

Assembly Resolution No. 196

BY: M. of A. Reilly

MEMORIALIZING Governor Kathy Hochul to proclaim
March 15, 2023, as Morquio A Syndrome 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 March 15, 2023, as Morquio A syndrome Awareness Day in the State of New York; and

WHEREAS, Morquio A syndrome, a classification of Mucopolysaccharidosis (MPS) disorders, is a rare, progressive genetic disorder that affects approximately 1 in every 300,000 births; and

WHEREAS, Individuals affected by Morquio A syndrome do not have or do not produce enough enzymes that break down sugar chains naturally in the body; the buildup of sugars negatively impacts the skeletal system and eventually the organ systems; and

WHEREAS, The condition of Morquio A syndrome worsens over time and there is no cure; and

WHEREAS, There is only one FDA approved medication for Morquio A syndrome, which is a synthetic version of the enzyme that patients lack; it is a four-hour weekly infusion that helps slow the rapid progression of the disease; and

WHEREAS, Patients going through treatment for Morquio A syndrome often need to see numerous specialty doctors frequently, and may also require many services for school age children; and

WHEREAS, Reed Rinon is a six-year-old from Staten Island, New York who lives with Morquio A syndrome; and

WHEREAS, Diagnosed at three-years-old, after being worked on by every specialist possible, Reed Rinon now receives the FDA approved medication every Tuesday in his chest port wall and has to wear a back brace each night to help slow the curvature of his spine, in addition to wearing hearing aids daily; and

WHEREAS, The experiences young Reed Rinon has had to go through has taken an emotional toll on his family, and he is scheduled for bilateral hip, bilateral knee, bilateral ankle, and growth plate surgery to help further treat his condition; and

WHEREAS, There are others like Reed Rinon who struggle every day to live comfortably with Morquio A syndrome, and March 15th should inspire

New York citizens to learn and educate others about this life-altering condition; 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 March 15, 2023, as Morquio A Syndrome 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.