

Pre-Budget Submission 2025

Equitable Care for Lung Fibrosis Patients

Interstitial Lung Disease (ILD), also called Lung Fibrosis or Pulmonary Fibrosis (PF), is the name for a group of diseases in which scar tissue (fibrosis) develops in the lungs. Lung fibrosis is a chronic, progressive, and life-limiting disease that results in severe shortness of breath, relentless cough, low oxygen levels, and extreme fatigue. There is no cure for lung fibrosis, but for some there are therapies that slow disease progression and for a lucky few, a lung transplant.

For more than 20 years, the Irish Lung Fibrosis Association (ILFA) has provided education, advocacy and direct supports to patients and the wider ILD community. We promote change, we challenge current practice, we speak up on behalf of our community, and we collaborate with other patient organisations, alliances, and networks.

Despite our progress over the years, today the vast majority of ILD patients are still forced to fight a battle on two fronts – against the progression of their disease, and against an inequitable ‘healthcare system’ that denies them access to the care they need. The ultimate solution is a Clinical Care Programme, but in the interim, we are calling on the Government to fund an ILD audit, resource the development of a Clinical Care Pathway and expand pulmonary rehabilitation access to include ILD patients. We’re also seeking the establishment of a tax rebate programme to ensure patients depending on oxygen are not forced to ration oxygen supplies because of increased electricity costs.

€150,000

ILD Registry Audit

Funding to conduct a National Clinical Audit supporting the establishment of an ILD registry.

€2.2M

Tax Relief

Tax relief for oxygen patients like the programme in place for kidney dialysis patients.

€40,000

0.2 WTE Clinical Care Pathway

Ringfenced funding for a resource to manage the ILD Care Pathway assessment.

€1.5M

Pulmonary Rehabilitation Access

Expand existing pulmonary rehabilitation programmes to include ILD patients.

Our Ask:

Ring-fence €150,000 in funding for a National Clinical Audit for Interstitial Lung Disease (ILD) to support the establishment an ongoing ILD patient registry.

We request ring-fenced government funding to address a foundational inequity in care for lung fibrosis patients - a lack of accurate, valid, reliable and timely health information for this underserved patient group.

Health record information is vital for improving the care and service provision for lung fibrosis patients. "The need for patient registries arises from a desire to have accurate, valid, reliable and timely information about a particular patient group or condition. Although examples of good practice exist, the current health information technology infrastructure in Ireland is highly fragmented with major gaps and silos of data. Difficulties associated with bringing data together from different sources makes informed decision-making a challenge for those planning health and social services."¹

The Irish Lung Fibrosis Association (ILFA) have met with and received advice from Future of Registries Taskforce (FORT) and from the National Organisation for Clinical Audits (NOCA) regarding the procedure for requesting a Clinical Audit. A structure for developing a standardised patient registry is available. The barrier to progress the establishment of an ILD patient registry is funding.

***"Data is not available at national level in Ireland on ILDs...also lacking at national level is data on the impact of these diseases on GP services, Emergency Department services, and out of hours services."* (Irish Thoracic Society)**

We are therefore calling on the Government to ring-fence €150,000 in funding for an ILD patient registry audit. This funding would be provided to NOCA who would in turn provide project management (identification of the

¹ Health and Information Quality Authority, 2017 'Catalogue of National Health and Social Care Data Collections' <https://www.hiqa.ie/reports-and-publications/health-information/catalogue-national-health-and-social-care-data>

data set, information governance, report metrics, etc.). NOCA would also provide ongoing engagement with the HSE and ILFA to ensure the information is being understood and used, and to help with any data collection issues during the audit. Funding would also allow for the establishment of a governance structure to oversee the management of the registry as well as consideration of changes to the registry in light of new healthcare policy². Once the ILD registry was established, it's estimated to cost €200,000 per year in ongoing management and administration costs³.

Without a registry, the number and conditions of patients with ILD across Ireland remains unknown. Some ILD patients receive good or excellent care⁴, but in our experience, many do not, and it is those patients who would benefit the most from this foundational healthcare component.

A patient registry would allow for greater coordination and planning for this disease, potentially saving the HSE ongoing costs. We estimate that there are approximately 5,000 ILD patients in Ireland and the median cost per patient (based on UK models) is approximately €10,000 per year^{4b}. Assuming the direct and indirect patient costs are similar to the UK, this means that the total cost to manage this disease could be up to €50 million per year, but without an understanding of the actual number of patients affected and the types and levels of supports they require in total, it's impossible to know. A patient registry would ensure the correct costs could be identified and properly managed, providing the HSE and the Department of Health with a realistic understanding of funding required to manage this debilitating, life-limiting disease.

