

*Book excerpt: The Sensitive Patient's Healing Guide*

# THE LYME TIMES

*The Journal of LymeDisease.org*

**SPECIAL ISSUE**

## **The Agony of Mast Cell Activation Syndrome**



*What to eat when you're allergic to everything?*

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# The Agony of Mast Cell Activation Syndrome

Mother recounts daughter's precipitous health decline from tick-borne illness and severe allergies to chemicals and food

*By Lonnie Marcum*

**I**n the winter of 2016, my 17-year-old daughter was dying. She had severe allergic reactions every day, was in constant pain, and was losing weight at a rate that was not sustainable to life. She had reached the end of her rope, and I was completely out of ideas on where to turn for help.

Those are among the findings of a recent study that analyzed information from Eighteen months earlier, after a long illness and finally completing treatment for Ehrlichia chaffeensis, Bartonella and Lyme disease, she had been doing great. Unfortunately, she soon caught the flu and then everything went south. Over the next year, one setback after another landed her in the hospital every other month with atrial-fibrillation (irregular



and/or near-anaphylaxis (acute allergic reactions). Each trip to the doctor took one more piece of hope away from us, since no one could pinpoint the cause of her rapid decline.

Over time, my daughter developed allergies to soaps, perfumes, juices, fruits, vegetables, and lunch meats. Eventually, she was down to only three foods that didn't make her lips swell, mouth break out in blisters and throat tighten—chicken sautéed in our home-grown olive oil and brown rice noodles.

Not knowing what to do, I reached out in desperation to the “LymeParents” Yahoo group. Another mother recognized the symptoms I was describing as mast cell



activation syndrome (MCAS) and connected me with Dr. Lawrence Afrin at the University of Minnesota. Dr. Afrin consulted on my daughter's case, then referred us to Dr. Mark Renneker, a mast cell specialist at the University of California, San Francisco. Soon, she received a diagnosis of MCAS, and with it a path to healing.

Coincidentally, one month after my daughter's diagnosis, I attended Dr. T.C. Theoharides' lecture on mast cell activation at ILADS in Philadelphia. In his words:

*Mast cells are the "universal alarm cell" that starts the inflammatory cascade. They can be triggered by infection, allergens, environmental factors like pollution, or even emotional stress. Once that happens, mast cells set into motion a series of inflammatory reactions, including the activation of immune cells and the release of tumor necrosis factor-alpha (TNF-a), a pro inflammatory protein or cytokine.*

If you or a loved one are in a similar situation, here's what you need to know.

## MCAS Diagnosis

MCAS is a clinical diagnosis based upon signs, symptoms, and response to treatment. There are several tests available to confirm the diagnosis, but negative tests do not rule out MCAS.

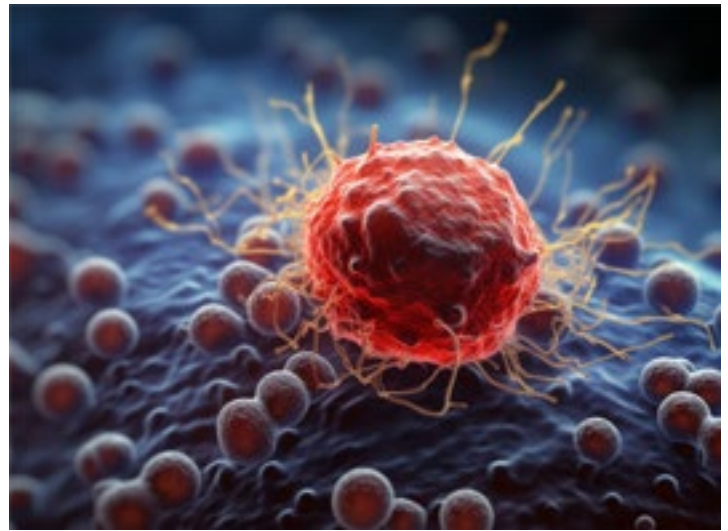
## Mast Cell Activation Diseases

Mast cells are a normal part of our immune system. They are located in every tissue of the body, but in higher concentration in areas of the body that come into contact with the outside world (eg. skin, sinuses, throat, lungs, gastrointestinal tract, etc.) When mast cells detect stress, injury, toxins or infection, they release specific chemicals which trigger an immune response. Think of them as sentries or guards.

When mast cells perform properly, they are our friends. When mast cells are agitated or over-reactive, the immune system goes haywire and starts to attack the body, triggering auto-inflammatory processes or some types of autoimmune illnesses.

## THERE ARE TWO MAJOR FORMS OF MAST CELL ACTIVATION DISEASES (MCAD)

**MASTOCYTOSIS** — the abnormal accumulation of mast cells in one or more organ systems (cardiovascular, central nervous, digestive, endocrine, genitourinary,



lymphatic, muscular, peripheral nervous, respiratory) which is diagnosed by a bone marrow biopsy or a C-Kit genetic mutation.

**MAST CELL ACTIVATION SYNDROME** — the inappropriate release of mast cell mediators including: histamine, interleukins, prostaglandins, cytokines, chemokines, and heparin.

As far back as 1999, researchers were able to demonstrate how *Borrelia burgdorferi* induces mast cell activation, contributing to greater illness in Lyme disease. Somehow, I feel this fact has remained under-appreciated until just recently.

## PTSD of the Immune System

When I describe my daughter's condition to non-medical folks, I say it's like her immune system has post-traumatic stress disorder (PTSD). After going a year with multiple untreated infections, her immune system was depleted, and the combination of antibiotics she needed to fight her infections added additional stress. As she completed antibiotic treatment for her infections, we added supplements to boost her immune system and promote healing. Or so we thought.

Unbeknownst to her doctors and me, one of her prescription medications (ketotifen) contained lactose, to which she is intolerant. In addition, she had developed an allergy to microcrystalline cellulose (MCC), one of the most common fillers in prescription medications, vitamins, and supplements. Eliminating these two allergens was a major turning point in her healing.

## Accepting that you have a problem

This is a tough one. It reminds me of my daughter's childhood friend, who was diagnosed with diabetes in second grade. After years of failing oral medications, he eventually received an insulin pump that inserts directly into his abdomen. It completely changed the type of sports he could play and the way he had to live his life. But within a year, he had adjusted and could do nearly everything other kids his age did, as long as he adhered to a routine.

My daughter had to come to grips with the fact that she may never be able to roll in the grass or eat many of her favorite foods again. She also had to accept that she lost five years of her life and a lot of childhood dreams. Not only that, but fighting our way through the medical system to a diagnosis and treatment left a lot of emotional scars and a type of trauma caused by medical treatment (iatrogenic)– very similar to post-traumatic stress disorder (PTSD). This is where I truly believe a compassionate therapist is needed.

So, to me, healing from MCAS not only requires lowering histamine levels and retraining your immune system, but also retraining your mind, creating a safe environment within your restrictions, and designing a lifestyle that continues to bring you joy.

## Our Five Steps to Healing

### STEP 1: Reduce or eliminate mast cell triggers (common triggers)



- Insect bites (spiders, ticks, fleas, mosquitos, bed bugs)
- Stress (heat/cold, weather changes, fatigue, emotional stimuli)
- Foods (dairy, high histamine foods, fermented or aged foods, wheat, shellfish, sugar, certain preservatives)
- Drugs (alcohol, opioids, aspirin, NSAIDS, excipients, other medications)
- Dyes (food coloring, radiographic dyes, pigments in makeup)
- Environmental toxins (pollen, dust, mold, animal dander, heavy metals, pesticides)
- Noxious odors (perfumes, smoke, exhaust fumes, smog)

## STEP 2: Assemble the “A TEAM” (example)

- Physician knowledgeable about Lyme and other tick-borne diseases (treat infections)
- Physician knowledgeable about mast cell activation syndrome (lower histamine, stabilize mast cells)
- Psychotherapist (emotional support, lower stress)
- Physical therapist (modalities for pain, cranial-sacral therapy, lymphatic drainage, home care instructions)
- Doctor of Osteopathy (functional medicine, supportive hands-on therapy)

## STEP 3: Working with your team, find the right combination of medications/supplements

Many people with mast cell issues will improve by taking antihistamines. Antihistamines are medications that block or inhibit the histamine receptors on mast cells and other cells found throughout the body.



Histamine is a unique chemical produced primarily by mast cells that causes inflammatory reactions and the itching feeling most of us are familiar with. Histamine also signals the immune system, regulates the digestive system, and acts as a neurotransmitter in the brain, spinal cord and uterus.

**Caution:** Most MCAS patients are hypersensitive. My advice when trying anything new is to go low and slow. Micro test the first dose. If no reaction, wait a day

or two and try again. If you find something that works, don't assume more is better. Try not to add more than one new medication in a four-day period, as this makes it too difficult to detect which one is helping or potentially hurting the condition.

We ran a complete vitamin and mineral panel to pinpoint nutrient deficiencies. Then, we designed a custom nutrition plan that was specific to her needs. Basic diet: Clean, fresh (nothing cured, processed, or fermented), organic, gluten-free, dairy-free, dye-free, sugar-free, low-histamine, low-citrus, low-oxalate, low-nightshade, also consider elements of a low FOD-MAP diet.

## STEP 4: Customize Nutrition

Patients with certain genetic defects are more prone to MCAD. Looking into your genetics can help determine your predisposition to MCAD and/or histamine intolerance and help you design a customized nutrition plan.



## Genetic defects related to MCAS

- **KIT-D816V** — KIT is a master regulator protein found on and in mast cells. A KIT mutation typically results in the mast cell being constantly activated. About 90% of patients with mastocytosis have a KIT-D816V mutation (there is a PCR test for this mutation).
- **MTHFR** — The body makes several enzymes called MTHFR that are critical for the production of folate and many cellular functions. Patients with MTHFR defects may have an inability to clear histamine leading to MCAS and histamine intolerance.



- **HNMT** — In the central nervous system, histamine is broken down by histamine methyltransferase (HNMT). Patients with a lot of HNMT defects will have trouble clearing histamine from the brain and nerves. Moodiness, sleep disturbance and frequent rashes or hives can be a sign of this.
- **ABPI** — In the digestive tract, histamine is broken down by diamine oxidase enzymes (DAO). Defects in ABPI lead to lower levels of DAO and higher levels of histamine.
- **HLA** — Variations in the HLA gene can increase the chances of gluten intolerance.
- **VDR** — VDR defects may lead to lower levels of Vitamin D, which is critical to immune health.
- **MAT** — MAT gene is involved in the conversion of the amino acid methionine into SAME. SAME has 100s of critical functions throughout the body. If vitamin B12 makes you feel sick, you may have a lot of MAT defects. Your doctor can order blood work to check methionine and SAME levels.

## Nutrition

We ran a complete vitamin and mineral panel to pinpoint nutrient deficiencies. Then, we designed a custom nutrition plan that was specific to her needs.

**BASIC DIET** — Clean, fresh (nothing cured, processed or fermented), organic, gluten-free, dairy-free, dye-free, sugar-free, low-histamine, low-citrus, low-oxalate, and low-nightshade. You might also consider elements of a low FODMAP diet (a specialized elimination plan to help you identify which foods are troublesome for you).

## STEP 5: Stick to a Routine

- **Avoid stressful situations**
- **Maintain the same sleep schedule**
- **Maintain the same eating schedule**
- **Maintain the same basic level of activity from day to day**
- **Pace yourself and avoid overexertion.**

## Putting it all together

These steps may seem daunting. But when you are in a crisis like my daughter was, you are willing to go to extremes to get your life back.

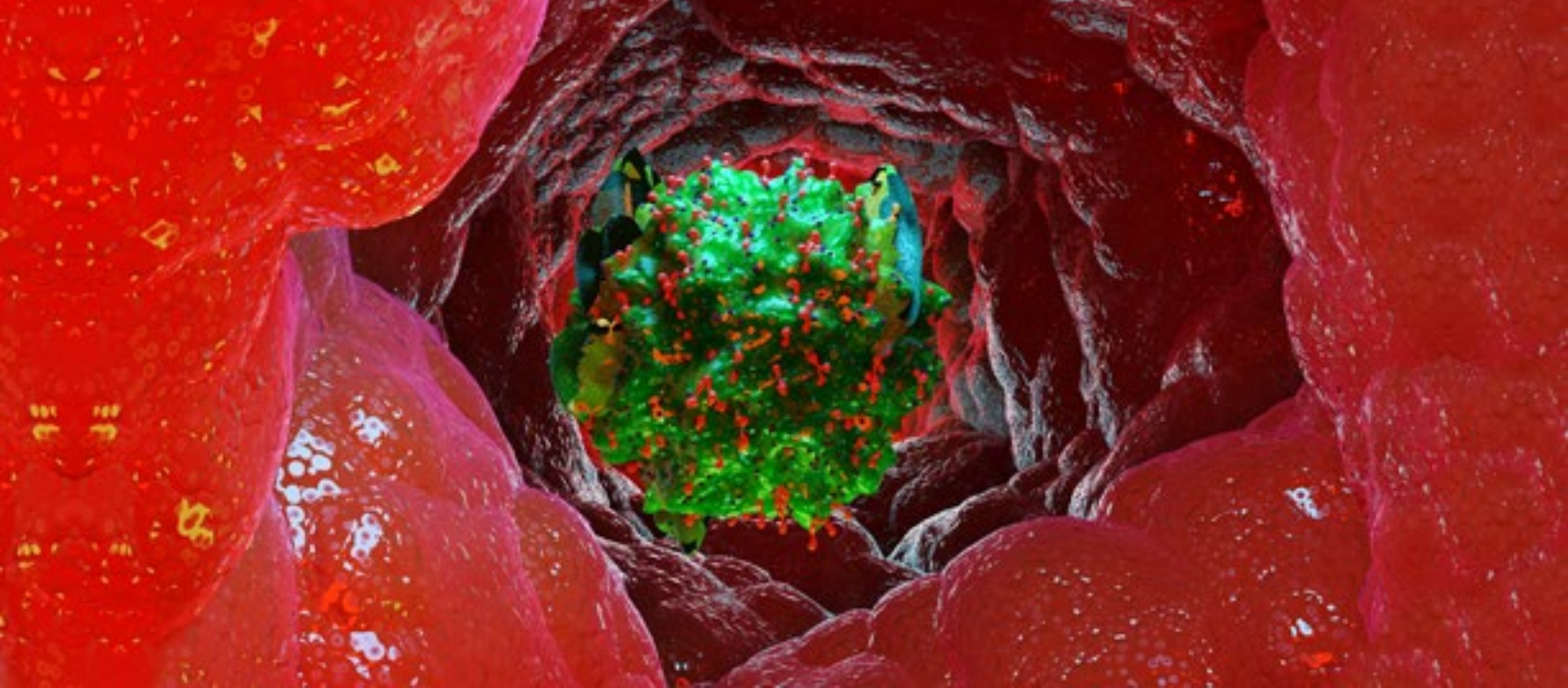
**DOWNLOAD EMERGENCY ROOM RESPONSE PLAN**

### References:

1. *Mast cell activation disease: a concise practical guide for diagnostic workup and therapeutic options* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3069946/>.
2. *Borrelia burgdorferi Spirochetes Induce Mast Cell Activation and Cytokine Release* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC96436/>.
3. *Recent Publications and Presentations by Theoharis C. Theoharides, Ph.D., M.D.* <http://mastcellmaster.com/publications.php>.

