Irish Lung Fibrosis Association

Pre-Budget Submission 2027

Equitable Care for People Living with Lung Fibrosis

Interstitial Lung Disease (ILD), also known as lung fibrosis or pulmonary fibrosis, is a progressive, incurable, life-limiting condition causing irreversible scarring of the lungs. People living with lung fibrosis experience severe breathlessness, chronic cough, fatigue and declining mobility. There is currently no cure, and for many patients, everyday activities become increasingly difficult as the disease progresses.

An estimated 5,000 people in Ireland are living with ILD, yet access to essential services remains highly dependent upon geography. Many struggle to access pulmonary rehabilitation, specialist nursing support, psychological services, palliative care and affordable oxygen therapy.

Budget 2026 marked a major step forward for people living with ILD with the allocation of €500,000 in dedicated funding for lung fibrosis priorities. This investment has already delivered measurable improvements in patient care, including:

- A dedicated ILD Nurse Advice line
- Virtual Pulmonary Rehabilitation services
- Daily exercise and wellbeing programmes
- Psychological counselling for patients and families

Demand for these services has been extremely strong. In the first six months of 2026:

- 134 patients enrolled in Virtual Pulmonary Rehabilitation
- More than 180 patients received support through the Nurse Advice line
- Patient satisfaction with the Advice Line is 4.92 out of 5
- Waiting lists have already emerged for some services

The funding also supported an HSE National Framework for Interstitial Lung Diagnosis and Care in Ireland which identified care inequities and made recommendations to improve outcomes for people living with lung fibrosis nationwide. The recommendations were submitted to the CCO in June. As the CCO and HSE Regions consider implementing the framework recommendations, immediate investment is required to maintain progress thus far and address critical gaps in care.

ILFA 2027 Budget Priorities

€302,000
ILFA Multi-disciplinary Patient Support Programmes

€141,500
ILD Clinical Advisory Recommendation Leadership

€87,100
National ILD Registry Pilot

€7.7M
Patient Affordability Measures

Why Action Is Needed Now

- In a 2021 ILFA study, 75% of ILD patients surveyed had never been offered pulmonary rehabilitation.
- In a 2023 ILFA study, more than 40% of respondents reported rationing oxygen because of cost and delivery difficulties.
- In that same study over 80% worried about increased utility costs caused by oxygen therapy.
- Access to specialist nursing, physiotherapy, psychological support, palliative care and rehabilitation remains highly dependent on geography.
- The National Framework for Interstitial Lung Diagnosis and Care in Ireland has now identified how these inequities can be addressed, creating an immediate and urgent need for implementation.

Without targeted investment, these inequities will persist, patients will continue to experience avoidable deterioration in health and quality of life and the healthcare service will continue to spend money on unnecessary hospital utilisation. Opportunities to reduce acute hospital costs and to improve long-term care planning will be lost.

ILFA's Goal

Everyone living with lung fibrosis in Ireland should have access to the right care, in the right place, at the right time, by the right person. Wherever they live, whatever their circumstances.

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Our Ask:

Ringfence €302,000 in funding for ILFA to maintain our ILD nurse advice line, continue our Virtual Pulmonary Rehabilitation (VPR) Programme and exercise classes, and provide much needed nutritional and psychological counselling to ILD patients, increasing access to multi-disciplinary care.

Why: In 2026 we utilised HSE funding to begin to deliver multi-disciplinary services to approximately 500 patients and family members. Demand for these services has been very strong; we are meeting or exceeding all agreed targets and the virtual pulmonary rehabilitation programme is in such high demand that there is a waiting list. In 2027, expanding our services will allow us to better meet patient demand. Patients who are better informed, have gained physical and mental coping strategies, and who have been made stronger by exercise and conditioning programmes are healthier and place less of a demand on public health services.

In 2025, Ireland spent approximate 6.3% of GDP on Health, compared to an OECD average of 9.3%[1]. Additionally, there are significant issues of equity. While overall life expectancy and macro health indicators in Ireland rank highly, according to the OECD's Country Health Profile data, "roughly 91% of adults in the highest income brackets report being in good health, compared to a steep decline down to 67% in lower-income echelons."[2]

For ILD patients, there are limited services available in the community to support their ongoing care. 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.

