State of Vermont Executive Department A Proclamation

WHEREAS, Spinal Muscular Atrophy is the number one genetic cause of death

for infants under two, and affects approximately one in 11,000

babies, and one in 50 Americans is a genetic carrier; and

WHEREAS, Spinal Muscular Atrophy is a disease that reduces an individual's

physical strength by affecting the motor nerve cells in the spinal cord, taking away the ability to perform basic functions of life,

including breathing and swallowing; and

WHEREAS, Spinal Muscular Atrophy can affect any race, ethnicity, or gender

and can take a powerful emotional toll on patients and their

families; and

WHEREAS, there is now an FDA-approved treatment for Spinal Muscular

Atrophy, which is proven to be most effective when administered as soon as possible, and while this treatment is a breakthrough, there remains a pressing need for continued research as treating some cases of Spinal Muscular Atrophy will require a combination of

therapies; and

WHEREAS, screening newborns for Spinal Muscular Atrophy is key to

preventing the detrimental effects of the condition; and

WHEREAS, Spinal Muscular Atrophy has both devastated and inspired families

and their communities throughout the state, nation, and world, and finding a cure will require increased public awareness of the disease, the need for increased research and screening, and the

challenges it presents to patients and their families.

NOW, THEREFORE, I, Philip B. Scott, Governor, do hereby proclaim August 2019 as

SPINAL MUSCULAR ATROPHY AWARENESS MONTH

in Vermont.

Given under my hand and the Great Seal of the State of

Vermont on this 1st day of August, A.D. 2019

Philip B. Scott

Governor

Brittney **E**. Wilson

Secretary of Civil and Military Affairs