Introduction and Guest Background

For the. Welcome back to this episode of the Reversing Marcel Activation Syndrome and Histamine Intolerance Summit. I'm your host, Beth O'Hara of Mast Cell 360, and I'm really excited today to have with us Doctor Kelly McCann.

And this is going to be a super interesting interview about conditions that are very common that occur with MCs and how do we address them? Things like EDS, things like Pots.

So if you're dealing with those types of things, I think you're going to love this interview. And I want to tell you a little bit about Doctor Kelly. Her passion is for understanding why certain people develop specific conditions.

And this drove her beyond conventional medicine to study complementary alternative integrative functional medicine and environmental medicine. And she really specializes today in complex chronic illnesses Lyme disease co-infections, environmental toxicants, mold and mycotoxins.

Illness, mast cell activation syndrome. And one of the things I love about her is that she's also pulling in a psychological and spiritual aspect that are related these chronic illnesses.

And she practices at her thriving, practice, which is the Spring Center in Costa mesa, California. She's also on the board of directors for the American Academy of Environmental Medicine and the International Society for Environmentally Acquired Illnesses.

Finally, she was the host of the recent many manifestations of mast cell activation syndrome. And this summit. And if you didn't check that one out, it's very different than our summit with lots of wonderful information there, too.

Thank you so much for joining us. And I'm really delighted to have you. Thank you so much for having me. Beth, could you tell us a little bit first before we dive into the nuts and bolts of what we're going to talk about?

How did you get into this area? It seems like we all who are specializing in people who are really chronically ill and struggling. There's a personal story to that. Sure.

I'm happy to share that story. I knew that I wanted to do holistic medicine, and that had been a driver, from the very beginning. And so I did acupuncture and all sorts of these other, kinds of modalities to have as many tools as possible.

And then after residency, I was living in Oregon and I got really sick, and I didn't understand what it was at the time. Fortunately, I was able to leave Oregon, move to Arizona and recover.

But in hindsight, I realized actually that I was mold exposed, develop chronic fatigue, etc. and I had had a number of mold hits, as we talked about earlier, over the course of my lifetime.

Grew up in a moldy basement. Things like that. And then, and then it happened again. So, so the chronic fatigue, the, the food sensitivities, daily hives, bloating, you know, the GI symptoms, and, and I really felt that it was muscle activation.

And somewhere along that journey, I also found out that in addition to the mold in the Marcel, I also had Lyme and Bartonella that I probably got from my mom, or from growing up in upstate New York, because that's where it's very prevalent.

And many of the things that I've learned for helping my patients is because I had to deal with that, too. Sometimes,

not to the extent, as some of the patients, but, it really brings, a level of, of compassion and deep understanding as, as you experience as well.

So that's part of the story. And I'm really grateful that I was able to go through that and get through the other side and be able to share this information with patients.

I'm so grateful that you have to.

Personal Journey Into Root-Cause Medicine

And I know we've worked together on some cases, which has been a pleasure, and we're going to dive into the what are called pin tags. And these are conditions that can coexist with mass activation syndrome, because we know that the mast cells are at the interface of the nervous system, and rest of the body is key cells in so many processes.

So it absolutely makes sense that there going to be involvement in a number of different systems related to mast cells. And this is a, a phrase that may be new to people, the pin tags.

But can you talk about just what that means and what these conditions are? So I'm happy to and I can't take credit for it. This was really coined by my colleague Andrew Maxwell, who's a pediatric cardiologist, and we're in a group of practitioners who focus on mast cell activation and related conditions.

And he kept noticing that patients who had mast cell activation often had these affiliated conditions as open had means five and he found that there were five and perhaps more related, primarily related conditions.

And those include, Ehlers-Danlos syndrome, hypermobility parts or Dis on omega. So Pot stands for postural orthostatic Tachycardic syndrome. And autoimmune conditions.

And then gastroparesis, which and I think that gastroparesis and Sibo are kind of hand in hand there too. So those are the five and several colleagues have proposed that there are probably a tad.

