Pre-Budget Submission 2026

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. It 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 engaged in advocacy, education, research and provided direct supports to patients and the wider lung fibrosis 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.

Last year ILFA advocated for and was granted €500,000 historic funding for lung fibrosis priorities in Budget 2025. Additionally, in 2025 a Clinical Advisor Lead was appointed to assess the current state of lung fibrosis care. What at first seemed like progress has turned into disappointment though. The €500,000 remains an unspent budget item in the HSE National Service Plan. One year on from our previous pre-budget submission, our patients still 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.

ILFA continues to fight for equitable care in the form of a Clinical Programme, but in the interim, we ask the Government to fund these priorities in budget 2026:

1. **Ongoing funding for an ILD patient registry.**
2. **Expand pulmonary rehabilitation community access to ILD patients**
3. **An ILFA support line staffed by specialist nurses and a grant programme for patients to offset out of pocket treatment costs.**
4. **Tax relief for electricity costs and travel for patients dependent on supplementary oxygen.**

€371,000

Patient Registry

Ongoing funding and staffing for an HSE-managed patient registry.

€3M

Tax Relief

Tax relief for patients reliant on home oxygen therapy.

€125,000

ILFA Funded Programmes

Funding for ILFA to provide a nurse line and patient grant programme.

€1.6M

Pulmonary Rehabilitation

Expand pulmonary rehab services to accommodate ILD patients.

Our Ask:

Ring-fence €371,000 (5 WTE) in initial funding and €350,000 5 WTE) in ongoing funding thereafter to establish and maintain an Interstitial Lung Disease (ILD) patient registry.

We request ring-fenced government funding to address a foundational inequity in care for ILD 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 ILD 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]

> ***No one knows how many people in Ireland have lung fibrosis. "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)*

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. Part of the funding allocated for ILD in ILFA's Budget 2025 submission (€150,000) must go toward the clinical audit which identifies the data set, establishes information governance and report metrics, and addresses any data collection issues during the initial establishment of the registry.

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[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

Assuming this is carried out in 2025 then, the funding requested for Budget 2026 is for the next phase of the registry and includes headcount and software to manage and maintain the registry at each of the eight ILD specialist centres with a national Data Manager to oversee the full data set.

Without a registry, the number and conditions of patients with ILD across Ireland remains unknown. Some ILD patients receive good or excellent care[2], 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[2b]. 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.

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[2] https://ilfa.ie/wp-content/uploads/2023/07/Access-to-Specialist-and-Multidisciplinary-Healthcare-for-Pulmonary-Fibrosis-1.pdf

[2b]. 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 €3M in income tax relief (modify tax policy) for patients receiving supplemental oxygen therapy[3].

We request the Government modify tax policy, expanding the existing tax examption for kidney dialysis patients, to help offset the financial burden of living with this debilitating disease.

ILD affects the movement of oxygen from the lungs into the blood meaning blood oxygen level drop leading to the body's organs, tissues and cells not getting the oxygen they need. "Oxygen therapy keeps the level of blood oxygen above a minimum threshold, which reduces breathlessness. It can, therefore, help people with ILD to stay active.[4]" Staying active is critical with ILD as it helps slow the rate of health decline, leading to a longer lifespan (median 3 years post-diagnosis) and helps maintain patients' mobility and independence. Patient ability to access sufficient oxygen is critical to remaining active. Unfortunately, because electricity costs can increase dramatically when using home oxygen concentrators, ILD patients may be unable to get the oxygen they need to maintain safe blood oxygen levels.

In a letter submitted to the Joint Oireachtas Committee on Health in 2024, the HSE stated they provided home oxygen to approximately 4,200 patients (all lung diseases) with an estimated 420-630 additional patients receiving oxygen through private means[5]. During the oxygen contract changeover, the HSE discovered this had been grossly underestimated, as oxygen companies reported actual numbers of approximately twice the 2024 HSE estimate. There are a variety of conditions that require oxygen, but ILD patients have significantly higher oxygen requirements and sometimes multiple oxygen concentrators are needed in a household. This leads to a

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[3] While current estimates of oxygen patients across Ireland are over 8,000, not all would avail of the scheme (estimate 5000 households) at 20 pc tax rate with average annual electricity cost 2,574 (1,752 Irish average +1210 average increase due to oxygen equipment)

[4] https://patient.boehringer-ingelheim.com/lwpf/living-with-pulmonary-fibrosis/treatments/oxygen-therapy

[5] 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.