² HSE National Centre for Clinical Audit (NCCA) Commissioning National Clinical Audits within the HSE Standard Operating Procedure (SOP), NCCA-SOP-002, January 2024.

³ Discussion with Future of Registries Taskforce (FORT) representatives 9-7-2024

⁴ <https://ilfa.ie/wp-content/uploads/2023/07/Access-to-Specialist-and-Multidisciplinary-Healthcare-for-Pulmonary-Fibrosis-1.pdf>

^{4b}. Wong AW, Koo J, Ryerson CJ, Sadatsafavi M, Chen W. A systematic review on the economic burden of interstitial lung disease and the cost-effectiveness of current therapies. BMC Pulm Med. 2022 Apr 20;22(1):148. doi: 10.1186/s12890-022-01922-2. PMID: 35443657; PMCID: PMC9020025.

Our Ask:

Provide €2.2M in tax relief for oxygen patients like the programme in place for kidney dialysis patients⁵.

We request the Government develop and fund a tax rebate programme for patients who require oxygen on par with the benefits received by kidney dialysis patients to help offset the financial burden of living with this debilitating disease.

Lung fibrosis “can affect the movement of oxygen from the lungs into the blood. This means that the oxygen level in the blood may drop, and the body’s organs, tissues and cells may not get the amount of oxygen they need. Oxygen therapy keeps the level of blood oxygen above a certain level, which reduces breathlessness. It can, therefore, help people with pulmonary fibrosis to stay more active throughout their day.”⁶ Staying active is critical with lung fibrosis as it helps slow the rate of health decline, leading to a longer than average lifespan (median 3 years post-diagnosis). A patient’s ability to access sufficient oxygen is critical to remaining active. Unfortunately, because electricity costs can increase dramatically by using home oxygen concentrators, lung fibrosis patients may be unable to get the oxygen they need to maintain safe blood oxygen levels.

According to a recent letter submitted by the HSE to the Joint Oireachtas Committee on Health, the HSE provide home oxygen to approximately 4,200 patients (all lung diseases) with an estimated 420-630 additional patients receiving oxygen through private means⁷. There are a variety of conditions that require oxygen, but lung fibrosis patients have significantly higher oxygen requirements and sometimes multiple concentrators are needed. This leads

⁵ Assumes all oxygen patients across Ireland (4200 households) at 20 pc tax rate with average annual electricity cost 2,574 (1,464 Irish average +1210 average increase due to oxygen equipment)

⁶ <https://patient.boehringer-ingelheim.com/lwpcf/living-with-pulmonary-fibrosis/treatments/oxygen-therapy>

⁷ 2nd July 2024 forwarded communication from the HSE to the Oireachtas Joint Committee on Health in response to ILFA’s oxygen briefing and questions provided to the Committee 8th May.

to a dramatic increase in utility costs. While anecdotally we have heard of electricity bill increases of up to €500 per month, we estimate the average annual increase to be approximately €1,210 for patients using a single oxygen concentrator⁸. For those dependent on multiple oxygen concentrators, this cost could increase exponentially. Because most lung fibrosis patients are unable to work, the increased utility cost can force very difficult choices like rationing oxygen. Low income, economically vulnerable patients are being denied a fundamental human right, the right to breathe.

Over 40% of patients responded that they must ration oxygen due to high utility costs and delivery delays. Over 80% worry about their utility cost increases due to oxygen use. (October 2023 Patient Survey, Irish Thoracic Society)

Fortunately, there is a tax rebate system in place for kidney dialysis patients to serve as a model for ILD patients to help offset their increased costs. The system provides a rebate for electricity costs (up to €4,425 for 2023), Laundry and Protective Clothing (not applicable), and telephone (up to €370).

While this could represent a significant investment in Government funding (we estimate €2.2M) there would be savings to offset. Encouraging patients to use home oxygen could reduce the amount (and therefore cost) of oxygen deliveries. Additionally, it has been shown that the use of oxygen by patients helps increase conditioning and thusly slow disease progression, resulting in lower overall demand for oxygen and less frequent hospitalisation brought on by hypoxemia.⁹ This would, in turn, result in lower HSE medical costs (estimated to be approximately €10,000⁴ per patient per year, a large portion of which is hospitalisation) and reduce demand on HSE services.

Kidney dialysis patients currently benefit from a tax rebate programme which partially offsets the increased costs of managing their condition. Because the programme is condition specific, ILD patients are excluded. This inequity of care between the two conditions can be rectified by funding the provision of a similar tax rebate scheme for patients who require the use of supplementary oxygen.

⁸ Assuming an average kWh cost of .28 and a 500 watt concentrator running 24 hours per day, 365 days per year.

