Introduction to Mast Cell Activation Syndrome

Hi. Welcome. I'm doctor Roger Murphy, and I'm your host of the freedom from Fibromyalgia summit. And I'd like to welcome Doctor Kathleen McCann. She's going to be joining us today.

We're going to be talking about mast cell activation syndrome. If there's not enough, challenges out there for you now we're going to throw something else out there.

This thing called mast cell activation syndrome, which I have unfortunately found to be a potential trigger for many of my fibromyalgia patients over the last several years as I'm learning more and more about this.

But doctor McCann is a specialist. This is one of her things is, she has several specialties, including mold and Lyme. But we're going to be focusing on mast cell.

Let me take a look. Doctor McCann is a triple board certified internal medicine, pediatrics and integrative medicine, as well as a certified as well as certified with the Institute of Functional Medicine.

You've got a really interesting background, like a I think I like a lot of physicians who come over from and I shouldn't say it this way, but from the dark side, I shouldn't say it that way.

But, because it's really, you know, there's a time and a place for conventional medicine, but really, functional medicine is something that really lends itself to going to, you know, many layers deep.

And that's why we both love it. So Kelly, thank you so much for being part of this summit. Tell me a little bit about mast cells. What are they all right. Roger, thank you for having me.

I love talking about mast cell activation, as you know. So mast cells are a normal part of our immune system. And they're a pretty ancient part of our immune system.

They are the part that, actually born in the bone marrow, and they move to the periphery, meaning they line our areas of interface between ourselves and the outside world.

So they line our upper respiratory tract, sinuses, nasal passages, gastrointestinal tract all the way down there on our skin. They have an affinity for our brains and our, lymphatics, our vascular system.

And their job is to fight foreign invaders. And so they are constantly surveilling for foreign invaders. And when they see them, they are filled with these, little packets of chemicals called mediators.

And then they release their mediators when they perceive a threat. And those mediators are filled with a variety of different inflammatory chemicals called cytokines, chemokines and prostaglandins.

And one of the most famous ones is histamine.

What Mast Cells Are and Why They Misfire

And so when these mast cells, degrade and release all their inflammatory mediators, we can get a whole host of symptoms. And so mast cells, there's a connection between the immune system.

You pointed that out, but also the immune system and the nervous system. So that's a there's a communication there. There's a communication. And oftentimes they're released, as you said, when they when the body feels threatened.

So the cells feel threatened from some type of could be an infection. There's a connection with mast cell and some underlying triggers as well, like mold and and Lyme disease.

Right. Sure. So mold is a foreign invader, Lyme disease as a foreign invader, all of the, all of the bacteria or internal parasites that are related to, Lyme, the Busia, Bartonella, those will all trigger a mast cell activation.

Potentially, they will trigger mast cells even in somebody who doesn't have the full on presentation of mast cell activation syndrome. Those cells can also release mediators when they're exposed to, other environmental chemicals, glyphosate, heavy metals, PCBs, all all of those things.

So they're really, they're primed for protecting us from foreign invaders. And then the problem with NASA activation syndrome is that these, mast cells have now gone rogue, and they start to perceive threats where there may not be a threat, like with eating certain kinds of foods or smelling certain chemicals.

And we know that, you know, smelling chemicals like, gas exhaust and all of the, the chemicals in the soaps, in the cleaning aisle, in the grocery store or scented candles.

None of these things are great for us. But for patients who have mast cell activation, their mast cells, are on heightened alert. And so they're constantly dumping their inflammatory mediators, causing lots of symptoms in people, making them exquisitely sensitive to their environment and to the foods that they eat.

So this really falls into the category, of, cell danger theory and survival paradox, which I know you're familiar with, which I think is a great paradigm.

You know, just it's really opened my eyes and explained some of my patients that are, if done well over the years, and then, you know, they have these fibro flares that we often see.

But anytime the body feels threatened, these mast cells are being released. That's their best part of their job. But if they don't get turned off, as you mentioned, they go rogue.

What what are some of the symptoms of mast cell activation syndrome? So you could imagine that if you've got these muscles everywhere in the body, that you can have a whole host of symptoms and no one, no two people present the same way.

So you can have, sinus symptoms, upper respiratory symptoms, post nasal drip like allergy type symptoms. You can have sore throats. You can have gastrointestinal issues from IBS type symptoms, gas, bloating, diarrhea, constipation, abdominal pain.

You can have itchy skin and hives. You could have, cardiac symptoms, palpitations, chest pain. You can have shortness of breath because they themselves can be in the lungs too.

