

119<sup>TH</sup> CONGRESS  
1<sup>ST</sup> SESSION

# H. RES. 507

Expressing support for the designation of June 10 as “FSGS Awareness Day”.

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## IN THE HOUSE OF REPRESENTATIVES

JUNE 12, 2025

Mr. BILIRAKIS submitted the following resolution; which was referred to the Committee on Energy and Commerce

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## RESOLUTION

Expressing support for the designation of June 10 as “FSGS Awareness Day”.

Whereas approximately 1 in 7 American adults have chronic kidney disease, and the third leading cause of chronic kidney disease is glomerulonephritis, often caused by rare kidney diseases such as focal segmental glomerulosclerosis (FSGS);

Whereas focal segmental glomerulosclerosis is a condition referring to the scarring in the kidneys, often leading to a difficult journey that can in many cases result in kidney failure, requiring dialysis, transplant, and often cycles of remissions and relapse;

Whereas 50 percent of patients with FSGS require dialysis or a kidney transplant within 5–10 years of their diagnosis;

Whereas FSGS is a severe disease because it often progresses rapidly to kidney failure and even for patients with primary FSGS who receive a kidney transplant;

Whereas FSGS can recur in their transplanted kidney up to 50 percent of the time;

Whereas FSGS recurrence can happen quickly posttransplant, sometimes hours to days, and increases the recurrence risk in a future graft to 80 to 100 percent;

Whereas FSGS is a burden on our health care system, with a 2019 study estimating that FSGS costs Medicaid, Medicare, and private health insurance about \$2,000,000,000 annually in direct medical costs, not including indirect and quality of life costs;

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

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

Whereas FSGS disproportionately impacts minority populations, including African Americans, often occurring at a rate 4 to 5 times higher than White Americans;

Whereas, because of certain variants of the APOL1 gene that significantly increase the risk of developing FSGS and other kidney diseases, and because these high-risk variants are found almost exclusively in individuals of Af-

rican ancestry, FSGS contributes to the disproportionate burden of kidney disease in Black communities;

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;

Whereas patients, families, advocacy organizations like NephCure, health care providers, industry, and researchers are working tirelessly to raise awareness, promote early detection, and develop new innovative therapies for FSGS;

Whereas millions of dollars have been raised for research on the severe rare kidney disease FSGS at the Tampa Pig Jig, an event started in 2011 when 3 friends wanted to raise money for a friend diagnosed with the rare kidney disease FSGS and is now attended by about 10,000 people annually in pursuit of a cure for this devastating disease; 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 to promote the efforts needed for better diagnosis and access to future treatments that can transform the course of the disease: Now, therefore, be it

- 1       *Resolved*, That the House of Representatives—
- 2               (1) expresses support for the designation of
- 3       “FSGS Awareness Day”;

1           (2) applauds the efforts of advocates and orga-  
2           nizations that encourage awareness, promote re-  
3           search, and provide education, support, and hope to  
4           those impacted by FSGS, including those suffering  
5           from recurrent FSGS; and

6           (3) recognizes the commitment of parents, fam-  
7           ilies, researchers, health professionals, industry, and  
8           others dedicated to finding an effective treatment  
9           and eventual cure for FSGS.

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