



# The Mastocytosis Society

## The Mastocytosis Society Honors Rare Disease Day

The world is coming together as many organizations join forces to jointly recognize the second Rare Disease Day on February 28. The Mastocytosis Society has partnered with these organizations to further the goals of this momentous day. Here are the goals of this initiative, taken from the Rare Disease Day website:

More specifically, this year we are seeking to achieve the following objectives:

- Promote research interest in the field of rare diseases
- Promote collaboration between patients and researchers
- To shape public policy and the research agenda
- To empower patients as actors in research
- To define research needs and priorities for rare diseases

This year, The Mastocytosis Society would like each person with a mast cell disorder to take the time to take action to bring awareness for Rare Disease Day. Here are some suggestions to get you started:

1. The National Organization of Rare Disorders suggests that you write to the governor of your state, and ask him to issue a proclamation recognizing Rare Disease Day. We took this a step further, and composed a letter that includes mention of Mastocytosis and Mast cell activation Disorders as rare diseases that need to be recognized, so that we can educate our health care professionals about these disorders, support patients and families, and promote research into finding treatments and a cure. Email the TMS Board when a proclamation is issued for your state! If you send me an email to [chairman@tmsforacure.com](mailto:chairman@tmsforacure.com), I will send you a letter already written, suitable for a governor in Microsoft word, specific to TMS and mastocytosis. All you have to do is change any word in red so that it is appropriate for your state, i.e. change the name and address of your governor, and put the name of your state whenever you see a red "Massachusetts". At the end of the letter, after my name, add your own name and address. The more letters to each state governor the better!!!

Here is a link to all of the state governor's offices:

<http://www.usa.gov/Contact/Governors.shtml>

Need help? Contact me, at [chairman@tmsforacure.org](mailto:chairman@tmsforacure.org), Erin, our technology chair at [websitetech@tmsforacure.org](mailto:websitetech@tmsforacure.org), Lisa at [fundraising@tmsforacure.org](mailto:fundraising@tmsforacure.org), or Jody at [mediarelations@tmsforacure.org](mailto:mediarelations@tmsforacure.org).

Let's get all 50 states to issue a proclamation!

2. Take a copy of the TMS video "Mast Cell Activation Symptomatology" to one of your doctors who have not yet seen it. If you do not have a copy, email [jbar51@verizon.net](mailto:jbar51@verizon.net) and ask Rita to send one to you, shipping expenses free of charge for Rare Disease Day!

3. Ask all of your friends and relatives to remember Rare Disease Day by making a donation to The Mastocytosis Society, either by going to our website, [www.tmsforacure.org](http://www.tmsforacure.org), and clicking on the Donate button, or mailing a check to The Mastocytosis Society, PO Box 731, Brenham, TX 77834. The check should have the notation Rare Disease Day, and funds will be used for research, education, and catastrophic emergencies for patients.
4. Contact your TMS local support group leader, ask for a meeting, and ask how you can fundraise to support all of the terrific initiatives that TMS is embarking on, including new research grants being handed out, translation of our video into French and Spanish, a survey to give input to the physicians working on the diagnostic criteria for mastocytosis and mast cell activation syndrome, a survey on coping with the stress of mast cell disease, a terrific annual conference with not one, but three different types of panel discussions planned, and working with other mast cell disease groups on joint ventures!!! You will be the person who benefits from these efforts!
5. Look at the TMS website, [www.tmsforacure.org](http://www.tmsforacure.org). Check out the store, and see if you can pick up a sale item to support TMS. Look at our different activities, and see where you might volunteer! Get a friend or neighbor to help you, as you teach one more person about mast cell disorders!
6. Think about how you might volunteer your services for TMS. Right now we have a very small board doing a huge amount of work. Call us and offer your services! We can use help as we work together for a cure!
7. Tell your family and friends about this important day. Go to the NORD website, [www.rarediseases.org](http://www.rarediseases.org), and read all about the many activities planned for rare disease day. Watch the video and learn about other rare diseases. Educate yourself about how a rare disease becomes politically and socioeconomically relevant.

Each year, it will be up to us, the patients and caregivers, to make Rare Disease Day the most positive of experiences! Together with hope, we work for a cure!

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To follow is the letter that I wrote to Governor Deval Patrick of Massachusetts: again, anything in red will have to be changed to personalize for your state and your governor.

February 1, 2010

{Governor Deval Patrick  
Massachusetts State House  
Office of the Governor  
Room 280  
Boston, MA 02133}

Dear Governor {Patrick}:

We are writing to ask you to declare February 28, 2010, Rare Disease Day in {Massachusetts}. On that day, millions of people around the world will observe the 2nd Annual Rare Disease Day to raise awareness of these diseases and the special challenges encountered by those affected.

In {Massachusetts}, thousands of patients, their families, medical professionals, researchers, educators, social workers and others will join in this observance of Rare Disease Day. Rare diseases are those that affect fewer than 200,000 Americans, and there are nearly 7,000 such diseases affecting nearly 30 million Americans, according to the National Institutes of Health (NIH). {Here in Massachusetts, we have the new Center for Excellence for Mast Cell Disorders being established at Brigham and Women's Hospital in Boston.} Mast cell disorders, including mastocytosis and the disorders of mast cell activation, are rare disorders that affect more than 20,000 infants, children, and adults who need the attention that Rare Disease Day will bring.

Rare Disease Day was observed for the first time in the United States last year and was a great success. This year, Rare Disease Day will be observed by millions of people throughout the U.S. and around the world. We respectfully ask you to consider designating the last day of February Rare Disease Day in {Massachusetts} on the basis that:

- Thousands of residents of {Massachusetts} are affected by rare diseases, as patients, friends and family, caregivers, physicians and other medical professionals, providers of social services, and researchers seeking to develop safe, effective treatments
- Many rare diseases are serious or even life threatening
- Most rare diseases have no treatment
- About half of the people affected by rare diseases in the U.S. are children since many rare diseases are genetic
- Research on rare diseases is important because it often adds significantly to the general understanding of more common diseases

People with rare diseases experience certain challenges that occur as a result of the fact that their diseases are rare. These include:

- Difficulty in obtaining a timely, accurate diagnosis. For example, the average length of time from the first symptom to diagnosis in adults is nine years.
- Limited treatment options

- Difficulty in finding physicians or treatment centers with needed expertise
- Treatments that are generally more expensive than those for common diseases
- Reimbursement issues related to private insurance, Medicare and Medicaid
- A sense of isolation and hopelessness

Rare disorders affect the entire family of an individual patient. Caregivers endure ongoing stress and isolation managing the medical and financial issues that arise. When there is delay in the diagnosis of a rare genetic disorder, siblings may be born with the same condition. When a rare genetic disorder is diagnosed during adulthood, other family members may need to be informed that they may also be at risk...and this may lead to difficult decisions regarding genetic testing, if such testing is an option.

On the basis of all of the above, we hope you will join other governors around the nation in declaring February 28, 2010, Rare Disease Day in your state.

With best regards,

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