



Focal Segmental Glomerulosclerosis

What is it?

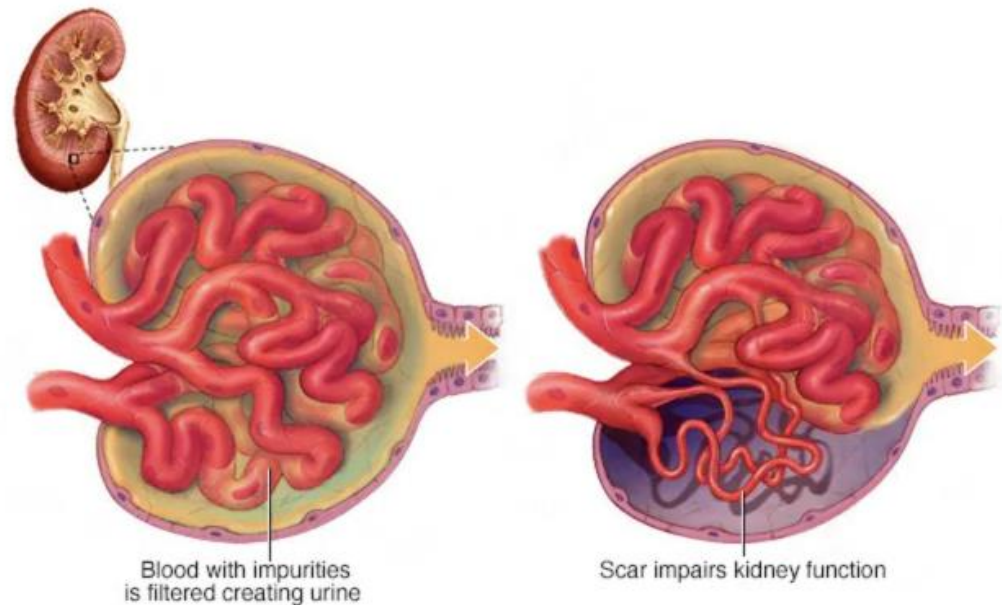
Focal segmental glomerulosclerosis (FSGS) is a kidney disease that affects the glomeruli – the tiny filters of the kidneys. It is a major cause of nephrotic syndrome, a condition where too much protein leaks into the urine.

Here's what happens in FSGS:

- In focal segmental glomerulosclerosis, **some** of the glomeruli (**focal**) and only **parts** of each affected glomerulus (**segmental**) become **scarred (sclerotic)**.
- This scarring prevents the kidneys from properly filtering waste and proteins, allowing protein, especially albumin, to leak into the urine. Normally, proteins should stay in the blood.
- Once scarring happens, it can't be reversed, and if the damage spreads, kidney function can get worse over time. In some cases, this can lead to chronic kidney disease or even kidney failure.

There are two main types of FSGS:

1. **Primary (idiopathic) FSGS** – this type happens for no clear reason and is believed to be linked to problems with the immune system.
2. **Secondary FSGS** – this type happens because of other health issues like obesity, infections, harmful effects of certain medications, another kidney problem, or genetic factors.



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Figure source: <https://www.mayoclinic.org/diseases-conditions/fsgs/symptoms-causes/syc-20354693#dialogId42663901>

The symptoms of FSGS may develop gradually or suddenly, depending on the type of FSGS, and may include:

- Swelling (edema) – puffiness in the legs, ankles, feet, and/or around the eyes.
- Foamy or bubbly urine – due to excess protein leaking into it.
- Weight gain – caused by fluid retention, not actual fat gain.
- Feeling tired.

The complications of FSGS may include:

- Risk of declining kidney function, which may lead to kidney failure.
- Elevated cholesterol (fats) in your blood.
- More frequent infections – the immune system may not work as well due to protein loss.
- Risk of blood clots – the clotting system may not work as well due to protein loss.
- High blood pressure – the kidneys help regulate blood pressure, so damage to the kidneys can cause it to rise.



What happens after you have been diagnosed with FSGS?

- After your kidney biopsy is reported and a final diagnosis of FSGS is made, your kidney doctor (nephrologist) and/or kidney care team may order further tests or scans, and will discuss appropriate treatment with you.
- The effects of FSGS on the kidneys are variable and the path of the disease is different for each patient. For some people, FSGS may progress slowly; for others it may progress more rapidly. Your kidney care team will talk to you about the seriousness of your case and your treatment plan.

How is FSGS treated?