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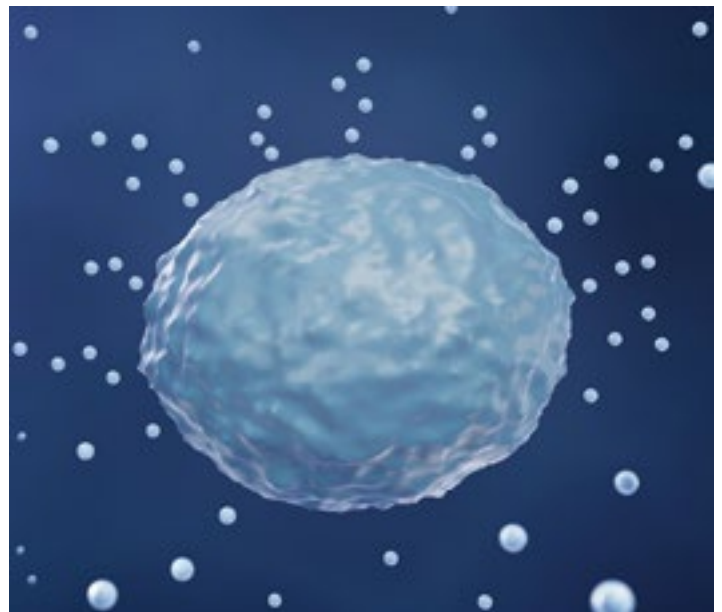


# An Overview of Mast Cell Activation Syndrome

MCAS, an inappropriate release of chemical mediators, can cause inflammatory symptoms anywhere in the body

*By Dr. Todd Maderis*

**M**ast cells are a part of the human immune system and protect against foreign invaders. Mast cells are concentrated in areas where the external environment comes into contact with the human body, such as the skin, the lungs, the mucous membranes inside the nose, and the gastrointestinal tract. In normal circumstances, mast cells release various compounds called mediators in response to foreign substances to keep us safe. In mast cell activation syndrome (MCAS), there is an inappropriate release of the chemical mediators that can cause inflammatory symptoms anywhere in the body. Many people (including physicians) mistakenly refer to these symptoms as histamine intolerance, when MCAS is the cause.



For some people, mast cells are more prone to release the mediator contents. However, for many, there is an underlying cause (or causes) that increases the risk of developing mast cell activation syndrome.



## CAUSES OF MCAS INCLUDE:

- Bacterial infections
- Viral infections
- Fungal infections
- Heavy metals
- Herbicides
- Mold illness
- Allergens – food and environmental
- Genetically predisposed

In addition, some triggers cause mast cells to degranulate and release mediators in those who are susceptible.

## MCAS TRIGGERS ARE:

- Heat
- Stress
- Exercise
- Physical trauma
- Alcohol
- Foods
- Hormonal changes
- Medications
- Odors
- Insect stings

## Mast Cells Release Chemical Mediators

Inside of each mast cell, there are tiny sacs called granules. Granules contain up to a couple of hundred chemical mediators that get released when a trigger such as an allergen or toxin binds to a mast cell. Histamine is the most common mediator released from mast cells in response to an allergen such as pollen. Other mediators include tryptase, heparin, prostaglandins, leukotrienes, and cytokines. Different mediators can cause a unique physiological reaction to surrounding tissue. For example, tryptase is a proteolytic enzyme and can break down nerve endings.

Since mast cells are present in all humans, there is the potential anyone can develop mast cell activation syndrome. People who have developed immune

dysfunction from chronic infections, toxin exposure, repeated allergen exposure, and individuals with genetic variations are at an increased risk of developing MCAS.

One study reported on over 400 patients with MCAS and identified the prevalence of specific characteristics. Women made up 69% of patients with mast cell activation syndrome, and 75% were Caucasian. The most frequent age at onset of symptoms was nine years old, and in most patients, it took 30 years to get a diagnosis of MCAS. This implies people with MCAS may spend a good portion of their life without a proper diagnosis. Other surveys have confirmed females have an increased incidence of MCAS.

## Symptoms of Mast Cell Activation Syndrome

After receiving a diagnosis of mast cell activation syndrome in adulthood, many people realize the symptoms they have experienced since childhood were related to MCAS. It is common for children (and their parents) to be told by their pediatrician they will “outgrow” their symptoms. Because mast cells are located throughout the body and contain over a hundred inflammatory compounds, symptoms can occur in every organ system. This multi-symptom, multi-system involvement—and because mast cell activation syndrome is not well-recognized—creates an extreme challenge for physicians to diagnose.

## THE MOST COMMON MCAS SYMPTOMS ARE:

- **SYSTEMIC** — fatigue, sensitivity to food and medication
- **RESPIRATORY** — nasal congestion, shortness of breath, asthma, throat swelling
- **NEUROLOGICAL** — headaches, migraines
- **MENTAL/EMOTIONAL** — decreased concentration, memory; anxiety, depression
- **MUSCULOSKELETAL** — aches, bone pain, osteoporosis
- **DIGESTIVE** — nausea, vomiting, heartburn (GERD), diarrhea, abdominal cramps
- **SKIN** — flushing, itching, hives, temperature dysregulation



- **CARDIOVASCULAR** — high and low blood pressure, lightheadedness, racing heart, hypercoagulation
- **GENITOURINARY** — irritable bladder, interstitial cystitis

Here are several conditions associated with mast cell activation syndrome. It can be difficult to distinguish if the illness or disease has caused MCAS or MCAS has caused symptoms that present like the illness or disease.

### **CONDITIONS ASSOCIATED WITH MCAS INCLUDE:**

- Chronic Lyme disease
- Fibromyalgia
- Autism
- Hypercoagulation
- ME/CFS (chronic fatigue syndrome)
- Irritable bowel syndrome (IBS), small intestine bacterial overgrowth (SIBO), leaky gut syndrome
- Mold illness
- POTS/Dysautonomia
- Ehlers-Danlos hypermobility
- Multiple chemical sensitivity
- Autoimmune conditions

### **Mast Cells Release Chemical Mediators**

Mast cells are highly concentrated in the gastrointestinal tract to protect humans from any foreign invaders they may swallow. Whether triggered by bacteria, parasites, or food allergies, mast cell activation in the gut can contribute to digestive symptoms such as heartburn, nausea, vomiting, constipation, and diarrhea. Digestive conditions associated with MCAS include IBS, small intestine bacterial overgrowth (SIBO), eosinophilic esophagitis, and leaky gut syndrome.



After testing patients with persistent IBS-like symptoms for mast cell activation syndrome (MCAS) and small intestine bacterial overgrowth (SIBO), a group of researchers published their findings. Of all the patients that tested positive for MCAS, 66% had digestive symptoms before any other MCAS symptoms. The most common symptoms these patients experienced were abdominal pain (87%), bloating (75%), constipation (67%), nausea (62%), and heartburn (54%). SIBO was present in 31% of the patients with MCAS, and the authors concluded mast cell mediators in the gut could contribute to altered digestive motility, which may lead to SIBO.

## **MOST COMMON DIGESTIVE SYMPTOMS OF MCAS**



A percentage of my patients with MCAS have reported they react with digestive or systemic symptoms to many foods, so they have to eat a limited diet. This reaction is caused by antibodies that have been formed against certain foods and then bind to mast cells. When the food is consumed, it binds to the antibodies and causes the mast cells to release inflammatory mediators.

There may also be increased inflammation in the small intestine from increased mast cell activity. Small intestine inflammation (also termed leaky gut syndrome) allows food particles to easily cross the intestinal barrier, enter the bloodstream, and trigger an immune response. In my experience, when mast cell activation and leaky gut syndrome are treated effectively, people can eat more variety in their diet without adverse reactions.

## High Histamine Foods

Certain foods are high in histamine or cause histamine release from mast cells. Below is a list to guide you to help you identify which foods cause a reaction in your body. In general, there is a direct correlation between the reduction of high-histamine and histamine-releasing foods and the improvement in MCAS symptoms.

### HIGH HISTAMINE FOODS

- **FERMENTED FOODS** — kombucha, miso, kimchi, sauerkraut, soy sauce
- **PICKLES AND PICKLED VEGETABLES**
- **DAIRY** — aged cheese, yogurt, sour cream, kefir
- **VINEGAR** — possibly in salad dressings, mayonnaise
- **CURED MEATS** — deli meats, salami, ham, sausages
- **VEGETABLES** — tomatoes, eggplant, spinach

- **NUTS** — peanuts, cashews
- **ALCOHOL** — wine, beer, champagne
- **FISH** — herring smoked mackerel, sardines, tuna, anchovy
- **BONE BROTH**
- **CITRUS FRUIT**
- **CHOCOLATE**

### FOODS THAT CAUSE HISTAMINE RELEASE

- **CITRUS FRUIT**
- **FISH**
- **PAPAYA, STRAWBERRY, PINEAPPLE**
- **ALCOHOL**
- **PEANUTS**
- **TOMATOES, SPINACH**
- **CHOCOLATE**



## Lyme Disease is Associated with Mast Cell Activation Syndrome

Pathogens such as viruses, bacteria, fungi, and parasites can contribute to mast cell activation syndrome. The mast cell reaction is an immune response in an attempt to protect the human from the pathogen.



About half of the patients I see with tick-borne infections also experience MCAS. Many symptoms of MCAS overlap with Lyme disease, and effectively treating MCAS not only helps the patient feel better, but it also helps to clarify what symptoms remain from Lyme disease. In severe cases of MCAS, it may be necessary to treat mast cell activation syndrome before people can take natural or prescription medications to treat Lyme disease and associated infections without experiencing adverse reactions.



When Lyme disease – or other infections – and mast cell activation syndrome are present, MCAS is part of the immune dysregulation and contributing to symptoms. A research study confirmed that the bacteria that causes Lyme disease triggers mast cell degranulation. I like to approach treating illness and disease by addressing the root cause. It is important to test for Lyme disease and associated infections to determine if the infections are driving the mast cell mediator release.

### Mold Exposure can Cause Mast Cell Activation

Human exposure to environmental molds and their toxins (mycotoxins) causes immune dysfunction and immune suppression. Mold and mycotoxins are also involved in mast cell activation syndrome. Suppose someone is experiencing any MCAS symptoms and has been exposed to a water-damaged building or

environmental mold. In that case, it is critical to test for mold illness properly. Addressing mold toxicity helps to improve the outcome of mast cell activation syndrome.

## Diagnosing Mast Cell Activation Syndrome

The clinical symptoms of mast cell activation syndrome should clue the physician in to order laboratory tests to confirm this suspicion. Multiple diagnostic criteria for mast cell activation syndrome have been proposed by mast cell researchers, physicians, and organizations. In my clinical practice, I use the diagnostics criteria outlined by mast cell experts Lawrence Afrin and Gerhard Molderings.

The greatest challenge in diagnosing MCAS with laboratory testing is the proper handling of blood and urine samples. The samples require constant chilling to maintain stability. A 24-hour urine sample is collected at home before the blood draw. It is kept in the refrigerator and transported in a cooler to the lab. The laboratory phlebotomist also needs to be aware of keeping the samples chilled at the time of the blood draw. Proton pump inhibitors (Prevacid, Prilosec, etc.) and NSAIDs (Advil, Tylenol, etc.) need to be avoided five days before testing.

Even if the specimens are handled properly, it can be challenging to see even one mediator elevated due to the timing of mast cell degranulation. One approach is to collect the samples during a flare of MCAS symptoms.

### THE DIAGNOSTIC WORKUP FOR MCAS INCLUDES:

- **TRYPTASE, SERUM** — (frozen)
- **CHROMOGRANIN A, SERUM** — (chilled)
- **PROSTAGLANDIN D, PLASMA** — (chilled)
- **HEPARIN, PLASMA** — (chilled)
- **HISTAMINE, PLASMA** — (chilled)
- **LEUKOTRIENE E4, URINE** — (chilled)
- **N-METHYLHISTAMINE, URINE** — (chilled)
- **11B PROSTAGLANDIN F2, URINE** — (chilled)



Click below to download and print a list of MCAS tests and handling instructions for your physician or lab.

### Is it Mast Cell Activation Syndrome?

Mast cells are located throughout our bodies and are an essential part of our immune system. There has been an increased awareness and – likely incidence – of mast cell activation syndrome in the past decade. If you have symptoms consistent with MCAS, it is necessary to get properly tested for the above mediators. There may be underlying causes of mast cell activation syndrome for many people, including toxins, mold exposure, infections, and other environmental exposures. It is important to identify the potential causes with proper testing to improve symptoms and improve the outcome of treating mast cell activation syndrome.

[DOWNLOAD MCAS TESTS HANDLING INSTRUCTIONS](#)

*Dr. Todd Maderis is Founder and Medical Director of Marin Natural Medicine Clinic in Larkspur, CA. This article is republished from his blog, [DrToddMaderis.com](http://DrToddMaderis.com).*

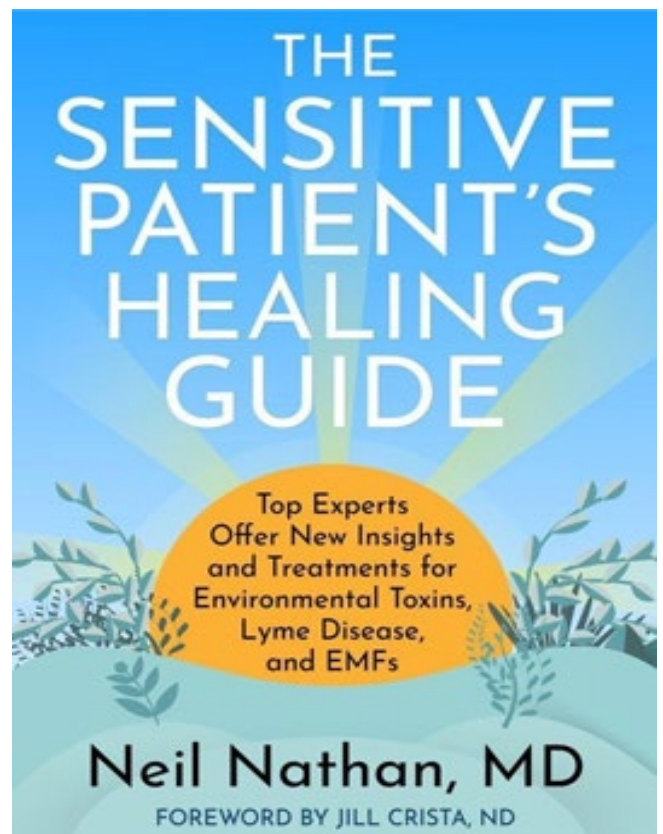


# Sensitive Patient's Healing Guide offers Hope and a Game Plan

In New Book, Top Experts Offer New Insights and Treatments for Environmental Toxins, Lyme Disease, and EMF's

*By Dorothy Kupcha Leland*

**P**eople coping with Lyme disease and co-infections are often plagued with a host of additional complications. For example, they may be suddenly hypersensitive to smells, sounds, or lights. Foods they used to eat with no problem may now make them horribly sick to their stomach. Standing next to someone wearing perfume might leave them gasping for breath. Living or working in a moldy building? Exposure to cell phones and other sources of electromagnetic frequencies (EMFs)? All can bring on serious and debilitating symptoms.



Unfortunately, individuals in that predicament typically don't find much help from traditional medical treatments and protocols. But now, there's an excellent new resource: Dr. Neil Nathan's book [The Sensitive Patient's Healing Guide: Top Experts Offer New Insights and Treatments for Environmental Toxins, Lyme Disease and EMFs](#).

In an introductory chapter, Dr. Nathan notes that for a wide variety of reasons, some people become highly vulnerable to specific stimuli that our nervous systems monitor constantly and carefully. He writes:

*"To clarify, when we speak about chemical sensitivity, we're not referring to a mere dislike of being around strong perfumes but to a significant reaction to any number of scents, including perfumes, of headache, fatigue, cognitive dysfunction and even certain types of seizures."*

Some noises, he explains, can cause a sharp startle effect. Light sensitivity may be so acute that a sufferer must wear sunglasses indoors. And exposure to EMFs can bring on intense fatigue, headaches, or cognitive impairment within minutes of using a computer.

*"Just when you thought it couldn't get any worse," he writes, "you notice that after eating many of your meals, you immediately begin to itch all over, or have heart palpitations, or an increase in brain fog and fatigue, or bloating and abdominal pain."*

## Hypervigilant nervous system

According to Dr. Nathan, this sensitivity is created by a hypervigilant nervous system that is not convinced it is "safe." He continues, "In fact, it is not safe, so the parts of the brain, specifically the limbic system...the vagus nerve...and the associated cranial nerves...move from a protective mode into an overprotective mode and question every arriving stimulus."





He stresses the importance of not only accepting the reality of such sensitivities, but also the need to look for the root causes. Moreover, he emphasizes that in his experience:

*“Toxins (especially mold toxicity) and infections (particularly Lyme disease and Bartonella) are the most common causes I’ve found. More important, once found, they are treatable.”*

Dr. Nathan wrote much of this based on his 50 years of treating medically complex, highly sensitive patients. But he has also enlisted many other experts as contributing authors. Among them: Richard Horowitz, MD, on Lyme disease and Bartonella; Beth O’Hara, FN, on mast cell activation syndrome; and Annie Hopper, on retraining your brain’s limbic system. In all, some 20 specialists provide segments of [The Sensitive Patient’s Healing Guide](#).

