Introduction to MCAS and Lyme

There are also mast cell patients who have no allergic symptoms whatsoever. and the syndrome is being popularized. I think there are more and more practitioners who are starting to understand it to some extent, or at least they've heard it, but they make an assumption that there has to be, people have to have allergic symptoms.

They have trouble breathing or they have respiratory symptoms of various kinds. But there's a subset of patients with MCAS who do not have anything that even resembles allergy, and they still have mast cell activation syndrome.

Hi and welcome to the Lime Bites podcast, where we shine a light on the misunderstood science of Lyme and other vector-borne diseases, as well as the truths that many still miss.

I'm Dr. Mariah Hinchey, naturopathic physician and fellow of the Medical Academy of Pediatric Special Needs. I specialize in treating chronic Lyme disease as well as other complex inflammatory conditions.

In this podcast we break down what's working and what not. We share the facts that most people miss, we challenge outdated thinking, and we give both patients and practitioners the tools to heal smarter.

So let's get into it and change the way we heal Lyma. Welcome to another episode. I'm your host, Dr. Maria Hinchey. And today we're going to talk about mast cell activation syndrome in relation to Lyme disease and other vector borne illnesses.

So Lyma is an inflammatory immune dysregulating infection that infects and affects every cell in the body. It's not surprising that it's going cause dysfunction in mast cells in a lot of patients too.

Mass cell activation syndrome causes a ton of different symptoms, and they can affect every single system of the body, just like Lyme and vector-borne diseases.

And there's quite a bit of overlap in the symptoms. So here to talk us through, teach us more about what it is, what the relationship is and what to do about it, is Tanya Dempsey, MD.

So Dr. Dempsy is a board certified internist, and she is an expert in chronic disease, autoimmune disease as well as mast cell activation syndrome. So welcome Dr.

Dempsey. Thank you so much for joining us. Let our audience know how you came to specialize in this. Well, first off, thank you for having me. One of my passions is educating.

And so I love talking about what I do every day, and that is take care of patients with complex, chronic diseases. How I landed on mast cell activation syndrome is a little bit of an interesting story, but You know, the reality is that I've always been very sort of open and always with this mindset of root cause medicine.

Even when I was doing general internal medicine, I always wanted to understand why something was happening to a particular patient. And I, because I'm interested in root-cause stuff, also was always talking to patients and listening, and more importantly, listening to them.

And so when you listen, you're more likely to find things and start to understand how the pieces fit together. And actually looking back, the point is that I think I was seeing a lot of patients with mass selectivation syndrome, and now I can see that in retrospect.

Dr. Dempseyu2019s Path to Mast Cell Medicine

And I knew that there was something immune-disregulating, but I didn't really understand the full aspect of it until I was already on my own in my personalized medicine practice where I had that one patient that was not getting better and was getting worse and had multi-system symptoms that didn' really fit into any other box that we could find.

That there's nothing else that really explained her symptoms. I remember one day doing a little literature search, I was on PubMed, and I think I even was in Google because I really was determined to figure this out.

I came across Mass Cell Activation Syndrome and this was probably somewhere around 2014, maybe close to 2015. That was really just kind of the beginning of the information we had on MCAS.

But once I sort of looked at it and thought about and talked to the patient about it, it all made sense. And then I connected with Dr. Larry Afrin, who is really considered, I consider him the world's expert in mass selectivation syndrome.

Then eventually I brought him on board to my practice. So we're practicing together and researching and studying and really trying to understand this disease better so that we can help more patients.

So that's amazing. That's great. What better than to bring in the world expert, right, to your practice and work with him? I love that. Thank you for everything that you do.

So let's start by talking about what is mast cell activation syndrome for the listeners, you know, who are patients. So, you know, I think the best way to think about it, the quick version of it—the elevator speech on it really is, it's a chronic, complex, multi-system disorder.

And so what that really means is that this is a condition that affects multiple parts of the body. So symptoms in one part of body alone probably is not mast cell activation syndrome, and we're looking at Mast cells in particular, right?

So let's talk a little bit. To understand this syndrome, I think it's good to really even understand the cells involved in the syndrome. And these cells, these mast cells are white blood cells.

