



The Irish Lung Fibrosis Association Company Limited by Guarantee

TRUSTEES' REPORT AND FINANCIAL STATEMENTS

For the Year End 31 December 2024

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Charity Information

Name

The Irish Lung Fibrosis Association
Company Limited by Guarantee (CLG)

Registered Offices

Registered Business Address:

Lavery House,
Earlsfort Terrace,
Saint Kevin's,
Dublin,
D02 T625

Correspondence Address:

C/O Carmichael Centre,
4 North Brunswick Street,
Dublin 7,
D07 RHA8

Principal Advisors

Independent Auditors:

Whiteside Cullinan,
Fleming Court,
Flemings Place,
D04 N4X9

Bank:

Bank of Ireland,
Montrose,
Stillorgan Road,
Dublin 4
D04 W201

Solicitors:

Hayes Solicitors, LLP
Lavery House,
Earlsfort Terrace,
Saint Kevin's,
Dublin, D02 T625

Board Members

Eddie Cassidy, Chair
Liam Galvin, Treasurer
Nicola Cassidy
Jim Egan
Colin Edwards
Patricia Jones
Lynn Fox

Company Secretary

Nicola Cassidy

Executive Management

Maureen O'Donnell CEO

Registration Numbers

Company Number:

367940

Registered Charity

Number: 20053437

Revenue CHY

Number: 15462

Board Members and CEO

Eddie Cassidy Chairperson



Eddie Cassidy is Chairperson of the Irish Lung Fibrosis Association. He Joined ILFA in 2007 after caring for his wife Denise, who was diagnosed with Idiopathic Lung Fibrosis in 2003. His personal life experience of caring for a loved one with lung fibrosis has influenced his commitment to ILFA, its mission and values. Eddie was elected Chair in 2018 having previously served as Treasurer for 4 years and as a Director since 2016. Eddie is a member of the Advocacy Subcommittee

Liam Galvin Treasurer



In addition to his volunteer position with ILFA, Liam also leads the European Pulmonary Fibrosis Federation (EU-PFF) as it's unpaid CEO, is the elected chair of the European Lung Foundation Patient Advisory Committee and the Patient co-chair of the EU funded European Reference Network for Rare Respiratory Diseases (ERN-LUNG). His advocacy work is inspired by his family, being deeply impacted by familial idiopathic pulmonary fibrosis.

Nicola Cassidy Company Secretary



Nicola Cassidy joined the ILFA Board in 2007, became a Director in 2016, and was appointed as ILFA Secretary in 2023. Nicola serves on the ILFA Governance, Advocacy, Research, and Fundraising sub-committees and is a member of the ILFA PPI Research Advisory Group. She has a background in clinical science and has a special interest in ILD research and health literacy. Nicola was a carer for her mother, Denise, when she was diagnosed with IPF and her health deteriorated.

Prof. Jim Egan Board Member



Professor Jim Egan is a Consultant Respiratory and Lung Transplant Physician at the Mater Misericordiae University Hospital (MMUH). Professor Egan began working at MMUH in 2000 where he supported the development of the National Lung Transplant Service which began in 2005, to date 379 lung transplants have been performed. He was appointed Director of Organ Donation Transplant Ireland (ODTI) in 2011 and more recently appointed as Executive Clinical Director of the MMUH in 2020. In addition to this, Professor Egan is one of four founding members of ILFA.

Colin Edwards

Board Member



Colin Edwards founded Merlin Consulting Ltd in 2015 to advise digital health creators and co-develop robust assessments of new technologies on patient outcomes. He is a co-founder of patientMpower, an Irish digital health company focused on lung and kidney health, where he led the development and implementation of clinical and health economics evaluations for respiratory and renal conditions. Colin retired from patientMpower in 2022 but continues as an advisor and board member. He currently serves on the boards of the Irish Lung Fibrosis Association and Siel Bleu Ireland on a voluntary basis.

Lynn Fox

Board Member



Lynn Fox began her nursing career over 20 years ago and currently works as a Respiratory Advanced Nurse Practitioner at the Mater Misericordiae University Hospital. She is committed to raising awareness of ILFA and the valuable support it provides to IPF patients, their families, and healthcare professionals.

Patricia Jones

Board Member



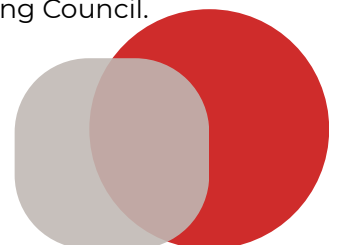
With a nursing career spanning over four decades, Patricia has dedicated more than 42 years to compassionate, patient-centred care. After qualifying as a registered nurse in SVUH, she pursued further education in respiratory nursing and advanced healthcare at UCD, Aintree University Liverpool, and RCSI. For the past 27 years, she has specialised in respiratory nursing, supporting patients with ILD, COPD, and asthma across hospital and community settings. Patricia is a proud voice for the nursing profession and a strong advocate for community-based respiratory care, supporting patients and families during key healthcare transitions.

Maureen O'Donnell

CEO



Maureen is Chief Executive Officer of the Irish Lung Fibrosis Association. Prior to taking up the role in April 2024 she ran the Responsible Business Audit Programme for Business in the Community Ireland. She has also held a variety of leadership roles in start-ups, social enterprises, and the charity sector in Ireland, and has significant industry experience in Finance and Information Technology in the US. She holds a Master's Degree in Business (Sustainability) and Bachelor's Degrees in Finance and English Literature. Maureen has also served on many Boards including the Dublin Food Cooperative, Camara Education, Three Rivers Food Cooperative, The Girl Scouts, and the Green Building Council.





Chairperson's Statement

For more than 20 years ILFA has been supporting patients, their families, and the wider lung fibrosis community with advocacy, education, research, and direct supports. 2024 witnessed a step change in our work across these four pillars when our first Chief Executive Officer, Maureen O'Donnell, took up her post in April. This strategic hire was the culmination of many years of planning, and I would like to sincerely thank the ILFA Board for their commitment to this next step in our evolution. It is helping ILFA to grow and be better equipped to serve the lung fibrosis community.

Special thanks to Maureen and her team, Gemma O'Dowd, Anne Griffin, and Eimear Bell for all their hard work. 2024 was a year of growth for ILFA, with revenue increased by 30% which allowed us to deliver more programmes than ever before.

In 2024 our activities were focused on four core aims:

- Advocating for equitable patient care.
- Educating patients, their carers, and the wider lung fibrosis community.
- Engaging in Research leading to earlier diagnosis and improvements in healthcare.
- Providing award winning Supports directly to patients.