⁹ <https://www.atsjournals.org/doi/10.1513/AnnalsATS.201705-372OC>

Our Ask:

Ringfence €40,000 in funding for the 0.2 WTE resource identified to manage the ILD Care Pathway as agreed by the HSE in April 2023.

We request the Government ringfence funding for hiring the 0.2 WTE previously agreed by the HSE to develop an ILD Care Pathway as a step toward establishing equitable ILD patient care which can only be realised through a Clinical Care Programme.

According to The Wheel, “the OECD Health at a Glance reports that Ireland spends 6.1% of GDP on Health, compared to an OECD average of 9.2%. Ireland is among the countries with the largest income gap, where people in the bottom 20% of the income distribution are at least twice as likely to have a long-term illness or health problem as those in the top 20%. The report also found that Ireland had the highest outpatient healthcare costs, accounting for an average of 40% of household spending on healthcare.”¹⁰

Sláintecare has left behind many ILD patients. Ireland’s 96 Community Health Network hubs provide improved access and speed to diagnostics for many patients with chronic conditions, but not necessarily those with ILD. GPs in North Wicklow for example can now refer patients for pulmonary testing to the Bray Integrated Care Hub who offer a range of advanced care services for chronic diseases¹¹. Unless the patient is an ILD patient. Bray, like most Integrated Care Hubs doesn’t accept patients with an ILD diagnosis¹².

As a result, many patients receive ongoing care from GPs and despite the severity of ILD (about 1 in 1600 people over the age of 65 die from ILD each year¹³), there is low awareness of this disease across the GP network. ILFA has received numerous anecdotal accounts of the consequences of this lack of awareness: delayed and inaccurate diagnoses, invasive and unnecessary

¹⁰ https://www.wheel.ie/sites/default/files/media/file-uploads/2024-06/16194_TheWheel_Budget_2025_Submission_Inners%20V6-1.pdf

¹¹ <https://www.gov.ie/en/press-release/1ca58-minister-for-health-stephen-donnely-publishes-the-slaintecare-progress-report-2021-2023/>

¹² 12-07-2024 Letter from Clinical Lead for Respiratory Care SVUH and CHEast responding to ILFA enquiry regarding whether ILD patients are treated at the Bray ICH.

¹³ 806,300 total population (Stastica.com) divided by estimated average 500 deaths per year

tests, and costly treatments which provided little benefit. The access to timely and effective medical care in local communities as promised by Sláintecare is helping some, but not ILD patients.

The alternative, referral to ILD specialty centres (most of which are in Dublin) increases the standard of care but forces patients to travel for the care they need. And the ILD centres are not necessarily designed for ongoing disease management. While specialist centres have clinical services, they may or may not have respiratory therapists, psychologists, dieticians, palliative care, and other supports required by ILD patients to manage their conditions on an ongoing basis. The standard of care in the community envisaged in Sláintecare is not being realised for ILD patients and must improve.

In 2023, the Government allocated €43 million in recurring funding for the HSE to implement care pathways. “The implementation of Modernised Care Pathways is a multi-annual change initiative that includes 72 pathways which have been designed to broaden the points of access to healthcare for specific conditions and ensure that patients are seen faster and progress through a simplified journey towards definitive treatment, often without having to visit hospital.”¹⁴ That funding was earmarked for 36 pathways but did not include ILD. Despite this, in April of 2023, ILFA was informed by the HSE that .2 WTE would be appointed to assess the environment for ILD patients and develop a Clinical Care Pathway. Recruitment of this resource to develop the Care Pathway was seen as a step toward establishing a Clinical Care Programme which would finally see our twenty-year goal of equitable care for ILD patients realised. That resource has yet to be appointed.

“As of July 2024, the 0.2 WTE Clinical Care Pathway development post has yet to be appointed. Recruitment of the resource never commenced...it appears to have been an empty promise”. Maureen O'Donnell, CEO of ILFA

A Care Pathway, however, is just the first step, addressing ongoing standards of care. A Clinical Care Programme is our ultimate goal because it would provide ILD specialist clinicians, multi-disciplinary teams, oxygen assessments and lung transplantation options. It would also ensure sufficient resources to deliver the level of care needed like a Clinical Lead for ILD, health outcome

¹⁴ <https://www.hse.ie/eng/about/who/strategic-programmes-office-overview/modernised-care-pathways/>

targets, administrative support and a governance structure. Finally, it would mean that ILD is properly prioritised, providing equitable care for all.

We have been told time and time again that HSE staffing and care models are designed to deal with sizeable populations of patients requiring standardised care. A standardised high-volume process is unsuitable for ILD patients and today, many are falling through the cracks of the system. For patients and their families going through what is the most difficult time of their lives, it's completely unfair to ask them to fight a battle against their disease on two fronts. The medical system must be adapted to support all ILD patients, not just a lucky few. This will happen with the development of a Clinical Care Programme.