Now we have white cells—lots of different ones—they fight infection, they help protect us from the environment, and they do a lot of things. Mast cells are white blood cells that actually live in tissue in the body.

So we have white-blood cells, that are flowing through the blood vessels. They're in your veins, they're your arteries, or they are circulating. Maste cells actually stay in tissues, in organs.

And that's where they, are our first line of defense against everything. The external environment, the internal environment. And they are part of what we call the primitive immune system or the innate immune systems.

So they're positioned to be the first line of defense. And one of the ways they protect us is that when they see something they don't like, they literally explode.

We call it degranulate. They release granules of chemicals, we call those mediators, in order to fight off what they see as foreign. Now, mast cells are involved in allergy, so I'll give you a little bit of a primer on allergy.

So if somebody has just allergies, they may or may not have mast selectivation syndrome, but they're, let's say, allergic to pollen. The mast cells in the respiratory tract see the pollen.

They see that they're allergic to the pollens. There's a signal to mast cell that the polon is bad and it needs to be dealt with. And the way that mast will deal with it is they'll explode, they release histamine.

That's one of the drivers of allergic symptoms. Histamine is very inflammatory, so in response to the histamine, everything swells up. You might get itchy, you might have trouble breathing.

There are lots of different things that happen, right? That's what mast cells are responsible for. again, towards this allergy. Now in an allergy situation, typically you sort of deal with the allergy, you avoid the allergies, and you get allergy shots, so you take allergy medicine.

And as long as you're not exposed to what you are allergic to, generally speaking, those mast cells will sort just hang out and wait for the next thing.

In mast cell activation syndrome, which by the way could include allergy but doesn't have to include an allergy, you can have mast-cell activation without allergy.

You can allergy without mast activation, and you have allergy and mast activity syndrome. But in people with this mast cells activation syndrom, what happens is these mastcells which I said are really all over the body.

I talked about allergy in the respiratory tract and in skin, but, again, mast cells are everywhere. When they read a signal that's abnormal to it, they will explode.

They will release various chemicals. Histamine is just one chemical that they can release. They don't have to release histamine. Many mast cells don' make histamines.

They make other chemicals or over a thousand different chemicals that mast cell can produce. And in this release of the chemicals, these chemicals then are, sure, they're sort of designed to maybe help kill whatever they are trying to kill, but really it backfires.

All of that, those chemicals are in our tissue and it causes inflammation. So again, mast-cell activation syndrome. These are mast cells that are abnormal.

They're reacting abnormally to the environment. There may be triggers that real, but they're probably not that bad. Somebody without mast cell activation syndrome may or may not even realize that there's something bad in the environmental.

But people with MCAS are reading things at a very, very low level. So they are more, it's more intense, more aberrant, and more abnormal and that leads to a variety of symptoms, and it can affect every single body part or, again, system in the body.

To meet the criteria for mast cell activation syndrome, you typically need more than two systems involved.

What Mast Cell Activation Syndrome Is

So again if you only have allergy and you'll only respiratory symptoms with the allergy, but you have no other problem in any other part of the If you have allergic symptoms, let's say, and you symptoms that involve, lets say you had bowel issues, gastrointestinal issues.

If have heart issues or palpitations, maybe you neurologic symptoms or neuropathies. You have things that are involved in other parts of the body, then you can say this is a multi-system condition and that may meet the criteria for mast cell activation syndrome.

But I want to make a point about allergy and histamine and that is that, again, you can have allergy, and mass selectivation syndrome, but—and you cannot have mass-selectivations syndrome that looks like allergy but is not truly allergy.

So, some of my patients wind up in an allergist's office and they know they're, let's say, reacting to pollen or they are reacting a food, they get tested and everything is negative.

It's not that they don't have allergy, but they have an exaggerated response from the mast cell through a different pathway. So it looks like allergy but it won't meet the criteria for a true allergy.

But there are also mast-cell patients who have no allergic symptoms whatsoever. And this is probably the most misunderstood piece, and I really want to drive this point home.

Because a lot of patients are discounted when they say they don't have allergic symptoms. I think that since this disease and the syndrome is being popularized, I they're more and more practitioners who are starting to understand it to some extent, or at least they've heard it.

