

Senate Resolution 844

By: Senators Albers of the 56th, Kirkpatrick of the 32nd, Watson of the 1st, Still of the 48th, Bearden of the 30th and others

A RESOLUTION

1 Recognizing June 9, 2026, as FSGS Awareness Day in Georgia; and for other purposes.

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

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

8 WHEREAS, 50 percent of patients with FSGS require dialysis or a kidney transplant within
9 5–10 years of their diagnosis; and

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

13 WHEREAS, FSGS can be diagnosed at any age, but is most commonly diagnosed in adults
14 rather than in children and most prevalent in adults over 45 years old; and

15 WHEREAS, FSGS is a burden on our healthcare system, with a 2019 study estimating that
16 FSGS costs Medicaid, Medicare, and private health insurance about \$2 billion annually in
17 direct medical costs, not including indirect and quality of life costs; and

18 WHEREAS, according to the RaDaR Database, rare kidney diseases like FSGS make up just
19 5-10 percent of chronic kidney disease patients but account for approximately 30 percent of
20 kidney failures; and

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

25 WHEREAS, FSGS disproportionately impacts minority populations, including African
26 Americans, often occurring at a rate 4–5 times higher than white Americans; and

27 WHEREAS, because of certain variants of the APOL1 gene that significantly increase the
28 risk of developing FSGS and other kidney diseases, and these high-risk variants are found
29 almost exclusively in individuals of African ancestry, FSGS contributes to the
30 disproportionate burden of kidney disease in Black communities; and

31 WHEREAS, FSGS is a significant burden not just to the health and lives of patients and their
32 families, but also incurs great challenges for the healthcare system and healthcare financing
33 of Georgia; and

34 WHEREAS, there is new hope for patients with FSGS, with clinical trials underway for
35 products that may delay progression of FSGS and the onset of kidney disease, including the

36 potential for FDA approved therapies in the near future, and significant progress being made
37 by scientists, regulators, patient groups, and industry through the PARASOL Project to
38 validate proteinuria as an indicator of improvement in patients; and

39 WHEREAS, patients, families, advocacy organizations like NephCure, healthcare providers,
40 industry, and researchers are working tirelessly to raise awareness, promote early detection,
41 and develop new innovative therapies for FSGS and other rare kidney disease patients living
42 in Georgia; and

43 WHEREAS, FSGS Awareness Day is designated to raise awareness of FSGS, provide
44 support and inspiration to patients and families struggling with the disease, and to promote
45 the efforts needed for better diagnosis and access to future treatments that can transform the
46 course of the disease.

47 NOW, THEREFORE, BE IT RESOLVED BY THE SENATE that the members of this body
48 recognize June 9, 2026, as FSGS Awareness Day in Georgia.

49 BE IT FURTHER RESOLVED that the Secretary of the Senate is authorized and directed
50 to make appropriate copies of this resolution available for distribution to the public and the
51 press.