And usually when you see a picture of this, it's going to show, additional related conditions like endometriosis, cranial cervical instability, tethered cord, median arcuate ligament syndrome, Sibo, as I mentioned, a variety of other conditions that tend to show up in these patients.

And it's a really helpful way for practitioners and patients to understand the overlapping nature of these conditions, because patients who have hypermobile connective tissue, when they get into a moldy situation, they're much more likely to have issues, and potentially develop mast cell activation, for example, which can then potentiate and exacerbate their hypermobility, leading to other conditions like CCI or a mouse.

That all makes so much sense. And we know the mold toxins. There's research showing that these micro toxins weaken the connective tissue. Bartonella weakens the connective tissue.

I see that quite a bit. I also I've had Aids myself, and I've had great improvement with recovering with those things. So I always like to add the little hope angle for people.

I don't know if I'll ever have normal connective tissue like somebody else does, but I don't have the subluxation. So I used to have, you know, that's great.

Yeah. And and I know we see a lot of these. And what's so important is that people realize it's all connected, that it's not because because we end up in all these specialists.

You know, we're at the gastroenterologist, the rheumatologist. We've got somebody else managing parts. We've got somebody else managing EDS because they're all, there's a connection underlying all of this.

Can you talk more about that? Sure. So we know that mast cells tend to live at the areas of interface. They hang out around the vascular system, they hang around the nerves.

And certainly if there's massive activation and the granulation of the mediators and those inflammatory, chemicals around the nervous system that can potentially lead to an autonomic nervous system issue, if that's where those mast cells are being, stimulated.

And, and then we also know that the muscles, exist all throughout the connective tissue as well. And so when you're dumping those inflammatory mediators, that's going to enhance, and exacerbate the connective tissue problems.

And, you know, in terms of the gastroparesis, again, that's a that's a disorder, Nomi a condition. And so that one makes sense. And in terms of autoimmune conditions and root cause, we know that many of the things that drive mast cell activation are molds and mold exposures, mycotoxins, Lyme, Bartonella and particular and those things also drive autoimmune conditions.

And so it does really make a lot of sense that we're seeing overlap of these conditions and many, many patients. This is where we think this root cause approach.

So I know you really specialize in we work in we've got to look at what's under the surface that's creating all of this dysregulation ation and and get at that layer and that level.

And that's what you're talking about in terms of the mold, the Bartonella, the Lyme. And then it's about how these show up in different people based on their individuality.

But we can we can trace it back to what's happening underneath, what's happening at this kind of root level. And that's our real way, our real road to healing rather than just keep suppressing symptoms.

Absolutely. Now, of course, we know that there is a genetic component with, EDS the lowest Danlos syndrome. And so we're not saying that you can change your genetics, but, the presentations and the manifestations can be improved upon, like you suggested.

Understanding PINTAGS and Related Conditions

And there is research in the literature, where a person presented with, hypermobility, they found out they were found out to have Bartonella treated the Bartonella and the Hypermobile hypermobility resolves.

And so, there definitely can be improvements in clinical presentation staff more deeply into EDS and then parts and autoimmune and kind of take these areas.

Sir, so many people are screened for EDS with the bite and scale. But I often wonder, well, what if those aren't the joints that are is heavily affected?

I know we have to have something. We're going to start somewhere, but I do wonder, how many people are we missing? But I'd love to hear about how you you're screening for hypermobility and then, what are you what are some of the ways that you're starting to support people and help people who are dealing with, if we want to call it hypermobility or EDS or that are on that slide, that spectrum. Sure.

I mean, I do start with the bite and scale because that's, you know, validated. It's very helpful. I also think that depending upon the age of the person, it's really important to ask the historical questions.

Or do, you know, an historical Biden score because, what a 60 year old person can do versus a 20 year old person is very, very different. And we know that there's a time, time course that changes with with hypermobility, where that repeated trauma as a younger person eventually turns into osteoarthritis.

