

**State of Vermont
Executive Department
A Proclamation**

WHEREAS, there are nearly 7,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States; and

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

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

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; and

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; and

WHEREAS, some rare diseases, such as “Lou Gehrig's disease” and Huntington’s disease, are relatively well known, many others are not known at all by the public so that patients and their families must bear a large share of the burden for things such as raising funds for research; and

WHEREAS, thousands of residents of Vermont are among those affected by rare diseases since nearly one in 10 Americans have rare diseases; and

WHEREAS, the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 29, 2016;

NOW, THEREFORE, I, Peter Shumlin, Governor, do hereby proclaim February 29, 2016 as

RARE DISEASE AWARENESS DAY

in Vermont.

Given under my hand and the Great Seal of the State of
Vermont on this 23rd day of February, A.D. 2016



A handwritten signature in black ink, appearing to read "Peter Shumlin", is written over a horizontal line.

Peter Shumlin
Governor