

WHEREAS, Spinal Muscular Atrophy is the number one genetic cause of death for infants under two; and

WHEREAS, Spinal Muscular Atrophy 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 robs people of 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

WHEREAS, apart from the physical effects, Spinal Muscular Atrophy 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

WHEREAS, screening newborns for Spinal Muscular Atrophy is key to preventing the detrimental effects of the condition; and

WHEREAS, while this treatment is a major breakthrough, there is a pressing need for continued research, as treating some cases of Spinal Muscular Atrophy will require a combination of therapies; and

WHEREAS, Spinal Muscular Atrophy has both devastated and inspired families and their communities throughout the state, nation, and world; and

WHEREAS, finding a cure for Spinal Muscular Atrophy 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, _____, **GOVERNOR** of the State of _____, do hereby proclaim **AUGUST 2018** as **NATIONAL SPINAL MUSCULAR ATROPHY AWARENESS MONTH** in ____ (state) _____ and urge all residents to learn about this ‘common rare disease’ and its impact on the families of ____ (state) _____.