

**BY:** Senator PERSAUD

**MEMORIALIZING** Governor Kathy Hochul to proclaim February 28, 2022, as Rare Disease 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 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, it is the sense of this Legislative Body to memorialize Governor Kathy Hochul to proclaim February 28, 2022, 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 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,** 2022 marks the 14th Anniversary of Rare Disease Day in the United States; in 2008, the first Rare Disease Day was held on February 29th, a 'rare' date which happens only once every four years; ever since then, Rare Disease Day has taken place on the last day of February, a month known for having a 'rare' number of days; and

**WHEREAS,** Rare Disease Day was established for the reason, according to the European Organization for Rare Diseases (EURORDIS), that 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, in 2009, 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 25-30 million Americans; and

**WHEREAS,** There are 7,000 known rare diseases affecting approximately 25-30 million Americans and approximately 1-in-10 individuals in New York State has a rare disease; and

**WHEREAS,** Of these 7,000 known rare diseases, more than 90% are without FDA approved treatment; and

**WHEREAS,** Many rare diseases and diseases of unmet need are genetic, and 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 due to 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 takes between five to seven years on average to receive an accurate diagnosis; and

**WHEREAS,** Biopharmaceutical research companies, academic researchers, patient groups, and others are applying the growing understanding of the causes of rare diseases to speed the development of new treatments for patients; the Orphan Drug Act of 1983 has been and continues to be an important force in driving treatment innovation for rare diseases; and

**WHEREAS,** Advances in DNA sequencing have led to the identification of the genetic cause of several rare disease, which can potentially lead to better understanding of the disease and development of targeted therapies; and

**WHEREAS,** In 2020, legislation creating a Rare Disease Advisory Work Group was signed into law; this Work Group will be composed of individuals with expertise in rare disease who will focus on best practices that will: improve awareness of rare diseases; and evaluate barriers to treatment including financial barriers on access to care; 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 Kathy Hochul to proclaim February 28, 2022, as Rare Disease Day in the State of New York, in conjunction with the observance of National Rare Disease Day; and be it further

**RESOLVED,** That copies of this Resolution, suitably engrossed, be transmitted to The Honorable Kathy Hochul, Governor of the State of New York; the New York State Rare Disease Alliance; and NORD.