

Irish Lung Fibrosis Association



DONOR REPORT 2025



Irish Lung
Fibrosis
Association

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CEO MESSAGE

We, at the Irish Lung Fibrosis Association (ILFA), would like to extend our deepest thanks to our generous donors who have been instrumental in advancing ILFA's work. 2025 was another year of growth, progress, and impact made possible through the extraordinary generosity of our donors, supporters, volunteers, and wider lung fibrosis community.



In 2025, donor funding supported our 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 improved healthcare.
- Providing award-winning **Supports** directly to patients.

2025 also marked an important period of organisational growth for ILFA. As awareness of lung fibrosis continues to grow, so too does our community and the demand for ILFA's trusted services. Thanks to your commitment, we have been able to respond to this growing need with compassion, innovation, and ambition for the future.

Every donation, fundraiser, and partnership has helped us move closer to our vision of ensuring that no one faces lung fibrosis alone. The impact of your generosity goes beyond financial support. It also brings hope, dignity, and reassurance to patients and families.

On behalf of everyone at ILFA and the community we serve, thank you for supporting our mission. Thank you for helping us continue to expand our impact. Together, we are building a brighter future for those affected by lung fibrosis.

With Deepest Gratitude,

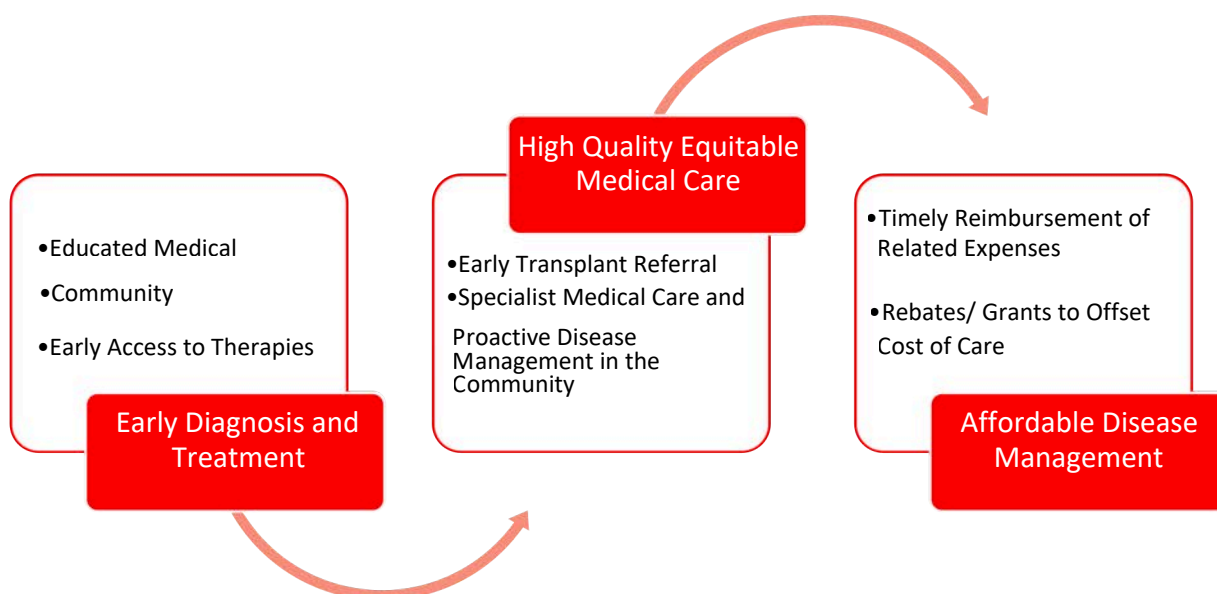
Maureen O' Donnell
Chief Executive Officer, ILFA

ABOUT ILFA

OUR MISSION

Our mission is to help and empower those living with lung fibrosis and the health care staff caring for them by providing evidence-based information, support and practical resources, by advocating for their needs, and by contributing to awareness, education and research in Lung Fibrosis.

