

Queen Elizabeth Hospital Birmingham



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NHS Foundation Trust



# Modified Ponticelli treatment record card

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Your kidney doctor has recommended that you start a course of treatment for your membranous nephropathy. This is a kidney condition which causes the kidneys to leak protein. More information about this condition is available in the information booklet, 'A patient guide to membranous nephropathy' produced by University Hospitals Birmingham. The treatment course is called a modified Ponticelli regimen which is a 6 month period of treatment using both prednisolone (steroids) and cyclophosphamide (immunosuppression) to reduce activity of the immune system.

The treatment course requires regular hospital appointments and blood tests to monitor your kidney function and to check for side effects. Most patients tolerate treatment well. Side effects are usually easily managed and if necessary your treatment dose will be reduced or paused. Your treatment plan will be discussed with you and you will be asked to sign a consent form before beginning cyclophosphamide. Information leaflets explaining more about cyclophosphamide and prednisolone will be given to you along with this information.

- **Prednisolone** is a steroid treatment which is given by intravenous drip (through a vein) for the first 3 days of month 1, 3 and 5 of your treatment. The drip is given during an outpatient appointment and should not take more than one hour. After the drip treatments have finished, steroid tablets are taken in the morning each day for the rest of the month.
- **Cyclophosphamide** is a strong form of immunosuppression given in tablet form every day during months 2,4 and 6 of your treatment. Weekly blood tests are needed to check your blood count has not been affected. Blood tests can be taken in hospital or sometimes with your family doctor. It is very important to attend your blood test appointments. Cyclophosphamide may also be given by drip infusion if Cyclophosphamide tablets make you feel unwell. In this case steroids may be given continuously throughout the treatment. The steroid dose will be reduced every couple of weeks during the treatment plan. Your doctor or nurse will explain this in more detail if this treatment plan is chosen.

It is important that effective contraception is used by both men and women during treatment with cyclophosphamide, and for 3 months after your treatment has ended. Cyclophosphamide should not be taken during pregnancy or whilst breast feeding. Cyclophosphamide may affect your fertility, your doctor or nurse will discuss this with you before you start treatment.

## What side effects may I experience?

- Prednisolone (steroids) and Cyclophosphamide increase the risk of infection
- It is very important to seek prompt medical attention if you develop signs of infection such as fever, shivers, pain passing urine or cough producing green sputum (phlegm)
- To reduce the risk of infection, an antibiotic (usually co-trimoxazole) is taken every other day during the six months of your treatment
- A stomach protecting tablet such as Ranitidine is usually given to protect against problems such as indigestion or stomach ulcers
- Feeling sick (nausea) and occasionally vomiting can be a side effect of cyclophosphamide. Please let us know if this is a problem as anti-sickness tablets can help
- Some patients may experience mouth ulcers, usually related to cyclophosphamide. Mouthwashes such as difflam can be obtained from your family doctor to help
- A sore red mouth, sometimes with white patches visible (oral thrush) can also occur. This can be treated with a nystatin solution used 4 times a day
- Prednisolone (steroids) can increase the risk of diabetes, blood tests will monitor this. Steroids can make you feel hungrier. It is important to eat healthily to try to avoid weight gain

## How often will I need to come to hospital for my modified Ponticelli regimen treatment?

You will need to attend hospital appointments on a regular basis during the 6 month treatment course, as well as having weekly blood tests during the months you take cyclophosphamide.

Your appointments are important as they:

1. Check how you are managing your treatments
2. Check and manage swelling
3. Check for side effects
4. Monitor kidney function
5. Measure blood pressure
6. Review the risk of blood clots

## What happens after I have received modified Ponticelli regimen?

After the modified Ponticelli regimen, you will continue to be seen in clinic by your kidney doctor or nurse. You may need to carry on taking blood pressure and cholesterol lowering medications. If the treatment is very effective, you will have a complete remission (no evidence of the disease) with no protein in the urine. In a partial remission (when a disease lessens) protein levels in your urine fall, but are still above normal. In some cases the condition can relapse and this may be seen with an increase in the amount of protein the kidneys are leaking. A small proportion (about 2 in 10) of patients do not respond to the modified Ponticelli regimen.

## What other treatments are available?

Other immunosuppression treatments used in membranous nephropathy include ciclosporin (neoral) and tacrolimus tablets. Alternatively, rituximab, which is a treatment given by drip is sometimes used. Rituximab is usually only available for people whose condition has not responded to other immunosuppression medications. Treatment for the underlying condition is usually given in cases of secondary membranous nephropathy.

# Modified ponticelli regime medication record:

**Name:**

**Unit number:**

## Month 1:

Number of intravenous (by drip) methylprednisolone days:

.....

then commence prednisolone tablets dosage ..... mg daily  
tablets for 28 days, to be taken in the morning.

## Month 2:

Oral cyclophosphamide tablets ..... mg daily

to start ..... and end .....

Weekly blood tests required at hospital  or family doctor

## Month 3:

Number of intravenous (by drip) methylprednisolone days:

.....

then commence prednisolone tablets dosage ..... mg daily  
tablets for 28 days, to be taken in the morning.

## Month 4:

Oral cyclophosphamide tablets ..... mg daily

to start ..... and end .....

Weekly blood tests required at hospital  or family doctor

## Month 5:

Number of intravenous (by drip) methylprednisolone days:

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Then commence prednisolone tablets dosage ..... mg daily  
tablets for 28 days, to be taken in the morning.

## Month 6:

Oral cyclophosphamide tablets ..... mg daily

to start ..... for 28 days.

Weekly blood tests required at hospital  or family doctor



**My hospital appointments:**

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**Blood tests I am due:**

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**Questions I want to ask?**

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**My flu jab date:**.....

**My pneumonia jab date:**.....

# Contact details

If you have any question please contact the Clinical Nurse Specialist or the Renal Assessment Unit:

## Clinical Nurse Specialist

Telephone: 0121 672 2518 or 07827 232 646 (available Monday to Friday between the hours of 08.15–16.15)

## Renal Assessment Unit

Telephone: 07766500092 or 0121 371 3017/3024.

The Renal Assessment Unit is available 08.00–20.00 Monday–Friday, 08.00–16.00 Saturday and Sunday.

Outside of these hours the on-call renal registrar can be contacted by ringing the Queen Elizabeth Hospital Birmingham switchboard on 0121 371 2000.



The Trust provides free monthly health talks on a variety of medical conditions and treatments. For more information visit [www.uhb.nhs.uk/health-talks.htm](http://www.uhb.nhs.uk/health-talks.htm)

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**Renal**  
**Queen Elizabeth Hospital Birmingham**  
Mindelsohn Way, Edgbaston, Birmingham B15 2GW  
Telephone: 0121 371 2000

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