General measures:

These measures are used in both types of FSGS as needed:

- Diuretics ("water pills") – these help remove extra fluid from the body to reduce swelling.
- Low-salt diet – eating less salt helps prevent swelling and fluid buildup.
- Medications that reduce protein in the urine – some blood pressure and other medications can help reduce protein leakage in the urine and slow down kidney damage.
- Cholesterol medication – if your cholesterol is high, statins may help reduce stroke and heart attack risk.
- Urine and lab tests: Your kidney doctor and/or kidney care team will follow you closely with frequent urine and lab tests to monitor your response to treatment and help you manage any symptoms.
- Antibiotics during immunosuppressive therapy: If you are receiving immunosuppressive therapy, depending on its type, you may be started on a combination of trimethoprim and sulfamethoxazole. These antibiotics are used to reduce the risk of very serious infection that can occur in patients on medications that reduce the immune response.
- Medication options: Your kidney doctor and/or kidney care team will help you to learn about the medication options that would be best for you.
- Medication cost: BC Renal covers the cost of a wide range of medications used for FSGS treatment.

Active (immunosuppressive) therapies:

- These are usually used in the primary (idiopathic) FSGS only. Not all cases require these medications.
- Their use depends on different factors such as the amount of protein leakage and scarring in your kidneys.
- Options include:
 - Prednisone
 - Tacrolimus
 - Mycophenolate mofetil
 - Cyclophosphamide
 - Rituximab
- During active therapy, you are at high risk of bacterial and viral infection. If you develop a fever, please seek medical attention immediately.



- **Important:** Patients need to check with their kidney doctor and/or kidney care team before taking any over-the-counter (OTC) medications and natural health products.
- **Important:** Patients with chronic kidney disease like FSGS need to keep their vaccinations updated, since some treatments may reduce the effectiveness of vaccination. You are encouraged to discuss with your kidney doctor and/or kidney care team what vaccinations may be appropriate for you.
- **Important:** Pregnancy may impact kidney function. If you are planning a pregnancy, please consult with your kidney doctor.
- **Important:** Smoking cessation is important – it can help slow down the worsening of kidney disease.

Living with FSGS

- **Support of kidney care team:** BC kidney patients registered with BC Renal have access to a comprehensive kidney care clinic team that includes nurses, dietitians, social workers, as well as pharmacists in most cases.
- **Support for your wellbeing:** It will be important for you to stay active and healthy. The Kidney Foundation's online Kidney Wellness Hub (<https://kidneywellnesshub.ca/>) has a lot of useful information. It covers staying active, eating well, mental wellbeing, and socially connecting, including peer support groups. It also provides online classes, webinar recordings, and activity suggestions for patients of all ability levels.
- **Ongoing follow-up:** Most people start feeling better within a few months, while others need more time to fully recover. Relapses can occur over the long term. You will need ongoing follow-up with your kidney doctor and/or kidney care team.
- **Relapses due to respiratory and other infections:** Please note that respiratory and other infections could trigger a relapse in the disease, and a sign of relapse may be visible as foam in the urine and/or swelling. Consult your doctor as early as you see foam in the urine, or you start to have swelling after an infection.
- **Risk of kidney failure:** There is a proportion of people living with FSGS who will end up with kidney failure despite treatment. If your kidneys fail, your treatment options may include transplant, dialysis, and conservative care¹. Your kidney doctor and/or kidney care team will be there to educate and support you throughout your journey.

¹ Conservative care, sometimes called conservative kidney management (CKM) or supportive kidney care, focuses on treating the symptoms of kidney failure to make you feel as well as possible. It does not treat the causes or attempt to cure kidney failure. Although conservative care does not include dialysis or transplant, it does include all of the other parts of kidney care and support from your team. For more information see this BC Renal's handout: http://www.bcrenal.ca/resource-gallery/Documents/Patient_Guide-Transitioning_to_Conservative_Care-Kidney_Care_Clinics.pdf.



- Participation in clinical trials: Sometimes, people living with FSGS may be invited to participate in a clinical trial for new therapies and medications. If you choose to volunteer in a trial, your kidney doctor and/or kidney care team will help you navigate the process.

Further information

- There may be a lot of confusing information about FSGS and other kidney diseases on the Internet. The following websites are good sources of information for people living with FSGS:
 - The Kidney Foundation of Canada - <https://kidney.ca/>
 - Kidney Wellness Hub - <https://kidneywellnesshub.ca/>
 - BC Renal GN web page - <http://www.bcrenal.ca/health-info/kidney-care/glomerulonephritis>
 - Focal segmental glomerulosclerosis webpage by Glomcon.org - [https://www.glomcon.org/kidney-diseases/focal-segmental-glomerulosclerosis-\(fsgs\)](https://www.glomcon.org/kidney-diseases/focal-segmental-glomerulosclerosis-(fsgs))
 - Focal segmental glomerulosclerosis video by Osmosis.org - [https://www.osmosis.org/learn/Focal segmental glomerulosclerosis \(NORD\)](https://www.osmosis.org/learn/Focal_segmental_glomerulosclerosis_(NORD))
- If you continue to have questions about your condition or treatment, please keep track of these questions and ask your kidney doctor and/or your kidney care team.