

Senate Resolution 990

By: Senators Albers of the 56th, Strickland of the 42nd, Dickerson of the 21st, Payne of the 54th, Goodman of the 8th and others

A RESOLUTION

1 Recognizing June 9, 2026, as FSGS Awareness Day at the state capitol; and for other
2 purposes.

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

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

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

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

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

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

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

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

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

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

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

35 WHEREAS, there is new hope for patients with FSGS, with clinical trials underway for
36 products that may delay progression of FSGS and the onset of kidney disease, including the
37 potential for FDA approved therapies in the near future, and significant progress being made
38 by scientists, regulators, patient groups, and industry through the PARASOL Project to
39 validate proteinuria as an indicator of improvement in patients; and

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

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

48 NOW, THEREFORE, BE IT RESOLVED BY THE SENATE that the members of this body
49 recognize June 9, 2026, as FSGS Awareness Day at the state capitol.

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