Focal Segmental Glomerulosclerosis (FSGS)

What is FSGS?

Focal Segmental Glomerulosclerosis (FSGS) describes a group of kidney diseases that all affect the filters (glomeruli) of the kidneys in a similar way, causing scarring and sometimes collapse of the filters.

What Causes FSGS?

The underlying cause of this damage is not known in “primary” FSGS. There are likely different causes in different groups of people. There may be problems in a person’s immune system that allows the damage, or there may be genetic mutations that weaken the proteins that help build the filters.

There are other forms of FSGS that are caused by certain diseases. After you have a kidney biopsy, your kidney doctor can tell you what kind of FSGS you have. Then they might be able to find out what caused it. Most of the time we don’t know the answer.

How common is FSGS?

While FSGS is not common, it is the cause of over 2% of the cases of kidney failure in the United States. There are over 10,000 people living with dialysis or with a kidney transplant because of FSGS.

What are the Symptoms of FSGS?

The main signs of FSGS are high blood pressure and high levels of protein in the urine. Sometimes people may develop “nephrotic syndrome”, where the amount of protein lost in the urine is so high that swelling (edema) in the body occurs. This may show up as puffiness around the eyes, or swelling in the legs.

How is FSGS Diagnosed?

Since FSGS is only one of many glomerular (filter) diseases that can cause similar problems, a kidney biopsy is needed to diagnose it.

How is FSGS Treated?

Several different medications are used to treat FSGS. Different treatments are used for different forms of FSGS.

Control of the blood pressure is very important, and a group of blood pressure medications called ACE inhibitors are usually used in FSGS. Not only do they help lower the blood pressure, but they also may help decrease the amount of protein in the urine, and protect the kidneys from more damage. Cholesterol medications may also be needed, since a high cholesterol level is often a problem in patients with FSGS, especially those with nephrotic syndrome.

Drugs used to calm down inflammation and the immune system (immunosuppressant drugs) may also be used, starting with corticosteroids (prednisone, or prednisolone). If these are not effective in controlling the disease, other medications which work through either the immune system or by stabilizing the structure of the glomeruli (kidney filters) may be added. The most common medications used for this are cyclosporine and tacrolimus. Mycophenolate has also been used.

What May Happen in the Future?

Some types of severe FSGS do not respond well to treatment, and may lead to rapid damage of the kidneys and kidney failure in 1-2 years. Other forms respond well to therapy, or damage the

kidneys much more slowly, and may never cause kidney failure. It is not always possible to tell which kind of FSGS a person has when they are first diagnosed, and there are no specific tests that tell doctors exactly which medication will work in which patient. Doctors and patients need to work together to find the best therapy for each person.

For more information on FSGS, the following links are helpful:
National Kidney Foundation
http://www.kidney.org/
UNC Kidney Center
http://www.unckidneycenter.org