IDEAL PATIENT OUTCOMES AND LEVERS



2025 IMPACT AT A GLANCE

Key achievements from a year of growth

9

Support Groups
Nationwide

1056

Youtube Video Replays

48

Mindfulness
Attendees

9

Educational Webinars

2658

Exercise Participant
Sessions

1

Research
Publication

1m+

People reached with
Awareness Campaign

24

Nurses completed
Mental Health Training

3544

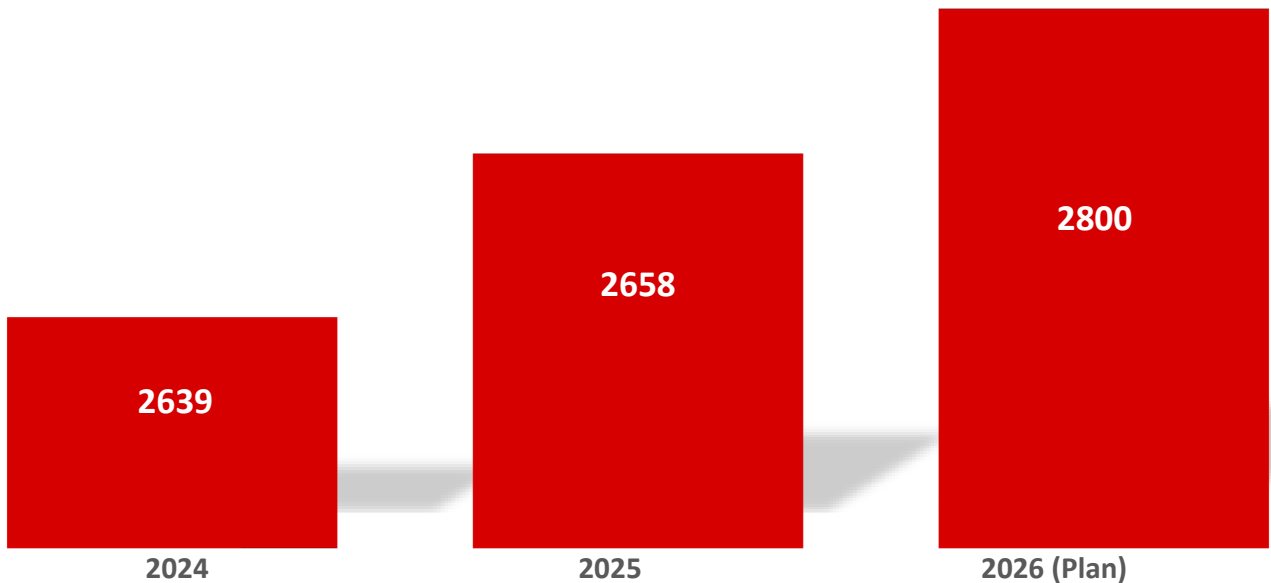
GPs Educated

Supporting the ILFA vision to enhance the quality of life for individuals
and families living with lung fibrosis

Irish Lung Fibrosis Association

HOW WE MEASURE IMPACT

Exercise Class Participant Sessions



Key Metrics 2025 - ILFA's key metrics for 2025 included Exercise Class Participant Sessions, Webinar Viewers, GP Education Leaflets distributed, Mindfulness Course attendees, Ecumenical Service Attendees and Patient Packs distributed. We also track the amount of money provided in educational bursaries to medical professionals.

KEY METRICS

Advocacy Metrics

2025

Parliamentary Questions	11
Meetings with Key Politicians	1
AV Room Briefings	1
2026 v 2027 Pre Budget Submission	28th July
Prospectus Report Launch	11th June