As a result, many patients are denied services or forced to travel sometimes great distances to receive ongoing monitoring and multi-disciplinary care. Care in the community is extremely limited. GPs find it difficult to support the needs of someone with the complexity and severity of the disease. Regional chronic disease hubs, offering pulmonary rehabilitation and other services to patients with lung diseases, offer limited if any access to pulmonary rehabilitation and no access to other services for ILD patients, they are instead referred to one of the eight ILD specialty centres (five of which are in Dublin). Here they can receive a higher (but still

[1] https://www.oecd.org/en/publications/health-at-a-glance-2025_8f9e3f98-en.html

[2] https://www.oecd.org/content/dam/oecd/en/publications/reports/2025/12/country-health-profile-2025-country-notes_7e72146d/ireland_6304dfa1/c879341f-en.pdf

variable) level of care but are forced to travel for the care they need. 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, not all ILD centres have all services. The standard of care envisaged in Sláintecare, even in specialist centres, is often not realised for ILD patients.

In June 2025 a Clinical Advisor (CA) Lead was appointed under the governance of NCP Respiratory to investigate the current state of ILD care and make framework recommendations for improvement. That framework was submitted to the Chief Clinical Officer (CCO) this year and is currently awaiting approval and publication. While this is an important step, until the framework's recommendations are funded and implemented, patients will continue to struggle to receive affordable community care.

While work continues on approving the national framework and planning for its funding and implementation, ILFA continues to provide services in the community at no cost to patients through programmes we began to offer in 2026 thanks to HSE NCP Respiratory funding. This includes:

- Virtual pulmonary rehabilitation (96 patients enrolled in the first six months of 2026)
- Daily exercise classes (average of 21 attendees per class)
- Psychological counselling (for 30 patients and family members)
- Specialist disease information through an ILD nurse adviceline (more than 180 patients advised in the first two months with a user satisfaction rating of 4.92 out of 5).

The funding allocated for lung fibrosis care in Budget 2026 has been transformational for ILD patient care. In 2027 we're requesting a slight increase (10K overall or 3%) to add Nutrition counselling as this is one of our most frequently requested services. These programmes, in addition to our existing programmes funded through general donations (including wellbeing classes, patient information guides, and educational webinars) provide vital support for lung fibrosis patients across Ireland.

Our Ask:

Ringfence €141,500 and allocate 0.4 WTE HSE resources to lead the implementation of the recommendations arising from the National Framework supported by NCP Respiratory.

Why: Funding these implementation roles would help translate the national framework recommendations into measurable improvements in patient care by strengthening referral pathways, expanding access to multidisciplinary services and supporting more consistent care across Ireland. This would improve patient outcomes, reduce avoidable hospital utilisation and help ensure that no person living with lung fibrosis is disadvantaged because of where they live.

The appointment of an ILD Clinical Advisor (CA) Lead in 2026 was an important step towards achieving equitable care for people living with lung fibrosis. The CA Lead under the governance of the NCP Respiratory submitted framework recommendations to the Chief Clinical Officer (CCO). The CA Lead then stepped down, the work having been completed. The recommendations are currently awaiting approval and publication. While the CCA Lead's work is confidential, it identifies significant gaps in care and recommends targeted actions to improve patient outcomes nationwide.

ILFA is seeking funding for 0.4 WTE HSE resources (0.2 WTE ILD Clinical Advisor Lead and 0.2 WTE Project Manager) to re-fill the posts for the next phase, working with NCP Respiratory to lead implementation of the framework recommendations. Without dedicated implementation capacity, there is a significant risk that the excellent work done thus far will not materialise into meaningful improvements for patients.

The requested funding would facilitate the transition from assessment to action by staffing a project to implement the recommendations. These coordination roles, in conjunction with Health Regions, would ensure that recommendations are realised in measurable patient service improvements.

An example of care inequity that could be improved is found in pulmonary rehabilitation. Pulmonary rehabilitation (PR) is a comprehensive, multi-disciplinary programme that uses a combination of strength training, education, and behaviour modification to reduce symptoms and optimise functional capacity chronic lung disease patients. Lung fibrosis patients who undergo pulmonary rehabilitation experience a measurable improvement in physical conditioning which in turn

reduces breathlessness and other symptoms[3]. In Ireland though, many patients are not referred to pulmonary rehabilitation, in fact, in ILFA's 2021 study, 75% of those surveyed had never received a referral.

