# MCAS

LDNRT MCAS search…. https://ldnresearchtrust.org/search-condition

Successful treatment of POTS and mast cell activation syndromes using LDN, immunoglobulin and antibiotic treatment… https://www.facebook.com/notes/340017730431225/

Discussion and links in this thread in the group Low dose Naltrexone (LDN) for chronic illness & infections…. https://www.facebook.com/groups/108424385861883

Especially in regard to the possible relationship of MCAS and the thyroid….
https://www.facebook.com/groups/108424385861883/posts/7343309612373288/

Is there a specific dose of Low Dose Can LDN help with Mast Cell Activation Syndrome (MCAS)? - Dr Leonard Weinstock… https://www.youtube.com/watch?v=ISNYx1essWg

If a MCAS patient has additional ailments, what should be treated first?
https://www.youtube.com/watch?v=UAy_9N7s0gA

Micaela's Story of Mold Toxicity, Lyme Disease, EDS and Mast Cell Activation Syndrome…
https://www.youtube.com/watch?v=kjKgi5chWDg

Naltrexone (LDN) that works best for MCAS?...
https://www.youtube.com/watch?v=L55rqwXNYzw

An excellent interview focusing on EDS, pain and MCAS (kind of long but can be understood at 2x speed :) )... Managing Ehlers Danlos Syndrome with Low Dose Naltrexone...

https://www.youtube.com/watch?v=gHIaqnJ0loE

Questions from The May Webinar www.ldnrtevents.com with Dr Leonard Weinstock and Dr Tania Dempsey.What would you put on a comprehensive list of Mast Cell inhibitors?
https://fb.watch/spO6O9iPQ9/

Comment from a member, "The American gastroenterologist who specializes in SIBO (small intestinal bacterial overgrowth) complicated by MCAS (Mast Cell Activation Disorder) advises that those who are sensitive to pine trees avoid medications with methyl cellulose.

I find that I react to the smell of burning pine trees and develop skin reactions when I consume pine nuts. I do seem to do better after limiting methyl cellulose. Not as easy task as it's in nearly every medication and supplement influenced I guess by the vegan movement. I now search for gelatin capsule versions over vegan capsules….I did hear Dr Leonard Weinstock the Gastroenterologist say this very clearly on a SIBO-SOS podcast but I can't find any journal articles of him stating this clearly on Google scholar.

The attached article by Dr. Bruce Hoffman at the very end lists Avicel and Hypromellose excipients as being problematic…

https://www.hoffmancentre.com/post/mast-cell-activation-syndrome-and-excipients

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“In Canada, most of the compounding pharmacies will use microcrystalline cellulose, known as Avicel, as a filler. This compound is derived from wood pulp and contains strings of glucose molecules strung together. It’s commonly used a texturizer, an anti-caking agent, a fat substitute, an emulsifier, an extender, and a bulking agent in food production.The most common form is used in vitamin supplements or tablets or as an alternative binder in compounding medications. Some people may also not tolerate gelatin capsules and are given vegicaps as a substitute. These are composed of hypromellose, short for hydroxypropyl mMethylcellulose (HPMC), a substance that’s prepared from cellulose, which is the main polysaccharide and constituent of wood and all plant structures.”

An interesting write-up from a patient about desensitization follows:

“As a highly reactive MCAS patient 8yrs into diagnosis and down to 4 foods for 4 years, my body reacts to practically anything that it is not used to.
Every new medication, every new supplement, every new food. Every change in my existing foods, supps or meds.
It is completely normal for me to have to desensitize against a new substance that I introduce into my body. Unless the substance is an actual histamine liberator, aka chemical mast cell degranulator, or cross reacting with one of my IgE allergies, then desensitization is usually successful, if done slowly enough.

Currently I am working on a new compounded version of famotidine. It's just pure famotidine in sterile water. I had desensitized famotidine before, but the medication was sourced from a different medical supplier up in Canada, and apparently the change between the US supplier and the Canadian supplier was enough to set my body off.
So I am back to the start on that one. The good news is that once I have this one on board, I can always get it sourced from this particular supplier by any compounding pharmacy within the US, since it is a large supplier and unlikely to run out.

Anyhow, this is how I desensitize:
I take my standard H1 blocker exactly 1hr before, and high dose Vit C 30 min before. To stabilize my mast cells as well as possible with the meds that I already have on board. Then I eat something before doing the exposure, so that it doesn't hit on an empty stomach. For me, I have found that to be helpful. Also, low blood sugar aggravates my mast cells.
Then I put 1 drop of the medication solution into one glass of water and stir it. How large of a glass and how much water depends on how worried I am about a substance. The bigger the reaction risk, the more I dilute it.
On the very first exposure, I only take one tiny sip from that glass, swish it around my mouth and spit it back out. It's really just about getting my mucosal mast cells and dendritical cells some exposure to the substance.
The next day, I take a tiny sip from that glass. The next day, I take two sips. And so on. Until one day, I drink the whole glass. Often not within one sitting. Often I take all day to make it through the whole glass. Because there is only so much that I can push my body.