The key metrics we report on included: 2,639 participant sessions for our exercise class, two successful, online Patient Information Days, six "Let's Talk" sessions, and six educational bursaries provided to medical professionals.

In addition, we collaborated with the Irish Thoracic Society for the Fergus Goodbody Memorial Lecture and the Terence Moran Memorial Award. We also released a strength and conditioning video in December

And then finally, the accomplishment I am perhaps most proud of, we secured €500,000 in historic funding for lung fibrosis in Budget 2025.

Our revenue growth is thanks to our amazing fundraisers. Without them, ILFA would not exist and over the course of 2024 there were many organised events that not only raised vital funds but also raised valuable awareness of lung fibrosis. A selection of fundraising events is highlighted in this report. Thank you to everyone who fundraised for ILFA in 2024!

In addition, we were delighted to have been selected by the Central Bank of Ireland for a two year partnership which has been absolutely transformational to our work. I am so grateful for that partnership and for the ongoing financial support provided to us through our partnership with Boehringer Ingelheim.

Last but by no means least, I would like to pay tribute to ILFA Board members for their guidance and support in 2024. As we move into this next phase of development as an organisation, the Board's deep commitment to ILFA's mission and values remains steadfast and strong.

Eddie Cassidy

Eddie Cassidy
Chairperson



Governance and Management

The Irish Lung Fibrosis Association (ILFA) is a registered charitable company in Ireland, limited by guarantee and not having a share capital, in accordance with Part 18 of the Companies Act 2014.

The charity is registered with the Charities Regulator under Registered Charity Number (RCN): 20053437, and was granted charitable tax exemption under CHY Number: 15462, pursuant to Section 207 of the Taxes Consolidation Act, 1997.

ILFA is in compliance with the Governance Code for Charities and maintains a record of compliance available for the Regulator to review.

ILFA is governed by its Constitution, dated September 2024. In the event of the charity being wound up, each member's liability is limited to €1, in line with the terms of the company's guarantee. As a company limited by guarantee, ILFA has no beneficial owners. Therefore, the senior managing officials, which include the Board of Directors, have been recorded in the Register of Beneficial Owners in compliance with regulatory requirements.

ILFA has a small virtual staff team headed by a Chief Executive Officer who reports directly to the board through the Chairperson. The CEO is not a member of the Board.

Oversight and strategic direction are provided by the Board of Trustees. The following decisions are reserved for the Board to make and approve:

- The Company's strategic plans and annual operating budgets;
- Projects outside the scope of the strategic plan;
- Business acquisitions and disposals;
- Decisions on Litigation;
- Appointment/Removal of subcommittee Chairs and Members;
- Appointment/Removal of Chief Executive Officer;
- Appointment/Removal of Auditors;
- Approval of Borrowing/Finance Facilities;
- Approval of Supplier Contracts with term exceeding one year or financial liability on ILFA exceeding €10,000;
- Ongoing Review of Risk and Internal Controls;

Board Governance and Oversight

The Irish Lung Fibrosis Association (ILFA) is governed by a voluntary Board of Directors who provide leadership and oversight to ensure ILFA's mission and values are upheld.

Board members are recruited through nomination by existing members, often following active participation in ILFA's work. New Directors are proposed and seconded at the Annual General Meeting (AGM) and formally registered with the Companies Registration Office. While there are no fixed term limits due to ILFA's small size and specialist focus, directorships are reviewed annually at the AGM.

All new Board members receive a formal induction, which includes training on ILFA's governance policies, code of conduct, and ethical responsibilities. Ongoing training is provided as needed to support members in fulfilling their duties effectively.

The Board is responsible for providing strategic leadership, overseeing the CEO, maintaining financial oversight, and ensuring compliance with legal and ethical standards. Members actively participate in Board meetings, subcommittees, and ILFA initiatives, and commit to collective decision-making in line with ILFA's values.

ILFA's Board operates under a Board Handbook and is guided by a Code of Conduct and a Conflict of Interest and Declaration of Loyalty Policy, last reviewed in September 2022. Board members declare any relevant interests on appointment and update the Register of Interests annually. All governance policies are reviewed on a scheduled basis or as needed.

ILFA is committed to involving its community in shaping its direction. In 2025, ILFA planned a World Café event—an online facilitated discussion—to gather stakeholder insights as part of a mid-point review of its strategic plan. The session was structured around ILFA's four core aims, with small group discussions on Research, Support, and Education & Advocacy, designed to explore what is working well and identify areas for future development. Additional engagement mechanisms, such as direct contact with service users and satisfaction feedback, continue to inform Board decision-making and ensure ILFA remains responsive to the needs of those it serves.

ILFA established five committees over the year, each led by a Trustee or the CEO. The subcommittees are: Advocacy, Governance, Finance and Audit, Research, and Fundraising. While the Advocacy Committee met formally over the year and is at a relatively mature stage, the remaining committees were in development at the end of the year with draft Terms of Reference.

Responsibility for the day-to-day operations is delegated to the Chief Executive Officer, Maureen O'Donnell. Delegated functions relate to operational management, including record-keeping, directing resources and spending in line with the annual approved budget, reporting, and regulatory compliance.

ILFA maintains a performance management system which includes an annual review for all members of staff carried out by the CEO (except in the case of the CEO which is carried out by the Board). There are also informal interim reviews on a quarterly basis where performance and development are discussed and actioned.

