

ILFA Newsletter



Patrons: Michael Darragh Macauley, David Gilna, Charlie Bird, Andrea Corr.

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Irish Lung Fibrosis Association
www.ilfa.ie

ILFA wins at the Irish Healthcare Awards 2023



The Irish Healthcare Awards are Ireland's most prestigious medical awards. The 2023 event was the 22nd year of the awards that recognise and celebrate the impressive projects in innovation and excellence across the Irish healthcare sector. The Irish Lung Fibrosis Association was delighted to receive news that our project entitled "Dancing for health and wellbeing: A feasibility study to examine the health impacts of dancing for lung fibrosis patients" was short-listed.

The ceremony took place in Dublin on the 5th December and was compered by Anton Savage. The gala dinner was attended by Dr Vikram Niranjana who led the project, Matt Cullen (lung fibrosis patient, dance class participant and one of the patient co-authors on the research papers), and Gemma O'Dowd and Nicola Cassidy from ILFA.

The ILFA team was thrilled when our name was called out as the winner of the Irish Healthcare Award 2023 for Patient Organisation Group of the Year. There were great cheers and celebrations and disbelief too as the 4 representatives made their way to the stage to be presented with a beautiful crystal trophy.

The Dancing for Pulmonary Fibrosis project aimed to

evaluate a structured online dancing programme's physical and mental health benefits for patients living with lung fibrosis and assess the feasibility of a dance intervention.

Huge thanks to all the team involved with this project - Dr Vikram Niranjana (project lead), Tracey Barnes (choreographer), research team members - Giampiero Tarantino, Jaspal Kumar, Dr Raymond O'Connor, Dr Andrew O'Regan, ILFA's patient collaborators - Finola O'Neill and Matt Cullen, and the ILFA team - Liam Galvin, Gemma O'Dowd, and Nicola Cassidy who helped develop the project. This hugely valuable, successful, and fun initiative was funded with a grant from the Irish Research Council. Sincere thanks to all the patients who participated and provided valuable feedback for the study. The 2023 Irish Healthcare Award is a much appreciated and fitting tribute to celebrate this important and successful research collaboration!

Thank you to everyone who left messages of congratulations on ILFA's social media platforms. We were touched by the kind words of patients and family members who benefitted from ILFA's exercise projects and ongoing support.

Chairman's message

Warm wishes to all ILFA's members for a happy, healthy, and peaceful new year. Thank you for your great support in 2023. The Irish Lung Fibrosis Association (ILFA) relies on donations and fundraising to support our work and deliver our aims of providing 'Education, Research and Support' for Lung Fibrosis. Our fundraisers are amazing, and you can read more about

their heroic efforts in this newsletter.

ILFA also fulfils an essential role in advocating for lung fibrosis patients and members of the Board met with HSE representatives and politicians throughout 2023 to advance our call for a dedicated HSE Clinical Care Programme for Lung Fibrosis. We continue to seek political help to ensure that lung fibrosis patients have equal access to healthcare supports, highlight difficulties for lung fibrosis patients

accessing pulmonary rehabilitation, and the high costs associated with oxygen. Thank you to all our members who reached out to their politicians for support with this issue. Our advocacy work will continue in 2024 and is more important than ever with a local, national, and European elections approaching. We will keep you posted with developments. Take care and best wishes for a healthy 2024.

Eddie Cassidy

ILFA Ecumenical Service of Prayer and Reflection



The ILFA Ecumenical Service of Prayer and Reflection took place on 12th October 2023 at St Ann's Church, Dawson Street, Dublin. The service was very touching with wonderful readings, prayers, music and singing and a real sense of community. Sincere thanks to the members of the Culwick Choral Society, David Leigh, and Dr David O'Shea for providing wonderful, breathtaking music and song. Thank you to our readers, candle lighters, and volunteers who participated and made this a very special occasion. Tom O'Sullivan composed and read his own personal tribute to ILFA, and we were very touched and humbled by Tom's kind words and reflections.

Over 130 people attended the service with people travelling from as far away as Cork and Kerry. Unfortunately, we faced some last-minute challenges as 3 of the Clergy were taken ill unexpectedly. Sadly, Fr Brian McKay and Fr Paul Arbuthnot had to cancel their participation. Thankfully Canon Charles Mullen was able to muster enough strength to lead the service and deliver a great sermon. Unfortunately, the live-stream facility was not possible and we're sorry that people

were not able to join online. We are enormously grateful to Canon Charles Mullen and the staff at St Ann's for their warm welcome and kind hospitality.

