

ILFA Newsletter



Patrons: Michael Darragh Macauley and David Gilna.

Issue: Summer 2024

Volume 22 Issue 2 © ILFA 2024

Irish Lung Fibrosis Association
www.ilfa.ie

Welcome to ILFA's first CEO



The Irish Lung Fibrosis Association is delighted to welcome our first CEO, Maureen O'Donnell, to the role. Fittingly, Maureen started her new role on International Women's Day on 8th April 2024. The appointment of ILFA's first CEO represents a major milestone in the charity's growth and development and we're delighted to have Maureen as our new CEO. We look forward to an exciting future with Maureen at the helm. Please join us in welcoming Maureen O'Donnell, ILFA's CEO.

Chairman's message

Welcome to the summer ILFA newsletter. It's been a busy start to the year with lots of developments. Firstly, we are delighted to welcome Maureen O'Donnell as CEO. Over the last 2 years, the ILFA Board has worked strategically and efficiently to plan the transition from being completely volunteer led to having a CEO leading the charity. This exciting development will ensure that ILFA continues to grow and serve the lung fibrosis community.

ILFA is setting up sub-committees to further progress our work on Finance, Research, Governance, Fundraising and Advocacy. If you have skills and experience and would like to volunteer with ILFA, please contact us.

Thanks to all our fundraisers for their great support. Your efforts are making a great difference to ILFA's work. Thanks to the Board their commitment and support, to Gemma O'Dowd and Anne Griffin for all their work for ILFA, and a warm welcome to Maureen.

Eddie Cassidy

A Message from the CEO

It's been an exciting four months with ILFA! I've really enjoyed getting to know members of the lung fibrosis community. Everyone has been very generous with their time and advice, and it's been invaluable as I continue to come up to speed. Over the last few months, we've been very focused on advocating for the lung fibrosis community with the Irish Government and the HSE and I think we're starting to make some progress thanks to

the tireless efforts of our members and allies. We'll see the results of that progress if we can get funding in the 2025 budget for the priorities that we've outlined around oxygen provision, a patient registry, Clinical Care Pathway resourcing, and access to pulmonary rehabilitation. It would help a lot if, over the next month or so, you could contact your elected officials and remind them that our community needs their help. Our Political Ask document on page 10 of the newsletter has more details.

ILFA's new charity partner

The Irish Lung Fibrosis Association is delighted to announce that our charity was chosen as a charity partner with the Central Bank of Ireland. This two-year sponsorship is a wonderful honour, and we look forward to working with the Central Bank team over that time to help raise funds and awareness of lung fibrosis.

The Central Bank charity selection process begins with a nomination from an employee. The employee then works to secure votes from colleagues on

behalf of their charity. It's a lot of hard work and ILFA owes a massive debt of gratitude to the Central Bank employee who fought for us to be selected on behalf of his wife who died from lung fibrosis in 2023. It's so inspiring to see such an act of generosity arise from great loss. Pictured are Maureen O'Donnell (ILFA CEO), Sylvie Wieseler (volunteer) and Gemma O'Dowd (ILFA Administrator) who attended the Central Bank for the Charity Partnership announcement in May.

We have an exciting fundraising event coming up with the Central Bank on World Lung Day! If you're passing by South King Street in Dublin on the 25th of September from 12-3pm, be sure to say hello to the Central Bank relay team who will be "cycling" on behalf of ILFA. If you'd like to join the relay team or support the fundraising event in another capacity (we need coordinators, judges, musicians), please contact Gemma by emailing info@ilfa.ie or calling 086 871 5264.

The Human Tissue Act is signed into law

On 21st February 2024, the Human Tissue (Transplantation, Post-Mortem, Anatomical Examination and Public Display) Bill completed its passage through the Oireachtas, and it was subsequently signed into law by the President Michael D. Higgins, on 28th February. It is now referred to as the Human Tissue Act.

The Human Tissue Act allows for the introduction of an opt-out organ donation consent system in Ireland. This means that if someone dies in circumstances where organ donation may be possible, their next of kin will be asked for consent to proceed to organ donation unless the person has 'opted-out' and no approach to family members will be made. The Irish Lung Fibrosis Association has campaigned for an opt-out organ donation consent system since 2008 and welcomed the new law with great joy and hope.

ILFA has worked tirelessly with colleagues in other patient advocacy groups making up the Irish Donor Network to progress the law and campaign for better infrastructure, staffing, resources and investment in organ donation and transplantation services. We remember with great fondness the work of our former patron, the late Senator Feargal Quinn, who first introduced the call for a change in the law for an organ donation consent system in Seanad Eireann.

Given time, the new law has the potential to have a positive impact for the hundreds of people on the transplant waiting list. To achieve maximum success, there is still a need for investment and additional resources for organ donation and transplantation and an ongoing awareness campaign to inform people of the change in law.

Statement issued by the Irish Lung Fibrosis Association

The Irish Lung Fibrosis Association (ILFA) is delighted to welcome the passing of the Human Tissue Bill 2024 that incorporates an opt-out organ donation consent system.

The late Senator Feargal Quinn (former ILFA Patron) was the first politician to propose an opt out consent system for Ireland and together he and ILFA campaigned for this important legislation since 2008.

Today is a truly historic day for patients, families, healthcare professionals, patient organisations and the transplant community. Organ donation saves lives, and the new consent system will give hope to those in need of vital life-saving transplants.

Following this momentous landmark day, ILFA would like to thank all the Ministers for Health who have helped progress the legislation over the years; Mary Harney, James Reilly, Leo Varadkar, Simon Harris and Stephen Donnelly. Thank you to everyone at the Department of Health, Organ Donation and Transplant Ireland, the HSE, National Office of Clinical Audit and Dail Eireann, as well as our dear colleagues in the Irish Donor Network and patient organisations who have supported this legislation.

We encourage everyone to have a conversation with your loved ones to let them know your wishes on organ donation.

We remain forever grateful to organ donors and their families who have given the precious gift of life to those in need.

Organ Donation Awareness Week

Organ Donation Awareness Week took place from 20th-27th April. The theme for this year's awareness week was "Don't Leave Your Loved Ones in Doubt!" Eddie Cassidy (ILFA Chair), Maureen O'Donnell (ILFA CEO) and Gemma O'Dowd (ILFA Administrator) attended the launch event organised by the Irish Kidney Association.

The event featured many inspirational patient stories and highlighted the precious gift of life bestowed by organ donors and their families to those in need of life-saving transplants. In 2023, 265 transplants took place in Ireland including 24 lung transplants, thanks to generosity of organ donors and the skills and care of dedicated healthcare professionals.



Stephen Donnelly, Minister for Health, with representatives from patient organisations supporting organ donation.

The Minister for Health, Stephen Donnelly TD, spoke at the event and is pictured with representatives of the Patient Organisations that support organ donation and



ILFA Chairman Eddie Cassidy, Maureen O'Donnell, ILFA CEO and Gemma O'Dowd, ILFA Administrator.

transplantation.

ILFA encourages everyone to have a conversation with your loved ones and let them know your wishes on organ donation.

