

BY: Senator ROLISON

memorializing Governor Kathy Hochul to proclaim
May 16, 2026, as Congenital Disorders of
Glycosylation (CDG) Awareness Day in the State of
New York

WHEREAS, The State of New York takes great pride in recognizing days of awareness of serious medical conditions with hopes of increasing education as well as finding treatments and cures; 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 May 16, 2026, as Congenital Disorders of Glycosylation (CDG) Awareness Day in the State of New York, in conjunction with World Congenital Disorders of Glycosylation Awareness Day; and

WHEREAS, Congenital Disorders of Glycosylation (CDG) are a group of rare metabolic disorders that affect normal organ development and the neurological system, leaving children, adolescents, and adults impaired with significant physical and developmental disability; and

WHEREAS, CDGs have lifelong impacts on individuals with these disorders, and symptoms range from mild to severe; effects of CDGs include low muscle tone, failure to thrive due to slow growth, developmental delay, liver disease, bleeding and abnormal blood clotting, seizures, high susceptibility to illness, and cerebellar hypoplasia; and

WHEREAS, Individuals with CDGs often spend a significant amount of time in hospitals and seeing doctors and specialists, and caregivers dedicate countless hours to caring for, loving, and supporting individuals with CDGs; and

WHEREAS, CDGs are severely under-diagnosed and misdiagnosed, with only approximately 1,200 cases diagnosed with CDG globally, and only approximately 350 cases currently reported in the United States; PMM2-CDG is the most commonly diagnosed CDG, with roughly 900 patients identified worldwide; and

WHEREAS, Although most forms of CDGs do not yet have a treatment or cure, early diagnosis of CDGs is important to ensure timely management of clinical complications, genetic counseling, and available treatment and therapeutic remedies; and

WHEREAS, Lack of public awareness and visibility of CDGs contributes to under-diagnosis and difficulties in assessing specialized services and proper rehabilitation and support; and

WHEREAS, CDG Awareness Day provides the opportunity for families and patients affected by these conditions to share their experiences and

knowledge with the public, so that we all may be made more aware of how CDGs impact the lives of many individuals; 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 to increase awareness, spread education, improve diagnosis, and work towards effective treatment; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim May 16, 2026, as Congenital Disorders of Glycosylation (CDG) Awareness Day; 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.