ILFA Newsletter

Patrons: Michael Darragh Macauley and David Gilna
Issue: Summer 2025 Volume 23 Issue 1

Irish Lung Fibrosis Association
www.ilfa.ie

Exciting New Research Facility Opens

Maureen O'Donnell (ILFA CEO) and Nicola Cassidy (ILFA Director) were delighted and honoured to attend the official opening of the Ireland's first dedicated patient stem cell research facility at the Royal College of Surgeons in Ireland (RCSI) Education and Research Centre at Beaumont Hospital on 9th April 2025.

David Crosby, double lung transplant recipient and ILFA Ambassador, was tasked with performing the honours of the Ribbon Cutting Ceremony to officially open the laboratory named the RCSI Patient Stem Cell Discovery Core. David's family has been affected by lung fibrosis for many years, and he was honoured to witness history in the making.

The laboratory has a special plaque dedicated to David and his wife Katie for their great efforts in supporting pulmonary fibrosis research. David acknowledged the enormous hope that this important development will bring to patients and families affected by lung fibrosis, and he received a great round of applause from everyone present.

Warmest congratulations to Professor Killian Hurley and his great team of scientists for their hard work and dedication to advancing research in interstitial lung disease.

Patient Stem Cell Discovery Core Opening

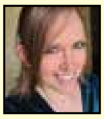
Dr Mari Ozaki, Research Fellow and Principal Investigator, Department of Medicine at the RCSI Education and Research Centre, Beaumont Hospital wrote this report for us. Mari said "On 9th April, RCSI opened Ireland's first patient dedicated stem cell research facility in the Smurfit Education and Research Centre at Beaumont Hospital. This facility is led by Professor Killian Hurley, Associate Professor of Medicine at RCSI and Consultant in Respiratory Medicine at Beaumont Hospital and the Living Lung Lab Group, with generous support from patient advocates, David and Katie Crosby.

The facility will allow us to carry out advanced stem cell research across all diseases, with research already begun in pulmonary fibrosis. Its proximity to the hospital allows us to obtain blood samples from patients, from which we can isolate peripheral blood mononuclear cells, turn them into stem cells and then grow them into lung cells. We can also edit specific genes in these cells so that we can understand the mechanism of disease. This will help us to identify novel targets and test new drugs on patient-specific cells, paving the way for advancing personalised and precision medicine. In addition, the facility's location on the RCSI's Beaumont Hospital campus ensures that patient outcomes are at the centre of research, and allows the insights generated in the lab to be communicated directly with clinicians and translated into patient care.

Professor Killian Hurley, Associate Professor of Medicine at RCSI and Consultant in Respiratory Medicine at Beaumont Hospital. David Crosby, Anne Coyle, Beaumont Hospital CEO, and Dr Seamus Browne, Head of Strategic Research Initiatives and Industry Partnerships. (Photo used with kind permission from RCSI)

New Appointments at ILFA

Gemma O'Dowd has worked diligently for ILFA for 9 years as Administrative Lead and has now moved into the role of Stakeholder Engagement Lead. Gemma said "I am delighted to be able to concentrate my time interacting with ILFA's key stakeholders – including our members, fundraisers, healthcare professionals, and corporate sponsors. I look forward to progressing our valued relationships and helping and supporting members and stakeholder's needs. Please contact me on 086 057 0310 or email Gemma@ilfa.ie if I can help you in any way."



Kelly McVicker recently started working as Administrative Lead. Kelly said "I've been working in the not-for-profit sector for over thirteen years, with experience in organisations like Dublin Simon Community and Active Retirement Ireland. I'm excited to be reconnecting directly with patients, it's the part of the work I've always loved most. Kelly can be contacted on 086 871 5264 or info@ilfa.ie

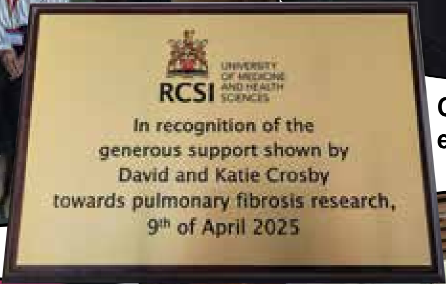
David Crosby and Nicola Cassidy.

Professor Killian Hurley, Associate Professor of Medicine at RCSI and Consultant in Respiratory Medicine at Beaumont Hospital. David Crosby, Anne Coyle, Beaumont Hospital CEO, and Dr Seamus Browne, Head of Strategic Research Initiatives and Industry Partnerships.

David Crosby.

PATIENT STEM CELL DISCOVERY CORE OPENING

Nicola Cassidy (ILFA Director) with Dr Mari Ozaki and Dr Anja Schweikert.



RCSI UNIVERSITY OF MEDICINE AND HEALTH SCIENCES

In recognition of the
generous support shown by
David and Katie Crosby
towards pulmonary fibrosis research,
9th of April 2025

Commemorative plaque at the entrance to the new research lab.

Above: Dr Anja Schweikert in conversation with Maureen O'Donnell, ILFA CEO.
Top: Attendees at the opening of the Patient Stem Cell Discovery Core Laboratory.

Nicola Cassidy (ILFA Director), Professor Killian Hurley, David Crosby (ILFA Ambassador), and Orla Veale (CEO of the Irish Thoracic Society).

A message from David Crosby, ILFA Ambassador

Hi all,

I have exciting news for lung fibrosis patients and patients with complex lung diseases - a new research facility opened at Beaumont Hospital on April 9th. This new facility will give great hope to patients with complex lung conditions and other diseases, help advance more effective and personalised treatments for those with lung disease, and deliver better outcomes.

Idiopathic Pulmonary Fibrosis (IPF) has been part of our family for almost 48 years. This past 9 years has been extremely difficult, not just for me but my family also. When I was diagnosed with IPF I felt like the ground beneath my feet fell away. I didn't know where to turn or where my life was going. After some sad and low days, I promised myself that I would never stop trying to gain back control for my life, not just for me but for my family also, who have had to deal with this new way of life. Sometimes people think of the patients only but as people living with a serious lung condition know, our families are hurting as much.

After my double lung transplant, I focussed on recovering and getting back to better health and I started thinking about marathons. Thankfully, my dream of completing a marathon became a reality and I have completed 3 so far. I also started to get involved in public speaking to raise awareness of IPF and organ donation and getting the word across that if you're strong enough mentally you can achieve most of your goals. I was speaking in Kilkenny at an ILFA Patient Information Day roughly 7 years ago, where Professor Killian Hurley was also attending. He heard my story and wanted to support me and my vision to take back control from IPF. From that day on, Killian has been in constant consultation with me. Together we decided we needed to get a plan of action together. Killian mentioned that he studied in Boston and there was hope that we could eventually find solutions with stem cell research. He did some work with me and his contacts in Boston, and we have been working on this ever since. We got so much help and support through fundraising for me, family, and friends who were completing the marathons. We raised significant funds, and I'd like to thank everybody who has ever supported us in any way. You will never know how thankful and grateful I am to anyone who donated to our charity, I wanted these funds to go and spark something positive. Killian spoke with me about possibly getting equipment like that which he was using in Boston and speeding up the research here in Ireland and have a more hands on and more personalised control on treatments for patients. With the help of Killian and his team of researchers, and with the opening of this new facility, I believe patients now have the upper hand and can take control back from complex lung conditions.

I know how hard it is to get the news that your life may be changed forever, but I strongly believe that with this new facility at Beaumont Hospital, patients can now look to the future with so much more hope and optimism. We are optimistic that new treatments can be found and developed to finally put IPF in its box where it belongs.

I'd also like to thank everybody in the ILFA community for all their love and support over the years. It has been a real source of energy for me and my family and has kept me focused and motivated to help others in similar situations that I went through. Hopefully, I can help show a way forward for them when they receive the diagnosis of IPF. Know that there is work going on every day in Beaumont to help fight lung diseases.

That is why I am so proud of us all who work with the charities and helped fundraise to get this new facility up and going. Thank you all for helping make this facility a reality.

Regards,
David Crosby, ILFA Ambassador

ILFA'S World Cafe Event 2025

The Irish Lung Fibrosis Association held an online World Cafe on Saturday 18th January 2025 with our stakeholders to strengthen our strategy of delivering Research, Support, Education and Advocacy for the Lung Fibrosis community.

Patients, family members, healthcare professionals, and pharmaceutical industry representatives joined online and were welcomed by Eddie Cassidy (ILFA Chair), Maureen O'Donnell (ILFA CEO), and Tony Shone (Invisio) who facilitated the event and guided us every step of the way.

Next Olive McCafferty, Respiratory Physiotherapist, encouraged everyone to try some gentle breathing and stretching exercises to energise us for the brainstorming session ahead.

The participants were split into different groups where they introduced themselves to each other. Each group was tasked with sharing their perspectives on what is working well, what can be improved, and what they would like to happen if finance and resources were limitless (a little 'blue-sky' thinking!) on Research, Support, Education and Advocacy for Lung Fibrosis.