Patient Information Day

The Irish Lung Fibrosis Association (ILFA) is the national organisation for lung fibrosis patients. ILFA's aims are to further research, education, support, and advocacy for lung fibrosis patients, families and the healthcare professionals caring for them. As part of our commitment to education, ILFA holds 2 online Patient Information Days annually. We invite a panel of clinical experts to deliver a series of educational talks on lung fibrosis.

The first Patient Information Day of 2004 took place on Saturday 13th April at 11am. Eddie Cassidy, ILFA Chair, extended a warm welcome to all attendees and introduced Maureen O'Donnell, ILFA's new CEO, who facilitated the rest of the webinar. Dr Eoin Judge, Respiratory Consultant at Connolly Hospital, delivered the first presentation entitled "An overview of recent advances in the diagnosis and treatment of IPF".

Helen Mulryan, Advanced Nurse Practitioner at Galway University Hospital delivered a great presentation entitled "Every day is a learning day". Helen highlighted the role of the Advanced Nurse Practitioner in patient care and the importance of good communication. In addition, Helen discussed entitlements such as the Medical Card, the discretionary Medical Card, GP visit card, Fuel Allowance, and other supports. Helen encouraged everyone to apply and said, "Don't be afraid to apply and look for help!"

Sinead Coyle, Senior Physiotherapist at Connolly Hospital gave a great presentation entitled "How to Successfully Exercise with a Lung Condition". Sinead discussed breathing, the benefits of exercise, increasing activity, and advised us not to compare ourselves to others.

The next speaker was Kathleen O'Meara, Public Affairs Consultant provided clear advice on how to seek political help from your local public representatives and politicians especially with elections on the way. Kathleen urged everyone to let politicians know about the issues facing them and the Irish Lung Fibrosis Association as we continue to advocate for equal healthcare access for lung fibrosis patients.

Louisa Power, HSE Medication Safety Specialist Pharmacist, delivered a fantastic patient-centred presentation "Medication Safety". Louisa encouraged everyone to be familiar with their medicines, keep good records, report side effects, and ask questions of your doctor, nurse and pharmacist.

Professor Roisin Cahalan, Associate Professor Respiratory and Cardiovascular Physiotherapy, University of Limerick, for a great talk on the BUILD 2K "Buddy Walking Scheme." Roisin looks forward to recruiting patients to be part of this exercise research in collaboration with ILFA and funded by the Irish Research Council.

Professor Killian Hurley delivered a fascinating talk on "Results of Familial Pulmonary Fibrosis Research Studies" that his research team is conducting. If you are diagnosed with lung fibrosis and have at least 1 relative with lung fibrosis and would like you to take part in their research study, you can contact ILFA for more information.

The last speaker was Tom Murray, our patient speaker, who shared his heartwarming patient story at ILFA's Patient Information Day. Tom expressed his gratitude to all the healthcare professionals caring for him and gave a great

endorsement to ILFA's exercise class that he credits for helping him with his fitness.

Attendees were asked to give feedback via an online questionnaire and the results were very favourable

- ◆ 58.54% rated the event as excellent and 34.13% rated it as very good.
- ◆ 84% strongly agreed / agreed they would attend another event.
- ◆ 88% strongly agreed / agreed they would recommend the event to another patient.

We were delighted to receive kind feedback via Facebook after the event.

- ◆ "Enjoyed the webinar this morning. It was really well organised and informative. Well done to all involved. It made me realise that I need to engage more with ILFA especially around wellness and exercise. Thank you!"
- ◆ It really was a very informative, as always, webinar. Very grateful to have ILFA support and their classes are great."
- ◆ "So very Informative. Thank you all."

It takes a lot of preparation to deliver these events and we are grateful to everyone involved. Thanks to Gemma O'Dowd and Anne Griffen for the work behind the scenes, to all our wonderful speakers, to Justin Dawon for managing the technology and to our fundraisers who make educational events like this possible.



Let's Talk

The Irish Lung Fibrosis Association hosted a 'Let's Talk' session on keeping well and coping with pulmonary fibrosis with Dr Elizabeth O'Brien, Principal Specialist Psychologist, Respiratory Medicine, at the Mater Misericordiae University Hospital. Maureen O'Donnell of ILFA moderated. The recording of the 'Let's Talk' is available to watch on ILFA's YouTube Channel. Keep an eye out for future Let's Talk sessions on www.ilfa.ie and or social media channels.

Education

The Fergus Goodbody Memorial Lecture



Professor Kaminski

The Irish Lung Fibrosis Association was delighted to partner with the Irish Thoracic Society (ITS) for the virtual ITS Interstitial Lung Disease Study Day for healthcare professionals on 9th February 2024. During the event, the Fergus Goodbody Memorial Lecture took place. This educational lecture for healthcare professionals is held annually to honour the memory of the late Fergus Goodbody whose family and friends founded ILFA in 2002. ILFA invites a leading international expert to deliver a state-of-the-art lecture on pulmonary fibrosis. This year the renowned respiratory physician and scientist, Professor Naftali Kaminski, Yale School of Medicine, delivered the Fergus Goodbody Memorial Lecture.

Professor Naftali Kaminski's presentation was entitled "Genomic approaches to improve the diagnosis and treatment of Idiopathic Pulmonary Fibrosis". Professor Kaminski is a scientist-physician who has published over 340 research papers in some of the most prestigious and highly respected medical and scientific journals, as well as review articles and book chapters, and has given numerous invited talks at national and international conferences. There was great excitement in the lead up to the event and Professor Kaminski even tweeted "So excited and honoured! Can't wait!" to his 12.8 thousand followers. Professor Kaminski's gave a fantastic lecture detailing the latest in scientific and clinical approaches to diagnosing and treating lung fibrosis. His fascinating research, truly collaborative partnerships and wide network and his constant patient focus were inspiring.

Terence Moran Memorial Award

The Terence Moran Memorial Prize from the Irish Lung Fibrosis Association is awarded for the best case presentation by a Specialist Registrar in Respiratory Medicine at the Irish Thoracic Society Interstitial Lung Disease Study Day. Terence Moran was a gifted solicitor, a founding member of ILFA, and the ILFA Chairman for 15-years. Five Specialist Registrars were short-listed to give presentations at the Study Day and all described interesting cases that involved multi-disciplinary team input. The winner of the 2024 Terence Moran Memorial Award was Dr Aoife Carolan, Beaumont Hospital.



Dr Carolan was presented with the 2024 Terence Moran Memorial Award and an educational bursary by Professor Killian Hurley, ITS ILD Chair, Maureen O'Donnell, ILFA CEO and Eddie Cassidy, ILFA Chair. ITS ILD Chair. Sincere thanks to the ITS for supporting this educational initiative from ILFA Ireland.

EUPFF Summit



The 3rd European Pulmonary Fibrosis Patient Summit took place near Barcelona from April 26-28th 2024 and brought together representatives from the lung fibrosis patient community, researchers, clinicians, pharmaceutical companies and advocacy groups. ILFA awarded educational bursaries to two researchers, Carita Bramhill (Trinity College Dublin) and Emer Gunne (University College Dublin) and two patient advocates Sean O'Se and Robert Hurley to attend the conference. Matt Cullen (patient contributor) and Colin Edwards (ILFA Director) were invited speakers. ILFA was represented by Maureen O'Donnell (CEO) and Liam Galvin (ILFA director and EUPFF CEO).

