



Oxford University Hospitals  
NHS Foundation Trust

# **Ponticelli regimen for the treatment of membranous nephropathy**

**Information for patients**



**Oxford Kidney Unit**

This leaflet will provide you with information about the Ponticelli regimen. If there is anything else you feel you need to know after reading the leaflet, please speak to your kidney doctor. This leaflet should be read alongside the Oxford Kidney Unit information leaflet on membranous nephropathy.

## **What is the Ponticelli regimen?**

The Ponticelli regimen is a combination of drug treatments which is used to treat a kidney disease called membranous nephropathy. The Ponticelli regimen is named after Professor Claudio Ponticelli, an Italian doctor, who first demonstrated that it was effective in treating some people with membranous nephropathy. It is a 6 month treatment to dampen (or lower) your immune system.

In the Ponticelli regimen, you will be given the following treatments:

- a steroid called methylprednisolone (as a liquid infusion)
- steroid tablets (called prednisolone)
- cyclophosphamide tablets (a type of chemotherapy medication).

More details about these treatments are given in later sections of this leaflet.

## **Why has my doctor recommended this treatment?**

The Ponticelli regimen is given to people with membranous nephropathy whose condition is unlikely to get better without medication. The decision to start this treatment will be made by your kidney doctor after discussion with you.

# What does the Ponticelli regimen involve?

Your treatment will be given to you over a six month period. In the first month you will be given the steroids and in the second month you will be given the cyclophosphamide. This two month cycle will then be repeated twice more for a total of **six months**.

At the start of each of the months of steroid treatment (months one, three, and five) you will need to come to the Renal Day Case Unit every day for three days. You will have the steroid infusion through a cannula (small plastic tube) into a vein in your hand or arm on each of these days.

When you have each steroid infusion you will need to stay in the Renal Day Case Unit for about an hour. If you would like to, you can have a friend or relative stay with you to keep you company while you are being treated.

On the third day, you will be given a supply of the steroid tablet, to take for the rest of the month, starting from the next day.

## **Month 1, 3 and 5: Steroids**

Days one, two and three come to the Renal Day Case unit for the steroid infusion. Day 4 onwards for the rest of the calendar month take steroid tablets.

You should take your steroid tablets with food, as this helps to prevent them irritating the lining of your stomach.

## **Month 2, 4 and 6: Cyclophosphamide**

Tablets to be taken for the full calendar month.

Cyclophosphamide should be taken in the morning, so that your body processes it throughout the day. It is best taken on an empty stomach, but can be taken with food if you find it makes you feel sick.

You will also be given the following medications to take for the whole six months of treatment:

- **Antibiotics, such as co-trimoxazole.** These help to protect against certain lung infections.
- **Ranitidine** or other medication to reduce the amount of acid in your stomach and protect your stomach lining.
- Some tablets to protect your bones, such as risedronate, calcium and vitamin D supplements.

## **What are the benefits of the treatment?**

In research studies, people with membranous nephropathy who are treated with the Ponticelli regimen have less protein in their urine at the end of the 6 month treatment.

The Ponticelli regimen has been shown to reduce the risk of people developing advanced long-term kidney damage due to the reduction of protein in their urine.

Your doctor will measure your protein leak in your urine. This is a test called protein: creatinine ratio (PCR).

If your PCR level is less than 30mg/mmol your membranous nephropathy is under control (in remission).

If your PCR is greater than 30 but less than 300mg/mmol you will have partial remission. This means there is a chance the disease will start to get worse.

9 out of 10 people (90%) will achieve complete remission from having the Ponticelli regime treatment.

1 in 4 people (25%) will experience a relapse in their condition within 30 months of completing the Ponticelli regime treatment.

