PE1714/C
British Lung Foundation submission of 9 August 2019

I write in response to your request for further evidence from the British Lung Foundation in respect of petition PE1714: Interstitial Lung Disease and Home Management.

We would like to put on record our thanks to James MacLachlan, Ivy Dodds and Jean Watson for raising this important issue before Parliament. Representatives of the British Lung Foundation attended the meeting of the Petitions Committee on 07 February 2019 to listen to their reasons for supporting the petition. Jim and Jean's evidence underlined the emotional and psychological impact that ILD has on people's lives, as well as on the lives of their loved ones.

Lung disease is Scotland's third biggest killer[1] and we believe that the petitioners have done an important job in highlighting an important, yet poorly understood, type of lung condition.

Interstitial lung disease (ILD) is a collective term for lung diseases which cause fibrosing or scarring of the lungs. The scar tissue usually forms within the alveoli (air sacs) within the lung, which act as the interface to transfer oxygen from the air we breathe into the bloodstream. The scarring stiffens the lung, which makes it much harder to take in air to the lung. The scar tissue also disrupts the efficient flow of oxygen from the air sacs into the bloodsteam.

There are more than 200 different types of ILDs, however we will primarily focus our remarks on idiopathic pulmonary fibrosis (IPF), which is the most common type of ILD. Idiopathic is a medical term which means that we do not know what causes the disease. Therefore, for the vast majority of people living with ILD, it is not possible to identify the factor(s) involved in their condition. IPF is an incurable condition and the average survival time after diagnosis is 2-3 years[2].

There are currently two drugs which are licensed for treatment of IPF on the NHS – nintedanib and pirfenidone – both of which can slow down the rate at which scarring occurs within the lung. However, these drugs are prescribed based on the patient's lung capacity at the time of diagnosis, meaning that not all people living with IPF will have access to these drugs. Other treatment options focus on relieving the symptoms, of which the most common options are oxygen therapy and pulmonary rehabilitation.

As current treatment options for IPF are dependent on lung capacity at the time of diagnosis, earlier diagnosis of IPF is essential to give people as much time as possible with their loved ones and expand the treatment options available. Improved clinical data recording is urgently needed to identify those at greatest risk of developing IPF. Currently, neither the NHS Information Services Division nor the Scottish Government holds data centrally on how many people in Scotland are diagnosed with IPF or any other form of ILD[3]. However, the most recent estimates from our Battle for Breath report suggest that around 50 in every 100,000 people in the UK will be diagnosed with IPF at

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[1] National Records of Scotland *Vital Events Reference Tables 2018*. Available from: https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/vital-events-reference-tables/2018 (accessed 25th July 2019)
[2] Strongman et al, "Incidence, Prevalence, and Survival of Patients with Idiopathic Pulmonary Fibrosis in the UK" *Advances in Therapy* 35, no. 5 (2018), pp 724–736.
[3] Response to written question S5W-21020, February 2019

some point in their life. In Scotland, this figure is much higher at 67 in every 100,000 people diagnosed with IPF. We estimate that 32,500 people are currently living with ILD in the UK, with around 2,500 people living with it in Scotland[4]. Across the UK, our estimates suggest that 5,292 people will die from IPF each year[5]. To put that into context, more people die from IPF every year than from leukaemia[6].

We support the petitioners' view that a stronger focus on recording of ILD is essential to improve care for these conditions. Better recording would also assist the Scottish Government, clinicians and key stakeholders to raise awareness of ILD among the public.

We support the petitioners' calls for a public awareness-raising campaign for IPF. The Scottish Government have an ongoing commitment to work closely with third sector organisations to raise awareness of respiratory conditions, including ILD[7]. We would welcome a greater emphasis on this joint working, so that we can together make people more aware of symptoms and when to see a GP. We would like to take this opportunity to highlight our accredited health information booklets, which healthcare professionals can order from our website at shop.blf.org.uk.