The lively, interactive discussions were facilitated by 6 skilled leaders (Colin Edwards, Seán O'Sé, John Sheridan, Maureen O'Donnell, Lynn Fox, and Nicola Cassidy), and ably captured by 6 busy notetakers (Bernie Shone, Olive McCafferty, Gemma O'Dowd, Elaine Craven, Rachael Pender, and Jason Nichol). The discussions were also captured artistically by graphic artist Philip Barrett whose work is featured below.

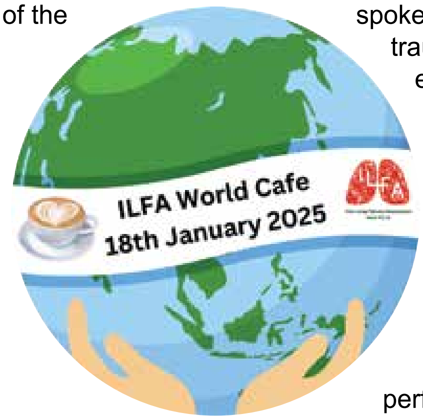
After each group had contributed to 3 rounds of discussion, our leaders and notetakers compiled a summary of the main fundings.

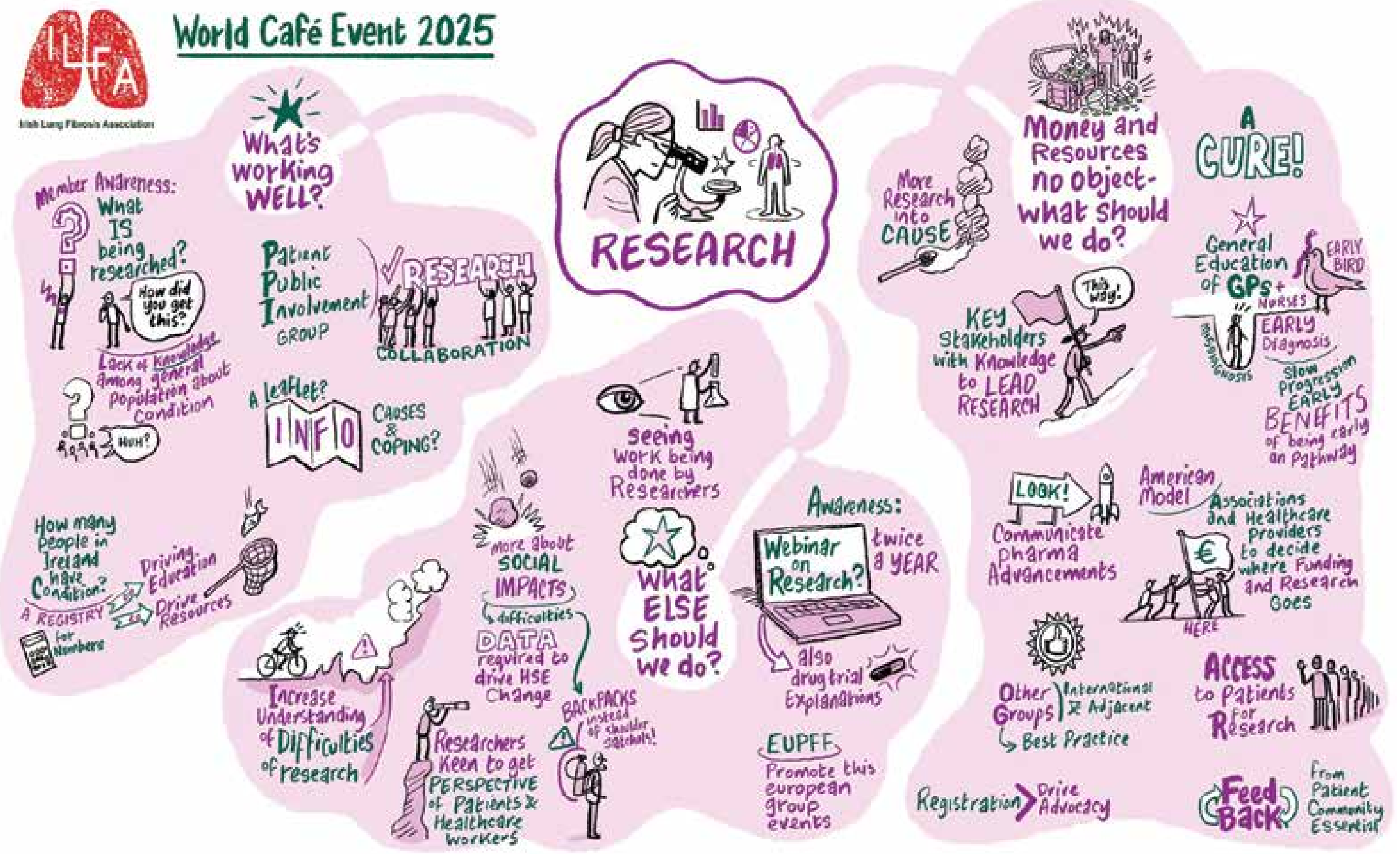
During this time, our guests enjoyed the creative talents of our keynote speaker, David Gilna, ILFA Patron, playwright, screen writer, actor, and poet. David spoke about his experience of overcoming trauma and adversity and finding his energy to rebuild his life, and he shared a touching poem called "The Waiting Room".

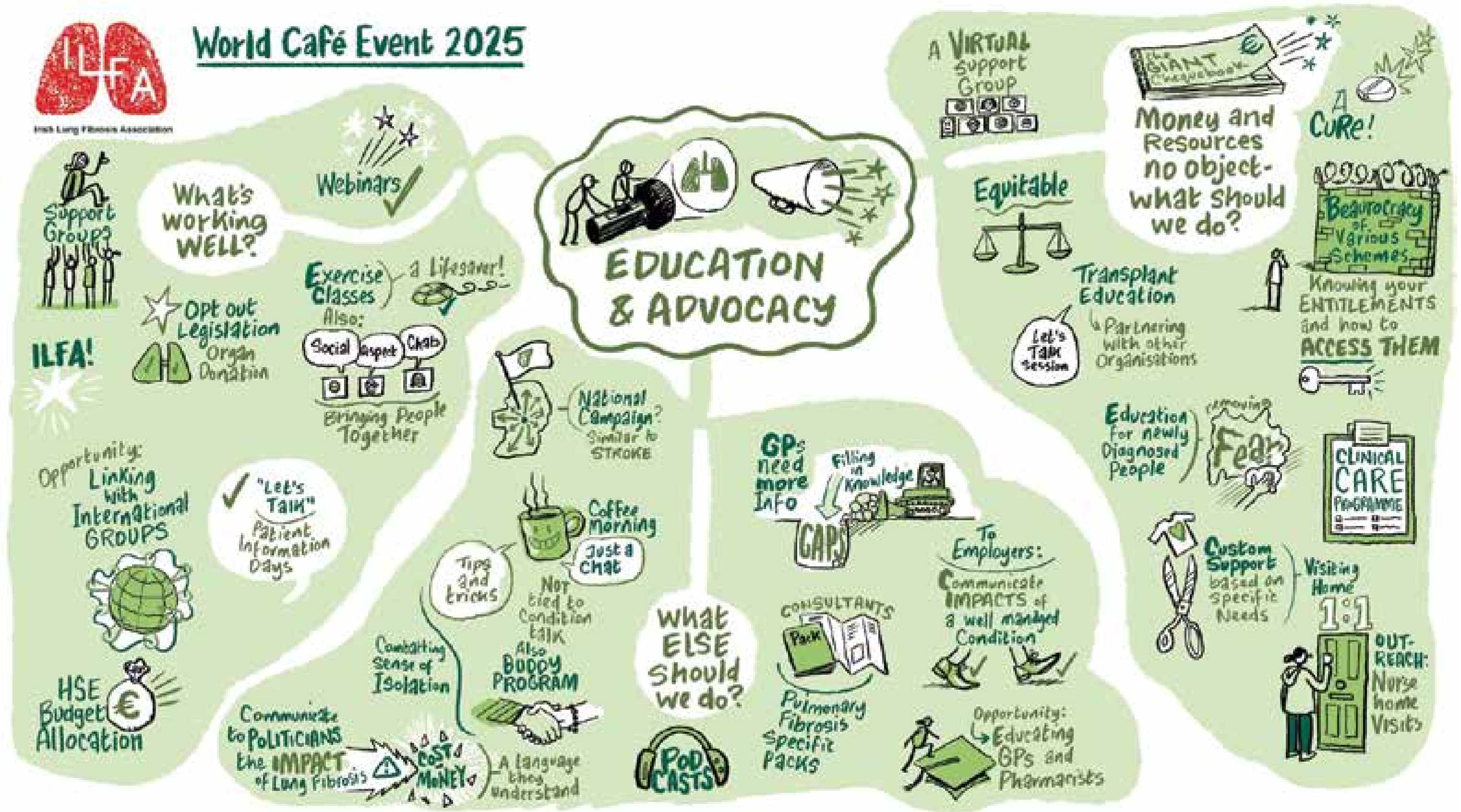
Next Maureen O'Donnell and the leaders shared the summarised learnings and insights with everyone. Our stakeholders' valuable experiences and perspectives will help shape the direction of ILFA's future work and goals.

