

Letter to the Editor

Tips

- * Be professional
- * Identify yourself as a mast cell disease patient advocate
- * Letter should be short, to the point, and concise (approx. 150-200 words)
- * Before writing a letter, check the publication's website to see if they recommend word counts or have guidelines/requirements
- * Use simple language; avoid jargon
- * Personalize your experience
- * Sign the letter and include contact information
- * End with a call to action, if appropriate/relevant

Template

Dear Editor,

Rare Disease Day is February 28, 2018, and as a patient advocate for The Mastocytosis Society, Inc., I am raising awareness for mast cell diseases, which come in a variety of forms, including mastocytosis, mast cell activation syndrome and hereditary alpha tryptasemia. Mast cells are immune system cells that are involved in allergic reactions, from minor swelling and stuffy noses to life threatening, **full-blown anaphylaxis**. Mast cell diseases may come in a variety of forms, but what they all have in common is that something is wrong with the patients' mast cells, whether in how they grow and accumulate or behave. Patients with mast cell diseases often suffer tremendously due to constant exposure to seemingly innocuous stimuli that trigger acute reactions. Stimuli include foods, alcohol, chemicals, medications, odors, smoke, weather, hot & cold temperatures, friction or vibration, insect stings & bites, fatigue, exercise, and stress. Reactions include flushing, itching, skin rashes, headaches, gastrointestinal symptoms, low blood pressure, difficulty breathing and anaphylaxis.

Often patients go many years before being properly diagnosed, frequently being dismissed by physicians unfamiliar with mast cell diseases. Even after being diagnosed, patients struggle with limited treatment options, insurance barriers, financial burden of care and access to appropriate care.

Raising awareness about mast cell diseases can empower and guide patients to speak with their doctors about considering mast cell diseases as a possible cause for their symptoms, leading to earlier diagnosis and finding potentially life-changing treatments. It can also bring much-needed awareness to physicians, putting these rare diseases on their radar so they can recognize the symptoms. Although there is no cure and the journey to finding the right combination of treatments is no easy task, a proper diagnosis and an educated patient and provider team is a patient's first step to leading a healthier, happier, and safer life.

For further information about mast cell diseases, please visit The Mastocytosis Society, Inc. (<https://tmsforacure.org/>).

Sincerely,

NAME

The Mastocytosis Society, Inc.