



Advocacy Update from ILFA

One of the Irish Lung Fibrosis Association's (ILFA) aims is advocacy. It's an important part of our work and ILFA has been advocating on behalf of patients with lung fibrosis for more than 20 years. Equitable care, where every patient receives the care they need to manage their condition, continues to be something that we fight for with the support of our community. Some patients, particularly those with access to specialist medical care in Interstitial Lung Disease (ILD) centres, receive excellent care. But this isn't the case for all patients. While support from the HSE for patients has improved, there are still major issues with timely diagnosis, access to treatment, and affordable disease management.

- In 2021, after ILFA's World Café event provided us with a clear mandate, we began advocating for a Clinical Care Programme for Lung Fibrosis. This is our strategic goal and if implemented, will provide a framework for a higher standard of care for all patients. Fighting for this priority has been an uphill battle, but along the way and thanks to many of our members, we've had some successes.
- In 2023, the HSE agreed to staff a part time resource to investigate the viability of a Clinical Care Pathway, the first step in establishing a Clinical Care Programme.
- In April 2024, ILFA presented the need for actioning this commitment as well as several other priorities to the Joint Oireachtas Committee on Health.
- In May 2024, ILFA utilised the Health Committee to put pressure on the HSE regarding its mishandling of the oxygen contract changeover.
- In July 2024, ILFA released its Pre-Budget Submission calling on the Government for €5 million to fund a tax rebate for patients on oxygen therapy, an Interstitial Lung Disease registry, the previously promised Clinical Care Pathway investigation, and equal access to pulmonary rehabilitation.
- In September 2004, ILFA representatives met with the Minister for Health Stephen Donnelly T.D. John Lahart T.D. and representatives from the Department of Health to discuss ILFA's priorities and pre-budget submission.
- In October 2024, ILFA was notified that €500,000 had been earmarked for lung fibrosis in Budget 2025. We were delighted to be informed of this historic award and are planning discussions with the Department of Health and the HSE to determine how this funding will be applied to best serve lung fibrosis patients' needs.

ILFA will continue to work with the new Government after the elections to ensure that lung fibrosis remains a priority. We are deeply grateful for our advocates, both in and outside of Government who have worked with us to progress our



Members of the ILFA delegation who attended the Joint Oireachtas Health on Health in April 2024.

priorities. For those patients and family members who have contacted their elected representatives to tell their story and ask for a commitment to proper care, thank you. It's made a difference!

A Date for Your Diary

The Irish Lung Fibrosis Association (ILFA) will hold a hybrid World Café-style workshop with patients, carers, family members, healthcare professionals and industry representatives on Saturday 18th January in Dublin. The event will start in the morning and last approximately 3 hours.

Our World Café workshop will create a space for participants to share ideas on how ILFA's four strategic themes (Education, Support, Advocacy and Research) can best address the needs and priorities of the lung fibrosis community. The information gathered will guide our work over the next few years of our 2022-2027 strategy. As a patient-centred organisation, your voice is critical, and we promise a fun and engaging experience where you'll have a chance to make your voice heard and connect with others in our community. If you would like to take part in the ILFA World Café, please register your expression of interest by emailing info@ilfa.ie or calling 086 871 5264. Please let us know whether you can attend in person in Dublin, or whether you would like to attend virtually.





ILFA Ecumenical Service of Prayer and Reflection



Mary O'Donovan, Anne Casey and Ann Kennedy.



Members of the Tierney Family.



Denise O'Hanlon, Caroline O'Hanlon Grehan, Eddie Cassidy and Laura Grehan.



Members of the Kennedy Family.

The ILFA Ecumenical Service of Prayer and Reflection took place on 5th October 2024 at Our Lady of Mount Carmel, Whitefriar Street Church, Aungier Steet in Dublin. We gathered in this beautiful church once again for the annual ILFA Service and we were joined online by many people across the country who tuned into the live stream of the event.

The ILFA Service was led by the Reverend Canon Brian McKay O.Carm, Prior of Terenure College and his good friend The Reverend Canon David Oxley, Rector of Santry, Glasnevin and Finglas. Unfortunately, the Reverend Canon Charles Mullen, Dean's Vicar at St Patrick's Cathedral was unable to continue in his role as ILFA Chaplain, but we were

delighted to welcome Canon David Oxley for his first ILFA Service. We are very grateful to the clergy for their support. Special thanks to Fr Brian for a very moving address that focussed on the importance of living in the day and having hope to sustain us.

The ILFA Service contained meaningful readings, prayers, poem and hymns. This year we were joined once again by our dear friend Harry Carpendale who played exquisite music on the harp including some of his own compositions. Simon Morgan was a fantastic cantor, and he was accompanied by on the organ by Dr Carole O'Connor. We are so grateful to our musicians and singer for providing wonderful, breathtaking



Eddie Cassidy, the Reverend Canon David Oxley and the Reverend Canon Brian McKay.



Austin Byrne, Eddie Cassidy, Pauline Byrne, Philo Mullanney and her grandchildren, Conor and Charlotte.

music and song. The candle lighting ceremony was touching especially for those remembering loved ones. Thanks to Carolyn, Lindsay, Caroline and Harry for coordinating this element so beautifully.

Thank you also to our readers, candle lighters, and volunteers who participated and made this a very special occasion.

We are enormously grateful to the staff at Our Lady of Mount Carmel Church and the Carmelite Community Centre for their warm welcome and kind hospitality. We were very well looked after. It was great to see so many people enjoying the social gathering in the community hall afterwards and lovely

to welcome so many children and grandchildren. Thank you to all our guests who brought delicious home bakes and treats to share with everyone.

That evening ILFA's members were invited to light a candle at home in support of those living with lung fibrosis and to remember loved ones who have passed away. We hope this brought comfort to people across the country and further afield.

Thank you to everyone who contacted us after the Service to express their appreciation for the annual ILFA Ecumenical Service of Prayer and Reflection. Your wonderful feedback means so much to us.



Nicola Cassidy, Olive McCafferty and Eddie Cassidy.

Denise Cassidy Memorial Prize for Excellence in Patient Care

The Denise Cassidy Memorial Award recognises and celebrates an act of kindness shown by a healthcare worker to a lung fibrosis patient. The winner of the 2024 Denise Cassidy Memorial Award was Olive McCafferty, Senior Respiratory Physiotherapist at the Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital in Dublin.



Brigid and Frank O'Connor with Olive McCafferty.

Olive was nominated by Frank O'Connor from Dublin for her exceptional dedication and kindness to him while he was in hospital for an extended stay. In nominating Olive, Frank said "I have so many fond and everlasting memories from my long stay in the Intensive Care Unit (ICU), High Dependency Unit (HDU) and the recovery ward post-lung transplant, a total of 132 days. It was all made tolerable knowing that Olive was on duty, her distinctive upbeat voice in the morning filled the ward with a warm glow as she set about doing her magic - i.e. getting me out of my comfortable ICU bed and getting me ready for my daily walk.

Olive has demonstrated to me her ability to multitask beyond all reasonable expectations, particularly as she engineered the complexity of and secured the complete ICU monitoring equipment and the life-support equipment to a simple stainless-steel table, and still managed to get you to walk the ICU corridors for your daily exercise. Olive would literally jump over backwards to help her patients.

Olive also treated her students with great care, guidance and always led by example. Overall, I have no hesitation in recommending Olive McCafferty for the Denise Cassidy Memorial Award for Outstanding Patient Care. She is most deserving of this prestigious award."