Key Education Metrics

2025

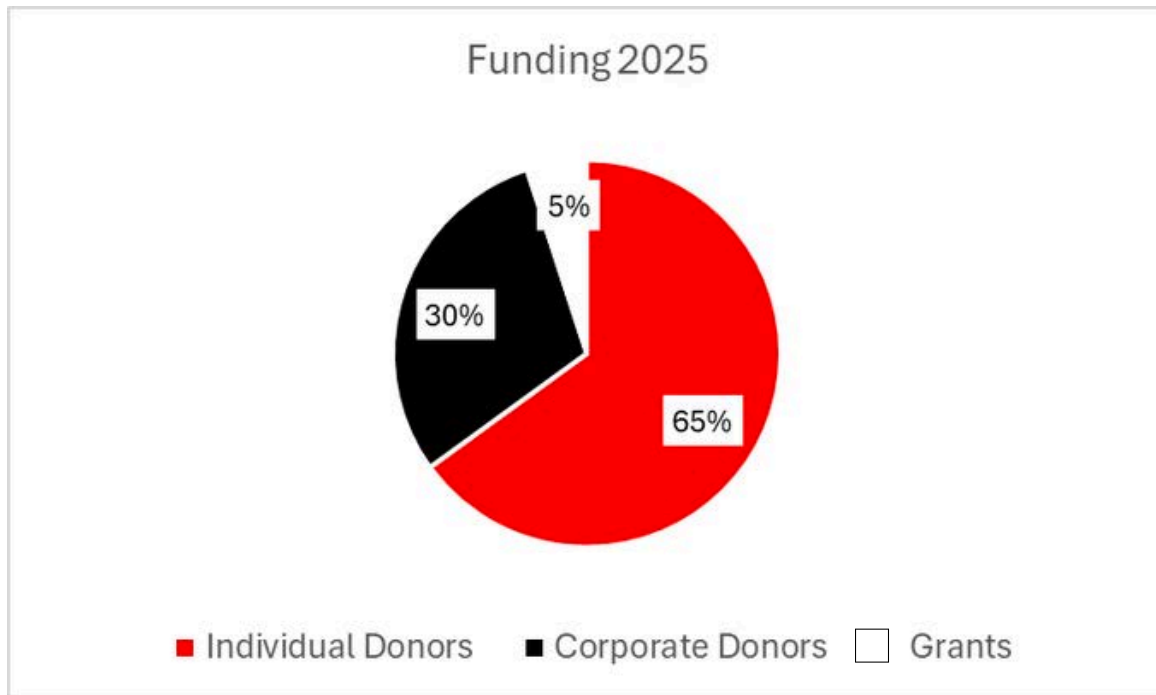
Webinar Views	932
YouTube Channel Webinar Replays	1056
Patient Packs distributed (inc. exercise)	587
Bursaries Issued	€ 4,000
GP Education Campaign Reach	3544
HCP Mental Health Training Day	24

Key Support Metrics

2025

Mindfulness Course Attendees	50
Ecumenical Service Attendees	60
Let's Talk Sessions - Participants & Watch backs	922
Patient Information Days Attendees	171

PRIMARY FUNDING SOURCES



Community fundraising activities remained ILFA’s largest source of income in 2025.

ILFA also received significant grant support from key partners including Boehringer Ingelheim, Endeavor Biomedicines, the National Lottery Fund, Gossamer Bio, Hospital Saturday Fund, and the Central Bank.

These grants supported a range of important programmes, including exercise packs and classes, Let’s Talk sessions, a GP Education campaign, a national awareness campaign, mindfulness courses, HCP mental health skills training and patient information days.

PROGRAMME HIGHLIGHTS

ADVOCACY

Key Success: State funding allocated to key patient priorities

ILFA advocates across all levels of the political system for our members. Every day the HSE, Government departments, and State agencies make important decisions about the policies and resources that affect the lives and wellbeing of people with lung fibrosis. We aim to influence those decisions for the benefit of the lung fibrosis community.

In 2024 ILFA successfully advocated for an historic 1 million euros in lung fibrosis funding. Our advocacy in 2025 was centered on getting the allocated funding released for patient services. We met with TDs, we issued Parliamentary Questions, and we held meetings with the HSE and Department of Health. A key meeting that proved pivotal in moving the priorities forward was with the new Minister for Health in late August. Following this meeting, the HSE negotiated and signed a service agreement with ILFA to fund a pulmonary rehabilitation pilot, a nursing advice line, a psychological counselling grant system, and additional exercise classes to be carried out in 2026.

It took longer than we'd hoped, but in the end we prevailed thanks to our members who advocated with us throughout 2025. From contacting and meeting with TDs and Senators, to sharing your stories in the Dáil, on radio, in print media, and at our World Lung Day event, your contributions were invaluable. We are deeply grateful for all of these efforts, including those who joined us in meetings with the Minister and other key decision-makers across the political system.



ILFA's Advocacy Team meeting with Minister MacNeill and Deputy Callaghan

HSE A to Z Listing

ILFA advocated for the HSE's A to Z disease webpage to be updated, incorporating Idiopathic Pulmonary Fibrosis (IPF) into its list of diseases in 2025.

