

**PE1714/A**

**British Thoracic Society submission of 30 July 2019**

Thank you for inviting views from the British Thoracic Society on this Petition. We have read the report of the Petition with interest, and we are pleased to provide the following information in relation to the areas on which you have invited comments.

**Prevalence of the condition**

Death rates from Idiopathic Pulmonary Fibrosis (IPF) in Scotland are among the highest in the UK (age standardised mortality of 11.3 per 100,000 in 2011, compared with 9.41 per 100,00 for England and Wales) and mortality is rising throughout Europe, with the UK observing the largest increase (+3.8% for females and +4% for males) [Marshall et al ERJ 2018]. Historical figures show a progressive rise in both diagnosis and mortality in Scotland.

We acknowledge that the lack of comprehensive data on this condition across Scotland and the wider UK is a source of frustration for patients and clinicians alike. We are aware from clinical colleagues that local databases are in existence for ILD in Scotland but these do not provide the information required to assess the quality of care currently being provided.

It was for this reason that the British Thoracic Society (BTS) set up the BTS Lung Disease Registry in 2013, with the aim of collecting information on IPF (idiopathic pulmonary fibrosis) and sarcoidosis from centres across the UK. Our clinical colleagues in Scotland acknowledge the value of the Registry but it does require resource from within the institution to collect and input data and this would usually fall to the busy clinician. We are aware from clinical colleagues that there is a need for central administrative support for data entry to the Registry, as well as wider support for Multi-Disciplinary Team (MDT) meetings.

As noted above, The British Thoracic Society launched a Registry for IPF and Sarcoidosis (under the BTS lung disease registry programme) in 2013, and this now holds data on over 2000 patients which is, as far as we are aware, the largest patient registry on this condition in Europe. The aim of the Registry is to provide data which will support improvements in the care of patients with IPF and sarcoidosis in the UK. We note that the Petition has drawn information from a recent Registry report in its background information.

/continued

## **Awareness of the condition**

The petition rightly draws attention to the lack of awareness of this condition among the general public in Scotland, and the delays in access to specialist care and geographical inequity that still exists.

Action Pulmonary Fibrosis (APF) (<https://www.actionpulmonaryfibrosis.org/>) is the national charity for IPF which focuses on providing information and support for patients with this disease and their families.

BTS has close links with APF – the chair of APF sits on the BTS Registry Steering Group.

One of the prime aims of the charity is raising awareness of disease among the medical profession and the wider public.

We are also aware that the British Lung Foundation has recently published data on IPF

<https://www.blf.org.uk/support-for-you/idiopathic-pulmonary-fibrosis-ipf>

While these sources of information and support are to be commended, there is still work to do to ensure that all patients with ILD/IPF receive appropriate treatment and support.

## **Training for the medical profession**

We acknowledge that lack of awareness of this condition extends to the medical profession, including primary care and (non-respiratory) hospital medical staff. This undoubtedly leads to diagnostic delay and not only a lack of information for patients and their families, but often inaccurate and incorrect information being given in the first instance.

The British Thoracic Society provides a regular programme of education and training for its members (doctors and other health care professionals) who work in respiratory medicine in Scotland as well as the wider UK, but we support the extension of education and training in this condition (including when and how to refer to specialist care) for the broader medical profession.

## **Support for people who have the condition.**

While we recognise the difficulties that patients in Scotland may encounter in travelling long distances to attend clinics, we agree that a key priority for patients is being seen by an expert team. Access to expertise could be facilitated by virtual ILD clinics, but these are still uncommon. We note that it is possible to obtain CT imaging in remote areas of the country, (and this can then be easily seen anywhere in Scotland on the national imaging system.). Accessing detailed breathing tests (pulmonary function tests) however is restricted to larger centres. Support from the Scottish Government would help in this regard e.g. providing access to these tests in geographically remote areas such as Shetland and the Orkney Isles.

**We support the introduction of** nationally agreed, and enforceable, standards of care which could include:

- time to diagnosis
- time to treatment
- number of ILD nurses per region
- equity of access to oral anti-fibrotic treatments
- access to pulmonary rehabilitation / oxygen / palliative services etc.

The existence of such standards has assisted in driving improvement in England (following the introduction of NICE quality standards for IPF). Clinical colleagues are aware of substantial variation in prescription rates of oral antifibrotics throughout Scotland.

We also understand from colleagues that the provision of ILD Nurse Specialists in Scotland is very limited (for example, 1 Nurse for GGC Health Board which has a population of 1.14 million). The vast majority of Scottish patients with ILD will not have access to an ILD Nurse and this is far from the acceptable UK national standard of care.

We support improvement in access to palliative services for IPF patients. We are aware of Scottish Government proposals to have nationally agreed and enforceable standards in this area and we applaud and fully endorse the inclusion of ILD/IPF in the workplan of the Scottish Respiratory Improvement Plan.

In conclusion, the British Thoracic Society welcomes the Petition brought by Mr MacLachlan, Ms Dodds and Ms Watson and supports the call for Scottish Parliament to urge the Scottish Government to provide funding to raise awareness and standards of care for patients with ILD.

### *Reference*

Trends in mortality from idiopathic pulmonary fibrosis in the European Union: an observational study of the WHO mortality database from 2001–2013  
Dominic C. Marshall, Justin D. Saliccioli, Barry S. Shea, Praveen Akuthota  
European Respiratory Journal 2018 51: 1701603

