

MICHIGAN SENATE

Senate Resolution No. 59

Offered by Senators Hertel, Chang and Santana

A RESOLUTION TO RECOGNIZE JUNE 10, 2025,
AS FOCAL SEGMENTAL GLOMERULOSCLEROSIS (FSGS) DAY

WHEREAS, Approximately 1 in 7 American adults have chronic kidney disease. The third leading cause 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 the scarring in the kidneys, often leading to a difficult journey that can result in kidney failure requiring dialysis, transplant, and often cycles of remissions and relapse; and

WHEREAS, Fifty percent of patients with FSGS require dialysis or a kidney transplant within 5-10 years of their diagnosis; and

WHEREAS, FSGS is a severe disease because it often progresses rapidly to kidney failure. For patients with primary FSGS who receive a kidney transplant, FSGS can recur in their transplanted kidney up to 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 old; and

WHEREAS, This disease is a burden on our healthcare system, with a 2019 study estimating that FSGS costs Medicaid, Medicare, and private health insurance about \$2 billion annually in direct medical costs, not including indirect and quality of life costs; and

WHEREAS, FSGS is a significant burden not just to the health and lives of patients and their families, but also incurs great challenges for the healthcare system and healthcare financing of Michigan; and

WHEREAS, According to the RaDaR Database, rare kidney diseases like FSGS make up just 5-10 percent of chronic kidney disease patients but account for approximately 30 percent of kidney failure; and

WHEREAS, Many patients face delays in being diagnosed with FSGS, due both to the difficulty of the rare disease diagnostic odyssey averaging 5-7 years and challenges in accessing nephrology care that specializes in rare kidney diseases as there is currently a shortage in the United States; and

WHEREAS, Certain variants of the APOL1 gene significantly increase the risk of developing FSGS and other kidney diseases; and

WHEREAS, These high-risk variants are found almost exclusively in individuals of African ancestry. FSGS contributes to the disproportionate burden of kidney disease in Black communities, often occurring at a rate 4-5 times higher than white Americans; 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 potential for FDA approved therapies in the near future, and significant progress being made by scientists, regulators, patient groups, and industry to validate proteinuria as an indicator of improvement in patients; and

WHEREAS, Patients, families, advocacy organizations like NephCure, healthcare providers, industry, and researchers are working tirelessly to raise awareness, promote early detection, and develop new innovative therapies for FSGS and other rare kidney disease patients living in our state; now, therefore, be it

RESOLVED BY THE SENATE, That the members of this legislative body recognize June 10, 2025, as Focal Segmental Glomerulosclerosis (FSGS) Day; and be it further

RESOLVED, That FSGS Awareness Day is designated to raise awareness, provide support and inspiration to patients and families struggling with the disease, and to promote the efforts needed for better diagnosis and access to future treatments that can transform the course of the disease.

Adopted by the Senate, June 11, 2025.



Secretary of the Senate