

BY: Senator THOMAS

MEMORIALIZING Governor Kathy Hochul to proclaim September 7, 2024, as Duchenne Muscular Dystrophy Awareness Day in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official days 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 Kathy Hochul to proclaim September 7, 2024, as Duchenne Muscular Dystrophy Awareness Day in the State of New York, in conjunction with the observance of World Duchenne Muscular Dystrophy Awareness Day; and

WHEREAS, Duchenne muscular dystrophy is the most common fatal genetic disorder diagnosed in childhood, affecting approximately one in every 5,000 male births (about 20,000 new cases each year worldwide); since the Duchenne gene is found on the X-chromosome, it primarily affects boys, however, it occurs across all races and cultures; and

WHEREAS, Duchenne muscular dystrophy results in progressive loss of strength and is caused by a mutation in the gene that encodes for dystrophin; since dystrophin is absent, the muscle cells are easily damaged; and

WHEREAS, The progressive muscle weakness leads to serious medical problems, particularly issues relating to the heart and lungs; young men with this debilitating disease typically live into their late twenties; and

WHEREAS, Duchenne muscular dystrophy can be passed from parent to child, but approximately 35% of cases occur because of a random spontaneous mutation; in other words, it can affect anyone; and

WHEREAS, Although there are now seven FDA approved medical treatments that may help slow its progression, there is currently no cure for Duchenne muscular dystrophy; and

WHEREAS, World Duchenne Muscular Dystrophy Awareness Day will highlight the importance of identifying and communicating early signs of this genetic disorder is the key to early diagnosis; and

WHEREAS, As one of the first states to add Duchenne to its newborn screening panel, New York continues to be a leader in early diagnosis and treatment of this disease; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim September 7, 2024, as Duchenne Muscular Dystrophy Awareness 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.