The Link Between Mast Cell Activation and Burning Mouth Syndrome Transcript

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Introduction to Burning Mouth Syndrome and Mast Cell Activation

Hi, good afternoon everybody. We are back on Instagram talking about burning mouth syndrome and mast cell activation. we did this last month, but unfortunately it didn't save to Instagram.

So I'm going to do it again and hopefully we'll be successful or I'll successful in saving the recording to instagram so people have access to it later.

So I want to tell you a little bit about my journey taking care of patients with burning mouth syndrome and how I got into it and what mast cell activation has to do with Burning Mouth Syndrome and other neuropathic pain conditions.

Early on in my experience as an anti-aging practitioner, working with hormones and mainly with women who are going through the perimenopause and menopausal transition, I had a patient who wrote a testimonial about how successful her hormone restoration program was in helping her perimentoposal transitions symptoms.

And in that testimonial, she mentioned burning mouth syndrome. And she said something like, my energy in the two months I've been on my hormone program, My energy is much better.

My moods are better, by libido is better my muscle definition is. Better and my burning mouse syndrome isn't nearly as bad. And we posted it on my rudimentary at that time website 15 years ago and didn't really think much about what burning mouth syndrome was until other people started approaching me and saying, I have burning mouse syndrome.

Do you treat that? And I had to say, Not really, but I will look into it. And so I did a huge amount of reading in the scientific literature and thought, why would hormones help a pain condition?

And of course, in 15 years since that initial foray into the science literature, there's been a lot of information about what hormones have to do with chronic pain conditions and how hormones can help.

So at the Sklar Center, we have a number of ways of addressing burning mouth syndrome.

Hormones as the Foundation of Treatment

And in addition to the usual medical approach, which is to use either anti-seizure medications like gabapentin or anti depressant medications, like Paxil or Prozac, We use hormones really as the foundation of our treatment program.

and we have been successful in anywhere from two-thirds to three-quarters of our patients getting significantly better and significantly means It's not ruling your life anymore.

And those of you who have Burning Mouth Syndrome that is significant, understand how it rules your lives. How chronic pain depresses you, makes you anxious, cuts you off from socializing, and cuts off living your best life.

So hormones turn out to be the foundation of what we do because it's been so successful. Some of the other approaches we have, which have added to that, are replenishing vitamins like vitamin D, vitamin B12 and folate and other B vitamins that are so important to nerve function, replenish those vitamins.

looking at minerals that are deficient like zinc and iron, which have been associated with worsening pain in neuropathic pain conditions. We treat viral infections, which for some people seem to be an underlying cause.

Things like herpes virus, herpies type one and two varicella, the virus that causes chicken pox and then later on in

life shingles. These have been associated with burning mouth syndrome and in some patients treating them with antiviral medications has brought about relief of pain.

One area that we explore, and it's been shown in the scientific literature, there's a few articles written by Dr. Lawrence Afrin, who's the hematologist oncologist on the issue of histamine and other chemicals released by mast cells.

And so mast cell activation and overactivity of mast cells seems to be a significant factor in burning mouse syndrome for a number of people. So let's talk about what mast sales are and how we approach treating somebody who we think might have mast-cell activation, and we would go about treating it.

Mass cells are in many places in our bodies. They are the interfaces of our body with the outside environment. So what does that mean? They line our mouths and our digestive tract because substances come from outside when we eat and out bodies have a very complex and sophisticated way of determining if what we're taking in in the form of food or whatever comes in out mouth is safe for us.

Mass cells are part of that. Mass cell line are respiratory passages. They line the linings around our eyes. So people who have environmental allergies, pollen, dander, activates mass cells.

And what do you know? Your nose is running. Your eyes are tearing. You may have asthma and activation of your respiratory tract with contraction of the bronchioles, which is what asthma is.

And because the mast cells are in so many areas of our bodies, the symptoms of overactivity are hugely varied. Mast cells even in our brain. Mass cells in the fear center of the brain, so the kinds of symptoms that come from over activity of mast cell are really varied, And it turns out that mast cells contain a thousand chemicals.