It was great to see so many people enjoying the social gathering afterwards where lots of old friends reunited and new friendships made. We would like to extend a special thank you to the three generations of the Mullaney family (pictured above) led by Philo who helped serve tea and coffee to guests after the service. They were amazing – working in harmony and making sure that everyone was well looked after.

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. It is a very special event in the calendar, and we look forward to welcoming you to the Service in 2024.

A tribute to ILFA - Composed by Tom O' Sullivan

O Lord, we give thanks for the inspiration and vision that you gave to those in 2002 who founded the Irish Lung Fibrosis Association to provide support, education, and guidance to those suffering from the progressive, debilitating, and terminal condition.

Since its foundation, ILFA has raised the awareness of the needs and difficulties of those diagnosed with lung fibrosis diseases by publicising the nature of the diseases and by promoting research. The aims were, and are, to assist in providing those, and their carers and families, with support to improve their quality of life.

ILFA seeks to focus on positivity and health promotion thus encouraging patients to embrace

the things that they can do to optimise their health, wellbeing, and quality of life.

In addition to promoting research, a significant tool in ILFA'S armour, is the arranging of regular Support Group Meetings. During these meetings information is disseminated on developments that may be of benefit. An equally important feature of these meetings is the exchange and sharing of ideas of the participants and the many friendships that develop.

Again, Lord, we give thanks for the inspiration, vision and for the courage and determination of those who put into being ILFA in order to promote the aims that they envisaged.

The Denise Cassidy Memorial Prize 2024

Who is your healthcare hero? Would you like to nominate them for a special recognition award?

The Irish Lung Fibrosis Association (ILFA) is excited to announce the 2024 Denise Cassidy Memorial Prize for excellence in healthcare. This award recognises and celebrates the kindness, compassion, and humanity of a hospital healthcare worker to a lung fibrosis patient or their family. Patients and carers are invited to nominate a person who showed you or your loved one a special act of kindness that helped you cope with your illness better.

Please fill out the nomination form that is on the ILFA website (www.ilfa.ie, News and Events section) or available from ILFA by calling 086 871 5264 or emailing info@ilfa.ie. Tell us why your healthcare hero deserves to be honoured. You can nominate a doctor, nurse, physiotherapist, social worker, counsellor, dietician, pharmacist, healthcare assistant, member of the chaplaincy team, clerical worker, catering or cleaning staff - in fact anyone who works in healthcare. The more information you can provide, the better as this helps us make the important decision regarding the overall winner. Everyone who is nominated will receive a certificate of excellence and the winner will receive a special commemorative Dublin crystal award.

The award is named in honour of Denise Cassidy who was diagnosed Idiopathic Pulmonary Fibrosis at the age of 56 and passed away 3 years later. During her illness, Denise met many kind, caring, and dedicated healthcare staff and other lung fibrosis patients who helped and supported her enormously. Denise's husband Eddie is Chairman of ILFA,

and her daughter Nicola is an ILFA Director. Both have served on the ILFA Board since 2007. Denise's family are loyal fundraisers for ILFA and are honoured to have this special award dedicated to her memory.

Previous winners of the Denise Cassidy Memorial Prize are;

- **Katie Barry**, staff nurse from Cork University Hospital, was awarded the inaugural prize in 2015 and was nominated by Vicki Jolly for the exceptional care of her late father.

- **Olivia Mulvaney**, staff nurse from Cavan General Hospital was awarded the 2017 prize and was nominated by Bridget McEneaney for the outstanding care of her late husband, Dessie McEneaney.

- **Nelson Gallarin**, staff nurse at the Mater Misericordiae University Hospital was awarded the Denise Cassidy Memorial Prize for Excellence in Patient Care in 2019 and was nominated by Peter Gallagher for his exceptional kindness and compassion while Peter was in hospital.

- **Mary Ward**, Clinical Nurse Specialist at St Michael's Hospital in Dublin, was the 2021 winner and was

nominated by Paula Jacob whose mother, Marie, received exceptional care over 8-years.

We hope you will get behind this important initiative and reward someone who made a special difference to you or a loved one.