But they make an assumption that there has to be, people have to have, allergic trouble breathing or they have to have respiratory symptoms of various kinds or hives.

But there's a subset of patients with MCAS who do not have anything that even resembles allergy, and they still have mast cell activation syndrome. So if I can send this message home to the patients, to maybe their practitioners listening, If the patient has multiple symptoms in other parts of the body, but they don't have allergy, they can still have nasal activation syndrome.

Okay. And we need to have at least two systems being affected. Correct. Two questions. The first one is, so what are the common, like obviously we're talking about infections inducing this.

So in addition to infections, what're some other things that would cause someone to develop mast cell activation syndrome? Are you ready to transform the way you diagnose and treat complex chronic inflammatory illness?

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So join us in Pompano Beach or from anywhere in the world. Don't get left behind. Register now at limebites.com. That's L Y M E B Y T E S dot com. What we understand is that the vast majority of people with mast cell activation syndrome are probably born with a predisposition.

They're born, we'll call it, somewhat dysfunctional mast cells. Maybe there's a familial history. There usually is other family members who have some flavor.

of mass cell activation syndrome. So they're born with this predisposition and we call this idiopathic really mass activation syndromes. It starts at a very young age and then they have the predisposition, it doesn't mean they are going to go on and develop full-blown MCAS.

But they might have mast cells that are a little bit more finicky. And so over time, with various insults, various exposures, those dysfunctional mast cell can become more dysfunction, and then over-time lead to the full-blown development of mast-cell activation syndrome.

So there are patients with Lyme disease, with infection, who had mast cell activation syndrome before the infection but maybe they had very mild symptoms.

And then they get the infections and it could be Lyne, it can be Bargnella, Babesia, a parasite, or a virus. could be the flu, could COVID, it could Epstein-Barr.

Could be even a toxin in the environment, a pesticide, mold toxins. There are lots and lots of things in environment that can trigger the mast cell and with every trigger of something sort of dangerous, foreign, toxic, these mast cells sort basically reach a new sort-of baseline where they're more reactive and more and reactive over time.

So I would say that that is definitely the majority of patients, at least that I see in my practice. When you take a really good history, sometimes patients think that a particular incident is what caused their mass selectivation syndrome.

We see this a lot actually in the long COVID world. Very healthy people who then got COVID and then have lingering symptoms. But really, the majority of them, I would say, and I'd never say all of the them.

But the majority of had some flavor probably of MCAS. When we take a good history, we see that there were some things already sort of at a very low level, but these are very healthy people, so it's not really affecting them but then that major trigger brought it out.

There are, there is a subset of patients though who have what's called secondary mass selectivation syndrome. and they have, let's just say, totally normal mast cells.

There's no genetic predisposition, there's not family history, they're born normal, normal history. But then at some point in their life there is a trauma, an infection, a toxin exposure that then literally mutates these mast cell to become dysfunctional.

In that case of secondary, The taking away the trigger may actually reset the mast cells back to completely normal. Someone who was normal, lived in a moldy home, got mast cell activation syndrome, gotten mold exposure and microtoxin illness, and then they're treated.

They leave the house, they get treated, And for them, if they didn't have anything wrong before, it's possible that their mast and their health will just go back to where they were before.

I would say that's actually unfortunately rather rare because most of those patients with secondary, those mast cells get mutated in a way that they may not return to normal.

And then that does suggest that maybe there was something going on earlier that we just didn't even realize. So it's complicated, but that sort of the way I think about this.

Causes, Triggers, and Diagnosis

Okay. Is it a clinical diagnosis or are there tests that you can do to diagnose it or is it combination of the two? Yeah, I think the best way to think about it is that it really should be a combination.

You need the clinical symptoms, you need to clinical sort of manifestations. The patient has to meet those criteria of multi-system disease or symptoms that are not explained by other diseases.

But sure, I'm a scientist at heart, and so I really would like to have a diagnosis. I think that getting a diagnoses, using testing, validates the patient, gives them a credible diagnosis that they can then tell their other providers about that, again, then they have that credibility that again they're not discounted, they are not disbelieved, right?

I think it's important. The challenges of testing can be difficult. And so I there's always going to be people who are not going be able to either do the testing or they do testing but the test doesn't show anything abnormal.

