

Focal Segmental Glomerulosclerosis

Overview and Symptoms

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.

- Protein in the urine, which can be foamy (called proteinuria)
- Low levels of protein in the blood
- Swelling in parts of the body, most noticeable 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

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.

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

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

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

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

Please visit [NephCure.org](https://www.NephCure.org) to learn more about FSGS & Nephrotic Syndrome.