Please send your entries to ILFA, PO Box 10456, Blackrock, Co Dublin or email info@ilfa.ie. The closing date for entries is Friday, 19th April 2024.



“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around” - Leo Buscaglia

Research

Patient and Public Involvement (PPI) Research Advisory Group

ILFA's Patient and Public Involvement (PPI) Research Advisory Group was set up in 2022 and members were recruited via announcements on the ILFA website, social media, and newsletter.

ILFA is grateful to everyone who has joined the group to share their perspectives on research. The group consists of patients, carers, academic personnel, and healthcare professionals.

Over the last year, several researchers have discussed their research projects with the PPI group and have received valuable feedback and insights from the group. It is exciting to hear about the varied research projects being undertaken in science, clinical research, and epidemiology.



Statement from Seán Ó Sé, Chair of ILFA's PPI Research Advisory Group:

"The Patient and Public Involvement (PPI) Research Advisory Group was established by ILFA in 2022. The first meeting as a group was held online in September 2022. There were over 20 attendees including lung fibrosis (pulmonary fibrosis) patients, carers, health professionals and researchers concerned with lung fibrosis investigation. I attended in the capacity of Chairperson of the group, and I am continuing in that role for future group meetings. I am a patient of the disease.

This advisory group is very important as it enables sufferers of the disease, together with their carers, and health professionals to participate in the research process. They can provide direct experience, ideas, and concerns of the disease process and its impact within the community to those personnel carrying out research projects.

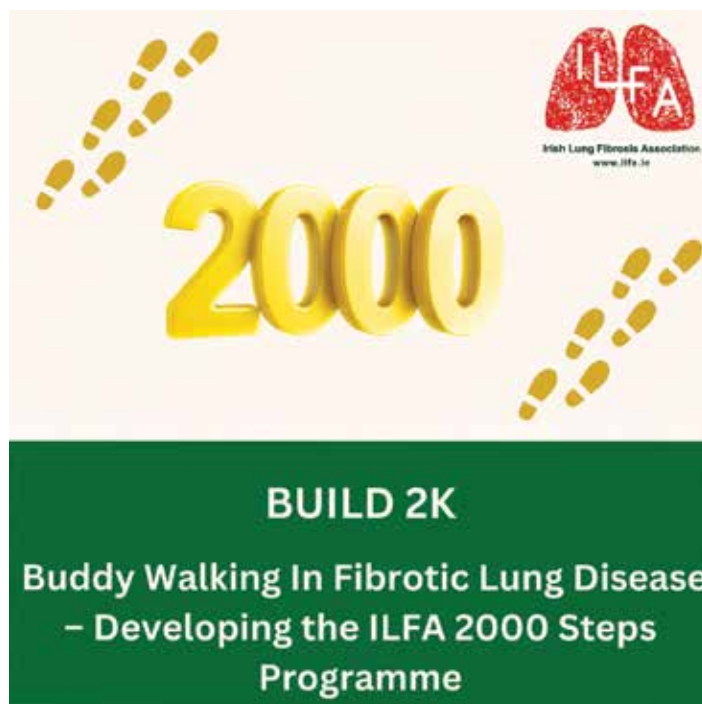
During the first meeting, I observed active participation and interest from every attendee, which demonstrated to me that the PPI Research Advisory Group can be a serious and valuable support activity for current and future lung fibrosis research."

We need your help!

The PPI Research Advisory Research Group is looking to recruit new patient members. The group meets online a few times during the year. No research experience is necessary. Patient members are asked to contribute to discussions on research projects by sharing their insights and perspectives on what is important to you as someone living with lung fibrosis.

Please contact ILFA by emailing info@ilfa.ie if you would like to know more. We look forward to hearing from you.

BUILD 2K: Buddy Walking In Fibrotic Lung Disease Research Project



Dr Roisin Cahalan, Respiratory and Cardiovascular Physiotherapy, Faculty of Education and Health Sciences at University of Limerick, is undertaking a research project entitled "BUILD 2K: Buddy Walking In Fibrotic Lung Disease – Developing the 2000 Steps Initiative (ILFA/ 2000 Step Programme).

If you have used the ILFA 2000 Step Walking Programme recently, we are asking you to participate in a survey that will help the future development of the 2000 Steps Programme and other projects. Based on the findings from the survey, a focus group will be set up to further develop this research project. If you would like to take part in the survey or if you have any questions, you can contact Roisin Cahalan or Ciarán Purcell at the email addresses listed below at any time before, during or following the study. You can ask any questions you might have when you fill in the questionnaire, or during the physical screening.

