



some = Focal
 sections of = Segmental
 kidney filters = Glomerulo
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How can research help?

Research, which often requires patient participation, can lead to a better understanding of the causes, provide better diagnoses and more effective treatments, and ultimately help to find a cure.

Be part of the discovery: By studying patients, researchers can more quickly unlock the mysteries of this disease.

To get involved in research and stay informed, go to:

www.Nephrotic-Syndrome-Studies.org

or call 1-866-NephCure



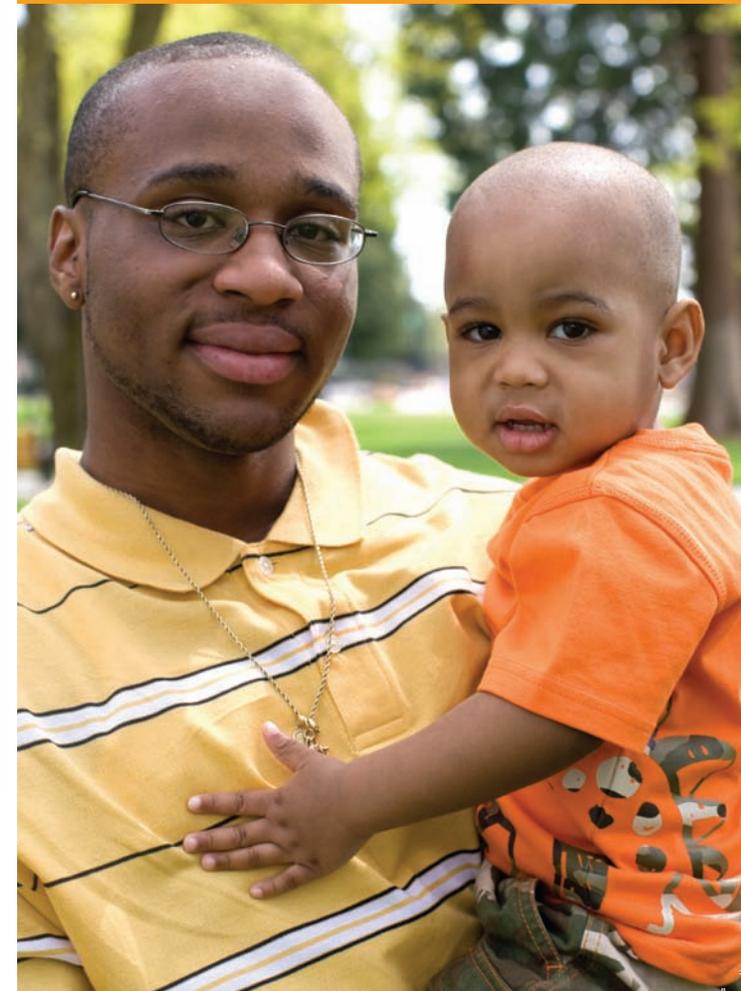
Nephrotic Syndrome Study Network

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FSGS

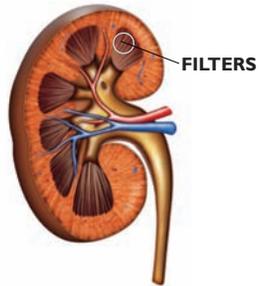
Focal Segmental
 Glomerulosclerosis



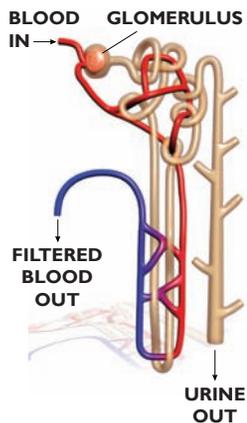
What is Focal and Segmental Glomerulosclerosis?



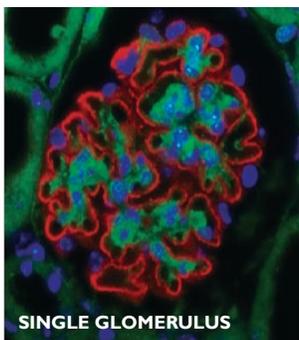
Each person has two kidneys in their lower back.



The kidneys continuously filter blood and produce urine to remove waste products, salts and excess fluid.



Each kidney is made up of approximately one million tiny filters called "glomeruli." Much as a coffee filter keeps coffee grounds in, glomeruli keep valuable cells and protein in the blood.



When glomeruli become damaged, proteins begin leaking into the urine (proteinuria). Proteinuria causes fluid to accumulate in the body and prolonged leakage can lead to kidney damage and even failure.

Symptoms, Diagnosis and Treatment

Focal Segmental Glomerulosclerosis (FSGS) is a rare disease that attacks the kidney's filtering system (glomeruli) causing scarring of the filter. FSGS is one of the causes of a condition known as Nephrotic Syndrome (NS).

What are some symptoms of FSGS?

- Proteinuria – Large amounts of protein "spilling" into the urine
- Edema – Swelling in parts of the body, most noticeable around the eyes, hands and feet, that can become painful
- Hypertension – High blood pressure
- Hypoproteinemia – Low blood protein
- Hypercholesterolemia – High level of cholesterol in the blood

How is FSGS diagnosed?

A series of tests are ordered:

- Urine: determine the amount of protein in the urine
- Blood: determine levels of protein, creatinine, albumin, cholesterol and others
- "Glomerular Filtration Rate" (GFR): an estimate of kidney function
- Kidney ultrasound
- Kidney Biopsy: Removal of a small portion of the kidney for examination under the microscope
- Genetic testing may be helpful in some cases

How is FSGS treated?

Currently there are no FDA approved treatments, but usually a steroid called prednisone or prednisolone, is given to control proteinuria.

Your nephrologist may also recommend:

- 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 control cholesterol
- Maintaining a healthy diet – Correct amounts of protein and fluid intake according to your nephrologist's recommendations
- Exercising
- Not smoking
- Vitamins

What causes FSGS?

Some cases of FSGS are "idiopathic" which means it occurs with no known cause. Others are due to genetic mutations. Some cases are secondary to various medical conditions. Researchers are actively trying to learn more.

Who gets FSGS?

Children and adults of all ages and races can get FSGS. People of African ancestry have an increased risk of getting FSGS. In children, it is the second most common cause of NS and the second leading cause of kidney failure.

What are the complications of FSGS?

A high percentage of patients with FSGS do not respond to steroids. Other treatment options are available to control proteinuria but some carry significant side effects. FSGS can recur in some patients who receive a kidney transplant.