And so I don't expect, you know, most of the older patients to be able to do all of the, the hypermobile things that they could do when they were younger.

So there is, in addition to the Biden score, which I can go through quickly. And I can't I am not hypermobile, so I'm not a good, illustrator, perhaps.

Beth, you can illustrate for us, but, the thumb get pulled down to the forearm. Yeah. There's no, no, I, I've never had that one, but but many people can get through their thumb to touch the forearm this way.

Great. And then pinky back more than 90 degrees. Yeah. So I'm at 90 now, but I used to be able to go back about this far. Wow. And you'll see a lot of times I know you see this, people can really pull their fingers back.

And so you get one point for each side with that. And then there's the elbow, hyperextended more than ten degrees. It's just been straight, right? Yeah.

And my spine don't hyper extend anymore, but I used to get I mean, maybe it's very subtle, but I used to have a lot here. Yeah, but I'm saying the palm has to be up.

I just want to show people. Promise. And then the knees. So, knee hyperextension. Greater than ten degrees when you're standing up straight, and straightening your knees. Yes.

And then there's the bending over, palms flat on the floor, right. With your knees straight so that is nine points. One point for the bending over, two points each for each side, and the higher the score.

So, for somebody over 50, if it's four points or out of nine, that is considered positive for a, preteen, it's six out of nine. And then for regular other people, it would probably be five out of nine.

So that's one way to screen. And I think it's useful. There's also the Graham and Hagan, five point score where you ask, can you, could you now or can, could you ever place your hands flat on the floor with your without bending your knees and then asks about the historical, or if as a child, did you amuse your friends by putting your body into strange, shapes or contortions and, or could you do the splits?

That's another one. Or did you ever dislocate shoulder, knee, etc., or consider yourself double jointed? And so sometimes those are useful health help.

Useful screening questions as well. And then it's really about the exam. So you're right. People may have other joints. Because we don't ask about shoulders really other than dislocation.

But some people do have very hypermobile shoulders. Hypermobile ankles. And so I think you start the question, you start the questions, do the, the quick, button assessment.

And then if things seem suspicious, you can go a little bit deeper with more historical questions and a physical exam. And then we know that there are these rarer forms that have really stretchy skin.

I'll sometimes just ask people to show me how much they can scratch their skin. But I've and I've only seen this twice where people have had the actual, rare genetic eds where their skin is just going to really stretch a lot.

There's visceral involvement. Can you touch on just a little bit of those in comparison with the more common hypermobility forms? Sure. Those those forms actually have a known genetic variant.

So we can test for those, the Hypermobile eds. We do not know the genetics of that. Although it seems to be somewhat autosomal, dominant in that, you know, one parent has it oftentimes the children do.

So the other forms are, as you mentioned, much, much less common. There's a classical form. There are, other forms related to the vascular system. And these can all be tested through genetic testing these days.

And so when somebody presents with extreme hypermobility with soft, flexible skin or some of the other, some of the other, signs of, these other conditions, then that's where we would send people for genetic testing to rule it out.

And then let's talk about options for people before we go to the next condition. I've gotten huge amounts of relief in both strength training with a EDS aware physical therapist, and that was a game changer.

So my understanding the EDS because normal PT actually made me worse. I've done bracing and periods of time when I didn't have the structural, the strength to hold the joints in place, but keeping that strength up, that's been huge for me.

And then there's some supplements that have been helpful. And prolia, platelet rich pro therapy. PRP has been a game changer. What are you finding that's really helping people?

I agree, the physical therapist, somebody who really understands EDS, I think that that's one of the most important things for people.

Screening and Supporting EDS and Hypermobility

I do think that just having an awareness of the, the fragility of the tissue is really important. You know, what happens is a lot of people think it's kind of cool and fun to put their bodies in weird contortions, and unfortunately, that is damaging the tissues and they'll end up with problems later on.

So actually, I find a big component of, this is, is really education, for patients to understand more about how to protect their bodies and then informing their families.