Carita Bramhill was thrilled to receive the award for best clinician poster. Carita's poster was entitled "Embedding Patient and Public Involvement in a mixed methods study to explore the unmet needs of patients with Idiopathic Pulmonary Fibrosis". Matt Cullen gave a platform presentation at a session entitled "Supportive Care" and discussed his experience of being diagnosed with lung fibrosis, finding ILFA, attending a support group, the benefits of pulmonary rehabilitation that is tailored for lung fibrosis, and remote monitoring.

Research

Patient and Public Involvement Research Advisory Group

Did you know that ILFA has a Patient and Public Involvement Research Advisory Group as part of our commitment to Patient and Public Involvement (PPI) in research? The group is made up of patients, family members, healthcare professionals, scientists, and researchers and meets online a few times during the year. The group is often asked to continue their perspectives on all types of lung fibrosis research projects and grant applications and great discussions take place. New members are always welcome. No research experience is necessary. Patients and family members are asked to contribute to discussions on research projects by sharing their insights and perspectives on what is important to you as someone with lived experience of lung fibrosis. Please email info@ilfa.ie or call 086 871 5264 for more information.

RCSI PPI Knowledge Exchange Event



The Irish Lung Fibrosis Association was delighted to attend the Royal College of Surgeons in Ireland's PPI Knowledge Exchange Event on 20th March 2024 in Dublin. Representatives of ILFA's Patient and Public Involvement (PPI)

Research Advisory Group - Dr Chiara de Santi, Matt Cullen and Nicola Cassidy prepared a presentation about ILFA's Research Commitment and shared meaningful examples of PPI in action. It was a great event with powerful presentations from the speakers and a lovely opportunity to meet other PPI contributors from all research disciplines. Thank you to the organisers for inviting ILFA to share our patient engagement story. **Pictured are Dr Chiara De Santi (RCSI), Nicola Cassidy (ILFA Director), Dr Mari Ozaki (RCSI) and Anja Schweikert (RCSI).**

New and important publications in the medical literature

"A scoping review of the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis (IPF)"

Congratulations to Carita Bramhill (Trinity College Dublin), Donna Langan (Galway University Hospital), Helen Mulryan (Galway University Hospital), Professor Anne Marie Russell (University of Birmingham) and their colleagues on the publication of their research paper entitled "A scoping review of the unmet needs of patients diagnosed with idiopathic pulmonary fibrosis (IPF)". The ILFA Patient and Public Involvement (PPI) Research Advisory Group was acknowledged for their contributions to this research.

This valuable work states that "The literature highlights the continued lack of integrated clinical care programmes in many jurisdictions for the management of IPF, which can result in unstructured and fragmented care delivery for patients. This

study also highlights that patients living with a diagnosis of IPF experience a diverse scope of unmet needs across a broad range of areas and require a comprehensive multi-disciplinary approach to care, with equal access to services and tailored information to support them over the course of the disease."

"A roadmap to precision treatments for familial pulmonary fibrosis"

Congratulations to Professor Killian Hurley, Respiratory Consultant at Beaumont Hospital/RCSI, and his team including David Crosby (ILFA Ambassador) and his wife Katie, and ILFA Board Member Liam Galvin on the publication of their research paper entitled "A roadmap to precision treatments for familial pulmonary fibrosis". This important research paper was recently published in the *Lancet eBioMedicine*, one of the world's leading medical journals. The authors convened an expert working group to identify research gaps and areas for future development of preclinical models, candidate medications and innovative clinical trials in the context of familial lung fibrosis. They produced a valuable Position Paper that summarises the working group discussions, recommendations, and unresolved questions concerning precision treatments for familial lung fibrosis.

The authors thanked the European Lung Foundation, the European Idiopathic Pulmonary Fibrosis Foundation and the Irish Lung Fibrosis Association for their support and their invaluable patient perspective.

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 See livinglunglab.ie for more details.**

Awareness

The Late Late Show



On Friday 10th April, ILFA Patron and former GAA All Star and 8 time All Ireland Winner Michael Darragh Macauley and his sister Margaret, pictured above, were guests on *The Late Late Show*. Michael Darragh and Margaret spoke with Patrick Kielty and the nation about how lung fibrosis has affected their lives and the transformative impact of organ donation and transplantation.

Michael Darragh spoke about his dad who had lung fibrosis and although he was on the transplant waiting list, sadly he didn't get a lung transplant. More recently, Margaret was diagnosed with lung fibrosis and faced many health challenges. Margaret received a life-saving lung transplant thanks to the generosity of an organ donor. Michael Darragh encouraged everyone to discuss organ donation and asked people to put their wishes in their family What's App group. The touching interview received a lot of media attention and has raised valuable awareness of lung fibrosis and organ donation. The powerful and emotional interview is available to watch on YouTube in case you missed it. Thank you to Michael Darragh, Margaret and Patrick for such an impactful conversation that helped raise valuable awareness. Margaret shares her story in her won words below.

My Story

My name is Mags Sheridan, and I was diagnosed with pulmonary fibrosis in March 2020 - the day after the schools closed due to covid. Although my diagnosis came as a massive shock, I was familiar with the condition. My father has passed away from pulmonary fibrosis in 2012 - 7 years after his diagnosis. Being familiar with the condition perhaps made it more difficult as I was aware of what was in store for me in the years ahead! As I was diagnosed very early (I was asymptomatic at diagnosis), I was young (I was 41 years of

age) and I was relatively fit (kind of!!) I had hoped that the necessity for transplant would be a long way off!

Unfortunately, that did not turn out to be the case! I continued to gradually deteriorate over the course of three years at which point I was on oxygen and admitted for work up for a lung transplant. Over the course of the three years, I attended numerous yoga classes, meditation sessions and undertook the mindfulness-based stress reduction course. These are some of the positive things that I did to try and stop the deterioration in my breathing. I believe these all stood to me throughout my journey although they did not appear to halt my decline. It goes without saying that I continued my exercise regularly and massive credit must go to Exwell and to ILFA for providing the exercise classes – the ILFA classes were invaluable especially at a point in time when my oxygen requirements were very high and it was difficult to have sufficient oxygen to leave the house, do a class and return home. I was also involved in a trial at the National Institute of Health in the United States to try and address the root cause of my pulmonary fibrosis which although was effective did not stop the deterioration.

In March 2023, exactly three years after my diagnosis, I was put on the transplant list. I required several admissions to the Mater Hospital while on the list to optimise my health and the autumn of 2023, while I was an inpatient, I was first worked up for transplant but unfortunately the transplant did not go ahead for anyone. This is extremely difficult to hear – all you want to know / hear is that someone is going to be on the other side even if it is not you! However, just one week later, I was advised that I was being worked up again and this time I was going forward for transplant! It is a very surreal experience to be told the transplant is happening! It is the news you are waiting anxiously to hear but when it comes it is also a daunting prospect too.