Palliative care represents another area of significant inequity for people living with lung fibrosis. Although lung fibrosis is a progressive, life-limiting condition associated with severe breathlessness, fatigue, cough, anxiety and psychological distress, access to specialist palliative care services remain inconsistent. It is often introduced too late in the disease course. Evidence demonstrates that early palliative care involvement improves symptom management, advance care planning, patient wellbeing and caregiver support, while also reducing unnecessary hospital utilisation[4].

Another example of an inequity is a lack of access to specialist ILD nurses. Specialist ILD nurses are internationally recognised as a cornerstone of high-quality lung fibrosis care. They provide patient education, treatment monitoring, symptom management, care coordination and a consistent point of contact for patients navigating a complex and progressive disease. The role is particularly important for patients receiving antifibrotic therapies and/or supplementary oxygen[5]. A 2025 study found that the introduction of a specialist ILD nurse was associated with reduced acute healthcare utilisation among patients, while additional research has shown substantially improved adherence to antifibrotic therapies when specialist nursing support is available[6]. Despite these benefits, access to ILD specialist nurses remains limited and is frequently confined to ILD specialist centres. Patients living outside these centres often have no direct access to disease-specific nursing support.

The psychological burden of lung fibrosis is substantial but often overlooked. Studies consistently report high rates of anxiety and depression among people living with idiopathic pulmonary fibrosis and other ILDs, driven by progressive breathlessness, uncertainty about prognosis, loss of independence and social isolation[7]. Research has shown that anxiety and depression are strongly associated with worsening breathlessness, fatigue and reduced quality of life, regardless of disease severity. Experts increasingly recommend that psychological assessment and support be embedded within routine ILD care pathways rather than being treated as an optional add-on service[8]. Currently, access to psychological support for lung fibrosis patients is inconsistent across Ireland and largely dependent on local resources.

[3] https://www.resmedjournal.com/article/S0954-6111%2824%2900411-6/fulltext
[4] https://academic.oup.com/annalsats/advance-article/doi/10.1093/annalsats/aaoag070/8537194
[5] https://publications.ersnet.org/highwire_display/entity_view/node/479028/full
[6] https://pmc.ncbi.nlm.nih.gov/articles/PMC11869855/
[7] https://publications.ersnet.org/content/erjor/early/2026/04/16/23120541.01732-2025.full.pdf
[8] https://journal.chestnet.org/article/S0012-3692%2826%2900424-1/fulltext

Access to these services would improve overall wellbeing, strengthen self-management and support patients to live as well as possible[9].

Pulmonary rehabilitation, palliative care, specialist nursing support and psychological services are all recognised as essential components of comprehensive lung fibrosis care. However, access to these services in Ireland remains inconsistent and those who do not live near specialist centres must travel, sometimes great distances, to receive care that should be available in the community. This funding and resourcing request is focused on leading the implementation of the framework recommendations which, if implemented, will significantly reduce care inequities. It provides the seed funding to develop a costed and resourced implementation plan which, if progressed, would fill the service gaps and result in more equitable care.

In 2026, the ILD Clinical Advisor, supported by NCP Respiratory and working with patients, clinicians and the wider lung fibrosis community, developed a framework to address inequities in lung fibrosis care across Ireland. The framework now requires dedicated implementation support to translate recommendations into action. Funding 0.4 WTE resources would help deliver more equitable access to multidisciplinary care, improve patient outcomes, reduce avoidable hospital utilisation and ensure that no person living with lung fibrosis is disadvantaged by where they live.

[9] https://journal.chestnet.org/article/S0012-3692%2826%2900424-1/fulltext

Our Ask:

Ring-fence €87,100 in funding and allocate 0.9 WTE in HSE resources to conduct a pilot as proof of concept for nationwide Interstitial Lung Disease (ILD) patient registry.

Why: A national ILD registry would 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 the recent implementation of the HSE Health App is an example of a national data effort, the current health information technology infrastructure in Ireland remains highly fragmented with major data gaps and silos. Difficulties associated with bringing data together from different sources makes informed decision-making a challenge for those planning health and social services."[10]

The Clinical Advisory Lead's framework recommendations were developed, in part, to document the prevalence of ILDs across Ireland. The data gathered from this report is a glimpse into the intelligence that a registry could provide. It is data that could be used for healthcare budgeting and improved service provision. This data, not yet published, will quickly be obsolete without an ongoing and expanded effort to document the conditions of those affected by ILD.