So we just have to careful. There are cases where we can't find the abnormal results But really, there's everything about their clinical picture, including response to treatment.

You know, they've tried things for mast cell activation syndrome and they seem to get better. So, we make an assumption that they probably have it. The testing involves really a handful of tests that we can measure.

Mediators that measure actually, these are the things that mast cells release when we try to grab them from the blood or the urine. I said earlier that masts cells make over a thousand chemicals.

If we only have a couple of handfuls of things we could measure, At most, there are going to be people who don't meet the criteria by our testing, but that's because maybe they have one of the mediators that we just don t have the testing for.

So I think we have to treat the patient ultimately, and that the patients is the one that needs to, you know, be treated, not just the tests themselves.

Yeah, absolutely. Do you want to share with the listeners what like those, you know, handful of tests are? Because I know like testing for histamine is not, like that's not it.

So what are the other mediators? I mean, I But as you've pointed out to me, histamine is not the end-all be- all. So what are the other things that we can look at and evaluate again with the clinical picture?

So a plasma histamines and a whole blood histamin might be worth doing because when you get it, it's helpful. It's one piece of information that can be used towards making the diagnosis.

And ideally, I would want to, not only do I want two body parts affected essentially, but I wanted two pieces of laboratory evidence to support the diagnoses.

So, histamine can certainly be positive and that could be one point of reference. In addition, we have chromogranin A, Some of these mediators are not specific to the mast cell.

They have other cells that are being made, are making them I should say, but we can use some of this depending on the level, chromograndinase I. Triptase is the one that gets the most press and unfortunately because Triptase is made by mast cells.

There are lots of people who do not have elevated triptases, but some of the old thinking on this is that you need an elevated trip taste to make the diagnosis and you to be testing when people are really symptomatic in order to see if the trip tastes goes up.

And I will just say that again, I think that's a different way of approaching this. And so our way of approaching it is saying, sure, if we get an elevated tryptase, we're going to act on it.

We're just going try to figure out what that means. But if it's negative, it doesn't mean that patient doesn' have a mast cell condition. Elevated tryctase though can mean other things, and so that's going require other types of testing.

but it rarely is a marker for mast-cell activation syndrome alone. That's what I'll say about trytase. And then there are markers like heparin. Heparin is a really interesting chemical.

It is blood thinner. it's used in hospitals when people have blood clots. The mast cell is the only cell in the body that actually makes heparin in really, really miniscule amounts.

But there are certain labs that can measure down to those minuscule amount. And when we catch an elevated heprin, in blood, then we know that it must be mast-cell activation syndrome.

That's a very specific marker because And sensitive actually, sensitive and specific marker because there's really nothing else that could be doing that unless somebody is actually taking heparin.

So that's a really great test. And then there are urine markers, mediators that we can detect both in random urine samples and in 24-hour urine And we have things like N-methyl histamine, which is a metabolite of histamines.

We have leukotrienes. Yeah, a little bit. Dr. Afrin does it so seamlessly. It's just so beautiful, but I usually stumble on it. But in any case, so we have these various meteors that we can collect in the urine.

The challenge is really that the people who are collecting it, the labs that you're going to, they have to know how to handle the specimens. At home, people have to be really careful with the specimens.

They have keep it cold. So there's a whole routine. We don't do the testing in our lab per se, but we do have a lab here in the office where we process everything and then get it to the lab that's actually going to run the samples.

And we have whole technique here on how we educate our patients and how process things so that we get, hopefully, more reliable results. Right. Wow. Okay.

So Dr. Dempsey, let our listeners know how and where they can contact you if they're interested in more information or becoming a patient and let them know if you have any upcoming events or exciting news to share.

Sure. So, um, you know, I'm on social media. Instagram is Dr. Tanya Dempsey, MD, Facebook, DrTanyaDempsey. My website drtanyadempsy.com. Lots of, lots of information.

I do lots videos and podcasts. So I have a, a new podcast. so I put that on my social, but if people want to listen, it's called Amassed Cell Matters.

And that's been exciting. We have. A few more. already released and we have a few more coming down the pike. But I think that having this podcast about mast cell activation syndrome is really great and exciting and just want to keep getting the word out and interviewing some of the best of best in this field.

