State of Vermont Executive Department A Proclamation

WHEREAS, there are more than 6,000 diseases and conditions considered rare

(each affecting fewer than 200,000 Americans) in the United States,

according to the National Institutes of Health (NIH); and

WHEREAS, while each of these diseases may affect small numbers of people,

rare diseases as a group affect an estimated 25 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 575 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, 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; and

WHEREAS, thousands of residents of Vermont are among those affected by rare

diseases since nearly one in 12 Americans have rare diseases; and

WHEREAS, the National Organization for Rare Disorders (NORD) is organizing

a nationwide observance of Rare Disease Day on February 28, 2017;

and

WHEREAS, thousands of patients and caregivers, medical professionals, researchers, companies developing orphan products to treat people

with rare diseases, and others in the United States around the world

will participate in that observance.

NOW, THEREFORE,

I, Philip B. Scott, Governor, do hereby proclaim February 28, 2017 to be

RARE DISEASE AWARENESS DAY



in Vermont.

Given under my hand and the Great Seal of the State of Vermont on this 28th day of February, A.D. 2017.

Philip B Scott

Governor

Brittney L. Wilson

Secretary of Civil and Military Affairs