State of Vermont Executive Department A Proclamation

WHEREAS, there are more than 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); and

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

rare diseases as a group affect an estimated 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, only 5 percent of rare diseases have FDA approved treatments, and

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 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 thousands of residents of Vermont are among those affected by rare diseases since nearly one in 11 Americans have rare

diseases: and

WHEREAS, the last day of February each year is recognized globally as Rare

Disease Day, with 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 this observance.

NOW, THEREFORE, I, Philip B. Scott, Governor, hereby proclaim February 28, 2019 as

RARE DISEASE AWARENESS DAY

in Vermont.

Given under my hand and the Great Seal of the State of Vermont on this 15th day of February, A.D. 2019.

Philip B. Scott

Governor

Brittney L. Wilson

Secretary of Civil and Military Affairs