Olive was nominated by Frank O'Connor from Dublin for her exceptional dedication and kindness to him while he was in hospital for an extended stay. In nominating Olive, Frank said "I have so many fond and everlasting memories from my long stay in the

Olive was presented with her Dublin Crystal trophy and a framed certificate in November 2024. Joining in the celebrations were Frank O'Connor and his wife Brigid, and members of the Cassidy family, Eddie Cassidy (ILFA Chair), and Nicola Cassidy (ILFA Director). Eddie, Nicola and the rest of Denise's family are thrilled that the award named after their beloved Denise was awarded to such a kind and patient-centred healthcare professional. Nicola said "This special prize is named after my mam, and it means so much to me and my family that her name is associated with an award that recognises the best and kindest healthcare professionals in Ireland. I am thrilled that Olive is this year's winner as I know firsthand her great commitment, energy, and passion to always help patients. Well done Olive!!! You're a star!"



On learning of her award, Olive said "I can't thank Frank and all at ILFA enough. I am truly honoured to receive this award and especially an award honouring Denise Cassidy. I know so many healthcare professionals working hard to improving the care for lung fibrosis patients, so to be picked amongst those is very special to me. Everyone at ILFA has been so kind and supportive of me, and I'm very grateful to be able to say thank you all for this wonderful award".

Well done and congratulations to the other nominations for the Denise Cassidy Award. These were (1) Dr Michelle Murray, Transplant Consultant at the Heart and Lung Transplant Unit, Mater Misericordiae University Hospital, Dublin, (2) Lindsay Brown, Respiratory Advanced Nurse Practitioner at St Vincent's University Hospital, Dublin and (3) Dr Liam Chawke, Respiratory Consultant at Kerry University Hospital.

Education

ILFA Educational Bursaries to Attend the European Respiratory Society International Congress

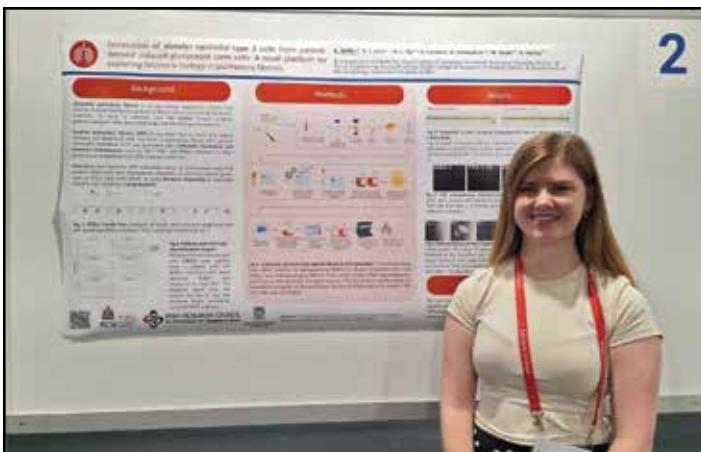
Congratulations to Nora McNamara, Respiratory Advanced Nurse Practitioner at Tipperary University Hospital and Amy Duffy, PhD Scholar at Royal College of Surgeons in Ireland who were the recipients of an ILFA educational bursary. Nora and Amy attended the European Respiratory Society International Congress in Vienna, Austria from September 7th-11th. Supporting education for the healthcare and research community is a key aim of ILFA. Below are the reports from Amy and Nora.

Amy Duffy, Ph.D Student, Royal College of Surgeons in Ireland: "I want to thank the Irish Lung Fibrosis Association for this amazing opportunity! I am a first-year PhD student, and this was my first time presenting my work at the ERS Congress. My work focuses on how to model pulmonary fibrosis in a human in vitro model, to study the role of short telomeres and sex hormones in inherited pulmonary fibrosis. The ERS Congress was an amazing opportunity to share

current international collaborators. While the ERS had over 20,000 attendees, the atmosphere is one of collaboration. I had the opportunity to communicate with researchers and medical doctors at all stages of their careers. I spoke to many people in the poster sessions and after oral presentations about the content of their work but also about career development.

This congress was a successful event for me in creating my scientific network, with a possibility arising to travel abroad to learn techniques in a collaborator's lab.

Exposure to diverse perspectives: Scientific research doesn't happen alone, the more we collaborate the better our understanding of pulmonary fibrosis grows. The ERS Congress brings together basic scientists, medical doctors, and patient advocates. Learning from each of these groups was a massive benefit of attending the congress. Beyond differing fields, the international aspect of the ERS Congress allowed me to hear perspectives of research aims and patient care from different countries and cultures. Meeting with peers has allowed me to gain alternative ways to view my own project and shape my work moving forward."



my research, gain wider perspectives, and create my own scientific network. My main aims for the conference were **Present my current work to peers and partake in knowledge sharing:** Presenting my poster on the generation of a novel familial pulmonary fibrosis model using patient derived induced pluripotent stem cells (iPSCs) was an honour. I gave my presentation to many delegates, each with their own perspective on my work. The questions they posed created new avenues for my work in order to create the most well rounded result.

As we are working with induced pluripotent stem cells (iPSC) and differentiating these cells towards alveolar spheroids, a highly complex and challenging model, it brings a lot of challenges. The opportunity to speak with delegates working with similar protocols was hugely beneficial. We had a chance to discuss some of the problems we have faced and solved, as well as learn some tricks of the trade from others.

Increase my scientific network: The ERS was a great opportunity for me to meet with and strengthen ties with



Nora McNamara, Respiratory Advanced Nurse Practitioner, Tipperary University Hospital: "I recently was extended the opportunity by ILFA to attend the 2024 ERS International Congress in Vienna, Austria. The congress provided an excellent platform for networking, knowledge exchange, and collaborative discussions. There was an extensive array of information available for my areas of speciality, Interstitial Lung Disease (ILD), COPD, and Asthma.

There were many highlights from the weekend, primarily, meeting people with a willingness to share their knowledge to improve and enhance patient care across the globe. There were numerous presentations, case discussions, and stands on Progressive Pulmonary Fibrosis highlighting the importance for a proactive approach to treatment in conjunction with a multidisciplinary team for management. Seeing the data on Nerandomilast which will hopefully improve the outcome for patients with Idiopathic Pulmonary Fibrosis and ILD is very encouraging. I left Vienna feeling energised and positive, thanks to all the key speakers, presentations, case discussions and literature available, which will continue to provide me with new knowledge and drive me to improve the care I deliver to ILD patients who attend Tipperary University Hospital. Much thanks to ILFA for this amazing experience."



CBT Reports

ILFA offered education bursaries to healthcare professionals to study Cognitive Behavioural Therapy. Here are short reports from some of the successful bursary recipients.

Ciara Scallan, Clinical Specialist Physiotherapist, Tallaght Hospital: “Many thanks to ILFA for giving me an educational bursary to attend Cognitive Behavioural Therapy (CBT) training. I recently completed the course and have learned many new skills and techniques that I hope will benefit my lung fibrosis patients.

I feel my clinical practice has changed since doing the course. CBT is a nice skill to have as it can have enormous benefits - it can help patients identify any challenges or issues they may have and learn ways to manage them quite quickly.

By using the different techniques taught during the course, I hope to help patients adopt a healthier thought process to change their thoughts, attitudes and beliefs. In doing so, this will improve their quality of life and maximise their physical and emotional functioning.

Each person on the course had to complete a case study. This allowed me to practise the techniques I had learned and get feedback from the course instructors. This feedback was vital, as it really consolidated the learning I had already received. Listening to the other participants talking about their case studies was also beneficial. I would highly recommend this course to any healthcare professional working with lung fibrosis patients.”

Carol Doherty, Candidate ANP Respiratory Integrated Care: “I would like to sincerely thank ILFA for giving me the opportunity to partake in the CBT course. I had previously heard positive reports from colleagues that had already completed the course. I now appreciate the concept of CBT being introduced into consultations. I have a better understanding of recognising patterns of unhelpful thinking but more importantly I have learned valuable methods to address unhelpful thoughts that may help improve the quality of life for patients in my care.