PROGRAMME HIGHLIGHTS

EDUCATION

Key Success: Increased Awareness and Education Events

Let's Talk Sessions - Let's Talk Sessions are an important part of ILFA's educational offering, providing members with practical guidance to help improve their quality of life while living with lung fibrosis. These sessions create a welcoming platform where members can engage, learn, and share experiences, while gaining expert knowledge on key aspects of their health and wellbeing. There are a variety of topics covered, ensuring participants are equipped with everyday strategies and tools to better manage their condition.

Our 2025 series included:

- Managing Pulmonary Hypertension.
- Accessing Virtual Pulmonary Rehabilitation.
- Understanding the Role of Lung Inflammation during IPF
- Navigating the financial impact of chronic illness.
- Practical mental health support.
- Advocacy
- Oxygen Therapy

Patient Information Days

ILFA hosted two Patient Information Day webinars on April 30th and October 21st, 2025. These sessions provided expert insights into the latest clinical research, treatment breakthroughs, and symptom management. The webinars always conclude with a patient discussing their experience with the disease.

All of our webinars are recorded and shared via the ILFA YouTube channel for on-demand viewing.

HCP Educational Bursaries

Throughout 2025, ILFA continued to support the professional growth of healthcare staff through our bursary programme. These grants for conferences and educational events ensure HCPs stay up to date on the latest lung fibrosis treatments and techniques.

PROGRAMME HIGHLIGHTS

EDUCATION



2025 Lung Fibrosis Awareness Campaign

In partnership with Boehringer Ingelheim, ILFA rolled out a Lung Fibrosis Awareness Campaign in September (Lung Health Awareness Month). The campaign "Every Breath Matters, Know the Signs" aimed to create public awareness of Lung Fibrosis and the importance of early diagnosis while promoting the Irish Lung Fibrosis Association as a resource for vital information and support. The target was to reach 1.5 million people including health care professionals and those affected by Lung Fibrosis. A number of events were held throughout the month, along with impactful patient storytelling to strengthen the messaging. The campaign web page provided a wealth of resources for patients and their carers. A mix of social media, traditional marketing tools and media outreach were utilised to maximise the impact and people reached across Ireland.

Mental Health Training for Health Care Professionals (HCPs)

Boehringer Ingelheim funding also support ILFA's Mental Health Training Day at the Mater Misericordiae University Hospital in Dublin, tailored specifically for healthcare professionals working in respiratory care.

The programme focused on equipping attendees with the skills to recognise signs of mental health challenges and distress in their patients, while also strengthening their ability to communicate with empathy and understanding. In addition, the training emphasised the importance of self-care and resilience for healthcare professionals operating in high-pressure environments.

GP Education Campaign - BI grant funding also supported a campaign to provide educational information for GPs throughout Ireland. ILFA designed and posted leaflets with key information about diagnosing and treating lung fibrosis. 3,544 GPs were successfully reached through this campaign.

PROGRAMME HIGHLIGHTS

RESEARCH

Key Success: Award Winning Research

ILFA is dedicated to supporting lung fibrosis research. We do this by funding studies and through our Patient and Public Involvement (PPI) group.

Patient Research Surveys

Lung Disease Registry Attitudes - A patient survey was commissioned in 2023 to gain insight and valuable feedback from the patient perspective on having a lung disease registry. The findings were presented to the Irish Thoracic Society in 2025 through a poster and a full-length paper. The paper was subsequently accepted for publication in the Irish Medical Journal.

Exercise Classes - Following on from previously published research about virtual exercise programs, a survey was conducted in 2025 with exercise class participants. That research is awaiting publication and articulates the need for funding and improved access to virtual pulmonary rehabilitation programs for those living with interstitial lung diseases.



Rare Disease Research Conference
ILFA attended the conference which took place in April 2025 at UCD, Dublin. ILFA held an exhibition stand on the day. The conference was led by experts on Disease Registries, Clinical Trials and Public Patient Involvement.

PPI Involvement - Patient and Public Involvement (PPI) remained an important focus for ILFA in 2025, with regular PPI meetings continuing throughout the year. ILFA actively supported research initiatives, including a mental health study brought forward by Elizabeth O'Brien and her team at the Mater Hospital.

ILFA's PPI work is focused on ensuring patient lived experiences are represented in research, helping to inform and improve outcomes for those affected by lung fibrosis.

