

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

Fast Facts

- 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
- Every FSGS patient follows a unique journey.

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.

In the US, approximately **40,000 patients** are living with FSGS.

In the US, there are approximately **20,000 patients** with end-stage kidney disease (ESKD) due to FSGS.

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

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

More than **60% of patients** do not have a durable response to current FSGS treatments

Approximately **1000 FSGS patients** receive kidney transplants every year.

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 specializes in FSGS** 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](https://www.NephCure.org) to learn more about FSGS & Nephrotic Syndrome.