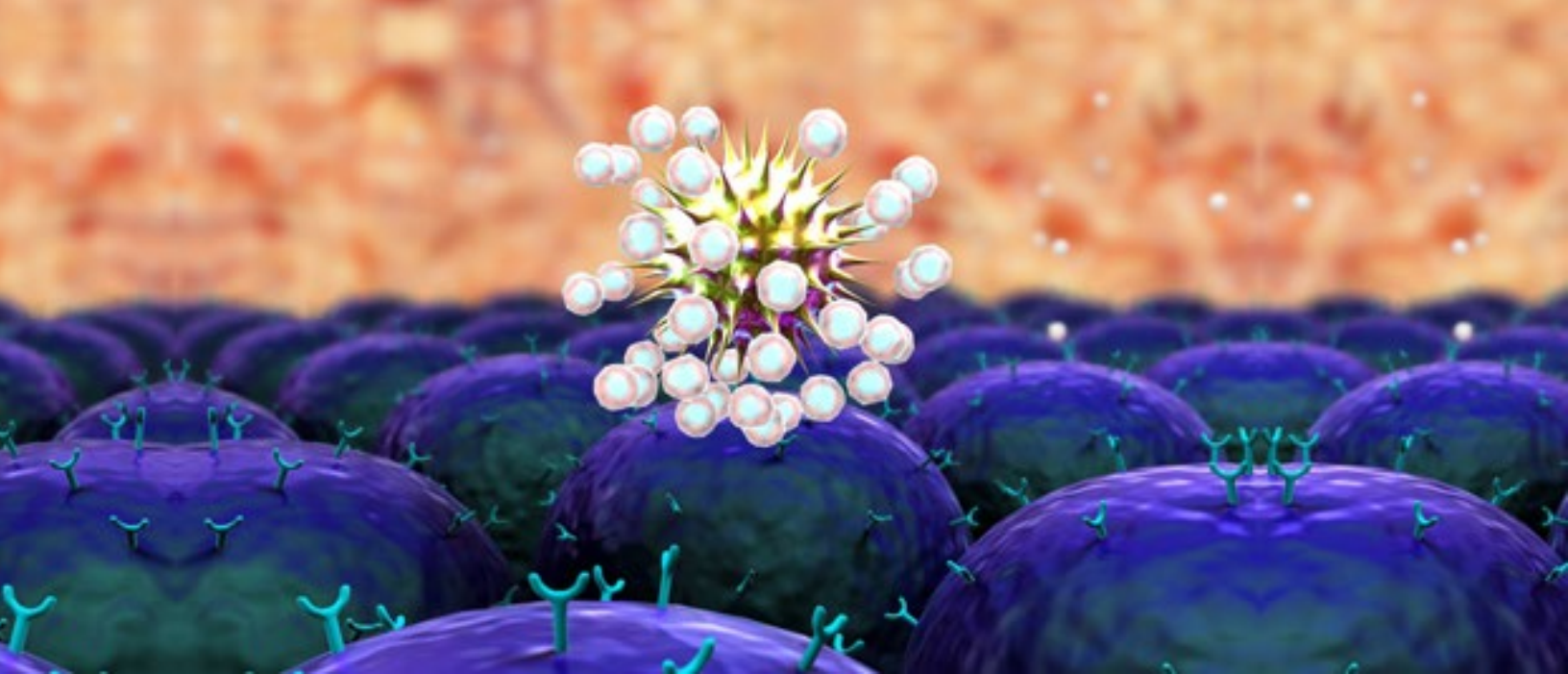
### **THE BOOK IS DIVIDED INTO FIVE MAIN PARTS:**

- 1. The Neurology, Biochemistry and Physiology of Sensitivity**
- 2. The Most Common Triggers for Development of Sensitivity**
- 3. Other Triggers and Conditions for the Development of Sensitivity**
- 4. Treatments for Sensitive Patients**
- 5. Putting it all together (A Guide to Evaluation and Treatment of the Sensitive Patient)**

If you or a loved one suffers from these kinds of sensitivities, I urge you to get your hands on a copy of [The Sensitive Patient’s Healing Guide](#). It offers a wealth of information about many topics that mainstream medicine barely acknowledges. Furthermore, it will legitimize your personal experience and offer you a game plan for recovering your health.

### **ORDER THE BOOK**

*Dorothy Kupcha Leland is President of [LymeDisease.org](#). She is co-author of [Finding Resilience: A Teen’s Journey Through Lyme Disease](#) and of [When Your Child Has Lyme Disease: A Parent’s Survival Guide](#). Contact her at [dleland@lymedisease.org](mailto:dleland@lymedisease.org).*



# How Do These Mast Cells Get So Dysregulated?

As environmental toxins, pathogens and stress loads pile up, many people's mast cells can no longer keep up

By Beth O'Hara, FN

**I**n normal mast cell activity, the mast cells are stimulated by a trigger, which may or may not evoke the mast cells to activate and release certain appropriate mediators.

For example, if you twist your ankle, causing injury, your ankle may get red, hot, and swollen. Your mast cells (and other related immune cells) are on the scene protecting your body and creating inflammation to evoke a healing response. Likewise, if you cut your finger and it gets infected, it may get hot, red, and itchy. Again, your mast cells and other immune cells are there sensing the injury and for pathogens to protect you while communicating to the rest of your immune network to mobilize to attack the infection and invoke healing. If you catch a respiratory virus, your mast



cells will be involved in creating inflammation in your mucosal tissues of your sinuses, nose, and throat to protect you. If you get food poisoning, your mast cells will be a big part of the response of vomiting and diarrhea to help you purge the pathogenic bacteria.

Most people have experienced these various types of normal mast cell activation. And if you don't have MCAS, then once your ankle or cut heals, once you get over the cold or food poisoning, their mast cells calm back down again, and they usually forget anything that happened.

## Mast Cell Triggers



What's happened, though, is that we now live in a world where we're bombarded by mast cell triggers all the time. We're surrounded by both chemicals and artificial EMFs at levels we've never experienced in human history. Our food, air, and water supply is highly contaminated with pesticides, herbicides, microplastics, pharmaceuticals, heavy metals, and a number of other toxins. Due to a variety of factors, environmental mold is at epidemic levels. The incidence of Lyme and other tickborne infections has skyrocketed. We now have super viruses, super bacteria, and super molds. Candida has become more resistant and widespread as well.

Technology has forced upon us a constant stream of sensational, stressful news. Pandemics have contributed to a global level of traumas. What is considered a "normal" lifestyle of working 40-55 hours a week, driving kids to extracurriculars every night of the week across town in rush hour traffic, trying to cram in a healthy meal, pack lunches, barely being able to catch our breath, is actually a highly stressful way to live.

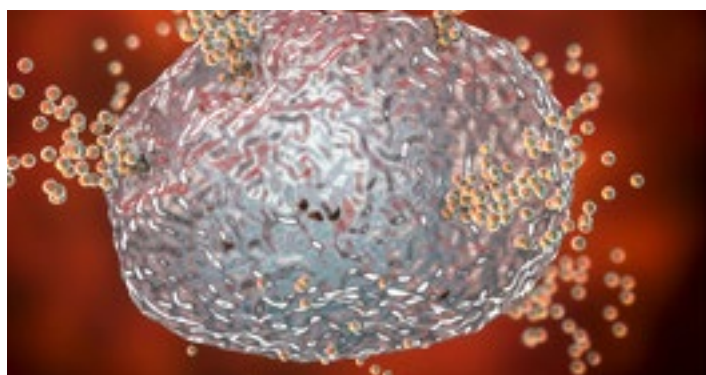


These stressors deplete important nutrients, creating numerous cascading biochemical imbalances. All of these factors contribute negatively to epigenetic expression of a number of genes, including those for mast cells, histamine regulation, detoxification, and so on.

## Mast cells can no longer keep up

Mast cells these days have a constant onslaught of triggers. As the underlying toxin, pathogen, and stress loads pile up, many people's mast cells can no longer keep up. Some people are more genetically predisposed, but for others even without genetic predispositions, we all have a certain threshold of how much of these triggers our bodies can handle.

"It's like your mast cells are on a hair trigger and can't tell the difference anymore between the real threats and the butterflies, so they start to fire machine guns at everything."



When mast cells are continually triggered, they start to lose their fine tuning. Their ability to stabilize themselves decreases. The mast cells receptors become overly sensitive and overly responsive, releasing inappropriate numbers and types of mediators. You can think of it like this – if the guards of the castle gate must be on duty 24/7 for weeks, months, and years on end, you can fully expect they'll get wonky. It's like your mast cells are on a hair trigger and can't tell the difference anymore between the real threats and the butterflies, so they start to fire machine guns at everything.

When you add to the picture how much mycotoxins, tick-borne infections, constant stress, B-1 deficiency, and trauma dysregulate the nervous system signaling, communicating to the mast cells to continue sounding the alarm bells of danger, you can see how mast cells can become so dysregulated, developing hypervigilance for triggers, hypersensitivity to triggers, and over-responsiveness in mediator release.

## **TO RECAP, HERE ARE THE MOST COMMON ROOT TRIGGERS I SEE IN THE MCAS POPULATION I'VE WORKED WITH OVER THE LAST SEVERAL YEARS:**

- Mold toxicity
- Tick-borne infections Lyme and Bartonella
- COVID
- EMFs
- Food triggers
- Chemical toxicity (such as Glyphosate, organophosphates, perchlorates)
- Heavy metal toxicity
- Nutrient imbalances
- Hormone imbalances
- Epigenetic factors
- Physical stressors (surgeries, illnesses, injuries, airway obstructions)
- Chronic emotional and/or mental stressors

## **How is MCAS diagnosed?**

MCAS only received a diagnostic code in 2016, giving it a bit of an “official” status. For a few decades before then, there were case presentations, theories, and preliminary research. There is naturally still a lot of debate occurring in terms of what technically constitutes MCAS.

**There are two types of diagnostic criteria being debated, what are called consensus-1 and consensus-2 criteria.**

### **THE CURRENT, AND STRICTER CONSENSUS-1 CRITERIA REQUIRE ALL THREE OF THESE CRITERIA BE MET:**

1. MCAS-associated symptoms in two or more systems, with periodic flares;
2. Increase in serum tryptase during a flare, having already excluded other differential diagnoses that could explain these symptoms; and
3. Improvement in symptoms with H1 or H2 receptor blocking medications or mast cell targeting medications.

### **THE CURRENT CONSENSUS-2 CRITERIA REQUIRE:**

1. MCAS-associated symptoms in 2 or more systems, with periodic flares, having already excluded other differential diagnoses that could explain these symptoms
2. Increase in one of these mast cell mediator markers during a flare:
  - Chromogranin A
  - Leukotriene E4
  - Total serum tryptase
  - 11-b-PGF2a
  - Heparin
  - Histamine
  - Urinary 24-hour N-methyl histamine
  - Urinary PGD2



3. Improvement in symptoms with H1 or H2 receptor blocking medications or mast cell targeting medications (minor criterion, not required);
4. Tissue biopsy with CD 117 staining (skin, GI tissue, etc.) (minor criterion, not required);
5. Certain genetic variants in the more rare clonal MCAS disorders (minor criterion, not required).

## MCAS testing challenges

Just like with any good research, this healthy debate will continue to evolve and expand as more information becomes apparent. There have been some challenges with testing in MCAS and with getting a positive response to medications that are still being explored. These include: Mast cell blood markers can elevate and then return quickly back to a normal level in the blood within minutes, begging the question of whether sometimes mediators are missed due to the timing of blood draws.

What if the handful of accepted mediators aren't the ones that are problematic for that particular person? What if some of the 990+ other mediators that can't yet be measured are the ones that are actually elevated?

Blood and urine samples have to be kept chilled processed by cold centrifugation to be reliable, yet most labs still don't have this equipment.

The mast cell and antihistamine medications as formulated have likely mast cell triggering excipients (dyes, titanium dioxide, corn starch, plastic residues). This means they may not help because the excipients, rather than the substance itself, may be triggering a reaction and masking improvements.

## Mast Cell Activation Syndrome still in it's infancy

Compared to the diagnosis of more established chronic illnesses, like diabetes or Parkinson's, mast cell activation syndrome is still in its infancy. Further, it takes years for medical schools to update their curriculum with the significant amount of emerging research. Regardless, huge strides are continuing to be made in diagnosing MCAS and addressing it, and I fully expect that understanding, awareness, and effectiveness will only continue to grow as time goes on.

*Excerpted by permission from [The Sensitive Patient's Healing Guide](#), by Neil Nathan, MD. (Cypress House, 2024.)*

*Beth O'Hara is a functional naturopath specializing in complex chronic immune conditions related to mast cell activation syndrome and histamine intolerance. Her website is [MastCell360.com](http://MastCell360.com).*



# Triggers, Symptoms & How to Cope with MCAS

With MCAS, the immune system is stuck in high alert mode; more than one trigger can set off a response, and triggers may change over time.



*By Jenny Buttaccio, RawlsMD.com*

If you spend time in online Lyme disease forums, support groups, or other gatherings of Lyme patients, you'll definitely hear people talk about mast cell activation syndrome (MCAS). The conversation tends to be fraught with frustration — and understandably so.

MCAS might be a factor in people whose mild sensitivities or reactions to food, stress, chemicals, or something else have suddenly accelerated into a list of life-altering, distressing symptoms. Often,

these patients struggle significantly as they attempt to identify the hidden triggers making them miserable.

The syndrome is one subclass of disorders that fit into a category known as mast cell activation diseases (MCADs). Historically, the medical community has viewed MCAS as rare, but one study in the *Journal of Hematology and Oncology* suggests it's a relatively common problem in patients with chronic health conditions.



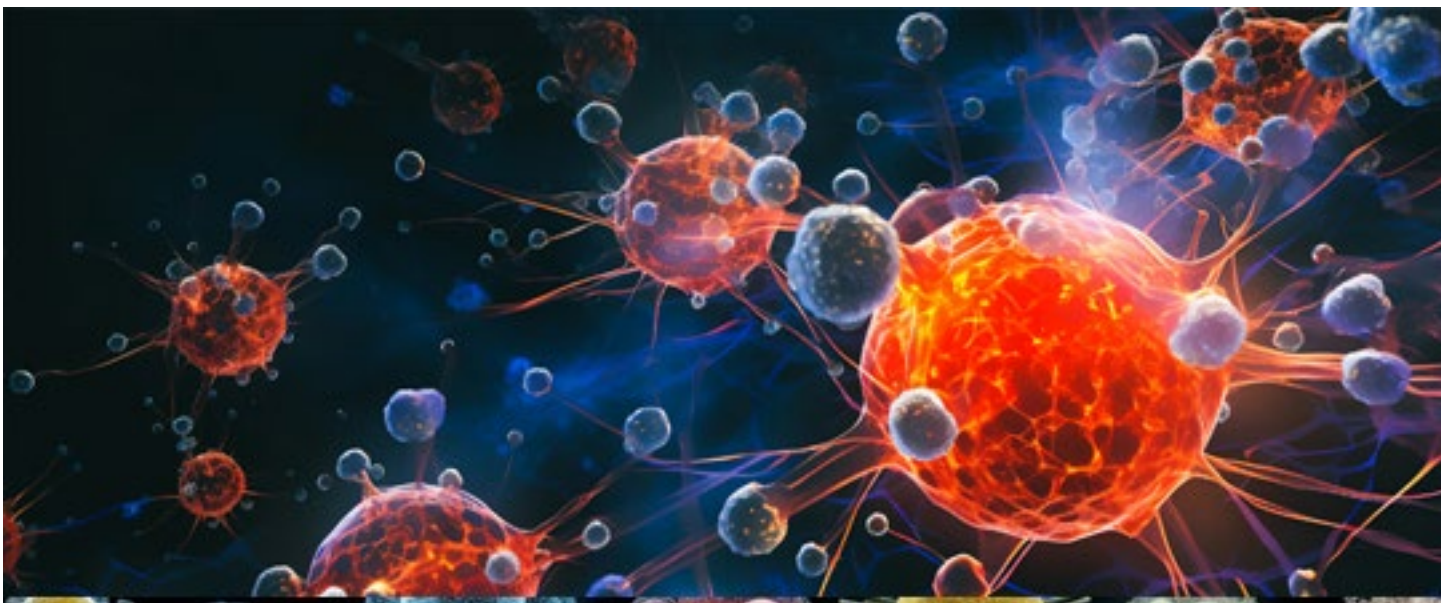
Signs and symptoms associated with mast cell overactivity are not uncommon in people struggling with chronic Lyme disease and similar chronic illnesses such as fibromyalgia,” says Dr. Bill Rawls, Medical Director of RawlsMD and Vital Plan.