I have already started using skills learned on the CBT course which is incorporated into my practice. I am hopeful that providing a more holistic approach will help manage breathlessness for patients living with chronic respiratory conditions.”

Maedhbh Ni Chléirigh, Clinical Specialist Respiratory Physiotherapist, Integrated Care Hub: “The benefits of attending this course are many. CBT is a treatment option that I had heard of and had dabbled a little bit in, in terms of goal setting and acknowledging barriers to exercise or discussing anxieties around a respiratory exacerbation, but my understanding and knowledge to equip myself with treatment techniques was an area I wanted to develop.

The course consisted of e-learning and live sessions with an instructor and other course participants, followed by some skills practice / homework. The group sessions were very encouraging and supportive, a mix of physiotherapists, nurses and occupational therapists so I think the wealth of experience and the holistic contribution made it not only more interesting but allowed the discussions to evolve.

I learned about the importance of questioning the persons’ thoughts / feelings / behaviours and to support the person to come up with new ways to thinking / ways to move their outlook on an area that caused them anxiety / depression.

Overall, the experience was very positive, and I would highly recommend this course.”

Eva Byrne, Senior Occupational Therapist in Palliative Care, Our Lady’s Hospice & Care Services: “I was very lucky to receive the ILFA Educational Bursary which facilitated my participation with this professional development course. I am very grateful to ILFA for the opportunity.

I found this course very useful, and the skills learned applicable to a variety of patients. In our outpatient palliative care service and the attached Multidisciplinary Breathlessness Support Service, I meet countless individuals with respiratory conditions, lung fibrosis among them. Patients with these conditions have not only physical difficulties - the anxiety and psychological aspect of respiratory disease and breathlessness is very complex and burdensome. This CBT specific training allows me to be better placed to support patient and help them understand their own thoughts and emotions around different scenarios. Ultimately, this skill puts the patient at the centre, where the healthcare professional is a facilitator to help the individual to problem solve independently. Training in CBT techniques has helped me guide patients and has supported me to navigate more complex scenarios. From engaging in this CBT course, I can offer a more holistic approach to patient care and support the palliative care approach whereby physical, psychological, social and spiritual aspects are considered.”

Zita Lawler, Cardio Thoracic Transplant Coordinator, Heart and Lung Transplant Unit, Mater Misericordiae University Hospital: Firstly, thank you to ILFA for offering us the opportunity to complete the Pivotal course in Cognitive Behavioural Therapy (CBT).

As Heart and Lung Transplant co-ordinators, we meet patients and their families at the point of referral for assessment and aim to develop a trusting and supportive relationship as we accompany them on their journey. Our patients and families are faced with a physical diagnosis that leads to referral for transplant, and this brings with it significant emotional and psychological stress.

The waiting period for a lung transplant can be stressful, as patients and families are often unsure when or if they will receive a donor organ and face the prospect of becoming sicker as well concerns about the potential surgery and its risks.

This course helped us to help patients identify and challenge harmful thought patterns, modify their behaviours that contribute to stress, and develop healthier coping strategies. The course was facilitated by excellent experienced practitioners, who offered us an interactive course with participants coming from varying specialities, all with the same common goal - to offer best care for our patients.

Some key points I feel were:

- Learning how to help identify unhelpful thinking patterns and ways to replace them with more balanced thoughts.
- Encouraging engagement in positive, meaningful activities to improve mood and reduce feelings of helplessness and isolation.
- Setting small, achievable goals for daily activities (a short walk, a hobby, or socializing) which can help improve mood.
- Highlighting the benefit of mindfulness practices and relaxation techniques such as breathing techniques or guided imagery that can help manage stressful moments.
- Using a structured problem-solving approach by breaking down problems into manageable steps, considering possible solutions to develop a plan to address concerns thus enhancing one's sense of control.
- Practicing self-compassion by helping patients accept that waiting and living with illness is challenging and encouraging them to treat themselves with care and kindness throughout the process.
- I aim to share the knowledge with our patients, their families and our team, and in doing so provide lifelong tools for coping with stress and difficult emotions, for patients, families and for ourselves."

Rita Corcoran, Respiratory Clinical Nurse Specialist, Mayo Ambulatory Care Hub, Castlebar, Mayo: "I was lucky to be selected as one of the recipients for the CBT training bursaries awarded by ILFA Ireland. The course included pre-coursework, two online training days and post-

course learning. I will share my learning from this excellent course.

Cognitive behavioural therapy (CBT) can be broken down into its defined components. Cognitive refers to our mind therefore our thoughts, images, dreams, and memories. Behaviour applies to what we do or choose not to do, and therapy is a method of treating a problem. Our belief system affects the way we see the world and our experiences and reactions to events.

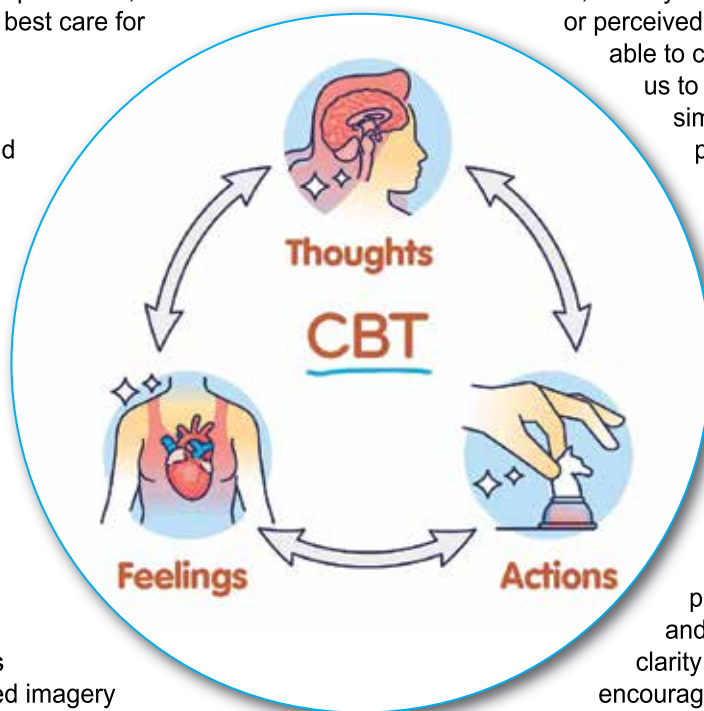
The fundamental concept of CBT is that what we think affects how we feel and what we do. In the course, this was shown as a circular diagram: Thoughts affect feelings - feelings affect behaviour -behaviour affects thoughts. And the cycle continues. CBT is a way of encouraging the person to question their cycle of thoughts through a self-management approach which helps patients to develop skills to manage their difficulties themselves face to face CBT is proven to be effective treatment for psychological problems such as anxiety and depression which are common symptoms in patients who live with chronic medical problems for example pulmonary fibrosis, COPD, heart failure.

The course highlighted that while it is normal to become anxious, anxiety tends to occur when we feel a real or perceived threat, or we feel we will not be able to cope. The course also introduced us to depression which described in simple terms, is the absence of positive affect the loss of interest and enjoyment in ordinary things and experiences. And a low mood. Depression is two to three times more common in patients with the chronic illness.

Treatment options covered included the hot cross bun formulation. This involves dividing your page in four, giving each section a heading; physical, behaviour, emotional and cognitive. This provides the health professional and the patient a structure and clarity for the CBT assessment. It encourages the shared gathering of information through the health professional asking questions, listening, summarizing and together with the patient analysing or synthesising the information. This empowers the patient to identify vicious cycles impacting their thoughts, feelings and behaviours.

