Introduction to MCAS Summit and Dr. Dempsey

Hello and welcome back to our Reversing Mast Cell Activation Syndrome and Histamine Intolerance Summit. I'm your host, Dr. Meg Mill. And today, I'm joined by my esteemed colleague, Dr. Tania Dempsey.

Dr. Dempsey is an expert in chronic disease, autoimmune disorders, and mast cell activation syndrome. She uses integrative medicine to get to the patients a root of their illness.

She is an expert in mast cell activation syndrome, and I'm so excited to have her here to talk about how we diagnose this, because it can be very complex.

So we want to get into the tools we use to diagnose and what she does to start treating her patients. Thank you so much for being with us today, Dr. Dempsey.

Well, thanks so much for having me. I'm so lucky to be here and so excited to talk with you today about everything. The Mast Cell Activation Syndrome.

But before we dive into all the good stuff, can you just give us a little bit about your background and how you really came to specialize in this? well, you know, I come from a very traditional, conventional medical background.

I'm trained as an internist. and, you know, I was always interested in, sort of complex patient, issues. And so even as an internist, where I didn't have a lot of time, I always wanted to understand all the things that patients were dealing with and all the connections.

How Dr. Dempsey Discovered Mast Cell Activation Syndrome

And so I, you know, often got in trouble for spending too much time with patients. which is really sad, right? I love doing that. So. But I eventually realized that I needed to do to go on my own and, take care of patients the way they deserved to be taken care of.

And when you start to spend time with patients and really, really start to dig and start to think about things right, you start to come up upon things that, you know, maybe, you know, I didn't know about.

I didn't really understand. and I'm, I'm relentless when I don't understand something, I will do everything possible to understand it for the for the patient.

And I remember this one patient who I think probably was, well, I think of her as my first patient, but really, now I know that there were many, many patients before her who had this.

And, and I've had actually the privilege of, of seeing some of my old, old patients prior to my knowledge of MCAS, come back to me and then realize that they actually, you know, had this.

But the first patient that I really identified, it, she was really struggling with, a variety of symptoms involving, lots of different systems in the body.

Right. And we've come to know MCAS as a multisystem inflammatory condition. So she had multiple systems involved, inflammation, and I just couldn't figure out how the pieces fit together.

And I remember one day I was, I was probably it was either pub med. It could have even been Google. I don't, you know, honestly, I was I was looking everywhere to try to figure out how all the pieces connected.

And I came across this condition known as Mast Cell Activation Syndrome. And I remember when she came to the office after I had done this research, I said, you know, there's this condition and I'm thinking, that's what you have.

But now we have to figure out, you know, how, how to diagnose you if this is if this is in fact, the problem. So she did her own research and she came across Dr. Lawrence Afrin, and, and she had some connection, family connection, actually, to him.

And so she said, well, listen, I think, I think you need to talk to this guy. He's he's the world's expert in mast activation syndrome. I want you to talk to him.

And back then I thought, really? I mean, I'm going to just call him, and he's going to talk to me, you know? And in fact, that's exactly what he does, right?

I called, I talked to the secretary, I scheduled a meeting like, I don't know, the next day, and he spent an hour and a half with me, maybe two hours talking about everything that he knew about, cars and, and then, you know, I actually the patient diagnosed her and, and then the rest is history, because once you start to see this, you start to understand that it is unfortunately quite pervasive.

it's, you know, it may affect up to 17, maybe 20% of the population, according to, the research. And so that's oh, that's a lot of patients, right? There's a lot of people out there.

And so once you start to see it, once you start to put the connections, you can't unsee it. And then the rest is history. Because the more I started to see it, the more, you know, more I started to diagnose, the more interested I was in it, the more that Dr. Afrin and I collaborated.

And eventually, you know, he came. He's in my practice, me and my practice now. You know, we collaborate and research and publishing, because we have that that passion for, you know, again, the more we understand, the less we understand.

Right? Really? Actually, the more questions we have, the more will we want to we want to help, understand it for the patients, because we have a lot of patients that we have to get better.

and I loved how you said once you see something, you can't unsee it. That's so true. Yeah. It is. It's like, oh, wait, that's what I've been missing in this picture for all of this time.