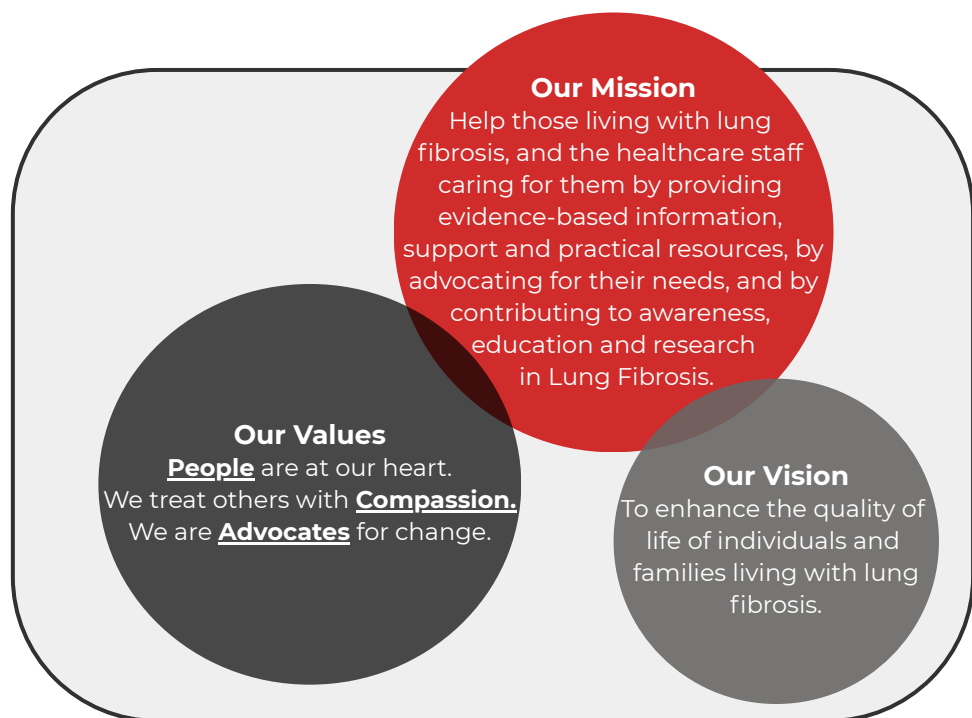
The Irish Lung Fibrosis Association (ILFA) maintains a prudent investment and reserves strategy in line with its Reserves Policy, most recently reviewed in June 2024. The organisation aims to hold reserves equivalent to at least one year's operational costs, ensuring its core activities can continue uninterrupted in the event of unforeseen circumstances or income shortfalls. ILFA's reserves are carefully managed to support short- and long-term goals, including safeguarding against risk, funding unexpected costs, and enabling planned future projects. While reserves are maintained at a sustainable level to ensure stability, funds are not held unnecessarily and are used in a timely and transparent manner in accordance with ILFA's charitable objectives. Investment and budgeting decisions are reviewed annually by the Board and aligned with ILFA's Financial Policy and good governance standards.

An independent audit is conducted annually by our appointed auditors. ILFA's annual report, which includes the audited financial statements and the Strategic Plan, is published on our website and is also available upon request from our registered office.

As part of our commitment to transparency and good governance, ILFA includes a summary of Board meeting attendance to demonstrate accountability and active engagement by Board members throughout the year.

Board Member	AGM	Feb	Mar	Apr	May	Jun	Jul	Sep	Oct	Nov	Dec
Eddie Cassidy	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Liam Galvin	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
Nicola Cassidy	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓
Colin Edwards	✓	✓		✓	✓		✓	✓		✓	✓
Patricia Jones	✓	✓			✓	✓		✓	✓		
Lynn Fox		✓	✓			✓			✓		
Jim Egan	✓	✓	✓	✓	✓			✓	✓	✓	
Marie McGowan					✓	✓	✓		✓		✓

ILFA Strategy



History

ILFA was established in 2002 to provide support to people diagnosed with lung fibrosis, and to provide education and research into the condition. The charity was founded by a group of volunteers including Nicola Goodbody, the late Terence Moran, Marie Sheridan, and Professor Jim Egan.

ILFA is a small charity, and throughout our history we've benefitted from many talented volunteers and staff. Our most recent operational model began in 2016 when we brought in Gemma O'Dowd to work with the Board as an Administrator. In 2020, with the onset of the pandemic, demand surged, and we realised we needed more support. We brought in a second Administrator, Anne Griffin who worked with Gemma to manage operations until 2024 when ILFA took the next big step in evolution and hired Maureen O'Donnell as ILFA's first Chief Executive Officer, adding her to the small team of staff and volunteers. Hiring Maureen was intended to bring about a step change in the professionalisation of the organisation and the Board is excited about ILFA's prospective growth for the future.

Over the past 22 years ILFA has successfully advocated for, educated, and supported the lung fibrosis community. We've engaged in meaningful research that we hope has contributed to the great body of work that forms lung fibrosis care in Ireland. We recognise though that there is still a long way to go, and as ILFA continues to grow, building upon the solid foundation from which we were founded, the services we provide and the community we serve will remain at the centre of our focus. The same vision, mission and values that formed our organisation still guide us and remain relevant to our work today.

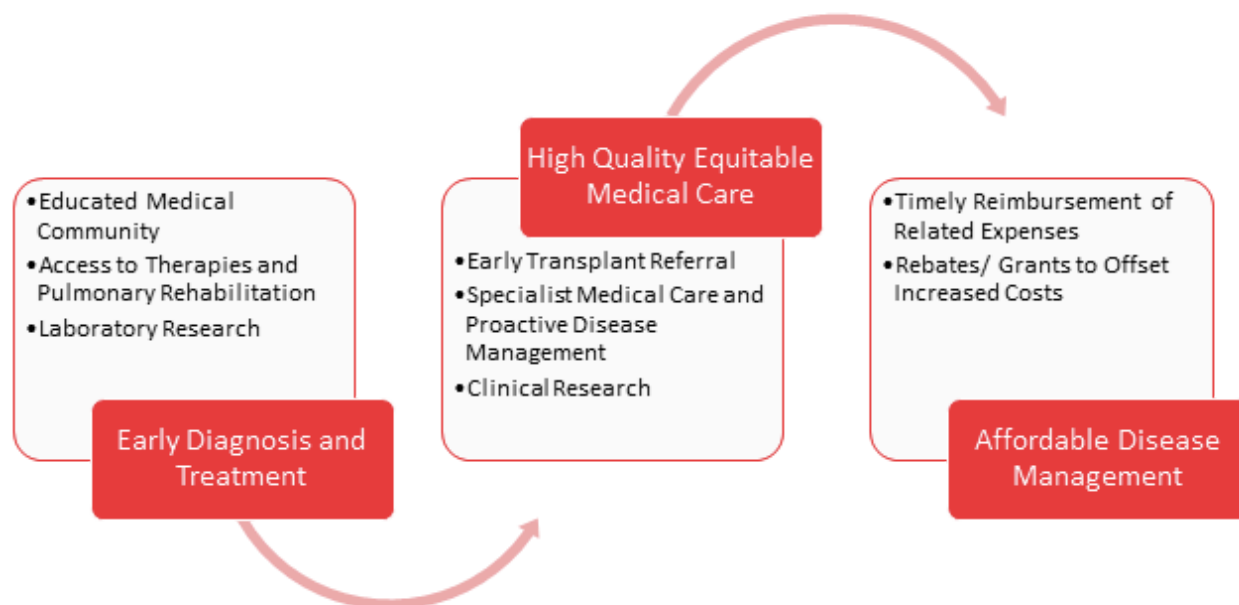
Context and Risks

The landscape of lung fibrosis care in Ireland is one of evolving progress tempered by persistent challenges, with the charity sector and ILFA in particular playing a pivotal, often indispensable, role. Lung fibrosis is a progressive, life limiting disease, and because of its relative rarity, diagnosis remains a critical hurdle. While awareness is growing, early and accurate diagnosis can still be elusive, often leading to delayed care. With a disease as severe as lung fibrosis, a delayed diagnosis can shorten patients' lives. Access to specialist multidisciplinary teams, essential for comprehensive care, is not uniform across the country, creating disparities in patient journeys. Treatment options, particularly anti-fibrotic medications, have transformed the prognosis for some patients, slowing disease progression. However, these treatments are not universally effective, and access to these therapies and to clinical trials as well which can lead to new and improved therapies can be limited, often requiring patients to travel to one of eight specialist centres, most of which are in Dublin.

