Senate Resolution No. 2047

BY: Senator RIVERA

MEMORIALIZING Governor Kathy Hochul to proclaim June 9, 2026, as FSGS Awareness Day in the State of New York

WHEREAS, Chronic kidney disease affects approximately 1 in 7 adults in the United States, and glomerulonephritis-often caused by rare kidney diseases such as focal segmental glomerulosclerosis (FSGS)-is among its leading causes; and

WHEREAS, FSGS is a serious and progressive disease characterized by scarring of the kidney's filtering units, frequently resulting in significant health complications, including kidney failure, the need for dialysis or transplantation, and cycles of remission and relapse; and

WHEREAS, Approximately 50 percent of individuals diagnosed with FSGS will require dialysis or a kidney transplant within 5 to 10 years; and

WHEREAS, Even following kidney transplantation, FSGS may recur in up to 50 percent of patients, underscoring the severity and persistence of this disease; and

WHEREAS, FSGS can affect individuals of all ages but is most commonly diagnosed in adults, particularly those over the age of 45; and

WHEREAS, Rare kidney diseases such as FSGS represent only a small percentage of chronic kidney disease cases, yet account for a disproportionately high percentage of kidney failure; and

WHEREAS, Patients living with FSGS often face significant delays in diagnosis, frequently enduring a diagnostic journey lasting several years, compounded by limited access to specialized nephrology care; and

WHEREAS, FSGS disproportionately impacts minority populations, including African Americans, in part due to genetic risk factors such as variants of the APOL1 gene, contributing to longstanding health disparities; and

WHEREAS, The burden of FSGS extends beyond individual patients and families, placing substantial strain on healthcare systems, including those serving the residents of the State of New York, and contributing to significant public and private healthcare expenditures; and

WHEREAS, There is new hope for patients with FSGS, with clinical trials underway for products that may delay progression of FSGS and the onset of kidney disease, including the first FDA approved therapy in April 2026, and significant progress being made by scientists, regulators, patient groups, and industry through the PARASOL Project to validate proteinuria as an indicator of improvement in patients; and

WHEREAS, In New York State, a diverse population and persistent

health disparities make awareness, early detection, and equitable access to specialized care for rare kidney diseases especially critical; and

WHEREAS, New York is home to leading medical institutions, researchers, and patient advocacy organizations working to advance innovation, improve outcomes, and support those affected by rare kidney diseases such as FSGS; and

WHEREAS, Promising research and clinical trials are underway that may lead to new therapies capable of slowing disease progression and improving quality of life for patients with FSGS; and

WHEREAS, Patients, families, healthcare providers, researchers, and advocacy organizations-including NephCure Kidney International-are working diligently to raise awareness, promote early diagnosis, and expand access to effective treatments; and

WHEREAS, Designating FSGS Awareness Day will help increase public understanding of this rare disease, support those affected, and encourage continued investment in research and care; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim June 9, 2026, as FSGS Awareness Day in the State of New York, and to recognize the importance of education, early detection, and continued research to improve outcomes for all those affected; 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.