

## 2013-K1132

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to declare May 2014, as ROHHAD Disease 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 declare May 2014, as ROHHAD Disease Awareness Month in the State of New York; and

WHEREAS, Rapid-onset Obesity with Hypothalamic dysfunction, Hypoventilation and Autonomic Dysregulation (ROHHAD) is a very rare disease with approximately 75 cases documented worldwide; and

WHEREAS, Children with ROHHAD typically have shallow breathing that, if not addressed, deprives the brain of oxygen which can lead to neurological disabilities, seizures, or cardiac arrest; and

WHEREAS, Currently, there is no treatment or cure for ROHHAD and the source of this disease has not yet been determined; and

WHEREAS, Symptoms of ROHHAD, which varies for each child and are usually misdiagnosed, generally start with rapid onset obesity in the first two to four years of life then lead to impairment of the nervous system and inevitably reduced lung function leaving most ROHHAD patients unable to breathe without the assistance of a ventilator; and

WHEREAS, Unfortunately, very little research has been done due to the lack of awareness and lack of funding as most people have never even heard of ROHHAD; and

WHEREAS, ROHHAD Fight, Inc. is a not-for-profit 501(c)3 organization that has been created to raise awareness and funding for research and to help children and families who suffer from ROHHAD to pay for travel

expenses and un-reimbursed medical costs to ease the financial burden of the disease; and

WHEREAS, Since there are so few cases and a limited number of doctors who have heard of it, children suffering from ROHHAD often have to travel to other parts of the country for proper medical attention; and

WHEREAS, Marisa Carney is a seven-year old girl, born on March 31, 2006, and was diagnosed with ROHHAD in June of 2010, at the age of four; and

WHEREAS, Most patients, like Marisa, begin life as healthy babies but in early childhood start to gain weight rapidly, and develop serious breathing problems; and

WHEREAS, Marisa Carney uses a ventilator to breathe 24 hours a day, and is limited to a 1,200 calorie diet; her father pricks her finger every night to draw blood to test for her sodium level; her parents spend countless hours, day and night, monitoring her carbon dioxide levels, and making sure she is getting enough oxygen; 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 to assist in research funding; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to declare May 2014, as ROHHAD Disease Awareness Month 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 the Carney Family.