Q: Best Medications to take during a reaction or flare?

Benadryl or Attarax better? Is one stronger than the other?
What do you take extra when you are maxed out on daily meds?
Which meds should not be taken with each other?

A: Most people take diphenhydramine (Benadryl) as their rescue med of choice. Hydroxyzine is commonly used as a rescue for skin symptoms. If people have respiratory symptoms, nebulized racemic epinephrine, nebulized cromolyn, and nebulized corticosteroids can be help with airway swelling/reactivity. Additional doses of second generation H1s like cetirizine are sometimes used as well as additional doses of H2 meds like famotidine. In the event of a bad reaction or anaphylaxis, patients usually use diphenhydramine, famotidine and a systemic glucocorticoid like prednisone or methylprednisolone.

Second generation H1s and H2s are sometimes dosed multiple times a day in a way that is not as commonly seen in the non-mast cell population. Some mast cell patients take cetirizine 3x a day at baseline, for example. Mast cell patients often tolerate much higher doses.

For vomiting, ondansetron, prochlorperazine, and metoclopramide are examples of meds used for nausea and vomiting in mast cell patients.

For delayed symptoms, some patients find that taking a COX inhibitor like aspirin or ibuprofen can be helpful.

Always speak to your provider about any changes to your medication as only a provider familiar with you can identify your specific needs.

Q: What medications are good for Angioedema?

A: The best med for angioedema is very dependent upon what is triggering the angioedema. Some patients do well with diuretics like furosemide or spironolactone. Massage can help, especially lymphatic massage. Some people find that wrapping a swollen area gently can help to push the fluid back into the right spaces.

In short courses, glucocorticoids can help angioedema. At high doses or as longer courses, they can contribute to edema.

Q: For urine N-Methylhistamine and PG2Fa tests...how long at room temp before they start to degrade? How can you insure they're handled correctly?

- For 24 hour urine methylhistamine test where the bottle has preservatives: do the preservatives affect the accuracy of the test results?

A: The amount in the sample begins to go down almost immediately. You keep it cold both to help preserve the structural integrity of the molecule and to discourage enzyme activity in the sample that could break it down.

I'm pretty sure it doesn't affect the accuracy but I'm making a note to review this before I respond.

I would speak with the lab manager before you start the test to give them time to verify storage instructions and make sure it has been communicated correctly to staff.

Q:

Why might it be that 2nd generation antihistamines (specifically Allegra) are tolerated just fine but not 1st generation (both Benadryl and Atarax)?

A:

1st generation H1s cross the blood brain barrier strongly while 2nd generation H1s only cross in very small amounts. For this reason, first generation H1s are much more available to act on the brain and so neurologic side effects are more pronounced.

Q:

What is the Relationship between mast cell disease and dystonia?
Why the loss of motivation with mast cell diseases (as shown in studies). I've read existing studies, including the recent one with the fMRI results that show changes in the brain that seem (through self-reports) correlated with the loss of motivation (but in a small-N study). It is a scary thought that the structure & function of the brain can be changed by mast cell disease.

A:

This relationship is not well understood but it's well reported. Mast cell mediators often influence the nervous system and can also influence muscles. Likewise, medications to treat mast cell disease can also cause these effects. Inadequate bloodflow can also cause dystonia. I have been doing a lot of research on this and while I have found some interesting facts, there's not that screams, "This is why mast cell patients sometimes have dystonia." In my experience, the dystonia is more common in people with metabolic disorders. This is just my experience and I haven't formally collected data on this.

I would not consider low motivation a stand out symptom in mast cell disease. It's certainly present in some people, but it is more commonly part of an overarching neuropsych symptoms profile that can improve with meds and, in some instances, coping mechanisms.

Q:

Good Prep for colonoscopy that is well tolerated?

A:

For two days before surgery, I eat only clear liquids. I also do a full bottle of magnesium sulfate and 600mg docusate on each of those days. The day of the scope, I do two saline enemas an hour before leaving the house. I increase oral steroids and increase daily H1/H2 meds in addition to using benadryl. Again, this protocol is what has worked for me, and only a provider that knows you can determine exactly what is safe for you.

