

2023-K454

Assembly Resolution No. 454

BY: M. of A. McDonald

MEMORIALIZING Governor Kathy Hochul to proclaim October 2023, as Rett Syndrome Awareness Month in the State of New York

WHEREAS, The State of New York takes great pride in recognizing official months established to increase awareness of serious health issues that affect the lives of all New Yorkers; and

WHEREAS, This Legislative Body is justly proud to memorialize Governor Kathy Hochul to proclaim October 2023, as Rett Syndrome Awareness Month in the State of New York, in conjunction with the observance of National Rett Syndrome Awareness Month; and

WHEREAS, Rett syndrome is a postnatal genetic neurological disorder that occurs primarily in females and rarely in males; and

WHEREAS, Symptoms in children usually do not appear until 6 to 18 months, and a regression period leads to lifelong impairments with multiple dysfunctions: speech is lost, seizures can develop, scoliosis occurs, many develop irregular breathing patterns, and more than half of the people with Rett syndrome lose their ability to walk; the hallmark sign of Rett syndrome is near constant retentive hand movements while awake; and

WHEREAS, Those diagnosed with Rett syndrome require maximum assistance with daily living activities; however, the disorder is not degenerative, and biomedical research suggests that neurological symptoms may be reversed even after decades of severe symptoms; and

WHEREAS, With the discovery of the gene that causes Rett syndrome,

research in the lab proves the theory of reversibility of the disease, the discovery of breakthrough testing in vitro models, and the launch of multiple disease-modifying human clinical trials; we have now reached an unprecedented and historic moment in time where we must do everything possible to fund the truly life-changing research in front of us; and

WHEREAS, It is imperative that there be greater awareness of this serious health condition, and more must be done to increase activity within the medical community, therapists, teachers, caregivers, and the general public as well, and it is important for funding to be available for researchers who are dedicated to finding a cure for Rett syndrome; through these efforts, it is possible to create a world without Rett syndrome; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim October 2023, as Rett Syndrome Awareness Month in the State of New York; and be it further

RESOLVED, That a copy of this Resolution, suitably engrossed, be transmitted to The Honorable Kathy Hochul, Governor of the State of New York.