This is where Ireland's dedicated charity sector, exemplified by the Irish Lung Fibrosis Association (ILFA), becomes vital. ILFA works tirelessly to fill the gaps in care, offering crucial support, education, and advocacy for patients and their greater lung fibrosis community. ILFA's initiatives include providing patient education materials, a non-medical support line, linkage to support groups across the country, and facilitating access to mental and physical health classes that enhance quality of life. Furthermore, ILFA actively engages in fundraising to support research, which is fundamental to understanding the disease better and discovering new treatments. ILFA also advocates with the Irish Government and the HSE for improved healthcare policies and services, and better access to diagnostics and therapies.

ILFA's principal risk is one of funding. ILFA has supported lung fibrosis patients for more than 20 years, and across that time horizon, despite our significant contributions, we have never received any meaningful State funding. Over 90% of ILFA's funding comes from individual fundraising and corporate partnerships and this lack of diversity in funding is a risk to our sustainability. The collective effort of healthcare professionals, policymakers, and a robust charity sector is essential to ensure that all individuals living with lung fibrosis in Ireland receive timely diagnosis, equitable access to best-in-class treatments, and comprehensive supportive care. As ILFA's ambition is to grow its service portfolio to support all the estimated 5,000 lung fibrosis patients across Ireland, lack of State funding remains the biggest barrier to achieving our goals.

Key Outcomes and Levers



Strategic Objectives

ADVOCATING for equitable patient care

ILFA advocates for equitable care for lung fibrosis patients. Unfortunately today, while some patients receive excellent care, many, particularly those outside of the eight major specialist centres in Dublin, Limerick, Cork, and Galway, are left behind. These patients face a battle on two fronts – against the progression of their disease and against a health system that doesn't provide them with the care they need. Equitable care for patients means they will receive an earlier diagnosis, better treatment, and proper supports to help them manage their disease. ILFA, understanding the political system and the Department of Health both play a powerful role in holding the HSE to account, develops relationships with key politicians and DoH staff, leverages the political process (parliamentary questions, committees and etc.) and gathers information from our key stakeholders that can be utilised to strengthen our case for equitable care. Equitable care will ultimately come in the form of a Clinical Programme, but in the interim our nearer term advocacy priorities include: a patient registry, community access to pulmonary rehabilitation, medical cards and tax rebates to offset the high cost of disease management.

EDUCATING patients, their carers, and the wider lung fibrosis community

There are two primary unmet educational needs in regard to lung fibrosis. The first is that because of the relative rarity of the disease, awareness is low. It's often confused with other lung diseases and conditions and so misdiagnosis and delayed diagnosis are often the result. ILFA seeks to increase awareness and understanding of lung fibrosis across society, but particularly with healthcare professionals. The second unmet educational need is that once diagnosed, patients often lack information about their condition, what types of healthcare interventions can improve their prognosis, and where to get the support they need. ILFA empowers patients by providing them with the information they need to be advocates for effective care. We educate patients and the wider lung fibrosis community through webinars, classes, events, and public awareness campaigns.



Engaging in RESEARCH leading to earlier diagnosis and improvements in healthcare

Engaging in lung fibrosis research in Ireland offers vital benefits, including improved patient outcomes through earlier diagnosis and tailored treatments. Research also supports healthcare planning and policy development, ensuring better resource allocation. Despite these benefits, lung fibrosis research in Ireland is often underfunded, and Ireland as a country is overlooked for clinical trials. Additionally, there is no national patient registry and a lack of national coordination between hospitals and research institutions leading to fragmented data collection. While there are dedicated researchers and emerging interest in respiratory diseases, lung fibrosis remains under-recognized, impacting both public awareness and investment in research. Greater collaboration and funding are essential for meaningful advancement and ILFA works with researchers and the pharma sector to support research across a variety of areas. ILFA's Patient and Public Involvement (PPI) Group regularly shape research design and engage directly with studies to help improve patient outcomes and increase understanding of the disease.

Providing award winning SUPPORTS to patients

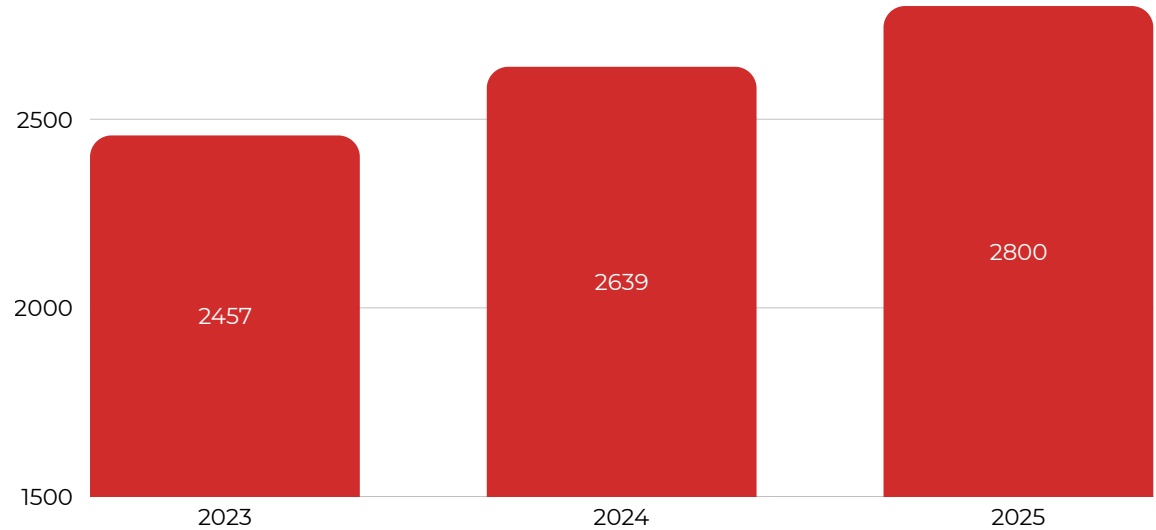
Lung fibrosis patients in Ireland often do not receive the care they need. For example, 75% of patients in a survey ILFA conducted in 2023 had never been offered pulmonary rehabilitation despite the evidence based benefits provided by this therapy. This therapy has proven to be effective and is offered to people with other lung conditions like COPD and asthma which have a better prognosis. Often patients, when they receive their diagnosis, are overwhelmed and shocked. Despite this, there are no mental health supports offered, in fact, there rarely is any ongoing support offered beyond monitoring the patient's condition on an ongoing basis. Slaintecare, which is supposed to provide care within the community, provides no community support for lung fibrosis patients. ILFA fills the gap in healthcare services by providing a non-medical advice line, patient information and exercise packs, exercise classes, connection to support groups around the country. ILFA recognises patients are part of a larger family system, and as such, also provides an annual ecumenical service where those who have lost someone dear to them can come together with others in grief and remembrance.

