2017-K1333

Assembly Resolution No. 1333

BY: M. of A. Rules (Cusick)

MEMORIALIZING Governor Andrew M. Cuomo to proclaim September 9-15, 2018, as Duchenne Muscular Dystrophy Awareness Week in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official weeks 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 Andrew M. Cuomo to proclaim September 9-15, 2018, as Duchenne Muscular Dystrophy Awareness Week in the State of New York, in conjunction with the observance of National Duchenne Muscular Dystrophy Awareness Week; and

WHEREAS, Duchenne muscular dystrophy is the most common fatal genetic disorder diagnosed in childhood, affecting approximately one in every 3,500 live 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, Becker muscular dystrophy, which is less severe than

Duchenne muscular dystrophy, occurs when dystrophin is manufactured, but

not in the normal folin or amount: 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 medical treatments that may help slow its progression, there is currently no cure for Duchenne muscular dystrophy; and

WHEREAS, Jar of Hope's mission is to find a cure through accelerated research, calls for action in Washington D.C., demand optimal care for all young men, and educate the global community; and

WHEREAS, Scientists around the globe are conducting intense research to understand what causes muscle dysfunction in Duchenne muscular dystrophy and to apply that understanding to the development of effective treatments; and

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

therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim September 9-15, 2018, as Duchenne Muscular Dystrophy Awareness Week in the State of New York; 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; and Jar of Hope.