

## 2011-J4294

LEGISLATIVE RESOLUTION memorializing Governor Andrew M. Cuomo to proclaim June 10, 2012, 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 10, 2012, 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 disease that affects the autonomic and sensory nervous systems of children from birth; and

WHEREAS, This special day is also known as the 27th Annual FD Day Conference presented by the Dysautonomia Foundation, Inc. and the Dysautonomia Center of New York University; festivities will be held at New York University's Langone Medical Center; and

WHEREAS, It is estimated that one in 27 individuals of Eastern European Jewish ancestry is a carrier of the gene for Familial Dysautonomia; New York has the highest concentrations of FD patients in the United States; and

WHEREAS, The most striking symptoms of Familial Dysautonomia are reduced sensitivity to pain and temperature, and the inability to produce tears; it affects every major system of the body, causing severe respiratory, cardiac, orthopedic, digestive, renal and vision problems; and

WHEREAS, Children with Familial Dysautonomia lack the most basic reflexes and instincts resulting in an inability for their bodies to

function normally; and

WHEREAS, Children affected by Familial Dysautonomia cannot control their blood pressure or heart rate; they lack the ability to suck at birth and the ability to swallow properly and are at a greater risk of developing pneumonia; and

WHEREAS, Familial Dysautonomia was once thought of as a fatal childhood disease with most children expected to live, on average, only to five years of age; advances in treatment have dramatically extended life expectancy, but children with Familial Dysautonomia still suffer from chronic and often debilitating symptoms that prevent them from leading normal lives; and

WHEREAS, Currently, the average lifespan of the Familial Dysautonomia population is approximately 15 years; the major causes of death are the result of pulmonary complications or sudden death due to autonomic instability; and

WHEREAS, Due to medical advances, it is projected that babies born with Familial Dysautonomia within the last five years will have a 50% chance of surviving to 40 years of age; and

WHEREAS, At present, there is no cure for Familial Dysautonomia; treatments are supportive and preventative; and

WHEREAS, Supportive therapies for Familial Dysautonomia include medications to maintain and regulate cardiovascular, respiratory, and gastrointestinal function; surgical interventions include fundoplication, gastrostomy, spinal fusion, and tear duct cauterization; and

WHEREAS, General population genetic screening is now available; such screening can significantly reduce the frequency of new cases of Familial Dysautonomia; 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 promote screening and to support the patients as well as their families; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim June 10, 2012, 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 to David Brenner, Executive Director, Dysautonomia Foundation, Inc.