And I that's all I can think of for now. Okay, great. I'm excited to hear your podcast. Definitely want learn more. The tip of iceberg here with mast-cell activation syndrom.

So, Dr. Dempsey, I have so many more questions for you. We haven't even really talked. Now, we talked about how it's multi-system, but we haven' even even gotten into what the actual symptoms of mast cell activation are.

So can you share that with us? Sure. Well, start from sort of head to toe. You know, that's probably the easiest way to do it. And again, you know, there are some symptoms that can be linked to other conditions.

So just because you have this symptom doesn't mean you'll have Mass Effectivation Syndrome. We want to be clear, right? Headaches are, let's say, a symptom of MCAS.

Migraines can actually be a symptoms related to MCAs. But people can have migrains and not have MCas, so I just want it to clear that we'd be careful not to attribute everything to a MCA.

Headaches definitely are a possible symptom. We see eye issues, blurry vision, change in vision. Ringing in the ears, changing hearing, trouble swallowing.

There's various digestive issues.

Testing and Biomarkers for MCAS

We've seen SIBO and slow motility issues, gastroparesis, colitis, respiratory issues can be like an asthma-like situation, could be a cough, just reactivity in general to things in the environment that way.

The skin, there could be hives, but there can be other kinds of skin manifestations. Things that look like eczema, psoriasis. There are lots of different things that may be linked to MCAS or may manifest like MCAs.

I think about going down to the pelvic region. In men, we sometimes see pelvic pain. They can have testicular pain, So, they can have post-orgasmic pain.

Women too, can they have the same, post orgasmic, pelvic pain, endometriosis, various menstrual irregularities, and various hormonal irregularity. And then osteoporosis associated with MCAS, arthritis.

you know, muscle issues, neuropathies, other neurologic issues. Neuropsychiatric issues depression, anxiety, OCD, eating disorders. You know again, like the list goes on, I'm probably forgetting something in that mix.

Connective tissue issues cranial cervical instability, tethered cord, sleep apnea. The list is on. How does Lyme, in your opinion, how does that infection induce mast cell activation syndrome?

Is it infecting the mast cells? is it just a part of the immune dysfunction? Do we know what the actual connection is that triggers this in some patients?

Because as you're rambling off the symptoms, it's like, yep, that's a symptom of Lymes. On and on and it's like, you know, there's just, it is very close to being 100% overlap in the symptom.

Are you suffering from Lyme disease or another complex chronic illness and aren't sure who to trust when it comes to herbal supplements? Hi, I'm Dr. Mariah Hinchey, founder of Lime Core Botanicals.

As a naturopathic physician specializing in complex, chronic, infection-driven illnesses like Lymedisease, i needed herbal medicine I could truly trust.

That's why I formulated Lime Core Botanicals, where our herbal tinctures are handcrafted in small batches right here in Connecticut. We use the whole herb, never isolates, to preserve the full spectrum of medicinal compounds.

Every single step from sourcing to extraction is done with precision to ensure maximum purity, potency, and consistency. These are the same herbal formulas I used to heal myself and have used for years to help my patients and family members heal too.

And now I'm making them available to practitioners and patients everywhere. Lyme Core Botanicals, herbal medicine you can trust from a doctor who lives this work.

Learn more at LymencoreBotanicles.com Absolutely. So the way I look at it is that for some patients, the line is a trigger for their mast cells. I said early on that the mast cell are reading your environment.

We know that as part of the primitive part the immune system, from thousands, tens of thousands of years ago, mastcells were helping us fight off parasites.

They were help us to fight of funguses and bacteria and lots of things. If that's their job to help us fight those infections, you can imagine if you get a chronic infection like Lyme, or potentially chronic infections like lyme that you're going to set off that part of the immune system and rev it up.

The problem is that in chronic type cases, the mast cells are then constantly seeing this infection. and they're constantly reacting. So I think there are a couple of different things that happen.

The line kind of spurs on those mast cells, the mast cell talks to other parts of the immune system, they talk to the part of immune that produces antibodies.

