

# Idiopathic Focal Segmental Glomerulosclerosis (FSGS)

## What is it?

Your kidney biopsy has shown that your swelling and protein leak (nephrotic syndrome) is caused by a condition called 'Focal Segmental Glomerulosclerosis' (FSGS). This means that there is a lot of damage and scarring to the kidney. Little is known about the actual cause of the damage, but it appears to be some sort of antibody (a special kind of blood protein) in your own circulation that attacks the kidneys.

While the symptoms of the nephrotic syndrome may be unpleasant, the main worry with this condition is that it damages kidney function in the longer term. There is a 50% risk of renal failure after five years, and this rises with the amount of proteinuria (protein in your urine). It is also a condition that is very likely to recur after a kidney transplant.

There is a type of treatment that has been shown to cure about one third of people with FSGS. If the treatment works, the risk of future kidney failure is very small. If the treatment does not work, then the 50% risk of kidney failure remains.

## What is the treatment for FSGS?

### Initial treatment

The treatment, which we offer at this hospital, is one that is quite intensive for six months and may have side effects. This needs to be balanced against the risk of kidney failure without treatment.

<i>Prednisolone</i>	1mg/kg of body weight (max 80mg) daily minimum 4-6 months
<i>Lansoprazole</i>	30mg daily
<i>Alendronate</i>	70mg weekly
<i>Nystatin</i>	1ml four times a day
<i>Seprin</i>	480mg daily
+ Nephrotic syndrome treatment if appropriate	

You will have a monthly Outpatient clinic appointment with a blood test for kidney function, cholesterol, full blood count (to check your white blood cells) and 24hr urine collection for protein and clearance which will show how much protein is leaking from your kidneys and how well they are working.

As steroids may have many side effects, you will also be given additional medication to protect you from some of the more serious ones.

## What are the side effects of the treatment?

- Infection: Steroids (*Prednisolone*) make you more prone to 'opportunistic infection' (so-called, because they only affect vulnerable people). You will be given antibiotics (*Septin* and *Fluconazole*), to protect against thrush and pneumonia. If you have had previous TB exposure, you will be given *Isoniazid*. If you develop fever, cough, sore throat contact us immediately.
- Osteoporosis: There is a risk that higher doses of steroids may weaken bones. You will be given *Alendronate* to prevent this.
- Stomach irritation: You will be given *Lansoprazole* to prevent irritation to the lining of your stomach.
- Appetite: Steroids nearly always increase appetite. To avoid gaining weight, you may need to be careful about the amount you eat. (Advice available from Dietician)
- Diabetes: High doses may affect your body's ability to handle sugar. Up to 20% of patients may develop temporary diabetes, some requiring treatment.
- Skin and muscles: Steroids may make the skin thinner and more likely to bruise and the larger muscles weaker.
- Blood Pressure: A degree of fluid retention may cause the blood pressure to rise.
- Mood: Some patients find steroids cause mood disturbance - mood change, psychosis, insomnia.

## If the condition responds to steroids

If the protein leak has gone, the steroids will be reduced slowly over the following four months.

Week 1-8	<i>Prednisolone</i>	60mg	alternate days	
Week 9	<i>Prednisolone</i>	45mg	alternate days	stop <i>Nystatin</i>
Week 10	<i>Prednisolone</i>	30mg	alternate days	
Week 11	<i>Prednisolone</i>	15mg	alternate days	stop <i>Septin</i>
Week 12	<i>Prednisolone</i>	10 mg	alternate days	
Week 13	<i>Prednisolone</i>	5mg	alternate days	stop <i>Lansoprazole</i>
Week 14	<i>Prednisolone</i>	5mg	alternate days	
Week 15	Stop	<i>Alendronate</i>		

## If there is no response to a full course of 6 months steroids

If 6 months high dose does not cure the protein leak, then it is considered steroid unresponsive. The dose is reduced quickly over 2 months.

Week 1	<i>Prednisolone</i>	60mg alternate days	
Week 2	<i>Prednisolone</i>	45mg alternate days	stop <i>Nystatin</i>
Week 3	<i>Prednisolone</i>	30mg alternate days	
Week 4	<i>Prednisolone</i>	15mg alternate days	stop <i>Septtrin</i>
Week 5	<i>Prednisolone</i>	10mg alternate days	
Week 6	<i>Prednisolone</i>	5mg alternate days	stop <i>Lansoprazole</i>
Week 7	<i>Prednisolone</i>	5mg alternate days	
Week 8	Stop <i>Alendronate</i>		

Kidney Care Nurses 0118 322 7899      Victoria Ward 0118 322 7476

This document can be made available in other languages and formats upon request.

Renal Medicine, March 2019

Review due: March 2021