Has been profoundly helpful for people to really start to understand how they can protect themselves. There are some people who do parallel therapy. Again, you really need to find a practitioner who understands how to use, therapy or parallel therapy with the connective tissue.

That's special. Those are probably the biggest things I have seen. Some people use braces, with different joints as well. Or even, you know, a stiff collar if they're having, cranial cervical instability issues.

Yeah. I love that education piece. And that was also huge for me because I, I had, I can do everything kind of attitude and I would I mean, I'm a small person, but I would be carrying 25, 50 pound bags of malt myself and be in pain, but not realize the damage that I did over and over to my ligaments.

And learning to listen to and respect my body, even just carrying a heavy purse. I switched to a lightweight backpack. Really helped me neck and my shoulders.

Yes. Now let's shift gears to pots. You tell us more about the relationship with Pots. How does it present? How are you diagnosing it? How are you treating it?

Sure. So Pots is postural orthostatic tachycardic syndrome, which essentially means when you stand up too fast, your heart rate skyrockets. And, and you might the patients might feel dizzy, lightheaded or really fatigued.

They kind of have an exercise intolerance. They can feel nauseated, just not well in general. Oftentimes they don't like to eat, in the morning. They tend to be, you know, not feeling well in the morning because they've been lying flat for so long, and then standing up makes them not feel well, they tend to feel better lying down.

So these are some of the things that I might hear that make me suspicious. That sort of dizzy, lightheaded piece. And then patients also do complain about, palpitations, tachycardia.

They feel like their heart is pounding. They may be really anxious as well, not realizing that it's actually a physiological response. And it's, may not be, psychological response.

So, very often it tends to be women and it tends to be younger women, though that's kind of the classic person, you know, 20 year old stands up, feels dizzy, lightheaded and anxious.

Maybe she's not anxious. Maybe she has parts. And, you know, one of the first things that we do to identify this is to actually just have people, track their heart rate in their blood pressure.

So you can even do this at home with a pulse ox or blood pressure cuff if you have one. But the pulse ox is nice. Because we're really just tracking the the heart rate.

So I have patients lie down, for about ten minutes to stabilize the heart rate. Check the heart rate when they're when they're finally stable after about ten, 15 minutes and then have them stand up, and then they'll check the heart rate every minute for ten minutes.

And if the heart rate increases, more than 30 beats per minute from standing to, to from sorry, lying to standing, then that meets the criteria. If they're under 2021, usually you want to see a bump up about 40 points.

Another related condition that is important to screen for as well is orthostatic hypotension. And so that's when the blood pressure drops. When you go from lying to standing.

And so if somebody says that they feel poorly, but maybe the heart's pounding, but not necessarily fast, then we should check the blood pressures. And so again, check the blood pressures after lying down for 10 to 15 minutes and then stand people up and they if they don't feel well, they can lean against a wall.

They don't have to stand up in the room. But, then you're checking the blood pressure every minute and in, in order to meet criteria for orthostatic hypotension.

Now we're looking at the systolic or the top number. And the top number needs to drop more than ten points. And the bottom number needs to drop more than I'm sorry, 20 points.

And the bottom number needs to drop more than ten points. So definition of orthostatic hypotension systolic blood pressure drops more than 20 and diastolic drops more than ten.

And that meets the criteria. Now, there are other forms of dysautonomia that are less common. Those are probably the most common ones. Technically the gold standard for, for diagnosis is a tilt table test.

I have rarely, rarely gotten a cardiologist. To prescribe one because basically they strap them in, they flip them upside down and wait till then they pass out.

And, so the cardiologists tend to think of it as torture or so they don't they don't like to order them. They don't like to do them. And unfortunately, there are a lot of cardiologists out there who won't deal with parts.

They don't seem to want to take that on. Unfortunately. But some of the treatments early on are really simple, like making sure you're getting adequate fluid and electrolytes and salt.