Mast Cells and Their Role in Pain and Allergies

So they release histamine, what are called cytokines that you've heard of ever since the COVID pandemic, which are inflammatory chemicals, and they have been associated with allergic responses, They guide tissue development and growth, so they're not necessarily always a bad thing.

And they regulate a number of different processes in our bodies. It turns out mast cells weren't, and the importance of them really wasn't recognized until pretty recently in the history of medicine, which goes back thousands of years.

it's really been in last fifteen years that we've begun to understand so many conditions that we're puzzling that now we know are due to overactivity of mast cells.

So there's a lot of things we can do to treat an overactive mast cell and even more than that, we want to try to figure out why these cells are over active and in many cases we are able to So things that are signs of mast cell overactivity are everything from gastrointestinal disorders like abdominal pain and bloating because of the over activity of mass cells in the colon and stomach, headaches, poor concentration and poor memory.

Other GI symptoms like diarrhea, nasal or eye symptoms, like the ones I mentioned, swelling, redness and tearing. Interstitial cystitis, which is an overactivity of the bladder where you have to keep urinating with great frequency.

Small fiber neuropathy, Which is a nerve condition of certain fibers, the small fibers which we think play a role in burning mouth syndrome for some people.

Being intolerant to pharmaceutical medications can be a sign of over activity of mast cells. Brain inflammation with brain fog can also come from overactivity of mast cells in the brain.

And we know that stress destabilizes mast cell in brain and so with the release of the chemicals from mast like histamine, which is a pain producing chemical, we see associated pain conditions like trigeminal neuralgia.

And its furthest and most serious manifestation of mast cell activation is anaphylactic reactions, which is a very severe allergic reaction where your bronchioles in the lungs constrict and becomes difficult to breathe, blood pressure plummets, And it is a life-threatening condition.

That is due to mast cells, and it can happen as a result. You know, peanut allergies that are life threatening, that's an anaphylactic reaction. Mast cells are involved in that.

So why might somebody have overactivity of their mast cell? We're learning more and more about this. For one thing, we're learning more about the importance of mold in our environment and water damage buildings and the mold that grows after a building has become water damaged.

This obviously is going to become more and more significant with climate change and increased flooding. So if you have water in your home, don't just pass it off as a nothing.

Within 48 hours of water, mold is starting to grow in the drywall in you walls and it needs to be attended to. Viral infections, we think, can cause mast cell activation.

And we notice in a lot of our burning mouth patients, Epstein-Barr virus reactivation. So, epstein bar virus is in the herpes virus family of viruses.

Most of us in the United States, by the time we're two years old, 90% of have been exposed to Epstein-Barr virus. And usually it is dampened and contained by our immune system, if our system is healthy, and doesn't bother us.

for the most part, until possibly later on in life. And it comes out as mononucleosis, which young people, teenagers, and college students tend to have.

It can show up later in live as reactivation and cause of fatigue and a number of other problems, including Burning Mouth Syndrome. There are other viruses as well, and Lyme disease has been known to be Lyne infection and lyme co-infections are some of the causes of mast cell overactivity.

Toxins can also trigger mast cells. So the toxins that are produced by mold, they're called mycotoxins. They're volatile organic compounds. that can make us very ill and in addition heavy metals like mercury can cause mast cell activation.

Causes and Signs of Mast Cell Overactivity

Some intestinal infections will increase histamine, like E. coli in the intestine and some of the other issues of small bowel intestino overgrowth and small bow fungal over growth, which cause a lot of GI symptoms, but at their root may have mast cell activation.

So you can treat the gut and treat that gut, But if you don't do something about the mast cells, the symptoms will continue. So how do you know if you might have mast cell activation?

If you have a lot of seemingly unrelated symptoms, they may end up being unified in a diagnosis of mast cell activation. So, you've have GI problems, diarrhea, environmental allergies, a dizziness when you stand up, intolerance to medications.

A regular dose of medications will completely throw you for a loop. One of the cardinal signs of mast cell activation is called dermatographism. That means writing on your skin.