Key 2024 Metrics

ILFA's key metrics for 2024 included Exercise Class Participant Sessions, Webinar Viewers, and Patient Packs distributed. We also track the amount of money provided in educational bursaries to patients and medical professionals (less reimbursements from grants).



Exercise Class Participant Sessions



	2023	2024	(planned) 2025
Exercise Class Participants	2457	2639	2800
Webinar Views		429	500
Youtube Channel Webinars		1008	1250
Patient Packs Distributed		469	500
Bursaries Issued	€7000	€3000	€5000
Newsletters Reached		3750	5000

Programme Highlights

Advocacy

Key Success: The first ever State funding (€500,000) for lung fibrosis.

For many years ILFA has advocated for equitable care for lung fibrosis patients. The sad reality is that while some patients receive excellent care, many do not. ILFA envisions a world where all patients, regardless of post code or economic status, have the support they need to live longer and healthier lives. Our advocacy work centres on this aim.

- In April 2024 ILFA testified before the Joint Oireachtas Committee on Health.
- In May ILFA raised oxygen queries with the HSE through the Health Committee.
- In July ILFA sent a pre-budget submission to the Departments of Finance and Health.
- In September ILFA met with the Minister for Health regarding the submission.
- In October we were notified of the historic funding allocation.

In 2025 we continue our advocacy work, focusing primarily on how the allocated funding will be utilized to support lung fibrosis patients, and working with the Government and the HSE to ensure priorities not funded in Budget 2025 will be funded in Budget 2026.



Members of ILFA's Advocacy Team meeting with Minister Donnelly and Deputy Lahart

Education

Key Success: ILFA members shared their stories at the European Lung Fibrosis Patient Summit.

Thanks to the generous support of EU-PFF, we were able to send four patients to the 3rd European Patient Summit in Barcelona Spain. This bi-annual event provides a forum for the exchange of ideas and best practices across the lung fibrosis community.

In addition, ILFA provided educational bursaries to medical professionals, allowing them to attend the European Respiratory Society (ERS) Conference in Austria.

We also held six 'Let's Talk' webinars where experts from our medical community discussed issues unique to lung fibrosis patients. The sessions included: Keeping Well and Coping with Lung Fibrosis, Oxygen use and Cough Management, Medication, Nutrition, Patient Entitlements, and Exercise.

Two Patient Information Days were also held, providing vital information and resources to those newly diagnosed with the disease.

In 2025 we are significantly expanding our education efforts to focus on mental health for front-line medical professionals, GP and Acute Centre awareness, and a multi-media public campaign for lung fibrosis awareness month in September.

Research

Key Success: ILFA released a new Strength and Conditioning video, providing lung fibrosis patients with a tailored exercise regimen for home use across three levels of fitness.

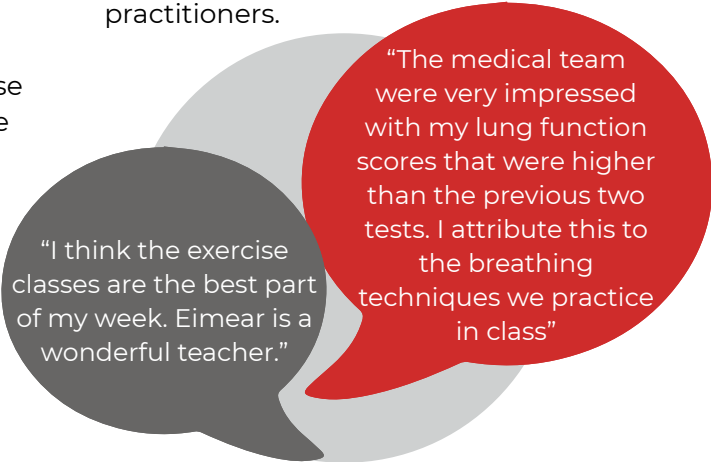
ILFA provides a variety of direct supports to patients and their caregivers including on-line exercise classes, patient information and exercise packs, and a non-medical patient support line.

In 2024 ILFA held on-line Exercise Classes led by a specialist respiratory physiotherapist three times per week. These classes were well attended with an average of 20 participants in each session.

ILFA also distributes patient packs to both patients and hospitals across Ireland with information and supplies that support newly diagnosed lung fibrosis patients. In 2024 we distributed 469 of these packs.

One of the most important service areas ILFA has is our patient support line. Anyone can call us seeking non-medical lung fibrosis advice. In 2024 alone we helped over 300 people struggling to come to grips with their condition.

In 2025 we will continue our patient support programme, and with sufficient funding, we hope to expand our patient support line with medical advice from nurse practitioners.



"I think the exercise classes are the best part of my week. Eimear is a wonderful teacher."

"The medical team were very impressed with my lung function scores that were higher than the previous two tests. I attribute this to the breathing techniques we practice in class"

Patient Supports


Key Success: ILFA received an award from the Irish Thoracic Society for our Patient Public Involvement (PPI) Group's work.

ILFA is dedicated to supporting research into lung fibrosis. We do this by funding research studies and through involvement in research development and studies by our PPI group.

In 2024 ILFA's members and the PPI Group engaged with several studies including:

- Build2K walking programme assessment.
- Patient and medical community attitudes to the establishment of a disease registry.
- HRB/HRCI research proposals.
- Design of a study on the mental health impacts of living with lung fibrosis.

In 2025, with our PPI group continuing to engage with researchers across the country, ILFA would like to see and support more clinical trials in Ireland. We will continue to engage in research, with the first example of this work being our World Cafe in January.



"The PPI group is doing fantastic work putting patients and their voice at the heart of every research study. It's so important to work together to ensure the best possible research questions are asked."