You can have, bladder issues, irritable bowel. I'm sorry. Herbal bladder symptoms. Interstitial cystitis, which I know is common in patients with fibromyalgia as well.

And then, of course, all of the inflammatory symptoms too, because it's not just about histamine. There are all these cytokines and chemokines that are being released.

And so people have joint pain. They have muscle pain. They have neurological symptoms. They have headaches, they have migraines. And they may be reactive to certain chemicals.

So multiple chemical sensitivity is also often. And mast cell presentation. So those that are watching this interview are going yep yep check check check.

Because these are the many the symptoms that you would see for fibromyalgia which you know, that's what makes one of the things that makes fibromyalgia such a challenge is you've got all these symptoms.

We see this, you know, we see the smoke, but we can't find the gun. We know there's inflammation. But oftentimes when you do bloodwork, the CRP is normal.

Said rates normal and there's no autoimmune disease that's showing up. And yet we know there's inflammation. So this is another another example of how you can have inflammation that just is not going to show up on a traditional test.

How is this diagnosed. That's that's that's it's tough right. Stuff. Yeah. Yeah. It is tough to diagnose. So we've got all these inflammatory mediators.

But unfortunately I mean and there are thousands of them that these mast cells are producing. Unfortunately most labs can't process these, these tests.

So there are probably half a dozen, maybe a dozen labs that we can check, through specialty labs. There are a handful couple that we can check through commercial labs.

So you can check for histamine level in blood. You can check for triptychs, and you can check for chroma grant in a in blood. Now, triptychs is an interesting measure because it is.

Symptoms and Overlap With Fibromyalgia

There are some, practitioners, mostly allergists and immunologists, who believe that the only way that you can diagnose mass cell activation is if you have an elevated taste level when you're having a flare.

And this is what we, what some of us call consensus one, because many people are in a flare all the time. How do you get a baseline and then show that you haven't have had a specific increase amount in your chip?

Taste level and taste is also a measure of the amount of mass cells in the body. And you know, as the name implies, it's an activation problem, not a number of mast cell problem.

So if if there are too many mast cells, that's actually a different condition called systemic masto. So ptosis, which is actually a form of cancer of the mast cells.

So if there's an elevated taste level, above like 12, you know, if it's a couple points above 12 that can support the idea of mass cell activation. But if the taste level is 80 or 90, that person really needs to be evaluated by an oncologist.

So that's triptychs. And then there are a couple of other markers that we can look for with, with specialty labs, making sure that the labs know how to manage these things.

You can look for urine and blood, prostaglandins, leukotrienes, and there, and other metabolites, methyl histamine, for example. The last way that you can do this is, looking for stains of biopsies in either bladder or anywhere along the gastrointestinal tract.

So a lot of people get colonoscopy is when you reach a certain age, many people get endoscopy is, you know, the upper and ask a, B. And so those if there are biopsies available, you can have your physician right.

For CD 117 stands for mast cell. And again, if there are elevated levels of mast cells, they're greater than 20 per high power field. That is a one of the supportive ideas, supportive labs for the definition.

But fortunately, the definition is now considered to be, clinical diagnosis. So if you have, history that's, supportive of it, and, there's labs that are supportive of it, and you have a response to treatment, that will get you the diagnosis.

So what is so I want to go back just a second. You talked a little bit. You mentioned, it was brought out that I want to make sure this is clear. One of the because this is such a difficult thing is, is how do you separate an allergic

reaction from a mast cell reaction?

Because there are different there. This is not a this is really not an allergic reaction. This is something different than that. Yeah. So an allergic reaction, is going to be pretty finite.

And it may involve IgG E which is an immunoglobulin. So for example I have a shrimp allergy. You can check my blood IGI levels to shrimp. They're going to be high.

You could also do, patch test with an app with an allergist and show that I have a specific, allergy to shrimp. And then I have a very known reaction to shrimp. Right.

So a shrimp, I exercise, I get anaphylaxis, not so pretty. So that's that's an allergy. And for most people, that's going to be fine. It whether you have a allergy to trees or grasses or what have you, it's typical, you know, sort of itchy, runny, itchy eyes, runny nose, sneezing, coughing, etc.

can trigger more severe reaction. And there's grades of allergic reactions, but with mast cell activation there are more symptoms. So you're not often going to get cardiac symptoms with an allergy.

You may not get bladder symptoms with an allergy. You may not get, the extreme amount of inflammatory reaction all over the body with an allergy per se.

