens. Okay. Now if that's happening in the brain right.

You can imagine that the signals now are going to be affected. The neurotransmitters are going to be affected. And that's going to cause various whether it's brain fog, whether it's, OCD, whether it's extreme anxiety or depression or, paranoia or psychosis or.

Right, I mean, there's so many manifestations, right? But also there are other cells in the brain that are also immune cells. There are astrocytes and microglia, and they're responsible to, you know, sort of also protect like mast cells.

They release their own set of mediators and chemicals to sort of control what they're seeing going on in the brain. And they talk to the mast cells and the mast cells talk, talk to them.

And so there's this really great paper that, that has a great, picture or an image of the all the area arrow, er arrows going from it. It starts with some kind of infection.

They in this in this picture it's like a virus or bacteria or something. And then you have the arrows and arrows and how it's affecting the microglia, the astrocytes, the neurons, the mast cells and everything is going, you know, in different directions.

And setting up this perfect storm of, of inflammation. And it's just going, you know, in a, in a loop. And so, and, and or to or to stop it. Right. So that's how I think about Pans pandas autoimmune encephalopathy, neuropsychiatric neuropsychiatric disorders is that there's this loop.

The mast cells are involved, whether they are the primary, right trigger of all this or whether they're just, you know, kind of playing along with the other immune cells and other cells in the body.

We don't know. Right. Chicken or the egg, but, you know. Right. Probably a little bit of both. And, and the key that that I have found in my practice is, is that, yes, you have to deal with the, the trigger if the triggers an infection or mold or, or whatever it is you've got to eliminate like the first step in, in treating muscle activation syndrome is eliminating triggers.

Testing for Mast Cell Activation Syndrome

But if you could also figure out a way to stop and, you know, minimize the amount of mediators that the mast cells are releasing, stabilizing the mast cells so that it's not as reactive, then that helps all these other processes, right?

Kind of calm down. Yep. And and it's pretty. It's pretty. Miraculous when it when it works. When, when you got,

when you get it and you find the thing that's going to shut down the mast cell, and you see the neuroinflammation disappear, like, I have this one case that was like, just just mind blowing with just an antihistamine sometimes as simple as that.

You know, it's like, like the inflammation just goes away and the blood comes out. And so addressing this mast cell activation syndrome can decrease the neuroinflammation and, and and then decrease the symptoms and and rather than the, the SSRI SSRI to address the anxiety or, you know, OCD or whatever, or maybe in addition to it, you know, addressing this can really make.

So what do you use, what strategies to address mast cell activation syndrome? You know, you mentioned anti histamines I mean simple over-the-counter antihistamines.

Yeah. Yeah. Again step one is eliminating triggers. So you're always always going back to the history with the patient and trying to determine, you know is there something that is within their control that they can eliminate.

Sometimes it's not in their control okay. They have Bartonella right. That's not in their control. But we're going to help them deal with that. But if there is, you know, let's say someone in the home is, using scented products or cleaning products or, there's a, a gas stove in the, in the home that may be triggering somebody right there.

And all these things that you don't even think about in some of those, or controllable or fixable or, you know, so you always do that first. And while you're trying to figure that out.

Yeah. Then you go for, the treatments and, and I think that the, the easiest or the, the antihistamines now antihistamines can be there are pharmacologic antihistamines and then there are, nutraceutical.

You know, antihistamines. Right. Right. So, you know, it really depends on the patient. So it could be, there are a number of over-the-counter each one blockers.

Those are the antihistamines that block the histamine one receptor. Yeah. Claritin or loratadine, Zyrtec or certain Visine cetirizine, which is Eisele.

And then Allegra which is fexofenadine Benadryl which is diphenhydramine. And so you have the brands, you have the generics and you have all this stuff that you can try over-the-counter liquid pills.

Sometimes you got to try, you know, variety of them. And sometimes when you find, you know, one that works, it's it's great. Sometimes we have to move on.

And, there are a number of prescription H1 blockers. There are also some H1 blockers that we have to get from overseas that we don't have available in the US, but I do recommend that patients work to try to figure out if there's an H1 blocker that is particularly helpful for them, even if it doesn't eliminate all their symptoms.