We have these other white blood cells lymphocytes that are involved in, we have T cells and B cells. And we had these cells that make antibodies. Some Lyme patients have positive ANAs and rheumatoid factors and they have Hashimoto's and all of a sudden they all have these antibodies and so what we believe is actually that the mast cell may be responsible for sending the signal to these cells like there's danger, we've got to do something and that part of the immune system starts to get dysregulated and starts making antibodies just trying to fight Not very

effectively, unfortunately, but nonetheless trying to fight off infection.

So I think that's one part of this. I don't think Lyme is directly infecting mast cells, although I guess that is absolutely possible. We just haven't seen that yet.

You know, I just think there's more research that needs to be done. And then I think the other part is that once you've had an infection like Lyme, so for some patients, the immune dysregulation piece of it is more pronounced than the infection piece a bit.

So even in some people who are treated and may be treated effectively, maybe their immune system continues to fight.

Symptoms and Lyme Overlap

And there are others where I don't really think the infection is gone, and I think that the immune system is dysregulated, but I also think infection still there, spurring this on and keeping the mast cells continuously in this state of disarray, constantly releasing these chemicals, causing inflammation.

And the way I think about it is I thing the symptomatology. Some of the stuff I'm saying, we have not published on yet, but it needs to be published. But what I believe is that the symptoms that patients are experiencing with, let's say, Lyme or Babesia or Bartonella or whatever the vector borne infections we're talking about, some of these symptoms are actually, I thinking, driven by the mast cell.

and some of them are being driven by the actual organism. I think it's a combination of both. And I thing in some cases when you treat infection and you get what we sometimes call a Herxheimer reaction, for some patients that Herzheimer Reaction is in fact mast cell activation syndrome.

It is the release of toxin, let's say when your treating those infections, but then that is flaring the mast cells even more. causing that whole set of symptoms that looks like it could be a worsening of their Lyme, but may in fact be part of the mast cell response.

Right. And we know that so much of The Herx is inflammation driven too. So like this makes sense, right? That the mass cell is actually playing a role, like in reaction to the LPS maybe and causing part this inflammatory piece of Herximer reaction.

That's very interesting. So, what treatments and interventions, and please talk about pharmaceutical as well as nutraceutical or herbal, whatever you would like to comment on, you know, do you like use or are available to treat mast cell activation syndrome?

Well, first and foremost, the number one thing you need to do when we think about treatment is really to first make sure that you eliminate triggers. So if you know that you're exposed to mold, you that there's something in your environment, your dealing with a very stressful event, whatever it is, You've got to deal with those things first before even thinking about medication and all that.

Those are going to be important, but as long as you are constantly being exposed the triggers, it's going be hard to treat. And that includes the infection itself.

Sometimes with some patients, there is a little bit of a I think of it like a seesaw type of thing going on between, I'm trying to treat the line, but I know if I don't treat that mast cell piece, they're going to flare more.

But if don' t treat line their mast cells flares more, so it kind of is a little bit of a catch-22 in some ways. And so that's like the one part. to treat the mast cell directly, to basically calm this situation down, first line would be what we call antihistamines, H1 blockers and H2 blocker.

So we said earlier, histamine may not be the whole story, but having said that, mast cells typically do have

histamine receptors on their surface. those receptors on their surface or what is what they are reading the environment with.

And so they have these histamine receptors and even if histamines isn't a major issue or a mediator, sometimes putting that H1 blocker that Histamine 1 receptor blocker antihistamine can maybe send a signal to the mast cell like, hey, calm down, stop reacting so much.

For some people where histamine is an issue, yeah, blocking histamines at the level of the mass cell but also in other cells in the body can be helpful and reduce symptoms.

And there are lots of over-the-counter antahistamins and there is some prescription antohistamin. We have different histamine receptors all over our body.

So we're talking about these typical sort of antihistamines or what we call H1 blockers. Claritin, xyzol, zyrtec, benadryl, things like that. And then we have these other antahistamine, they're called H2 blocker because they block a different history receptor.

The H-2s tend to be more in the GI tract. They are sort of elsewhere, but a lot of them in the GI tract. And so a of these drugs are used actually for GI symptoms, for reflux and heartburn, But they can help block histamine.

