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, according to the National Institutes of Health; and

WHEREAS: While each of these diseases may affect a small number of people, rare diseases as a group affect almost 30 million Americans. Children represent about one-half of affected individuals with a rare disease; and

WHEREAS: Many rare diseases are serious and debilitating conditions, which have a significant impact on the lives of those affected; and

WHEREAS: While 400 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; 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 the public is familiar with some rare diseases, 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; and

WHEREAS: The National Organization for Rare Disorders (NORD) is organizing the nationwide observance of Rare Disease Day on February 28, 2015, and patients, their families, caregivers, medical professionals, researchers, companies developing treatments, and others in the state of Minnesota will participate in that observance.

NOW, THEREFORE, I, MARK DAYTON, Governor of Minnesota, do hereby proclaim Saturday, February 28, 2015, 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 23rd day of February.

GOVERNOR

SECRETARY OF STATE