Senate Resolution No. 269

**BY: Senator RIVERA** 

MEMORIALIZING Governor Andrew M. Cuomo to proclaim May 2019, as Amyotrophic Lateral Sclerosis Awareness Month in New York State

WHEREAS, It is the custom of this Legislative Body to help increase awareness of serious health conditions 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 May 2019, as Amyotrophic Lateral Sclerosis Awareness Month in the State of New York, in conjunction with the observance of National ALS Advocacy Month; and

WHEREAS, Amyotrophic lateral sclerosis (ALS), sometimes called Lou Gehrig's disease, is a progressive disease that attacks the nerve cells that control voluntary movement; and

WHEREAS, In ALS, both the upper motor neurons and the lower motor neurons degenerate or die, ceasing to send messages to muscles; unable to function, the muscles gradually weaken, waste away, and twitch; eventually the ability of the brain to start and control voluntary movement is lost; and WHEREAS, Once ALS starts, it almost always progresses, eventually taking away the ability to walk, dress, write, speak, swallow, and breathe, and shortening the life span; and

WHEREAS, ALS is 100% fatal and has few treatments to improve the quality of life; and

WHEREAS, There are two different types of ALS, sporadic and familial; sporadic, which is the most common form of the disease in the U.S., is 90 - 95 percent of all cases; it may affect anyone, anywhere; familial ALS (FALS) accounts for 5 to 10 percent of all cases in the U.S. and means the disease is inherited; and

WHEREAS, Most people who develop ALS are between the ages of 40 and 75, with the majority after age 60, although it can occur at a younger age; and

WHEREAS, Approximately 5,000 people in the U.S. are diagnosed with ALS each year; the incidence of ALS is two per 100,000 people; and

WHEREAS, It is estimated that more than 30,000 Americans may be living with ALS at any given time; and

WHEREAS, Most surveys find that ALS is more common in men than women, though that gap may be closing; in addition, military veterans are approximately twice as likely to develop ALS; and

WHEREAS, ALS occurs throughout the world with no obvious racial, ethnic or socioeconomic boundaries; and

WHEREAS, Amyotrophic Lateral Sclerosis Awareness Month increases the

public's awareness of ALS patients' circumstances and acknowledges the terrible impact this disease has not only on patients but on their families as well; and

WHEREAS, The National ALS Registry was created by Congress in 2008, to gather and organize information about who gets ALS and the potential causes of ALS; the Agency for Toxic Substances and Disease Registry (ATSDR) is charged with developing and managing the Registry; and

WHEREAS, The National ALS Registry collects, manages and analyzes data about persons with ALS; it includes data from existing national databases and information provided by persons with ALS who choose to participate; and

WHEREAS, In addition, researchers can use Registry data to look for disease pattern changes over time and try to identify whether there are common risk factors among persons with ALS; the Registry also provides updated links for participant resources like ALS clinical trials; and

WHEREAS, Scientists need the assistance of New Yorkers living with ALS to further their research into the causes of the disease, and help scientists defeat ALS; and

WHEREAS, It is the sense of this Legislative Body to encourage those New Yorkers who live with ALS to join the Registry online at the Center for Disease Control's Agency for Toxic Substances & Disease Registry; and

WHEREAS, It is imperative that there be greater awareness of this serious health condition, and more must be done to increase activity at the local, State and National levels; now, therefore, be it RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim May 2019, as Amyotrophic Lateral Sclerosis Awareness Month in the State of New York; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Andrew M. Cuomo, Governor of the State of New York.