

## SENATE RESOLUTION NO. 59

Senators Hertel, Chang and Santana offered the following resolution:

1       A resolution to recognize June 10, 2025, as Focal Segmental  
2       Glomerulosclerosis (FSGS) Day.

3       Whereas, Approximately 1 in 7 American adults have chronic  
4       kidney disease. The third leading cause of chronic kidney disease  
5       is glomerulonephritis, often caused by rare kidney diseases such as  
6       focal segmental glomerulosclerosis (FSGS); and

7       Whereas, FSGS is a condition referring to the scarring in the  
8       kidneys, often leading to a difficult journey that can result in  
9       kidney failure requiring dialysis, transplant, and often cycles of  
10      remissions and relapse; and

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

13      Whereas, FSGS is a severe disease because it often progresses

1 rapidly to kidney failure. For patients with primary FSGS who  
2 receive a kidney transplant, FSGS can recur in their transplanted  
3 kidney up to 50 percent of the time; and

4       Whereas, FSGS can be diagnosed at any age, but is most  
5 commonly diagnosed in adults rather than in children and most  
6 prevalent in adults over 45 years old; and

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

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

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

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

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

27       Whereas, These high-risk variants are found almost exclusively  
28 in individuals of African ancestry. FSGS contributes to the  
29 disproportionate burden of kidney disease in Black communities,

1 often occurring at a rate 4-5 times higher than white Americans;  
2 and

3       Whereas, There is new hope for patients with FSGS, with  
4 clinical trials underway for products that may delay progression of  
5 FSGS and the onset of kidney disease, including the potential for  
6 FDA approved therapies in the near future, and significant progress  
7 being made by scientists, regulators, patient groups, and industry  
8 to validate proteinuria as an indicator of improvement in patients;  
9 and

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

15       Resolved by the Senate, That the members of this legislative  
16 body recognize June 10, 2025, as Focal Segmental Glomerulosclerosis  
17 (FSGS) Day; and be it further

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