

Focal Segmental Glomerulosclerosis

Focal Segmental Glomerulosclerosis (FSGS) is a rare kidney disease characterized by dysfunction in the part of the kidney that filters blood (glomeruli). Only some glomeruli are affected, but continued damage can lead to kidney failure.

Focal = Some Segmental = Sections Glomerulo = of the Filtering Units Sclerosis = Are Scarred

FSGS Symptoms

Early symptoms of FSGS are the same as Nephrotic Syndrome.

Common Symptoms:

- Protein in the urine, which can be foamy (called **proteinuria**)
- Low levels of protein in the blood
- Swelling in parts of the body, most noticeably around the eyes, hands, feet, and abdomen (called **edema**)
- Weight gain due to extra fluid building up in your body
- Can cause high blood pressure (called **hypertension**) and high fat levels in the blood (**high cholesterol**)

Fast Facts

The only way to differentiate FSGS from other primary Nephrotic Syndrome conditions is to have a kidney biopsy.

FSGS in Adults

- FSGS occurs more frequently in adults than in children and is most prevalent in adults **45 years** or older.
- African Americans are **5 times more likely to get FSGS** in comparison with the general population.

FSGS in Children

- Focal Segmental Glomerulosclerosis is one of the leading causes of **End Stage Renal Disease (ESRD)** in children.
- FSGS is associated with up to **20% of all new cases of Nephrotic Syndrome** in children each year.

The exact cause of primary FSGS is **unknown and not precisely understood**. However, genetic and environmental factors may be associated with the disease.

With FSGS, many individuals experience **cycles of remission and relapse**.

Remission means there is **currently no protein spilling** into the urine.

50% of patients with FSGS will progress to kidney failure.

Every FSGS patient follows a **unique journey**.

Some patients receive a kidney transplant to treat their kidney failure due to FSGS, but **FSGS comes back to attack the new kidney 30-50% of the time**.

Treating Your Disease

Short-Term Goals

The short-term goal of treatment is to **stop protein spillage completely** (remission) or lower the amount of protein lost in the urine as much as possible.

Long-Term Goals

The long-term goals of treatment include **preventing relapses** of protein in the urine and **preventing the deterioration** of kidney function.

There are currently **no FDA-approved treatment options** for FSGS. The standard first-line treatment for FSGS is **Prednisone**, a corticosteroid.

How to Live With Your Disease

- 1.** Following a **low-fat, low-sodium diet** will help improve your kidneys' function and your FSGS symptoms.
- 2.** **Finding a nephrologist that you trust** is very important to your long-term health.
- 3.** Learn about your disease, treatment options, and clinical trials in order to **better advocate for yourself.**
- 4.** **NephCure Kidney International can help** you connect with other patients and find support to manage your disease.



NephCure Kidney International is working every day to leverage support to find better treatments and a cure for **Focal Segmental Glomerulosclerosis.**

Please visit **NephCure.org** to learn more about FSGS & Nephrotic Syndrome.