Community Stories

Frank Branigan is living with lung fibrosis and needs a lung transplant. He's hoping the Human Tissue Act 2024 will increase his chances of receiving an organ donation. Frank's daughter Niamh is an actor, producer, and writer, and wanted to use her talents to raise awareness. Niamh brought the concept of a film to Banjoman Films and together they developed this powerful film.

"Speak Now"- A powerful short film from Banjoman and Elk Films



Frank Branigan is pictured with his daughter Niamh.

RCSI PPI Knowledge Exchange



ILFA was delighted to attend the Royal College of Surgeons in Ireland's PPI Knowledge Exchange in March. Representatives of ILFA's PPI Research Advisory Group provided a presentation that shared meaningful examples of their PPI group in action.

Over 30 volunteers from the Central Bank of Ireland turned out on World Lung Day (25th September) to raise awareness of lung fibrosis and to raise funds for ILFA. The stationary cycle event, held in front of the Gaeity Theatre saw five teams pitted against each other in a head to head competition. The weather was dismal but the mood of the participants could only be described as bouyant!

World Lung Awareness Day





The Kerry Pulmonary Fibrosis Support Group organised a talk in the Meadowlands Hotel in Tralee in October with presentations from medical professionals from University Hospital Kerry.



Frank O'Connor, an ILFA member and lung transplant patient, published *Dying for a Breath*, a courageous story of his journey with lung fibrosis and transplant.

“Frank shares so openly of his journey that as you turn the pages you will find moments of vulnerability and resilience that mirror your own. Each chapter serves as a reminder that no matter how difficult the path may be there is strength to be found in shared stories and human connection.”

Treasurer's Statement

The Irish Lung Fibrosis Association is committed to the utmost transparency and accountability to our community and the many fundraisers who support our small charity. Our annual audited accounts are published on our website as soon as they are signed off by our auditors and approved by the Board. Our website also contains the audited accounts for previous years alongside our annual reports and news on our activities.

The ILFA financial year for 2024 which ran from the 1st of January to the 31st of December once again as in previous years saw that our main income was from individual acts of generosity and fundraising from the community we serve. Our fundraisers used both novel and ingenious methods and events to fund raise alongside traditional and popular events such as the women's mini marathon. Online funding platforms are now also commonly used by our fundraising community, and we have also seen increased income directly from the website. The Board would also gratefully acknowledge the kindness of legacy bequests and donations from the families of those within our community who lost their brave battle with lung fibrosis.

The support of our dedicated fundraisers is vital as are our corporate partnerships. In 2024 these two sources comprised 90% of ILFA's revenue, the balance from State and applied grants. ILFA grew revenue by 30% in 2024 which enabled us to expand our programmes and services. In 2024 we took a significant step forward in our evolution by hiring a CEO. The CEO managed operations supported by a small team of Administrative Assistants, a Respiratory Physiotherapist, and engagement with several consultants for project-related support. Management of ILFA's accounts are supported by a certified accountancy and book-keeping practice.

In the year to 31 December 2024, the cost of administrative consultants, projects, online activities, postage, printing, office, and general expenses came to €251,504 whilst overall income was €225,252 resulting in a deficit of €26,252 for the financial year. This deficit reflects that whilst income grew significantly and remains strong the demands and unmet needs of our community remain high. ILFA reacted to this by investing in additional services, supports and education for the lung fibrosis community. The Board made this decision, in part, because of the strength of ILFA's reserves, which, despite the high growth in revenue, continue to be in excess of one year's operational budget. ILFA retains cash reserves that would be available to continue its work even in the face of an increasingly unpredictable economic situation. As we move into 2025, ILFA remains viable going forward in its mission and objectives.



Liam Galvin

Liam Galvin
Treasurer and Vice-Chair.

Statement of Directors' Responsibilities

The directors are responsible for preparing the Directors* Report and the financial statements in accordance with applicable Irish law and regulations.

Irish company law requires the directors to prepare financial statements for each financial year. Under the law the directors have elected to prepare the financial statements in accordance with the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council. Under company law the directors must not approve the financial statements unless they are satisfied that they give a true end fair view of the assets, liabilities and financial position of the company as at the financial year end date and of the surplus or deficit of the company for the financial year and otherwise comply with the Companies Act 2014.

In preparing these financial statements, the directors are required to:

- select suitable accounting policies for the company financial statements and then apply them consistently;
- make judgements and accounting estimates that are reasonable and prudent;
- state whether the financial statements have been prepared in accordance with applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards;
- and prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company enable at any time the assets, liabilities, financial position and surplus or deficit of the company to be determined with reasonable accuracy, enable them to ensure that the financial statements and Director's Report comply with the Companies Act 2014 and enable the financial statements to be readily and properly audited. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Disclosure of Information to Auditor

Each persons who are directors at the date of approval of this report confirms that there is no relevant audit information (information needed by the company's auditor in connection with preparing the auditors report) of which the company's auditor is unaware, and the directors have taken all the steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the company's auditor is aware of that information.

Signed on behalf of the board



Edward Cassidy
Director



Liam Galvin
Director

The original financial statements were approved and signed by the directors on:

Date: 20th June 2025

Independent Auditor's Report

Opinion

We have audited the financial statements of The Irish Lung Fibrosis Association CLG ('the company') for the financial year ended 31 December 2024 which comprise the income Statement, the Balance Sheet, the Cash Flow Statement and the related notes to the financial statements, including the summary of significant accounting policies set out in note 2. The financial reporting framework that has been applied in their preparation is Irish Law and FRS 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland' issued in the United Kingdom by the Financial Reporting Council.

In our opinion the financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31 December 2024 and of its deficit for the financial year then ended;
- have been properly prepared in accordance with FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland"; and
- have been properly prepared in accordance with the requirements of the Companies Act 2014.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are described below in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of financial statements in Ireland, including the Ethical Standard for Auditors (Ireland) issued by the Irish Auditing and Accounting Supervisory Authority (IAASA) and the Provisions Available for Audits of Small Entities, in the circumstances set out in note 4 to the financial statements, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other Information

The directors are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our Auditors Report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2014

In our opinion, based on the work undertaken in the course of the audit, we report that:

- the information given in the Directors' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Directors' Report has been prepared in accordance with applicable legal requirements.

We have obtained all the information and explanations which, to the best of our knowledge and belief, are necessary for the purposes of our audit.

In our opinion the accounting records of the company were sufficient to permit the financial statements to be readily and properly audited and the financial statements are in agreement with the accounting records.