If the first step in establishing a Clinical Care Programme is to develop a Care Pathway, and if the first step in developing a Care Pathway is appointing a 0.2 WTE resource to assess its viability, then we request specific funding be ringfenced in the budget for this purpose to ensure that, as has been for over a year, the process is no longer stalled.

Our Ask:

Provide €1.5M to expand the existing Respiratory (COPD/asthma) pulmonary rehabilitation programme to ensure ILD patients are referred as part of routine care¹⁵.

Sufficient funding should be provided to expand the existing COPD/asthma pulmonary rehabilitation programme to allow access for ILD patients.

Research has demonstrated that pulmonary rehabilitation can significantly improve health outcomes and lifespan in patients with lung fibrosis and yet most are denied access to the pulmonary rehabilitation services which are available to every single COPD or asthma patient. This systemic inequity is shortening patient lives and increasing hospitalisation costs and demand on the health system.

While there are approximately 760,000 people in Ireland with COPD and asthma compared to only approximately 5,000 people in Ireland with Interstitial Lung Disease, a higher percentage of the patient population die from ILD annually (estimated at 7% to 10% of the total patient population¹⁶) as asthma and COPD combined (0.2%¹⁷). In fact, with just 72 deaths per year, asthma is nearly seven times less lethal than ILD.

Despite the severity of this disease, a 2021 ILFA survey of over 100 lung fibrosis patients found nearly half had received no specialty care referral¹⁸. For those who received a referral, only 25% were referred for pulmonary rehabilitation.

75% of lung fibrosis patients have never received a referral to pulmonary rehabilitation. (2021 Patient Survey, Irish Lung Fibrosis Association)

¹⁵ .5 WTE (40,000) at each of the 34 centres across Ireland plus 140,000 for procedural change.

¹⁶ <https://irishthoracicsociety.com/wp-content/uploads/2019/04/Chapter-8-Chronic-Interstitial-Lung-Disease-and-Sarcoidosis-1.pdf>

¹⁷ Patient population and mortality data from COPD.ie and Asthma Society of Ireland

¹⁸ <https://ilfa.ie/wp-content/uploads/2023/07/Access-to-Specialist-and-Multidisciplinary-Healthcare-for-Pulmonary-Fibrosis-1.pdf>

One reason patients are not referred is because pulmonary rehabilitation programmes are targeted toward COPD and asthma patients. “Pulmonary rehabilitation (PR) is a comprehensive, multi-disciplinary programme that uses a combination of strength training, teaching, counselling, and behaviour modification techniques to reduce symptoms and optimise functional capacity in patients with chronic lung disease. Based on the well-documented effectiveness of PR in chronic obstructive pulmonary disease (COPD), over the years supportive evidence of its benefits for other respiratory diseases has been emerging.”¹⁹

A 2024 literature review found that “[lung fibrosis] patients who undergo [pulmonary rehabilitation] programmes....experience a significant improvement in exercise capacity, dyspnoea, HRQOL, and cardiopulmonary endurance in the short term”, even when the programme is designed for COPD¹⁰. It also postulated that amendments could be made to COPD/asthma programmes to suit the specific needs of lung fibrosis patients, for example the increased use of oxygen during exercise, to have an even greater and longer-term benefit on patient lung condition¹⁰.

Adding just .5 WTE to each of the 34 COPD/asthma pulmonary rehabilitation clinics across the country trained in the needs of ILD patients would provide access for the 75% of patients currently excluded. Amending the COPD/asthma programmes to suit the needs of ILD patients and providing ongoing access to programmes for patients (as studies show decline can occur after 6 months) would improve health outcomes and reduce demand on hospital and A&E services.

Despite a lower mortality rate in Ireland, all COPD and asthma patients can access pulmonary rehabilitation while 75% of lung fibrosis patients remain excluded. This systemic inequity is shortening patient lives, increasing hospitalisation costs and putting an unnecessary strain on the Irish health system. Funding the expansion of the existing COPD/asthma pulmonary rehabilitation programme to incorporate the specific needs of ILD patients and recommending regular referral as standard diagnostic practice would result in improved health outcomes for patients and support a more equitable health care environment across all lung disease patient groups.

¹⁹ Zamparelli, S.S.; Lombardi, C.; Candia, C.; Iovine, P.R.; Rea, G.; Vitacca, M.; Ambrosino, P.; Bocchino, M.; Maniscalco, M. The Beneficial Impact of Pulmonary Rehabilitation in Idiopathic Pulmonary Fibrosis: A Review of the Current Literature. *J. Clin. Med.* **2024**, *13*, 2026. <https://doi.org/10.3390/jcm13072026>