

CITY OF ORLANDO



Proclamation

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 10,000 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 walk, crawl, eat or breathe; and

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

WHEREAS, on December 23, 2016, the FDA approved the first-ever treatment for SMA, making this an historic year for the SMA community; and

WHEREAS, access to treatment is limited and remains out-of-reach to many children and adults affected by SMA; and

WHEREAS, there are currently 18 additional drug programs in development, including five in phase two clinical trials, representing a variety of therapeutic approaches with the goal of treating all different types, ages and stages of SMA; and

WHEREAS, researchers have made major breakthroughs that have strengthened bodies and extended lives, and will eventually lead to a cure; and

WHEREAS, Spinal Muscular Atrophy has both devastated and inspired families and their communities throughout the Sunshine State and increased awareness will lead to expanded knowledge and increased support for both research and affected families, hopefully leading to a cure; and

WHEREAS, the non-profit organization Cure SMA has raised more than \$62 million for Spinal Muscular Atrophy research programs, leading to clinical trials and the discovery of new drugs that have provided new hope to families and patients; and

WHEREAS, patient groups, including Cure SMA, have named August as National Spinal Muscular Atrophy Awareness Month to raise awareness and help promote research into this devastating disease;

NOW, THEREFORE, I, Buddy Dyer, Mayor of the City of Orlando, hereby do proclaim August 2017 as

“National Spinal Muscular Atrophy Awareness Month”

in the City of Orlando and urge all residents to learn about this ‘common rare disease’ and its impact on the families in our great state.

IN WITNESS WHEREOF, I hereto have set my hand and caused the Seal of the City of Orlando to be affixed this 1st day of August 2017.




Buddy Dyer
MAYOR