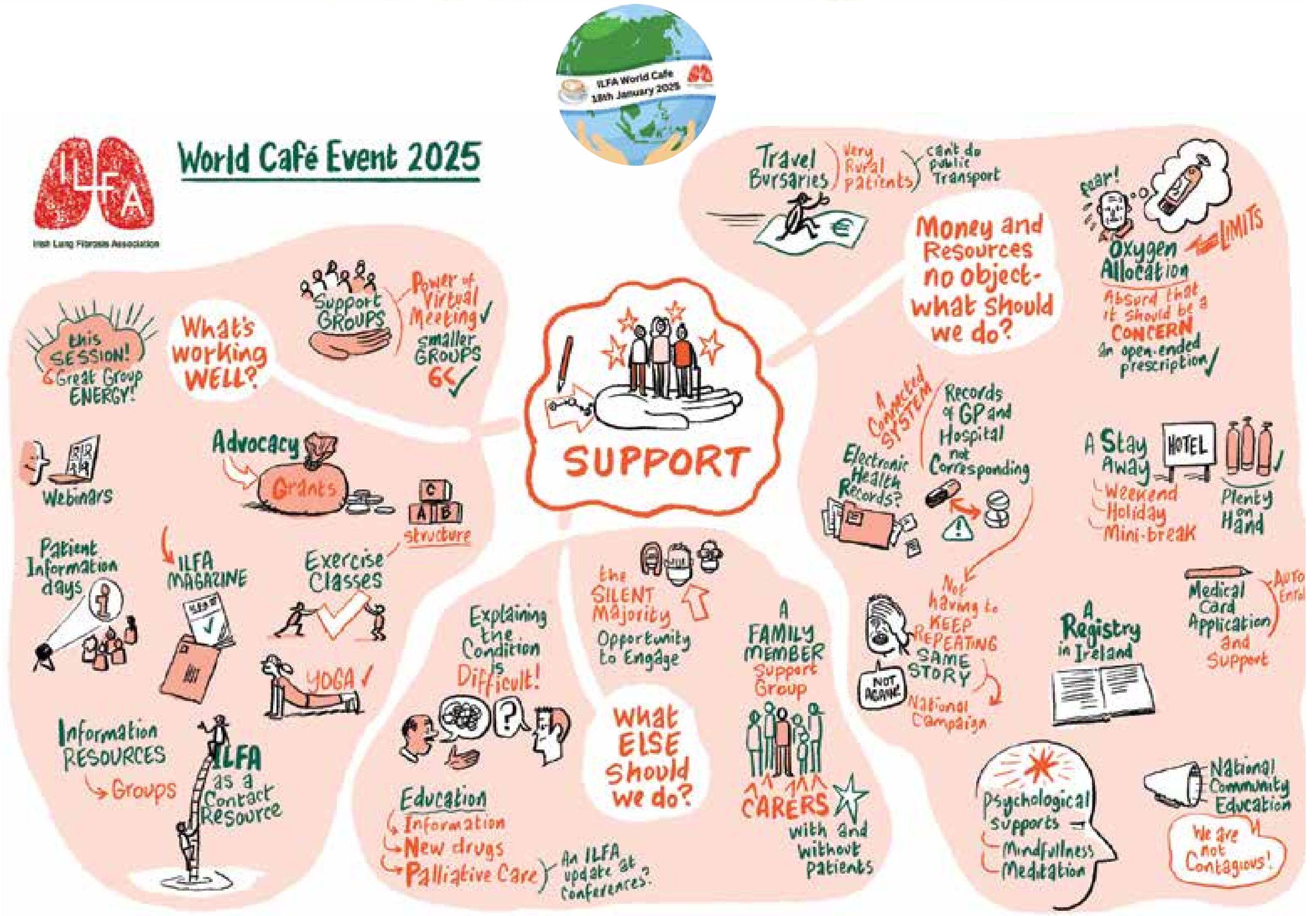
The event concluded with a performance from Harry Carpendale (harpist) who performed a selection of musical pieces including a special piece that he composed for ILFA!

We are indebted to our stakeholders, the World Café leaders, notetakers, facilitators, talented orator and musician, and Tony Shone and his great team at Invisio for their time, skills and exceptional help and support in delivering a hugely successful, enjoyable, engaging, and interactive session. Warmest thanks to everyone involved.






ILFA
Irish Lung Fibrosis Association
World Café Event 2025
EDUCATION & ADVOCACY
What's working WELL?
Support Groups
Webinars ✓
Exercise Classes
a Lifesaver!
Also:
Social
aspect
Chat
Bringing People Together
Opt out Legislation
Organ Donation
ILFA!
Opportunity: Linking with International GROUPS
"Let's Talk"
Patient Information Days
HSE Budget Allocation
Communicate to POLITICIANS the IMPACT of Lung Fibrosis
COST MONEY
A language they understand
Combatting Sense of Isolation
National Campaign?
Similar to STROKE
Coffee morning
Just a Chat
Tips and tricks
Not tied to condition talk
Also BUDDY PROGRAM
What ELSE should we do?
PODCASTS
GPs need more Info
Filling in Knowledge
GAPS
CONSULTANTS
Pack
Pulmonary Fibrosis Specific Packs
To Employers:
Communicate IMPACTS of a well manged Condition
Opportunity:
Educating GPs and Pharmarists
A VIRTUAL support Group
Equitable
Transplant Education
Let's Talk session
Partnering with other Organisations
the GIANT Chequebook
Money and Resources no object - what should we do?
A CURE!
Beaurocracy of Various Schemes
Knowing your ENTITLEMENTS and how to ACCESS THEM
Education for newly Diagnosed People
removing Fear
CLINICAL CARE PROGRAMME
Custom Support based on specific Needs
Visiting Home 1:1
OUT-REACH: Nurse home visits


ILFA World Cafe
18th January 2025
ILFA
Irish Lung Fibrosis Association
World Café Event 2025
SUPPORT
What's working WELL?
this SESSION!
Great Group ENERGY!
Support GROUPS
Power of Virtual Meeting ✓
smaller GROUPS
6 ✓
Webinars
Advocacy
Grants
C A B
structure
Patient Information days
ILFA MAGAZINE
Exercise Classes
YOGA ✓
Information RESOURCES
Groups
ILFA as a Contact Resource
Explaining the Condition is Difficult!
?
Education
Information
New drugs
Palliative Care
An ILFA update at conferences?
the SILENT Majority
Opportunity to Engage
What ELSE should we do?
A FAMILY MEMBER Support Group
CARERS
with and without patients
Travel Bursaries
Very Rural patients
Can't do public Transport
Money and Resources no object - what should we do?
Fear!
Oxygen Allocation
LIMITS
Absurd that it should be a CONCERN
an open-ended prescription ✓
A Connected SYSTEM
Records of GP and Hospital not Corresponding
Electronic Health Records?
Not having to KEEP REPEATING SAME STORY
NOT AGAIN!
National Campaign
A Stay Away
HOTEL
Weekend
Holiday
Mini-break
Plenty on Hand
A Registry in Ireland
Medical Card Application and Support
Auto Enrol
Psychological supports
Mindfullness
Meditation
National Community Education
We are not Contagious!

Advocacy Update

An update from Maureen O'Donnell, ILFA CEO

At our recent Patient Information Day on 30th April, Frank Brannigan, a patient and ILFA member, told his story of awaiting a lung transplant while living with lung fibrosis. Three times he has travelled to the transplant centre since he was diagnosed in 2018, hoping to receive this life-giving procedure. Three times he has gone back home disappointed; the match wasn't right. Despite this, he remains optimistic, hoping that one day a match will be found.

Frank's story is all too common for lung fibrosis patients. Despite legislation coming into effect next month providing a "soft opt out" for organ donors which should result in more organ availability for transplant patients, ILFA remains concerned that this will not translate into more lung transplants for lung fibrosis patients. The number of lung transplants in Ireland has been in decline. In 2019 there were 38, but the numbers dropped during the COVID-19 pandemic and never fully recovered. In 2024 there were just 13. It is important to understand the reasons behind the dramatic decline and work collaboratively with others to find a solution.

This year ILFA will be expanding our advocacy work, seeking to reverse the decline in lung transplant procedures. We will also continue to fight for the Clinical Care Pathway Advisor position (originally promised in April 2023 but as of this writing, still not in post), and the historic €500,000 funding allocated to lung fibrosis in Budget 2025 that remains unspent by the HSE. That funding could be going toward a disease registry, pulmonary rehabilitation, a nurse to improve ILFA's medical support to patients, and grants to help offset the high cost of electricity and travel for patients

Instead, the money remains a line item on the HSE National Service Plan while the HSE refuses to meet with us, refuses to answer parliamentary questions, and refuses to make any meaningful progress on supporting lung fibrosis patients and the lung fibrosis community. It's discouraging, but like Frank Brannigan we refuse to lose hope. We know there is a better model of care – we've seen it in other countries. In Ireland, the better model of care is the Clinical Programme. This is just one of the recommendations outlined in the groundbreaking report delivered on behalf of the lung fibrosis community by Prospectus Management Consultants, a leading research company in Ireland. We'll be launching the Prospectus report (A Strategy for Equitable Care) on 11th June at Leinster House.