But what is interesting with Marshall and really, I think, almost infuriating if you have if you or these individuals are have it is that it's not like a food allergy.

You know, you eat their food, you're going to have a reaction, right? It changes all the time. And this kind of explains why some people will say, you know, I've gone to where now I'm down to all I can do is eat rice.

That's it. I've everything our their world has shrunk. They're, they're they're really at the mercy of stimulation and things that are going on. And again that goes back to the cell danger theory and the survival principle.

How in conventional medicine. And I made it the doc said, I'm so sorry you said that because some of my best friends are, you know, still practicing conventional medicine.

How Mast Cell Activation Is Diagnosed

They do wonderful jobs, and I refer patients to them and thank goodness we have them. But, obviously, I'm a fan of functional medicine the way we practice.

But, in, in the conventional world, this is this is something that is not acknowledged for sure. I mean, it's known about their studies. There's papers, there's people who allergists who, you know, treat this.

But for the most part, people fall through the cracks that have this. Whether you go to the conventional practitioner or you go to a functional medicine practitioner integrative, it doesn't matter.

These are the people that kind of go everywhere and try everything. And for whatever reason, they just can't get the relief that that they're seeking.

Right? Right. Yeah. I mean, it's tough. Muscle activation syndrome was only, seen first in the medical literature in 2007. That's not that long ago. And so there are practitioners now.

And of course, we're trying to get more information out there, so that patients can get the help that they need. The way that my colleagues and I who treat mast cell activation, in the way that I think is most useful for patients, where we call ourselves consensus two, and this is Doctor Lauren Safran, Doctor Cossey and Theodora's, doctor Tanya Dempsey, doctor Jill Carnahan, doctor, Neil Nathan, myself and many others.

As opposed to your traditional conventional allergist who tend to be more consensus one, which is that whole trip taste thing. So if you don't meet the criteria according to an allergist, and you're convinced that you have nasal activation, keep seeking because there are other practitioners out there who who have better tools, right, who have an ability to make that diagnosis.

Because the challenge with this is if you can't if you don't diagnose it, you can't treat it appropriately. And I think for many patients with fibromyalgia, they may have an underlying muscle activation, condition.

And there's so much hope. There's so much that we can do from when we understand that the condition is mass activation. So what is the percentage, that are, that are affected with mast cell activation?

So I'm just in North America. What are those numbers? So in the developed world, I can't even say North America because the literature came out of Germany, but in the developed world, it's thought to be 17% of the population.

Yeah, yeah. 17%. That's a huge percentage. It's a huge percentage when you get it, when you, you know, realize that fibromyalgia is maybe 6%, 7% and I'll be the first, you know, just be candid about it.

I think the way that I've been successful helping my patients with mast cells, I never knew what it was. You know, I just applied the functional medicine principles of looking for the root causes and, and cleaning those up, whether that, you know, whatever that is.

And oftentimes, you know, for fibromyalgia, that could be numerous things. But we already mentioned mold is a big one. Is a big one. Yeah. So oftentimes just just getting these foreign invaders where the or whatever it is, it's the body feels that it's being threatened.

If you can clean that up. And again, there could be several food allergies, I mean, numerous that leaky gut. But as you do that, then this mast cell activation syndrome starts to, to, to tone down.

Yes. Yeah. Now with some people, you know, who are very limited in their diet, very limited in their capacity to take meds or supplements, because of the mast cell activation that definitely hampers treating Lyme or mold.

So oftentimes with the more sensitive Marcel patients, that's where I start. As to quiet everything down, because once we start to quiet things down, then they're better able to tolerate the treatments.

So we could talk about treatment of mast cell now if you want. Yeah, absolutely. And I think the I just want to, point this out there, but I found, you know, two decades treating fibro.

Is that the first thing you really do have to do is calm everything down because they're nervous. System as other speakers will share on here, is overstimulated and they perceive stimulation, stimuli in a overabundant, a manner where they overreact to it.

So the first thing I find is calming everything down. And that's usually calming down the different neurotransmitters, making sure the serotonin level is built back up, gamma amino butyric acid, some of these other things.

But but I, I totally agree. If you don't calm everything down, then if you try to be too aggressive and and helping them navigate some of these things, it backfires.

Yeah. So so what are so what are some of the treatments both conventional and and and natural. What are the what are the treatments that you like? So I start with simple things, inexpensive things, you know.

So, everyone has access to over-the-counter antihistamines. Now, not everyone with meso activation has histamine as an issue. And I think that that's a really important.

