

## 2017-J5296

Senate Resolution No. 5296

BY: Senator MARCHIONE

MEMORIALIZING Governor Andrew M. Cuomo to proclaim June 24, 2018, as Cystinuria 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 diseases 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 June 24, 2018, as Cystinuria Awareness Day in the State of New York, in conjunction with the observance of National Cystinuria Awareness Day; and

WHEREAS, Cystinuria occurs in individuals in which a rare genetic defect prevents the body from regulating amino acid concentrations, subsequently leading to elevated levels of cystine and the formation of cystine stones in the kidney, ureter, and bladder; and

WHEREAS, The American Urological Association recognizes Cystinuria as the most common monogenic kidney stone disorder; and

WHEREAS, The majority of Cystinuria patients start to suffer from chronic cystine stone formation before the age of 20; and

WHEREAS, Cystinuria patients often endure episodes of debilitating pain (typically known as renal colic), nausea, vomiting, and recurrent urinary tract infections; and

WHEREAS, The majority of Cystinuria patients will require numerous stone removal procedures and surgeries; and

WHEREAS, Studies have demonstrated Cystinuria patients have worse health related quality of life than the general population, specifically in areas of general health, bodily pain, and mental health; and

WHEREAS, Cystinuria patients may suffer from life threatening complications, such as hypertension, renal insufficiency, end stage renal disease, and the need for a kidney transplant; and

WHEREAS, The majority of Cystinuria patients forming recurrent stones will develop some form of chronic kidney disease in their lifetime; and

WHEREAS, There is no cure for Cystinuria, treatment options significantly reduce medically necessary surgeries and some patients can live a stone-free life; and

WHEREAS, Cystinuria can be diagnosed from analysis of a 24-hour urine test; and

WHEREAS, Detection may be improved by increased education and screening, as many patients do not receive a diagnosis until after enduring one or more stone episodes; and

WHEREAS, Early diagnosis is important to the long-term management of a Cystinuria, which can potentially limit permanent kidney damage and

persevere maximal kidney function; and

WHEREAS, One in every 10,000 Americans are believed to be genetically at risk for Cystinuria; and

WHEREAS, Cystinuria has been documented as a leading risk factor for one of the top most common forms of kidney stones; and

WHEREAS, A significant economic burden is associated with kidney stones, with annual estimates exceeding \$5 billion; this economic toll includes both direct treatment costs, and the indirect costs associated with lost worker productivity; and

WHEREAS, Doctors at New York University-Langone have world-leading expertise on Cystinuria; and

WHEREAS, Well-supported research funding for Cystinuria will lead to improved screening and treatment, improved quality of life, and expedite the development of a cure; and

WHEREAS, This Legislative Body encourages steps be taken to raise awareness of and increase public knowledge about Cystinuria; to inform all people in New York about the dangers of Cystinuria; to disseminate information on the importance of early diagnosis and management of Cystinuria patients; to support research funding of Cystinuria at New York medical research centers to improve screening and treatment for Cystinuria; to support efforts that may improve the quality of life for Cystinuria patients; and to develop a cure for Cystinuria; now, therefore, be it

RESOLVED, That the Legislative Body pause in its deliberations to memorialize Governor Andrew M. Cuomo to proclaim June 24, 2018, as

Cystinuria Awareness Day in the State of New York, in conjunction with the observance of National Cystinuria Awareness; and be it further

RESOLVED, That this Legislative Body pause further to call on the people of New York, interest groups, and affected persons to promote awareness of Cystinuria, to take an active role in the fight against this devastating disease, and to observe National Cystinuria Awareness Day with appropriate ceremonies and activities; 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.