ILFA's research "*Safety and feasibility of a virtual exercise program for pulmonary fibrosis patients*" was published in the Irish Medical Journal.

PROGRAMME HIGHLIGHTS

PATIENT SUPPORTS

Key Success: Expanding Our Service Offerings

More Support Groups

ILFA added further support groups in 2025 bringing the total number of groups to nine. Plans are already in place to continue the expansion, with new on-line and regional groups scheduled.

The continued success of these support groups is made possible through the dedication and commitment of our support group leaders and the healthcare professionals whose expertise and compassion underpin every session.

Mindfulness Classes - ILFA ran six Mindfulness and Self Compassion courses throughout 2025. These six-week virtual courses were facilitated by Helena Dilleen or John Douglas and provided participants with a structured programme for incorporating mindfulness into their routines. Thanks to the HSE National Lottery Fund for providing grant funding for these classes.

Creative Resilience Course - ILFA hosted a course in 2025 titled “Breath and Resilience”, thanks to funding from the Hospital Saturday Fund. This highly rated course brought together experts in the health and wellness sectors to address themes in wellbeing, self-care, breathwork and creativity.

Exercise Classes - ILFA has facilitated our highly popular online exercise classes since 2020 and participation continues to grow. These classes ran 3 times weekly throughout 2025 taking place, Monday, Wednesday and Thursdays with an average attendance of 17 participants.

Through our work we continue to demonstrate our commitment to supporting both physical and emotional wellbeing for people living with Lung Fibrosis across Ireland.

COMMUNITY HIGHLIGHTS

Family Fundraising in support of Brendan Leech

In 2025, ILFA supporters Ed Swain and Ian Macbeth undertook an extraordinary Triple Threat Fundraising Challenge in support of Ed's father-in-law, Brendan Leech from Roscommon.

Their challenge included a 100-mile endurance event, two World Series races across Snowdonia involving eight peak climbs, 6,400 meters of ascent, and 103 kilometers of mountain running, and concluded with a run from Dublin to Galway.

As they set off from the Dublin Spire for the final stage, they were supported by Eddie Cassidy, ILFA Board Member. This exceptional community effort raised awareness of lung fibrosis and highlighted the passion and commitment of those who support ILFA's mission. They raised a total of €6,234.

Bingo Loco - Brendan's daughter Mary organised an evening of fun, community and incredible support with her Bingo Loco fundraiser at Kenny's bar in Ballintober, Roscommon which raised €6,155 for ILFA.



Ed Swain, Eddie Cassidy (ILFA) and David Swain



Mary Leech and team at Kenny's Bar

Roscommon University Hospital - Friends and colleagues of Brendan at Roscommon University Hospital made a sizeable donation of €1,200 to ILFA to show their support for Brendan and his family.

In Memory of Brendan Leech (RIP) - ILFA would like to express its sincere condolences to all the family, friends and colleagues of Brendan who has sadly passed since these incredible events took place. We are deeply grateful for the generosity of Brendan's friends and family over the past 12 months.

What a wonderful way to honour Brendan's memory.

COMMUNITY HIGHLIGHTS

In 2025 we had some incredible supporters and fundraisers taking on long distance endurance races. A true test of resilience and determination to support those with Lung Fibrosis.

- Thanks to The Hussey family who ran the Clew Bay Memorial Run in memory of their dad and grandad Paul (RIP). They raised over €1,000 in his memory.
- Emma Daly and Lucja Lojko ran the Cork Echo Marathon in support of Emma's aunt Irene McGrath (lung transplant recipient and ILFA member) and raised €1,860.
- Ciaran O'Brien and his friend Sean ran the Clontarf Half Marathon in July in support of Ciaran's dad Aidan. ILFA supporter Rebecca Tansey also took on the 21km challenge through Clontarf.
- Declan Tohen took on a series of marathons including the Dublin Half and Full Marathon, Limerick Half Marathon and Tullamore Half Marathon. He raised €1,450.
- We had four supporters running the Dublin City Marathon, Declan Toland, Birgit Kterchsmann, David Markey and Gill Hegarty who collectively raised €6,185.



THANK YOU to all our runners, joggers and walkers!