So that really means lots and lots of salt to help get the fluid to stay in the vasculature. And so many patients will take, you know, salt tablets because it's really hard to eat that amount of salt that they need.

They're looking to have. Excuse me, between, two and five grams of salt in a day. And then ideally, you're getting in the amount of fluid, I'd say a, an ounce for every kilo.

So if somebody's 60 kilos, you want to get like 60oz. And at least sometimes a little bit more, especially if you have that salt on board. And I just want to highlight you're saying 2 to 5g.

POTS and Dysautonomia Basics

And many people are so afraid of salt. But it's absolutely critical. And 2 to 5g is a good amount of salt. And I had a young girl, she was 14 when I started, and as soon as she would get out of bed every morning, she would pass out and all we did was start putting a glass of salt water by her bed, have her drink it rarely, salt to salt water.

Have her drink it before she got out of bed. And and that and vitamin C, which they figured out, stopped the passing out first thing in the morning. Yeah. That's great.

Other things that people have tried in addition to vitamin C, I've just been other minerals, selenium, zinc, magnesium, just to really try and hold more fluid in the vascular space, in the blood vessels.

And so those are some of the simple things, that people can do. And, and they can be profoundly helpful. There are a couple of medications that can be used for Pots.

One of the ones that I've used successfully is called coral liner. Sometimes it's a little tricky to get without a cardiologist. But it has been very helpful for patients with Pots.

Tends to regulate the the heart rate a little bit, and support the, support the vasculature. Patients sometimes will use beta blockers. Beta blockers will slow the heart rate down.

Sometimes it drops the blood pressure a little bit. Some people don't like blood pressure. Sorry. Beta blockers very much because they, can be sedating and people can feel fatigued on them.

So they're not my favorite go to. I've really found that the coral and are is much better tolerated for pots. Some patients have to use compression stockings.

So again, to really try and keep the blood, up into the brain, that's what you're trying to do. So if you wear compression hose on your feet and your legs, and that will help push the, the fluid back up into the rest of the, the brain.

So that's, that's really some of the best things for pots. And I found getting some exercise is keeping the movement going and keep the blood flowing.

And that's part of the fatigue that people often don't realize when the blood pressure is drop so much, you're not going to be thinking straight. You can't get that pressure to get it.

Get it up there. Those are wonderful tips. I've also seen people and I, experienced myself getting improvements with, oral hydrocortisone for the mineralocorticoid effect.

And help with that. Yeah. So that may help a little bit more with the, with the orthostatic hypotension piece. So and there are more medications that are available for the orthostatic hypotension and like Mid Adriene or the floor enough.

The mineral core coins. Exactly. They don't tend to work as well on the parts side of things, they're more indicated for the orthostatic hypotension. And again, it's a little tricky to get practitioners who know enough to feel comfortable enough to prescribe these medications.

I will say that in my patient population, you know, young molds, Marcel patients, I do eds patients. I do tend to see far more pots than orthostatic hypotension.

And so we're we don't have as many medications, that are available to us when we're dealing with the Pots disorder. Nahmias. So we've been under this category, this autonomy is which we know have a huge relationship with vagal nerve.

And we've got lots of lots of interviews about vagal nerve and improving vagal nerve signaling. And we've got a really fascinating interview about thiamin deficiency that ties in with the disorder.

Nomi, as I wrote, for anybody dealing with this, definitely grab those as well. So we've covered the dis autonomia realm, in terms of parts and anything else you want to touch on before we move on to autoimmunity?

No, I think we can move on. Okay, so then we've got this autoimmunity connection. Can you talk more about that? Why is that happening with mast cell activation syndrome?

Doesn't mean that you development immunity, but the risk is much higher. And we see a lot more correlation. And what are you doing. What are your go tos when people are dealing with autoimmunity.

So autoimmune conditions are very, very common when you're dealing with mold and Lyme and and any environmental toxicants I mean those are the drivers for autoimmune conditions.

