

## 2017-J565

Senate Resolution No. 565

BY: Senator PARKER

MEMORIALIZING Governor Andrew M. Cuomo to proclaim February 28, 2017, as Rare Disease Awareness Day in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official days set aside to increase awareness of serious issues which affect the lives of citizens of New York State; and

WHEREAS, Attendant to such concern, and in full accord with its long-standing traditions, it is the sense of this Legislative Body to memorialize Governor Andrew M. Cuomo to proclaim February 28, 2017, as Rare Disease Awareness Day in the State of New York, in conjunction with the observance of National Rare Disease Day; and

WHEREAS, National Rare Disease Day is an observance held on the last day of February every year to raise awareness of rare diseases and diseases of unmet need, few of which have cures or specific drugs to treat symptoms, and are often not diagnosed for many years; and

WHEREAS, In 2008, Rare Disease Day was established for the reason, according to the European Organization for Rare Diseases (EURORDIS), treatment for many rare diseases and diseases of unmet need is insufficient, as are the social networks to support individuals with rare diseases and diseases of unmet need and their families; and

WHEREAS, One year later, Rare Disease Day went global as the National Organization of Rare Disorders (NORD) mobilized 200 rare disease patient advocacy organizations in the United States in an effort to coordinate activities and better promote the day; and

WHEREAS, In 2013, in recognition of the needs of patients with rare diseases, Albany Medical Center and College established the Albany Medical Center's Rare Disease Forum which was the genesis of the New York State Rare Disease Alliance, whose purpose is to promote faster diagnosis of rare diseases, research into therapies and cures, and to foster wider public recognition of public health problems affecting 30 million Americans; and

WHEREAS, There are nearly 7,000 diseases and conditions considered rare, each year affecting approximately 200,000 Americans; and

WHEREAS, Of these 7,000 rare diseases, more than 80 percent are considered ultra rare, affecting less than a few thousand Americans; and

WHEREAS, While each of these diseases and disorders may affect small numbers of people, rare diseases affect more than 30 million Americans; and

WHEREAS, Since many rare diseases and diseases of unmet need are genetic, tragically, approximately half the people affected by rare diseases in the United States are children; and

WHEREAS, Research on rare diseases, which are serious and often life-threatening, is vitally important because it frequently adds significantly to the general understanding of more common diseases and conditions; and

WHEREAS, People suffering from rare diseases typically experience difficulty in obtaining a timely, accurate diagnosis, finding physicians or treatment centers and experience limited treatment options, options generally considered more expensive than those for common diseases; and

WHEREAS, It is imperative that there be greater public awareness of rare diseases and diseases of unmet need, and more must be done to increase activity at the local, state and national levels to support those afflicted as well as their families and caregivers; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim February 28, 2017, as Rare Disease Day in the State of New York, in conjunction with National Rare Disease Day; 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; the New York State Rare Disease Alliance; and NORD.