Right. And I think that's an important point, because I think sometimes the patients are looking for that one intervention that's going to help everything.

Right? Right. So sometimes they take an H1 blocker and it helps you know I don't know we'll take a sip job like it's help. It helps your headaches. But it didn't help their anxiety and it didn't help their itching or whatever the other symptom is.

Right. And that's okay. You know, if you if you, if you get something that works on one symptom, it means that the mast cells in that area are responding to that.

But the mast cells in a different area have different mediators, have a different way of responding. So you have to you have to keep sort of working through.

So there are patients who need multiple H1 blockers to try to achieve that or, or their histamine is not an issue for

them at all. And there are definitely patients where antihistamines are just not going to do anything.

And so it's not even worth having them on that. You know, there are H2 blockers that block the other type of histamine receptor. Those histamine receptors tend to be primarily GI, but.

Right. I have patients who take these H2 blockers who don't have GI symptoms, who get, you know, relief of other systemic symptoms that are not GI, right, right, right.

So it's always worth trying. So one of them is famotidine or Pepcid tagamet is another one. And and Zantac was, was one that was nicotine was one that a lot of people did well with, but it was pulled from the markets.

Very hard to get right now. So but I hear I heard it's coming back, so we'll see. Okay. And then, you know, there are a number of, nutraceuticals that, I turn to early.

These are like the early days of, like, we're trying to just figure out, and deal with the because the low hanging fruit things that are sort of crazy.

Vitamin C is a natural antihistamine. Quercetin is a, nasal stabilizer with some antihistamine properties. Is, woody. Woody Allen is another very interesting, compound with these sort of nasal stabilizing properties.

And then there are others, but those are other ones that, you know, also kind of easy, easy to try. They work in some cases. They don't work in others.

Sometimes they cause side effects in others. Right? So the challenge is really like to be very vigilant about what it's doing, knowing when to move on.

And then, you know, again, sometimes we have to move on to the more I don't want to say aggressive, but, you know, a little bit more involved treatments.

Right. And and do you give each, a period of time? I mean, are you saying to your parents, hey, let's try this or patients, let's try this one for x amount of time.

I mean, one of the things, I think so much of the time we're looking for the magic bullet. We're looking for that one thing. And part of what you're saying is something that I learned very early on.

You know, if they've tried one antihistamine, they've tried one antihistamine. They, they they that's it. You know, it may be that a different antihistamine would work or a different nutraceutical, like, how do you are you talking about all of that with your patients?

I find that to be a difficult piece of this. It's very narrow. It's very difficult. And and I think that, yes, I think a lot of people just sort of feel like, okay, I tried to Claritin and it didn't do anything.

So I must not have a muscle problem because I didn't right to do anything. So that's also difficult, right? So what I say to people is that the mast cells or the sickle there, we don't we don't know.

We don't have the research yet. It's coming. But you know, we know that, that the mast cells have these mutations, they're called somatic mutations.

Treatments, Antihistamines, and Excipients

And and anyone, everyone's mast cells have different. Anyone who has mass occupation syndrome will have different mutations. Those mutations dictate which mediators the mast cells.

Which of those 1200 mediators are making. Yeah. Eventually we'll be able to do a test where we test your mast cell and we know exactly what mutation it is and what your cells are making.

And then we can target, you know, the treatment to it. I don't think we're that far away from doing that. And I and there are a few labs that are studying that.

But until we get to that right now, we we have no idea other than yes, we've done these mediator tests and maybe we we know that the patient makes leukotrienes.

So we sometimes, you know, we'll try to go after that. But other than that it's difficult. So it's trial and error. And I say look you know typically first of all you're going to know pretty quickly if you don't react well to it.

Usually within a few doses, it's going to be clear. This is either either not the right drug or the drug has an excipients, which we should talk about.

Has something I that was on my list. Yep. Okay. We'll talk about that. Something in it the that the person's reacting to. So then you have to move on.