You can support our advocacy work in three ways:

1. On launch day (11th June) there will be media attention – share the news stories across your network of family and friends.
2. We will publish a "Contact Your TD" toolkit. Follow the instructions in the toolkit and during the week before the report launch, we ask you to call or visit your TD and ask them to attend ILFA's AV Room Briefing of the Report (11th June at 10 am in Leinster House).
3. Lung fibrosis is a relatively rare disease and as such, diagnosis is often delayed because of a lack of GP awareness. You can support early diagnosis by delivering the "Rapid Referral" insert included in this newsletter to your GP.

Support Group News

Maureen O'Donnell (ILFA CEO) visited the Cork Pulmonary Fibrosis Support Group at their monthly meeting on Thursday 27th February 2025. Maureen received a warm welcome and enjoyed meeting all the members and hearing about their experiences.

Pictured are the Cork Pulmonary Fibrosis Support Group.

Maureen also visited the Kerry Pulmonary Fibrosis Support Group on Saturday 29th March 2025 at the Meadowlands Hotel in Tralee. The group had an in-depth discussion about ILFA's activities and advocacy work on behalf of patients and the lung fibrosis community.

Front row (left to right) - John P O'Sullivan, Maureen O'Donnell, Mary Kelly, Annette Cremin. Back row (left to right), Seán O'Sé, Sean O'Connor, Gerry Redican, Robert Hurley, and John Hanlon.

For more information and contact details for the support groups please see the last page of the newsletter or visit www.ilfa.ie

Advocay Update ctd.

Pulmonary Fibrosis Patient Advocacy Forum

Maureen O'Donnell (ILFA CEO), Patricia Jones and Liam Galvin (ILFA Trustees) represented the Irish Lung Fibrosis Association at the European Union Pulmonary Fibrosis and Related Diseases Federation (EU-IPFF) Patient Advocacy Forum in Frankfurt in April. This event provided comprehensive training and resources for patient advocates, fostered collaboration, and enhanced the effectiveness of advocacy efforts at both national and international levels.

Launch of Organ Donor Awareness Week

Eddie Cassidy (ILFA Chair) and Gemma O'Dowd (ILFA Stakeholder Engagement Lead) attended the Irish Kidney Association (IKA) Launch of Organ Donor Awareness Week at the Mansion House, Dublin, on Tuesday 6th May. The launch was hosted by IKA Chairman, Edward Flood, and IKA Chief Executive Officer, Carol Moore.

The event was well attended by patrons, patient advocacy groups, organ donor recipients and their families, organ donor families, HSE representatives, and healthcare professionals. It was a fabulous turnout on a beautiful sunny day, and the life-changing impact of organ donation was championed and showcased. Speaker representatives shared their experiences and delivered powerful and moving stories. The speakers included a heart transplant recipient, lung transplant recipient, kidney transplant recipient, liver transplant recipient, a person on dialysis and on the kidney transplant waiting list, and a donor family representative.

In 2024, 263 organ transplants were carried out thanks to the generosity of 84 deceased donors and 30 living kidney donors.

This included:
175 Kidney transplants
53 Liver transplants
16 Heart transplants
15 Lung transplants
4 Pancreas transplants.

There are over 600 people currently on transplant waiting lists for organs including the heart, lung, liver, kidney, and pancreas,

Dr. Brian O'Brien, Clinical Director of Organ Donation Transplant Ireland urged everyone to have a conversation with your loved ones to let them know your wishes on organ donation. Please have the chat!

Thanks to the IKA for hosting this special event.

Gemma O'Dowd (ILFA), Robert McCutcheon (Irish Heart and Lung Transplant Association), Dr Brian O'Brien (Organ Donation Transplant Ireland) and Eddie Cassidy (ILFA).

Gemma O'Dowd (ILFA), Robert McCutcheon (Irish Heart and Lung Transplant Association), Nicola Fox (Cystic Fibrosis Ireland) and Eddie Cassidy (ILFA).

Dr Brian O'Brien, Clinical Lead at Organ Donation Transplant Ireland.

Education

The Irish Thoracic Society Interstitial Lung Disease Study Day

The Irish Lung Fibrosis Association was delighted to once again partner with the Irish Thoracic Society (ITS) for the online ITS Interstitial Lung Disease Study Day on 7th February for healthcare professionals. Firstly, a series of fascinating case reports with multi-disciplinary team (MDT) input was presented by respiratory doctors competing for the Terence Moran Memorial Prize.

All the finalists and the MDT panel did a super job. Before the prize winner announcement, Nicola Cassidy (ILFA Director) spoke about the late Terence Moran and the major influence he had on the establishment of ILFA and directing the advocacy work of the charity. Terence passed away suddenly in 2018, and his gentle ways and professionalism have had a lasting impact on the charity's Directors and their work. Professor Killian Hurley, Respiratory Consultant and Chair of the ITS ILD Group, announced the winner of the 2025 Terence Moran Memorial Prize, as Niamh Logan. Congratulations to Niamh and the other finalists. Later this year Niamh will be presented with a Dublin Crystal Plaque and an educational bursary.

Professor Simon Walsh, Consultant Thoracic Radiologist and National Institute of Health and Care Research Clinician Scientist at Imperial College London, delivered the Fergus Goodbody Memorial Lecture. Prof Walsh's lecture was entitled "Imaging biomarker development in fibrotic lung disease; applying deep learning to unsolved problems."

ILFA is proud to support this important educational event for respiratory healthcare professionals.

Educational Bursary to attend International ILD Course

ILFA is proud to support educational opportunities for healthcare professionals and we were delighted to award educational bursaries to attend the European Respiratory Society's 'Interstitial Lung Diseases 2025' course in Mainz Germany. The reports from the successful bursary recipients are included below.

Grainne Coffey, Respiratory Advanced Nurse Practitioner at Kerry University Hospital said "I recently had the privilege of attending a three-day international course on Interstitial Lung Disease (ILD) in Mainz, Germany. From the beginning it was clear that this was a unique opportunity to learn from some of the world's leading experts in the field, all gathered with a shared goal to improve the lives of those affected by ILD.

The course was incredibly interactive and engaging. One of the standout moments for me was witnessing a live cryobiopsy. Seeing this modern bronchoscopic procedure performed in real time gave me a clearer understanding of how lung tissue samples are collected in a minimally invasive way. It really helped me appreciate the technical skill involved and the role this plays in supporting timely, effective ILD management. There was also a strong focus on interpreting high-resolution CT scans – a crucial tool in the diagnosis and monitoring of ILD. The discussions around HRCT were particularly thought-provoking, with experts debating scan patterns and sharing their insights on how to distinguish between various types of ILD. It was a great reminder of how much skill and collaboration goes into making the right diagnosis.

Throughout the course, we explored a wide range of topics, from the various types of ILD—including rare and unclassifiable forms—to the diagnostic tools like pulmonary function testing and bronchoscopic techniques. We also looked at current treatments, promising new therapies, clinical trials and the impact of comorbidities on disease progression and quality of life.

What struck me most was the sheer amount of research being conducted globally to improve our understanding of ILD. Knowing that so much work is being done behind the scenes to find better treatments and improve outcomes for patients was incredibly reassuring.

One of the most valuable aspects of the course was the opportunity to learn through interactive and practical discussions. These sessions focused on the management of common ILD symptoms such as cough, breathlessness and fatigue. The speakers shared insightful guidance on how to tailor treatments to individual patient's needs, emphasising person centred care. Overall, it has reminded me of the importance of continuous learning and collaboration in providing the best care possible. I would like to sincerely thank the Irish Lung Fibrosis Association for sponsoring this trip. I found the experience incredibly valuable, and it has already enhanced my clinical practice. I look forward to using what I've learned to support and advocate for our patients living with ILD."

Dervla Leonard, Senior Respiratory and Sleep Physiologist, Letterkenny University Hospital said "Firstly, I would like to express my gratitude to ILFA for being given the opportunity to attend

Educational Bursary recipients: Grainne Coffey, Lindsay Brown, Dervla Leonard and Carol Doherty.

such a prestigious event like the ILD ERS Conference, especially in such a nice setting in Mainz, Germany.

During the week, I got an in depth understanding of Interstitial Lung Disease from not only a pulmonologist, but also a radiologist and pathologist's point of view which was incredibly insightful. The detail they went into for each presentation, and the clinical explanation (all whilst breaking it down into laymen's terms) was fantastic.