Things like Pepsid, or famotidine, Tagamet, Xantax, so things like that. So finding the right one of the H1, finding a right for the h2, that sometimes is really, really helpful.

There are other medications that we use, there are mast cell stabilizers, ketadiphen is one, chlomalin is another, low-dose naltrexone is on of my favorites.

This certainly doesn't work for everyone but can help modulate the immune system beyond the mast cells. From a supplement perspective, from a nutraceutical perspective there Things that digest histamine down, diamine oxidase.

There are things that block histamines, vitamin C, quercetin. They also can be mast cell stabilizers. A number of other sort of natural products, resveratrol is another one.

Lots of them that actually have some mast cells stabilizing properties. And then again, lots of drugs potentially that can help. All the way over to chemotherapy agents potentially.

I have no idea that this is the problem, what for each person is going to work for them, which one is gonna work best. That's some of the research actually that we're trying to do, is trying look at the mast cells to see if we can do genetic sequencing to figure out that this particular mast cell maybe is making more of histamine.

So we know that we're going to use everything possible for histamines, but maybe that's the cell that is more prostaglandin D2. Maybe we need to target things and use things like Celebrax or MoBEC or NSAIDs.

Once we can get to the part of the research where we really can determine what the person's main issue is, I think it's going be much easier. But right now, it is a lot of trial and error.

So it sounds like there's kind of three goals. So number one is to block the two histamine receptors. Number two would be to do things to stabilize the mast cell and make it a little bit more tolerant to the environment so it doesn't degranulate as easily.

And then number three would to kind gobble up the histamines and the inflammatory compounds, so maybe proteolytic enzymes, something like that. But the big above all of that is finding what that trigger is, especially if it's an infection or a toxin or something that we need to actually focus on either getting out of the patient or getting the patients out if that environment, if its an environmental trigger.

So with any of these interventions that you've mentioned, are there side effects that people should be on the lookout for? I think there are a couple of key points that I need to talk about.

Treatment Approaches and Trigger Management

In addition to all these big triggers that we talked about in the environment, medications and supplements are combined with excipients during the manufacturing process.

You know, you take a claritin. There are different formulations of clarotin, some of them have lactose in them, and some have mannitol, there are various ingredients in different forms.

And so, for some patients, they don't realize it, but they may be actually sensitive to one of these excipients. So, they may react, let's say, to an intervention.

It may not be the drug itself, it might very well be one of these fillers or excipients. We see that in the pharmaceutical side and we see it on the nutraceutical side.

Magnesium stearate, microcrystalline cellulose, there are a number of things that are quite ubiquitous in supplements but that for some patients might be an issue and for others, not at all.

I think paying attention. If you're someone who trials lots of medications and supplements and reacts a lot, my guess is you are not reacting to all those compounds.

You're probably reacting something that's in the mix with them. I have patients who create elaborate spreadsheets. to try to figure out what the overlap between the different medications are.

To try and figure it out, oh, wait a second, there's this one ingredient that's been in everything I've tried, now maybe that is why I'm reacting. So now, either you have to find a formulation without that, or you need to compound it.

It can be complicated, but definitely can very much worthwhile because if you could figure that out, you then wind up having options and maybe being able to tolerate a lot more than you thought.

So that's the one thing that I would always keep in mind. In general, these drugs can either work beautifully, not work at all. or cause weird reactions, and these reactions may be the excipient part, but it could be, the compound, drug, or the supplement.

So, again, working through all that I think is important. And having somebody, you know, I feel bad because there are lots of patients out there who are trying to manage this on their own because they don't have providers, but I hope that the more we educate, the providers that will be out there who can support patients.

It's much easier to do this. You know, it's easier for me to work with my patients on this than for the patients who do it completely alone. But if you have to it alone, there are ways to to.

And you just have be rather methodical about it. Yeah. Are there things from like a lifestyle perspective that patients can do to help to mitigate some of the symptoms?

So yeah, that's a good question. And it depends. I think it's important for patients to try to find things that generally help their reactions acutely.

There may be things like some patients know that dye-free, benadryl liquid is a rescue for them and they know if they're having a reaction they can turn to that.

let's say they're trialing something else, you know, they can always turn to their rescue Benadryl if they, let say, reacted to the Claritin that they took or something.