The CBT course helped to expand my knowledge of specific approaches and techniques used to change the way we think and feel for example practicing mindfulness, being present, and breathing techniques. The practice of gratitude was also a key component of this course, and it was described with the lovely quote "happiness is not getting what you want but wanting what you have" and to appreciate the little things in life that make us grateful.

I found this course fantastic, insightful and full of practical tools to assist the people with chronic respiratory conditions who I meet day-to-day. It has piqued my interest in this aspect of symptom self-management, and I hope to do further work in this area to benefit the quality-of-life patients with chronic respiratory conditions have."



Awareness

Awareness raising activities

September was Pulmonary Fibrosis Awareness Month – a global initiative to raise awareness of pulmonary fibrosis among the public, healthcare professionals, and policy makers. Pulmonary fibrosis is the name for a group of diseases in which scar tissue (fibrosis) develops in the lungs. Pulmonary fibrosis is also known as lung fibrosis and is a serious, life-limiting condition.

The month got off to a good start when ILFA representatives Maureen O'Donnell (CEO), Michael Darragh Macauley (ILFA Patron) and Nicola Cassidy (ILFA Director) met with Stephen Donnelly, Minister for Health, John Lahart T.D., and Department of Health officials to discuss the needs of lung fibrosis patients and families.



John Lahart T.D, Nicola Cassidy (ILFA Director), Stephen Donnelly Minister for Health, Maureen O'Donnell (ILFA CEO) and Michael Darragh Macauley (ILFA Patron).

Throughout the month, ILFA highlighted some patient stories on our social media channels and website to showcase the strength and resilience of our patients. We are grateful to Breda Coughlan, Matt Cullen, and Charlie Campbell for sharing their experiences of being diagnosed with lung fibrosis, managing their condition and maximising their health.

There were also several fundraising and awareness activities that took place across the country, and we are grateful to everyone who helped raise awareness and funds for ILFA. More details are included in the fundraising section of the newsletter.

Raising Awareness in Memory of Tom Pender



Rachel Pender writes touchingly about her motivation to raise awareness of lung fibrosis in memory of her father Tom.

“In May of 2022, Thomas Pender began suffering from increased shortness of breath more than he had in previous years, which he had put down to years of smoking and increasing age. Finally, Dad



The Pender family.



attended his local GP who quickly referred him initially for an x-ray to try to find the root cause of the shortness of breath. A short two months later, in July 2022, Dad was subsequently diagnosed with Idiopathic Pulmonary Fibrosis (IPF).

As a family, we had little to no knowledge of what IPF was or what the next steps were for Dad in terms of treatment. Thankfully, there was an anti-fibrotic medicine that the Consultant was able to prescribe in the hopes that it would slow the progression.

After Dad's diagnosis, I began to research IPF for information about the condition and support from others. The Irish Lung Fibrosis Association (ILFA) was one of the first websites that I came across. I reached out to the ILFA and received multiple leaflets, newsletters, exercise guides all to try and aid my Dad. ILFA was instrumental in guiding us through what would be significant changes in not just Dad's life but ours's as a family.

My Dad was a family man at heart and worked tirelessly to support our family. He spent years in Saudi Arabia, working on oil refineries and then moved to Intel and lastly Pfizer in Grange Castle, where he continued to work until his passing in April 2024. Whilst he was an inpatient in St. Vincent's hospital, I was requested to bring his laptop to the hospital!

Dad had several and many interests from astronomy to zoology and everything in between. This led to many fascinating conversations with anyone and everyone that Dad met in his lifetime. What he really enjoyed was local history, and this led to the development of his Facebook page, “Avoca Through The Years”. With over 3,000 followers it connects people far and wide who have a shared love of Avoca.

Since Dad's passing in April, I have taken it upon myself to help spread awareness of this disease to as many people as I can and raise vital funds for the ILFA. Initially, I set up a GoFundMe page, which currently has raised €1,205.



Kerry Pulmonary Fibrosis Support Group Meeting

The Kerry Pulmonary Fibrosis Support Group organised a talk in the Meadowlands Hotel in Tralee on Saturday 19th October 2024. Here is a report from Robert Hurley who attended the meeting.

“Huge congratulations to Gerry Redican, JP O’Sullivan and the Kerry Pulmonary Support Group for inviting Dr Liam Chawke (Respiratory Consultant), Niamh O’Flaherty (Clinical Specialist Physiotherapist) and Grainne Coffey (candidate Advanced Nurse Practitioner) at University Hospital Kerry to attend and meet the group for a catchup.

All in attendance were delighted to have such experts

in the respiratory field who answered all our questions. We are very grateful to them for sharing their knowledge with us. It was a huge benefit to all of us living with lung fibrosis.

Many thanks also to the Meadowlands Hotel who provided the room and refreshments on the day. The support group is indebted to the management and staff at the Meadowlands Hotel for their ongoing support that is very much appreciated by the pulmonary fibrosis community in Kerry.

Míle buíochas”

In September, Pulmonary Fibrosis Awareness Month, I also hosted an information day in my local shopping centre with the help of ILFA members, my sister Sarah and my daughters. My Mam, Mary, also came to support us on the day. We also held an awareness raising event in Athlone Town Centre on November 9th.

On March 9th, 2025, what would have been Dad’s 72nd birthday, with the help of Wayne O’Driscoll from Bling Hunters and JustRuns Events, we are organising a memorial run to raise funds and awareness of the work that the ILFA continue to do for many families like ours. I remain fully committed to raising awareness of Pulmonary Fibrosis and gathering vital funds for the Irish Lung Fibrosis Association.”

The ILFA Board would like to extend our sincere thanks to members of the Pender Family from Wicklow who held a fantastic awareness and fundraising event at the Bridgewater Shopping Centre in Arklow on 21st September and in Athlone Shopping Centre on 9th November. Rachel Pender along with Sarah Pender, Mary Pender, Alana Barnes and other family members wanted to raise awareness of lung fibrosis in memory of their beloved father, Tom. Rachael’s story was

published in the Wicklow People. Gemma O’Dowd (ILFA Administrator), James Kavanagh (ILFA Supporter) and Maureen O’Donnell (ILFA CEO) attended the event in Arklow to lend their support.

The Pender family raised over €700 for ILFA and raised invaluable awareness by speaking with many people about lung fibrosis and ILFA’s work. What an amazing team!

ILFA Advocacy Activities

An article entitled “Interstitial Lung Disease – An update from the Irish Lung Fibrosis Association” written by Nicola Cassidy, ILFA Director, was published in Hospital Professional News.

Maureen O’Donnell, ILFA CEO attended the HSE Patient and Public Partnership Conference at The Printworks, Dublin Castle, on 24th of September. This year’s conference theme was ‘Changing patient outcomes: one partnership at a time’. Colin Edwards, ILFA Director attended the Future of Registries Taskforce meeting on 24th of September to represent the lung fibrosis community.

Advocacy

“Speak Now” - a powerful short film from Banjoman and Elk Films

Frank Branigan is living with lung fibrosis and needs a lung transplant. He is hoping that the Human Tissue Act 2024 (when it's eventually enacted) providing for an opt-out organ donation system, will increase his possibility of receiving the gift of life from an organ donor and their family.

Even with the new law, a potential organ donor's next of kin will still be asked to give their consent for organ donation to proceed even if the organ donor has indicated they would like to donate their organs. The final decision rests with the person's next of kin and sometimes the family decides not to proceed.

Frank's daughter Niamh is an actor, producer, and writer, and wanted to use her skills and talents to highlight the need for people to have a conversation with their loved ones to discuss their wishes on organ donation.



Frank Branigan is pictured with his daughter Niamh.