Yeah, yeah. And, you know, it's interesting. I, as I said, this was my my first patient that I really identified it in. But, you know, I started practicing medicine, right out of residency in 1999.

And I, I identified this patient. I was probably 2014, 2015, maybe that's sort of in that time frame. So it's almost ten years at this point. but I had a patient recently come back to me who was really one of my first patients from 1999, right out of residency.

In my first practice, one of my first patients. And she recently, came back to see me. She see me periodically over the years. But but that's I mean, that's what, 25 years?

Okay. And, you know, she had all these multisystem, inflammatory things that, you know, I was trying I tried so hard to help her manage. And I think she, you know, thankfully did she did well enough to to, you know, live her life.

But she, you know, really we never really got to the sort of the, the bottom line, you know, what was really the connection. And she when she came back to me, I remember, I think she had started to maybe hear a little bit about what I was talking about, and I just I looked at her and I said, oh, my gosh, this is what you have.

Clinical Diagnosis: Symptoms, Mediators, and Biopsies

And and it makes so much sense. And again, a patient from 25 years ago coming back, diagnosing her, I mean,

she she actually had, you know, a very, actually easily diagnosed condition because she had high hyper levels twice.

She had, urine mediators that we found. And so she made the criteria very quickly made the diagnosis. And now it really it has improved her quality of life so dramatically.

Just having this piece of this information, first of all, because it validated everything that she has dealt with for so many years that no one has understood.

And now she has tools that she didn't have before. so it's pretty powerful. Yeah. You know, I yeah. Yeah. So let's jump into diagnosis a little bit because it's it's hard I know some to diagnose Mast Cell Activation and I know it's complicated.

So can you get into a little bit about how what towards you use and how you diagnose her. So Dr. Afrin and a group of myself and I, we, I think there were 40 other or 39 other, physicians, you know, joined up, wrote a consensus article about diagnosing Mast Cell Activation Syndrome.

So, you know, I recommend people are really interested to, if people are hearing this and they want to work with a practitioner, you know, they can get this article, it is open access and then give it to their, you know, practitioners to read, and hopefully that will be helpful. Right.

But basically what we said in this article was that, you know, this is, truly a clinical, you know, diagnosis in some ways, you really do need the clinical features first and foremost.

but you really also need, to mediate two markers of activated mast cells. So we know that mast cells, when they get activated, they granular, they release various mediators.

We now know there are 1200 mediators that mast cells can make. we just actually I've been saying that mediators are like over a thousand mediators, but we just had some confirmation.

We have a we have a colleague who's, doing some research and trying to identify all the mediators and all the literature on a mediator. So we're up to 1200 mediators at mast cells can make we cannot measure everything.

We don't have the ability. Okay. And the technology. But there are a handful of, of mediators are these chemicals that these mast cells make when they're activated.

And we can identify them, some of them in the blood and some of them in the urine. And, and we, we do random urines. We do 24 hour urine. And so that so if you can get two pieces of a laboratory evidence in addition to the clinical, features, that is very supportive of the diagnosis.

And lastly, one of one of the tools you can use is, biopsy samples that could be used as one piece of laboratory evidence. So, a lot of our patients have had GI issues.

That is one of the systems that's very frequently affected by, tests. And, so, you know, they've gone to GI doctors, they've had scoping, they've had endoscopy, colonoscopies and the like since.

And so they you can request, biopsies have been take that have been taken. and if you have a pathologist you work with, we have a pathologist that that does this for us.

But they're pathologists all over the country who are interested in this. Who will stain? They'll do a special stain called the CD 1/17 stain, and they'll be able to identify in that tissue, next cells.

And then you can count how many mast cells and, and, the literature suggests that if you see more than 20 mast cells per what they call high power field.

So they're looking under the microscope. If you they see more than 20 in a sample that is very also supportive of the diagnosis of mast cell activation syndrome.

so these are, these are, you know, the tools to make the diagnosis. I feel very strongly my colleague, Doctor Afrin feels very strongly about trying to make that diagnosis.

But there are patients who, maybe they have, their mast cells are making these mediators that we can't measure. And so for some patients that is going to be difficult, to find, you know, the mediators and really get them a formal diagnosis, they're going to be some patients who are not going to be able to access this testing.

