

## 2013-J5372

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to proclaim June 8, 2014, as Familial Dysautonomia 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 issues 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, it is the sense of this Legislative Body to memorialize Governor Andrew M. Cuomo to proclaim June 8, 2014, as Familial Dysautonomia Awareness Day in the State of New York; and

WHEREAS, Familial Dysautonomia, also known as FD and Riley-Day Syndrome, is a rare genetic neurological condition that affects the sensory and autonomic nervous systems, causing severe gastrointestinal, cardiovascular, pulmonary, orthopedic, renal and ophthalmologic problems that affect children from birth; and

WHEREAS, Children with Familial Dysautonomia lack the most basic reflexes and instincts such as the ability to suck at birth or to swallow properly and their bodies cannot control blood pressure or heart rate; and

WHEREAS, It is estimated that FD primarily affects one in 27 children of Eastern European Jewish descent but genetic carriers of the disease have also been found in the general population; and

WHEREAS, New York State has the highest concentration of FD patients in the country and the Dysautonomia Foundation, located in New York City, operates the only FD treatment and clinical research facility in the United States; and

WHEREAS, There is no cure for Familial Dysautonomia but advances in research and treatment have dramatically extended life expectancy and

babies born with Familial Dysautonomia within the last five years will have a 50% chance of surviving to 40 years of age; and

WHEREAS, While children still struggle with the life-threatening challenges brought on by FD, there are supportive therapies including surgical interventions and medications to maintain and regulate cardiovascular, respiratory and gastrointestinal function; and

WHEREAS, General population genetic screening is now available which can significantly reduce the frequency of new cases of Familial Dysautonomia; and

WHEREAS, It is imperative that there be greater public awareness of this devastating medical condition and more must be done to increase activity at the local, state and national levels to promote screening and support patients and their families; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim June 8, 2014, as Familial Dysautonomia Awareness Day 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, the Dysautonomia Center of New York University, and David Brenner, Executive Director, Dysautonomia Foundation, Inc.