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 concentrator[6]. For those dependent on multiple oxygen concentrators, this cost could increase exponentially. Because most ILD patients are unable to work, increased utility costs force very difficult choices. Patients with the lowest incomes, those who are most vulnerable, are being denied the fundamental human 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 €2.96M) 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.[7] This would, in turn, result in lower HSE medical costs (estimated to be approximately €10,000[4] 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, lung fibrosis patients are excluded. This inequity of care between the two conditions can be rectified by funding the provision of a similar tax rebate scheme lung fibrosis patients who rely on supplementary oxygen.

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

[7] https://www.atsjournals.org/doi/10.1513/AnnalsATS.201705-372OC

Our Ask:

Ringfence €125,000 in funding for ILFA to establish and maintain a medical advice service and provide grants to the ILD community to offset the high cost of care.

We request the Government provide funding for ILFA to implement a patient grant system to offset the high cost of care and to hire a specialist nurse who will lend medical expertise to ILFA programmes and provide advice to ILD patients.

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."[8]

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 refer patients for pulmonary testing to the Bray Integrated Care Hub who offer a range of advanced care services for chronic diseases[9]. Those advanced care services are not offered though for ILD patients. Bray, like most Integrated Care Hubs doesn't accept patients with an ILD diagnosis[10].

As a result, many patients are forced to either receive ongoing, but unspecialised care from their GPs, or travel sometimes great distances (and at great cost) to receive ongoing care. Unspecialised care from GPs is problematic as the complexity and severity of the disease make it difficult to manage. GP offices aren't equipped with high flow oxygen, respiratory physiologists and nurses, mental health professionals and other expertise needed to help patients effectively manage their disease.

The alternative, referral to one of the eight ILD specialty centres (five of which are in Dublin) improves the standard of care but forces patients to travel for the care they

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[8] https://www.wheel.ie/sites/default/files/media/file-uploads/2025-06/The%20Wheel%20Budget%202026.pdf
[9] https://www.gov.ie/en/press-release/1ca58-minister-for-health-stephen-donnelly-publishes-the-slaintecare-progress-report-2021-2023/
[10] 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.

need. And the ILD centres are not necessarily designed for ongoing disease management. While ILD specialist centres have clinical services, support services like respiratory therapists, psychologists, dieticians, palliative care, and other supports required by ILD patients to manage their conditions on an ongoing basis are inconsistent. The standard of care envisaged in Sláintecare, even in specialist centres, is often not realised for ILD patients.

In June 2025, two years after the HSE committed to appointing a Clinical Advisor (CA) Lead to investigate the current state of ILD care and recommend improvements, the resource was finally appointed. The CA Lead role is a critical step toward establishing a Clinical Programme which would finally see ILFA's twenty-year goal of equitable patient care realised. While this is an important step, until the CA Lead's recommendations are implemented, patients will continue to struggle to receive affordable community care.

During this time (2025 and 2026 at least) ILFA will continue to fill the gap in community care with non-medical advice, exercise classes, patient care guides, mental health courses and informational webinars. Additional funding should be given to the HSE so they may engage in a contract for services with ILFA. The funding will be used toward a nurse to strengthen patient supports with specialist respiratory expertise on staff and a grant programme managed by ILFA to provide small grants to patients to offset the high cost of care (travel) and additional paid medical services like psychological supports and pulmonary rehabilitation.

HSE care models are designed for high volume, standardised care. This inflexible, economies of scale model means ILD patients are turned away from community services they need. For these 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.

While the Clinical Advisor does the work to assess and eventually recommend a model for equitable care, ILFA will continue to fill the gap in services. Our capacity to support patients would be greatly improved with a nurse on staff, and a grant programme would reimburse patients , partially offsetting the cost of necessary community services which today they are denied.

Our Ask:

Provide €1.6M to expand the existing Respiratory (COPD/asthma) pulmonary rehabilitation programme to ensure ILD patients are referred as part of routine care[11].

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 ILD 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 population[12]) as asthma and COPD combined (0.2%[13]). In fact, with just 72 deaths per year, asthma is nearly seven times less lethal then ILD.

Despite the severity of this disease, a 2021 ILFA survey of over 100 ILD patients found that only 25% were referred for pulmonary rehabilitation.

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

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

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[11] .5 WTE (40,000) at each of the 34 centres across Ireland plus 140,000 for procedural change.

[12] https://irishthoracicsociety.com/wp-content/uploads/2019/04/Chapter-8-Chronic-Interstitial-Lung-Disease-and-Sarcoidosis-1.pdf

[13] Patient population and mortality data from COPD.ie and Asthma Society of Ireland

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."[14]

A 2024 literature review found that "[ILD] 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 COPD[10]. It also postulated that amendments could made to COPD/asthma programmes to suit the specific needs of ILD patients, for example the increased use of oxygen during exercise, to have an even greater and longer-term benefit on patient lung condition[10].

Adding just 0.5 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.

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[14] 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