

BY: Senator LANZA

MEMORIALIZING Governor Kathy Hochul to proclaim June 9, 2024, as Batten Disease 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 Kathy Hochul to proclaim June 9, 2024, as Batten Disease Awareness Day in the State of New York, in conjunction with the observance of International Batten Disease Awareness Day; and

WHEREAS, Batten Disease, also known as Spielmeyer-Vogt-Sjogren-Batten Disease, is an extremely rare, fatal, and inherited disorder of the nervous system which usually begins in childhood between the ages of five and ten; out of every 100,000 babies born in the United States, it is estimated about two to four have this disease that is passed down through families; and

WHEREAS, These nervous system disorders are called neuronal ceroid lipofuscinosis (NCLs) which get worse over time; and

WHEREAS, There are four different types: Congenital NCL which affects babies and can cause them to be born with seizures and abnormally small heads; Infantile NCL (INCL) usually shows up between the ages of six months and two years, and can cause microcephaly, as well as sharp contractions in the muscles; Late Infantile NCL (LINCL) typically starts between the ages of two and four with symptoms like seizures that do not get better with medication, and includes the loss of muscle coordination; and Adult NCL (ANCL) which starts before the age of 40; unfortunately, all types lead to premature death; and

WHEREAS, Buildup of fatty substances, called lipopigments, in the cells of the brain, central nervous system and retina in the eye causes seizures, cognitive decline, loss of eyesight, speech, and mobility; and

WHEREAS, Batten Disease was first recognized in 1903, by Dr. Frederick Batten, however, the first genes causing Neuronal Ceroid Lipofuscinosis were not identified until 1995; and

WHEREAS, Although there is currently no known cure for Batten Disease, some symptoms, such as seizures, can be treated with medication, and treatment for one of the forms (CLN2 disease) has been approved by the United States Food and Drug Administration; and

WHEREAS, Founded in Spanaway, Washington, by Judith A. Grant, the Batten Disease Support and Research Association (BDSRA) is the largest support and research organization dedicated to all forms of Batten

Disease in North America; and

WHEREAS, The Batten Disease Registry was established in 1987 at the NYS Institute for Basic Research in Staten Island, as a national database for individuals with Batten Disease for researchers, and remained there until 2019 before being moved to the national BDSRA office in Ohio; and

WHEREAS, The Metro NY/NJ Chapter of BDSRA was formed in 2001, after recognizing there were several families in the Metro area with children stricken by Batten Disease; and

WHEREAS, BDSRA helps to provide the following to those afflicted with this incurable disease and their families by organizing an annual conference, and providing monthly e-newsletter and email alerts, phone consultations to find community resources and provide support, closed Facebook group for parents and caregivers, "Ask-an-Expert" Facebook chats, outreach to bereaved parents, educational consultations and advocacy and referrals for carrier/genetic testing; and

WHEREAS, It is imperative that there be greater awareness of this serious health condition, and more must be done to increase activity at the local, State and National levels; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim June 9, 2024, as Batten Disease 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 Kathy Hochul, Governor of the State of New York; and the Metro NY/NJ Chapter of BDSRA.