It was great to see the relationship and rapport needed between clinical, radiology and pathology when it comes to diagnosing ILD as all the departments' different opinions and expertise on the differential pathways of diagnosis and treatment.

In addition, it was insightful to learn of how positive Home Spirometry was for patients with ILD especially for those who are able and fit enough to do so themselves which prevented clinic numbers from being sky-high for Consultants and Physiologists but also taught patients to alert their relevant team if their Forced Vital Capacity had dropped by more than 10%.

I also got an insight into bronchoscopic and surgical diagnostic procedures in ILDs. We got the opportunity to see a cryobiopsy being performed via webcam, so it was great to get a better understanding of why and how the biopsy procedure is performed. As a physiologist, it was good to see how invasive this type of biopsy is with regards to the patients' recovery and being able to perform pulmonary function tests post biopsy.

On reflection of attending the ERS Conference, I am eager to investigate on how the Respiratory Investigations Department would get funding to source home spirometry kits for ILD patients to manage their disease progression as I think it would be of great benefit to not only the Respiratory Department but also for patients."

Carol Doherty, Respiratory Advanced Nurse Practitioner at Letterkenny University Hospital said "I would like to sincerely thank ILFA for granting me a bursary to attend the ERS ILD meeting which took place in Mainz, Germany from the 26th-28th March. To set the scene, Mainz is a beautiful city nestled on the banks of the river Rhine, the old town is truly charming, represented by beautiful medieval styled buildings, narrow streets and many churches dotted throughout the city. The ERS ILD was a three-day conference which comprised of fascinating talks that focused entirely on interstitial lung disease (ILD) whereby various conditions that come under the umbrella of ILD were discussed. The timetable over the three days was impressive to say the least whereby presentations were delivered by leading experts in the field of ILD.

During the three days, presentations were delivered which provided me with a deeper insight into the pathophysiology, working diagnosis, treatment, and management pathways of various ILD's aiding my understanding of the complexities of ILD's. From a nursing perspective, I found the talk entitled 'holistic care in ILD' extremely interesting. It discussed symptom management of Idiopathic Pulmonary Fibrosis and Progressive Pulmonary Fibrosis based on the latest research. The presentation on lung transplantation discussed the referral, risk prediction, contraindications, and addressed barriers to transplant. Both these talks provided practical advice which fundamentally will enhance my clinical skills to improve patient care by enabling me provide education and to better communicate to patients and families. Over the three days, participants were invited to partake in workshops and discuss case studies. I found these invaluable as clinicians from various countries shared their expertise and experiences. It was a great way to participate in group discussion which certainly will enhance my clinical skills and expertise.

ILD is a dynamic field with ongoing research and clinical advancements. A talk entitled 'Clinical year in review: treatment aspects' highlighted current research, latest treatment recommendations and emerging therapies. Furthermore, diagnosing ILD's in the future will involve the use of specific blood tests-biomarkers, currently there is ongoing trials looking into the use of these tests which would potentially reduce length of time to get a diagnosis.

Attending the ERS ILD meeting has been an incredible experience. On reflection, I feel honoured to have been part of such a prestigious gathering. It was wonderful to get the opportunity to network with other clinicians including nursing colleagues. I feel enriched with new knowledge, and I am motivated to learn more and to bring the latest research into my practice. This experience will improve my personal growth and more importantly enhance my contribution to ILD care, making me a more informed, skilled, and resourceful nurse."

Lindsay Brown, Respiratory Advanced Nurse Practitioner at St Vincent's University Hospital said "I had the most wonderful opportunity funded by ILFA to attend the European Respiratory Society Interstitial Lung Disease Course in Mainz, Germany. The course involved lectures, case-presentations and workshops from renowned experts across Europe in Interstitial Lung Disease (ILD). It was an honour to be in their presence and to learn and engage directly with them. I delivered a presentation at the event and was overwhelmed by the kind and positive feedback. I want to outline the key learning points for ILFA members

Definition of Idiopathic Pulmonary Fibrosis (IPF): IPF is a chronic, progressive disease that cause scarring in the lungs. The cause is unknown. It usually occurs in older adults, predominantly males. On x-ray and under a microscope, the typical appearance is called a UIP pattern (usual interstitial pneumonia).

Genes: TERT and RTEL1 are the genes associated with IPF in 32% of cases. Another gene called MUC5B may help identify individuals who may be at high risk of developing IPF. Researchers are exploring a gene called KL-6 as a potential biomarker for predicting disease progression in IPF. Artificial Intelligence may help scientists to identify new targets and develop new drugs in the future.

Familial ILD (FPF): There is a familial (family) connection in up to 10% of all ILD cases and up to 20% in IPF cases. FPF may develop in young adults under 50 years of age.

Diagnosis of IPF: All patients should have a high-resolution CT scan that is discussed at a multidisciplinary disciplinary team (MDT) meeting at specialist hospital centres. If a UIP pattern is seen on the lung scan, there is no need to conduct a lung biopsy. If the distinctive pattern is not present, then a lung cryobiopsy is an acceptable alternative to open surgical lung biopsy.

Treatments: The two anti-fibrotic medications, Nintedanib and Pirfenidone, can slow the decline in lung function over time and reduce mortality in IPF. Therefore, anti-fibrotic medicine should be started early. Nintedanib slows the rate of decline in other ILDs such as Progressive Pulmonary Fibrosis (PPF) and Systemic Sclerosis-ILD (SSc-ILD). Another drug, Rituximab improves lung function, 6 Minute Walk Distance, Quality of Life and progression-free survival in Connective Tissue Disease-ILD. Morphine sulphate can help to reduce cough in IPF and improve quality of life.

New Horizons: A Phase II clinical trial of a PDE4 Inhibitor for IPF looks favourable at stabilising lung function at 12-weeks and over time in all patients. Another study called Fiboneer has a Phase III drug trial for IPF and PPF. For more information on clinical trials, visit https://clinicaltrials.gov

Acute Exacerbations of IPF: An acute exacerbation is a sudden (acute), clinically significant respiratory deterioration characterised by evidence of widespread air sac abnormality on a lung CT scan. It may be due to acid reflux into lung or secondary to immunosuppression, chemotherapy, lung surgery, bronchoscopy, or viral infections. The risks for developing an acute exacerbation are shortness of breath, low Forced Vital Capacity/lung function at baseline, oxygen therapy, pulmonary arterial hypertension, the extent of fibrosis on a CT scan, high body mass index (BMI), the use of antacid medicines, and smoking. The annual incidence 5-20%. To prevent an acute exacerbation, avoid the potential causes, ensure you practice hygiene measures, keep up to date with vaccinations (including influenza, Covid, and pneumococcal pneumonia vaccines):

In conclusion, the field of ILD medicine is complex and is advancing through laboratory and clinical research. The experts that I encountered are dynamic individuals who are driven to find treatments that will not only slow the progress of ILD but stop the disease in its tracks.

"It was great to see the relationship and rapport needed between clinical, radiology and pathology when it comes to diagnosing ILD as all the departments' different opinions and expertise on the differential pathways of diagnosis and treatment."

- Dervla Leonard

Research

ILFA Research Sub-Committee: Guiding Progress in Pulmonary Fibrosis Research

ILFA is committed to funding and supporting research into lung fibrosis and related conditions. In August 2024, ILFA established a Research Sub-committee to guide and advance our research efforts and to align these with the needs of ILFA stakeholders.

Objectives and Scope

The Research Sub-committee plays a crucial role in shaping ILFA's research strategy. Its objectives include (1) Providing guidance and feedback on research conducted by or on behalf of ILFA (2) Planning and budgeting for research initiatives (3) Liaising with researchers and contributing to publications. The Sub-committee's work encompasses a broad range of research areas relevant to pulmonary fibrosis, including:

- Incidence and prevalence of interstitial lung disease (ILD).
- Basic scientific research into pulmonary fibrosis.
- Better understanding of treatment data and patient outcomes and factors affecting the timeframes between first symptoms, diagnosis and treatment.
- Access to treatments and health economics.
- Patient and carer experience surveys.

Strategic Goals for 2025-2026

Looking ahead, the Research Sub-committee has set ambitious goals for 2025-2026:

- Developing comprehensive research objectives and budgets, potentially including the establishment of a national ILD registry.
- Gaining a deeper understanding of health economics and approval pathways for new medicines.
- Maximising opportunities for patient participation in clinical studies.
- Investigating the impacts of pulmonary fibrosis on patients, families, and carers.
- Addressing critical issues such as oxygen access, psychological impacts, nutritional challenges (for example, muscle loss, loss of appetite), and gender differences in the disease.
- Sharing research findings effectively, including ILFA's own research and relevant research by others, such as pharmaceutical clinical trials.
- Developing an education program tailored for primary care healthcare professionals.

Collaboration and Governance

The Research Sub-committee operates with a strong emphasis on collaboration and good governance and works closely with the PPI Research Advisory Group to ensure that the patient perspective is central to research efforts. The committee is committed to transparency and accountability, reporting regularly to the ILFA Board. ILFA adheres to principles of ethical research conduct, as outlined in guidelines from organizations like Health Research Charities Ireland (HRCI).

