

_____, 20__

To whom it may concern:

_____, is a patient applying for disability for _____.
_____. Mast cell diseases, including mastocytosis and mast cell activation syndrome, are rare disorders as designated by the National Organization for Rare Disorders. Currently, there is no cure for mastocytosis or mast cell activation syndrome. Patients are maintained on a protocol of medications to control their symptoms and advised to adapt their lifestyle in such a way as to avoid known triggers, whenever possible.

_____ has a diagnosis of _____, made by Dr. _____ of _____, _____ in 20___. Patients who receive appropriate care for mast cell diseases can have more positive outcomes, but they live a challenging life as they try to avoid triggers surrounding them and have to deal with the cascade of symptoms that result if they are exposed to such triggers. Mast cell diseases may arise as a clonal or non-clonal variant. Although these patients may not exhibit abnormal growth and subsequent proliferation of mast cells as seen in systemic mastocytosis, the function of their mast cells is impaired, resulting in many of the same life threatening symptoms, including the ever present risk of anaphylaxis in response to seemingly innocuous triggers such as heat, cold, temperature change, friction, vibration, anesthetic agents, perfumes and odors, insect and jellyfish stings and other venoms, certain foods, stress, medications, fatigue, infections, sun and exercise.

The symptomatology of these diseases is highly variable and unpredictable in nature, making it difficult for patients to know when they might suddenly suffer extremely disabling symptoms. The unpredictability of the onset of symptoms with no warning is what makes patients with mast cell diseases very often unable to work at any job, inside or outside of the home.



Such symptoms may include diarrhea with acute urgency, nausea and vomiting, lightheadedness which precedes syncope (fainting), weakness, overwhelming fatigue, brain fog and neuro-cognitive dysfunction, including difficulty with word retrieval, organizing thoughts, remembering tasks, uncontrollable itching with and without skin lesions, chest pain, migraine headaches, bone pain from osteopenia/osteoporosis and anaphylaxis can all present symptoms on a daily basis. It is impossible to maintain reliable attendance at a workplace, or even to do phone work from home while dashing to the bathroom, very ill.

Despite the strong desire to work and continue to be productive and to be able to be self-supportive, many patients with mast cell diseases are unable to work in any job in any capacity and be any kind of a reliable employee.

It should be noted that the average time from the onset of symptoms until a confirmation of diagnosis for mast cell diseases is *nine years!* Once a patient finally gets such a diagnosis, they are entitled to appropriate treatment.

Finding a physician to competently treat a patient with mast cell diseases is difficult; patients often have to travel long distances to access care, and it involves both travel and hotel costs to do so.

Thank you for your understanding of this patient who is totally disabled by _____, and who is unable to work because of their symptoms.