*“Microbes and other stress factors associated with these conditions disrupt immune system functions and push certain aspects of the immune system, like mast cells, into overdrive.”*

So what exactly is MCAS, and more importantly for people with the condition, what can be done about it? Here, we’ll explore this multisystemic syndrome and discuss the various strategies you might find helpful for coping with and overcoming it.

## MCAS Explained

Mast cells are small, wandering immune cells that move throughout the various types of connective tissues in your body, including the skin, blood, bone marrow, and lining of the intestinal tract. We all have them, and their primary function is to alert the body when a disturbance has occurred.



Mast cells help keep infections in check, manage gastrointestinal health, allergens, the invasion of pathogens, the inflammatory process, and more. They contain small sacs, also known as granules, that store potent signaling agents, or chemical mediators, like heparin, histamine, and others. When the cells become aggravated by illness, injury, or an infection, even to a mild degree, they selectively release these mediators, which initiates an inflammatory response in the body.

For instance, mast cells are involved in allergic reactions: They secrete histamine, the chemical that, when produced in excess, causes allergy symptoms like itchy skin, rashes, watery eyes, swelling, and a runny nose. Histamine dilates blood vessels and helps clear the irritant.

In a healthy person, when mast cells are triggered by harmful internal and external circumstances, the cells respond in a productive way — by communicating with other cells that control the body’s physiological and immunological responses, suggests an article in the *Journal of Histochemistry and Cytochemistry*. For most of these people, short-term use of an over-the-counter antihistamine combined with avoiding the bothersome substance can ease the annoying symptoms.

The psychiatric manifestations of Lyme disease, one of the most common tick-borne illnesses, can be both profound and diverse. Clients may experience

### **MCAS can cause widespread, debilitating symptoms**

But in people with MCAS, the mast cells demonstrate an exaggerated and disproportionate release of chemical mediators across many systems of the body. The syndrome can cause widespread, debilitating symptoms that pop up suddenly, change from one day to the next, and shift in intensity. They also vary vastly from person to person. For example, one person may experience typical allergy symptoms like itchy skin, rashes, or swelling; another may encounter more food-related challenges, and a third may have every symptom in the book.



Furthermore, Lyme disease and fibromyalgia patients aren’t the only ones prone to mast cell involvement. It can also be found in people with idiopathic anaphylaxis (an anaphylactic reaction where the cause is unknown), interstitial cystitis (IC), and irritable bowel syndrome (IBS) due to the ability of the mast cells to generate chronic inflammation.



Researchers also speculate there could be a connection between MCAS and people who have postural orthostatic tachycardia syndrome (POTS) and the hereditary condition known as Ehlers-Danlos syndrome (EDS). But because this illness triad has several overlapping symptoms, it’s challenging for experts to determine which symptom is attributed to which disease.



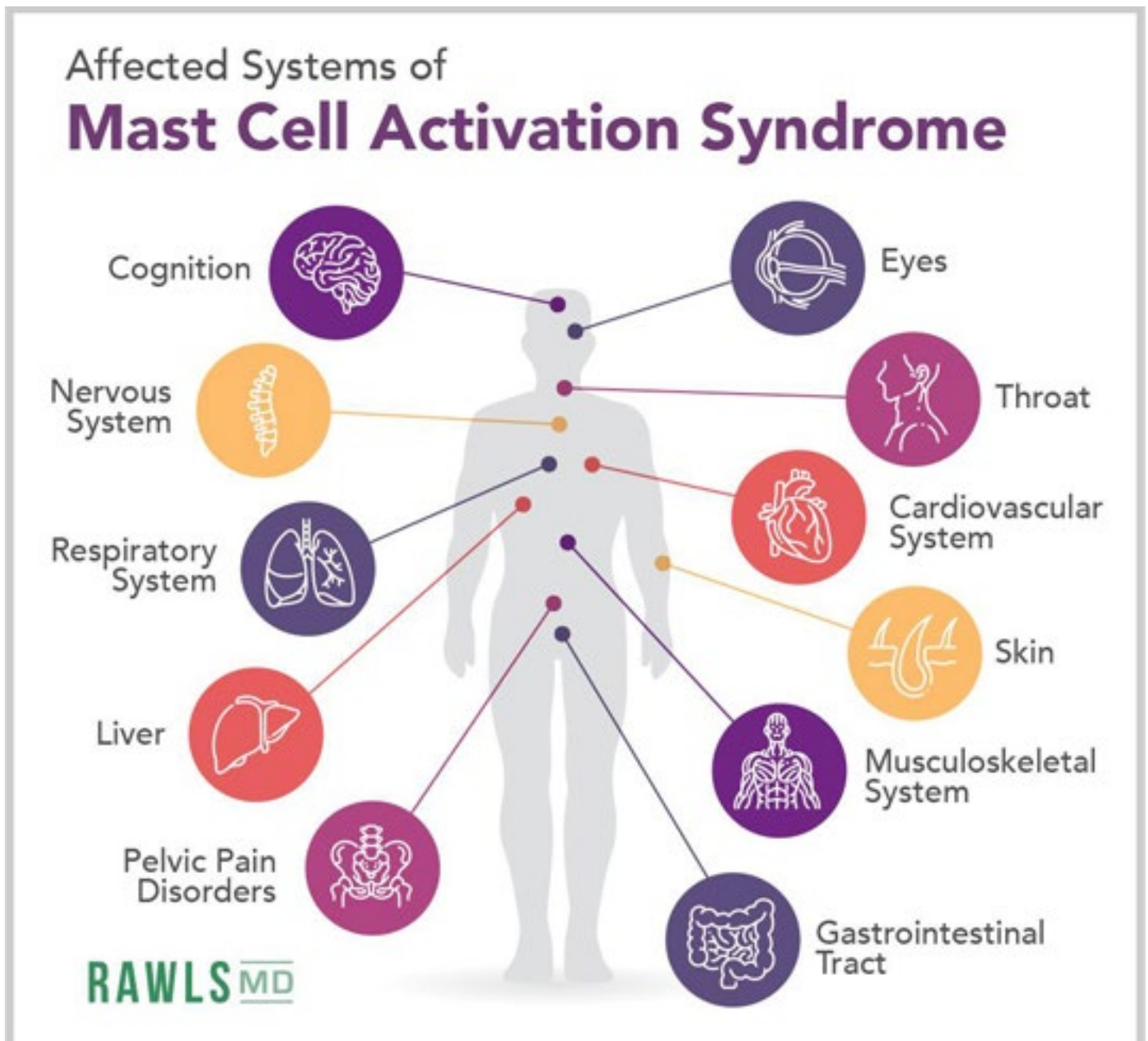


Furthermore, scientists conjecture there may be a link between people diagnosed with MCAS and the severity of acute COVID-19 illness and long COVID symptoms based upon the shared hyperinflammatory cytokine storm. Although this association has yet to be proven, it may provide new insights into treatment options for MCAS and the novel coronavirus if it holds up.

Since many chronic diseases are associated with excessive inflammation, we're probably just getting started with our understanding of the numerous conditions that may be connected to MCAS.

## MCAS Symptoms

MCAS may be a possible diagnosis when people are chronically ill, demonstrate signs and symptoms in multiple systems of the body, and have a primary diagnosis that doesn't account for a large part of their clinical presentation. In other words, if a person has a number of symptoms that fall outside the scope of their primary chronic illness diagnosis, they could be exhibiting signs of mast cell activation involvement.



The symptoms of MCAS can affect both children and adults. Occasionally, multiple family members can exhibit signs of the condition, pointing to a possible genetic component.

## THE SYSTEMS IMPACTED AND RELATED SYMPTOMS CAN INCLUDE ANY COMBINATION OF THE FOLLOWING:

- **GASTROINTESTINAL TRACT:** — abdominal pain, cramping, diarrhea, bloating, nausea, vomiting, difficulty digesting certain foods, food intolerances
- **MUSCULOSKELETAL SYSTEM:** — muscle and bone pain, migratory arthritis, muscle weakness
- **NERVOUS SYSTEM:** — nerve pain, headache, neuropathy, vertigo, tinnitus, insomnia, depression, anxiety
- **COGNITION:** — difficulty concentrating, reduced attention span, brain fog, trouble with memory
- **PELVIC PAIN DISORDERS:** — endometriosis, IC or painful bladder syndrome (PBS), vulvodynia
- **SKIN:** — itching, rashes, hives, inflammation, swelling, spider veins, flushing
- **EYES:** — inflammation of the eye or conjunctivitis, trouble focusing eyes, itchy and watery eyes
- **THROAT:** — a burning sensation, ulcers on the tongue or in the mouth
- **RESPIRATORY TRACT:** — coughing, wheezing, difficulty breathing, runny or stuffy nose, sneezing, sinus pain or pressure
- **LIVER:** — enlarged spleen, increased bilirubin levels, elevated liver enzymes, high cholesterol
- **CARDIOVASCULAR SYSTEM:** — rapid heart rate, abnormal blood pressures (either too high or too low), fainting
- **OTHER:** — fatigue, lethargy, fevers, anaphylaxis, chemical and environmental sensitivities

That's a giant list of symptoms! To make matters worse, standard lab tests or imaging may not reveal any abnormalities or clues to the underlying cause that's driving a hypersensitive mast cell process, making the diagnosis of MCAS all the more challenging to obtain.

## MCAS Testing and Diagnosis

The first diagnostic criteria for MCAS came from a group of international physicians in 2011, so the present knowledge about mast cell disorders is still in its infancy. Due to the complexity of the illness and lack of mainstream medical awareness, patients struggling with MCAS may find it difficult to obtain an accurate diagnosis, and they might see many specialists to no avail in the process of searching for relief.

However, more healthcare professionals are slowly becoming aware of the havoc an extreme and prolonged mast cell reaction can have on the body. The Mastocytosis Society, a nonprofit organization with a mission to provide support and resources to patients, contains a [Physician Database of medical professionals](#) who may be able to help you.

In many circumstances, a diagnosis of MCAS may be suspected based on a person's clinical presentation, lab work indicating the presence of histamine or other chemical mediators, response to medications, and the diagnosis or exclusion of overlapping diseases.

## Currently, there are three key diagnostic criteria for MCAS:

### 1. SYMPTOMATOLOGY

When discussing your condition with your doctors, it's crucial that you provide them with a detailed list of your symptoms. People who have MCAS tend to note symptoms that occur in two or more systems of the body at the same time; the symptoms can wax and wane or be chronic, and there's no known underlying cause for them.

### 2. DOCUMENTATION OF MAST CELL INVOLVEMENT

Your physician must be able to document that your symptoms are associated with mast cell activity and may order blood or urine tests to check for an increase in mediators like tryptase (an enzyme that's present in



allergic reactions), histamine, or prostaglandin levels. During a flare-up of MCAS, one or more of these mediators are apt to be elevated.

### 3. RESPONSE TO MEDICATIONS

You may be asked to track your response to medications that interfere with the release of mediators — namely histamine. A favorable response to drug therapy, meaning your symptoms lessen or resolve completely, points to some amount of mast cell activation as the culprit.

If you think you might have MCAS, a multi-faceted treatment approach centered around providing symptom relief, balancing the immune system, and searching for underlying factors will be of significant benefit to you.

### Underlying Causes and Triggers

To date, no single factor has been decided upon as a cause for MCAS, but researchers believe genetic variants play a role in who's likely to develop the syndrome. A study in the [peer-reviewed online journal, PLoS ONE](#), showed that 74 percent of people with MCAD had at least one first-degree relative with disorders affecting mast cells, adding further credence to the idea that there's a genetic component involved with MCAS.

Beyond genetics, immune dysfunction in people with chronic Lyme disease and other chronic illnesses is most likely a piece of the puzzle contributing to an unruly activation of mast cells. But what is the driving force behind the illness?

*“Various microbes associated with these illnesses manipulate the immune system and cause it to go haywire,”* explains Dr. Rawls.

*“Because the spectrum of microbes is different in every person, the types of symptoms are also different. It's not one microbe, but a disruption of the entire balance of the microbiome that is the most likely culprit.”*

Other pieces of the puzzle are the factors that allow troublemaking microbes deep in tissues of the body to flourish. Dr. Rawls calls them “cellular stress factors,” and they include a poor diet, toxins, stress, lack of movement, and poor sleep. When that microbial burden becomes too great, it tips your microbiome balance in the wrong direction and further disrupts immune function, driving inflammation and initiating symptom.

With MCAS, the immune system is stuck in high alert mode, so it shouldn't be surprising that more than one trigger can set off a response, and triggers may change over time.

### THE LIST OF SOME OF THE MORE COMMON TRIGGERS INCLUDES (BUT IS NOT LIMITED TO):

- Exposure to heat, cold, or abrupt changes in temperature
- Mental or physical stress
- Environmental factors like pollution, mold, pollen, and other toxins or allergens
- Food sensitivities
- Food and drinks containing bioactive amines, such as wine, beer, and fermented foods
- Foods high in naturally occurring histamines, including cured meats, aged cheese, and beans
- Over-the-counter and prescription medications like ibuprofen, opiates, antibiotics, local anesthetics, and contrast dyes used for imaging
- Exercise
- Scented products, whether natural or synthetic
- Exposure to chemicals
- Venomous bites like snakes, bees, wasps, spiders, and jellyfish
- Insect bites, including mosquitoes, flies, ants, and fleas
- Infections, whether bacterial, viral, fungal, or a combination of the three
- Hormonal fluctuations
- Irritants to the skin
- Sun exposure

## How to Cope with Mast Cell Activation Syndrome



“As with any illness, easing symptoms is important — H1 blockers, like antihistamines Benadryl and Claritin, and H2 blockers, like Pepcid and Tagamet, can provide relief in the short term,” says Dr. Rawls. Other types of medications that can ease symptoms include aspirin, mast cell stabilizers, leukotriene inhibitors, and monoclonal antibodies. Additionally, a clinical trial using the drug masitinib is set to wrap up in December 2022. Masitinib is in the category of drugs called tyrosine kinase inhibitors, and it regulates certain aspects of mast cell activity.

However, treating symptoms alone doesn't always produce a satisfactory solution. The reason: Over time, you can build up a tolerance to these drugs, requiring more potent medications like corticosteroids and immune blockers, which can lead to a whole host of undesirable side effects.

*“To treat the problem, you have to address the underlying causes,” says Dr. Rawls.*

Of the utmost importance is avoiding triggers that spark a flare-up of MCAS. Keep the list of common triggers handy and add any new ones you discover to your list. Implementing an elimination diet and keeping a daily log of your foods, activities, medications, and supplements, as well as the timing and nature of any symptoms you experience, is an incredibly useful way to identify things that could be problematic for you.



Keep tabs on your stress levels, too. Chronic stress is another factor that sends the immune system into high gear; herbs can be very beneficial here. Dr. Rawls recommends CBD (cannabidiol) from hemp, which has an overall calming and balancing effect on both the nervous system and the immune system. Other herbs such as motherwort, bacopa, and passionflower can also help bring about a sense of calm and minimize symptoms, as can learning and practicing relaxation techniques such as qigong, meditation, and yoga.

Additionally, environmental toxins in food, beverages, and the air we breathe can aggravate immune hypersensitivity or trigger reactions. Ways to curtail toxins include eating organic foods, filtering your water and air, and looking for sources of hidden toxins in your environment, especially mold, and cleaning them up. Furthermore, increasing your level of physical activity as your body allows enhances the body's natural detoxification abilities.

Herbal therapy is an effective way to manage the microbial load in the body without disrupting the normal flora in the gut microbiome, which is critical to digestive health.

All herbs have some antimicrobial properties; below are a few of the more powerful ones Dr. Rawls relies on most.