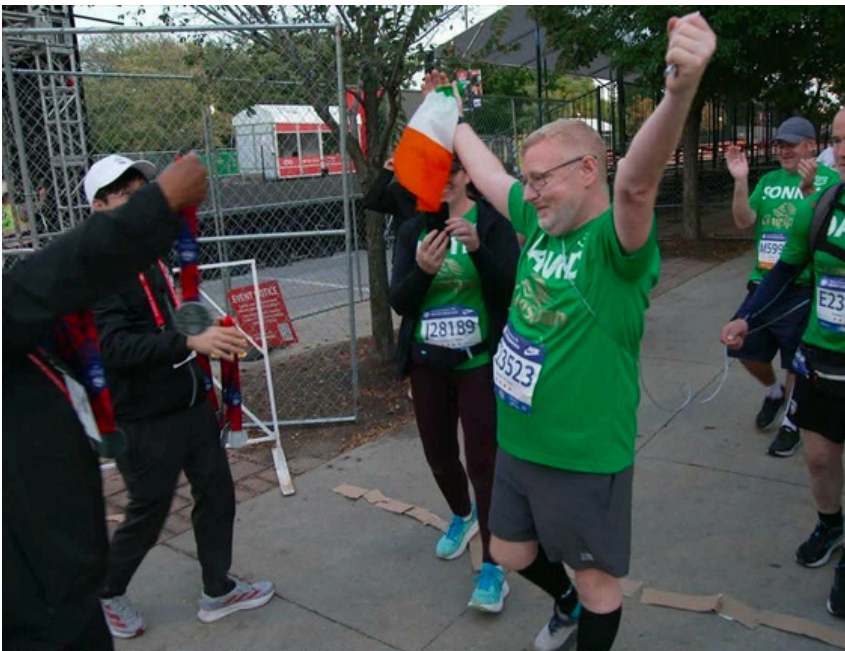


COMMUNITY HIGHLIGHTS

Connemarathon - In June 2025, Darren Little presented a cheque to ILFA for €12,000 raised while completing the Connemara Marathon (Connemarathon). Darren ran the race in April in memory of his dad, Martin Little (RIP). His family members including mother Lillian, aunt Veronica and brother Conor all showed up to support his remarkable efforts.



Darren Little and Family



David Crosby At the Finish Line

Chicago Marathon - A long-term ILFA supporter, lung fibrosis patient, and transplant recipient, David Crosby showed true resilience and dedication by completing the Chicago Marathon in November. He raised €5,000 for ILFA. David is a true advocate and inspiration for those living with lung fibrosis.

The Cook Medical Mini Marathon - Megan O'Donnell embarked on the Cook Medical Mini Marathon, Limerick in October to create awareness and raise funds in support of her aunt Noreen O'Carroll. She raised €3,180.

COMMUNITY HIGHLIGHTS

Le Grande Classique Paris to Versaille

The McNeill brothers took on the Le Grande Classique Paris to Versailles challenge on their parents' 50th Wedding Anniversary in memory of their father Michael (RIP).

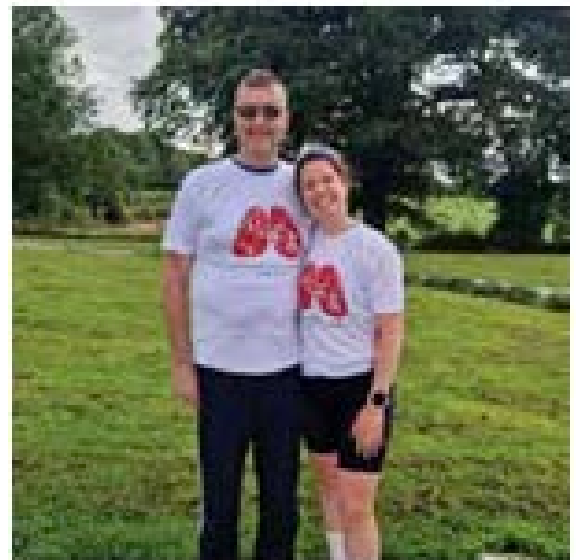
The iconic run took place on the 28th of September and they raised an incredible €8,368 which included a generous matching donation from Rory's employer, Ecocem.



Copenhagen Iron Man Triathlon

"I dedicated the race to the work of the Irish Lung Fibrosis Association, and to everyone affected by this illness."