So just because you may or may not respond well to antihistamines doesn't mean that you don't have mass activation. I mean, it just means histamine is not a player in in your, in your presentation.

Allergies vs Mast Cell Reactions

But I love over-the-counter antihistamines, things like Zyrtec, Claritin, Allegra, XYZ, all Benadryl, all. There are some prescription versions of that, Clarin X or hydroxy Zin.

Some older medications, they can work really, really well. Also the H2 blockers. So the Pepcid works really well. We used to have Zantac. We don't have that anymore. Unfortunate.

And then oftentimes I'll move on to, well, we can talk about the conventional things too. So, the, the leukotrienes, inhibitors, singulair. And, and, similar medications work.

Well, aspirin can actually be really helpful with some patients. There are some more aggressive medications, more unusual medications. That can be helpful.

Hydroxyurea. Imatinib, which, you know, is, a tyrosine kinase inhibitor. I don't tend to use it very often, but it is available. Things like Crumlin, which is great.

That's a muscle stabilizing medication key taught often, which is also a nasal stabilizing medication. It has to be compounded in the US. I've been playing around with Rupert padding after talking with doctor theories.

Repetitive is a, it has an antihistamine effect, but it also has, platelet activating factor inhibitor effect. And that one is only available through, Canadian pharmacies at this point.

But I do find that that's very, very effective. You can use the Cromwell in, nasally or orally, for gastrointestinal issues. You can use, it nebulizer for respiratory issues.

So those are many of the pharmaceuticals that we'll use. And then in terms of the supplements, I did some research from, for the Mast Cell Summit or at least 65 different supplements that are helpful for massage.

I think I've got maybe 6 or 7 written down that I wanted to make sure we brought up. So this is, you know, this is going to open up my armory, you know, to be aware of that. Yes.

To get. Yeah, yeah. One of the main ones you found that are, that are the most helpful, do you think, quercetin works really great for a lot of people.

Woody Allen, which is another one that Doctor SEO recommends. I like pyrimidine for people are perilla seed. Pick nada. No, actually, I love that. Works great.

Some people do very well with low histamine probiotics. I also like resveratrol for patients. Let's see Dao enzymes. Now, do enzymes are a little bit different due out is the enzyme that breaks down histamine in the gastrointestinal system.

And so it's really good for people who have more histamine intolerance type symptoms where they eat something and they have a reaction. And oftentimes you can have histamine intolerance and mast cell activation.

But not everybody who has mass or activation has histamine intolerance. So the Dao enzymes have to be taken, before a meal, before you eat a high histamine food or what have you.

So those are some of the ones that I use. Do you, find so you mentioned so many of these that you mentioned or any histamine. They're natural antihistamines, but but they also have some other, some other effects as well.

Now, quercetin I know is one that I really like. And dao but you're but you mentioned energy, which I have not heard of. Reverse the trial, which I had not heard of.

I mean, I use those for other things, but they're great for asthma and some other things, but. So you're saying that

those can be very, very helpful as well, just taking as a as a preventative ongoing basis.

Yes. Yeah. And you know, depending upon what you're, what the patient is working on, of course, you want to minimize the number of supplements that you're taking and maximizing the effect, you know.

So if they have cardiovascular issues the resveratrol might be really great with that if they have headaches or migraines.

Treatment Options and Supplements

But maybe you're using something like butterbeer or a dollar box or, you know, one of those that have, effects with, with, with headaches and migraines?

I also like skull cap. So say there's a patient with Lyme disease, and you want to use, skull cap with, the Lyme patient. So there are ways to do double duty with a variety of different herbs, provided that they're helpful. Right.

So, you know, if you got 60 plus herbs that you could use, and the patients are super sensitive, how do you choose? Right. That becomes very challenging.

I do a lot of muscle testing, honestly. Yeah. As a conventional doctor, it's a little strange. But I find, you know, for many patients are like. Yeah, I love to have a tool.

So I teach them how to do muscle testing. Yeah. So, you know, that's an art. There's a there's the science behind it to some people or, you know, good debate.

But it's definitely there's science behind it. And, and it's a, it's an art form. It's you know, it's like anything. And you're some people are better at it than others.

Tell me about I wanted to ask you a little bit more. How would someone know? How what what would they suspect? How would someone who's listener listening?

So thinking, you know, maybe I have that, maybe I don't. Are there any telltale signs that that person should be thinking of that may clue them that, yeah, this this could be an issue for me.