Niamh brought this concept to her friend Dermot Malone, writer and director with Banjoman Films and together they developed it into a powerful short film called “Speak Now” with the help of a wonderful team of actors, writers, camera operators, and light and sound technicians.

This collaborative effort sets the scene (with the inclusion of some artistic licence) of a bride being escorted down the aisle by an organ recipient and pays homage to the bride's late father's generosity for being an organ donor. Everyone can appreciate the significance of the life-affirming scene and the enormous impact the gift-of-life has on all the parties involved.

Please have a conversation with your loved ones to ensure your wishes are carried out if you support organ donation.

Watch “Speak Now” on YouTube.

ILFA becomes a member of the Charities Institute of Ireland

The Irish Lung Fibrosis Association is pleased to announce that we have joined the Charities Institute of Ireland (Cii). Cii is the representative body for Ireland's leading and high-impact fundraising charities. We look forward to engaging with Cii and

its community of members to avail of valuable knowledge-sharing, learning, and networking opportunities.

ILFA Campaigns for Better Lung Fibrosis Care



September was Pulmonary Fibrosis Awareness Month and ILFA took advantage of this special month to raise awareness and champion the cause of patients and the lung fibrosis community. Maureen O'Donnell (ILFA CEO), Nicola Cassidy (Board Member), and Michael Darragh Macauley (ILFA Patron) were invited to attend a meeting with the Minister for Health Stephen Donnelly T.D., Department of Health Officials, and John Lahart T.D. on 2nd September 2024.

The ILFA delegation shared their experiences of lung fibrosis care and discussed ILFA's pre-budget submission in detail. The need for an Interstitial Lung Disease Registry, supports for oxygen users, improved access to pulmonary rehabilitation, appointing a Clinical Lead to advance an ILD Clinical Care Pathway, and ensuring equitable healthcare access for lung fibrosis patients were discussed at length. The meeting was constructive and valuable, and the ILFA delegation was optimistic that progress would be made.

Thomas Pender Memorial Run 2025

Rachel Pender and her family are holding a 5km and 10km fun run for all the family on Sunday 9th March 2025 in memory of her father, Tom Pender. The event will start at 10am from the Coral Leisure Centre, Arklow, and will raise funds for ILFA. All welcome to take part.

All finishers will receive a specially commissioned medal. Sign up at the address below to register to run, jog and walk on 9th March 2025. **See also** <http://www.justrunsevents.ie/>



ILFA's PPI Research Advisory Group

ILFA established a Patient and Public Involvement (PPI) Research Advisory Group to ensure stakeholders' perspectives and priorities are embedded in lung fibrosis research. Patient and Public Involvement (PPI) empowers patients and values their voice and lived experience and offers benefits to researchers, clinicians, the scientific community, patients, and the public through improved high-quality, design, accessibility, and relevance of research, which in turn directly increase its impact.

ILFA's Strategic research priorities are

- to value all research that advances our understanding of lung fibrosis including basic science, clinical research, behavioural science, epidemiology, treatment pathways, health economics, and patient-reported outcomes relevant to lung fibrosis
- to embed the patient-voice and PPI in lung fibrosis research
- to share plain English research updates with our members, clinical and research communities, and the public
- to conduct research surveys with ILFA members on matters impacting them.

Sean O'Sè is the Chair of the ILFA PPI Group and the membership includes 6 patients, 2 family members of patients, 5 academic researchers, and 3 ILFA representatives. ILFA's role is to facilitate the PPI meetings in a safe, respectful, and collaborative forum, and to support the Chair. ILFA also liaises with researchers who contact the charity seeking PPI input for research projects. Researchers who are interested in partnering with the PPI group are invited to join the PPI meetings and present their research and requirements. PPI participants are encouraged to ask questions, make observations, and engage in discussions.

The PPI group is an active and supportive community of key stakeholders that directly influences lung fibrosis research. Recent projects have included (1) development of the PPI Handbook and the PPI Application Form for Researchers, (2) contributing perspectives to 7 research projects (3) 4 PPI members were patient contributors on three separate research funding applications for the 2024 Health Research Board/ Health Research Charities in Ireland Joint Funding Scheme.

Recently we conducted a PPI member survey, and the results were overwhelmingly positive. Here are some of comments received;

- "I like the mix of people from different backgrounds. The group is very inclusive. It is great to have so many research projects cross our paths. The group is making a difference."
- "The PPI group is doing fantastic work putting the patient and their voice at the heart of every research study. The researchers are open, enthusiastic and appreciative of our help. It's so important to work together to ensure the best possible research questions are asked. I am proud of what the ILFA PPI group has achieved and look forward to being involved in more research projects."

Recently ILFA's entry entitled "Establishing a Lung Fibrosis Public and Patient Involvement Research Advisory Group" was shortlisted for Patient Organisation Project of the Year

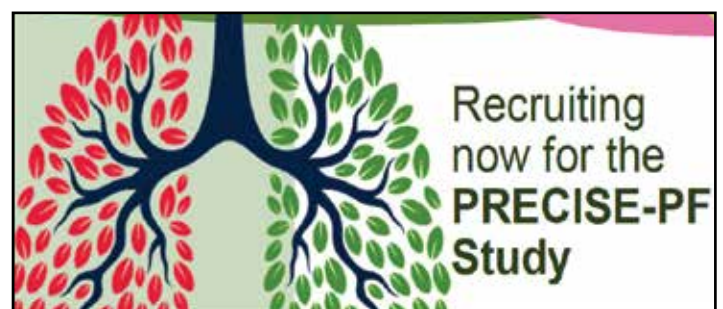
at the 2024 Irish Healthcare Awards. This wonderful honour is testament to the commitment, dedication, resolve, and teamwork of the patients, carers, researchers and clinicians on ILFA's dynamic and inclusive PPI Research Advisory Group.

International Colloquium on Lung and Airway Fibrosis Meeting



ILFA CEO, Maureen O'Donnell, attended the 22nd International Colloquium on Lung and Airway Fibrosis (ICLAF) in Athens from 12th to 16th October 2024. This specialist conference is dedicated to lung fibrosis and brings together leading and emerging researchers, scientists, and clinicians, as well as patients from across the world. Fittingly, the conference opened with 'The Patient Journey' and the ILFA logo was included on a slide along with other international patient organisations! Over the 5 days, there were some fascinating discussions on cellular biology, genetics, biomarkers, screening, treatments, new therapeutic targets, clinical trials, environmental factors and lots more.

Research Opportunity for Families with Lung Fibrosis



If you have a diagnosis of pulmonary fibrosis and have at least one relative with pulmonary fibrosis, Professor Killian Hurley and Dr Aoife Carolan at Beaumont Hospital would like you to take part in their research study called the PRECISE-PF Study. The research team is looking to improve knowledge of how pulmonary fibrosis behaves in patients with a family history of pulmonary fibrosis in comparison to those who do not have a family history. They are also looking to find out more about the genetics of familial pulmonary fibrosis in Ireland.

Contact details:

Email: aoifecarolan@beaumont.ie

By post: ILD Clinic, Beaumont Hospital, Beaumont Rd, D09V2N0. **More details at livinglunglab.ie**

“Dying for a Breath”

A Journey of Courage and Hope for Those Living with Lung Fibrosis



Lung fibrosis is a silent battle faced by thousands across Ireland. It's a condition that can often feel overwhelming, isolating, and misunderstood by the world around us. Whether you're living with this disease or caring for someone who is, the emotional and physical toll can be immense. Amidst these daily challenges, we all seek something that resonates deeply with our experiences—a narrative that not only illuminates our struggles but also uplifts, encourages, and reassures us that we are not alone. This is a book written with raw emotion where you will feel a heartfelt connection to the experiences Frank shares so openly on his journey. As you turn the pages, you will find moments of vulnerability and resilience that mirror your own, drawing you into a powerful narrative that doesn't shy away from the realities of being diagnosed with IPF and undergoing a one hundred- and thirty-two-day life-giving lung transplant in the Mater Hospital. It offers a sense of understanding that can be rare when battling a condition that often feels isolating. Each chapter serves as a reminder that no matter how difficult the path may be, there is strength to be found in shared stories and human connection.