Matters on which we are required to report by exception

Based on the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified any material misstatements in the directors' report.

The Companies Act 2014 requires us to report to you if, in our opinion, the requirements of any of sections 305 to 312 of the Act, which relate to disclosures of directors' remuneration and transactions are not complied with by the Company. We have nothing to report in this regard.

Respective responsibilities

Responsibilities of directors for the financial statements

As explained more fully in the Directors' Responsibilities Statement set out on page 5, the directors are responsible for the preparation of the financial statements in accordance with the applicable financial reporting framework that give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, directors are responsible for assessing the company's ability to continue as a going concern, disclosing, if applicable, matters related to going concern and using the going concern basis of accounting unless management either intends to liquidate the company or to cease operation, or has no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditor's Report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAS (Ireland) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is contained in the appendix to this report located at page 8, which is to be read as an integral part of our report.

The purpose of our audit work and to whom we owe our responsibilities

Our report is made solely to the company's members, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's members those matters we are required to state to them in an Auditor's Report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume any responsibility to anyone other than the company and the company's members, as a body, for our audit work, for this report, or for the opinions we have formed.



Mark Hamill for and on behalf of WHITESIDE CULLINAN
Registered Auditor and Chartered Accountants
Fleming Court
Fleming's Place
Dublin 4
D04 N4X9

20th June 2025

APPENDIX TO THE INDEPENDENT AUDITORS REPORT

Further information regarding the scope of our responsibilities as auditor

As part of an audit in accordance with ISAS (Ireland), we exercise professional judgement and maintain professional skepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our Auditor's Report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our Auditor's Report. However, future events or conditions may cause the company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Financial Activities

Income Statement

for the financial year ended 31 Dec 2024

	Notes	2024 €	2023 €
Income		225,252	151,113
Expenditure		(251,504)	(153,609)
Deficit for the financial year		(26,252)	(2,496)
Total comprehensive income		(26,252)	(2,496)
Retained surplus brought forward		365,778	368,274
Retained surplus carried forward		339,526	365,778

The original financial statements were approved by the Board on 20 June 2025 and signed on its behalf by:

Edward Cassidy *Edward Cassidy*
Director

Liam Galvin *Liam Galvin*
Director

Balance Sheet

for the financial year ended 31 Dec 2024

	Notes	2024 €	2023 €
Fixed Assets			
Investments	6	<u>1,436</u>	<u>-</u>
Current Assets			
Debtors	7	<u>5,535</u>	<u>3,200</u>
Cash and cash equivalents		<u>362,464</u>	<u>367,099</u>
		<u>367,999</u>	<u>370,299</u>
Creditors: amounts falling due within one year	9	<u>(29,909)</u>	<u>(4,521)</u>
Net Current Assets		<u>338,090</u>	<u>365,778</u>
Total Assets less Current Liabilities		<u><u>339,526</u></u>	<u><u>365,778</u></u>
Reserves			
Retained surplus		<u>339,526</u>	<u>365,778</u>
Equity attributable to owners of the company		<u>339,526</u>	<u>365,778</u>

The financial statements have been prepared in accordance with the small companies' regime

The original financial statements were approved by the Board on 20 June 2025 and signed on its behalf by:

Edward Cassidy
Director

Edward Cassidy

Liam Galvin
Director

Liam Galvin

Cash Flow Statement

for the financial year ended 31 Dec 2024

	Notes	2024 €	2023 €
Cash flows for operating activities			
Deficit for the financial year		(26,252)	(2,496)
		<u>(26,252)</u>	<u>(2,496)</u>
Movements in working capital:			
Movement in debtors		(2,335)	(3,200)
Movement in creditors		<u>24,779</u>	<u>(2,287)</u>
Cash used in operations		<u>(3,808)</u>	<u>(7,983)</u>
Cash flows from investing activities			
Payments to acquire investments		<u>(1,436)</u>	<u>-</u>
Net decrease in cash and cash equivalents		(5,244)	(7,983)
Cash and cash equivalents at beginning of financial year		<u>366,774</u>	<u>374,757</u>
Cash and cash equivalents at end of financial year	8	<u><u>361,530</u></u>	<u><u>366,774</u></u>

Notes to the Financial Statements

1. General Information

The Irish Lung Fibrosis Association CLG is a company limited by guarantee incorporated and registered in Ireland. The registered number of the company is 367940. The registered office of the company is Lavery House, Earlsfort Terrace, Dublin 2. The nature of the company's operations and its principal activities are set out in the Directors' Report.

Currency

The financial statements have been presented in Euro (€) which is also the functional currency of the company.

2. Summary of Significant Accounting Policies

The following accounting policies have been applied consistently in dealing with items which are considered material in relation to the company's financial statements.

Statement of compliance

The financial statements of the company for the year ended 31 December 2024 have been prepared on the going concern basis and in accordance with generally accepted accounting principles in Ireland and Irish statute comprising the Companies Act 2014 and in accordance with the Financial Reporting Standard applicable in the United Kingdom and the Republic of Ireland (FRS 102) issued by the Financial Reporting Council.

Basis of preparation

The financial statements have been prepared on the going concern basis and in accordance with the historical cost convention except for certain properties and financial instruments that are measured at revalued amounts or fair values, as explained in the accounting policies below. Historical cost is generally based on the fair value of the consideration given in exchange for assets. The financial reporting framework that has been applied in their preparation is the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council.

The company qualifies as a small company as defined by section 280A of the Companies Act 2014 in respect of the financial year, and has applied the rules of the 'Small Companies Regime' in accordance with section 280C of the Companies Act 2014.

Income

Income comprises the amounts received from donations, fundraising activities and deposit interest receivable.

Investments

Investments held as fixed assets are stated at cost less provision for any permanent diminution in value. Income from other investments together with any related withholding tax is recognised in the Income Statement in the year in which it is receivable.

Taxation

The company is a registered charity, CHY 20053437, and has been granted charitable tax exemption under Section 207, Taxes Consolidation Act 1997. The CHY (Revenue) number is 15462

3. Departure from Companies Act 2014 Presentation

The directors have elected to present an Income and Expenditure Account instead of a Profit and Loss Account in these financial statements as this company is a not-for-profit entity

4. Provisions Available for Audits of Small Entities

In common with many other businesses of our size and nature, we use our auditors to assist with the preparation of the financial statements.

5. Employees

The average monthly number of employees, including directors, during the financial year was 1, (2023 -0)

	2024 Number	2023 Number
Administration Staff	<u>1</u>	<u>-</u>

6. Investments

Listed investments

Investments	€
Cost	
Additions	1,436
At 31 December 2024	<u>1,436</u>
Net book value	
At 31 December 2024	<u>1,436</u>

The company received shares by the way of a donation during the year end 31st December 2024 to the value of €1,436. As at the 31st December 2024 the value of those unlisted shares was €1,507.

