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Focal Segmental Glomerulosclerosis (FSGS)

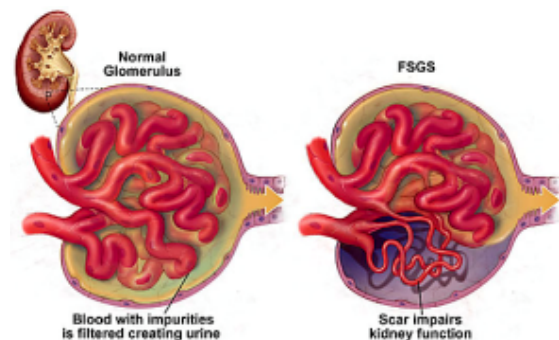
What is FSGS?

Focal = some

Segmental = sections

Glomerulo = of kidney filters

Sclerosis = are scarred



FSGS is a rare disease that attacks the kidney's filtering units (glomeruli) causing serious scarring which leads to permanent kidney damage and even failure. FSGS is one of the causes of a serious condition known as Nephrotic Syndrome.

Each kidney is made up of approximately one million tiny filters called "glomeruli." Much as a coffee filter keeps coffee grounds in, glomeruli filter the blood, taking out the water-like part which becomes urine and leaving the protein in the blood. When glomeruli become damaged or scarred (sclerosis), proteins begin leaking into the urine (proteinuria). The word "focal" is added because in FSGS, only some of the glomeruli filters become scarred. "Segmental" means that only some sections of the glomerulus becomes scarred, just parts of them.

How is FSGS Diagnosed?

FSGS is diagnosed with renal biopsy (when doctors examine a tiny portion of the kidney tissue), however, because only some sections of the glomeruli are affected, the biopsy can sometimes be inconclusive.

What are the Symptoms of FSGS?

Many people with FSGS have no symptoms at all. When symptoms are present the most common include:

Proteinuria – Large amounts of protein “spilling” into the urine

Edema – Swelling in parts of the body, most noticeable around the eyes, hands and feet, and abdomen which causes sudden weight gain.

Low Blood Albumin Levels because the kidneys are removing albumin instead of returning it to the blood

High Cholesterol in some cases

High Blood Pressure in some cases and can often be hard to treat

FSGS can also cause **abnormal results** of **creatinine** in laboratory tests. Creatinine is measured by taking a blood sample. Everyone has a certain amount of a substance called creatinine floating in his or her blood. This substance is always being produced by healthy muscles and normally the kidneys constantly filter it out and the level of creatinine stays low. But when the filters become damaged, they stop filtering properly and the level of creatinine left in the blood goes up.

What Causes FSGS?

FSGS is usually “idiopathic,” which means it arises without a known cause. There are some known **genetic** causes of FSGS, with new gene variants continually being discovered.

FSGS can be “primary” or “secondary” in nature.

Primary FSGS means that the disease happened on its own with out a known or obvious reason.

Secondary FSGS means that doctors think the FSGS was caused by, or is associated with, another medical condition that occurred first. How the other condition caused the FSGS scarring is not always certain. Some causes of secondary FSGS include:

- Kidney defects from birth (dysplasia)

- Urine backing up into kidneys (kidney reflux)
- Obesity
- Obstructive Sleep Apnea
- Viruses and blood disorders (such as HIV and sickle cell anemia)
- Autoimmune disorders (such as lupus and HSP)

Who Gets FSGS?

More than 5400 patients are diagnosed with FSGS every year, however, this is considered an underestimate because:

- a limited number of biopsies are performed
- the number of FSGS cases are rising more than any other cause of Nephrotic Syndrome.¹

FSGS occurs more frequently in adults than in children and is most prevalent in adults 45 years or older.

FSGS is most common in people of African American and Asian descent.

How is FSGS Treated?

Currently there are few FDA approved treatments for FSGS, but usually a steroid called prednisone or prednisolone is given to try and control proteinuria. Proteinuria Treatment aims to decrease the amount of protein lost in the urine. The less protein in the urine, the better the patient will do. In FSGS, even partial remission is important.

Your nephrologist may also recommend:

- Medications that suppress your immune system
- Diuretics and low salt diet help to control edema
- A medication that blocks a hormone system called the renin angiotensin system (ACE inhibitor or ARB) to control blood pressure or lower urine protein
- Anticoagulants to prevent blood clots
- Statins to lower the cholesterol level
- Maintaining a healthy diet: Correct amounts of protein and fluid intake according to your nephrologist's recommendations. A healthy diet consists of low salt with emphasis on fruits and vegetables, low in saturated fat and cholesterol. A low salt diet may help with swelling
- Exercising
- Not smoking
- Vitamins

Learn more about specific medications in the [Treatment Options](#) section of our website.

Learn more here: [Focal Segmental Glomerulosclerosis Fact Sheet](#)

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NephCure Kidney International ® is the only organization committed exclusively to support research seeking the cause of the potentially debilitating kidney disease Focal Segmental Glomerulosclerosis (FSGS) and Nephrotic Syndrome, improve treatment and find a cure.

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CONTACT US

150 S. Warner Road
 Suite 402
 King of Prussia, PA 19406
 1.866 NephCure (637-4287)
info@nephcure.org

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