And so even if somebody doesn't have muscle activation or Eds or parts, if they are and you know, it could be a family member who, who doesn't have those things and they have the autoimmune piece.

And so just like when patients come in with mast cell activation, when they come in with, autoimmune issues, we're going to be looking for root causes.

My first go to is cleaning up the diet. No more gluten usually no more dairy, cows milk, dairy because those foods are so prone, inflammatory that they're going to, exacerbate the autoimmune attack that's already happening.

And then, I love LDN, actually. That's one of my favorite go tos for the autoimmune piece. I find it's very, very helpful. And treating the underlying cause.

So if patients have mold to fit the mold and I've been able to, I've really seen reversal of a positive and a reversal of Hashimoto's, reversal of, all sort of colitis, even rheumatoid arthritis with doing the, the treatments for the autoimmune condition and the root causes, whether that's mold or chronic infections or environmental chemicals.

And then the LDN for people have not heard that before is low dose naltrexone. And we also have, an interview on that if we want to find out more about it, really going to dive into that.

LDN that's the one with Darren Ingles. All right. So then we've got our last of the in the pinned tags. And it's this GI motility area. And you talked about before gastroparesis with Sibo.

Let's talk about how that's related what's happening and what are your go tos there. Yeah that gastroparesis is really tough. I mean I think it's a, more targeted, dis autonomia that's happening.

And that may be multifactorial. So it could be, because the mast cells are impacting the autonomic nervous system in that particular area. It could be vagus nerve related and it could be, a variety of it could be connective tissue related that the connective tissue doesn't work as well.

Autoimmunity and GI Motility Issues

So there's a variety of different considerations for the cause of gastroparesis. And then treatments are pretty tough. There are some medications out there that have been used over, the years.

I'm not sure how effective they are. Sometimes they can be helpful. I personally don't tend to use them. I things like Raglan, you know, because they have so many other potential side effects.

And I know with muscle patients, they don't really want to take a lot of medications unless, unless really, they have to, and then when you have, stomach that isn't working properly and the intestines are just sluggish.

People are much more at risk for developing small intestinal bacterial overgrowth and, you know, otherwise known as Sibo. And so, Sibo is a condition.

I'm not sure other folks have talked about it much where the there is bacteria in the small intestine where it's not supposed to be. We have a lot of bacteria and our large intestine, our colons, but not in our small intestines.

And when it, when that, they set up housekeeping in the small intestine and they tend to have a party, the bacteria ferment, and create gas, which then creates a lot of GI symptoms, nausea, sometimes, heartburn type symptoms.

If the bacteria tend to be on the upper end of the intestines, or they can, present with, bloating gas, flatulence, diarrhea, constipation. So those are some of the presentations that happen with gastroparesis, too, you may get more vomiting or heartburn type symptoms and things just tend to sit there.

Patients can get, a malabsorption presentation, as well. And just for people who maybe don't know that term gastroparesis, this is where the stomach's not emptying as quickly.

And all of this we're talking about in the realm of things not moving through the GI tract at the pace that it should be moving. And I've seen people get really good benefits with different vagal modalities, whether it's looking at osteopathic cranial work, making sure there's not pressure on those nerves, frequency specific microcurrent what's working in your practice?

Good question. I do have, patients do osteopathic manipulation. There are some physical therapists that have been trained in visceral manipulation. I think that that's helpful to and yeah, anything that's going to help stimulate the vagus nerve, whether that's humming or singing or, gargling or any of the, the devices.

I like the rosy Macs a lot. I think that can be very helpful, at supporting vagal little tone. Can you talk about that one? We haven't talked about that on the summit. Sure.

So, I can go get one, or I can go get it if you want. Sure. Let's see it. I love show and tell. So here is the resin, Max. It allows for vibration and has a variety of different speeds.

You can, place it on your hand. If you having headache, you can place it on your, you know, abdomen. The whole the whole device vibrates. And then it can use this as a target.

And there's a wide variety of different ways to use it. The man who developed it is a physical therapist, and he's delightful. He loves to talk to patients about how to use it.