### **FOR SUPPRESSING OVERGROWTH OF MICROBES IN TISSUES AND COOLING DOWN A HYPERSTIMULATED IMMUNE SYSTEM**

- **Cat's claw**
- **Garlic**
- **Andrographis**
- **Berberine**
- **Japanese knotweed**

People with MCAS may also benefit from herbs that assist the body with reducing elevated histamine levels. Natural antihistamines like quercetin, bromelain, and stinging nettle can be helpful. Some patients also report relief by supplementing with diamine oxidase (DAO), a key enzyme responsible for the body's ability to metabolize and break down histamine.

A word of caution when starting herbs: People with MCAS can react to herbal therapies, too. To avoid

overtaxing your body, ease into an herbal protocol. Instead of taking several supplements at one time, choose one herb and see how your body tolerates it.

Through a bit of trial and error, you may find that you can only take an herb a couple of times a week instead of every day. Ultimately, tolerance to herbal therapies will vary from person to person; a crucial point to remember is to always start low and go slow with your dosing.

### **The Bottom Line**

From time to time, you may experience a flare-up of MCAS, where you're unable to pinpoint a cause, sending you into panic mode.

### **IN THOSE SITUATIONS, GO BACK TO THE BASICS:**

- **Use medications as needed for more immediate symptom relief.**
- **Arrange your schedule so that you have adequate time to rest and sleep.**
- **Take a look at your log from the last few days to see if you can spot the potential offender.**
- **Make adjustments to your diet and daily activities as needed to reduce the risk of further flare-ups.**

Sometimes, contending with a chronic illness of any kind can make you feel powerless. "Of course, genetics and aging play a part in this illness, but remember that you do have a measure of control over a few things. You can change what you eat. You can manage toxins. You can get out and move." Ultimately, do what you can to feel better now while also addressing long-term recovery.

At present, there is no one-size-fits-all approach to beating or treating MCAS, but by decreasing your microbial burden, monitoring your intake of high-histamine foods, making healthy lifestyle choices, managing stress, and cultivating good sleep, you can do a lot to stabilize mast cells and balance and nurture your immune system.

*Dr. Bill Rawls is a physician who overcame Lyme disease through natural herbal therapy. This article is republished from his website, [RawlsMD.com](http://RawlsMD.com).*



# Mast Cell – What To Eat When You Are Allergic To Everything

What worked for this suffering teen was a diet that was gluten-free, dairy-free, low in sugar, low histamine, medium-oxalate and low in sulfite

By Lonnie Marcum

**W**hat can you do when everything your child eats makes her sick? When my daughter was in the throes of mast cell activation syndrome (MCAS), virtually anything she put in her mouth triggered a serious allergic reaction. However, with the help of an excellent medical team and my daughter's determination to succeed, we found a path to healing. I'm sharing what we did in hopes that it can help others in the same boat.



## Calming the immune system

When trying to calm mast cells, the key is to reduce the number of flares. Eliminating triggers, lowering histamine levels, and getting on the right diet and the right medication(s) are critical. Every time you have an allergic reaction, it reactivates the mast cells. This domino effect makes the body more sensitive to even minor triggers. The more you can lower your histamine levels and the longer you can go without an allergic-type reaction, the calmer the

immune system becomes. In our experience, if you can go three months without a reaction, you are on the road to healing.

**Here’s how my daughter got past her extreme food sensitivities.**

**Food Crisis 101**

At the beginning of this MCAS journey, our routine was very stringent. Once we found the right combination of antihistamines, and she went three months without an allergic reaction, we found we could relax a little.

In my daughter’s case, the foods we chose were specific for her genetics and their high nutritional value. Her diet is also gluten-free, dairy-free, low in sugar, low-histamine, medium-oxalate, and low in sulfites. Depending on your specific needs, you may not need to eliminate all of the above ingredients, or you may need to eliminate these plus others —like foods high in salicylate, a chemical found naturally in certain foods.

The key for us was to make everything from fresh,

wholesome, organic ingredients and fresh frozen organic meats. For example, buy organic chicken, cut and freeze in serving size packets. (I do one week’s worth at a time).

During her crisis, we went with frequent small meals. Because the act of chewing and digesting requires histamine, smaller meals were less triggering. We also eliminated all leftovers, because “aged” foods are higher in bacteria, higher in histamine and will trigger more mast cell reactions. As things improved, I cooked two meals at a time. She’d eat one immediately, I’d refrigerate the other in a glass container (no plastics), and she’d eat the next meal within 3-5 hours. (This allowed me to get other things done.) We also made sure each meal contained one protein, one carbohydrate and at least one fruit or vegetable which we rotated.

The following are a few suggestions of low-histamine foods that we rotated every three to four days during my daughter’s food crisis. Keep in mind if you are adding new foods the name of the game is low-and-slow.

**Low Histamine Guidelines (adapted from SIGHI)**

AVOID	RISKY	RECOMMENDED
<ul style="list-style-type: none"> <li>• Fermented products (e.g. alcoholic beverages, vinegar, yeast, bacteria)</li> <li>• Produce with uncertain freshness (e.g. packaged chopped lettuce, bean sprouts)</li> <li>• Canned, finished or semi-finished products (e.g. canned tuna, meal kits)</li> <li>• Reheated food (especially fish, meat and mushroom dishes)</li> </ul>	<ul style="list-style-type: none"> <li>• Meals from restaurants, snack bars, fast food (due to potential cross contamination of ingredients, uncertain freshness, and uncertain storage time)</li> </ul>	<ul style="list-style-type: none"> <li>• Wholesome, fresh, unprocessed or lightly processed foods.</li> <li>• The more perishable and protein-rich the food, the more important it’s freshness (e.g. fish that is caught, cleaned and flash frozen at sea, then refrigerated uninterruptedly until cooked is best)</li> <li>• Leftovers must be refrigerated immediately and eaten within hours or frozen.</li> </ul>

## This is what worked for us:

### BREAKFAST

- Gluten-free oatmeal, quinoa, or white rice with a dash of coconut milk or coconut oil
- Apple, blueberry, nectarine, or peach (baked is easier for her to tolerate)

### LUNCH

- Sautéed meat in extra virgin olive oil (EVOO) with seasonings
- Gluten-free brown rice noodles or quinoa noodles
- Boiled carrots, cauliflower, broccoli, or peas (I throw them in with the noodles)

### SNACK

- Baked pumpkin or sunflower seeds (soak 6-8 hours, rinse, bake in EVOO at 300 degrees for 15-25 minutes, until done)

### DINNER

- Baked meat, coated in EVOO\* and seasonings\*\*
- Baked butternut, acorn, or summer squash; sweet potato (the white one)
- Sautéed arugula, asparagus, butter lettuce, or watercress

\* I use our homegrown certified 100% extra virgin olive oil to sauté or bake everything (beware of fake EVOO that may contain mast cell triggers). If you are salicylate-intolerant, you may have trouble with EVOO. Coconut oil and nigella sativa oil (black seed oil) are also recommended.

\*\* Seasonings: Sea salt, pink pepper, ginger, chives, garlic (small amounts), basil, parsley, thyme, rosemary, and sage (dehydrated herbs are more tolerable when in a crisis.)

**Note:** I am not a doctor. Food allergies are unique to each individual, so it's important that you work closely with your doctor or a registered dietitian to find and eliminate your food triggers and then design a balanced plan that works for you.

#### References:

1. MSIGHI-Leaflet Histamine Elimination Diet Simplified histamine elimination diet for histamine intolerance (DAO degradation disorder). [http://www.histaminintoleranz.ch/downloads/SIGHI-Leaflet\\_HistamineEliminationDiet.pdf](http://www.histaminintoleranz.ch/downloads/SIGHI-Leaflet_HistamineEliminationDiet.pdf)
2. Swiss Interest Group Histamine Intolerance (SIGHI) Food Compatibility List. [https://www.mastzellaktivierung.info/downloads/foodlist/21\\_FoodList\\_EN\\_alphabetic\\_withCateg.pdf](https://www.mastzellaktivierung.info/downloads/foodlist/21_FoodList_EN_alphabetic_withCateg.pdf)
3. MastCell360 Low Histamine Foods List for MCAS and Histamine Intolerance. <https://mastcell360.com/low-histamine-foods-list/>

Lonnie Marcum is a physical therapist and mother of a daughter with Lyme. She served two terms on a subcommittee of the federal Tick-Borne Disease Working Group. Follow her on Twitter: [@LonnieRhea](https://twitter.com/LonnieRhea)  
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# Nine Treatments for Mast Cell Activation Syndrome

Managing MCAS requires a trial-and-error approach; experimenting with these suggestions to see what works best for you

*By Jill Carnahan, MD*

**W**hile there is no cure for MCAS, that certainly doesn't mean you're simply at the mercy of your misbehaving mast cells. There are a number of tools you can put into place that can work in conjunction to minimize or even eradicate symptoms and help restore balance to your immune system.

Because each person grappling with MCAS is unique, there is no one-size-fits-all treatment strategy. Rather, managing MCAS requires a trial-and-error



approach – experimenting with different treatments and lifestyle tweaks to see what works best for you.

**SO IF YOU'RE TRYING TO FIND RELIEF FROM MCAS SYMPTOMS, HERE'S WHAT I RECOMMEND:**

## TREATMENT 1:

### Eat a Low-Histamine Diet

Histamine is one of the primary pro-inflammatory mediators released when mast cells degranulate. So, getting your histamine levels under control is a top priority. One way to do this is by following a “low-histamine diet” – an elimination diet that aims to minimize the amount of histamine you ingest from foods and beverages.

While reducing high-histamine foods can be helpful, the best way to truly identify and track which foods may be a trigger, is to keep a daily log of what you’re eating and drinking and the severity of your symptoms. This will help you identify any patterns and more easily recognize foods that may be contributing to your symptoms. As someone who’s had to work through my own personal food sensitivities, I promise taking the time to get to the bottom of this is worth it.

## TREATMENT 2:

### Use a DAO Enzyme Supplement

Diamine oxidase (DAO) is the main enzyme responsible for degrading histamine. However, if you’re not producing enough of this crucial enzyme, histamine can begin to accumulate and run amok – triggering many of the symptoms associated with MCAS.



That’s where DAO supplements come in. DAO supplements increase the DAO levels in the digestive tract – reducing the level of histamine entering the bloodstream and floating around in your body which can provide some relief from the symptoms associated with histamine overload.

There are a number of DAO supplements available over the counter, but be careful – ordering from Amazon may be convenient, but it’s also where fake and/or poor quality supplements run galore. (See [my website](#) for supplements I approve of.)

## TREATMENT 3:

### Incorporate Antihistamines and Mast Cell Stabilizers

While DAO supplements are excellent for reducing the amount of histamine absorbed from the food you ingest, these mighty supplements are unable to enter your bloodstream to reduce the amount of histamine produced within your body. This means that excess histamine produced by your own cells needs to be addressed by other methods. Which is where natural antihistamines and mast cell stabilizers can be useful:



### ANTIHISTAMINES:

These compounds bind to histamine receptors – essentially blocking histamine from binding to receptors and triggering symptoms. You’ve likely heard of the common over-the-counter antihistamine Benadryl which can be great for immediate relief but can also cause you to build tolerance and require more and more to get the same relief. **Some better options to focus on are natural sources of antihistamines like:**



- Vitamin C
- Stinging nettle
- Butterbur
- Bromelain
- Local raw honey
- Probiotics
- Astragalus

**These natural antihistamines can help soothe symptoms and naturally reduce histamine levels.**

## MAST CELL STABILIZERS:

Mast cell stabilizers prevent degranulation and stabilize your mast cells. **A few well-known, natural compounds that exhibit mast cell stabilizing activities include:**

- Quercetin
- Resveratrol
- Luteolin
- Curcumin

But the truth is, having to take a conglomeration of antihistamines and mast cell stabilizers (on top of potential DAO supplements) can get expensive and overwhelming. To get relief without the expense or headache, I recommend a blend of flavonoids, antioxidants, enzymes, and botanicals that can help block histamine and stabilize your mast cells – providing you with comprehensive support for relief from MCAS symptoms.

## TREATMENT 4:

### Identify Sources of Toxins

There is no single factor that has been shown as the definitive cause of MCAS. However, various microbes can disrupt the immune system and cause mast cells to go haywire. Two major environmental triggers of MCAS include mold and an elevated overall toxic burden.

If you're struggling with MCAS, it's absolutely essential to reduce the body's microbial and toxic burden. This typically requires a thorough assessment of your environment as well as making some adjustments to your lifestyle to minimize exposure to mold and other environmental toxins.



## TREATMENT 5:

### Increase Exercise & Sweating

Once you minimize the inflow of toxins or triggers, you can take steps to mobilize toxins and enhance toxic outflow. One of the best ways to “distress” the toxins in your body is to get the blood pumping through exercise and sweating.

While it may not remove all pollutants, there are studies that show sweating is an effective and safe method for removal of toxic compounds that can accumulate within your body such as: arsenic, cadmium, lead, mercury, phthalates, and bisphenol A (BPA).

To work up a sweat and boost your detoxification, aim for at least 30 minutes of moderate exercise every day or incorporate regular infrared sauna sessions.



## TREATMENT 6:

### Promote Good Gut Health

The health of your gut and the composition of your gut microbiome play an intricate role in your immune system thanks to a channel known as the gut-immune axis. This bidirectional communication network allows your gut to directly communicate with and influence your immune system and vice versa. Pair that with the fact that a large percentage of your immune cells are housed within your digestive tract in what's known as gut-associated lymphoid tissue and it's easy to see how poor gut health can lead to an off-kilter immune system.



So ensuring your gut is happy, healthy, and balanced is a key piece of the puzzle when it comes to calming hyperactive mast cells. Some ways to support the health of your gut include:

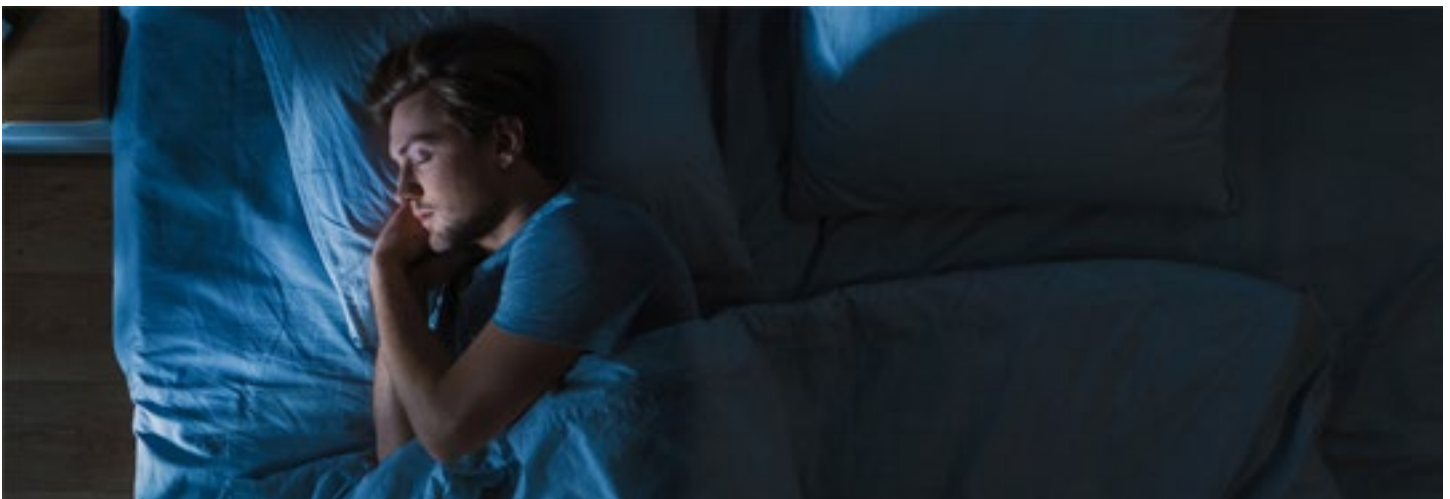
- Reintroduce a variety of beneficial gut microbes to support a diverse and flourishing microbiome with the use of probiotics.
- Give your gut the nutrients it needs to build a strong gut barrier so it can keep pathogens, toxins, and wastes sealed up tight in your intestines where they can be properly excreted.
- Eat a well-rounded, healthy diet full of microbiome-supporting foods. Eating plenty of quality protein and healthy fats paired with slow-digesting carbs will help fuel beneficial bacteria while starving out harmful bacteria. It's also helpful to opt for organic foods whenever possible to avoid ingesting microbiome-disrupting pesticides and chemicals.