So, the way that I would think about it is it's a multi system, multi symptom allergic inflammatory condition. So if you've got more than, you know three systems involved and multiple symptoms you want to start thinking muscle activation.

So you know with your fibro patients they've got sleep disorders. They often have just not just the fibromyalgia pain. But then they can have fatigue.

They can have headaches and migraines. They can have bladder issues. They might have anxiety, depression, insomnia. All of those symptoms could be explained by mast cell activation.

So I think it's when the when the patients experience multiple systemic symptoms, that's when you have to think about it. Yeah. And I find that it's really the folks that tend to tell you, oh yeah I'm allergic to everything.

Those are the people that instantly I'm thinking, okay. And I've already done a you know, if it's a new patient, I've already done a questionnaire or I'm asking about line mode and things that would tip me off.

But if they tell me, you know, chemical sensitive, that's a big one, right? Right. You know, they react to everything. I'm already thinking, man, this is massive.

Do you ever do just a challenge just to kind of see if they respond to an antihistamine like Claritin or something because it's non drowsy or, or if they're struggling with sleep, maybe put them on Benadryl at night and or take light

in the afternoon and just and just see if that alone makes a difference.

Absolutely. Yeah. I will do that very commonly. Or or the other telltale sign is when people come in on an antihistamine. Yeah. That's true. Yeah, yeah.

You know, okay, you've already started self-medicating. That's great. Yeah. That's great. Well, I'm going to place for sure, no doubt. Yeah, yeah. Now, for some of my patients, they're so sensitive that they can't tolerate those medications.

That's the other clue. If people come in and they're on, they have a lot of medication, medicine, allergies. It's oftentimes not the medication that people are allergic to.

It is the inactive ingredients in those medications. And so they need medications that are compounded. So I have to compound the antihistamines compound, you know, the Crumlin compound.

These are some some of my Marcel patients require everything to be compounded. But then we find stuff that they tolerate and it starts to work. Yeah. And most physicians see it.

And I guess you would if someone was, listening is to thinking, well, I'm going to this is me. I'm going to seek out doctor McCann. I mean, there's only, there's only I mean, there's just not that many people who specialize who know that much about it.

But if someone were seeking out someone locally, although most of us now practice tell this and I'm 100% down there, so what they look for an environmental allergy, practitioner or someone that's a little more open, to use the word open mind, I mean, you know, but someone that's a little more up on Messiah.

Would that be an environmental allergist? Not necessarily. So, yeah. Environmental medicine doctors? I would say yes, but not necessarily an environmental allergist.

Well, that's what I mean. I'm serious. Yes, yes. Yeah. So some people who are functional medicine trained may, may know about this, but they really need additional training.

They're not getting this in their, in their standard courses. You know, if they've just gone no offense I love have if they've just gone to you know they may not know enough about nasal activation to manage a patient.

So for example, there's a professional organization called the International Society for Environmentally Acquired Illness, or I c I s e a I, those docs know more about not only mast cell activation, but also some of the root causes Lyme, mold, etc.

and so you might have better success with somebody like that.

Who to See and Where to Learn More

Now, after my summit, so we, we have been trying to put together a list of, of practitioners, who are willing to take patients. You know, I'm on a listserv with over 300 practitioners.

But they're not all they're not all willing or able to put them put themselves on a list specifically for Marcel patients. So, but you could you could reach out and, you know, we can we can try and and get you in touch with somebody.

Kelly is. So, if someone wanted to know more about you and your your practice. Now you have a brick and mortar practice. I do, I have a brick and mortar practice called the Spring Center.

And and then if they wanted to learn more about you what's the website they would go to. So there are two websites. The brick and mortar practice is the spring center.com.

And then my online presence is Kelly K McCann imdb.com. And that one there's a blog and I have a couple of courses. I have an environmental medicine course, that I think is actually really great, where it kind of walks you through.

What are the things that you could be exposed to in your own life, your habits, your home, etc.? And then why, why and what are the what are the chemicals that you're being exposed to and what to do about it?

So, that's a great course. And I'm in the process of working on a mold course as well. Great. Fantastic. Okay. Thank you so much. This is been really insightful.

You know, this is a topic that again, most people really probably the first time they ever heard about it. You know, you're someone I think helped put it on the map and hopefully we're going to, you know, we're going to gather more and more research and more and more ways to be able to effectively diagnose somebody, you know, take that mystery out of the equation.

And it's people like you that's making that happen. So thank you so much. Oh you're welcome. Roger, thank you so much for having me. Yeah. Thanks.