But let's say there's no bad reaction but you're not sure if it's working or not yet. You know, I say 2 to 4 weeks is about the time sometimes I move it quicker, you know, especially if if it patients and the and parents are, you know, really observant and they feel like they really have a good feel for it.

Sometimes we can move it along, but at least two weeks to really know what it's doing. If it's not doing anything, then we move on. And and so again, we're trialing, I really tell my patients that ideally I would like to run through every antihistamine over the counter if we can two week trial, 2 to 4 week trials depending, and then many of them will at the end of all that.

And what even if they had a good response even after two weeks, they're like, yeah, you know, I actually think this is helping. I still tell them to move on because then the net, because the next one could be even better.

But then once they've done all of it, then they can look back and say, oh, you know what, XYZ l was the one that actually I did have the best response to.

Okay, so then go back to that. Now let's do that for longer. Let's keep that on board and then figure out what else we add on. So I do that's one thing I have never done is tried all of them.

I find that if I find one that's work I'm like stick with it. But that's very interesting because it may help other symptoms if because they're all so different, even though they're all H one blockers.

So that's a fascinating piece. Great tidbit. And and also you I don't want to cut you off, but but you did mention excipients and yeah, that is something else that you reminded me of not too long ago that I think is so vital for people to understand.

Do you want to talk about that a little bit? Absolutely. You know, all drugs and supplements contain other ingredients mixed with it. Okay. And there are a number of reasons why they do that.

You know, it could be to fill the capsule up. It could be to keep the tablet together. I mean, there's all kinds of I'm not in the pharmaceutical industry, but, you know, I understand that there's a there's a need for some of it.

There's also what I don't understand is why pharmaceuticals contain dyes. I don't I don't know why a pill has to be pink or the liquid has to be pink or has red.

I don't get me started on that. I know that's infuriating. Infuriating. And I will tell you, it's not like that in other countries where we're probably the worst at the, with this.

But the dyes can be a problem. The other ingredients can be a problem. You know, again, mast cells are really sensitive to these different chemicals. So sometimes the drug is perfectly fine.

But the drug is mixed with a dye or another filler. And the person is actually reacting to one of those things. And then they're dismissing the drug altogether, thinking that they have either an allergy or reaction to the drug.

And then, you know, we've taken that class of drugs off. They're off the table. But yet it may be that there is something mixed with and the same with supplements.

Right? I would say the the most common offenders are definitely the dyes in the, in the pharmaceutical world. I would say, methylene methyl cellulose or any kind of cellulose tends to be problematic.

You know, cellulose is a plant derivative. Now, what I understand is that, cellulose can come from different plants there. It can come from cottonseed plant, it can come from birch trees.

It can come from like there's a list. Yes. Oh, I can't tell you how many, you know, top of my head, but like, lots of different trees and plants, they can derive the cellulose from.

And a lot of times, either the pharmacies or the pharmaceutical companies, they don't even know where their cellulose is coming from. And so I have patients that have figured out that cellulose from whatever tree is fine, but cellulose from another is not.

But but for the most part, it's very difficult to figure that out. So very often cellulose becomes a problem. Because there's some kind of again, it's a it's a very, triggering for mass cells.

Not everybody. Right. But it does seem like that's a common offender. And and there are a number of others povidone is one I see sometimes titanium, sometimes, magnesium saturates, sometimes.

So, you know, if patients know that they or parents are seeing that they are reacting, you know, that the kid is reacting or they're reacting to something, it it pays to look at the ingredient list, which you can find online.

It's not always super accurate, but but for the most part, you can get at least like the broad strokes on on it. And what you can do is if you start to see that you're reacting to a number of drugs, you start to see what the what things they have in common.

Now. And very often there's like a stand out like, oh, these all these drugs, all have this ingredient. Then what you can do is then you can work on compounding it.

Right. So if cellulose is a problem then you use gelatin capsules and you use a rice flour filler. And so you find ways to get around because the problem is that even compounded drugs often will.

They'll use a cellulose. Veggie cap. Yeah. And they'll use, cellulose filler. And that's just sort of standard. So the excipients problem is very involved.

