

BY: Senator RIVERA

MEMORIALIZING Governor Kathy Hochul to proclaim June 10, 2025, as FSGS Awareness Day in the State of New York

WHEREAS, Approximately one in seven American adults have chronic kidney disease, and a significant driver of chronic kidney disease is glomerulonephritis, often caused by rare kidney diseases such as focal segmental glomerulosclerosis (FSGS); and

WHEREAS, FSGS is a condition referring to scarring of the kidneys, often leading to a difficult journey that can, in many cases, result in kidney failure, requirement of dialysis, transplant, and often cycles of remission and relapse; and

WHEREAS, Approximately 50 percent of patients with FSGS require dialysis or a kidney transplant within five to 10 years of their diagnosis; and

WHEREAS, FSGS is a severe disease because it often rapidly progresses to kidney failure; even for patients with primary FSGS who receive a kidney transplant, FSGS can return in a transplanted kidney approximately 50 percent of the time; and

WHEREAS, FSGS can be diagnosed at any age but is most commonly diagnosed in adults rather than in children and most prevalent in adults over 45 years of age; and

WHEREAS, FSGS is a burden on our healthcare system; a 2019 study estimated that this disease costs Medicaid, Medicare, and private health insurance approximately \$2 billion annually; and

WHEREAS, According to the RaDaR Database, rare kidney diseases like FSGS make up only five to 10 percent of patients with chronic kidney disease but account for approximately 30 percent of incidents of kidney failure; and

WHEREAS, Many patients face delays in being diagnosed with FSGS, due to the difficulty of the rare disease diagnostic odyssey, averaging five to seven years, and challenges in accessing nephrological care that specializes in rare kidney diseases of which there is currently a shortage in the United States; and

WHEREAS, FSGS disproportionately impacts minority populations, including African Americans, often occurring at a rate four to five times higher than with White Americans; Black Americans are also slower to receive access to kidney transplants; and

WHEREAS, African Americans may be impacted more because of certain variants of the APOL1 gene that significantly increase the risk of developing FSGS and other kidney diseases, and these high-risk variants

are found almost exclusively in individuals of African ancestry, contributing to the disproportionate burden of kidney disease in Black communities; and

WHEREAS, FSGS is a significant burden to the health and lives of patients and their families and a costly one, creating great challenges for the healthcare system and healthcare financing of New York State although it is currently a treatable condition; and

WHEREAS, There is new hope for patients with FSGS through numerous clinical trials for products that may delay progression of FSGS and the onset of kidney disease, significant progress being made to validate proteinuria as an indicator of improvement in patients, and a potentially first FDA-approved treatment which is set to be submitted for review later this year; and

WHEREAS, Patients, families, advocacy organizations, healthcare providers, industry, and researchers are working tirelessly to raise awareness, promote early detection, and develop new innovative therapies for FSGS; and

WHEREAS, FSGS Awareness Day is designated to raise awareness of FSGS, provide support and inspiration to patients and families struggling with the disease, and promote the efforts needed for better diagnosis and access to future treatments which can transform the course of the disease; now, therefore, be it

RESOLVED, That this Legislative Body pause in its deliberations to memorialize Governor Kathy Hochul to proclaim June 10, 2025, as FSGS Awareness Day in the State of New York; and be it further

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