We have met with and received advice from Future of Registries Taskforce (FORT), from the National Organisation for Clinical Audits (NOCA), and from the ILD Clinical Advisory (CA) Lead. The framework developed by the CA Lead has already identified the data set in ILD centres, acute care facilities, and in the community. The pilot would establish information governance and report metrics, and work through data collection issues during the initial establishment of the registry.

If this pilot can be carried out in 2027, the structure, in conjunction with the data already gathered in the framework would lay the groundwork for a wider registry implementation as part of the framework recommendations in 2028 and beyond.

[10] 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

Without a registry, the number and conditions of patients with ILD across Ireland remains unknown. Some ILD patients receive good or excellent care[11], but in our experience, many do not, and it is those patients who would benefit the most from the foundational healthcare component of a national ILD registry.

A national ILD registry would support better planning, service delivery and resource allocation across the health system. With an estimated 5,000-6,000 people living with ILD in Ireland and annual care costs potentially exceeding €50 million[14b], accurate information on patient numbers, disease burden and service needs is essential. An ILD registry would provide the evidence required to plan services effectively, target investment and support better long-term management of this condition.

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

[14b] 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 €7.7M in affordability measures for patients struggling with the cost of care.

Why: Affordability measures including medical cards for all ILD patients regardless of circumstances and a tax deduction for electricity and travel costs could help patients offset the financial burden of living with this debilitating disease.

The cost of medications, oxygen, and other therapies can be exorbitant for lung fibrosis patients. Antifibrotics, a critical medication for slowing the progression of the disease, cost between €800 to €1,400 per month. Supplemental oxygen, between 3-10 litres of liquid oxygen per day for some patients, can cost between €1000 to over €2,000 per month. While the Drugs Payment Scheme covers all but €80 per month for most medications and supplemental oxygen, in the case of supplemental oxygen in particular, the patient must still make a full upfront payment to the oxygen company. This payment is then reimbursed, but because the reimbursement system is paper-based and antiquated, it can take 30 days or more to process.

Supplemental oxygen is an important therapy for many lung fibrosis patients. "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.[12]" Staying active is critical with ILD as it helps slow the rate of health decline and maintain patient mobility and independence.

The high cost of liquid oxygen and slow reimbursement drives patients to use oxygen concentrators - machines that convert ambient air into a purified stream of oxygen. The machines run on electricity and unfortunately, because electricity costs can increase dramatically when using home oxygen concentrators, ILD patients are stuck between two very expensive options – higher liquid oxygen costs but reduced electrify, or higher electricity costs but lower liquid oxygen costs. Many are unable to get the oxygen they need to maintain safe blood oxygen levels. We have anecdotal accounts of electricity bill increases of up to €500 per month, but use an industry estimate to calculate an average annual increase at approximately €1,210 for single oxygen concentrator[13]. For those dependent on multiple oxygen concentrators, this cost is a multiple of €1,210 per year. These high costs force very difficult choices.

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

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

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)*

Affordability can be addressed in two primary ways. The first is to issue a medical card to all lung fibrosis patients regardless of means. Currently some, but not all, receive emergency medical cards, particularly as their disease progresses. If medical cards were issued earlier, then patients would be more likely to fully utilise life extending therapies like oxygen because with a medical card, upfront payment to oxygen companies is covered by the State. Medical cards should be issued to all patients at diagnosis as a matter of routine care.

Medical cards will not reduce electricity costs though. For this there is a tax rebate system in place for kidney dialysis patients which should be extended to patients on home oxygen therapy. The rebate (note figures are 2025) includes electricity costs of up to €3,614, travel (.24 per kilometre), and telephone (up to €390)[14]. The tax rebate, in addition to medical cards for all ILD patients, would make a transformative difference in the affordability issues lung fibrosis patients face.

While €7.7M would be a significant investment by the Irish State (we estimate €2M in tax relief and €5.7M in medical cards[1]) we believe these costs would be offset by savings. For example, studies show supplemental oxygen helps to increase conditioning and thusly slow disease progression, resulting in lower overall demand for oxygen and less frequent hospitalisation brought on by hypoxemia.[1] Much of the estimated per year patient cost (based on the UK model) of €10,000 per patient per year (€50M in estimated total) is acute hospitalisation, some of which would likely be offset by these proactive measures.

[14] https://www.revenue.ie/en/personal-tax-credits-reliefs-and-exemptions/health-and-age/health-expenses/additional-expenses-for-a-kidney-patient.aspx