Roberta McDonald



Roberta McDonald pictured with dad Ciaran McDonald

Roberta McDonald took on the incredible task of the iron man triathlon in Copenhagen and raised €6,861. Roberta accomplished this feat in support of her dad, Ciaran McDonald, who had a lung transplant some years ago.

COMMUNITY HIGHLIGHTS

VHI Women's Mini Marathon

The VHI Women's Mini Marathon continues to be one of the biggest events in ILFA's fundraising calendar year where our supporters show up time and time again to raise vital funds and awareness for lung fibrosis. 2025 was no exception with over 31 women running, walking and jogging for Team ILFA.

Our incredible turnout included long-term supporters, nurses and healthcare professionals, and those who have lost loved ones to lung fibrosis. Our group came from across Ireland, travelling in from as far as Donegal and Tipperary.

Over €21,500 was raised in 2025, with individual efforts raising upwards of €1,000. These generous donations go a long way towards supporting those affected by lung fibrosis.

**Biggest
Fundraiser
2025**

**€21,500+
raised**



COMMUNITY HIGHLIGHTS

Music and Song

Bel Canto Choir Fundraiser

The Bel Canto choir in Cork held a special concert in March in memory of Dr Jack Griffin (RIP) who was a member of the choir. The event took place in the St George's Arts and Heritage Centre and raised €4,000.



The Bel Canto Choir with Gemma O'Dowd (ILFA)

A Night of Music and Song

The Heavey family organised an incredible Night of Song at Oranmore Hotel, Galway on the 7th May. Several local choirs were involved creating a truly magical night of song and music in memory of Eddie Heavey (RIP).

The event raised a total of €5,000.

Ceili and Old Time Music Fundraiser

The Joyce and Burke families organised this wonderful fundraiser in memory of Austin Joyce (RIP).

The event was held at St Brigids GAA, Castleknock in November and raised €6,180.

UCC Carols by Candlelight Choir Fundraiser

In December University College Cork held a concert in memory of Garry Drumm, grandfather to Molly (choir member).

This incredible evening raised €2,504.



UCC Choral Society

Christmas Carols - Hayes Solicitors arranged a Christmas Carol Fundraiser on Grafton Street, Dublin on the 11th December. They raised €750.

COMMUNITY HIGHLIGHTS

Tractor Runs

West Kerry Tractor Run - Thanks to JP O'Sullivan and the organisers of the West Kerry Tractor Run, the drivers, and supporters like the Marina Inn for their steadfast support. For seven years proceeds from this event have funded critical ILFA programmes. This year was no exception with the community raising €8,000.

We remain deeply grateful for the enormous generosity of the West Kerry community.



Charlie Duffy Memorial Tractor Run, Donegal - Darren McLaughlin organised this Vintage Tractor Run in memory of his friend Charlie Duffy (RIP).

It was a great day all around, with the sun shining down on the participants and €2,300 received from donations for the event.



COMMUNITY HIGHLIGHTS

Liverpool Jersey Raffle - Pamela Martin, a long-standing ILFA supporter and avid Liverpool fan, won a signed Liverpool jersey and very kindly decided to raffle it off to raise vital funds for ILFA.

Over a 3-week period she sold tickets for a raffle through Facebook. Through her incredible efforts she raised €3,400.



Table Quiz Fundraiser - James McAuliffe organised a table quiz at the Gortroe Inn in memory of Donal McAuliffe (RIP) in May.

James raised €4,127 in memory of Donal. We are very grateful to all who supported this event.



Garden Party - Anne Oglesby held a garden party in Carlow on 6th September.

The weather was truly fine and she had a fantastic day, raising €1,000 in donations.



COMMUNITY HIGHLIGHTS

Supervalu Collection Day.

Organised with Supervalu, Togher and ILFA Cork Support Group members Anne, Mary, Daniel, William, Declan, and Angela, they raised a remarkable €1,116 in donations.



HOSPITAL AWARENESS DAYS

Beaumont Hospital Awareness Day - Thank You to our supporters at Beaumont who organised their event during Lung Health Awareness Month on 16th September. Organisers Anja, Jis, Killian Hurley and the Respiratory team hosted an incredible day and raised €1,500 for lung fibrosis.



