

BY: Senator TEDISCO

MEMORIALIZING Governor Kathy Hochul to proclaim
September 15, 2022, as Myotonic 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 15, 2022, as Myotonic Dystrophy Awareness Day in the State of New York, in conjunction with the observance of International Myotonic Dystrophy Awareness Day; and

WHEREAS, Myotonic dystrophy is a rare, multi-systemic, inherited disease that affects an estimated 1 in 2,100 people, or over 3.6 million individuals across the world; and

WHEREAS, Myotonic dystrophy is commonly referred to as DM, an abbreviation of the Latin name used by doctors and researchers worldwide: dystrophia myotonica; other names for DM include myotonic muscular dystrophy, Steinert's Disease for DM1, and proximal myotonic myopathy for DM2; and

WHEREAS, Globally, millions of people are living with myotonic dystrophy but do not know they have the disease and are in need of care; and

WHEREAS, Myotonic dystrophy is the most common form of adult muscular dystrophy and considered the most variable of all known conditions; and

WHEREAS, Mutations prevent genes from carrying out their functions properly, which can impact multiple body systems; and

WHEREAS, Myotonic dystrophy is inherited; people living with myotonic dystrophy have a 50% chance of passing on the mutated gene to their children; and

WHEREAS, Myotonic dystrophy does not always look the same; the different body systems affected, the severity of symptoms, and the age of onset of those symptoms vary greatly between individuals, even in the same family; and

WHEREAS, People living with myotonic dystrophy experience varied and complex symptoms, from skeletal muscle problems, to heart, breathing, digestive, hormonal, speech and swallowing, diabetic, immune, excessive daytime sleepiness, and early cataracts and vision challenges, as well as cognitive difficulties; and

WHEREAS, Myotonic dystrophy symptoms usually become more severe with each generation, yet there is currently no cure and there are no approved treatments; and

WHEREAS, Over 35 biopharmaceutical companies are leading promising research which may result in new treatments for myotonic dystrophy, and one day, a cure; and

WHEREAS, It is imperative that there be greater awareness of this serious health condition, and more must be done to increase activity at the local, state and national levels; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim September 15, 2022, as Myotonic Dystrophy Awareness Day in the State of New York; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Kathy Hochul, Governor of the State of New York.