Ponticelli regimen for
the treatment of
Membranous Nephropathy

Information for patients
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 proved that it was effective in treating people with membranous nephropathy. It is a 6 month course of treatment to dampen the immune system. In the Ponticelli regimen, you will be given the following treatments:

- steroids given by a drip into your vein (called methylprednisolone)
- steroid tablets (called prednisolone)
- cyclophosphamide tablets.

More details about these treatments are given in the 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 to dampen their immune system (see information leaflet on membranous nephropathy). 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 steroids and in the second month you will be given tablets called cyclophosphamide. This two month cycle is then 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, to have a steroid drip through a cannula (small plastic tube) into a vein in your hand. When you have the steroid drip 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 your third day, you will be given steroid tablets, to take for the rest of the month.

**Month 1: Steroids** (Days one, two and three come to the Renal Day Case unit for the steroid drip. Day 4 onwards for the rest of the calendar month take steroid tablets.)

**Month 2: Cyclophosphamide** (tablets for the full calendar month)

**Month 3: Steroids** (Days one, two and three come to the Renal Day Case unit for the steroid drip. Day 4 onwards for the rest of the calendar month take steroid tablets.)
Month 4: Cyclophosphamide (tablets for the full calendar month)

Month 5: Steroids (Days one, two and three come to the Renal Day Case unit for the steroid drip. Day 4 onwards for the rest of the calendar month take steroid tablets.)

Month 6: Cyclophosphamide (tablets 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 nauseated.

You will need to take your steroid tablets with food, as this helps to avoid irritating the lining of your stomach.

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

- **Co-trimoxazole**, which helps to protects against certain lung infections.
- **Ranitidine** or other medication to reduce the amount of acid in your stomach.
- **Calcium, vitamin D** and a tablet called **risedronate** to help protect your bones.

These medicines help to reduce some of the side effects of the treatment (see later section).

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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 (an important marker of kidney damage) and are less likely to develop kidney failure.
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-lived. The following is a list of 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 nauseated (sick)
- heartburn or indigestion (we will give you a medication called ranitidine to help to prevent this)
- increased risk of stomach ulcers
- 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 sugar 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 sugar levels will be higher, so we will advise you to measure your blood sugars 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 using a blood test.
- nausea and/or vomiting
- irritation of the bladder lining and, rarely, may cause bladder cancer.

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:

Churchill Hospital switchboard **01865 741 841**
and ask 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 surgery or at the Kidney Unit. Please plan with your kidney doctor where these blood tests will be done so that 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.
Further information

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

**National Kidney Federation**
Helpline: 0845 601 02 09 (Freephone from UK landlines)
Website: www.kidney.org.uk
A UK based charity, run by kidney patients for kidney patients.

**The Renal Association – RareRenal.org**
Run by UK based kidney doctors promoting research into membranous nephropathy. There are links from the website to join a patient register and be the first to hear about potential new treatments and clinical trials.
Email: admin@rarerenal.org
Website: http://rarerenal.org/patient-information/membranous-nephropathy-patient-information/

**Edinburgh Renal Unit**
Website: http://www.edren.org/pages/edreninfo/membranous-nephropathy.php

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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