



## Focal and Segmental Glomerulosclerosis (FSGS)

### What is FSGS?

FSGS is a disease of the filters of the kidney (glomeruli). Diseases of the filters of the kidney are called glomerulonephritis. FSGS has its name because of the pattern that the doctor sees when looking at the kidney biopsy under the microscope.

In FSGS, the filters of the kidney are partially scarred in some areas of both kidneys. The name literally means “partial scarring in some areas of the filters of the kidneys”.

Why are the filters of the kidney important?

The filters do the work of the kidneys – they clean toxins from the blood, and prevent cells and protein from spilling into the urine.

### What causes FSGS?

This pattern of kidney scarring can happen for many reasons including high blood pressure, diabetes, having a single kidney, or narrowing of the small blood vessels in the kidney. Rarely infections or medications can cause FSGS. There are some genetic conditions that cause FSGS, but most of the time it does not run in families. Your doctor may test for these conditions.

Often we do not identify the cause for FSGS. It can develop very quickly without a trigger. It is believed that the immune system, which normally fights off infections, may cause FSGS.

### What are the symptoms and signs of FSGS?

The group of signs and symptoms of FSGS are referred to as the “nephrotic syndrome” which can include:

“Proteinuria” refers to protein spilling in the urine and it is found by testing the urine. Higher levels create bubbles in the urine. When a lot of protein leaks into the urine, blood protein levels can be low.

“Edema” means swelling and it can be a sign of GN. Swelling can mean that extra salt and water are being retained by the kidneys.

High cholesterol is part of the nephrotic syndrome and is frequently seen in FSGS.



# Focal and Segmental Glomerulosclerosis FAQ

“Hypertension” means high blood pressure. It has no symptoms unless dangerously high. It is common in FSGS.

Sometimes FSGS can be silent with no symptoms at all. It does not cause pain.

“Creatinine” is a blood test used to estimate how well the kidneys are cleaning. Lower values mean the better the healthier kidneys.

## **What are the treatment options?**

These fall into two categories:

1 – Treatments that do not affect the immune system: These include medicines to control blood pressure, manage swelling, and lower cholesterol. Stopping smoking and healthy lifestyle choices also protect kidneys.

2 – Immune system lowering treatment: These medicines lower the body’s immune system so that it does not attack the glomeruli. These medicines can have more side effects such as infections, and need to be carefully dosed and monitored.

## **How about my diet?**

Your diet did not cause your kidney disease and changes in the diet have not been shown to cure FSGS. However, some changes in diet (ex. Lowering salt) can definitely help with FSGS and treatment side effects. Ask your doctor!

## **What can happen to people with FSGS?**

Sometimes FSGS can permanently scar the kidneys and cause the kidneys to work less effectively (chronic kidney disease) or stop cleaning the blood (kidney failure). People with FSGS are also at higher risk of having infections and blood clots.

## **Hope for the future**

Stay hopeful! We have many treatments for FSGS, as well as the ways to manage swelling, high blood pressure, and high cholesterol. Your doctors will work closely with you to prevent kidney failure and keep you healthy! There are large networks of researchers studying FSGS and new treatments. Participation in a research study is always optional but can be a rewarding experience. Ask your doctor about opportunities to participate in helping to find a cure!