I don't want to make make it more than more than it is, but it is something to think about, especially when you have people, patients who are, reacting to a lot of things.

Right? And you can't get them on anything. You have to go back and say, I think really reacting to all these drugs, or is there something else those drugs have in common?

Right. And I think exactly. We don't want to make it sound like it's everybody that comes down the pike and everybody has to get everything compounded, but for that multiply resistant child or adult, that seems like everything they're reacting to, thinking about the other things that are in it.

After we talked recently, I had been using, for instance, chromium and sodium in the little plastic vials, and when I changed it and compounded it, and not into a cellulose containing veggie cap, because I did that the first time.

It, it it worked. It worked beautifully. And so I think that's another little pearl that, that really can make a difference

when, you know, because so many of our patients or my patients at least are saying nothing's working, nothing, nothing worked for anybody else.

I'm not trying that again. And I have to say, let's just back up and let's look at why didn't that work, you know, and as you're saying, sometimes it can be the excipients.

Sometimes it was just the wrong H1 blocker. Go ahead. Yes, exactly. But I want to make a point about the plastic because I think that's really important.

So Lane is something that is you know, it's really easy to use because it's, you know, it's it's it's liquid in a vial especially for kids. Right. You just squeeze it into, into, some water.

But the plastic that the problem comes in is different depending on the company that makes the Crumlin, correct? Yeah. And the plastics, you know, degrade a little bit over time.

And, and there are patients who are really particularly sensitive to one type of plastic or another.

Hope, Resources, and Closing Remarks

I mean, listen, we want to avoid plastics as much as possible. Sometimes it's unavoidable. But I have patients who know that, they are sensitive to certain bottles of water.

Right. So you think how can they be? They're reacting to a particular brand of water, you know, let's say Poland Springs or something. And, like, is it the water or is it the plastic that the water is in?

So, so the plastic, you know, thing that now we I learned pretty early on with Crumlin is something that, you know, a lot of people are not thinking about but can be easily, you know, remedied because you.

Yeah, yeah, yeah. So so fascinating. Tania anything a we're, we're running a little bit long now and, and I just thank you so much for all of your wisdom and, and, information.

Is there anything else you want to leave the families or the practitioners with any other pearls or. Yeah. You know, look, I think you have to keep keep at this, you know, it's it is it is tough.

And especially, you know, when, when the kids are suffering, the families are suffering, you know, but I feel like there is a lot of hope. You know, I do think that there's there the answers are there, and and and and Marcel activation syndrome or mix may maybe a big part of this that you know will bring the pans and pandas under control.

So I, I really do encourage people to, you know, to talk to their practitioners about getting tested, you know, or trialing even, even if they can't get a diagnosis trialing these things.

Because if this is a piece of the puzzle that hasn't been explored, it could be really profound. And so I just I guess I just want to leave people with hope.

Like I believe that there's always an answer. They're out there and we just have to keep keep, you know, fighting for it and finding it. I so agree. There definitely is hope and and thanks for giving so many families hope.

Seriously. And, I know you're incredibly busy, but how do people find you if if they want to. So, social media, Instagram. Dr. Tanya Dempsey, MD, Facebook is doctor Tanya dempsey.

My, my website is Dr. Tanya Dempsey. Com and I have lots of content. I have a podcast called yes, you do Sell matters. You're going to be on my podcast soon.

Mast cell matters, where we take some deep dives on, Marcel and related, conditions. So I'm really, really proud of

of that. And so again, I education is my passion.

And so I like to I do put a lot of, you know, video and content out there. So I encourage people to to take a look. Yeah. Well you're great at it. And there really is a plethora of information out there.

So, Tanya, thank you. So great to be with you today. And thanks for everybody joining us. Thank you for tuning in to Doctor Talks. We hope today's episode has enlightened and inspired you on your path to optimal health.

Each day is a new opportunity to make choices that empower your well-being. For more insights and strategies, subscribe to our podcast and visit our website WW di doctor talk.com.

Stay connected, stay healthy and join us next time on Doctor Talks. Real talks from real doctors on the issues that matter to you most.