No sugarcoating the reality

The book does not sugarcoat the hardships and discomfort, but at the same time, it doesn't allow the narrative to become consumed by despair. It's this balance—between acknowledging the reality of the illness while also shining a light on moments of triumph, resilience, and even humour—that makes the book so relatable.

For anyone diagnosed with lung fibrosis, the initial feelings of confusion and fear can be overwhelming. Medical jargon, endless tests, and the uncertain outcome of the disease can leave you feeling confused and lost. This book steps in, providing readers with a relatable account that validates their feelings and experiences.

By delving into one person's struggles, readers will see their own similarities reflected at them, offering much-needed comfort and validation.

“When I wrote *“Dying for a Breath”*, I wanted to give hope to those living with the disease and acknowledge the amazing unconditional love I received from everyone in the Mater Hospital. My unwavering gratitude to the medical staff is captured in the opening lines of the book's back cover: “If you had an ultraviolet light at the Mater Hospital that Day, you would have seen invisible rays of love and energy flowing from these remarkable individuals”.

Hope and Connection

Perhaps the most compelling reason to pick up *“Dying for a Breath”* is the hope it imparts. The book is filled with stories

of perseverance and small victories, reminding readers that even though lung fibrosis is a progressive illness, there is still so much life to be lived. Whether it's through the support of loved ones, finding moments of joy in everyday life, or simply appreciating the breath we do have, the book encourages readers to focus on the things that truly matter. It shows you that you're not alone in your fears, your frustrations, or your hopes. In fact, there is an entire community, like our very own—Irish Lung Fibrosis Association (ILFA), who are ready to walk this journey with you.

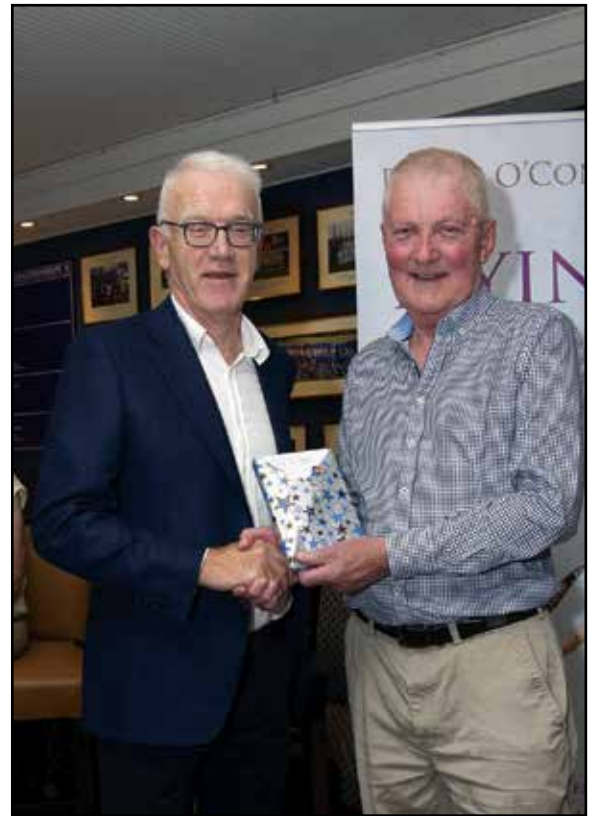
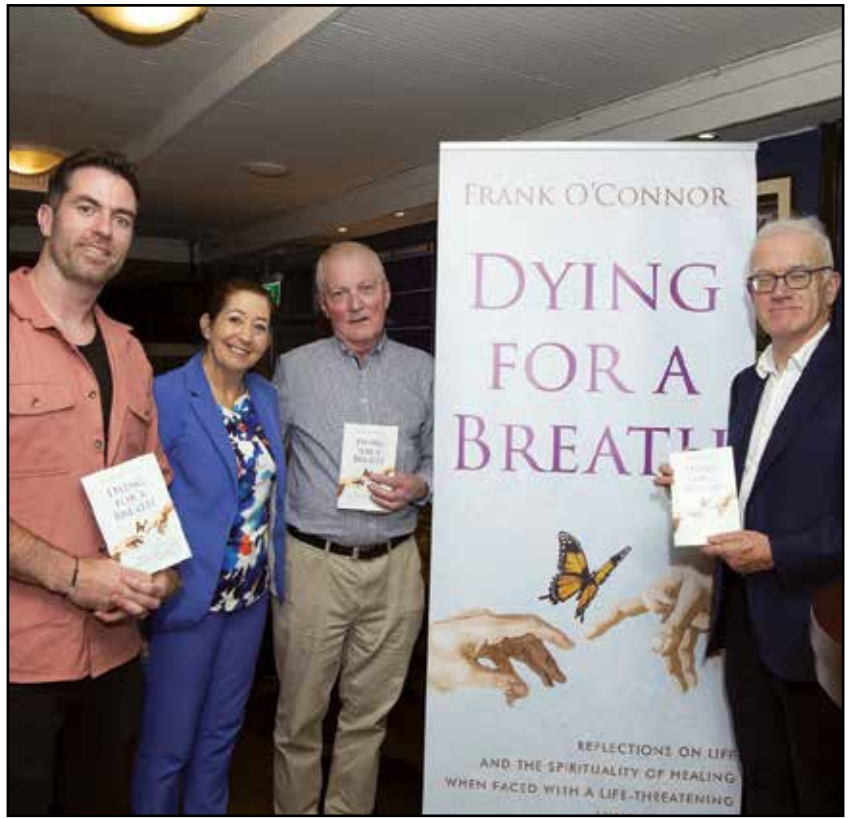
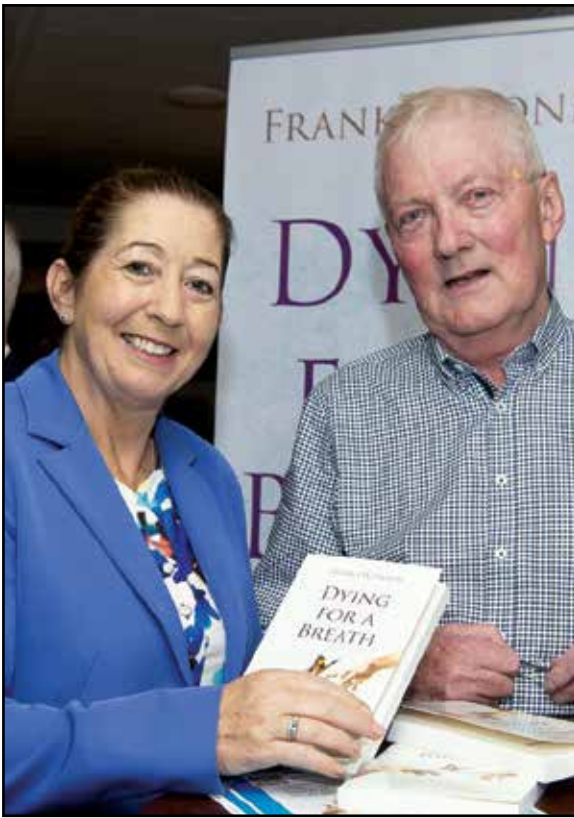
The book can be purchased online at: www.orpenpress.com and all proceeds from the sale of the book *‘Dying for a Breath’* go to two registered charities: The Irish Lung Fibrosis Association (ILFA) and the Mater Hospital Foundation-transplant clinic.