I had a bit of a rocky road post-transplant and spent nearly three months in hospital which I had not envisaged. It was 6 weeks after my operation that I finally got to see and hug my kids again. An emotional reunion seeing them again out in the Dublin city fresh air! It was a gradual process coming off the oxygen which I had not been prepared for but just before Christmas I was given the all-clear to discontinue it! What a Christmas present for me and my family!!!

The transplant team kept telling me to be patient and patience is definitely required after the operation. It can take time to come off the oxygen, there are often complications



‘I had a bit of a rocky road post-transplant and spent nearly three months in hospital which I had not envisaged. It was 6 weeks after my operation that I finally got to see and hug my kids again. An emotional reunion’

– Mags Sheridan

and things do not continue to progress in a straight line. There are lots of ups and downs. Life does not go back to the way it was before the diagnosis. It is worth considering what your life might be like after the transplant as I don't think it is something I had considered sufficiently. It is a tough path at times on both sides, but I am continuing to improve and get stronger so much so that I recently undertook the mini-marathon with 26 amazing friends to raise awareness of ILFA and to gather some fundraising.

This was an unforgettable experience – not only undertaking the 10K eight months on from having the transplant but because of the support I have received from family and many friends throughout this journey. We also managed to raise nearly fifteen thousand euro, thanks to all our very generous supporters, for ILFA, which is incredible.

Having lived through my dad having fibrosis and having it myself, my little nuggets of advice are:

1. Stay positive – acknowledge the difficult days but try and

move on and hope that tomorrow is going to be better!

2. Keep up the exercise – anything you can do is better than nothing!

3. Seek referral to the lung transplant service in the Mater Hospital at an early stage. They are brilliant at what they do and know when to begin that assessment.

Good luck on your journey whatever stage you are at!
Mag's story featured in the Irish Sun in June 2024.

Raising Awareness in Wicklow

Rachael Pender was interviewed by Eoin Mac Raghnaill and her story was published in the Wicklow People and Irish Independent newspapers in June. Rachael is committed to raising awareness of lung fibrosis in memory of her father Tom who was well known in Avoca and Wicklow for his popular historical Facebook page. Rachael also set up a fundraiser for ILFA Ireland in memory of her father, Tom Pender.

Advocacy

Leinster House Visit



On 10th April 2024, ILFA representatives Maureen O'Donnell (ILFA CEO), Michael Darragh Macauley (ILFA Patron) and Nicola Cassidy (ILFA Director) visited Leinster House with Kathleen O'Meara (Public Affairs Advisor). The aim of the visit was to meet politicians to tell them about ILFA's advocacy work, and the problems faced by lung fibrosis patients. Maureen, Michael Darragh, and Nicola Cassidy met many politicians from all political parties and informed them of ILFA's call for a dedicated Clinical Care Programme to ensure lung fibrosis gets the attention it needs and that patients have equal access to healthcare services. It was a busy, energetic and positive advocacy day. We are grateful to the politicians who spoke to us and offered support particularly with our request to appear before the

Joint Oireachtas Health Committee. A selection of photos is included here.

Oireachtas Joint Committee on Health

On Wednesday 24th April, a delegation of speakers and supporters of the Irish Lung Fibrosis Association (ILFA) was invited to attend the Oireachtas Joint Committee on Health at Leinster House. This was an historic day as it was ILFA's first appearance at the Health Committee. It was an honour and a privilege to attend the hearing and to respectfully expose the reality of unmet healthcare needs of lung fibrosis patients.

Maureen O'Donnell (ILFA CEO) delivered a strong opening statement describing the healthcare needs of lung

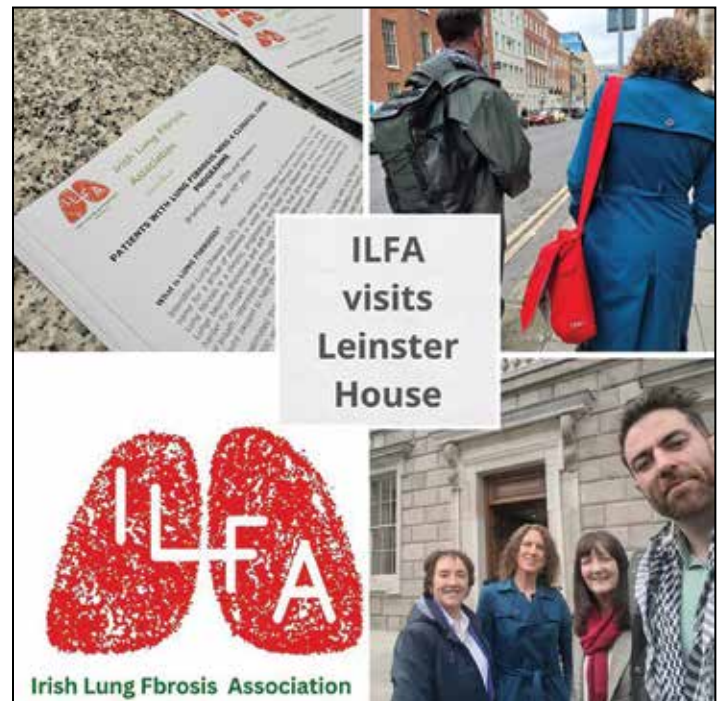


fibrosis patients and the urgent actions needed. Next Robert Hurley described his experience of being diagnosed with lung fibrosis, the daily challenges he faces, and how ILFA's exercise class has enabled him to maximise his health and wellbeing. ILFA's patron Michael Darragh Macauley spoke about how lung fibrosis has impacted on his family and how his knowledge of fitness helped his father and sister manage their lung fibrosis. The ILFA panel also consisted of Professor Killian Hurley from the Irish Thoracic Society, Olive McCafferty, Senior Respiratory Physiotherapist with the Heart and Lung Transplant Unit at the Mater University Hospital, and Nicola Cassidy (ILFA Board Member).

In the gallery observing the proceedings were Margaret Macauley, Lorcan McMahon, Lynn Fox, Advanced Respiratory Nurse Practitioner at the Mater University Hospital, and Gemma O'Dowd (ILFA Administrator).



After the powerful opening statements from ILFA, politicians from all parties were invited to ask questions. The ILFA team worked together and delivered impactful and factual answers to highlight the harsh reality that lung fibrosis patients are being excluded from pulmonary rehabilitation programmes in the community, and are not receiving the appropriate healthcare support and resources needed to optimise their health. The urgent need for a lung fibrosis registry, equal access to pulmonary rehabilitation, difficulties with oxygen supplies and the financial impact of having significant oxygen and electricity costs were highlighted, as well as the need for medical cards for patients irrespective of age. Ultimately ILFA is looking for a Clinical Care Programme for lung fibrosis but there are



also urgent issues of inequity that need to be addressed.

ILFA is grateful to the politicians for their interest, support and commitment to act. We are indebted to our wonderful speakers for taking time and consideration to prepare for the event and for delivering strong and compelling testimonies. Special thanks to Robert Hurley and Michael Darragh Macauley for sharing their inspiring personal stories and detailing their individual struggles.