Q:

Relationship of celiac disease, immune deficiencies and MCAS?

A:

MCAS can occur secondary to just about anything, including autoimmune diseases like celiac and immune deficiencies. Anything that impacts the efficacy of any part of the immune system can increase mast cell activation to try and compensate for the part that's not working.

Q:

Why do we react to viruses?

A:

Because mast cells professionally fight viruses. Its one of their intended functions.

Q:

CBD...what studies support its usage with mast cell and what does it impact at the cellular level?

A:

No studies in mast cell disease. We don't know what it does at the mast cell level aside from knowing that mast cells do have cannabinoid receptors, that cannabinoids can bind them, and that this can lead to decreased histamine release, which is used as a marker of mast cell activation in the lab.

Q:

Is doxepin a good medicine to take for this urticaria ?

A:

Doxepin is much, much more active as an H1 blocker than an H2 blocker, which is why it's not used for the purpose of blocking H2 receptors. It is an extremely potent H1 blocker and many patients find that it helps a lot of their symptoms. However, doxepin has the unusual side effect of being associated with fungal skin infections, so be aware of that.

Q:

Is it possible for mast cells in the brain to cause autonomic dysfunction, strange neurological symptoms and possibly even eye problems like peripheral vision loss and/or strabismus, none of which would show up at all on multiple MRIs, eye exams, or spinal tap pressure readings? Any thoughts?? Edited to add: Also "Rare white blood cells" in spinal fluid. Could those be mast cells?

A:

Yes, it can cause those symptoms. You have lots of mast cells in your brain. They get wacky like the rest of your mast cells and mast cell degranulation in the brain will not show up on any of those tests. Yes, it can cause eye problems, both by inflaming the eye, the nerves connecting it to the brain, or the brain region itself.

You're not supposed to find many white cells in CSF so a report of rare white cells is normal. It's theoretically possible that they are mast cells but you would need a lot of extra testing to determine that.

Q:

During anaphylaxis reactions potassium levels drop and blood sugar rise. Any thoughts why and whether it is caused by the reaction itself or the adrenaline treatment? May be the adrenaline and that I am reacting to it have you heard of this happening to anyone else?

A:

Mast cell reactions can cause rapid fluid shifts. This can affect how your kidneys regulate your potassium level and how they make urine. In a state of physiologic stress, the kidney will make less urine (usually) so your glucose metabolism slows, increasing the level.

Adrenaline can absolutely cause the increased blood sugar. I need to look up how adrenaline interacts with potassium.

Q:

One question from the advanced SM community is how should they compare whether Rydapt or Blu-285 (if they can get in trial) should be tried in their case? Do they target different things or act in different ways? (Not sure if you can answer because of Novartis affiliation, but thought I'd ask.)

A:

I'll write a post for the blog on how laypeople can interpret clinical and trial data to make an informed decision about choosing one of any available therapies for any disease.

Q:

Thoughts on Live Vaccines (example MMR) in adults. Besides initial allergic reactions anyone could have had - Is there a concise way to show or prove it caused additional adverse reactions with Mast cells such as taking a stable Masto patient to an exacerbating state?! Any similar experiences or studies avail where this has happened to others?

A:

Vaccines are by definition mast cell triggering. It is one of the intended steps in generating an immune response to the vaccine and thereby developing immunity. Infections are also mast cell triggering. There is anecdotal evidence that some mast cell patients do not react well to vaccines. I personally am fully vaccinated.

Q:

Is prolia safe for mast cell patients?

A:

I can't think of any obvious contraindication, but patients should always premedicate before an infusion

Q:

What is the connection between Mast cells and bone and soft tissue healing?

A:

Mast cells are involved in bone metabolism and mast cell disease can cause all kinds of bone irregularities, including overproduction of bone, production of brittle bone, or decreased production of bone. Mast cells are also important in tissue remodeling and wound healing. Mast cell patients might find that they form scar tissue much more quickly that normally (hypertrophic scarring) or that they don't close wounds or scar effectively. Additionally, a lot of patients have connective tissue disorders that can impede wound healing. Regular use of glucocorticoids and some chemo drugs can also make it very difficult to heal a wound.

Q:

Will anything lessen or take away urticaria spots?