Looking Forward

The ILFA Research Sub-committee is dedicated to driving meaningful progress in pulmonary fibrosis research. By focusing on key priorities and fostering collaboration, the committee aims to generate evidence that will ultimately improve the lives of those affected by pulmonary fibrosis. The current members are Colin Edwards, Nicola Cassidy, Seán O'Sé, Robert Hurley, and Maureen O'Donnell. If you would like to learn more, have any suggestions or would like to join the group please contact colin@ilfa.ie.

BUILD 2K Information Day at University of Limerick

An information day for new research developments in Pulmonary Fibrosis was held at the University of Limerick in November 2024. The event celebrated the release of findings from the "Buddy Walking in Idiopathic Lung Disease (BUILD)" project led by Dr Róisín Cahalan in association with Research Ireland and ILFA. The project also included a review of the "2000 Steps More" initiative championed by Irene Byrne (retired respiratory physiotherapist) and ILFA colleagues. The day also included guest presentations from ILFA CEO, Maureen O'Donnell, President of the European Pulmonary Fibrosis Federation, John Solheim, and leading international researcher in ILD, Professor Anne-Marie Russell. An excellent talk on being winter-ready was presented by two respiratory nurses from University Hospital Limerick, Eilís Gleeson and Noelle Ryan. Numerous patient presentations were made including one by Gerry Redican of the Kerry Pulmonary Fibrosis Support Group, and Robert Hurley speaking about his experience of the BUILD project.

A video featuring Robert Hurley and Lilly Garrett documenting their experience of the project was also launched, and the day concluded with round table discussions on future paths to support patients and family members affected by ILD. The event was attended by approximately 40 people from around the country and was an inspiring day of personal stories and promising developments.

Online Survey on Mental Health and Wellbeing of IPF Patients

The School of Psychology at University College Dublin is conducting a study on the mental health and wellbeing of people with IPF. The study is led by Dr Sonya Deschênes (Assistant Professor), Dr. Elizabeth O'Brien (Clinical Psychologist), and Alisa Oriol (MSc. Researcher). This study aims to analyse mental health and wellbeing in people with IPF in Ireland. For more information and to join the study: https://tinyurl.com/4cmkfdc8

Awareness

Rare Disease Research Conference

Representing ILFA at the Rare Disease Research Conference were Colin Edwards (ILFA Director), Liam Galvin (ILFA Director), Kelly McVicker (ILFA Administrative Lead), and Gemma O'Dowd (ILFA Stakeholder Engagement Lead).

The Rare Disease Research Conference took place on 10th April 2025 at the O'Reilly Hall, University College Dublin. Professors Rachel Crowley and Cormac McCarthy Co-Leads, Rare Disease Clinical Trial Network opened the event and welcomed everyone.

There was a wealth of experts delivering lectures during the day on Disease Registries, Rare Disease Clinical Trials, Public Patient Involvement Perspectives, Industry Perspectives, and Regulatory Perspectives, and a fascinating range of research posters on display. Thank you to the organisers for inviting ILFA to host an exhibition stand, and to all the healthcare professionals who called by to say hello and learn about ILFA's work.

Professor Cormac McCarthy and Professor Adam Byrne with Gemma O'Dowd.

Lung Transplant Study Day

Gemma O'Dowd, ILFA Stakeholder Engagement Lead, attended a fantastic and informative Lung Transplant Study Day at the Catherine McAuley Education and Research Centre, at the Mater Misericordiae University Hospital in April. Below is Gemma's report.

"There was a fantastic line-up of speakers and great presentations were delivered. Healthcare professionals (HCP) from all over the country attended, north south, east and west of Ireland. ILFA was highly recognised for our patient resources, information leaflets provided to patients, families and HCP's, support groups, and especially our online exercise classes. Exercise is so important for lung health and all patients with lung fibrosis and those who have received a lung-transplant are welcome to attend the online classes. Thanks to the organisers of the Lung Transplant Study Day for a great educational event."

Pictured left to right; Maya Ni Laoghaire, Sara Winward, Susan Towell, Linda Keen, Katherine Raleigh, and Fiona Lee.

Raising Awareness in Print

News of the 2024 West Kerry Tractor Run's incredible fundraising event was featured in The Kerryman and Kerry's Eye on 2nd April 2025. The event has raised over €100,000 for ILFA and local charities since 2017 and we are very grateful to John Patrick O'Sullivan, Séamus Devane, and their devoted, hardworking support team for their amazing fundraising and awareness raising efforts.

The announcement of the Thomas Pender Memorial Run was featured in The Wicklow People and online by the Irish Independent in February 2025. Thanks to Rachael Pender for sharing her father's story and raising awareness of pulmonary fibrosis.

Dr Aoife O'Carolan, Specialist Register in Respiratory Medicine at Beaumont Hospital, wrote an article entitled "An Update on Pulmonary Fibrosis" for the Medical Independent Respiratory Update in April and mentioned the work of the Irish Lung Fibrosis Association.

Thank you to everybody who supported the 2024 ILFA Christmas Card Campaign. We were humbled to have our support with donations and help raising awareness at Christmas time.

Share Your Story

If you would like to share your story and experience of lung fibrosis, we would love to hear from you. ILFA always needs people to share their personal story of being diagnosed with lung fibrosis and how they have adapted to living well with the condition. From time to time, media opportunities arise, and ILFA asks people to share their lung fibrosis story to highlight the importance of this life-changing condition among the public. Such stories are hugely valuable as they help raise awareness of lung fibrosis.

Email gemma@ilfa.ie or call 086 057 0310.

Activities and Events

Let's Talk

The first "Let's Talk" online webinar took place on 27th March 2025 and was devoted to Oxygen. A record number of attendees joined the live event. Our invited speakers were Sonia Morrison, Specialist Clinical Nurse / Specialist Sales at Air Liquide and Jo Hobbs, Clinical Manager at Vivisol. The event was a great success with excellent presentations and a lively Questions and Answers session. The presentations were recorded and are available to watch on ILFA's YouTube Channel.

Visit YouTube and search for Irish Lung Fibrosis Association to discover the video resources available to watch.

Please keep an eye on social media and on the ILFA website **(www.ilfa.ie)** for updates on future "Let's Talk" sessions.

ILFA Online Exercise Class

ILFA's online exercise classes take place on Monday, Wednesday and Thursday each week. The classes are delivered online by Eimear Bell, respiratory physiotherapist, and are free of charge to ILFA members.

Register by emailing info@ilfa.ie or calling 086 871 5264. We look forward to seeing you online! Remember exercise is the best medicine!

ILFA Strength and Conditioning Video

The Irish Lung Fibrosis Association launched a new exercise video on Strength and Conditioning in December 2024. This project was funded by a grant from the HSE National Lottery Grant Funding and was developed in collaboration with the amazing physiotherapists at the Mater Misericordiae University Hospital - Olive McCafferty, Grainne Murphy, and Patricia Costello. Our video stars three patients - Aidan Lawlor, Ann Markey, and David Moran, who show us expertly how the exercises should be performed. We are enormously grateful to everyone involved in the production including Maureen O'Donnell, ILFA CEO, and our videographers Fergal and Ray.

These exercises can be performed safely at home and are suitable for lung fibrosis patients including those using oxygen. This guided programme will help you build muscle and strength to optimise and maintain your fitness. You will find the video on ILFA's YouTube Channel.

New Resilience Course

ILFA is delighted to announce a new online six-week course starting soon to support your resilience. Lung fibrosis patients and carers can register their interest in an exciting course that will help build resilience through creative and mindful interventions. Each 90-minute session will feature a guest lecturer followed by group activities.

Topics include:

- Minding your mental health
- Supporting your breath
- Enhancing your creativity
- Practicing self-care
- Wisdom as we age
- Exercising compassion for ourselves and others

Funding for this course is generously provided by the Hospital Saturday Fund.

If you are interested in attending, please register your interest by emailing info@ilfa.ie or calling 086 871 5264.

Mental Health Training for Healthcare Professionals

There are many emotional challenges for respiratory medical professionals caring for patients with life-limiting diseases like lung fibrosis.

ILFA has previously funded Cognitive Behavioural Therapy (CBT) training courses for medical professionals to help patients.

Now, ILFA would like to host an in-person Mental Health Training Day for healthcare professionals on 18th June 2025 from 9am to 5pm. This training event will examine the benefits of mental health supports and offer strategies to healthcare professionals caring for seriously ill patients.

The interactive session, combining theory and practical exercises, has been developed by ILFA in collaboration with Dr. Elizabeth O'Brien, Principal Specialist Psychologist in Respiratory Medicine, Mater Misericordiae University Hospital. Key topics will include Understanding Mental Health Challenges, Communicating with Empathy, Caring for Yourself – a Mindfulness Based Support System, Caring for Your Colleagues - Mental Health First Aid Overview.

CPD accreditation will be available for attendees.