The word "powerful" was used by many politicians, observers and commentators and we are proud that the ILFA team delivered a strong, robust, powerful and united presentation. ILFA's advocacy work continues, and we remain focused and committed to improving care for lung fibrosis patients and families.

Thank you to the Irish Examiner and The Medical Independent for raising awareness about the unmet needs of lung fibrosis patients.

ILFA'S POLITICAL ASK

IN THE LEAD UP TO THE GENERAL ELECTIONS, the Irish Lung Fibrosis Association (ILFA) is asking you to take action for patients with Interstitial Lung Disease (ILD). We'd like you to contact your national representatives and let them know the challenges you face. Many ILD patients don't receive adequate healthcare. ILFA, with the support of the Irish Thoracic Society, believes the standard of care must be improved. We recommend a series of targeted interventions that will lead to better health outcomes.

Background: The Irish Lung Fibrosis Association (ILFA) has been advocating on behalf of patients with lung fibrosis for more than 20 years. While support from the HSE for patients has improved, there is much more work yet to be done. We need your help to raise awareness with politicians who can put pressure on the HSE.

Recently ILFA testified before the Oireachtas Committee on Health with the following demands:

1. A tax rebate for patients on oxygen therapy to offset increased utility costs, and a streamlined oxygen reimbursement system.
2. State funding for ILFA to expand existing programmes and develop new programmes to support lung fibrosis patients.
3. Act on the HSE's 2023 promise to resource a Care Pathway – a critical step in establishing a dedicated ILD Clinical Care Programme.
4. Stop excluding patients from community pulmonary rehabilitation programmes. These programmes are currently available only to COPD and asthma patients.

Next Steps: ILFA continues to advance these priorities with Government. Following our testimony ILFA provided a brief to the Committee in advance of the HSE testimony on oxygen provision. We have also now secured a formal meeting with Stephen Donnelly, T.D., Minister for Health, in early September and have launched a pre-budget submission to request funding for the above priorities.

Help Us: While we continue to put political pressure on the HSE, our case is much stronger coming from patients and their families directly affected by lung fibrosis. You can help us by taking the following actions between now and General Election:

- ✓ **Contact your T.D. through their office.** <https://www.oireachtas.ie/en/members/>
- ✓ **Attend public meetings and speak with candidates when they canvas in your local area.**
- ✓ **Spread the word across your family, friends, and social networks.**

For more information on ILFA's campaign, contact Maureen O'Donnell, Chief Executive Officer of the Irish Lung Fibrosis Association Email: Maureen@ilfa.ie Mobile: 085 707 4899

Irish Lung Fibrosis Association.

Company Registration Number 367940. Registered Charity Number 20053437, Charitable Exemption Number CHY 15462. ILFA is registered with the Register of Lobbying, maintained by the Standards in Public Office Commission

Exercise

ILFA's Online Exercise Classes



ILFA's online exercise classes take place on Monday, Wednesday and Thursday each week. The classes are delivered via Zoom by Eimear Bell, respiratory physiotherapist, and are free of charge to ILFA members. New members are always welcome. Register by emailing info@ilfa.ie or calling

086 871 5264. We look forward to seeing you there!

Here is some recent feedback from exercise class participants:

"Brilliant class, you can do at your own pace. Eimear is a great teacher. I enjoy attending and feel energised after class."

"I think it's the best part of my week. I really enjoy each class. Eimear is a wonderful teacher."

"I participate in the classes on Wednesdays and Thursdays, and I really enjoy them. Last week I attended my hospital's respiratory department for my regular check-up. The medical team was very impressed with my Pulmonary Function scores. These scores were significantly higher than the previous 2 tests. I attribute this to the breathing techniques we practice in the classes. The medical team agreed with me. So - thank you to Eimear and all involved in the classes."

"I really enjoyed the exercise class this morning. Eimear was excellent and I surprised myself that I could do most of the exercises and last for the hour. Looking forward to the next one. Thanks for all the work you all do at ILFA."

Grant Success with Age and Opportunity



The Irish Lung Fibrosis Association is delighted to have been awarded a grant from Age & Opportunity and Sports Ireland under the Age & Opportunity Active National Grant Scheme for Sport and Physical Activity for Older People.

We are very grateful for this very welcome news. The grant will be used to purchase medical grade therabands to encourage patients with lung fibrosis to engage in strength and conditioning exercises.

BUILD 2K - We're up and walking!

"Buddy walking in patients with Interstitial Lung Disease (BUILD)" is the new programme developed by ILFA and researchers at the University of Limerick. This ambitious project funded by the Irish Research Council, has recruited the first group of willing volunteers who have now been paired with their buddies and are on the move.

It is broadly accepted that physical activity including walking is a fantastic way of keeping healthy for all of us, including people with ILD. However, we also know that it can be hard to motivate ourselves to do the work.



The premise of the BUILD 2K project is that, by pairing with someone else with ILD, or a family member who understands the condition, we can act as motivators to each other to get out and walk a little more. It's like that friend who you can't refuse when they knock on the door to go for a walk.

The current stage of the project involves 16 volunteers with ILD. In most cases, these participants have been paired with people who have a similar physical capacity – so people who can walk roughly the same distance.

Most pairs are online buddies, communicating by WhatsApp, with a few in-person pairs also. We also have one pair involving a person with ILD and a family member, and even a trio of fantastic ladies with ILD who are online buddies.

The volunteers are nearly halfway through a 10-week process to explore the benefits or otherwise of walking with a buddy.

They are recording their activity every day and we look forward to hearing their feedback at the end of the project. There will be a new recruitment phase at the end of the Summer for more participants, so if you are interested contact roisin.cahalan@ul.ie or ILFA for more details.

Report from Associate Prof Roisin Cahalan, Respiratory and Cardiovascular Physiotherapy, University of Limerick.

VHI Women's Mini Marathon 2024

Thank you to all our amazing fundraisers who took part in the VHI Women's Mini Marathon on Sunday 2nd June 2024. This year's Team ILFA consisted of special individuals, family, friends and supporters all committed to making a difference for lung fibrosis patients. It was great to see so many ladies proudly wearing their ILFA T-shirts.

The weather was beautiful with warm sunshine, blue skies, and a gentle breeze. The air was filled with excitement and anticipation as the claxon got the start underway at 12.30pm. One hour later there was still a sea of ladies waiting to cross the start line! The ILFA cheerleaders at the start of the 10km were Michael Darragh Macauley (ILFA Patron), Nicola Cassidy (ILFA Director) and Annette Grehan (loyal ILFA supporter). The trio shouted encouragement whenever an ILFA lady passed by.

Mags Macauley had a team of 27 fantastic friends taking part to celebrate her return to good health after a double lung transplant. Mags was cheered on by her brother Michael Darragh, and by her cousin Ken, and her husband John and children who were waiting at Donnybrook. Her family wore special t-shirts with words of encouragement.

After the event, Team ILFA met up at the Harcourt Hotel and each group that arrived at the venue was greeted with a big cheer. The biggest welcome roar and a standing ovation were given to Mags on her arrival after completing the iconic 10km challenge. The support and admiration for Mags was phenomenal!