Contact name and email details of Research Investigators

Roisin Cahalan email: Roisin.Cahalan@ul.ie

Ciarán Purcell email: Ciarán.Purcell@ul.ie

Exercise

Weekly Online Exercise Classes

ILFA's online exercise classes for lung fibrosis patients take place every week and are free of charge to members. Classes are led by Eimear Bell, respiratory physiotherapist, and take place every Monday, Wednesday, and Thursday via Zoom.

The aims of the ILFA online exercise classes are to:

- help lung fibrosis patients and lung transplant patients to exercise, maintain their health, prevent deconditioning, and relieve loneliness for those living in isolated parts of the country.
- provide safe, engaging, interactive exercise classes suited to the needs of lung fibrosis patients that are delivered by specialist respiratory physiotherapists.
- enable patients to have access to experienced healthcare professionals and receive valuable peer support.

In 2023, the Irish Lung Fibrosis Association delivered 113 online exercise classes for lung fibrosis patients. At the start of the year, ILFA provided 2 classes per week but to meet the growing demand for places, ILFA expanded the programme and has provided 3 classes per week since March 2023. There were 2,457 participant sessions in 2023. ILFA is grateful to Boehringer Ingelheim for their support to facilitate the exercise classes. These data show that lung fibrosis patients want to engage in structured exercise and educational programmes to improve and maintain their fitness. There is an urgent need for pulmonary rehabilitation classes for lung fibrosis patients, however this group of patients is excluded from HSE pulmonary rehabilitation programmes in the community. ILFA will continue to highlight the health inequalities faced by lung fibrosis patients and campaign for a dedicated Clinical Care Programme for Lung Fibrosis in 2024.

If you would like to join the ILFA online exercise class, please email info@ilfa.ie or call 086 871 5264 or 086 057 0310 for more details. We can help you set up Zoom if you need any help to join the classes. All are welcome to this friendly, supportive, encouraging space to exercise to your ability.



**Join ILFA's online exercise classes on
Monday, Wednesday, Thursday
via Zoom**

ILFA Yoga Classes

A series of online yoga classes for lung fibrosis patients took place from September 2023. We are grateful to ILFA Patron and yogi, Michael Darragh Macauley, for delivering these tailored classes that incorporated stretching, breathing exercises and yoga poses for patients sitting or standing. A special festive yoga class took place in December 2023 and participants wore Christmas jumpers, hats, and headbands to mark the occasion.

ILFA asked the attendees of the classes to complete a questionnaire and here's some of the great feedback received.

