

SENATE RESOLUTION NO. 59

Senator Hertel 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
14 rapidly to kidney failure. For patients with primary FSGS who

1 receive a kidney transplant, FSGS can recur in their transplanted
2 kidney up to 50 percent of the time; and

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

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

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

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

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

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

26 Whereas, These high-risk variants are found almost exclusively
27 in individuals of African ancestry. FSGS contributes to the
28 disproportionate burden of kidney disease in Black communities,
29 often occurring at a rate 4-5 times higher than white Americans;

1 and

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

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

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

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