The petitioners highlighted in their evidence to the Petitions Committee their experiences of living with IPF, and their situation is not unique. We recently hosted patient engagement events in Aberdeen and West Lothian to hear from those directly affected by ILD and what they felt needed to improve. The anecdotal feedback we received was that ILD was often not well recognised by GPs and in some cases was misdiagnosed as COPD, asthma or even just a normal chest infection. We were also told about delays in accessing basic diagnostic tests, whether through capacity issues with referrals or through misdiagnosis from GPs. As incidence rates for IPF are higher in Scotland, it's clear that this disease, and other types of ILD, need to be treated with much greater priority than is currently the case.

One of the most common symptoms of ILD, and many other lung conditions, is chronic breathlessness. Getting people to recognise chronic breathlessness as a symptom of an underlying lung condition, rather than as a normal part of ageing or daily life, is an essential part of our work to ensure everyone can live well with healthy lungs. Although we have resources which can help (including our breath test, an online questionnaire which helps people to self-assess their breathlessness), these can only go so far in providing people with the information they need to get an accurate diagnosis. Breath testing at GP surgeries (spirometry) is the most common method for diagnosing lung conditions and we believe that all GPs should be fully trained to offer regular spirometry testing, especially for those who have a medical history of chronic breathlessness and/or frequent and recurring chest infections.

Since the full diagnosis of ILD also requires specialist techniques, including CT scan and biopsy, early diagnosis means that we need to see timely and accurate recognition of people at risk of developing ILD by GPs and quick referral to specialist respiratory consultants to undergo diagnostic tests. The Scottish Government's Referral to

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[4] British Lung Foundation *The Battle for Breath – the impact of lung disease in the UK*. Available from https://www.blf.org.uk/policy/the-battle-for-breath-2016 (accessed 25th July 2019)
[5] Ibid
[6] Cancer Research UK *Leukaemia (all subtypes combined) statistics* Available from https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/leukaemia (accessed 25th July 2019)
[7] Response to written question S5W-20840, January 2019

Treatment standard specifies that 90% of patients should wait no longer than 18 weeks from GP referral to commencing treatment, however as of March 2019 only 77% of patients met that standard[8]. At the very least, this standard needs to be met to ensure that people who are suspected to have ILD can start treatment at the earliest possible opportunity, buying them more precious time to spend with their loved ones.

As there are no treatment options which can reverse the damage caused to the lungs from ILD, management of the condition at home plays a large part in helping people to live with IPF. Many people with ILD will be provided with oxygen therapy, delivered via a concentrator or a cylinder, which in the most advanced cases is delivered 24 hours a day, 7 days a week. The severe breathlessness associated with ILD means that some people may need to have adaptations at home to enable them to continue to live independently or with the assistance of a carer at home. We support the petitioners' calls for funding to be made available for appropriate adaptations for people with ILD, where such adaptations are necessary to maintain independent living at home.

Delivering improvements in respiratory care means that we need a strategic approach to delivering these specialist services. These services also need to be properly resourced across NHS Scotland. In November 2017, the Scottish Government made a commitment to the publication of an action plan to improve respiratory care services in Scotland[9], and we welcome their commitment that ILD will be a core priority for the plan[10]. We expect the plan to be published in late 2019 and welcome this commitment from Ministers[11].

In conclusion, we hope that the evidence helps the Committee to better understand ILD and the concerns raised by the petitioners regarding early diagnosis and the availability of care. We thank the committee for asking for our views on the petition and we are happy to provide any further assistance to the Committee to assist with their future deliberations on this petition.

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[8] ISD Scotland *18 Weeks Referral to Treatment Quarter End – 31st March 2019*. Available from https://www.isdscotland.org/Health-Topics/Waiting-Times/Publications/2019-05-28/2019-05-28-WT-18WksRTT-Report.pdf (accessed 25th July 2019)

[9] SP OR 14 November 2017 cols 94-96

[10] Response to written question S5W-20842, January 2019

[11] Response to written question S5W-22346, March 2019