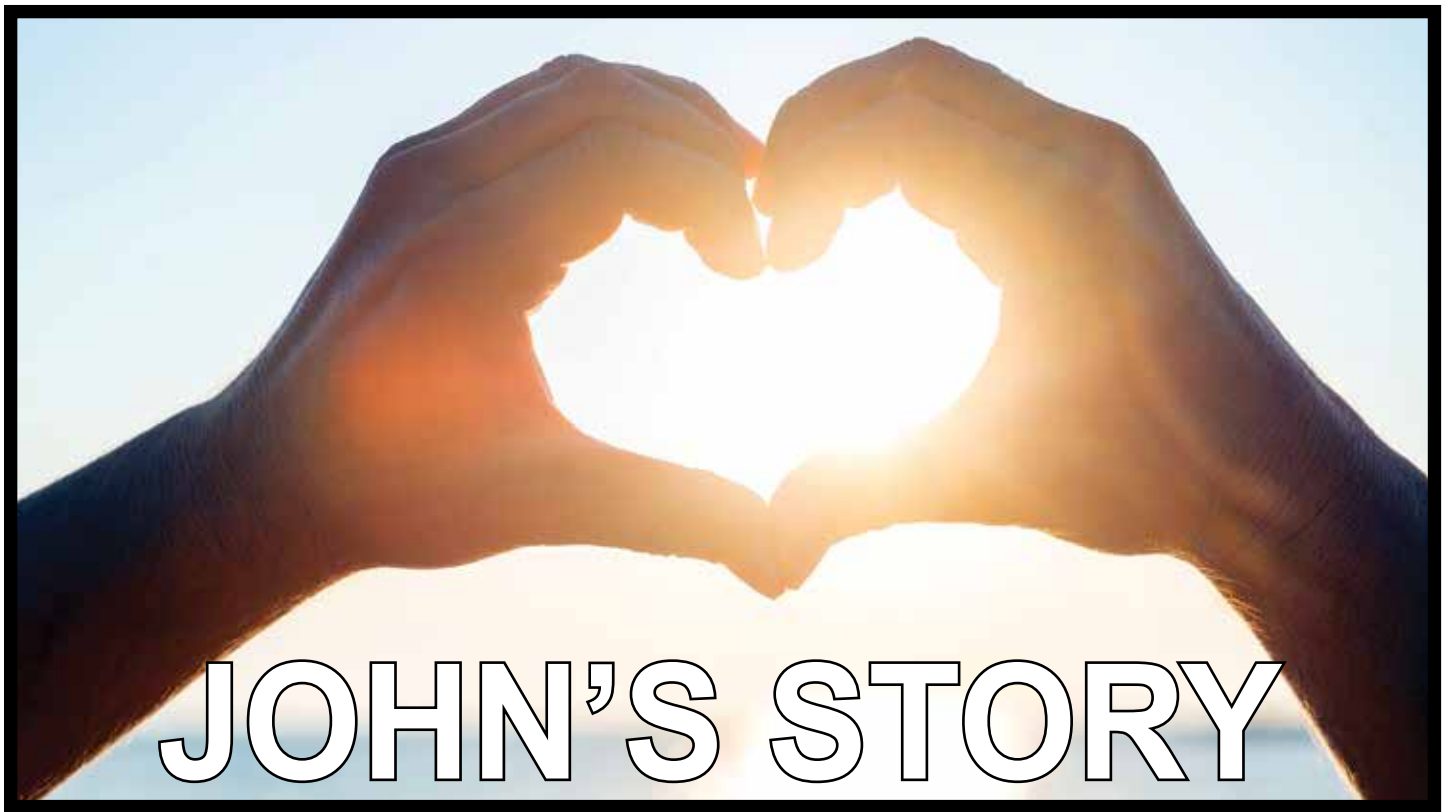
- 85% rated the classes as excellent or very good.
- 80% strongly agreed they felt more relaxed after the class.
- 70% strongly agreed they felt better after the class.
- 70% strongly agreed that the breathing exercises were useful.
- 90% strongly agreed that they enjoyed participating in the class.
- 100% would recommend online yoga classes to another patient.



**Thank you Age & Opportunity and
Sport Ireland for your support**

ILFA Awarded an Exercise Grant

The Irish Lung Fibrosis Association is thrilled to announce that we have received a grant from Age & Opportunity and Sport Ireland to purchase equipment for lung fibrosis patients. The Active National Grant Scheme from Age and Opportunity and Sport Ireland supports sport and physical activity among older people so they can experience the health benefits of being active. ILFA will purchase medical grade pedometers to encourage lung fibrosis patients to engage in physical activity via the ILFA 2000 Steps Walking Challenge. Thank you to Age & Opportunity and Sport Ireland for this funding.



An uplifting story of hope and gratitude from John McMahon, ILFA member

"In March 2020, I developed a cough. I took a couple of cough bottles that didn't have any effect, and so I continued my life, thinking it would eventually go away.

We have a camper van - I like going to Sligo camping and I always wanted to go up to Queen Maeve's grave. One Saturday morning, my wife and I decided to go up the hill but less than a quarter of the way up, I started to get breathless. At first, I put this down to a sandwich that I had eaten before setting off but 300 metres on, I just couldn't breathe. I knew something wasn't right and my wife said that when we got home, we would make an appointment to see my doctor which I did. I was referred to a respiratory specialist, Dr Aidan O'Brien, in Limerick University Hospital and it was nearly 7-months later when I got to see him and had some tests. Two days before Christmas Eve, he gave me news that I was not expecting! I was told I had hardening and scarring of my lungs; I had pulmonary fibrosis. He said I had a limited time to live unless I was able to get a lung transplant. I was referred to Professor Egan at the Mater Hospital in Dublin whom I met in early 2021. I was told a transplant was the only cure for me, but it takes time to get on list and a lot of tests would have to be done first.