And so has a, a great way of explaining a variety of different ways to use it. I had a patient who has M. S., and he was having some challenges. Evacuating his bladder just would have water retention.

You know, that could be very painful using the resin max for 15 minutes on the lower abdomen. No problems. So it was it was really profound to, use that for him.

I've used it for back pain just to try and, calm that down. So I think it can be very effective for a variety of different things. I had one patient with, heads and pots and Marcel and, lot of gastrointestinal issues, and she started using it just on her feet.

And that really brought a lot of relief. So wide variety of ways to use it. And there is money back guarantee, which is always nice when that makes so much sense, because everything's driven by the nervous system and we can get locked into these nervous system patterns.

So if we can just wake things up, if we can shift the pattern from a pattern that's not serving us any more than it opens the doorway to these new signaling patterns or going back into balance with those patterns.

So anyway, that's where my brain's going with it right now. Yeah. So it's one of many different tools out there, but one that I have, enjoyed a lot. So then the last in the stands is mast cell activation syndrome.

So we've talked about a lot, but we need as many approaches that are working for people as possible. We've

talked about a lot in the summit, but I want to hear what are some of your starter or your go to places for people that's working in your practice with mast cell activation syndrome.

So why don't I focus a little bit more on medications? As an MD, you know, I'm able to use more medications. And so, I do tend to start with over the counter.

Your H1 blockers. So your second generation H1 blockers, that's going to be XR tech, Claritin Allegra XYZ. All. I'll use some muscle testing of patients are open to that.

If not they have to kind of walk through and figure out which one works best. H2 blockers I really think we only have, Pepcid available at this point, unless you're elsewhere in the world, in which case maybe you have some more H2 blockers available.

I recently ordered some padding, from a Canadian pharmacy. So ru padding is an H1 blocker that has platelet activating factor inhibitors. And so it's more unique, as a prescription.

Doctor Theodora's has literature about that, where it can be helpful for, chronic urticaria, mass activation. The typical doses for ru padding are it's a ten milligram tablet, and you can take up to 3 to 4 a day.

So that's kind of neat. As another alternative, if you can get your, prescriber to write for a Canadian pharmacy, you can get them, I use a lot of Crumlin, and I'm sure other practitioners have talked about Crumlin.

I find that some people tolerate the commercial, Crumlin and many people don't the commercial, Crumlin is, liquid in a little plastic tube. And even though it's just water in Crumlin, sometimes plastic really bothers, Marseille patients.

And so they would need to have it compounded. And the doses with the Crumlin are about 100 to 200mg, up to four times a day. And again can be a game changer for for people.

Doesn't work at all for others. And some people find that they have to start with really low doses. I know your your listeners are very good at teeny tiny doses.

But that's what works. Yeah. Starting with just a drug, because it can be also not and I'm a nervous system response to that. Crumlin and Tania Dempsey in her interview has some great info about starting with little drop of Crumlin and building up slowly to just ease into that.

Yes, I find that that's a really important way to do it too. I like ketoprofen a key taut often is a mast cell stabilizing medication that's only available commercially as an eyedrop, which I haven't really used very much.

But it is available, compounded and actually love.

MCAS Treatment Approaches and Compounding

Ketoprofen. Some patients do fantastic with it. I tend to start small doses, usually 0.5mg twice a day. And with our ultra sensitive patients, then we're opening capsules and taking just pinches of that.

And you can work up to three times a day. Some patients, I have, one woman who slowly worked her way up, and now she said three milligrams three times a day, and that's just, golden for her.

She does really well with that dose. You can go a little higher if you want. And it just gets compounded as, higher and higher doses. But usually that 0.5 is a good place to start.

I let's see, what are some other things that we use. There are other medications that can be used. Hydroxyurea is one of them. For example, if somebody has muscle and has a lot of bone pain or they happen to have, elevated platelets.

So the hydroxyurea can be really helpful in a certain set of patients. Doctor Afrin wrote an article about that. It's a medication that is often used for sickle cell anemia.