If you're looking to soothe your mast cells and restore calm to your immune system, you simply can't afford to ignore your gut health.

## TREATMENT 7:

### Get Enough Sleep

In a world that idolizes intense productivity and doing “all the things,” it's tempting to sacrifice sleep. But doing so can upset the circadian clock of mast cells. Yes, you read that right, mast cells do indeed have a circadian rhythm – meaning your mast cells are more reactive during certain times of the day and less reactive during others.



This is why many people with allergies report experiencing “morning attacks” or sleep disruptions. Studies have found that serum mast cell histamine levels were lower in the afternoon and highest at night. So, if your circadian rhythm gets thrown off with irregular sleep patterns or poor sleep quality, mast cells can lose their own rhythmicity. This circadian rhythm disruption can cause mediator release to become uniform throughout the day and contribute to your mast cells’ overzealous response.

Thus, cultivating a good, regular sleep schedule and sticking to it can help keep your mast cells in check.

In a world that idolizes intense productivity and doing “all the things,” it’s tempting to sacrifice sleep. But doing so can upset the circadian clock of mast cells. Yes, you read that right, mast cells do indeed have a circadian rhythm – meaning your mast cells are more reactive during certain times of the day and less reactive during others.

## TREATMENT 8:

### Reduce Stress

Chronic stress can kick your immune system into overdrive and allow troublemaking microbes to flourish. Stress can also contribute to mast cell degranulation, which causes them to release mediators like histamine. It only makes sense, then, for patients with MCAS to minimize stress as much as possible.

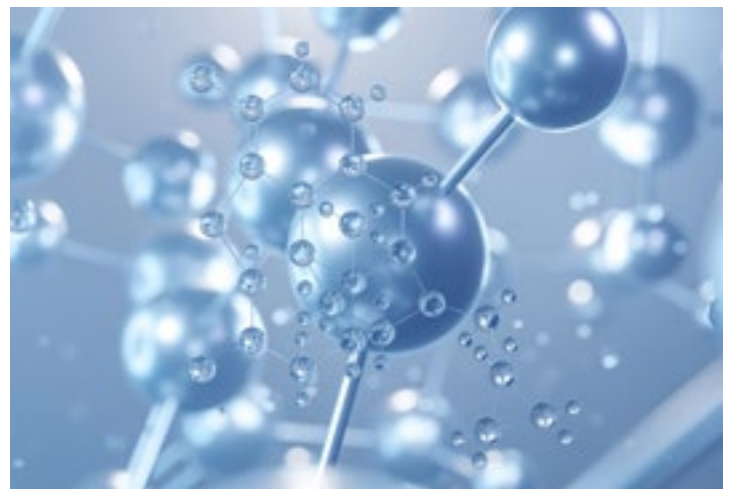


Because triggers for MCAS can be wide-ranging and unique to each individual, it can be helpful to keep a daily journal of any emotions, events, or activities that trigger your symptoms. And remember, the devil is in the details – if you suspect that you are suffering from MCAS, it’s crucial that you create a detailed list of triggers and symptoms to create an effective strategy to minimize your symptoms.

## TREATMENT 9:

### Low-Dose Naltrexone – The Surprising Newcomer

Even with all the treatment methods outlined above, some people may continue to struggle with MCAS symptoms. Recent research shows that a novel use of a medication known as low-dose naltrexone (LDN) may be able to help. At first glance, LDN may seem like a strange drug of choice for the treatment of MCAS – especially considering naltrexone is a drug that was approved to help prevent narcotics and alcoholics from relapsing.



As an opiate antagonist, naltrexone competes with opioid drugs for real estate on opiate and endorphin receptors. This helps patients feel less “high” from opioids or alcohol and reduces cravings. So how on earth does blocking opiate/endorphin receptors help MCAS patients?

You see, low doses of naltrexone essentially trick your body into producing more endorphins – the “feel good” chemical that is released during exercise. The influx of these natural endorphins stimulates your immune system by binding to regulatory T cells, which promotes an increase in T-lymphocytes. This upregulation of T-lymphocytes reduces cytokine and antibody production, restoring a more normal balance while pumping the brakes on overall inflammation.

## So, Can Low-Dose Naltrexone Treat Mast Cell Activation Syndrome?

Is low-dose naltrexone the inexpensive, safe, and effective therapy for MCAS we've been looking for all along? Of course, we'll need more evidence, but based on the evidence so far, it appears that LDN has the potential to treat a wide variety of conditions – MCAS included.

If you've been diagnosed with MCAS or are concerned you may be experiencing symptoms associated with hypersensitive mast cells, I cannot overemphasize the importance of working with an experienced integrative and functional medicine practitioner. They can help you pinpoint the root of your symptoms, identify

contributing triggers, and help you come up with a comprehensive plan to not only manage symptoms, but heal any imbalances at the source.

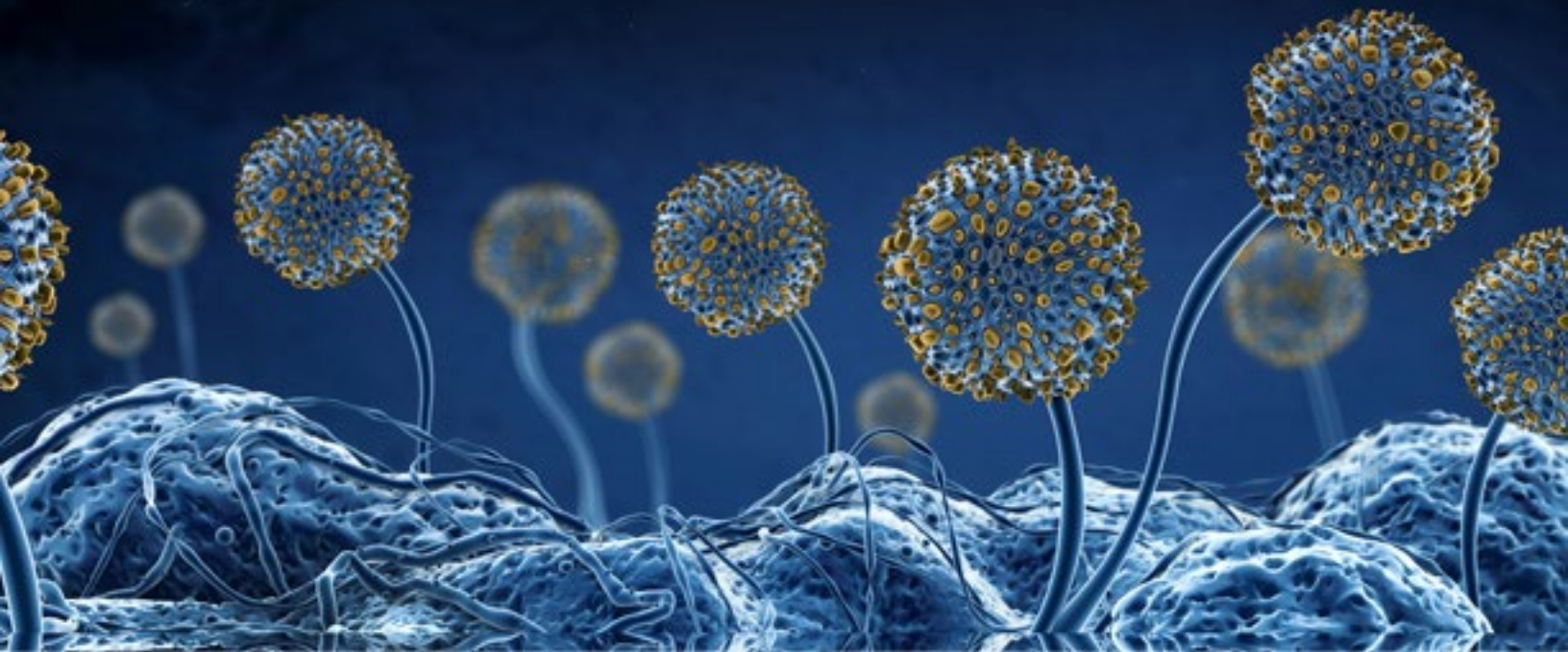


## Are You Concerned About Mast Cell Activation Syndrome?

Living with a chronic illness like MCAS can feel discouraging, frightening, and isolating. But there are things you can control. With the right strategies and combination of medications, supplements, and lifestyle tweaks, you can absolutely stabilize mast cells and bring balance to your immune system.

If you're grappling with MCAS or any other complex illness or if you're searching for answers to the barrage of unexplained symptoms you're experiencing, the future can seem bleak at times. But please know that you are not alone and there is hope for healing. If you're in a dark or challenging place right now, I've been there too – and I want to help you find your way back to health, happiness, and hope.

*Dr. Jill Carnahan is the founder and medical director of Flatiron Functional Medicine in Louisville, Colorado. Her [website](#), [blog](#), and [YouTube](#) channel offer resources for MCAS, Lyme disease, and other health conditions.*



# What's the Connection Between Mold Illness and MCAS?

Chronic mold exposure can lead to ongoing inflammation and a faulty immune response

By Tania Dempsey, MD

**M**old is a common problem in many households, yet it's often overlooked. It's more than a minor annoyance or cosmetic issue. Mold can have a serious impact on your health. It may disrupt your immune system, create chronic inflammation, and cause chronic symptoms, including allergies, respiratory symptoms, fatigue, brain fog, migraines, digestive complaints, and other chronic symptoms.

Chronic mold exposure may also result in overactive mast cells. The combination of mold toxicity and mast cell activation syndrome (MCAS) can wreak havoc on your entire body and lead to chronic, and sometimes debilitating, health issues. It doesn't have to be this way.

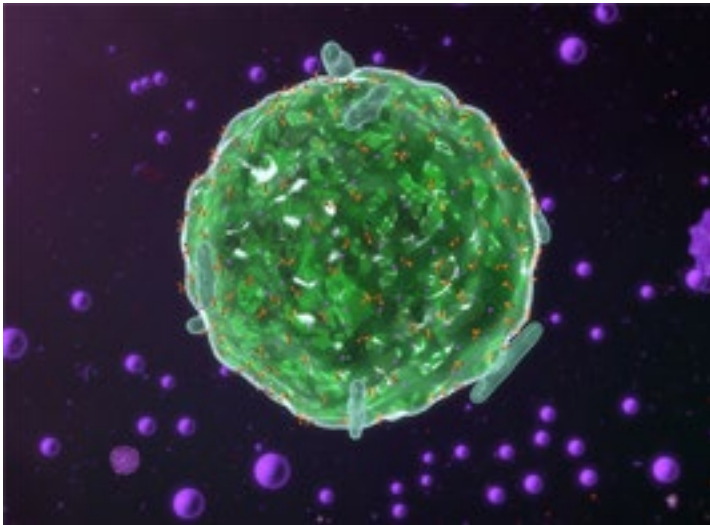


## Mold and Mast Cell Activation Syndrome

Mast cells are there to protect your body from harm. When they are triggered by toxins or pathogens, they will alert your immune system about the danger, which will lead to the release of various inflammatory mediators, such as histamine. This is what happens when mold mycotoxins enter your body.



Your mast cells will get triggered, which will lead to the release of various chemicals that, for some, may include histamine, leukotrienes, or other mediators and cytokines to protect you from harm. Under normal circumstances, this is a good thing. Your mast cells are doing their job trying to protect you from danger.



However, if you are experiencing chronic mold exposure from living in a home with mold in your bathroom or behind your wallpapers, working in a mold-infested building, or being exposed to mold on a daily basis for any other reason, it can turn into a serious issue. Chronic mold exposure means chronic mycotoxin exposure, causing your immune system to be on high alert at all times to protect you from ongoing danger.

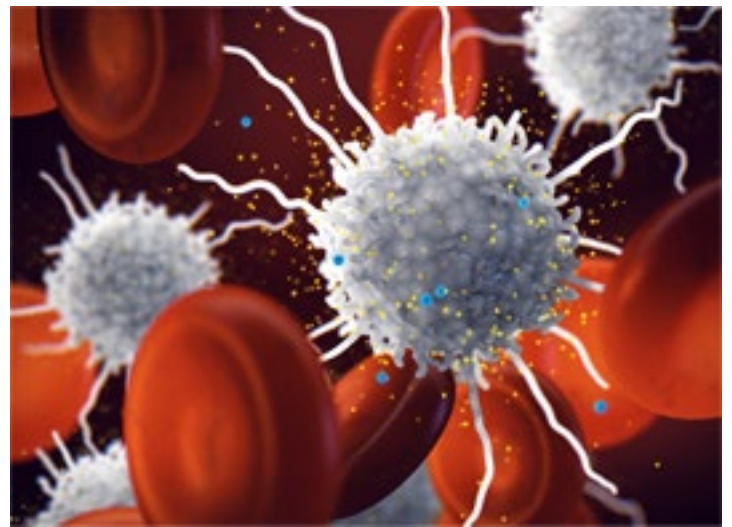
This can lead to ongoing inflammation and a faulty immune response with ongoing mast cell activation and overproduction of histamine and/or other chemicals. According to a 2018 study published in the *Journal of Regulators and Homeostatic Agents*, mold may trigger a mast cell-cytokine immune response aggravating asthma, respiratory issues, headaches, brain fog, nausea, and fatigue.

For some patients, when there is ongoing mast cell activation, it may make it increasingly difficult for your body to take care of excess histamine. As a result, you may develop histamine intolerance and related symptoms. Symptoms of MCAS and histamine intolerance may both mimic symptoms of mold illness.

## Cell Danger Response, Mold, and Mast Cells

In addition to increased mast cell activation, your body may also enter something called the Cell Danger Response (CDR) to protect you from mold toxicity. The role of the CDR is to guard your individual cells against any cellular threat or harm.

The CDR is a major shift in your physiology. It changes your body from cellular energy production and cellular metabolism to cellular defense. This means that the CDR will move your body from a fight-or-flight to a freeze mode, shutting various important pathways down in your body to stop the mold from spreading and harming you.



While the CDR is a very important part of your body's cycle of fighting and protecting you from harm, a chronic CDR state can turn into a problem. Chronic mold exposure may overwhelm your body and lead to ongoing CDR, causing a variety of chronic health issues. Chronic CDR may also further increase mast cell activation, histamine intolerance, and chronic symptoms and health issues. As you see, chronic mold toxicity, mycotoxin illness, chronic inflammation, CDR, and mast cell activation, may result in a vicious cycle unless you address all underlying issues.

## What can you do to protect yourself or improve your symptoms from chronic mold exposure?

### 1. CHECK YOUR HOME FOR MOLD

If you are experiencing symptoms of mold toxicity, it's critical that you look for signs of mold in your home. Even if you don't have any symptoms of mold illness, I recommend checking your home regularly for mold, and water-damaged areas to prevent future health issues.

#### SIGNS OF MOLD YOU CAN LOOK FOR MAY INCLUDE:

- General musty smell in your home
- Rotten or musty odor coming from the floor or the walls
- Black, grey, pink spots in your bathroom between the tiles, in the toilet or shower or on the wall
- Spots, spores, fuzz, or other signs on your furniture, under your rugs or carpeting, or on your clothes
- Bubbling paint
- Discoloration on ceiling
- Peeling or warped wallpaper
- Spotted walls
- Black spots on your AC
- Musty smell coming from your AC
- Past or present water leakage issues or water damage (e.g., flooded sink or toilet, leaky water tank, moisture in your water heater closet, or flooding in the basement)

You can buy some home testing kits online to test for mold, but you might want to consider working with a mold remediation specialist to check your home for mold.

### 2. REMEDIATE MOLD FROM YOUR HOME

While living in a mold-free home would be ideal, it is very difficult to rid your environment completely of all mold and mycotoxins. Mold issues can pop up from leakage, water damage issues, and other moisture problems. I recommend working with a professional mold remediation specialist to help find, identify, and professionally remove mold from your home. What's even more important is to reduce the risk of mold exposure and mold-related issues.

### 3. REDUCE THE RISK OF MOLD EXPOSURE AT HOME

Addressing any underlying issues that may drive mold can seriously reduce mold growth and mold exposure.