They don't have. They're not, you know, medical professionals who really understand it. and so, you know, I think that I think it's okay to at least start the treatment without the diagnosis, at least at the, at the sort of simple level, you know, antihistamines, there's some natural compounds.

There are things that people can try, even without a formal diagnosis, at least to get the ball rolling to see if they can get some relief. But ultimately, really, when you get to the point where some of those don't work, you really do need to figure out whether this is really the problem.

And, if it is the problem, why why is it is it the problem and what the triggers are. Yeah. Yeah, it's a huge piece. Right. And why. Yeah. That's that's the biggest. Yeah. Right.

Exactly, exactly. Biggest piece. So once you get that diagnosis well so so just to recap. So what I'm hearing you say is we're looking at multi-system.

we're looking at symptoms. Then we're looking at the urine and the blood markers. And you're also looking at the biopsies. You can look at all three of those at the same time to get that formal diagnosis correct.

Okay. Great. And so once you have a patient that you have diagnosed with cast, where do you start in the treatment process. Yeah, I mean, number one, step one is identifying the triggers.

And yes, very, very difficult. There's no question about it because some triggers are very, innocuous or they are not so obvious. other triggers are more obvious.

and some of the triggers are in the environment. Some of the triggers are internal. And so you really do need to identify that even before you think about treatment.

Because if there's something that is making you sick and making your massa's more reactive, didn't want to eliminate that. A lot of these treatments are not going to work fully.

But while you're working on that and trying to figure out identifying the triggers, and we should spend some time to talking about triggers that maybe are not things that people are thinking about.

we I do start with treatment, you know, again, we want to provide some relief. we want to help the immune system. And so the first line is typically some sort of antihistamine.

I might start with an H1 blocker. Those are the antihistamines that block the H1 receptor. So those are the the ones that we know of as the allergy medicines that you can get over the counter.

There are numerous you know, there are really five over-the-counter. Yeah. Benadryl. You have Claritin and the generic so that you have Zyrtec, diesel and Allegra.

Starting Treatment and Finding the Right Antihistamines

and then so we always have patients, try to figure out if there's any antihistamine that would be helpful for them. It's a trial and error, one thing at a time.

Watching for responses, either positive or negative, and then moving on and trialing another one. Right. I think it's really, really important that patients identify which antihistamine is really going to be best for them.

I do have a handful of patients who are antihistamines are not helpful at all. Maybe because histamine is not one of the mediators that that you know is being released by their mast cells.

Maybe these are just not the right, you know, antihistamine means there are lots of reasons why that could be. But, but the vast majority will have some response to an antihistamine.

So I think it's important to do that. We do have natural antihistamines, vitamin C, quercetin. So patients feel more comfortable starting the natural route first before going to, to medications.

my preference actually is to start with the medications. They have a little bit more bang for the buck initially, but but I absolutely have patients who use vitamin C, for instance, to get out of, out of a flare.

So so again, everyone is individual. I'm going to say that a thousand times. Everyone is different. And you have to listen to your it, listen to your body, and you have to sort of figure out, okay, where you know what is going to work best for you.

and then and then once you sort of establish those types of, antihistamines, then you move on to see whether an H2 blocker or an antihistamine that, that binds to the H2 receptors is, you know, is helpful sometimes the synergy between H1 and H2, drugs, can be very, very helpful.

Some patients don't do well with H2 drugs or vice versa. Some patients do better with H2 drugs than H1 drugs. Again, trial and error. you know, unfortunately we don't have as many H2 drugs as we used to.

now we have tagamet. We have, no, we used to have Zantac. I'm hoping that's coming back online. Sounds like that is coming back on the market, but it's still taking some time to, you know, sort of be available, all over the country.

You have Pepcid, you have the generics of those, and then you have a prescription, nice editing, which, also, I understand is hard to get right now. So not a lot of options.

But again, that's kind of where we start patients. And then there are there's a next level of treatments. Again you're doing that. You're figuring out triggers.

And then you know if that's not enough then you keep you know, you keep working through, in a systematic way, trying to figure out, you know, what is going to be the way to what's going to help calm themselves down, reduce inflammation, ultimately, and.

