

2025-K149

Assembly Resolution No. 149

BY: M. of A. Jones

MEMORIALIZING Governor Kathy Hochul to proclaim October 2025 as Cockayne Syndrome Awareness Month in the State of New York

WHEREAS, It is the custom of this Legislative Body to recognize official months that are set aside to increase awareness of serious health 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 Kathy Hochul to proclaim October 2025 as Cockayne Syndrome Awareness Month in the State of New York; and

WHEREAS, Cockayne Syndrome (CS) is a rare and terminal neurodegenerative disorder caused by mutations in the ERCC6 or ERCC8 genes, classified as one of more than 50 types of leukodystrophy, with incidences in approximately two to three newborns per million in the United States and Eastern Europe; and

WHEREAS, Cockayne Syndrome is a terminal autosomal recessive genetic disorder with a life expectancy of 12 to 20 years, profoundly affecting children and their families; and

WHEREAS, Individuals with CS are characterized by certain physical traits, including short stature, microcephaly, sunken eyes, a beaked

nose, and prominent ears, as well as progressive symptoms such as rapid aging, hearing and vision loss, speech and mobility impairment, and difficulties with swallowing; and

WHEREAS, Children with CS face additional challenges, including developmental delays, joint pain, hip abnormalities, thermodysregulation, elevated liver enzymes, and extreme sensitivity to sunlight, while also being recognized for their uniquely jovial and joyful demeanor; and

WHEREAS, Many families affected by CS experience immense financial burdens due to the high costs of adaptive supplies and equipment, medical travel, home and vehicle modifications, and therapies such as physical, occupational, speech, aquatic, and hippotherapy, which are essential for symptom management but often not covered by insurance; and

WHEREAS, Raising awareness of Cockayne Syndrome is critical to supporting research, improving access to care, and fostering understanding and compassion for those affected by this devastating disorder; and

WHEREAS, New York State has previously proclaimed October as Cockayne Syndrome Awareness Month to bring attention to this rare disease and the challenges faced by affected families; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim October 2025 as Cockayne

Syndrome Awareness Month in the State of New York, to recognize the strength and resilience of families affected by this disorder, and to encourage continued efforts to support research, education, and

advocacy; 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.