A:

Currently, the only things known to decrease mastocytosis spots (which is different from urticaria) are chemo or a bone marrow transplant. Urticaria is hives and antihistamines and steroids can help with urticaria in many people. The anti-IgE ozalizumab was approved last year for chronic urticaria, too.

Q:

Is there any evidence that effective mast cell treatment or stabilization can help have a direct effect on symptoms associated with Ehlers-Danlos (former type III/hypermobility type) or Hypermobility Spectrum Disorders?

A:

This is a great question. Not to my knowledge, no. But patients having autonomic symptoms are more likely to have hypermobility issues, and mast cell mediators can certainly contribute to autonomic symptoms.

Q:

Can MCAS go into remission, my doc says yes but online I'm reading conflicting info!

- As I as best meds/care during a flare such as self care, what usually helps ease flares

A:

Yes, it can. One study says that about 1/3 MCAS patients have full resolution of symptoms after a year on correct meds and another 1/3 have a strong resolution of symptoms after a year on correct meds. Keep in mind that the people who improve quickly are often not the people posting online for support so we suffer a bit from the fishbowl effect. We definitely need more recent data in a larger population but I know MCAS patients who can mostly manage their symptoms with med and lifestyle changes, mostly around food.

Q:

I have lupus and as my body always thinks it's under attack it seems like my "allergic reactions" may be mast cell related. I've been to two allergists. I have NO reactive allergies per the scratch test. Yet I go into anaphylaxis, get hives and itch constantly.

A:

Scratch test has no correlation at all to mast cell reactions. Some people don't react at all. Some people react to every single stick. There is not currently a test that reliably identifies triggers for individual patients.

Q:

I have been told by my hematologist that I am reacting to medications in a way that is even extreme for Mastocytosis, which I have been diagnosed with. What else could possibly be causing reactions to low doses of anti histamines, sodium cromoglycate, singular?

A:

That is extreme but there are people here like that. (That react to the plastic vials that cromolyn comes in) Many people react immediately to cromolyn and it improves over time. I would consider compounding these meds to start with. If you can find a safe strong antihistamine and glucocorticoid, your doctor may be okay with doing desensitization in the office to help you gain meds that can help you.

Karlie is right that CYP mutations (as well as other genetic changes) can affect drug metabolism greatly.

Q:

Could MCASers get early onset of temporal arteritis (before 50) because of increased inflammation?

A:

Sure.

Q:

Is an elevated SED rate cause by MCAS?

A:

This is a good question. My response has always been no but I'm starting to doubt that, to be honest. I would say it is not diagnostic for MCAS but like a positive ANA, sometimes it shows up without any logical reason for it to be there.

Q:

Why am I obese when I'm in aggressive form of Systemic Mastocytosis?

A:

Because your mast cells think yours having an eergency starving situation and they are trying to help you.

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Q:

I need a really simple explanation of MCAS.

A:

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Q:

Why do patients on Gastrocrom experience tachyphylaxis to it? What can be done to manage this problem?

A:

We don't know why this happens. I have a pet theory that cromolyn suppresses release of good mast cell mediators in addition to bad ones. If your body needs those good mediators, it could find a way to work around the cromolyn. But this is a theory. There is no evidence for this. It's on my short list of things I look for in new literature.

Q:

Exercise routine?

A:

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Q:

Can you describe the mechanism behind how MCAD/ Mastocytosis may cause arrhythmia and sudden BP spikes?

A:

This is the first post in a five part series that explains how mast cells cause various cardiovascular symptoms, including arrhythmia and BP spikes. https://l.facebook.com/l.php?u=http%3A%2F%2Fwww.mastattack.org%2F2016%2F04%2Fcardiovascular-manifestations-of-mast-cell-disease-part-1-of-5%2F&h=ATNrlIUMtA8Nw19zALcDhgFzkH6wqC61jIMOemGmGMx8bC1oxuuII-DDo-36_vtIFhcKPTK8SIB78AGcVeUrv-Msmf6n09SRPIbzwxOjtkc1-D93m2ar7w0IFa0OOsb0PsHGXrHU5w

Q:

What labs are used to dx MCAD? Could MCAD trigger EBV?