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After that, I put two drops into the glass. And make it through the day drinking the whole glass. Then 3, and so on.
When doing this, I try to stay BELOW my reaction threshold. Or within the very mild reaction range. If I have a considerable reaction, I usually take the next day off and slightly lower the dose again.
Because the last thing I want to do is slowly elevate my mast cell reactivity level and push myself into an inflammatory flare.
I am also very considerate of my hormonal cycle and other factors that affect my general reactivity. Stress, sleep deprivation, other allergen exposure.

I often do neurological training before an exposure, things like diaphragmatic breathing, meditation, structural vagus nerve exercises. To calm my body down as best as I can.
If I have a mild reaction, I usually use vibrational vagus nerve stimulation to bring myself back out of it. If the reaction is significant, I take an extra dose of my H1 blocker, and more high dose Vit C. Which is usually enough. As long as I keep the exposure dose low enough, my reactions are self limiting. No epi necessary. For me that is.

But again, I am very considerate of my overall condition and reactivity any day that I do this. What I have experienced, is that I am usually the most reactive during the first two weeks of doing this. Where I have to be pretty careful. And then at some point my body just goes: Oh sure, we know this dude, he's cool, we're cool.

Like, the famotidine I am currently working on, is compounded as 20mg/ml watery suspension. It's not a well soluble medication, so I have to shake it up well before drawing it from the bottle. I draw it from the bottle with a skinny milliliter syringe, for better accuracy. One drop of this solution is roughly 0.05ml. So when I put that one drop into my glass of water, that is roughly 1mg of famotidine in that glass of water. Which in this case I started with only about a half cup of water, so not super diluted. 1mg of medication in a half cup of water is NOT a homeopathic dilution. Every sip of this watery solution is a significant level of medication exposure, from an allergy perspective. Which why I have to go so slow, and baby my body along the way.
I started doing this at a doctor's office btw, not home alone. But in the end it was the ONLY way for me to stop moving backwards, and start moving forwards.

The realization that I am not actually ALLERGIC to most things, just REACTIVE to them, did help in my mindset. Of course anaphylaxis is anaphylaxis, no matter the linguistics around its causality.
But the personal experience that slow and steady wins the race was very helpful for me. I am now about 2 weeks into my current famotidine adventure, although I took a few days off in between, and yesterday was the first time that I had zero reactions whatsoever from the slight dose increase.
From past experiences I know that once I reach this state, I can go faster. But not before. If I increase too much, too early, I just go into a flare. And then have to take several days off to calm it back down.

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Anyhow, I figured I would share this, since I see so many people walk away from supplements or medications because they reacted to them. After they took them in a somewhat therapeutic dosage.
I have been past trying to do that for about 5 years now. If I tried to take ANYTHING new in a considerable dosage, I would go into severe anaphylaxis. Slow desensitization is my normal. Obviously I am not telling anyone else to do this at home or otherwise by themselves, I did this under provider guidance at first. But now I know my body well enough to where I even do it when I am home alone.

None of what I just said is medical advice of any kind, just my personal experience with desensitization.
Any desensitization is a risk. To me, it became a necessary risk, because after a decade of leaving out anything I reacted to, I was suffering from life threatening vitamin malnutrition and very little tolerated meds and supps. I had to move to learn forward, instead of backwards.
I am not going to lie, intentionally taking stuff that you already know you are going to react to is both emotionally and physically uncomfortable. It takes serious willpower. And the management of one's fear, so that the fear does not set off its own mast cell reaction. Which in highly reactive patients, it absolutely can. Mast cells have sympathetic nervous sytem neurotransmitter receptors for a reason. Forcing myself to chill and not freak out after an exposure was probably the most important thing I learned. Because when you start reactive a little, that fear response is like pouring gasoline onto the fire.

So, instead of going into a reaction panic spiral, I turn on my vagus nerve stimulator and watch some TV. Or otherwise distract myself. Call family or a friend and pretend it's not even happening. Being great at denial has its advantages.

Especially with these limited reactions to very small amounts of substances during desensitization, I have found that the more I ignore my reactions, the faster they go away again. That is NOT because the reaction was in my head. It is because of the autonomic nervous system sending feedback signals to the mast cells. We now know that the dozen neurotransmitter receptors on a mast cell's surface make it one of the primary interfaces between the autonomic nervous system and the immune system. So when the amygdala goes into panic mode and throws the entire ANS into panic mode, that will have an effect on mast cells. And just like parasympathetic/vagus nerve activation calms down mast cells, sympathetic/fight-and-flight activation will aggravate them.

So, pretending like I didn't just take a bunch of new medication, while doing vagus nerve stimulation, is really just how I hack my nervous system into supporting my new substance desensitization instead of boycotting it.

I know it is weird. But the more reactive I became, the more I realized that the neurological component is HUGE. My flares used to last weeks. Now I can have them calmed down within a day or two, using parasympathetic nervous system measures. And I don't just mean the limbic

feedbacks approaches like Gupta & Co. I now use about half a dozen devices and about a dozen exercises to improve my vagus nerve signaling. But that's a story for another post.”