

# Sourcing antifibrotic medicine from outside the UK

Information for patients



Specialist Interstitial  
Lung Disease Service  
at Leeds

You have made us aware that you are sourcing an antifibrotic medication (either **pirfenidone** or **nintedanib**) from outside the UK (and therefore outside the NHS).

As the medications have not been given to you by an **NHS approved pharmacy**, caution should be applied in assuming the exact constitution of the medication delivered.

NICE (National Institute for Clinical Excellence) have strict criteria as to the eligibility for antifibrotic medications. We are unable to provide these medications on the NHS to patients in whom the eligibility criteria are not met.

## Side-effects

Antifibrotic medications can have significant side-effects, and require regular clinical reviews and blood tests. For your information and safety, we are sending you this information so you can arrange the appropriate monitoring. However, we are unable to perform this monitoring at the Interstitial Lung Disease (ILD) service, and you will need to discuss with your GP/ healthcare provider how best to ensure your ongoing health and wellbeing.

Both antifibrotic agents can cause nausea, vomiting, and diarrhoea. We normally prescribe an antisickness medication (e.g. cyclizine) and an antidiarrhoeal medication (e.g. loperamide) with the antifibrotic, so that patients can take them as and when they have symptoms. Pirfenidone also causes sun sensitivity, so we advise the use of Factor 50 sunblock and a sunhat, when outside (even in overcast conditions), in order to prevent sunburn.

Both medications can also cause problems with your liver, which can occur without any symptoms of ill health until the damage is severe. To prevent this, we normally advise regular liver function blood tests (minimum of every four weeks for the first three months, and then every 12 weeks thereafter).

**Pirfenidone should not be used in patients with kidney failure (eGFR <30).**

Patients already on blood thinning medication (such as clopidogrel, ticagrelor, dipyridamole, warfarin, dabigatran, rivaroxaban, apixaban) can experience more complications with nintedanib use than patients not on any anticoagulation.

Patients on omeprazole (a medication commonly used for the treatment of reflux/ heartburn) should be switched to an alternative (such as lansoprazole) before starting on an antifibrotic medication, to prevent drug interaction.

Any changes to your other medications, or the addition of new medications, will need to be reviewed in the context of antifibrotic use.

We at the ILD clinic will continue to review you according to your diagnosis (we normally review patients with IPF up to four times per year), and will continue to review all other aspects of your care e.g. oxygen requirements, pulmonary rehab, symptom control, palliative care support. If NICE criteria for antifibrotic treatment are met during our review, we would then take over the prescription and monitoring of the antifibrotic agent, as we would for any NHS patient.

***Should you have any further questions regarding the contents of this leaflet, please ask one of the doctors/ nurses in clinic, who would be happy to assist you further.***

## References

1. ***National Institute for Health and Care Excellence.***

Pirfenidone for treating idiopathic pulmonary fibrosis (TA282). London: The National Institute for Health and Care Excellence; 2013.

2. ***National Institute for Health and Care Excellence.***

Nintedanib for treating idiopathic pulmonary fibrosis (TA379). London: National Institute for Health and Care Excellence; 2016.

## What did you think of your care?

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