Glomerulonephritis Series

Focal and Segmental Glomerulosclerosis (FSGS)

What is Focal and Segmental Glomerulonephritis (FSGS)?

FSGS is a disease of the filters of the kidney. Your kidneys have 1 million filters that clean toxins (harmful substances) from your blood. These filters, called glomeruli, also prevent cells and protein from spilling out from your blood into the urine.

FSGS is a type of glomerulonephritis (GN), an inflammation in the filters in your kidneys. This is a rare condition that affects your kidney and overall health.

How is FSGS diagnosed?

A kidney biopsy is used to diagnose FSGS. This means a small sample of tissue is taken from your kidney. There are different types of GN. Your doctor will use a microscope to look at the patterns in your biopsy sample to determine the type you have.

FSGS has its name because of the pattern that doctors see when looking at a kidney biopsy sample. Focal and Segmental Glomerulosclerosis literally means “partial scarring in some areas of the filters of the kidneys”.

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What causes FSGS?

FSGS can happen for many reasons. This may include high blood pressure (hypertension), diabetes, having only one kidney, or having small blood vessels in your kidney. The condition can develop quickly without any known trigger.

Sometimes, infections or medications may cause FSGS, but this is rare. Some genetic conditions may also cause the condition, but most often it does not run in families.

Your doctor may do tests to see if you have any other conditions for your FSGS. Often, we aren’t able to find out what the cause is. It’s believed that the body’s immune system, which usually fights off infections when we are sick, may cause FSGS.

Signs and symptoms

The group of signs and symptoms of FSGS are sometimes called the “nephrotic syndrome”. They are often silent and can only be found using blood or urine tests. Once you are diagnosed with FSGS, it is important that you continue to have blood and urine tests to monitor your condition with your health care team.

Some signs may include:

**Swelling (edema)** – Swelling is usually first noticed in the feet, but sometimes also in the face, hands, and belly. Swelling, also called edema, can be a sign that protein is leaking into your urine. It can also mean that salt and water are not being filtered properly by your kidneys.

**High blood pressure (hypertension)** – High blood pressure cannot be felt. It can only be found by measuring the blood pressure in your arm.
Protein in the urine (proteinuria) – High levels of protein create bubbles in the urine. This can be an early sign of GN. When too much protein spills into the urine, the level of protein in your blood is lowered. This can make you more likely to get infections or have other health issues.

Blood in the urine (hematuria) – Blood in the urine may be invisible, or it may make the urine look red.

High creatinine levels – Creatinine is a normal part of your blood. It is measured with a blood test. If your kidneys aren’t cleaning your blood well, they will remove less creatinine from your urine, and more creatinine will appear in your blood. Creatinine levels tells us how well your kidneys are cleaning. Low creatinine levels in the blood mean healthier kidneys.

High cholesterol – Cholesterol levels are often high in the blood of people with GN, even if they eat healthy.

FSGS does not usually cause pain. Tell your doctor if you feel any new pain in your back or legs.

Treatment options
There are 2 types of treatments for people who have FSGS. Your doctor will work with you to decide what treatment will be best for you:

• Option 1: Treatments that do not affect the immune system
  These treatments include medicines to control your blood pressure, manage your swelling, and lower your cholesterol. Quitting smoking and making healthy lifestyle choices are also important ways to protect your kidneys. Some research shows that fish oil supplements may also be helpful.

• Option 2: Immune system lowering treatment
  Medicines are used to lower the body’s immune system response so that it doesn’t attack the kidneys. These medicines can put you at risk of infections. They need to be carefully monitored to be sure you have the right dose.
Do certain foods cause FSGS?
Diet is not considered to be a cause of GN. Changing what you eat will not cure your GN. But, some changes in your food choices like eating foods with less salt, and other changes, can help your symptoms improve. Your treatment side effects may also improve. Ask your health care team for tips on healthy living.

What can I expect living with FSGS?
There are many treatment options for managing your FSGS and your symptoms such as swelling, high blood pressure, and high cholesterol. Your doctors will work closely with you to prevent further scarring, which can lead to kidney failure.

Taking part in research studies
Many scientists are studying FSGS and testing new treatments. Some patients find it rewarding to join research studies, but this is voluntary. Ask your care team if you want to learn more about studies that are happening at your clinic that can help find a cure.

Visit www.uhnpatienteducation.ca for more health information.
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