Well done and sincere thanks to our amazing fundraisers. Please know that your efforts are making a real difference to ILFA's work and our commitment to helping those affected by lung fibrosis. Mile buiochas!



Team ILFA consisted of ladies taking part for the first-time including Sarah (our youngest participant) and some who took in previous years (thank you everyone for your loyalty!). Lynn Daly Whelan from Athy ran the course carrying a full oxygen cylinder on her back in support of her partner Eddie

and we admire her strength and determination. Niamh, Ellie and Sadhbh took part in memory of Sadhbh's mam Catriona McLoughlin and her relatives. Lauren O'Keeffe took part to raise funds for the Irish Lung Fibrosis Association in memory of her nanny.



Some personal stories from the mini-marathon fundraisers are included here.

Lynn's extra challenge



"Hi, my name is Lynn Whelan. I am a part-time carer to my husband Eddie, who has idiopathic pulmonary fibrosis. His diagnosis was confirmed the year pre-COVID. At this time, life was very normal, and he had a slight cough. However, on the June bank holiday two years ago, his illness progressed rapidly during a stage of rapid worsening with pneumonia. He came home after 6 weeks in hospital, on 20

litres of oxygen during the day and 10 litres at night. This meant huge changes in his life and that of our daughter (18 now). He was told to expect the worst. However, now two years on, he is on zero oxygen at resting and between 6L and 8L on exertion.

I had never heard of ILFA, if I'm being honest. I found them on social media and joined that September. Eddie at this time was slowly improving. I had seen ILFA's online exercise classes and Eddie started them the following year - he is really enjoying them. It really boosted him knowing that the classes were on, and he was doing whatever possible to help his slow recovery. We have both attended the ILFA Patient Information Day webinars, and they are so informative.

This year I decided to run the VHI women's mini marathon to help fundraise for this fantastic organisation. I decided I would dress-up to add to my fundraiser. Brainwave! ... if a fireman can run in his or her work suit with oxygen, sure I could do same. I decided to carry Eddie's full oxygen canister on my back. This wasn't easy, as it's awkwardly heavy and when you bounce, it moves too. I strapped it on the best way I could to reduce as the bounce as much as possible. In training, I went from 2km to 7km over 4-weeks.

On the day of the mini-marathon, I got the train to Dublin. I had received a beautiful thank you card from ILFA for taking

part in the fundraising event. Little did I know there was more to come. I was invited to pre-photos in town and to refreshments afterwards in the Harcourt Hotel. The day of the mini marathon was so hot. I got myself strapped up with the oxygen tank and started running. Imagine my delight at the 8km mark to meet another ILFA runner amongst 25,000 ladies. I even asked (Sarah) for a selfie. When I finished the 10km, I made my way to the Harcourt Hotel, and I was blown away. Out in the beautiful Garden Room, I was greeted by Gemma and her husband. Then I got talking to Nicola. More and more ILFA ladies kept arriving and wow - the huge welcome for Mags Macauley who recently had a lung transplant brought a tear to my eye. Thank you, ILFA for making the day extra special. It will be my yearly tradition now."

My First 10K



"It was a day I will never forget. As I (Carita Bramhill) lined out in glorious sunshine at the start of the VHI mini marathon in Dublin in early June, all my nerves disappeared. My two friends, Emma and Sinead, and I, had trained hard for

the event - my first attempt as a novice runner at completing 10km. Such was the sense of camaraderie and goodwill that any apprehension I had harboured about completing the challenging course through the Irish capital quickly vanished. Proudly sporting our new ILFA T-shirts, we had raised €1,465 through our fundraising efforts, whilst increasing awareness of pulmonary fibrosis along the way. But the still daunting challenge of completing my first mini marathon remained. I needn't have worried. Buoyed by the cheers and encouragement of so many at ILFA - not least the patients and carers who lined the route - it was impossible not to feel humbled to be part of such an inspirational event. I'm already counting down the days to next year's mini marathon!"

Easter Monday 2000 Steps Extra Challenge

The ILFA 2000 Steps Extra Challenge took place on Easter Monday, 1st April 2024. We asked our members to lace up, wrap up, and head outdoors for a walk. The aim was to walk an extra mile (approximately 2000 steps more) to help raise awareness of lung fibrosis. The weather can be unpredictable at this time of year, so we encouraged everyone to remember the advice “Remember there is no such thing as bad weather, only bad clothing”. Thankfully the day was a good one and there are lots of smiling photos from people all over Ireland and abroad! Thank you to everyone who took part and helped raise awareness and funds for ILFA. We enjoyed hearing how you got on and looking at your photos. A selection is included here.



Thanks to David Gilna, award-winning screenwriter, actor, poet, performer and ILFA Patron, for his great support for ILFA and for taking 2000 Steps Extra on Easter Monday. in sunny New York.



Freya Healy and her cousins Sadie, Milie-Mae and Dan Collins in Kerry enjoyed their Easter Monday 2000 Steps

challenge and took part from their home county of Kerry. Well done everyone and thank you for your amazing support!



Birgit Kretschmann donned her ILFA t-shirt and snood and ran 2000 Steps Extra at St Annes' Park in Dublin to support ILFA. Thank you, Birgit, for your great efforts and kind support.



Angela Shafer took part in the ILFA 2000 Step Challenge on Easter Monday to help raise awareness of lung fibrosis and fundraise for ILFA. We are so grateful to Angela for her kind support.



Billy Barry and his family took part in the ILFA 2000 steps extra challenge in Youghal on Easter Monday. They said, “We are delighted to raise

awareness for ILFA and all the support you offer to patients.”



Anne Griffin took part in the ILFA 2000 Steps Challenge along the new Midleton Greenway today under beautiful blue skies and sunshine. Well done and thank you for your great support Anne!



mile!

Gemma O'Dowd and James Kavanagh took part in the ILFA 2000 Steps Extra Challenge in Wicklow. Gemma and James are always so supportive and always go the extra



Mary O'Sullivan and her family took part in the ILFA 2000 Steps Extra Challenge. Mary said, “I’m attaching some photos of my family raising awareness for ILFA and the wonderful

support provided by you for patients with respiratory ailments”.



Breda Coughlan and her family supported ILFA's 2000 steps Extra Challenge on Easter Monday from sunny Cobh. What a lovely, happy photo. Well done

to all of you and thank you for your kind support!



Pam Martin from Dublin took part in the ILFA 2000 Steps Extra Challenge while on her holidays under blue skies and 27-degree heat! Thank you for your wonderful support, Pam!



Congratulations and warmest thanks to Mary O'Dowd, who took part in the ILFA 2000 Steps Extra Challenge making her contribution from Fatima Nursing Home in Tralee. What a superstar! Thank you, Mary, for your support!



Well done to Matt Cullen who took part in the ILFA 2000 Steps Extra Challenge earlier today. Matt said “I have just completed the 2000 Steps Challenge. It was from Malahide to Portmarnock and back to Malahide, which is approximately 8k”.

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.

