Idiopathic Focal Segmental Glomerulosclerosis

This leaflet explains what Idiopathic Focal Segmental Glomerulosclerosis (FSGS) is and how it is treated.

What is FSGS

Your kidney biopsy has shown that your fluid retention, leading to tissue swelling and protein leak (nephrotic syndrome), is caused by a condition called 'Focal Segmental Glomerulosclerosis' (FSGS). This means that there is damage and scarring to the kidney. In most cases, little is known about the actual cause of the damage, but it appears that in some patients, a substance in your own circulation 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 leak) in your urine. It is also a condition that is likely to recur after a kidney transplant.

What is the treatment for FSGS?

There is a 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.

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.

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

You may have a regular outpatient clinic appointment with a blood test for kidney function, cholesterol, full blood count (to check your white blood cells) and urine test (24 hour 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 have possible side effects, you will also get 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 'opportunist infection' (so-called, because they only affect vulnerable people). We will give you antibiotics (*Septrin* and *Nystatin*) to protect against thrush and pneumonia. If you have had previous TB exposure, you will get *Isoniazid*. **If you develop fever (temperature over 38c), cough or sore throat, contact us immediately.**
- **Osteoporosis:** There is a risk that higher doses of steroids may weaken bones. You will get *Alendronate* to prevent this.
- **Stomach irritation:** You will get *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 is available from the renal dietitian)
- **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 your blood pressure to rise.
- **Mood:** Some patients find steroids cause mood disturbance – mood change, psychosis and sleep disturbances. This usually rapidly improves after reducing /stopping the dose.

If the condition responds to steroids

If the protein leak has gone, the steroids will be slowly reduced over the following 4 months.

Week 1-8	*Prednisolone*	60mg	alternate days	
Week 9	*Prednisolone*	45mg	alternate days	stop *Nystatin*
Week 10	Prednisolone	30mg	alternate days	
Week 11	Prednisolone	15mg	alternate days	stop *Septrin*
Week 12	Prednisolone	10 mg	alternate days	
Week 13	*Prednisolone*	5mg	alternate days	stop *Lansoprazole*
Week 14	*Prednisolone*	5mg	alternate days	
Week 15	Stop *Alendronate*			

If there is no response to a full course of six months' steroids

If a high dose over six months does not cure the protein leak, then it is considered unresponsive to steroids. The dose will be reduced quickly over 2 months. Other treatments may be offered, depending on the risk / benefit of these.

Week 1	*Prednisolone*	60mg	alternate days	
Week 2	*Prednisolone*	45mg	alternate days	stop *Nystatin*
Week 3	*Prednisolone*	30mg	alternate days	
Week 4	*Prednisolone*	15mg	alternate days	stop *Septrin*
Week 5	*Prednisolone*	10mg	alternate days	
Week 6	*Prednisolone*	5mg	alternate days	stop *Lansoprazole*
Week 7	*Prednisolone*	5mg	alternate days	
Week 8	Stop *Alendronate*			

Contacting us

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To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

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