



# The Mastocytosis Society

The Mastocytosis Society • P.O. Box 731 • Brenham, TX 77834

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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,

Valerie M. Slee, Chair  
The Mastocytosis Society  
23 Camelot Dr  
Shrewsbury, MA 01545  
Phone: 508-842-3080  
Fax: 508-842-2051  
Email: [chairman@tmsforacure.org](mailto:chairman@tmsforacure.org) , [vmslee@aol.com](mailto:vmslee@aol.com)

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