	2024 €	2023 €
7. Debtors		
Trade debtors	-	3,200
Other debtors	3,427	-
Prepayments	<u>2,108</u>	<u>-</u>
	<u>5,535</u>	<u>3,200</u>

8. Cash and cash equivalents

	2024 €	2023 €
Cash and bank balances	58,061	152,271
Bank overdrafts	(934)	(325)
Cash equivalents	<u>304,403</u>	<u>214,828</u>
	<u>361,530</u>	<u>366,774</u>

9. Creditors

Amounts falling due within one year

	2024 €	2023 €
Amounts owed to credit institutions	934	325
Trade creditors	16,873	975
Taxation	1,919	-
Pension accrual	1,447	-
Accruals	<u>8,736</u>	<u>3,221</u>
	<u>29,909</u>	<u>4,521</u>

10. Status

The liability of the members is limited.

Every member of the company undertakes to contribute to the assets of the company in the event of its being wound up while they are members or within one year thereafter for the payment of the debts and liabilities of the company contracted before they ceased to be members and the costs, charges and expenses of winding up and for the adjustment of the rights of the contributors among themselves such amount as may be required, not exceeding €2.

11. Post-Balance Sheet Events

There have been no significant events affecting the company since the financial year-end.

12. Approval of financial statements

The financial statements were approved and authorised for issue by the board of directors on 20 June 2025.

Corporate Partnerships: Thank You

We are incredibly grateful to our corporate partners who supported ILFA throughout 2024. Your contributions have helped us reach more patients, families, and healthcare professionals with vital information, support, and care.



We are thankful to Boehringer Ingelheim for their continued partnership and generosity in 2024.

Highlights of Support:

Patient Education: Grant funding enabled two Patient Information Days and six Let's Talk webinars, reaching 429 patients and carers.

Exercise & Wellbeing: Boehringer Ingelheim funded 50% of ILFA's Exercise Classes, supporting over 1,300 participant sessions throughout the year.

Professional Engagement: ILFA also participated in a Boehringer-hosted charity roundtable in May, and joined ILD nurse education events in July and November.

Your support has had a direct and lasting impact on patient wellbeing, professional education, and ILFA's capacity to grow.



We extend our heartfelt thanks to the Central Bank Charity Committee, Conor McCabe, and all Central Bank staff and volunteers for your transformational support in 2024.

Highlights of Support:

- Your contributions helped ILFA grow its funding by 25%.
- For Patients: Enabled provision of information packs, support groups, exercise classes, and online forums.
- For Carers: Allowed ILFA to offer guidance and practical help during times of uncertainty.
- For Healthcare Professionals: Supported continued engagement with research and professional development.

This partnership has brought hope to our community and strengthened ILFA's ability to advocate, educate, and support.



Gratitude to Our Community

We would like to express our sincere thanks to all our donors, fundraisers, and volunteers who supported ILFA in 2024. Your generosity, time, and commitment have made a meaningful difference in the lives of those affected by lung fibrosis. Together, we are bringing hope, support, and strength to our community and we couldn't do it without you.



2024 Top Fundraisers

Mags MacAuley

Amount Raised: €14,385

Mags raised money taking part in the VHI Women's Mini Marathon

West Kerry Tractor Run

Amount Raised: €8,250

Organisers: JP O'Sullivan and team

A sixth annual tractor run took place in Dingle, West Kerry. ILFA received 50% of the proceeds from this fantastic community-led event.

Deborah O'Connor & Team

Amount Raised: €7,846

Deborah and her team raised awareness and funds with a 5km Cork mini-marathon.

Jason Nichol

Amount Raised: €7,370

Jason completed the grueling 252km, 6-day desert race, the Marathon Des Sables, and was the first Irish man to finish. An incredible achievement.

The Hennigan Family

Amount Raised: €7,329

Walked 100km of the Portuguese Camino in memory of Dermot.

Second Chance Pop-up Shop

Amount Raised: €7,224

Organisers: Mary Lawlor, Joanna Redmond, Brigid Nolan

A second-hand pop-up shop in memory of Dermot Lawlor raised a generous sum through sales and donations.

Joe Browne

Amount Raised: €4,276

Joe ran the Cork City Marathon in memory of his father and was joined by his son Sé at the finish. A deeply meaningful family moment.

Michael Flynn

Amount Raised: €4,000

Michael ran the Dublin City Marathon in memory of his mam, Rosie.

Gary Meyler

Amount Raised: €3,340

Gary ran the Wexford Half Marathon in memory of his dad Marty, supported by his mam Sandra and the local community

Frank O'Connor

Amount Donated to ILFA: €3,125

Frank, a lung transplant recipient, donated half the proceeds of his book sales "Dying for a Breath" to ILFA.

2024 Top Fundraisers

Clive Bourke

Amount Raised: €3,500

Ran the Dublin City Marathon in memory of Sadie Mannion and in support of the McNulty family.

Yvonne Boyle

Amount Raised: €2,850

Yvonne ran the Dublin City Marathon in memory of her father-in-law Frank and was supported by her family, including grandchildren who ran beside her.

Michelle Duffy

Amount Raised: €2,791

Michelle walked an impressive 350km in 30 days, in memory of her dad Charlie in Donegal.

Nora McNamara & Kate Bannon

Amount Raised: €2,500

Organised in Tipperary to do the Ballycahill 5km Walk, with great support from the community and camogie team.

Kevin Mullaney, Sean Parry, David Reynolds

Amount Raised: €2,055

This trio ran over 50km in the Dublin Mountains in memory of Liam Mullaney.

Living Lung Lab

Amount Raised: €1,067

Hosted a coffee morning at RCSI/Beaumont Hospital in support of lung fibrosis research and awareness.

James McAuliffe

Amount Raised: €1,905

Held a coffee morning in Banteer, Cork in memory of his father Donal.

Dave O'Byrne & Camron Crowe

Amount Raised: €1,683

Organised a St. Stephen's Day soccer match in Limerick in memory of John Meaney, Snr.

Leah Symes

Amount Raised: €1,500

Selected ILFA for €1,000 competition prize and €500 corporate donation from her workplace.

Eibhlin Mulhall

Amount Raised: €1,272

Walked the Camino in memory of her grandfather and exceeded her personal distance goals.

The Irish Lung Fibrosis Association

Company Number: 367940

Registered Charity Number: 20053437

Revenue CHY Number: 15462