And what I keep hearing you saying and what I, I totally agree. And I think it's really important for this, for our audience to hear is that it's so individualized.

And you have to have that patience to say, okay, well, I tried this, that one wasn't the right one for me, but that doesn't mean that my story is over.

There's another option, okay? And really be having the patience to systematically try some of these things. I know when you want to feel better so much, it's sometimes hard and frustrating when you're getting that, having that patience.

Really? Yeah. Yeah. No, exactly. But I think it really it really is so important. One of one of the triggers that I think also really needs to be talked about.

There are few triggers that I, want to bring up. obviously there are probably thousands of triggers, if not more. but the two things that I think are, maybe not talked about enough.

One is, excipients, excipients or fillers that are mixed into drugs. They're mixed with vitamins. they're mixed with, with just about anything, even food.

and, very often the fillers of from things that people take are was actually, driving some of their, mass cell activation. it could be that it's exacerbating things.

It could be a driver. You know, I've had patients who, probably had underlying empaths but maybe didn't really realize it, was given a drug for their blood pressure was given a drug for some some condition, then didn't have an adverse reaction to the drug.

So, you know, no one really thought that the drug was the problem. And that fully had started to have, you know, these, various inflammatory, multi-system symptoms.

And, lo and behold, it's the filler in the drug, not the drug that's actually making somebody sick and includes even the things that we use to treat, cars.

You know, that's can be very, very challenging. you know, there are some big ones that that come up a lot doesn't need. You know, if I'm mentioning this, it doesn't mean that you have this problem.

And I have plenty of patients who are fine with any of these, but microcrystalline cellulose, can be problematic depending on where the cellulose is derived.

We, you know, there are various, trees and plants where cellulose that's used for different products on the market, are derived from. So, there may be a tree could be like site or tree or a cot or cotton plant or something else.

And you might react to one and another. And I have patients who have been able to identify the particular cellulose that's problematic. any take that this takes a lot of like, detective work, you know, really tough to figure it out.

But excipients are a big thing, and people have to think about it. If you have a problem with, you know, let's just say you try Zyrtec and, and let's say you try Claritin and you try, like, let's say you're trying all the antihistamines and you keep reacting, you know, quote unquote reacting to those interventions.

Right. The question is, are you reacting to the drug or you're reacting to some common excipients that may be found in all of them? And I've had patients who have been able to find a particular brand that doesn't have, the filler that's maybe found in the other things.

sometimes we have to I'll pound it. And sometimes that makes a huge difference.

Hidden Triggers: Excipients and Foreign Bodies

So my patients who think that they cannot tolerate antihistamines, but in fact, they can tolerate the, the bands that are next with the antihistamines.

And when we compound it, and we figure out what, what excipients can be used by the compounding pharmacy, then we can we can really, you know, it can help dramatically sometimes.

So so again, a lot of detective work, a lot of patients. and that's a, that's unfortunately not feeling well. It really, it's not fair. It would be great if we'd be able to identify these things quicker, figure it out quicker.

you know, maybe research eventually will get us there. The other trigger that I think, I think is getting a little bit more, publicized, but I just want to bring it up because it it really does the starting to come up more and more or, foreign bodies, that are in your body.

Right. So we think about things in our environment as triggers, you know, like it could be allergies in the air, could be mold, could be, various smells and fragrances and pesticides and the list goes on.

There's just so many things in our environment. But we have to also think about what may be in us that we may be not thinking about. So, a dental implants, breast implants, mesh used for hernia repairs, clips that were placed after gallbladder, removal, clips are used sometimes in the body of metal.

if you have a problem with nickel or metal and you have something in your body that's foreign, could be, could be, joint, implants, joint replacements.

So, you know, those are those are complex issues, if that's the case. But, you know, for some patients, identifying it, figuring it out, removing it, if possible, if you can't remove it, trying to figure out how you can live with it, I think is really, really important.

And, and, and I think it needs to be talked about, more, you know, we, we forget that we are our immune system is always on alert. Right. And so it's just sort of funny to think that, you know, there are surgeons and there are other people like putting things in us, you know, thinking that, you know, like, why would it be a problem?

