

2013-K1237

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to proclaim May 2014 as Sanfilippo Syndrome Awareness Month in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official months 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 May 2014 as Sanfilippo Syndrome Awareness Month in the State of New York; and

WHEREAS, Sanfilippo syndrome is a rare genetic disorder caused by a disruption in the body's metabolism; children afflicted with this condition are missing or are deficient in the enzyme which breaks down the Mucopolysaccharides, molecules responsible for building connective tissues; instead, the body stores these molecules in the cells, causing much damage; and

WHEREAS, Sanfilippo syndrome is a progressive disorder, meaning that at birth, children appear typical and do not show signs of any illness; as the disease progresses, those afflicted experience seizures, joint stiffness, upper respiratory infection, hearing loss, dementia, hyperactivity, partial paralysis, blindness, and eventually, death; and

WHEREAS, First described in 1963 by Dr. Sylvester Sanfilippo, this affliction is considered rare, with an occurrence of one in every 70,000 births; and

WHEREAS, The Team Sanfilippo Foundation is a non-profit medical research organization; its mission is to find potential therapies that can be tested clinically; this internationally supported group is working to advance research and education to improve the quality of life for

those young people affected by this disorder and ultimately find a cure;
and

WHEREAS, Recent scientific advancements in the areas of enzyme replacement, gene therapy, and small molecules have led to the initiation of clinical programs for Sanfilippo syndrome and other lysosomal storage diseases; a new focus is being placed on the development of combined therapies to give children the best possible treatment strategies; and

WHEREAS, It is imperative that there be greater public awareness of this serious health issue, 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 Andrew M. Cuomo to proclaim May 2014 as Sanfilippo Syndrome Awareness Month in the State of New York; and be it further

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