



SR0757

LRB104 21607 RMO 37068 r

1 SENATE RESOLUTION

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

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

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

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

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

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 such as
8 FSGS comprise only 5% to 10% of chronic kidney disease
9 patients but account for approximately 30% of kidney failure;
10 and

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

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

19 WHEREAS, Due to certain variants of the APOL1 gene that
20 significantly increase the risk of developing FSGS and other
21 kidney diseases and the fact that these high-risk variants are
22 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 first FDA-approved therapy in April 2026, and
11 significant progress is being made by scientists, regulators,
12 patient groups, and industry through the PARASOL, or
13 Proteinuria and GFR as Clinical Trial Endpoints in FSGS,
14 Project to validate proteinuria as an indicator of improvement
15 in patients; and

16 WHEREAS, Patients, families, advocacy organizations such
17 as NephCure, healthcare providers, the healthcare industry,
18 and researchers are working tirelessly to raise awareness,
19 promote early detection, and develop new innovative therapies
20 for FSGS patients and those living with other rare kidney
21 diseases in Illinois; and

22 WHEREAS, FSGS Awareness Day is designated to raise

1 awareness of FSGS, to provide support and inspiration to
2 patients and families struggling with the disease, and to
3 promote the efforts needed for better diagnosis and access to
4 future treatments that can transform the course of the
5 condition; therefore, be it

6 RESOLVED, BY THE SENATE OF THE ONE HUNDRED FOURTH GENERAL
7 ASSEMBLY OF THE STATE OF ILLINOIS, that we declare June 9, 2026
8 as FSGS Awareness Day in the State of Illinois to bring
9 attention to focal segmental glomerulosclerosis (FSGS)
10 disease.