One way to know if you have that is to take your forearm and make a scratch. If that scratch turns pink, That is the result. If it turns pink along the line where you scratched, those are mast cells getting activated, mast cell in your skin and releasing histamine, which creates a small inflammation and turns your pink.

So that can be one of the ways that you know if you might have mast-cell activation. The question is, how do we

diagnose it and what do you do about it?

There is not one lab test that will tell you if you have mast cell activation. There are tests that would tell if have the more severe manifestation called systemic mastocytosis, which is a very serious health condition.

And so doing a lab tests called a tryptase level. It's done on blood, it's a serum tryptase. If that's high, that can be an indication of a more severe condition called systemic mastocytosis.

And somebody who has that, you would definitely want to see a hematologist for treatment. Most of the people that we see do not have that condition, but they have these myriad of other symptoms due to overactivation of their mast cells.

Not systemic mastocytosis, a lesser sign of lesser activation, nevertheless with many health problems resulting. Burning mouth syndrome is one of things that can happen with mast cell overactivity.

So there are a few different protocols that we use to try to help with mast cell activation if we think somebody has it. So if somebody had environmental allergies and they are sensitive to medication, signs like that and have dermatographism with their burning mouth syndrome, I really go for treatment of mast-cell overactivity as one of the initial things that So two types of medications that we use.

One is a histamine type one blocker, which are the usual antihistamines for allergies that you're familiar with. Things like Zyrtec and Allegra and Clarinex and Claretin.

The one that weave like the most is newer one called Zizol, also known as Levociturazine. And Zizzol's available without a prescription at the pharmacy.

and it is a histamine type one blocker. And so we have people start using Zizol, taking a half a tablet a day and eventually getting to a table a week over the next week if it's not sedating, and then add to that a histogram type two blockers which are the ones that help with too much stomach acid.

So things like famotidine or pepsid which is the brand name. And we have our patients start with a capsule a day, 40 milligrams. And again, this is available without a prescription at the pharmacy.

Taking one a and if no side effects, after a while go to two a. We combine that with a low histamine diet, because not only does our body release histamines, we get histamin in some of the foods that we eat.

And some foods actually have a lot of histimine in it, and some food are histomine activators, even though they don't have lot a of them. So we try to have people on a general low-histamine-diet.

The guidelines for that are avoiding canned foods, ready-made meals. As food sits, it tends to produce histamine. Actually, as much as we like fermented foods for the probiotics in fermented food, fermented have a lot of histamine in them.

So things like older cheeses, kimchi, sauerkraut, those wonderful fermented that are great for so many people are not great if you have histamines problem.

don't allow foods to linger outside the refrigerator, especially meat products, they will develop histamine. And so it means eating freshly made, freshly bought foods, things to avoid, and fresh fruits, fresh vegetables, egg yolks are good, chicken, milk and milk products.

Treatment Approaches for Mast Cell Activation

most leafy herbs, things to avoid because they have high histamine, alcohol, pickled or fermented foods like I said like sauerkraut, mature aged cheeses tend to have a lot of histamines, smoked meat products and preserved meat like salami, ham and sausages, shellfish has a lots of Beans, unfortunately, chickpeas, soybeans, peanuts have a

lot of histamine.

A number of nuts do, like walnuts and cashews. And salty snacks and sweets that are made with preservatives and artificial colorings tend to be histamines activators.

So we have people avoid histamine-containing foods and histamines-releasing foods while being on antihistamins. In addition to the two that I mentioned, xyzol and pepsid.

Sometimes people need to go further in terms of using antihistamines. One of the things that we like to use a lot for burning mouth syndrome because it is a good anti-inflammatory and releases natural endorphins in our body, which is our natural pain relievers, is called low-dose naltrexone.

And naltrexones seems to be especially good for what are called central pain syndromes, where the pain isn't just happening out at your tongue or in your lips, it now lives in part of your brain.

That's what happens with chronic pain. A lot of chronic pains becomes a central or brain problem, and low dose naldrexxone turns out to for those central pain syndromes.

Low-dose naltrexone has antihistamine action and we've had a lot of good luck with patients who are on our hormone program and then add low- dose naltrexon.