Waterford Awareness Day - Waterford University Hospital held an Awareness Day for ILFA on the 25th September organised by Natalya Tkach.

Letterkenny Coffee Morning - Letterkenny Hospital hosted a coffee morning on the 30th April organised by Carol Doherty.. This was a Fundraising and Awareness event for ILFA and €640 was raised.

COMMUNITY HIGHLIGHTS

45 Card Drive - Michael Walsh (patient) and daughter Bebhinn organised this fundraising evening with a Raffle on the night to raise much needed funds. They raised an incredible €4,795



Wedding Favours - Thank You to those who chose to make ILFA part of your special day by donating in lieu of wedding favours. A total of €360 was raised

**Over
€165,000
Raised
in Community
Fundraising
2025**

LOOKING AHEAD TO 2026

2026 will be a pivotal year for lung fibrosis. Having supported patients and their families for nearly 25 years, ILFA is well positioned to ensure the work ahead will lead to earlier diagnosis, improved patient care, and affordable disease management.

TRENDS AND ISSUES

In 2025 a new antifibrotic drug was approved by the FDA and is currently awaiting approval in Europe. It will be important when that therapy is approved, that it is made available and affordable to the Irish patient population. It will also be important that Ireland play a part in new drug trials and other research.

Additionally, lung fibrosis patient priorities continue to be underserved and care remains inequitable. In 2026 ILFA will use HSE seed funding to implement new programmes, but it will be important for additional funding to be secured in following years as well, and for those services which are so critical for equitable patient care, be continued in 2027 and beyond.

It will also be important, as we continue to see increasing numbers of lung fibrosis patients come to us for support, that we have the necessary unrestricted funding and resources to meet growing demand.

ILFA will continue to offer the same core services as outlined in this report. In addition, we have an ambitious plan for growth.

In 2026, ILFA will significantly expand its services to better support the lung fibrosis community including:

- A National Nursing Advice Line, providing guidance and signposting to patients and their carers.
- A Virtual Pulmonary Rehabilitation Pilot Programme, providing nearly 100 patients with an eight-week structured strength and conditioning programme. This landmark pilot will inform the future of HSE pulmonary rehabilitation services for people living with lung fibrosis.
- We've increased our popular exercise classes to 5 times per week, improving access to regular, supervised physical conditioning.
- A new psychological support grant scheme, enabling patients and their caregivers to access up to six professional counselling sessions.
- We're also expanding our on-line and in-person support groups, strengthening community connection and peer support.
- An expanded national awareness campaign across print, radio, and digital channels, to reach more people affected by lung fibrosis.
- A national Patient Summit in Dublin, bringing the community together for a dedicated day of learning, engagement, and connection.

HOW YOU CAN HELP

ILFA's Mission - Our mission is to help individuals and families living with lung fibrosis, and the healthcare staff caring for them by providing evidence-based information, support and practical resources, by advocating for their needs, and contributing to awareness, education and research in Lung Fibrosis.

Volunteering - You can volunteer your time to support us for different campaigns, events, or if you have a particular skill set, to support our projects.

Fundraising - You can organise a Fundraiser to raise much needed funds for ILFA to continue to support those with Lung Fibrosis through our four core aims of Advocacy, Education, Research, and Support Services.

Corporate Fundraising/Sponsorship - We welcome support from companies across Ireland. You can organise a fundraiser, sponsor upcoming events, become a charity partner or support us with Corporate Volunteer Days.

Become an Advocate - There is nothing more impactful than hearing directly from someone who knows firsthand the impact of living with lung fibrosis. You can tell your story and support us in our advocacy work.

Make a Donation

1. Scan the QR code

2. OR...Call us at +353 1 592 2501 to donate over the phone

3. OR...Consider becoming a Sustaining Donor - You can sign up for monthly direct debit by emailing fundraising@ilfa.ie



Did you know if you donate an average of €21 per month in a calendar year or €250 in total, ILFA can claim up to 31% of your donation back from Revenue?

This boosts your €250 donation at no extra cost to you! Contact us to learn more.

THANK YOU

ILFA would like to extend heartfelt thanks and gratitude to all those who supported us in 2025 – our advocates, fundraisers, corporate partners, members, volunteers, and everyone who helped support our mission.

Without your continued support we would not be able to provide the vital services, research, education and advocacy for those affected by Lung Fibrosis.