“Dying for a Breath”: Book launch

The launch of *“Dying for a Breath”* took place on 19th September at Ballyboden St. Enda's GAA Club, marking a significant and heartfelt occasion. The event drew a warm and supportive crowd of family, friends, the Mater Foundation and members of the Irish Lung Fibrosis community, all eager to celebrate the release of a deeply personal and inspiring book.

Opening Remarks

The evening began with a welcome from the launch MC for the evening - Michael Darragh Macauley, who emphasised the significance of the book and its importance to the lung fibrosis



community. There was a heartfelt introduction to the author, touching on the personal journey that led to the writing of “Dying for a Breath” and the courage it took to share such an intimate story with the world.

Book Reading

In a deeply emotional and powerful reading, Therese Kevil brought to life a poignant passage from “Dying for a Breath”, reflecting on Frank’s profound love and gratitude toward his lung donor. Through her reading, Therese captured Frank’s

heartfelt appreciation for the donor’s selfless act, highlighting the emotional and physical bond that connects them. This moment in the book powerfully conveys how such an experience can inspire immense gratitude and the motivation behind sharing this story.

The evening at Ballyboden St. Enda’s GAA Club concluded with uplifting remarks from Prof. Jim Egan, who emphasized the strength of community, and the resilience required to face life’s challenges, reminding everyone of the power of support and solidarity in times of hardship.

Report by Frank O’Connor



Members of the Central Bank team with friends of ILFA who also joined in the fun.



Central Bank and ILFA Stationary Cycle Challenge

The 25th September, was World Lung Day. To celebrate this important day, to raise awareness of lung fibrosis, and to fundraise for our organisation, ILFA joined together with our charity partner, the Central Bank of Ireland, in a relay cycle challenge in Dublin City Centre. We had four relay teams of enthusiastic cyclists lined up to cycle for 5 minutes at a time, over a 3-hour period. To add to the excitement, there was a prize up for grabs for the team that travelled furthest. We were absolutely thrilled to partner with Central Bank volunteers for this fun event.

We gathered outside the Gaiety Theatre on King Street from 11am in anticipation of the start of the event at midday. Despite the rainy weather, it was great to feel the excitement building and at 12 pm on the dot, Maureen O'Donnell, ILFA CEO, kicked off proceedings with a welcome speech and

words of encouragement to all the volunteers helping to raise awareness of lung fibrosis. Following a countdown, the team captains started pedalling furiously and we were underway.

Team captains Eoin, Elizabeth, Chloe, and Kevin gave great encouragement and support, while keeping a watchful eye on the stopwatches and kilometre trackers. We were thrilled when ILFA members joined the teams as well - including 2 lung transplant patients; David Crosby and Mags Sheridan who wholeheartedly threw themselves into the event and shared their inspiring stories with the participants. Mags' husband John and friend Anne-Marie also jumped on the bikes for a few rounds as did Olive McCafferty (respiratory physiotherapist), Philo Mullaney, Ann O'Flaherty, Maureen O'Donnell and Nicola Cassidy.

The atmosphere was electric, and everyone cycled as fast



as they could to clock up as many kilometres as possible.

We were also joined by Timmy Kavanagh from Wicklow who played his guitar and sang a selection of much-loved songs. Despite the rain, people danced and swayed to the tunes, especially James Kavanagh (Timmy's Dad). Also supporting the day were Eddie Cassidy (ILFA Chair), Colin Edwards (ILFA Director), Gemma O'Dowd (ILFA Administrator) and a team of ILFA supporters - Rachael Pender and her family. Another member of the Pender family, Tomas, served as the Safety Officer at the event.

Even though it was raining, we were delighted to have the shelter of the awning over the Gaiety Theatre, and we are grateful to the management for their permission to use this wonderful location. Before we knew it, the countdown to the finish line was underway and the cycling event ended with a

great cheer. We adjourned to The Duke Pub for some warm food and refreshments. Team 1 (led by Eoin) was the winner of the trophy having completed an impressive 129.64km in 3 hours! Eoin accepted the award on behalf of the team and gave an Oscar-worthy speech! Maureen then presented sunflowers to the Central Bank organisers of the event, Ciara, Niamh and Michelle in thanks.

The 4 teams travelled an incredible 478km in total which is the equivalent of cycling from the Central Bank in Dublin to Fermoy, Co Cork and back again!!!!!!!

The event was a great success, and we are deeply grateful to Conor McCabe and rest of the phenomenal Central Bank Team, Gemma O'Dowd (who organised the event for ILFA), Dublin City Council, the Gaiety Theatre, An Garda Siochana and our wonderful supporters for their contributions.

Irish Life Dublin City Marathon 2024

Clive Bourke



Congratulations to Clive Bourke from Mayo who ran the Dublin City Marathon on Sunday 27th October in memory of Sadie Mannion and for all the McNulty clan of Donegal. Clive had a great run and has raised over €3,000 for ILFA Ireland. Huge thanks to Clive and to everyone who sponsored him so generously. We are enormously grateful for this wonderful support. Mile buiochas!



and run further and faster. ILFA Cheerleaders (Annette Grehan, Birgit Kretschmann and Nicola Cassidy) were especially delighted to surprise Niamh by dressing up as a trio of ghosts to cheer her on the final stretch of the marathon. The 3 ghosts really enjoyed Niamh and Adrians' reaction when they heard their names and saw the poster with their names on it. Congratulations to Niamh

and Adrian - we're so proud and grateful to you.

Michael Flynn



Huge congratulations and thanks to Michael Flynn who ran the Irish Life Dublin Marathon on 27th October to raise funds for ILFA Ireland in memory of his mam Rosie. Here is a great photo and few words from Michael ...

"I just wanted to share this photo with you, of me being very tired but very happy and proudly wearing my ILFA t-shirt after the marathon on Sunday! I still can't walk properly, but it

was well worth it. I had a great day, had some lovely memories of Mam (and carried her photo with me) and was absolutely thrilled to raise over 4k for ILFA. I really didn't think it would reach that much, and the purpose really added to my day. I'm really happy to be able to give back to a charity that gave a lot to Mam, and I hope it helps. Thanks for all the support and for everything you do."

Niamh English

Niamh English and her husband Adrian, pictured, ran Irish Life Dublin Marathon together on Sunday 27th October to raise awareness and funds for ILFA. Niamh dedicated each mile to someone special. Several ILFA friends were included on the list, and they inspired Niamh to dig deep

Paul Giles



Paul Giles donned his "Lucky ILFA T-shirt" for his third Dublin City Marathon on 27th October and ran in memory of his aunt, Denise Cassidy. Paul had a great run and gained a new personal best time as he flew around the 42km course buoyed on by everyone calling out his name and shouting words of encouragement. He gave a great wave and a hearty laugh when he saw ILFA's friendly cheer-leading

ghosts cheering him on (one ghost was his aunt Annette and one was his cousin Nicola) as he raced to the finish line. Congratulations Paul and thanks for raising awareness of ILFA.

Yvonne Boyle

Yvonne Boyle had a great run at the 2024 Irish Life Dublin Marathon on 27th October. Yvonne ran for ILFA in memory of her father-in-law Frank Boyle. So far Yvonne has raised an incredible €2,850 and she is blown away by the generosity of her family and friends.

Yvonne said "I was so happy with how the day went. I had a small PB which was the icing on the cake! All the Boyle's were out in support as always, and I know Frank would have been so proud of that, being such a family person! Along the



way Frank's grandchildren Cillian and Sorsha ran some steps with me! The amount raised so far exceeded my expectations. I hope the money raised is a support to people needing the services of ILFA."

