



HR0326

LRB104 13381 LAW 25708 r

1 HOUSE 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, cycles of remissions and relapse, and even  
11 recurrence; and

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

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

19 WHEREAS, While FSGS can be diagnosed at any age, it is most  
20 commonly diagnosed in adults rather than in children and most  
21 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 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 HOUSE OF REPRESENTATIVES OF THE ONE  
5 HUNDRED FOURTH GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that  
6 we declare June 10, 2025 as FSGS Awareness Day in Illinois to  
7 bring attention to the focal segmental glomerulosclerosis  
8 (FSGS) disease.