A:

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EBV can trigger mast cell activation. I don't have a reference for mast cell activation reactivating EBV but I don't see why it couldn't do that.

Q:

Are there any studies or case histories showing a connection between Masto of any form and gastroparesis?

A:

There is a fair amount of literature on mast cell activation being linked to gastroparesis but not directly to mast cell disease. But it is a common comorbidity for sure.

Q:

1. What does it mean/what is the outlook for patients with pediatric onset mast cell disease who do NOT outgrow it?
2. When I experience mast cell degranulation, sometimes it physically feels like explosions are happening in my body. When I get brain fog, sometimes it is so intense that my brain has a physical sensation of being stretched and pulled like silly putty. It seems as though many of us have terrifying symptoms like this that are never addressed in any of the literature. Is there a reason for this?

A:

1. We have no real data on children with MCAS. We have some info on children with SM, which is not outgrown. Children with true SM often have a more severe disease presentation than do adults. But we don't have a lot of data on children who had CM as children that they "outgrew" who later developed mast cell issues in adulthood, leading

to the assumption that it never really went away. Mast cell disease overwhelmingly has a normal life span with the exception of malignant forms like mast cell leukemia and aggressive systemic mastocytosis, which is encouraging.
2. The visceral sensations are likely caused by mast cell mediators "stunning" your nerves. It's like when you hear a very loud noise and it causes your ears to ring for a while as your ears deal with the loudness it just experienced. When your mast cells dump mediators in large amounts quickly, it can cause some weird neurologic symptoms, including the strange symptoms you describe.

Q:

Do I need to go off Ketotifen and natural mast cell stabilisers like querciten and Vitamin C before a baseline Tryptase blood test? If so, for how long?

A:

None of these things are known to lower tryptase appreciably enough to affect a tryptase blood test, so no.

Q:

Are Mast Cell Disorders classified as Autoimmune conditions?

A:

Not currently.

Q:

I know you've written about Mastocytic enterocolitis several times already.

What sort of treatments are available for it?
Could sodium crom enemas or suppositories be made up somehow to help?

Would a cyclosporine enema or Mesalazine (5-aminosalicylic acid) make any difference?

Is it possible to have both ibd in colon (they're not convinced on Crohn's or UC yet) and Mastocytic enterocolitis?

Can it cause long term damage to the organ structure like SM?

Would it cause bleeding / ulcerations like ibd?

A:

Mastocytic enterocolitis is usually treated the way enterocolitis symptoms are treated in most mast cell patients. Some patients have success with oral budesonide. Some have success with mesalamine. Cyclosporin could theoretically help but I don't knowanyone on it for mastocytic enterocolitis.

We don't have much data on mastocytic enterocolitis but we know that long term enterocolitis of any kind can cause cellular changes and architecture changes, so yes, I imagine it could cause organ damage. Exactly how much this affects function is not clear.

Yes, it can cause bleeding and ulceration.

Q:

I understand my B12 deficiency with GIF factor, but dehydration not sure why? I use coconut water with some sea salt in water throughout the day, is there a reason for this?

A:

Mast cell mediators often push fluid out of the blood into the tissues, causing a functional dehydration.

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Q:

Does sodium cromolyn contain salicylates?

A:;

Not That I know of but i will check.

Q:

What should be done for a person who needs an antibiotic, but tends to react to most everything they ingest? (I have EoE and MCAS.)

A:

They can be admitted for the course of antibiotics. Some people tolerate them with high doses of antihistamines and glucocorticoids used for the duration of the therapy.

Q:

For 24 hour urine testing, do you need to be off antihistamines?

A:

Mast cell patients are not recommended to stop meds for testing unless absolutely possible because it can be very dangerous. Prednisone can suppress nmethylhistamine or prostaglandin levels. There's no reason to stop antihistamines.

Q:

What do you do when a patient cannot tolerate any new medicines that they try, and every medication trial seems to progress the disease further? (Including H2s, mast cell stabilizers, and compounded versions)

A:

Do desensitization under medical supervision with an epi drip if everything else fails.

