Senate Resolution No. 809

BY: Senator ASHBY

MEMORIALIZING Governor Kathy Hochul to proclaim May 15, 2025, as Prader-Willi Syndrome 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, It is the sense of this Legislative Body to memorialize Governor Kathy Hochul to proclaim Thursday, May 15, 2025, as Prader-Willi Syndrome Awareness Day in the State of New York; and

WHEREAS, Prader-Willi syndrome is a complex genetic disorder that occurs in approximately one out of every 15,000 births, and is the most commonly known genetic cause of life-threatening obesity; and

WHEREAS, Prader-Willi syndrome affects males and females with equal frequency and affects all races and ethnicities; and

WHEREAS, Prader-Willi syndrome causes an extreme and insatiable appetite, often resulting in morbid obesity, which is the major cause of death for individuals with the syndrome; and

WHEREAS, Prader-Willi syndrome also causes cognitive, learning, and behavioral difficulties, such as obsessive-compulsive disorder and difficulty controlling emotions; and

WHEREAS, The hunger, metabolic, and behavioral characteristics of Prader-Willi syndrome force affected individuals to require constant and lifelong supervision in a controlled environment; and

WHEREAS, Despite no cure, early diagnosis of Prader-Willi syndrome allows families to access treatment, intervention services, and support from health professionals, advocacy organizations, and other families who are dealing with the syndrome; and

WHEREAS, With the knowledge that a diagnosis can help families get the therapies and the equipment they need for a child to have a better-quality life, New York State officially added Prader-Willi syndrome to the definition of "Developmental disability" in July of 2017 in order to increase access to supports through the Office for People with Developmental Disabilities; and

WHEREAS, The Prader-Willi Alliance of New York, Inc was founded in 1990 to provide information, promote awareness, facilitate assistance and referral services to families, and to provide support to the national Prader-Willi Syndrome Association, USA; and

WHEREAS, The national Prader-Willi Syndrome Association, USA, is celebrating 50 years of support, advocacy, and progress, with a theme of

"Journey for Hope"; the association is led by CEO Stacy Ward and Board of Directors member Jeffrey Covington representing New York; and

WHEREAS, The Prader-Willi Alliance of New York, Inc's mission is for all people with Prader-Willi syndrome living in New York state to have the hope and support they require; the Alliance is led through the leadership of President Amy McDougall, 1st Vice President Dan Angilolillo, 2nd Vice President Dan Maillet, and countless volunteers and advocates; and

WHEREAS, Recently discovered treatments, such as human growth hormone, and many promising new research studies in New York State help the many difficult symptoms associated with the Prader-Willi syndrome, improving the quality of life for individuals with the syndrome and offering new hope to families; and

WHEREAS, Increased research into Prader-Willi syndrome can lead to a better understanding of the disorder, more effective treatments, and an eventual cure for Prader-Willi syndrome; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim May 15, 2025, as Prader-Willi Syndrome Awareness Day in the State of New York; and be it further

RESOLVED, That this Legislative Body pause further to support raising awareness and educating the public about Prader-Willi syndrome; to applaud the efforts of advocates and organizations that encourage awareness, promote research, and provide education, support, and hope to those impacted by Prader-Willi syndrome; to recognize the commitment of parents, families, researchers, health professionals, and others dedicated to finding an effective treatment and eventual cure for Prader-Willi syndrome; and to support increased funding for research into the causes, treatment, and cure for Prader-Willi syndrome; 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.