To register your interest, please email info@ilfa.ie

Thomas Pender Memorial Run

Huge thanks to the Pender Family who organised the Thomas Pender Memorial Run in memory of their father. The 5k and 10k course event took place on 6th April in Arklow. It was a glorious sunny day, and the event was a great success with lots of people running, jogging, and walking the course in great spirits. All the participants were rewarded with a beautiful commemorative medal designed by the Pender family. We are grateful to everyone who supported this event - especially the Pender the family, the team of organisers, volunteers, cheerleaders and all of those who took part and helped raise funds and awareness. Your great efforts are hugely appreciated by everyone at the Irish Lung Fibrosis Association and the lung fibrosis community.

A Family Day of Support and Celebration for the Coughlans!

Breda Coughlan and her family took part in the Thomas Pender Memorial Run and sent us a wonderful report and photo.

"As a 78-year-old living with Idiopathic Pulmonary Fibrosis (IPF), every day presents its challenges. However, on 6th April 2025, I was able to take part in something truly special with my family. Together, we travelled from Dublin to Arklow for the inaugural Thomas Pender Memorial Run.

With my trusty oxygen machine in tow, my wonderful husband by my side, and the full support of my family, I walked the 5km route. My youngest daughter, Niamh, was the first lady to cross the finish line in the 10km race, and I couldn't have been prouder. Three more of my daughters took on the 5km route as well, joined by my sons-in-law and my 8-year-old granddaughter. While some of my sons-in-law and grandchildren weren't running, they were there every step of the way, cheering us on and offering their support. It was a true family affair.

As we made our way across the finishing line, we were met with an eruption of cheers from the Pender family and volunteers – such an incredible, heartwarming reception. It made every step worthwhile.

Having my grandchildren walk with me and support me throughout the run made the experience even more meaningful. Though I was tired the next day, I was contentedly tired. The joy of participating in such a wonderful event with my family far outweighed any fatigue.

After the race, we had the pleasure of chatting with the Pender family, who set up the event in memory of their Dad, Thomas. Their warmth and kindness were a testament to the love and effort that went into organising such a special occasion.

To finish off the day, the Coughlan Family gathered at the Arklow Bay Hotel for a delicious meal, where we all caught our breath and chatted. It was clear how much energy and effort had gone into making the day a success. I am beyond grateful to have been a part of such a special day, and I thank everyone who made it possible. Events like these not only raise awareness for ILFA but also bring people together in support of one another. It was a day I will always cherish."

Fundraising Round Up

The ILFA Board would like to extend our sincere thanks to everyone who kindly supports ILFA's work through donations and personal fundraising challenges. Your kind and generous support enables ILFA to provide our services and supports free of charge to people with lung fibrosis, their families, and respiratory healthcare professionals. If you would like some fundraising ideas, please check out our **A to Z of Fundraising Ideas** article on the ILFA website, www.ilfa.ie. If you would like any information on fundraising or to request ILFA merchandise, **please email gemma@ilfa.ie or call 086 057 0310.** Thank you for your ongoing support.

West Kerry Tractor Run 2024

Maureen O'Donnell, ILFA Ireland CEO, travelled to the Marina Inn, Dingle, Co Kerry recently for a cheque presentation for €8,250 raised by the 2024 West Kerry Tractor Run. The event organised by JP O'Sullivan and Séamus Devane also raised valuable funds for the Friends of West Kerry Community Hospital. The West Kerry Tractor Run is a much-loved event that takes place in Dingle and the surrounding areas and is well supported by the whole community. To date, the impressive fundraising event has raised over €40,000 for ILFA and other local charities since 2018. ILFA is grateful to all the organisers, volunteers, and supporters of this wonderful event. Special thanks to John Patrick O'Sullivan from Lispole, who underwent a lung transplant in 2016 and co-founded the West Kerry Tractor Run with Séamus Devane. Míle buíochas!

St Stephen's Day Soccer Match

The 2024 Annual St Stephen's Day Charity Game and Soccer Match in Corbally, Limerick, was held in aid of the Irish Lung Fibrosis Association and raised a fantastic sum of €1,683.

Dave O'Byrne and Camron Crowe organised the charity soccer game on 26th December 2024 on behalf of their friend John Meaney Jnr, in memory of his dad John Meaney, Snr. Dave, Cameron, John and all the players wanted to fundraise for ILFA and dedicated their sporting efforts to helping lung fibrosis patients struggling to catch their breath. Pictured are Camron Crowe, Andrei Reaboi, and John Meaney Jnr and their teammates. Huge thanks from the lung fibrosis community to everyone involved in this great fundraiser. Mile buiochas!

Bel Canto Choir

Sincere thanks to The Bel Canto Choir for their special concert to raise funds for the Irish Lung Fibrosis Association in memory of Dr Jack Griffin. The concert took place on Sunday 23rd March at St. George's Arts and Heritage Centre, Mitchelstown, Co Cork. We are extremely grateful to the organisers and The Bel Canto Choir for their support.

International Charity Bazaar

Maureen O'Donnell, CEO of the Irish Lung Fibrosis Association, was delighted to attend the International Charity Bazaar (ICB) Grant Award Ceremony at the Mansion House, Dublin, where ILFA was one of four charities selected for funding. The generous grant from the ICB will fund our patient walking packs for 2025 enabling our members to exercise. The funds were raised from sales of an annual bazaar, held in Dublin each December, and organised by the diplomats of resident embassies and community groups from more than 40 countries. We are truly grateful to have been awarded this funding. Míle buíochas!

‘Dying for a Breath’ Book Sales

Frank O’Connor is a lung transplant patient who wrote ‘Dying for a Breath’ to tell his story. To date, ‘Dying for a Breath’ has achieved impressive sales amounting to €6,250.

Frank will donate this amount equally between The Irish Lung Fibrosis Association (ILFA) and The Mater Hospital Foundation (transplant section), resulting in €3,125 for each charity. We are extremely grateful to Frank for his generosity and for raising awareness of lung fibrosis, organ donation and lung transplantation.

Frank is pictured with Norman Kavanagh, Chairman of the Naas Community Men’s Shed, who presented a donation to Frank recently for ILFA following a talk that Frank gave to the group.

Thank you to everyone who has supported Frank and his chosen charities by purchasing his book.

Corporate Donations to ILFA

Huge thanks to Leah Symes who won a competition and selected the Irish Lung Fibrosis Association to be awarded €1,000. Leah is pictured being presented with a cheque for €1,000 from Georgina Stapleton of Greenscene/MCR Group. Leah also nominated ILFA as a beneficiary to receive €500 from Millimetre Designs Ltd. (who she works with) in lieu of their corporate Christmas gifts 2024.

We are extremely grateful to Leah and the companies who donated so generously to ILFA.

Kilrush Parish Choir Christmas Carols Fundraiser

Huge thanks to Lisa O’Sullivan and friends in the Kilrush Parish Folk Group, County Clare, who festively fundraised for the Irish Lung Fibrosis Association on 23rd December. The folk group raised an amazing €950 thanks to the kindness and support of the local community. Míle buíochas!

Ballycahill 5km Walk for ILFA

On 14th December 2024, Nora McNamara, Respiratory Advanced Nurse Practitioner at Tipperary University Hospital, and her friend Kate Bannon organised a 5k walk in their community to raise funds for ILFA. Here is a report from Nora.

"Last December, myself and Kate Bannon held a 5km walk around the rock in Ballycahill, Tipperary, to raise awareness about Lung Fibrosis and raise essentials funds for ILFA. We were supported by the Holycross/Ballycahill camogie girls who provided seven of the hampers, gave up a morning of their time to put the hampers together, and sold tickets.

Kate was the social media queen, using Facebook and Instagram to spread the word and promote the event.

Hampers were on display in the Coffee Dock at Tipperary University Hospital leading up the event. The word was spread far and wide across Tipperary and even reached as far as San Francisco! A special thank you to those whose 'revoluted' money when unable to attend. I initial sought to raise €1,000, however, due to the generosity and kindness of people, we raised €2,500.

The morning was a great success with people of all ages joining in the event. Some people had heard about lung fibrosis, some were living with family members with the condition, and some had lost someone dear to them to the disease.

ILFA is an essential resource to me for managing lung fibrosis in my role as a Respiratory Advanced Nurse Practitioner and provides support and knowledge to the patients whom I have the privilege to care for throughout their illness. To date in my career, ILFA has been instrumental in ensuring that I have opportunities to enhance my knowledge and have provided educational bursaries to allow me to fulfil this. I wanted to give back to ILFA, so organising a fundraiser was the way to go. A special thank you to Gemma O'Dowd who from the inception of my idea was as always extremely helpful, providing T-shirts, literature, pens, keys rings and was always available at the end of the phone, Gemma you're a lady!

It was a lovely fresh December morning where a community came together walked, laughed, ate and drank tea and supported a wonderful cause."

Giving in Remembrance

Thank you to families who requested donations to ILFA in lieu of flowers at the funerals of loved ones to honour their memory. We are always humbled by the capacity of people to think of ILFA at times of deep personal loss. Thank you for your kind support.