I was put in touch with the Lung Fibrosis Clinic in Ennis where I meet specialist nurses Carmel McEnerney and Paula Ryan, and I was started on anti-fibrotic medicine. Luckily, I didn't get any side-effects from the medicine. After a year,

my breathlessness started to get the better of me so portable oxygen was prescribed, and this really helped.

In 2022, I had to stop going to work as I found myself

exhausted and had no energy left. I was called to the Lung Transplant Unit at the Mater Hospital for a series of tests. I had to get an oxygen concentrator to give me enough oxygen to breathe - I felt like a prisoner in my own home and I could only get as far as the back door. My health deteriorated and I was brought to Limerick University Hospital and then transferred to the Mater University Hospital. There I was put on a new oxygen machine which really helped. I was there for over 2-months when one morning in the early hours, I was told there was a potential lung donation. This turned out to be a match for me and the lung transplant went ahead.

I will never forget the feeling of waking up without oxygen to help me breathe - that feeling was fantastic I have been lucky enough to have a second chance at life which I intend to use every day. The importance of organ donation to people like me is literally life-changing. I pray to my donor and their family every night and thank them for taking the difficult decision that day. Ever since, I have excelled in building up my weight from 52kg to my normal weight of 68kg. My walking is up to 5km a day so far and my leg strength is returning.

Many thanks for everything."

John McMahon



Awareness and Advocacy

Health Service Executive (HSE) Patient Partnership Conference



Bernard Gloster with Eddie Cassidy.

ILFA representatives Eddie Cassidy (ILFA Chair), Gemma O'Dowd, and Colin Edwards attended the first annual Health Service Executive (HSE) Patient Partnership Conference in October 2023. The event was organised by the HSE, the HSE's National Patient and Service User Forum, the Irish Platform for Patient Organisations, Science and Industry (IPPOSI) and Patients for Patient Safety Ireland.

It brought patient advocates, healthcare professionals, policymakers, and stakeholders together and showcased opportunities for patient engagement in healthcare and service delivery.

ILFA was fortunate to have an exhibition stand at the conference and a selection of our information leaflets, practical aids, and educational resources were available to share with visitors. ILFA is grateful to everyone who visited the ILFA stand including Stephen Donnelly T.D., Minister for Health, Bernard Gloster HSE CEO, Joe Ryan, HSE Office of National Director Operational Performance and Integration, Carol Munt, Keynote Speaker, and representatives from other organisations.

This conference was a great initiative that placed the patients voice centre stage and brought multiple stakeholders together for a valuable and inclusive shared learning experience.



Eddie Cassidy and Stephen Donnelly, Minister for Health.

Pulmonary Fibrosis Week



In September 2023, Grace O'Sullivan, Clinical Nurse Specialist, and her colleagues in respiratory medicine at Cork University Hospital hosted an information stand to raise awareness of pulmonary fibrosis. The Irish Lung Fibrosis Association was delighted to supply Grace with information

resources for the stand. Well done and thank you to Grace and everyone involved.



Advocacy

ILFA is actively campaigning for a HSE Clinical Care Programme for Interstitial Lung Disease to ensure lung fibrosis patients get the best standards of care and have equal access to healthcare specialities, treatment including medicine, oxygen, and pulmonary rehabilitation.

We are grateful to all the patients who have contacted local politicians to inform them of ILFA's work in addressing healthcare inequalities faced by patients. We have highlighted that lung fibrosis patients are excluded from pulmonary rehabilitation courses taken place in the community via Integrated Care projects. This is because the Respiratory Clinical Care Programme is for COPD and Asthma only. Lung Fibrosis patients need access to structured exercise and educational programmes to maximise their health and wellbeing.

ILFA is thankful to all the politicians who have supported our request to appear before the Joint Oireachtas Health Committee. In August, three of ILFA's Directors (Eddie Cassidy, Prof Jim Egan and Nicola Cassidy) met with Colm Burke TD at Leinster House to discuss the healthcare challenges faced by lung fibrosis patients. Our advocacy work continues!

Education and Travel Bursaries

The Irish Lung Fibrosis Association awarded 3 education and travel bursaries to researchers and healthcare professionals to attend the European Respiratory Society International Congress in Milan in September 2023. Here are the reports from the 3 bursary recipients - Anja Schweikert, PhD Student at the Royal College of Surgeons in Ireland, Dr Chiara De Santi, Lecturer at the School of Pharmacy and Biomolecular Sciences at the Royal College of Surgeons in Ireland, and Dr Roisin Cahalan, Senior Lecturer Respiratory and Cardiovascular Physiotherapy at University of Limerick.

