2015-J1289

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to proclaim August 2015, as Spinal Muscular Atrophy Awareness Month in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official months that are set aside to increase awareness of serious illnesses that affect the lives of citizens of New York State; and

WHEREAS, Attendant to such concern, and in full accord with its long-standing traditions, this Legislative Body is justly proud to memorialize Governor Andrew M. Cuomo to proclaim August 2015 as Spinal Muscular Atrophy Awareness Month in the State of New York; and

WHEREAS, Spinal Muscular Atrophy (SMA), is a rare genetic disease found mainly in newborns and children; it is a disease that affects the spinal nerves and causes weakness, especially in muscles closest to the spine; and

WHEREAS, SMA is a motor neuron disease; the motor neurons affect the voluntary muscles that are used for activities such as crawling, walking, head and neck control, and swallowing; it is a relatively common "rare disorder" and approximately one in 10,000 babies born are affected, and about one in 50 people are genetic carriers; and

WHEREAS, SMA affects muscles throughout the body, although the proximal muscles are often most severely affected; weakness in the legs is generally greater than in the arms, and sometimes feeding and swallowing can be affected; and

WHEREAS, Involvement of respiratory muscles can lead to an increased tendency for pneumonia and other lung problems, and sensation and the ability to feel are not affected; and

WHEREAS, Intellectual activity is normal and it is often observed that patients with SMA are unusually bright and sociable; patients are generally grouped into one of four categories, based on certain key motor function milestones; and

WHEREAS, SMA is an autosomal recessive genetic disease; in order for a child to be affected by SMA, both parents must be carriers of the abnormal gene and both must pass this gene on to their child; although both parents are carriers, the likelihood of a child inheriting the disorder is 25%, or one in four; and

WHEREAS, SMA crosses all racial, ethnic and gender boundaries and although it is primarily diagnosed in children, it can affect people of any age; and

WHEREAS, Formerly known as Families of SMA, Cure SMA, a grassroots organization, is working to help raise awareness and funding for research, education, advocacy, and patient services for this matter; there are currently three chapters of Cure SMA in New York State, Cure SMA of Greater NY, Cure SMA Greater NY- Capital Region Chapter and FSMA Western New York; these chapters serve hundreds of family members affected by Spinal Muscular Atrophy; and

WHEREAS, Individuals and organizations which bring greater awareness to physical health issues, and assist people in their quest to overcome these obstacles, are a great benefit to the health and welfare of all citizens; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim August 2015, as Spinal Muscular Atrophy Awareness Month in the State of New York; and be it further

RESOLVED, That copies of this Resolution, suitably engrossed, be transmitted to The Honorable Andrew M. Cuomo, Governor of the State of New York, and to Debbie Cuevas, Cure SMA.