Q:

Two parter: I have hypertensive variant and am sensitive to steroids. Can you tell me if Eplerenone is a steroidal drug contraindicated in patients sensitive to all things steroid. Specialists say no..one actually called it 'anti-steroid". My research says steroid nucleus. Your opinion trumps.

Your thoughts on Benadryl as a mast cell triggered crisis hypertension rescue drug? Triggered: 220/140 ish, normotensive sans degranulation. And lastly Clonidine for MC triggered crisis hypertension if one has multiple defective transporter genes.

A:

When you say "steroid", you mean "glucocorticoid." Steroid is a chemistry term that refers to the shape of the molecule and encompasses a huge array of things. Glucocorticoids are things like prednisone. Eplerenone is not a glucocorticoid and is not associated with the effects you can see from glucocorticoids.

I use Benadryl for just about everything. I would be sure to have a rescue plan specifically for high BP from your cardiologist. There's no obvious issue with clonidine.

Q:

I've read and heard that anticholinergics cause alzheimer's and that benadryl was an anticholinergic? Do you know anything about this.

A:

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Q:

What is our life expectancy if we keep flaring and never really stabilize. What can we do to help this?

A:

Normal. Overwhelmingly, life expectancy is normal for mast cell patients, even the reactive ones. In fact, some studies find that more symptoms is associated with longer life span.

Q:

Can mast cell degranulation mediators cause one sided muscle wasting?

A:

I don't see why not but I've never seen any literature suggesting that it does.

Q:

Are seasonal allergies separate from MCAS? can you be having a mast attack without full anaphylaxis?

A:

You can have true seasonal allergies or seasonal triggers from MCAS.

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Q:

Can someone have both MCAS and epilepsy or is it safe to assume that seizures in a MCAS patient that don't show up on EEG are being caused by MCAS?

A:

They can have both. It can hard to tease them out but I would not assume seizures are caused by MCAS without aggressively testing for other options.

Q:

How elevated does your chromogrannin A have to be to be considered a diagnostic marker? The test I've had done normal is 15 or lower. I've been consistently in the 20s

A:

It's not a matter of how high is diagnostic. It's a diagnostic mediator of exclusion. There are a lot of things that can cause high CgA. If you run down every other source and find nothing, and you have mast cell disease, it can be attributed to mast cell disease. But you have to be really exhaustive.

Q:

How does an enlarged spleen fulfilling "B" criteria for purposes of some SM classifications differ from a "swollen" spleen?

Can a swollen spleen come and go or be permanently swollen without intervention?

So a spleen can swell periodically and qualify for SSM if other criteria met?

A:

It doesn't. But you need 2 B findings to have SSM. Many people with ISM have 1 B finding, and it is often the swollen spleen. Splenomegaly just means swollen spleen.

Yes to both.

It depends what other criteria you meet for B findings. The B finding with splenomegaly is: Swelling of the liver that can be felt manually, no free fluid or signs of dysfunction, persistently swollen glands, swelling of the spleen that can be felt manually without signs of dysfunction. So it includes swelling of the spleen in the same B finding as swelling of the liver. In order to meet this B criterion, you only have to have one of them - swelling of liver OR swelling of spleen (or both). The size marker they use here is manual palpation, which happens when it is about twice normal size. So let's say you have tryptase over 200 for your other B finding. You have tryptase over 200 (1 B finding) and a swollen spleen you can manually palpate (2 B finding.) If this is ALL you have for B findings, and your liver is NOT swollen, if your spleen returns to normal size, you lose the B finding, meaning you would have ISM, not SSM. However, if you have tryptase over 200 (1 B finding) and a swollen spleen you can manually palpate AND a swollen liver (1 B finding), and your spleen swelling goes down, you would still meet both B findings. Does that make sense? So in this instance, you would retain the SSM diagnosis.

It has mostly been my experience that people who meet B or C findings don't generally get a spleen that has reduction in size but it happened to me and I was pretty shocked about that so it's possible.

Q:

Do you have any info about how mast cell gone wild can cause knee instability and pain?

A:

Mast cell activation can cause inability to correctly maintain connective tissues because mast cells are involved in tissue remodeling and repair. Pain can occur anywhere and histamine released by mast cells can irritate osteocytes on the outside of your bony structures