But some patients don't have that yet. They're still searching for the thing that's going to get them out of the flare. So there's no, unfortunately, yeah, there is no specific thing.

Everyone is different. So what would you say are your top three most important take-home points for our listeners? So I think number one would be to always really believe yourself, always trust your own instincts.

And if you feel like something is not right and you're not getting answers, to keep looking for someone who can help you with those answers. I think that MCAS is just so complex and so many patients are really not understood or are blamed for exaggerating or lots of thought.

You know, I hate the word gaslighting, but in a sense that is what it is. I think that just to trust your instincts, you know, your body best, if there's something not right, fight for it.

It's hard, but you got to fight it, that's the number one thing. And try to find people who will listen, because there are more and more. I mean, that's the thing that is reassuring to me is that every day I connect with other practitioners who didn't know about it yesterday, but today heard about from a patient and now want to learn more, now they're going to help more patients.

So I'm hopeful that they are out there to I guess the other thing I would think about is that, you know, if your symptoms are, a little more unusual, unique, again, don't fit into a box, keep working to try to figure out what may be missing.

I think there are lots of mast cell patients out there who actually don t know that they have Lyme disease, vector-borne infections, mull toxicity. So I'm going to say it like both ways.

There are lying patients who don't realize they have mass activation syndrome and vice versa. So, I really want to encourage people to keep searching for the root because there has to be an answer.

who don't have infection necessarily. I don' think there are a lot of them, though. That's a strong statement, but I do not think that there's something else that continues to drive and drive these symptoms.

But again, in medicine, nothing is ever all or nothing, right?

Patient Guidance and Resources

I just think that keeping aware of these things, asking to be tested, making sure that we're not missing something. At least in my practice, Bartonella is probably even more common than Lyme disease for lots of reasons.

And there's absolute overlap between the mast cell symptoms and Bartronella. More and more, we are seeing these patients who have done everything for their MCAS and are not getting better.

Really, the reason is they're are responding because there is infection there that hasn't been addressed. Yeah, and I agree with you. I think that that is more often than not.

Yeah. Sometimes I hope I have this sort of, not philosophy, but sort way of thinking that I wish it wasn't. I just wish that we could not have to worry about the infection piece of this.

It's exhausting, it's life-changing, and we're seeing so many young people afflicted with it. But the reality is, as much as I don't want that to be the case, the is the case and we have to search for it.

And one of the things that I really, really that gets under my skin the most is when people say, I was tested for Lyme and I don't have it, but they weren't tested it for Bardenella, and they were tested from Babesia, they wasn't testing for tick-borne relapsing fever, for all these other things.

So how do I know they don' really have Lymes? And they even weren' appropriately tested. Yeah, well that's a

whole lot. Okay. Anything else that you would like our listeners to know?

I don't know. We covered a lot. So if someone needs more information, what resources are out there and available for them? And again, please share your information in case somebody would to get ahold of you.

Yeah, I do a lot of writing. So I have my blog on my website, drtoniademsi.com. I'd do allot of Reels videos, webinars, things like that. And I post on Instagram, which is drtonyademsimd.

Then of course Facebook, Dr. Tonya Demsi, however you want to say it. And so I just like to put out a lot of, I do put on a lotta content. I'm always thinking about these questions.

People post questions on my Instagram all the time or Facebook, and I try to address those with new reels, because I am constantly, the patients, people out there who are listening are actually teaching me.

You know, I'm not just teaching them, they're teaching me because the questions they bring up are so profound, so insightful, makes me think even more that I want to get out there and do the research and provide more information.

So I, very interactive. I like that. Like I need to continue to learn because I know that, probably this much, even though I may seem like an expert, right?

I knew this like a tiny amount compared to what I think really that we really need. I think we all need to keep learning, keep searching, and our patients are our greatest teachers.

I know I learned so much from my patients. So much. Every day. Well, thank you so for joining us. Thank you for sharing your expertise. It's been amazing interviewing you.

And thank to all of our listeners at home. We will see you on our next episode. Have a great day! If this episode gave you an answer, brought you new insight, or made you think differently, subscribe to the Lime Bites Podcast and share with someone who's ready to take control of their healing journey.

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