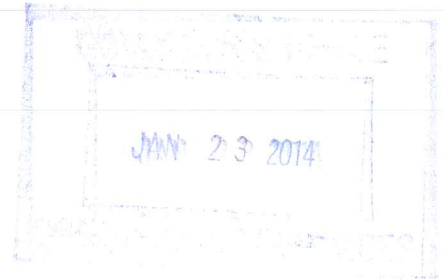




January 17, 2014

The Honorable Deval Patrick
Governor of Massachusetts
Office of the Governor
Massachusetts State House
Room 105
Boston, MA 02133



Dear Governor Patrick:

I am writing to ask you to declare that February 28, 2014, will be **Rare Disease Day** in Massachusetts. On that day, millions of people across the U.S. will join the National Organization for Rare Disorders (NORD) in observing this special awareness day.

As a resident of Massachusetts, I believe this is important because national statistics indicate that nearly 1 in 10 of those living in our state have rare diseases, such as narcolepsy, a devastating, lifelong sleep disorder. According to the National Institutes of Health (NIH), nearly 30 million Americans have rare diseases.

A disease is considered rare if it affects fewer than 200,000 Americans. There are nearly 7,000 such diseases, according to NIH. They tend to be serious and/or lifelong, and approximately two-thirds of those affected are children.

Special events and activities are planned in schools, hospitals, universities and medical schools for February 28th. Individuals and families affected by rare diseases will be sharing their stories on social media; in radio, TV, and newspaper interviews; and at community events throughout Massachusetts and across the U.S.

On the official national website for Rare Disease Day in the U.S. (www.rarediseaseday.us) hosted by NORD, residents of our state will be posting photos and messages, information about special events they are planning, and tributes to caregivers who have made a difference in their lives. Our state's support for Rare Disease Day also will be noted for all to see.

Massachusetts has a strong history of support for its citizens' causes. I hope that, as a state, we will step forward to show our concern for those who might otherwise feel isolated and let our neighbors living with rare diseases know that, while their diseases are rare, they are not alone.

Enclosed please find a Rare Disease Day proclamation template.

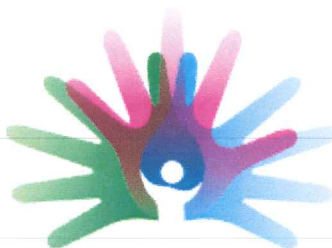
With best regards,

A handwritten signature in blue ink, which appears to read "Monica G. Gow", is written over the typed name.

Monica Gow
Executive Director & Co-founder
508-259-1100



US Sponsor



EURORDIS
Rare Diseases Europe

Global Sponsor

RARE DISEASE DAY

SAMPLE RARE DISEASE DAY PROCLAMATION

Whereas, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States, according to the National Institutes of Health (NIH);

Whereas, while each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans;

Whereas, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected;

Whereas, while more than 450 drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration (FDA), millions of Americans still have rare diseases for which there is no approved treatment;

Whereas, individuals and families affected by rare diseases often experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to treatments or ancillary services;

Whereas, while the public is familiar with some rare diseases such as “Lou Gehrig’s disease” and sympathetic to those affected, many patients and families affected by less widely known rare diseases bear a large share of the burden of funding research and raising public awareness to support the search for treatments;

Whereas, thousands of residents of (NAME OF STATE) are among those affected by rare diseases since nearly one in 10 Americans have rare diseases;

Whereas, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2014;

Whereas, thousands of patients and caregivers, medical professionals, researchers, companies developing orphan products to treat people with rare diseases, and others in the state of (NAME OF STATE) will participate in that observance;

Therefore, be it resolved that February 28, 2014, will be observed as Rare Disease Day in (NAME OF STATE).