2013-J4445

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to proclaim May 4, 2014, as Heterotaxy 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 Andrew M. Cuomo to proclaim May 4, 2014, as Heterotaxy Syndrome Awareness Day in the State of New York, in conjunction with the observance of National Heterotaxy Syndrome Awareness Day; and WHEREAS, Heterotaxy syndrome is a congenital condition that affects the development, placement and presence of internal organs; and WHEREAS, The public is unaware of heterotaxy syndrome, including many medical professionals; and

WHEREAS, Heterotaxy syndrome affects many body systems and requires a team of numerous specialists for treatment; and

WHEREAS, Families struggle to educate medical teams and are often the only common thread between medical specialties; and

WHEREAS, Mortality is high, but due to lack of tracking and research, the exact numbers are unclear; and

WHEREAS, Those with heterotaxy syndrome who survive to adulthood find their condition largely unknown to the community; and

WHEREAS, Funding into causes and holistic treatment of heterotaxy syndrome are low; and

WHEREAS, Heterotaxy Syndrome Awareness Day provides an opportunity for families whose lives have been affected to celebrate life and to remember loved ones lost, to honor dedicated health professionals, and to

meet others and know they are not alone; and
WHEREAS, The establishment of Heterotaxy Syndrome Awareness Day will
also provide the opportunity to share experience and information with
the public and the media, in order to raise public awareness about
Heterotaxy Syndrome; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim May 4, 2014, as Heterotaxy 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 Andrew M. Cuomo, Governor of the State of New York.