You know, some of these things are considered inert silicone for a long time was considered inert. That can't react. You know, we can't react to that cause it's not you know, it's not going to really affect our immune system.

And in fact, yeah, it's not inert. It leaches and it does affect our immune system. And our mast cells are our first line of defense against the environment.

So yeah. Those are great points because I you're right, I think a lot of people aren't thinking about that. You have a surgery. You're just trusting in that.

Okay. Whatever was put in my body was put in there on purpose. And they know what why? You know, what it will do to my immune system. So thinking of some of those things, do you see when you're looking at some of this, do you ever find that people are able to identify like, okay, I had that surgery or that change and this happened so many months later able to pinpoint those changes?

Yeah, yeah. Very often people can pinpoint when they start thinking about it. And sometimes it's not even they're not even thinking about it. I mean, I'll take a history, maybe even my test is not even on their radar.

I certainly see patients that actually have never heard of in case they come to me, because, you know, they've heard that I am like a medical detective.

And so they come and it's not on their radar, but they'll say, I know that after this particular event and it could be a surgery, it could be, it could be a viral infection, some other infection.

It could be anything that sort of happens. Many patients can identify that. That's the point when their health changed. And you have to listen to that.

You know. when you bring up virus, I think we have to just go to Covid a little bit because that is a huge increase and this is after Covid. So can we talk a little bit about that?

So what you're seeing and what sure. You know it's interesting I had a conversation the other night with with some colleagues about Covid and, you know, my lenses.

And so I do see Covid from the, test lens. And I think there's there's enough research now to support that. And I think it makes sense. But everybody has their own lens that they're starting to see Covid through.

Right. So, and maybe it's a combination of all the above, but at least from, from my perspective, we know that now cells are our first line of defense, right?

For the environment and for infections. We know that evolutionarily, mast cells are there to help us, fight off a parasites and viruses and bacteria, things like that.

Right. So it makes sense that a virus like Covid comes on board. Our mast cells have to react, our mast cells real talk to other cells, other white blood cells as part of how they work.

They will release mediators. They'll do granulation, but they will also send a signal to the macrophages, to the neutrophils to the other white blood cells.

Recruit everybody. they some of them release cytokines nasal release cytokines. We we talked we we heard a lot about cytokine storms early on in the in the Covid pandemic.

But we know that mast cells were responsible for a lot of that. Other cells were responsible for, you know, fighting the infection. But also unfortunately, that assault was also backfiring on the body.

So instead of, just trying to kill the virus, right. All these chemicals of cytokines were actually, you know, actually, now, causing more inflammation in our tissue, wherever that was happening.

So for, for early on in the pandemic, there was a lot of respiratory stuff. There still is. but I've seen this virus sort of change and affect people a little bit differently.

COVID, Long COVID, and Mast Cell Dysregulation

But let's say Covid gets into the into the respiratory tract where there's a lot of mast cells again, and that cells are going to release mediators, the other cells are going to release mediators and cytokines.

And then you wind up with this, you know, horrible inflammatory reaction in the lungs. Right. People were having trouble breathing. People were having trouble were winding up on respirators.

and so and then some patients, you know, recovered, and some patients recovered, fully. And so patients did not recover and are still not recovering. Right. And, and I think that, does I think from my perspective, mast cells are play a role in that.

and for many of these patients, what we're seeing, at least in my practice, is that patients had underlying nasal activation syndrome. They didn't know it, you know, they were considered healthy.

And then a, well, they consider themselves healthy, and then they got this infection and then they didn't get better. And they say that Covid was what made them.

Second, Covid did bring out that underlying susceptibility. and the masks all sort of never went back to normal. They just kept, reacting and reacting and, you know, again, thinking maybe the virus was still there.

You know, a lot of people talked about still talking about spike protein. And it's possible that that spike protein is still causing, the immune system to go awry.

And that may be part of it. It may be that the mast cells are already like, once they're so dysfunctional and, dysregulated, they just can't they just can't stop.

They can't reel it in. And so, there's this continued, inflammatory, you know, sort of state that, that people wind up in. And, and, you know, what we see in Long-Covid is that, you know, some patients have more respiratory symptoms post Covid.