West Kerry Tractor Run

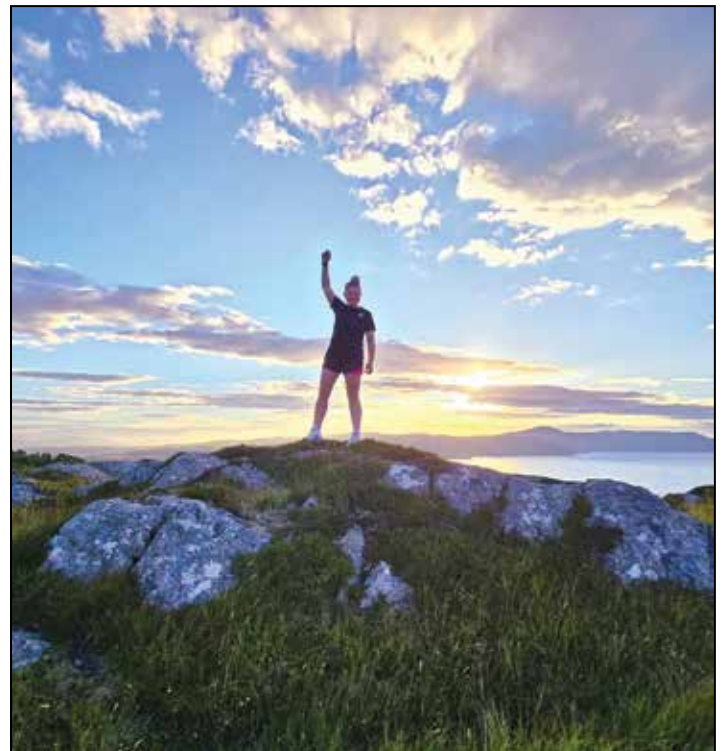


In July, Maureen O'Donnell (ILFA CEO) travelled to Dingle to meet with the organisers of 5th West Kerry Tractor Run for a cheque presentation. The tractor run took place on Sunday 26th November 2023 and the proceeds raised were kindly shared between ILFA Ireland and the Palliative Care Unit at Kerry University Hospital. Pictured are Michael O'Sullivan, Jackie Kavanagh, Mareen O'Donnell, JP O'Sullivan, and Annette Cremin. Huge thanks to JP O'Sullivan, his family, the fundraising team, the owners of the Marina Inn, the local community and the tractor owners for their enthusiasm, generosity and amazing fundraising. Thanks also to Declan Malone, Kerryman Newspaper, for this great photo! Go raibh mile maith agaibh!

Michelle Duffy's 300km Walk



Michelle Duffy from Donegal took on an ambitious walking challenge in June to raise funds for ILFA, in memory of her dad Charlie. Michelle planned to walk 300km over 30 days, but she reached her target distance before the month's end and decided to continue and set a new target. Michelle completed an impressive 350km distance in June and has raised over €2,600 with amazing support from family and friends. She is extremely grateful to everyone who supported her and donated to her fundraiser.



Michelle has sent us some words of thanks and a fabulous photo of her taken at Culdaff, County Donegal where she lives. Michelle said "It is my favourite spot because I feel closer to heaven."

Sincere thanks and congratulations to Michelle on her amazing fundraising.

That's Gas

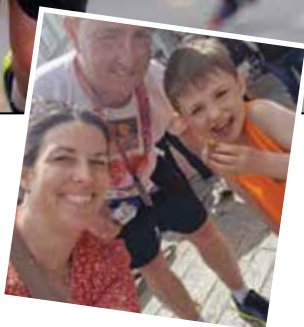
Matt Cullen (artist, volunteer extraordinaire and leader of the Dublin Pulmonary Fibrosis Support Group) from Dublin recently sold a painting at the Dunlavin Arts Festival and donated 50% of the proceeds to ILFA. The beautiful painting is called "That's Gas!" and is based on the iconic photograph of the gas lamplighters who worked on Chesterfield Avenue, in the Phoenix Park in Dublin. There is a great tradition carried on by the Flanagan family to still light the gas lamps which goes back many years. Well done and thank you Matt for sharing your wonderful talent with ILFA.



Cork Half Marathon



Congratulations to Joe Browne who ran the Cork half-marathon on Sunday 2nd June in memory of his father who had pulmonary fibrosis and passed away in February. Joe committed to 14 weeks of training to run in honour of his dad and raise funds for ILFA. Joe's t-shirt pictured a photo of him with his dad. Joe said he was inspired by kind words of encouragement from family and friends, and this helped him when running in the blistering heat. Joe was joined in the final stages of the half-marathon by his son, Sé. Afterwards Joe celebrated with Sé and his wife Maeave. Joe said, "What a great sense of achievement to finish my first half marathon, in dad's memory, and for a great charity." Joe raised over €4,000 for ILFA. Sincere thanks to Joe and all his supporters.



Coffee morning in aid of ILFA



Huge thanks to James McAuliffe from Banteer, Cork, for organising a coffee morning for ILFA Ireland in memory of his

dad, Donal. James raised the fantastic sum of €1,905 for ILFA. We are enormously grateful to James, his family and friends for their generosity. Mile buiochas!

Backyard Ultra Marathon

Kevin Mullaney, Sean Parry, and David Reynolds took part in a couch to ultra-marathon in Glencullen, Dublin Mountains, to raise funds for ILFA in memory of Liam Mullaney. Ahead of the event they said "We are attempting to run 50+ kilometres in the Dublin Mountains as part of the Dublin Mountains Running Clubs Backyard Ultra event. We are not runners by any stretch of the imagination but have been training since September 2023 aiming to go from the couch to 50+ kilometres in a day."

On 11th May 2024, the determined trio took part in the 50km running challenge with a total elevation of 6,453 metres. They worked hard and the day was especially meaningful as they remembered Kevin's dad, Liam Mullaney, on his birthday. They were cheered on by family and friends. Kevin said "We managed to get over the 50km distance - granted a little worse for wear! Our fundraising total was €2,055 thanks to many kind donations from our friends and family."

Congratulations to Kevin, Sean, and David. What an incredible achievement on one of the warmest days of 2024!





Walking the Camino

Mairead, Noirin, Antoine, Diarmuid and Roisin Hennigan from Cork walked part of the Camino de Santiago in memory of their loved one Dermot. The group completed the 100km Portuguese Camino from Tui to Santiago de Compostela on 10th May and raised funds for ILFA. The family have an online fundraising page available for donations. We are enormously grateful to for their wonderful support. The family have raised an incredible amount for ILFA in memory of Dermot and we are so grateful to them and to everyone who has supported them.

Eibhlin Mulhall also walked the final 100km section of the Camino Portugues, from Tui to Santiago and fundraised for ILFA in May in memory of her grandfather. Eibhlin got off to a great start covering more distance on day 1 than planned and was delighted with her progress. Thanks to Eibhlin for all her support!



Second Chance Pop-up Shop



Maureen O'Donnell, ILFA CEO and Gemma O'Dowd, ILFA Administrator, were delighted to meet Mary Lawlor, Joanna Redmond and Brigid Nolan for a cheque presentation on Thursday 9th May. The ladies set up a pop-up shop called "Second Chance" and fundraised for ILFA in memory of Dermot Lawlor. Thank you to everyone who supported this venture and kindly donated items for sale, purchased items and donated. Their amazing fundraising total was €7,224. ILFA is very grateful for this generous donation that will help our work supporting lung fibrosis patients.

