### **Patient Information**



### **Pirfenidone**

Please note the information in this leaflet is provided as additional information for you. It is important that you also read the information sheet that is provided with your medication.

#### Pirfenidone (Esbriet®)

You have been prescribed pirfenidone as part of treatment for your lung condition. Pirfenidone comes as white capsules or film coated yellow oval tablets, which contain 267 mg of pirfenidone each and film coated brown oval tablets which contain 801mg of pirfenidone each.

#### How is pirfenidone taken?

The capsules/ tablets are swallowed whole with food and a glass of water. Do not take any capsules/ tablets which are past their expiration date. When taking more than one capsule/ tablet at a meal take them separately from each other (i.e. swallow one at a time).

## How often should pirfenidone be taken?

We will build this dose up slowly with one 267 mg capsule/ tablet three times a day (801 mg daily) for one week, two capsules three times a day (1602 mg daily) for one week, then three capsules three times a day (2403 mg daily). The final maintenance dose is 2403 mg a day.

Once established in the full dose we may be able to change you to one 801 mg tablet three times a day. The 801 mg tablet should be taken immediately at the end of your meal.

#### What to do if you miss a dose?

Do not worry if you miss a dose, take the next planned dose with your next meal at the normal time. Do not try to "catch up".

# What should be avoided or added when taking pirfenidone?

- Always take pirfenidone with food and a drink of water
- Avoid grapefruit juice as it can reduce the efficacy of pirfenidone.
- If you take omeprazole, lansoprazole or another medicine for gastric reflux we will ask your GP to change this to pantoprazole as it is less likely to have an effect on the pirfenidone; however in exceptional circumstances omeprazole or lansoprazole can be used but this should first be discussed with your managing clinician.
- Avoid bright sunlight and wear high SPF sunscreen (at least SPF 25-50), even inside in winter to prevent a skin rash when exposed to ultraviolet light. It should be noted that it is ultraviolet light that induces the rash in the majority of instances, so care should be taken when outside, even in the absence of sunlight.

#### What are the benefits?

Pirfenidone helps slow the progression of fibrosis, which means the deterioration in your lung function may not be as quick as if you were not taking pirfenidone.

## Why do I need regular blood tests whilst on pirfenidone?

Pirfenidone may affect your liver so it is important that this is monitored with regular blood tests to make sure your liver function is not affected. Your blood count and kidney function should also be checked to make sure these are

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stable too. We recommend one blood test every month for 6 months, then one blood test every 3 months. We have provided a space at the end of this leaflet for you to record your blood results (please ask your GP for the details so that you can fill in the table).

It is your responsibility to contact your GP practice and ensure that you have appointments for these tests.

#### What are the side effects?

- Everyone is different so different patients may experience different side effects, but there are several important side-effects you should be aware of:
- Digestive system problems like heartburn, abdominal pain, feeling sick and diarrhoea
- Skin problems including a photosensitive rash; a rash that comes about from sunlight exposure (this is why we have recommended a high SPF sunscreen to be worn every day no matter the weather outside)
- Aches and pains
- Feeling dizzy and/or faint
- Having difficulty sleeping

#### What are the alternatives?

In addition to pirfenidone, you may be prescribed a steroid, oxygen and offered pulmonary rehabilitation, depending on your individual condition. This will have been discussed with you at your clinic appointment with your Respiratory Consultant and/or ILD/Respiratory Specialist Nurse, Sarah Lines.

## What happens if I don't take this medicine?

Pirfenidone may have side effects but it is important to take it as directed as it will not work properly otherwise. If you are having side-effects please get in contact with us straight away and we can advise what the next step should be. Often the side effects can be managed by simple modifications like changing the dose and when and how you take your capsules/ tablets.

# What to do if you are prescribed any new medicines.

We will have checked what other regular medicines you are taking at clinic, but please let us know if you are prescribed any new medicines by your GP so we can check that they do not interact with pirfenidone.

## How to store pirfenidone safely.

Please store your capsules/ tablets in their packaging at room temperature. Keep out of reach of children and check the expiry date regularly.

## Where to get repeat prescriptions.

We will prescribe the first month of treatment after your clinic appointment and if you are managing well with it we will then issue you repeat prescriptions directly from the hospital for up to three months at a time. The medication is delivered directly to your home.

## Who can I contact if I have any more questions?

Please contact the ILD/Respiratory Specialist Nurse by telephone on **07395 283159** who will be able to help you. If you are having trouble getting in touch with them the ILD Co-ordinator can also be contacted by telephone on **01392 403701** and they will pass the message on to the team. Your GP is also a good person to get in touch with as they can always contact us too.

Your GP can send results to us at **rde-tr. ildrespiratory@nhs.net**.

However, we ask that if you need to contact us you leave a message on the telephone.

#### **Record of blood tests**

Date:	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin					
White cell count					
Platelets					
Sodium					
Potassium					
Urea					
Creatinine					
Alanine aminotransferase (ALT)					
Alkaline phosphatase (ALP)					
Albumin					
Bilirubin					
Date:	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Date: Haemoglobin	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin White cell count	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin White cell count Platelets	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin White cell count Platelets Sodium	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin  White cell count  Platelets  Sodium  Potassium	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin White cell count Platelets Sodium Potassium Urea	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin  White cell count  Platelets  Sodium  Potassium  Urea  Creatinine	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY
Haemoglobin  White cell count  Platelets  Sodium  Potassium  Urea  Creatinine  Alanine aminotransferase (ALT)	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY

The Trust cannot accept any responsibility for the accuracy of the information given if the leaflet is not used by RD&E staff undertaking procedures at the RD&E hospitals.

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