Some of them have the fatigue, more of the chronic fatigue like picture. Some patients have, you know, more GI symptoms or I've been seeing a lot of that actually sort of residual GI symptoms that can then develop into colitis and various autoimmune issues and, and other things.

So again, we still actually have a lot to learn. And it's unfortunate that we're still going to be faced with this for some time. but, I think that again, what I have found is that if we if we think of ourselves as at least being part of the

problem, the maybe the whole problem, I don't know, but they're at least a part of the problem.

if we can, target the mast cells, if we can find the right treatment, at least to calm things down, that does seem to help a lot of patients post Covid.

the other piece of it is that I think that, Covid is also causing a reactivation of other viruses and other infections internally. And this is an area that I'm really interested in.

You know, I have a background. You know what? I, in addition to my expertise in MCAS, I also, really, have an interest in vector borne infections and infections in general.

And so, what we're finding is that some patients, when they get an infection like Covid, their immune system, it becomes so dysregulated again, the mast cells, we have to inappropriately.

But but other parts of the immune system not reacting appropriately at all and not kicking in. And then underlying viruses Epstein-Barr or herpes viruses of various kind start to come out and even, Lyme disease, Bartonella, Babesia of various infections that patients may have been exposed to years ago, that they didn't really realize that they even had because their immune system handled it and are now starting to come out.

And so some of these patients, mast cell targeted therapy alone is not going to be enough, because now there's another piece that I have to address, and that's the other infection piece.

Yes. Yeah. That's so true. And do you have an order of operations that you go through when you're looking into these root causes. Yeah, it's a good it's a good question.

So I think I think the most important thing is first off is, is taking a very thorough history for the patient. So my order of operations may be a little different depending on the patient.

Right. So I'm taking a very thorough history trying to understand, their history from the minute they're born, maybe even, you know, the health of their mother before they're born, all the way through current, times.

Now, there may be things in their history that are going to tell me that I need to go more in one direction initially than another. There may be very specific, events like mold exposure that I know that I'm going to we're going to have to deal with right now, or they're currently living in a place where, there's a lot of mold.

And, so that might be, you know, the order of operation. Excuse me.

Root-Cause Investigation and Where to Find Dr. Dempsey

I'm going to I'm going to definitely, go there, but, you know, mold is a problem for a lot of people. I might still be investigating it, but their history may be, you know, they were scratched by a cat when they were 20 years old.

And, then they remember that there were a number of things that happened after that. They had some lymph nodes that swelled up and but they weren't diagnosed with scratch fever.

And then they had another thing happen. So that's a patient that I'm going to say, well, there's infection. So I'm going to I'm going to try to go after the infection first.

But I'm always looking at other things. I always have to kind of shift gears and look at other things. Right. the mast cell piece is always on my radar.

And and then all these other pieces, depending on the history, kind of start to fall into place again. Some are higher in some people, some are lower.

And sometimes what I think is lower turns out to be higher. Once I start to test and treat, then it becomes things

become a little bit more obvious. Yes. Yeah.

It's very complex. It is. It's looking at that and I agree with you looking at that person individually. What is their unique set of symptoms. What is their unique set of triggers.

And and where do you need to go to exactly. Yeah. Well thank you so much. You've given us such helpful wonderful information. Can you share with everyone where they can find you?

Yeah, absolutely. So, my website, I just we did my website, which is, drtaniadempsey.com. We have lots of information, blogs, etc. and all the information about my practice.

Facebook of course. Tania Dempsey, Instagram, @drtaniadempseymd., and in YouTube. And then of course, I have a new podcast which can be found on all the podcast platforms, which is called Mast Cell Matters.

And we've been I've been interviewing it's it was part of the Pax Cast Podcast that we sort of rolled out on our own. But, Jill Brock, who's part of the PAX Community and Pax Cast with me and I interview various experts in and cars from different, specialties.

We've had a psychiatrist, we've had cardiologists, we've had, you know, various again, very we've had Dr. Afrin on I've done a bunch we have some more interviews.

in the, in the mix. We have a pain specialist. We've, we've done, interviews with and so really excited about the information that we're putting out there on the podcast.

So check us out, everyone. Check it out. That's a perfect place to learn more. Well, thank you so much for being with us today. Thank you for having me.

You have a great day, everyone.