



SR0273

LRB104 13378 LAW 25703 r

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SENATE RESOLUTION

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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); and

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WHEREAS, FSGS is a condition referring to scarring in the kidneys, often leading to a difficult journey that can, in many cases, result in kidney failure, requiring dialysis, transplants, cycles of remissions and relapse, and even recurrence; and

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WHEREAS, Of patients with FSGS, 50% of them require dialysis or a kidney transplant within 5 to 10 years of diagnosis; and

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WHEREAS, FSGS is a severe disease because it often progresses rapidly to kidney failure, and even for patients who receive a kidney transplant, it can recur in their transplanted kidney up to 50% of the time; and

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

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

6 WHEREAS, According to data from the National Registry of
7 Rare Kidney Diseases (RaDaR), rare kidney diseases like FSGS
8 comprise only 5% to 10% of chronic kidney disease patients but
9 account for approximately 30% of kidney failure; and

10 WHEREAS, Many patients face delays in being diagnosed with
11 FSGS, due both to the difficulty of the rare disease
12 diagnostic odyssey, averaging 5 to 7 years, and challenges in
13 accessing nephrology care that specialize in rare kidney
14 diseases due to the current shortage in the United States; and

15 WHEREAS, FSGS disproportionately impacts minority
16 populations, including African Americans, often occurring at a
17 rate 4 to 5 times higher than white Americans; and

18 WHEREAS, Due to certain variants of the APOL1 gene that
19 significantly increase the risk of developing FSGS and other
20 kidney diseases and the fact that these high-risk variants are
21 found almost exclusively in individuals of African ancestry,

1 the condition contributes to the disproportionate burden of
2 kidney disease in Black communities; and

3 WHEREAS, FSGS is a significant burden not only to the
4 health and lives of patients and their families but also
5 because the condition incurs great challenges for the
6 healthcare system and healthcare financing in Illinois; and

7 WHEREAS, There is new hope for patients with FSGS, as
8 clinical trials are underway for products that may delay
9 progression of the condition and the onset of kidney disease,
10 including the potential for FDA-approved therapies in the near
11 future, and significant progress is being made by scientists,
12 regulators, patient groups, and the healthcare industry to
13 validate proteinuria as an indicator of improvement in
14 patients; and

15 WHEREAS, Patients, families, advocacy organizations like
16 NephCure, healthcare providers, the healthcare industry, and
17 researchers are working tirelessly to raise awareness, promote
18 early detection, and develop new innovative therapies for
19 FSGS; and

20 WHEREAS, FSGS Awareness Day is designated to raise
21 awareness of FSGS, to provide support and inspiration to
22 patients and families struggling with the disease, and to

1 promote the efforts needed for better diagnosis and access to
2 future treatments that can transform the course of the
3 condition; therefore, be it

4 RESOLVED, BY THE SENATE OF THE ONE HUNDRED FOURTH GENERAL
5 ASSEMBLY OF THE STATE OF ILLINOIS, that we declare June 10,
6 2025 as FSGS Awareness Day in Illinois to bring attention to
7 the focal segmental glomerulosclerosis (FSGS) disease.