So if you are somebody that seems to have histamine problems, you may want to add low-dose naltrexone to the antihistamine zizol and the anti-histamine for the gut pepsid.

There are also some other ones. Singulair is something that lots of asthmatics take because it is a mast cell stabilizer. In addition, something called ketotipin, which is a mast cell stabilizer.

It blocks H1 histamine. it needs to be made in a compounding pharmacy because it's not commercially available. And the other one is chromaline, which a lot of asthmatics are familiar with because they're on chromalin, because it blocks mast cell release of histamine and some of the mast cells inflammatory chemicals.

So there are a lots of medications that are helpful. There are lifestyle things like a low histamines diet. Their are supplements that can help with histamin.

A lot of people are deficient in an enzyme called diamine oxidase. It's abbreviated DAO or DAW. it helps to break down and clear histamine. So a lot, of times while someone is on a low histamines diet and using antihistamine, we recommend a DAL containing enzyme preparation and a number of the supplement companies have enzymes preparations that contain diamine oxidase.

Wonderful natural antihistamines are quercetin, perilla, vitamin C, and some of the B vitamins, which we recommend being sure that you have adequate numbers if you burning mouth syndrome, because B-vitamins are so important to proper nerve function.

B12, B1, pantothenic acid and B6, these are all important for healthy nerve functions, but also for clearance of histamine. The other thing is if part of your histamine problem and histamine release is due to stress, it's really important to do activities that are stress reducing, that will lower the amount of histamin getting released from like the amygdala, the fear center of the brain.

So things that helpful are massage, craniosacral treatment, taking a walk in nature, listening to binaural beats, which are recordings that have particular wavelengths that are very brain calming.

And also things like lymphatic drainage and liver detoxes with preparations that have milk thistle or bitters. Bitters are a very old fashioned way of activating and processing things well through the liver.

So all of these things may help with the processing of histamine that's produced from mast cells. So that's to give

you an overview of mast cell activation and especially how it has bearing on burning mouth syndrome in particular.

And let's see, we have some questions so I'm happy to look at the questions while I am sitting here and see if I can answer some of these. Is a low histamine diet permanent or does the body eventually react less when a normal diet is introduced?

It really depends on if you've gotten to the underlying cause of why the mast cells are activated.

Questions, Practical Tips, and Closing

So if have a water damage mold situation in your home and have activation of your mast cell and histamine release, presumably as you repair your house and you have remediation done and remove the mold, you will remove source of the activation your mass cells.

all of the treatment things that we do, like the medications and the supplements and low histamine diet, presumably when you do no longer have the trigger for activation of mast cells, you would be able to reintroduce various high histamine foods.

The same thing goes for if Lyme is triggering your mast cell activation. As the Lyne and co-infections are treated, presumably you would have less mast-cell activation and less need for a low histamines diet.

Let's see, another one. When I was under high stress, my feet and hands burned when I went to bed and I noticed them burning as the day progressed. I started B12 vitamins and the burning stopped.

So that's the perfect example that very well could have been mast cell activation. And like I said, B vitamins, including B 12 help your body process the histamine.

That may have why the burn stopped with the use of B vitamin. Let's see if we have any other questions. And so it's toxic load, absolutely toxic burden plays a role in mast cell activation.

So we are always looking for where are the toxins coming from? How can we remove the toxin from the environment? how can remove toxins from your body?

So I hope this has been helpful for you in terms of understanding what's going on and when we talk about treatment for mast cell activation, when were taking care of our burning mouth patients, or if you are not a patient at the Sklar Center and you're seeing your own doctor, this is good information to take.

And especially it's helpful because a lot of this are things you can do on your own. And so the antihistamines like xyzol and hepsid, the low histamine diet, these are all things that you could try on you own But if you are running into problems and need lab testing or a discernment of could you have systemic mastocytosis, which is much more serious, then you would need to see a physician and have lab-testing done and get a serum tryptase test done.

So hopefully we will be able to save this recording and to have it on our Instagram. And also we'll post it to Facebook and YouTube. for your future viewing.

So thank you so much for listening today and we will be back. Bye now.