#### HERE IS WHAT I RECOMMEND:

- Check for mold issues regularly and use cleaning products designed for mold.
- Remove old carpeting, rugs, wallpaper, or paint that has had water damage
- Clean or dispose of any moldy items, including shower curtains or clothing.
- Fix moisture leaks and water damage issues.
- Make sure to wipe down the tiles after showering or taking a bath.
- Keep indoor humidity ideally between 30 and 50 percent.
- Use a high-quality indoor air filtration system.
- Make sure your home is well-ventilated.
- Try to hang your wet clothes outside instead of indoors or use your drier.
- Keep the detergent compartment of your washing machine open.



- Keep mold off your indoor plants, check them regularly for mold issues.
- Check your food for mold and avoid eating moldy food.
- Clean and repair the roof gutters of your home.
- Direct any rain or melted snow or ice away from your house.
- Check for signs of mold growth regularly and address any mold immediately.
- If uncertain, use a mold home test kit or call a specialist for a mold check.

#### 4. REDUCE YOUR RISK OF MOLD EXPOSURE AT WORK

Unfortunately, mold exposure at work is common, but it's the most difficult to control. You can be unknowingly exposed to mold at work. You should be on the lookout for mold and consider finding solutions to deal with it.

If possible, use a small high-quality air filtration system at your office or workspace. If there are on-

going mold issues or you are experiencing increased mold-related symptoms at work, you may need to consider looking for a new job or a new office to work out of.

#### 5. GET TESTED FOR MOLD ILLNESS WITH YOUR DOCTOR

If you have been exposed to mold or are experiencing symptoms of mold toxicity or MCAS, it is important to get tested for mold illness. I recommend working with an integrative medicine practitioner who is well-versed in both mold and mast cell activation syndrome.

#### 6. DETOXIFY FROM MOLD

Detoxify your body from mold and other toxins. Support hydration and detoxification through sweating and urine by drinking enough water throughout the day, at least 10 glasses. For those that can tolerate it, even a low level of exercise can help support the detoxification process, but if you have symptoms of post-exertional malaise, it is best to consult your medical provider about what is right for you. Some patients find infrared sauna helpful in encouraging detoxification through sweating but for those who are heat intolerant, it can be a trigger for MCAS, so I would recommend avoiding it.

#### 7. FOLLOW AN ANTI-INFLAMMATORY DIET

I recommend following the “Dempsey Diet.” This is an anti-inflammatory, nutrient-dense food plan. Remove inflammatory foods, including refined sugar, refined oils, additives, artificial ingredients, and highly processed foods. When possible, follow a nutrient-dense diet focusing on good quality, grass-fed or pastured meat and poultry, and low-carbohydrate vegetables and greens. Choose organic options whenever available.



In general, avoiding sugar and limiting fruit and starchy carbohydrates is helpful for MCAS and other chronic conditions I treat. Some patients find that lowering the intake of histamine in the diet is helpful. However, it doesn't work for everyone and, in some cases, can make things worse. To further support your gut and microbiome health, I would consider taking a high-quality probiotic supplement.

These are general dietary recommendations. Depending on your personal health issues, allergies, sensitivities, and preferences, you may need some modifications. My best recommendation is to an integrative medicine practitioner for personalized recommendations.

## 8. REMOVE OTHER MAST CELL TRIGGERS BEYOND MOLD

Mold is not the only trigger of mast cell activation. Other common triggers include allergens, toxins, chemicals, heavy metals, viruses, bacteria, parasites, and stress. Moreover, when we talk about mold as a potential mast cell trigger, we are not only talking about mold in our environment but also internal mold and fungal infections, such as Candida overgrowth. These internal fungi can also cause mycotoxin release and mycotoxin illness. Treating the underlying infection or fungal overgrowth can reduce your exposure to these mast cell triggers and may help to reduce your chronic symptoms.



Avoid chemicals, heavy metals, and other environmental toxins. Instead of using chemical-filled conventional cleaning, hygiene, body, and beauty products, choose organic, natural, and homemade alternatives. Reduce the use of plastics, especially BPA. There are great alternatives for plastic made from glass, wood, bamboo, organic cotton, and other natural materials based on your needs.

Use a high-quality indoor air-filtration system for better indoor air quality. Drink purified, filtered water to avoid toxins from city tap water or well water. Choose organic food whenever possible. Reduce stress.

### Next Steps

If you are experiencing symptoms of mold illness, MCAS, or other chronic health issues, working with a functional or integrative medicine practitioner is one of the best ways to find the underlying causes of your symptoms and find the right treatment plan.

*Dr. Tania Dempsey founded the AIM Center for Personalized Medicine in Westchester County, New York, where she specializes in treating MCAS, Lyme, and other complex diseases. This article is republished from her website [DrTaniaDempsey.com](http://DrTaniaDempsey.com).*



# Are Hidden Ingredients in Pills Making You Sicker?

Excipients — every ingredient in a medication that isn't the active drug — can cause severe MCAS reactions in some people

*By Lonnie Marcum*

Seven years ago, when my daughter's health was precipitously declining, we found out she was allergic to microcrystalline cellulose (MCC)—one of the most common fillers in medications and supplements. It turned out that everything we'd been doing to try to help her was in fact sabotaging her recovery.

Just two months prior to that discovery, she had been diagnosed with mast cell activation syndrome (MCAS). This followed a lengthy illness and treatment for Lyme, Ehrlichia and Bartonella. Despite treatment, her health continued to deteriorate. It was the most



her illness. Come to find out, reactions to medications are very common in patients with MCAS.

However, according to Dr. Lawrence Afrin, a specialist in hematology and mast cell disease, it's not usually the medications themselves that are the problem. Instead, MCAS patients are more likely to react to one or more of the “inactive” ingredients — the fillers, binders, dyes, or preservatives in their medications — known as excipients. (Only a handful of medications — as

opposed to their excipients — are known to trigger mast cells. These include some antibiotics and all SSRI anti-depressants.) At the time, I'd never even heard of excipients in medications, let alone MCC.

## What Are Excipients?

Every ingredient in a medication that isn't the active drug itself is labeled as an "excipient." Ideally, excipients are inert and have no pharmacological effect. But there have been growing reports of adverse reactions to these extra ingredients.

Excipients can range anywhere from simple organic ingredients (like corn starch or sugar) to more complex substances with potential for toxicity at higher doses or after prolonged use (like dextran or polyethylene glycol.)

## Here's how we figured out my daughter was allergic to MCC.

In the Fall of 2016, she had developed sensitivities to multiple chemicals and could eat only two foods without having an allergic reaction.

Thankfully, one of her doctors thought to question what fillers were being used in one of her medications — ketotifen, a mast cell stabilizer. I called the pharmacy and was told the prescription contained two ingredients: ketotifen and lactose. That hit me like a ton of bricks. She'd been lactose-intolerant for years! I felt angry and relieved all at once. Had we found the missing piece of the puzzle?

Later that day, her doctor called in the prescription for ketotifen with the request to use ascorbic acid (Vitamin C) as the filler. After picking up the new prescription, out of caution, I only gave her a half dose — and she had an allergic reaction. What was going on? Long story short, the pharmacy screwed up and used MCC instead.

**That day, I emailed Dr. Afrin, who had assisted me in finding a MCAS doctor in California. He replied:**

*"Yes, I've seen microcrystalline cellulose (MCC) act as a trigger in \*some\* mast cell patients. Sometimes it's any type of MCC, and sometimes it's specific to the type of plant from which the cellulose has been sourced. For example, some MCAS patients are sensitive to*

*cotton-derived MCC but not wood-derived MCC, whereas others are sensitive to wood-derived MCC but not cotton-derived MCC. (And there are plenty of other potential types of plant sources for MCC, too.)"*

I was not happy. But at least we had determined that she had a problem with MCC—something we hadn't even thought about before. I quickly went to the cupboard and discovered that every single one of her vitamins and supplements contained MCC. Without realizing it, we had been undermining our own efforts the entire time!

## Steps for Discovery

At that point, we'd just assembled a team of doctors who were very knowledgeable about MCAS. Under the guidance of this care team, we switched to a PCAB-certified custom compounding pharmacy with experience in MCAS patients. (PCAB is the Pharmacy Compounding Accreditation Board. Compounding pharmacies tailor the medication to a patient's personalized needs. They can add or subtract ingredients as the prescribing doctor specifies.)

## Here are steps we took to rule out any further allergies to her medications:

### STEP 1:

We had the pharmacy send us samples of two types of empty pill capsules. Hard capsules come in either vegetarian or gel capsules. Because the vegetarian capsules are made with cellulose, we opted to try the gel capsule first and she was fine. (Note: gel caps are made from animal products. So, if you have alpha-gal syndrome or are allergic to meat, stay with the vegetarian options.)



## STEP 2:

We had the pharmacy send three gel caps with three different types of fillers that are considered mast cell stabilizers or histamine reducers: ascorbic acid (Vit C), sodium bicarbonate (baking soda), and mango powder. (Other filler options included rice powder, ginger root powder and acidophilus.)



## STEP 3:

Once we determined she was okay with ascorbic acid in the gel cap, we had the pharmacy custom compound her medications accordingly.



That is how we have done all her prescription medications and supplements since — and it has worked well for us.

## Alternate Discovery Method

Another way to determine what you're reacting to is to enlist the aid of your pharmacist. Unlike over-the-counter medications, where the FDA requires every ingredient to be on the label, excipients are not listed on prescription medications.

Because of this, you must ask the pharmacist to do an internet search to discover all the ingredients and excipients in the medication you had an adverse reaction to.

Next you will need them to make a list of everything in a medication that you are okay with. From there, you will need to compare the differences between them and try to determine what gave you the adverse reaction.

One thing to keep in mind is that excipients can vary between brand name and generic medications. So, if you are taking a brand name medication and then switch to the generic, you may be able to quickly determine the culprit.

And just because you are okay with one generic brand doesn't mean you will tolerate the next one. Generic manufacturers are allowed to change formulations, whereas the patented name brand medication must remain consistent.

## What Is the Role of Excipients?

Another way to determine what you're reacting to is to enlist the aid of your pharmacist. Unlike over-the-counter medications, where the FDA requires every ingredient to be on the label, excipients are not listed on prescription medications.



Excipients are derived from either organic or inorganic chemicals and have different purposes. Primarily, they are used to enhance the manufacturing and proper absorption of a medication. Currently, there are nearly 14,000 different excipients listed on the FDA's [Inactive Ingredient Data Base](#).

In general, medications that are formed into hard tablets have more excipients than those in capsules. Because the active ingredient is often measured in micrograms (think grains of salt), the medication will be diluted along with a filler, so it can be more easily packaged and administered. In some pills, up to 90% of the volume can be excipients.

### The following excipients have also been reported to cause adverse reactions:

- **annatto** (yellow food dye, derived from achiote tree)
- **aspartame** (artificial sweetener)
- **benzoates & benzyl alcohol** (derived from tar oil)
- **carmine** (natural red #4, derived from dried insects)
- **casein, lactitol & lactose** (derived from dairy)
- **cellulose** (corn, cotton, various trees, wheat)
- **oleic acid** (fatty acid derived from animal or vegetable fats)
- **propylene glycol** (product of ethylene oxide gas)
- **sulfites** (used as a preservative)
- **saccharin** (artificial sweetener)
- **soya lecithin** (derived from soy)
- **sorbitan trioleate** (derived from sorbitol)
- **tartrazine** (FD&C yellow #5, synthetic)

Bottom line, if you're having frequent reactions to medications while being treated for Lyme disease, don't always assume it's a Herxheimer reaction. You may be reacting to one or more of the hidden ingredients in your medications.

### References:

1. *Pharmacological treatment options for mast cell activation disease.* [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4903110/pdf/210\\_2016\\_Article\\_1247.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4903110/pdf/210_2016_Article_1247.pdf)
2. *US FDA: Inactive Ingredient Search for Approved Drug Products.* <https://www.accessdata.fda.gov/scripts/cder/iig/index.cfm>
3. *Evaluating Quality in a Compounding Pharmacy.* <https://www.koshlandpharm.com/wp-content/uploads/2018/11/Evaluating-Quality-in-a-Compounding-Pharmacy.pdf>
4. *US FDA: Frequently Asked Questions.* <https://www.fda.gov/Drugs/InformationOnDrugs/ucm080123.htm>
5. *See how USP ensures safety, identity and quality of excipients in drug, food and dietary supplement formulations.* <http://www.usp.org/excipients>

*Lonnie Marcum is a physical therapist and mother of a daughter with Lyme. She served two terms on a subcommittee of the federal Tick-Borne Disease Working Group. Follow her on Twitter: @LonnieRhea Email her at: [lmarcum@lymedisease.org](mailto:lmarcum@lymedisease.org)*



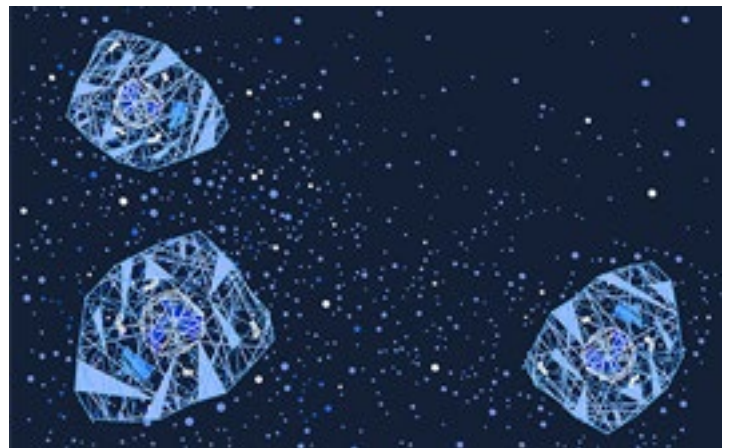


# Severe Weather can Worsen Mast Cell Activation Syndrome

Rapid changes in atmospheric pressure can alter the signaling pathways in mast cells, making them more reactive

*By Lonnie Marcum*

It's a fact, weather changes are a common trigger for patients with chronic illness and mast cell activation syndrome (MCAS). Rapid changes in the weather can have a significant impact on the functioning of mast cells. These changes can lead to an increase in the release of inflammatory mediators, alter the ability of mast cells to respond to allergens and pathogens, and affect the migration of mast cells in the body.



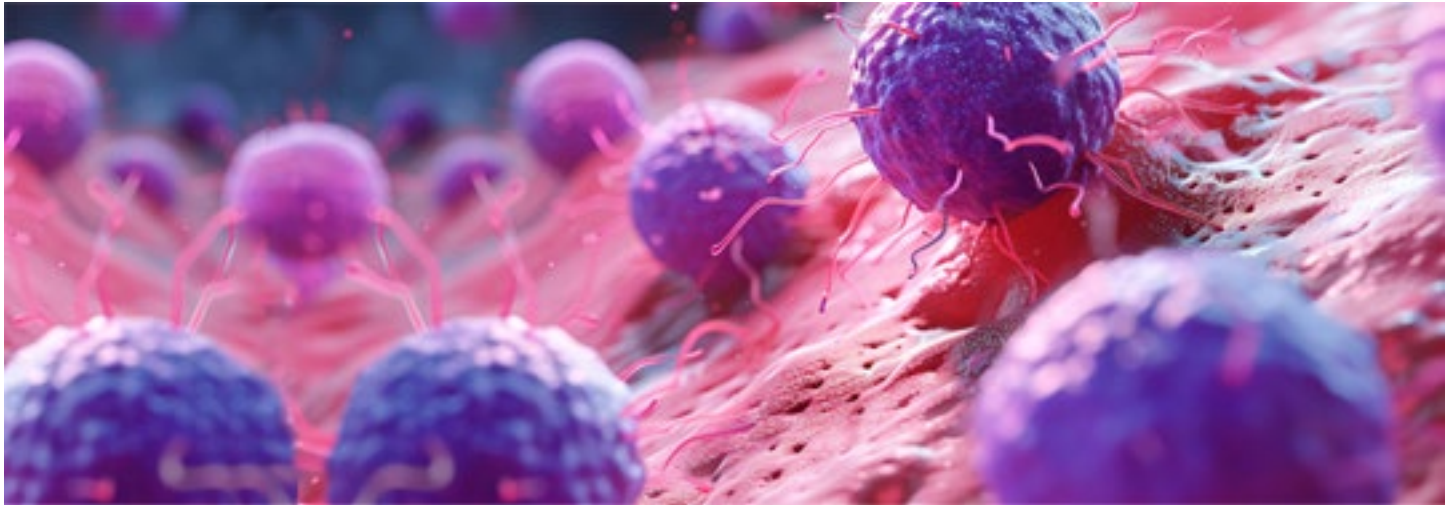
## Let me explain.