Donkey Cart Restoration

Robert Burke, Corofin, Galway lovingly restored a beautiful donkey cart that was recently auctioned with all proceeds raised going to the Irish Lung Fibrosis Association. The sale of the cart raised a fantastic sum of €1,200. Pictured from left to right are Joe Corcoran (the successful bidder), Robert Burke (cart restorer), and Mike Conlisk (promoter). Sincere thanks to

McGagh's Garden Centre for staging the cart at their premises for the duration of the promotion.

ILFA is especially grateful to Robert for using his amazing talents to benefit lung fibrosis patients. This was such a lovely, unusual, and creative fundraiser. Míle Buíochas!

Connemara Marathon

Huge congratulations to Darren Little who completed the Connemara Marathon on 26th April to raise funds for ILFA in memory of his father Martin. Darren is pictured with his wife Kate and sons Tadgh and Daithi, and with his friend Steven Nee who ran with him. Darren has raised an incredible amount for ILFA and we are enormously grateful for his support and thankful to everyone who kindly and generously sponsored him. "Míle buíochas!"

Friends fundraising for ILFA

Ashleigh and Raychel, left, are two best friends on a weight loss journey and they kindly donated to ILFA. Ashleigh said "This charity means so much to us as my Mam died with lung disease". Sincere thanks to Ashleigh and Raychel for their thoughtfulness and novel fundraising efforts.

Our Sincere Thanks

Thank you to each person who has supported the work of ILFA through fundraising, donations, regular giving via standing order, sponsoring family and friends in their fundraising activities, and buying our Christmas cards. We are so grateful to you all.
All amounts are gratefully received and facilitate our work on behalf of lung fibrosis patients, families, and the wider community.

Central Bank

Thank you to the Central Bank of Ireland for their ongoing sponsorship and partnership with ILFA in 2025.

For easy ways to DONATE to the Irish Lung Fibrosis Association

Please visit our website www.ilfa.ie. You can donate securely online using a debit or credit card, download a donation form or set up a standing order.

Partnering with ILFA

There are many ways your company, business, society, sporting body, school, college, or club can be involved in supporting the work of ILFA. We would be delighted to work with organisations of all sizes seeking a charity partner through corporate social responsibility or simply giving back to society to help raise awareness and valuable funds. In return, we will support your campaign with ILFA branded merchandise and fundraising assistance, and will gratefully acknowledge your support online, in print and via social media to recognise your commitment to charity. Please consider ILFA as a potential partner for the future and help make a difference. Contact ILFA on 086 057 0310 or email Gemma@ilfa.ie for more information.

New Pulmonary Fibrosis Support Group for Sligo

New Support Groups

Mary Geraghty, Respiratory Clinical Nurse Specialist at Sligo University Hospital would like to help patients set up a new local Pulmonary Fibrosis Support Group for Sligo and the surrounding areas. If you would like more details, please call Mary on 087 268 6222 or Gemma (ILFA's Stakeholder Engagement Lead) on 086 057 0310. In addition, there is interest in setting up a new Support Group in West Cork. Please call Gemma on 086 057 0310 if you are interested in joining.

ILFA Board News

The ILFA Board met for an in-person meeting on 15th February 2025 for the first time since 2020. Since the arrival of the Covid-19 pandemic, all ILFA Board meetings have taken place online, so it was nice to meet face to face once again. Attending the meeting were Eddie Cassidy (Chair), Liam Galvin (Treasurer), Nicola Cassidy (Secretary), Colin Edwards, Patricia Jones, Professor Jim Egan, Lynn Fox, as well as Maureen O'Donnell (CEO) and Gemma O'Dowd (Stakeholder Engagement Lead). The opening activity involved a discussion on ILFA's achievements and what makes us proud. Some notable highlights included ILFA's strong patient support, the online exercise programme, the IPF Patient Charter, how technology has allowed ILFA to serve all patients in Ireland, how the organisation remains sustainable over more than two decades, the strength of the ILFA brand, the generosity of ILFA fundraisers, strong advocacy and 2025 State funding for lung fibrosis, and ILFA's relationship with the healthcare community and other stakeholders.

A Board Self-Assessment exercise revealed that the ILFA Board considers risks and ILFA's stakeholders in shaping annual plans aligned with the charity's strategy. While the Board has diversity of characteristics, experience and skills, there is a need for succession planning and filling skills gaps. Ideally, new Board members would have personal experience and a passion for PF. The Board would welcome people experienced in finance, governance, and legal matters. Several sub-committees are now in operation or will start soon - Finance, Governance, Advocacy, Research, and Fundraising. If you have expertise and are interested in joining a sub-committee or learning more, please contact Gemma on 086 057 0310 or email Gemma@ilfa.ie

In 2024, the ILFA Board worked on updating the charity's Constitution (also called Memorandum of Articles and Association). This important project was undertaken under the guidance of our legal team and proved to be a very valuable and educational exercise. The new ILFA Constitution has been notified to the Charities Regulator.

The ILFA Board would like to extend thanks to our former voluntary Board members Lindsay Brown and Marie McGowan for their contributions to ILFA over the years. Lindsay and Marie stepped down as Board Members in 2024 and 2025 respectively. Thanks also to Anne Griffin, Contracted Administrative Assistant, for the excellent services she provided during her time with us. We wish Lindsay, Marie, and Anne all the best.

Patient Support Groups

ILFA's support groups hold face-to-face meetings around the country, and all lung fibrosis patients and family members are welcome to attend the meetings. For more information, please contact the leader in your area (details are included below). ILFA asks that all support group members do not attend the face-to-face meetings if feeling unwell to protect the health of others. If you would like help to set up a new support group in your area, please contact ILFA on 086 057 0310.

ILFA Support Groups:

Cavan-Monaghan Support Group

Please call Kevin on 087 762 3485 for more information.

Clare Support Group

meets on the first Wednesday of the month at the West County Hotel, Ennis at 12 noon. Please call Michael on 087 637 4068 for more information.

Cork Support Group

meets on the last Thursday of the month at the Elm Tree, Glounthane at 11am.
Please call Anne on 087 985 4587 for more information.

Dublin Support Group

meets on the first Tuesday of the month at 2pm at the Carmelite Community Centre, Our Lady of Mount Carmel, Whitefriar Street Church, Aungier Street, Dublin 2. Please call Matt on 086 244 8682 for more information.

Kerry Support Group

meets on the last Saturday of every month at 3pm in The Rose Hotel, Tralee.
Please call John on 087 280 9801 or Gerry on 086 838 7653 for more information.

Midland Support Group

meets on the 2nd Tuesday of the month at the Tullamore Court Hotel at 2.30pm. Please contact Val on 087 233 2653 for more information.

South-East Support Group

meets meets on the 1st Tuesday of the month. Please call Martina on 086 060 0515 or Anne on 087 692 3991 for more information.

Sligo Support Group

Please contact Mary Geraghty, Respiratory Clinical Nurse Specialist at Sligo University Hospital, on 087 268 6222 or Gemma (ILFA's Stakeholder Engagement Lead) on 086 057 0310

Legacy Giving

Please consider including a gift to the Irish Lung Fibrosis Association in your will. Legacy gifts, big or small, support ILFA's vital work. We are hugely grateful to those who have left thoughtful gifts to ILFA over the years. Your support is making a difference – thank you!

Dates For Your Diary

- **The ILFA Ecumenical Service of Prayer and Reflection will take place on 5th October at Our Lady of Mount Carmel, Whitefriar St. Church, Aungier Street, Dublin 2 at 4pm. If you would like your loved one remembered in the candle lighting service, please email Gemma@ilfa.ie**
- **The VHI Ladies Mini-marathon will take place on Sunday 1st June 2025. Please fundraise for ILFA if you are taking part. Call 086 057 0310 for a fundraising pack.**
- **ILFA Mental Health and Wellbeing Training for Healthcare Professionals will take place on 18th June at the Mater Hospital. Please call 086 871 5264 to register.**
- **Dublin City Marathon takes place on Sunday 26th October 2025. Please fundraise for ILFA if you are taking part. Call 086 057 0310 for a fundraising pack.**

Keep in touch with ILFA

You can keep in touch with ILFA by phone on 086 871 5264 (general enquiries) or 086 057 0310 (fundraising enquiries) by email - info@ilfa.ie on the web - www.ilfa.ie on Facebook, Instagram, X, YouTube and Linkedin - Search for us using @ilfaireland

Please contact ILFA if you would like your details to be added or removed from our mailing list.

Donate to ILFA:

The Irish Lung Fibrosis Association is committed to supporting patients and families living with lung fibrosis and provides all our resources free of charge, including this newsletter. We rely on fundraising and donations to carry out our work and all amounts are gratefully received. If you can and if you would like to make a small donation to cover the costs of newsletter production, printing and postage costs, we would be very grateful for your support. You can donate easily and securely to ILFA directly using your debit or credit card via the ILFA website www.ilfa.ie or via the QR code.