Wexford Half Marathon



Congratulations to Gary Meyler who ran the Wexford half marathon in April to raise funds for ILFA in memory of his dad, Marty. Gary is pictured with his mam Sandra Meyler, and with his mam's friends Kathleen, Cathy and Caroline before the run. Gary raised a fantastic sum for ILFA and said he was "really overwhelmed by the response to the fundraiser" and he is grateful to his family, friends and local neighbours and the community in Wexford who donated so generously and helped his fundraising target reach a phenomenal €3,340. Sincere thanks to Gary and all his supporters.

Marathon Des Sables



Jason Nichol took on an incredible challenge to raise funds for ILFA. He contacted us earlier this year and said "On 14th April 2024, I'm taking on the infamous Marathon Des Sables to raise money and awareness for ILFA, a charity close to my heart. The Marathon Des Sables is billed as the 'toughest foot race on earth'. Competitors must take on six marathons in six days across the scorching Sahara Desert, covering over 250km, in temperatures of up to 50 degrees Celsius. The rules require you to be self-sufficient, to carry with you on your back everything except water that you need to survive for the 6 days."

We were in awe of this epic and gruelling challenge that is a real test of fitness, determination and resilience! For 6 days we were on tenterhooks waiting for updates on Jason's progress. We posted support messages each day on Facebook to let Jason and his family know that we were cheering him on and were thrilled to hear back that Jason was well and making good progress.

We were over the moon to hear that Jason had finished – he ran an incredible 252km, equivalent to 6 marathons in 6 days, in soaring temperatures while running on sand. Jason was the 29th finisher out of an 800 plus field of runners and the first Irish man home. What an awesome and incredible achievement for our "superman". Huge thanks to Jason and his supporters for their incredible fundraising. Mile buiochas!

Birthday Fundraising



"Happy Birthday" and warmest thanks to Fr Brian McKay, ILFA Chaplain. Fr Brian who setup an online birthday fundraiser for ILFA and raised over €1,00 thanks to the generosity of his friends. Sincere thanks to everyone who donated.

Upcoming Events

Let's Talk Webinars

ILFA will host a series of 'Let's Talk' webinars with healthcare professionals over the coming weeks and months. The next event will take place online on 14th August at 3pm and is called 'Let's Talk - Oxygen Use and Cough Management'. Thanks to Lindsay Browne, Respiratory Advanced Nurse Practitioner, St. Vincent's University Hospital for delivering this educational event. Please check the website www.ilfa.ie for upcoming webinars and activities on the News and Events page.

Patient Information Day

The next online ILFA Patient Information Day will take place in November. More details on the topics and speakers will be announced nearer to the time. Please check the website www.ilfa.ie for updates and information on how to register.

ILFA Ecumenical Service of Prayer and Reflection



The ILFA Ecumenical Service of Prayer and Reflection will take place on Saturday 5th October at Our Lady of Mount Carmel, Whitefriar Street Church, Aungier Street,

Dublin 2 at 4pm. If you would like to help with a reading or have suggestions for a special poem or prayer, please get in touch. We would also be grateful to have some volunteers to help with the event on the day.

If you would like a family member remembered during the candle lighting ceremony, please email their name to info@ilfa.ie. We look forward to welcoming you to Whitefriar Street Church in October.

Fundraising Cycle with the Central Bank

A stationary relay cycle competition will take place on World Lung Day on Wednesday 25th September. Come and join the fun on South King Street in Dublin from 12-3pm and cheer on the Central Bank relay team who will be "cycling" on behalf of ILFA. If you'd like to join the relay team or support the fundraising event in another capacity (we need coordinators, judges, musicians), please contact Gemma by emailing info@ilfa.ie or calling 086 871 5264.

Are you interested in volunteering with ILFA?

ILFA Sub-committees

ILFA is setting up a series of sub-committees to further progress our work on Finance, Research, Governance, Fundraising and Advocacy. We would be very grateful to hear from people who would be interested in taking part. The sub-committees will be chaired by an existing board member and membership will be a mix of board members, the CEO, and non-board members. If you have skills and experience and would like to volunteer with ILFA, please contact us.

Marketing and Communications Projects

ILFA would love to hear from suitably qualified people with marketing and communications experience who would be willing to volunteer their time and talents either on an ongoing basis or for specific projects with our charity.

Also, if you have any connections with a Technical University or College whose students may be looking for a short-term placement or creative design project, please get in touch. Email info@ilfa.ie or call 086 871 5264

Thank You!

ILFA would like to express our warmest thanks to Sylvie Wieseler, a postgraduate communications student from Arizona, USA who volunteered with ILFA for 6-weeks. During that time, Sylvie supported several key projects while on placement from CIEE, a non-profit organisation promoting international education and exchange in Dublin City University. We are deeply grateful for all her hard work.

Thank you to all our Facebook and Instagram friends and followers for your wonderful engagement in recent times. We are grateful for the "likes", "shares" and "comments" on posts. All these interactions help strengthen our community, give great encouragement to our amazing fundraisers, and help raise awareness of lung fibrosis. Mile buiochas!

Rest in Peace Charlie Bird

The Irish Lung Fibrosis Association was saddened to learn that Charlie Bird passed away. Charlie was an early patron of our charity and attended several Patient Information Days and fundraising events over the years and he even took to chilly waters on Christmas Day to swim

in aid of ILFA. We wish to extend our deepest condolences to Charlie's wife Claire, his daughters Orla and Nessa, his wider family, and his friends. May Charlie rest in peace.



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 or Pam on 086 178 9055 for more information.

Kerry Support Group

meets on the last Saturday of the month at the Meadowlands Hotel, Tralee at 3pm. Please call John on 087 280 9801 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.

ILFA would like to thank the support group leaders for their commitment. Stay safe everyone and keep in touch. Please contact ILFA if you need help to join our virtual events.

Dates For Your Diary

- **ILFA 'Let's Talk' Webinar Series** – check the website and ILFA social media channels for updates on the next webinar.
- **ILFA's Patient Information Day** will take place online in November. See the website for more information closer to the time.
- **Central Bank Relay Stationary Cycle** on 25th September in Dublin. Please get in touch if you'd like to be part of a team or help on the day.
- **Echo Women's mini-marathon** takes place on Sunday 22nd September 2024.
- **Dublin City Marathon** takes place on Sunday 27th October 2024. General entries are sold out but charity entries are still available. If you would like to take part, please contact ILFA. 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 - www.facebook.com/ILFAIreland on Twitter - [@ilfaireland](https://twitter.com/ilfaireland)

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



Email Correspondence

If you are registered with ILFA and have an email address, we would be grateful if you would send it to ILFA (email info@ilfa.ie) so we can update our records. If you are happy to be contacted via your email address, ILFA can communicate with you more easily if we have upcoming events or important news to share. Rest assured your contact details are stored securely and not shared with other parties as required under GDPR.