



## STATE of MINNESOTA

# Proclamation

- WHEREAS: There are nearly 7,000 diseases and conditions considered rare (affecting fewer than 200,000 Americans) in the United States and their number is increasing with medical advances and improved diagnosis; and
- WHEREAS: While each of these diseases may affect a small number of people, rare diseases as a group, affect almost 30 million Americans, including 500,000 Minnesotans. Children represent between one-half and two-thirds of affected individuals; and
- WHEREAS: Many rare diseases are serious and debilitating conditions, which have a significant impact on the lives of those affected; and
- WHEREAS: While approximately 400 orphan drugs and biologics have been approved for the treatment of rare diseases, greater than 95% of rare diseases still lack treatment; and
- WHEREAS: Individuals and families affected by rare diseases often experience problems, including a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and
- WHEREAS: While some rare diseases, such as Cystic Fibrosis and Huntington's Disease, are relatively well known by the public, many others are not; and patients and their families bear a large share of the burden for raising funds and research; and
- WHEREAS: The National Organization for Rare Disorders is organizing the nationwide observance of Rare Disease Day on February 28, 2013, and patients, their families, medical professionals, researchers, government officials, and companies developing treatments are joining together to focus attention and awareness on rare diseases.

NOW, THEREFORE, I, MARK DAYTON, Governor of Minnesota, do hereby proclaim February 28, 2013 as:

## RARE DISEASE DAY

in the State of Minnesota.



IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Minnesota to be affixed at the State Capitol this 27<sup>th</sup> day of February.

  
GOVERNOR

  
SECRETARY OF STATE