Date of Hearing: June 30, 2025

### ASSEMBLY COMMITTEE ON RULES

Blanca Pacheco, Chair SCR 87 (Weber Pierson) – As Introduced May 28, 2025

#### SENATE VOTE:

**SUBJECT**: Focal segmental glomerulosclerosis.

**SUMMARY**: Designates June 10, 2025, as Focal Segmental Glomerulosclerosis Awareness Day. Specifically, **this resolution** makes the following legislative findings:

- 1) Approximately one in seven 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).
- 2) FSGS is a condition referring to the scarring in the kidneys, often leading to a difficult condition that can, in many cases, result in kidney failure, requiring dialysis, transplant, and often cycles of remissions and relapse.
- 3) FSGS is a severe disease because it often progresses rapidly to kidney failure, and even for patients with primary FSGS who receive a kidney transplant, FSGS can recur in their transplanted kidney up to 50 percent of the time.
- 4) Many patients face delays in being diagnosed with FSGS due both to the difficulty of obtaining a proper diagnosis of a rare disease, which averages five to seven years, and challenges in accessing nephrology care that specializes in rare kidney diseases, as there is currently a shortage of practitioners in the United States.
- 5) There is new hope for patients with FSGS, with clinical trials underway for products that may delay progression of FSGS and the onset of kidney disease, including the potential for FDA-approved therapies in the near future.
- 6) FSGS Awareness Day is designated to raise awareness of FSGS, to provide support and inspiration to patients and families struggling with the disease, and to promote the efforts needed for better diagnosis and access to future treatments.

**FISCAL EFFECT**: This resolution is keyed non-fiscal by Legislative Counsel.

## **REGISTERED SUPPORT / OPPOSITION:**

## **Support**

None on file

# **Opposition**

None on file

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