Huge congratulations and thanks to Yvonne from all at ILFA.



Cheering on our Marathon Heroes



ILFA Cheerleaders (Annette Grehan, Birgit Kretschmann and Nicola Cassidy) were up early to get to Ballsbridge on Sunday morning for

Irish Life Dublin Marathon. Here they are planning, carb-loading and getting into character as spooky ghosts to cheer on #Team ILFA and all the runners for the final stretch of the marathon.

Our cheerleaders had a long and fun-filled day as they clapped, cried with laughter, shouted words of encouragement, and even scared a few runners into running faster. Well done ladies! The power of support!



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. Thank you!



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 info@ilfa.ie or call 086 871 5264**. Thank you for your ongoing support.

Artistic Talent



Matt Cullen from Dublin is a great artist and a loyal supporter of the Irish Lung Fibrosis Association. Matt recently sold two of his paintings and donated 50% of the proceeds to ILFA. Matt's wonderful paintings are shared here. The first painting was of the Clock Tower and Round Tower in Swords. The second

painting is called: "Changing Forms", which is one of a series of paintings on that theme. Huge thanks to Matt for sharing his special and inspiring talent and good fortune with ILFA.

The Living Lab Coffee Morning in aid of ILFA



"On 25th September, World Lung Day, the Living Lung Lab based in the Royal College of Surgeons in Ireland (RCSI) on the Beaumont Hospital campus hosted a coffee morning in aid of ILFA and to raise

awareness of pulmonary fibrosis.

We, in the Living Lung Lab, are very interested in finding new treatments and cures for pulmonary fibrosis by using translational, regenerative, and clinical research methods. We are extremely grateful for the work that ILFA does, providing much needed support not only for patients and carers, but



also for researchers and clinicians.

We were delighted to be able to give back to the ILFA community by hosting a fundraising event. We were overwhelmed by the huge amount of support we received for our coffee morning in RCSI and Beaumont Hospital and raised a total of €1,067 for ILFA. Sincere thanks to everyone who baked, supported, donated, and bought our goodies!"

Report by Anja Schweikert, PhD Student, and Mari Ozaki, Research Fellow at Department of Medicine, RCSI Education & Research Centre, Beaumont Hospital.

VHI Mini Marathon



Bernadette Gallagher and her family took part in the VHI Women's Mini Marathon to remember her dad, John, and raise funds for ILFA Ireland

Here is a lovely report from Bernadette.

"My dear dad was born in Donegal in 1947. He met my mum Eileen in Edinburgh and moved to Dublin where me and

my 2 brothers and 2 sisters were brought up. My dad worked in construction and tunnelling work in Ireland and throughout the world. It was unfortunately down to all this hard work that he developed lung fibrosis because of exposure to silica and dust. He had to give up work due to his condition and he also developed a mixed connective tissue disorder on top of the lung fibrosis. This meant he couldn't have a lung transplant. My dad managed his condition as well as he could and always tried to stay active and busy, but as his condition progressed, he was able to do less and less. He eventually required oxygen and his ability to mobilise became more compromised. At the end, he spent 6 weeks in Tallaght Hospital, fighting hard to survive, but sadly he did not win the battle this time. My dad passed away peacefully under the care of the wonderful staff of Tallaght Hospital. He had fought so hard and was so brave and courageous through it all, but at last he was at peace.

We are all devastated by the loss of our dear dad. He was a much-loved husband, dad, grandad, brother, uncle, cousin and friend. There is a void that can never be filled, and he is missed so much every day.

We, his family, wanted to do some fundraising in my dad's name and to raise much needed funds for the Irish Lung Fibrosis Association. We decided to do the Women's Mini Marathon. Me, my sister Geraldine, my nieces Alana and Kayla, my sister-in-law Sinead and my cousin Maria all got on board. We set up our target at what we thought was quite an ambitious amount of €1,000. Through various social media platforms, we spread the word, and the money started rolling in. I had to increase the amount at least 5 times! Thanks to the generosity of all our family and friends we raised €5,405. We were blown away by the kindness of everyone and I know my dad would have been blown away by this amount being raised in his name. We had a great day at the mini marathon. It was a very emotional day, but a special day. We walked, we ran, we talked, we laughed, and we cried, but mostly we remembered my wonderful dad.

On behalf of the family, I wish to thank Gemma O'Dowd from ILFA for her assistance in helping us with our fundraising. She made everything so easy. She got our sponsorship t-shirts to us in plenty of time so we could get a picture of my dad put onto the t-shirt. We hope this money will help other families who are dealing with this awful disease."

Niamh and Donal's Wedding Day



Congratulations to Niamh and Donal who got married on 16th October 2024. They made a very kind donation to the Irish Lung Fibrosis Association (ILFA) in lieu of wedding favours and have shared some beautiful photos with us. Niamh is pictured with Donal on their wedding day.

We wish Niamh and Donal every joy and happiness for a wonderful future and thank them sincerely for their kind donation to ILFA.

Cork Mini-Marathon

Deborah O'Connor and her fantastic team of family and friends completed the Cork EchoLive.ie mini-marathon on



Sunday 22nd September to raise funds for the Irish Lung Fibrosis Association.

Deborah sent us a photo and said "We have 5k done and dusted. I got fantastic support. Thank you for all your help".

Huge thanks to Deborah and her amazing team!

ILFA fundraiser in memory of Micheál Byrne



Imelda and Byrne and her sister Geraldine held an 'afternoon tea' fundraiser in Galway on Saturday 28th September to raise funds for ILFA and create awareness in memory of their brother Micheál who passed away from pulmonary fibrosis. Here is a report from Imelda and Ger;

"We recently held an Afternoon Tea in our home in Barna, Galway in memory of our late brother Micheál Byrne and to raise vital funds for ILFA. We were joined by many family members and Cllr. Peter Keane, Mayor of Galway, Cllr. Neil McNeillis, Deputy Mayor of Galway, Cllr. John Connolly and Cllr. Frank Fahy. It was a very happy and successful afternoon. We hope that the funds raised will support the fantastic work of ILFA."

Thomas Pender Memorial Run 2025

Rachel Pender and her family are holding a 5km and 10km fun run for all the family on Sunday 9th March 2025 in memory of her father, Tom Pender. The event will start at 10am from the Coral Leisure Centre, Arklow, and will raise funds for ILFA. All are welcome to take part. All finishers will receive a specially commissioned medal. Sign up at the address below to register to run, jog and walk on 9th March 2025.

See also <http://www.justrunsevents.ie/>



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 086 871 5264. ILFA will continue to host online Support Group Meetings for people living in areas where there are no support groups and for those who may not be able to travel. Keep an eye on the ILFA website, www.ilfa.ie, for details of upcoming online support group meetings.

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

ILFA would like to thank the support group leaders for their commitment. Stay safe everyone and keep in touch.



Irish Lung Fibrosis Association
www.ilfa.ie

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

- **ILFA's World Café** will take place in Dublin and online on Saturday 18th January. Please see www.ilfa.ie for more information on how to get involved.
 - The Irish Thoracic Society ILD Group and the Irish Lung Fibrosis Association will host an online **Education Day for Healthcare Professionals** on 7th February 2025. Professor Simon Walsh will deliver the Fergus Goodbody Lecture.
 - **Dublin City Marathon** takes place on Sunday 26th October 2025. Please fundraise for ILFA if you are taking part.
 - **The VHI Ladies Mini-marathon** takes place on Sunday 1st June 2025. Please fundraise for ILFA if you are taking part. Watch out for early bird tickets on www.vhiwomensminimarathon.ie
- Email info@ilfa.ie or call 086 871 5264 for a fundraising pack. We would love to have your support.

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 -

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



Email Correspondence

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