# What are the side effects and risks?

## Steroids

Steroids can cause side effects, but most people find they can cope with these for the short time they are taking the treatment. These side effects are normally short-term. The following is a list of the more common side effects you may experience:

- a change in your sleep pattern (often difficulty in falling asleep). Taking your tablets in the morning should help with this.
- upset stomach or gut, including feeling sick
- heartburn, indigestion or stomach ulcers (we will give you a medication to help to prevent this)
- palpitations (a more noticeable or faster than normal heart rate)
- a change in your mood (feeling more up or down)
- a metallic taste in your mouth
- an increased appetite
- weight gain (this is usually short-term)
- flushing/reddening or a round appearance of your face
- fluid retention, ankle swelling and increased blood pressure. If this happens, your kidney doctor may need to adjust your water tablets.
- acne (this is also temporary)
- increased risk of any infection
- diabetes (your kidney doctor will measure your blood glucose level with each blood test when you come to clinic)
- thinning of bones (osteoporosis)
- changes in your eyesight due to conditions such as glaucoma and cataracts.

If you are diabetic you might find your blood glucose levels will be higher, so we will advise you to measure your blood glucose levels more frequently. Your treatment for diabetes may need to be adjusted.

Very rarely, some people can experience severe damage to their hip (known as avascular necrosis of the hip).

# Cyclophosphamide

Common short-term side effects of cyclophosphamide include:

- low white blood cell count (this can increase your risk of infection). This is measured and monitored using a blood test.
- feeling or being sick
- irritation of the bladder lining, which may cause bladder cancer (very rare).

Occasional side effects:

- hair loss (usually grows back after stopping the drug)
- diarrhoea
- mouth ulcers
- skin changes (skin may darken, but this is rare)
- low platelet count (this can cause unexplained bruising or bleeding).

Cyclophosphamide can also cause:

- Infertility: This is unlikely to occur with only 3 months of treatment, but you should discuss this further with your kidney doctor.
- Damage to an unborn child: Men or women who are taking cyclophosphamide should not try for a baby.
- Cancer: Cyclophosphamide causes a small increase in the risk of some cancers. Your kidney doctor will give you more information about this.

If you develop a **high temperature** whilst on the Ponticelli regimen please contact:

Oxford University Hospitals switchboard: **0300 304 7777**

ask for the Churchill Hospital and then to speak to the renal registrar on-call.

## How will I be monitored during the course of treatment?

You will be seen every month in the kidney clinic during the treatment. During the months that you are taking cyclophosphamide you will need weekly blood tests to monitor your blood count. Your blood tests can be done either at your GP's surgery or at the Kidney Unit. Please plan with your kidney doctor where these blood tests will be done, so they know where to look for the results.

# What happens after my treatment?

After you have finished the treatment, your kidney doctor will see you in the kidney clinic. They will measure your blood pressure, the amount of protein in your urine and will take a blood test to check on your kidney function. They will discuss your response to the treatment with you.

## Useful information

The following websites have useful information about the treatment of membranous nephropathy.

### **National Kidney Federation**

A UK based charity, run by kidney patients for kidney patients.

Website: [www.kidney.org.uk](http://www.kidney.org.uk)

Information: [www.kidney.org.uk/help/medical-information-from-the-nkf-/kidney-diseases-index/medical-info-kidney-disease-memb-neph](http://www.kidney.org.uk/help/medical-information-from-the-nkf-/kidney-diseases-index/medical-info-kidney-disease-memb-neph)

### **Kidney Care UK**

Lots of information and support for people with kidney disease.

Website: [www.kidneycareuk.org/about-kidney-health](http://www.kidneycareuk.org/about-kidney-health)

### **RareRenal (The Renal Association)**

Run by UK based kidney doctors, promoting research into membranous nephropathy. Link from the website to join a patient register and be the first to hear about potential new treatments and clinical trials.

Website: [www.rarerenal.org](http://www.rarerenal.org)

Register: [www.rarerenal.org/radar-registry](http://www.rarerenal.org/radar-registry)

Email: [admin@rarerenal.org](mailto:admin@rarerenal.org)

Information: [www.rarerenal.org/patient-information/membranous-nephropathy-patient-information](http://www.rarerenal.org/patient-information/membranous-nephropathy-patient-information)

### **Oxford Kidney Unit**

Useful information about the Oxford Kidney Unit for patients and carers.

Website: [www.ouh.nhs.uk/oku](http://www.ouh.nhs.uk/oku)

If you need an interpreter or would like this information leaflet in another format, such as Easy Read, large print, Braille, audio, electronically or another language, please speak to the department where you are being seen. You will find their contact details on your appointment letter.



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