The human body is made up of about 60% fluids. This percentage can vary depending on factors such as age, sex, and body style. For example, men tend to have a higher percentage of water in their bodies than women and younger people have a higher percentage than older individuals. As you know, water is essential for many bodily functions, including regulating blood pressure and body temperature, transporting nutrients to cells, and removing waste products from the body.

## Atmospheric pressure and Mast Cells

Water is also affected by atmospheric pressure. For example, water at sea level boils at 212°F, while water at an elevation of 5,000 feet boils at 202°F. The difference in boiling temperatures is due to the lower atmospheric pressure at higher elevations.

Mast cells are a type of immune cell that plays a crucial role in the body's immune response to pathogens and allergens. These cells are found throughout every system of the body, including the skin, lungs, organs, bone marrow and digestive system. Mast cells contain granules that are filled with mediators, such as histamine, cytokines and proteases. When mast cells are working properly, they are our friends. When mast cells become over-active, they release too many mediators into the surrounding tissues, causing inflammation and other immune responses.



Barometric pressure is the force exerted by the weight of the molecules in the Earth's atmosphere on to the surface of the planet. This atmospheric pressure is measured in units of millibars (mb), kilopascals (kPa), or inches of mercury (inHg.)

**Generally, barometric pressure can be classified as low, medium, or high based on the following ranges:**

- **Low barometric pressure:** below 1000 mb or 29.53 inHg
- **Medium barometric pressure:** between 1000 mb and 1013 mb, or between 29.53 inHg and 30.00 inHg
- **High barometric pressure:** above 1013 mb or 30.00 inHg

A storm is caused by the movement of air masses with different temperatures and pressures. When these air masses collide, they create instability in the atmosphere, which can lead to rain, thunderstorms,

and more severe weather conditions like hurricanes or tornadoes. And, yes, many of us can feel these weather changes.

### Feeling changes in the weather

In general, the lower the barometric pressure, the stronger the storm is likely to be. As a low-pressure system moves closer to the ground, it causes a drop in atmospheric pressure at the surface. This drop in pressure can be detected by barometers, which are instruments used to measure air pressure.

People can also feel the effects of a drop in pressure, such as a feeling of heaviness in the air. Most people are familiar with their ears or sinuses popping as the pressure changes in an airplane. You might remember a grandparent who would complain about body aches when a storm was moving in. These changes in atmospheric pressure can have various effects on the body, including headaches, joint pain, changes in mood (depression, anxiety), partly due to an increase in mast cell activation.

When the barometric pressure drops, such as before a storm, the decrease in pressure can cause the release of histamine from mast cells. Mast cells also have receptors on their surface that detect changes in their environment, such as changes in temperature, humidity, and pressure. When any of these factors change rapidly, it can alter the signaling pathways in mast cells, making them more reactive. This can lead to an increase in the release of inflammatory mediators and an exacerbation of symptoms.

Mast cells are also designed to migrate to sites of inflammation and injury, where they release mediators and promote healing. Changes in barometric pressure can affect the distribution of mast cells, causing them to accumulate in certain tissues and organs. This can lead to an increase in inflammation, swelling and tissue damage in those areas.

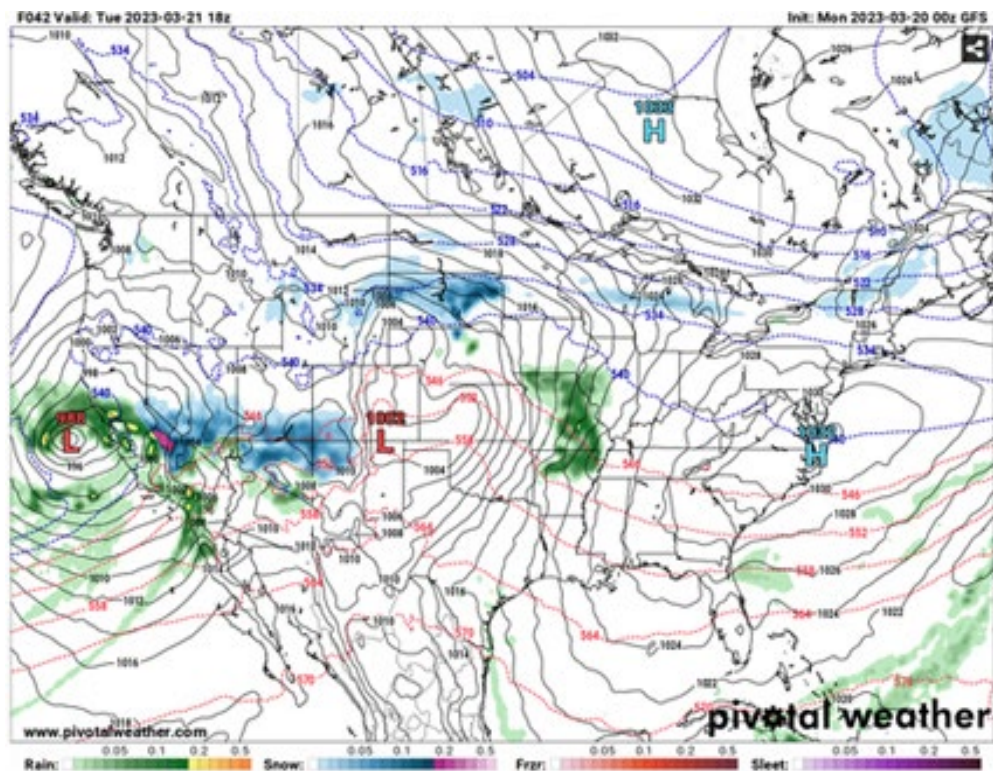
I can't tell you how many MCAS patients have told me how sick they got after a drive over a mountain range. I didn't put two and two together until I realized that the air pressure is lower at higher elevations and a rapid change can trigger mast cells.

## More pain

As the **Arthritis Foundation** states, “There’s no denying it, weather and climate can have a significant effect on arthritis and painful joints.” Even simple weather changes can cause the fluid-rich tissues around joints to expand or contract. This can put pressure on the nerves in the joint, leading to pain and discomfort. For example, when the barometric pressure drops before a storm, the tissues in the joint expand, which can lead to increased pain and tenderness. Cold temperatures on their own can cause the joint fluids to thicken, leading to stiffness, while high humidity can cause tissues around the joint to swell leading to more discomfort.

If you know a storm is coming it's always best to be prepared. Not just food and candles, but it also might be a good time to talk to your doctor about adjusting your medications accordingly.

The weather app on my cell phone shows barometric pressure in inches of mercury (inHg). A more detailed website I like to use is called Pivotal Weather. If you click on “Satellite” on the top bar, Model > “GFS”; Zoom > “Continental US”; Animation > “Forecast loop” you will be able to see any **upcoming storms** in your area.



In this image from 2023, you can see we have an extremely low pressure of 988 forecast to hit California on the first day of Spring—no kidding.

## Forewarned is forearmed

Seeing the forecast may help some people know when to ramp up their medications or adjust their schedule knowing they likely won't feel great when this storm hits.

In short, NO, you are not crazy. Changes in the weather can make you feel worse. People with arthritis, migraines, MS, lupus, Lyme disease, long COVID—pretty much any chronic illness—may experience a worsening of symptoms due to changes in temperature, humidity, barometric pressure and precipitation.

Knowing how to check the weather and when to adjust your medications and/or activities may help you literally weather the next storm.

### References:

1. Theoharides TC, Tsilioni I, Ren H. Recent advances in our understanding of mast cell activation – or should it be mast cell mediator disorders? *Expert Rev Clin Immunol.* 2019 Jun;15(6):639-656. doi: [10.1080/17446666X.2019.1596800](https://doi.org/10.1080/17446666X.2019.1596800). Epub 2019 Apr 22. PMID: 30884251; PMCID: PMC7003574.

*Lonnie Marcum is a physical therapist and mother of a daughter with Lyme. She served two terms on a subcommittee of the federal Tick-Borne Disease Working Group. Follow her on Twitter: [@LonnieRhea](https://twitter.com/LonnieRhea) Email her at: [lmarcum@lymedisease.org](mailto:lmarcum@lymedisease.org)*





# LymeDisease.org — 35 years of advocating for you

Starting as a small grassroots support group, LymeDisease.org has grown into an influential voice for Lyme patients

*By Dorothy Kupcha Leland*

In 1989, Phyllis Mervine published the first issue of the Lyme Times in Ukiah, California. It was two legal-size sheets of paper, folded in half into a little booklet which she created on a Macintosh Plus computer. Her goal? To help people with Lyme disease connect with each other, learn more about the illness, and find ways to get better.

Fast forward to today, 35 years later. The Lyme Times, now a digital publication, is read by Lyme patients throughout the world. And the organization that



Phyllis founded—now known as LymeDisease.org—has grown into one of the most influential Lyme disease advocacy organizations in the United States.

Somebody on Facebook recently called us “The CNN of Lyme disease.” He wasn’t wrong! We operate as a news hub for the Lyme community, striving to keep our readers informed about what’s going on in the world of tick-borne diseases. We use a variety of platforms to do so, including our website, news blogs, Facebook, X, Instagram, LinkinIn, and a weekly email newsletter.

But that’s only part of what we do. We also conduct research via our MyLymeData project, collaborate with scientists, advocate with legislators and healthcare policy makers, and represent Lyme patient interests in many other ways.

On this, our 35th anniversary, I’d like to look back at how far we’ve come.



## THE EARLY DAYS

In 1975, Connecticut mother Polly Murray first brought attention to a mysterious illness that would eventually be called Lyme disease. In 1982, Willy Burgdorfer identified the Lyme spirochete, later named *Borrelia burgdorferi* in his honor. But little was known about this newly recognized infection. Most doctors didn’t know how to diagnose and treat it, and patients were largely left on their own to figure out what to do about it. By the late 80s and early 90s, scattered Lyme support groups formed throughout the country, mostly in the northeast. That was the world in which the Lyme Times and Mervine’s fledgling California-based grassroots organization came into being. It was also when doctors who treated chronic Lyme disease with long-term antibiotics—the only available treatment at the time—were being hauled up on charges by state medical boards and threatened with losing their medical licenses.



## BRANCHING OUT

The rise of the internet offered new ways for our organization — then known as the California Lyme Disease Association (CALDA) — to spread our message to the Lyme community and beyond. In 2004, we set up a nationwide network of state-based Yahoo chat groups for Lyme patients, such as CaliforniaLyme, MassachusettsLyme, and NewYorkLyme. This was well before Facebook and other social media channels existed. (When the company disbanded Yahoo Groups in 2019, we moved to another platform and combined the state groups into the US National Lyme Support Group. It still flourishes today.)

As the targeting of Lyme-treating doctors continued, in 2004, our CEO Lorraine Johnson and our Medical Director Dr. Raphael Stricker began a professional collaboration to publish a series of medical journal articles focused on the “medico-legal” aspects of Lyme

disease. This side of Lyme disease — where medicine and the law intersect — had never been explored before. (In time, they published more than 40 articles.)



## CHALLENGING THE IDSA LYME GUIDELINES

In 2006, the Infectious Diseases Society of America released Lyme treatment guidelines that put even more of a target on the backs of Lyme-treating physicians, making it harder yet for patients to get the care they needed. (Though the IDSA is a private organization, its guidelines were endorsed by federal health officials and accepted by most insurance companies.) At that point, CALDA's Lorraine Johnson contacted the Connecticut Attorney General's office, calling their attention to serious financial conflicts of interest of many IDSA guidelines panel members. As a result, then-Attorney General Richard Blumenthal conducted a civil investigation of the IDSA for anti-trust violations. In 2008, he found the IDSA's guidelines development process “flawed” and “driven by conflicts of interest.”

The AG's settlement with the IDSA required the society to hold a review hearing in 2009, carried live over the internet. *Lorraine Johnson and Dr. Stricker were two of 10 speakers chosen to give comments. At the time, I wrote the following summary of Lorraine's presentation: Lorraine Johnson showed her own SPECT scans, showing major changes in her brain before and after long term antibiotic therapy. She presented results of CALDA's survey of 3,000 Lyme patients, indicating that more than half of respondents remained ill under the IDSA guide-*

*lines. Of those, more than 60% improved with additional treatment. She compared Lyme treatment (per IDSA—no options in treatment) with cancer and other diseases which allow for a wide variety of treatment options. Several panel members asked her questions, which allowed her more time to discuss insurance denials. Although the review process itself did not result in significant changes in IDSA policy, it marked a turning point in Lyme disease advocacy. The Lyme community had started playing on a much broader public stage.*



## SURVEYING THE LYME COMMUNITY

After the IDSA review hearing, we began conducting large-scale surveys of Lyme patients and getting them published in scientific journals. Our [Access to Care and Burden of Illness](#) study drew over 4,000 responses—at that time, the largest survey of Lyme patients ever conducted. Published in *Health Policy* in 2010, it revealed that 65% of patients with chronic Lyme disease had to cut back or quit work or school and 25% were on disability. (Once again, nobody knew this until we asked the questions and collected the answers.)

In 2011, we changed our name from CALDA to LymeDisease.org, because our efforts reached far beyond California. And we continued our surveys, including such topics as [Quality of Life](#) and [Outcomes Important to Patients](#). These led the way to our biggest survey of them all—the MyLymeData patient registry, launched in 2015.

In [MyLymeData](#), individuals report their personal experiences with tick-borne illness. How long to diagnosis? What treatments have you tried?

## TICK-BORNE DISEASE WORKING GROUP

In 2016, LymeDisease.org helped push for the formation of the federal Tick-Borne Disease Working Group, signed into law as part of the 21st Century Cures Act. Over the six years of TBDWG's existence, we played a big role. Representatives of LymeDisease.org participated on subcommittees, helping to research and write the Working Group's reports to Congress. We also delivered both verbal and written public comments to the panel. Furthermore, we kept the Lyme community informed throughout the whole process, reporting on and analyzing each meeting via blogs, social media posts, and our weekly email newsletters.

Over the last ten years, LymeDisease.org has elevated patient interests via a wide variety of forums. These have included 2016's Precision Medicine Summit at the White House and a pivotal 2023 workshop



**MyLymeData**  
A PROJECT OF LYMEDISEASE.ORG

What has helped the most? We partner with academic scientists to analyze the data. A recent finding: Women with Lyme disease take longer to get diagnosed, have more severe symptoms and experience higher rates of disability when compared to men. They may also be more likely to develop persistent Lyme disease. Distinctions like that are useful to researchers, treating doctors and patients themselves. Such real-world data is also eye-opening for legislators and healthcare policy makers. The project currently has over 18,000 enrolled participants and has produced [seven peer-reviewed journal articles](#).



sponsored by the National Academy of Science, Engineering and Medicine. Moreover, we've been quoted in such national publications as *U.S. News and World Report*, *Business Insider*, *The New York Times*, and *The Wall Street Journal*, regarding access to care, insurance, vaccines, and diagnostic issues. In all of these cases, we strive to represent the patient voice—too long ignored by most of the powers-that-be.



## The world is getting ‘tickier’

Almost every day brings news coverage of the continued rise of tick-borne diseases, in this country and throughout the world. (A recent report quotes a prominent entomologist as saying the world is getting ‘tickier.’) As much as we all might wish otherwise, the challenges brought on by these infections aren’t going away anytime soon. The people most affected by these illnesses—patients and their families—deserve access to appropriate medical care, period. Furthermore, more national resources must be focused on finding better ways of prevention, diagnosing and treating all tick-borne diseases.

We’ve been at this for 35 years, but in many ways, we’re just getting started. Won’t you join us?

*Dorothy Kupcha Leland is President of [LymeDisease.org](http://LymeDisease.org). She is co-author of [Finding Resilience: A Teen’s Journey Through Lyme Disease](#) and of [When Your Child Has Lyme Disease: A Parent’s Survival Guide](#). Contact her at [dleland@lymedisease.org](mailto:dleland@lymedisease.org).*

