2025-J100

Senate Resolution No. 100

BY: Senator PERSAUD

MEMORIALIZING Governor Kathy Hochul to proclaim
February 28, 2025, 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, 2025, 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, The first Rare Disease Day was held in 2008 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; 1 in 10 New Yorkers suffer from a rare disease; and

WHEREAS, There are nearly 10,000 diseases and conditions considered rare; it is paramount to stress the importance of early detection of said diseases, as well as work to minimize the severity of their effects through proper funding of research and public awareness; and

WHEREAS, Of these 10,000 rare diseases, more than 95% are without FDA approved treatment; 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 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 typically takes between six to eight 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, composed of individuals with expertise in rare disease, focused on best practices that will: improve awareness of rare diseases; and evaluate barriers to treatment including financial barriers on access to care; and the Rare Disease Advisory Work Group recommendations are contained in a final report shared with the Legislature in September 2023; and

WHEREAS, In 2024, legislation was introduced that would establish a permanent rare disease advisory council to identify best practices, raise awareness regarding rare diseases, evaluate barriers to access to care, and to make recommendations to the legislature and the governor; and

WHEREAS, Today, there is more hope than ever before with close to 800 medicines in development for patients with rare diseases; medicines in development include 168 for rare cancers and 120 for rare blood cancers, accounting for 35 percent of all rare disease medicines in development; 192 for genetic disorders, including cystic fibrosis and spinal muscular atrophy; 56 for neurological disorders, including amyotrophic lateral sclerosis (ALS) and seizures; 36 for infectious diseases, including rare bacterial infections and hepatitis; 51 for autoimmune diseases, including systemic sclerosis and juvenile arthritis; 54 for blood disorders, including sickle cell disease and hemophilia; and

WHEREAS, Currently, research has led to powerful new gene-editing techniques holding promise for cures for blood disorders (such as Sickle Cell Disease, Thalassemia, Hemophilia), Cancer, Blindness, Aids, Muscular Dystrophy, Cystic Fibrosis, and Huntington's disease; and

WHEREAS, These treatment options and medicines in development attack the root of the cause for these patients that had few or no treatment options before; 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, 2025, as Rare Disease Day in the State of New York; 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; The Wadsworth Center - New York State Newborn Screening Program, and NORD.