A little bit tough to take, but, works for the right patient. Let's see. There are other medications, like an IGA, blocker called Zola. So if patients have mass activation and have very high Ige levels, Zola, Zola can be used and can be quite helpful in that super allergic Marseille patient.

That usually requires, an allergist on board to help and get that and to hone in the dose. So this has been amazing information. Anything that you wanted to touch on, we haven't gotten to yet.

Other medications that I've used that have been successful are the Luca train inhibitors. Singulair is one that I've used, and there are a couple other that are less commonly used.

They can be very helpful. And I do find that for some patients they need much higher doses than the usual, you know, ten milligrams a day. So some people are on 20mg twice a day.

And I do find it's important that if a class of medications tends to work for people, it's worthwhile while trying some of the other medications in the class because they're one, 1st May work even better than another.

Addition nally there are some tyrosine kinase inhibitors. Imatinib is one that Doctor Afrin has used. And a number of my other colleagues have used as well.

I will admit I haven't really used it very much. I haven't felt that I needed to, but certainly there are some patients that do well with imatinib, and it is, not a cancer drug per se.

And we're certainly using much lower doses than are typically used for systemic masto psychosis. In terms of compounding to do have people talk about compounding medications much on the summit a little bit, but go ahead and dive into it.

So I found that with some of my exquisitely sensitive patients, they really need compounded versions of just about everything. And so it's critically important to find a compounding pharmacist who, understands the needs of a mass cell patient, understands that they often need, certain kinds of inactive ingredients that are better tolerated.

So sucrose can work for some people might use my micro cellulose can work for other people. But being able to have that conversation with the compounding pharmacist, is key.

I've compounded loratadine, which is Claritin. Zyrtec, which is a sort design, level switch. Azeem. And those have worked phenomenally well for those patients who really need that super clean, version of the medication.

One, thing that I like to share with my patients is that there's a great resource online that lists all the inactive ingredients called, NIH Daily Med.

And so you can just Google NIH Daily Med, look up your medication there. There's even a national drug code that's listed on every medication. So you can see exactly what is in the preparation that you have.

And so if patients are having reactions to medications, it may actually not be the medication. It may be the inactive ingredients. And then they can cross-reference the formulations that they're having problems with and figure out what are the inactive ingredients that they're reacting to.

So I think that that can be very empowering when you, and there's a long list of, medication allergies that are not true allergies. There are mast cell reactions to an active ingredients, and, just a few more words about compounding.

They compounders, community pharmacies can also, combine medications to which helps with the costs as well once you figure out what you need. And a few more words about meds.

Don't forget symptomatic relief. So, benzodiazepines can be mast cell stabilizing. And I have been able to compound some benzodiazepines for certain patients if necessary.

And, you know, some people do well with aspirin. Some people do well with low dose. Now trucks own and that can not only treat the autoimmune components of it, but it can actually stabilize themselves.

So there's a lot of options out there. In addition to all the supplements. And I think probably the most important thing that I want to share is that there are practitioners out there that can help.

And it's really important to have hope to be your own advocate, to continue to find the practitioners, that will help you on your journey and then know you've got a lot of work to do.

And this is this is not an easy thing, but you can get better. Yes. And I know you see it every day in your practice. We see amazing turnarounds. We're both walking cases of, these turnarounds.

And we're going to link to that's a great resource for people on the, NIH Daily Med. We're going to link to that on our summit resources page so people can find that at mast cell three 60.com/summit.

And I'll also include a list of the most common Marcelle triggering excipients. Those inactive ingredients that, people who are really sensitive sometimes have to watch for in there.

Thank you for just this incredible amount of generous sharing. Your wisdom and your knowledge here. I have always enjoyed our collaborations together, and I just want to tell you how much I appreciate the work that you do in the world.

Thank you. Beth, this has been fantastic. I'm so happy that we collaborate and that you're putting this information out there for the world.