Benefits of attending the ERS International Congress for my role as a PhD student by Anja Schweikert, Royal College of Surgeons in Ireland.

The 2023 ERS International Congress attracted over 20,000 delegates. 5 days filled with amazing science and multiple networking opportunities. 20 poster sessions were presented in parallel three times a day and oral presentations, symposiums and other state-of-the-art sessions in 14 different rooms completed the scientific content presented.

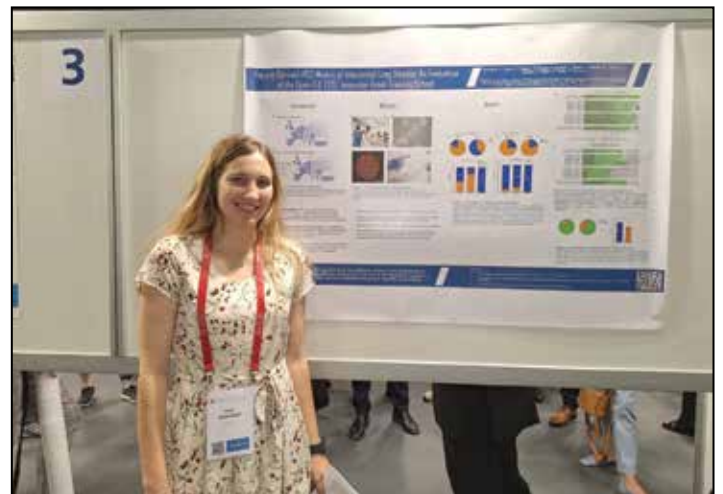
I am a second year PhD student working on the role of sex hormones in pulmonary fibrosis. This was my second time participating in the ERS congress. My three major aims on what to achieve whilst at the congress were:

1. Strengthen my presentation and communication skills:

I was delighted to present my poster about the Open-ILD Innovator Grant Training School in patient derived induced pluripotent stem cell (iPSC) Models of Interstitial Lung Diseases. Getting questions about the novel hybrid Hands-on and Observer teaching model we applied, as well as seeing other delegates presenting novel teaching methods increased my understanding and highlighted problems in this sector. Since the data of my poster is currently under review for publication, comments and questions asked as part of the poster presentation will help answer possible arguments stated by reviewers. This year, I was also given the chance to present my data on the effect of sex hormones on iPSC-derived alveolar epithelial type 2 cells in an oral presentation. There was major interest of the audience in this topic, which might build the basement of future collaborations.

2. Increasing my knowledge of the pulmonary fibrosis field: Listening to state-of-the art science in our field of research, as well of discussing science during poster presentations, increased my knowledge and showed me techniques to answer research questions that I did not think of.

3. Increase my scientific network: In addition, talking to peers that are working in the same research area and hearing about their experimental and methodical challenges, but also successes highlighted again that we are not alone. These



Anja Schweikert, Royal College of Surgeons in Ireland.

discussions, but also the Assembly 3 (Basic and translational sciences) networking event helped me to reach this aim.

In summary, this congress has not only taught me more about state-of-the-art research, but I also got to broaden my scientific network by getting to know expert scientists, as well as got feedback on my research. In the future, connections formed as part of the congress will help building new collaborations. I want to thank ILFA for giving me this opportunity and supporting me to go to the 2023 ERS International Congress.

ILFA ERS Congress Bursary report – Chiara De Santi

Thanks to the ILFA Educational Bursary, I participated to the European Respiratory Society Congress in Milan. I truly enjoyed this experience which benefited me from several points of view, as follows:

- I got exposure as emerging principal investigator in the field of pulmonary fibrosis – when presenting my poster, I received very informative feedback, had a lot conversation around non-coding RNAs and the human in vitro model we are using to mimic pulmonary fibrosis. I also connected with a professor in Northumbria University working on muscle and lung fibrosis and this may lead to future collaborations. I also got the chance to meet Prof Griese who I met online last year

about a potential research project together and finally met in person at the conference. Lastly, I met with another emerging investigator who is part of the research team in another grant I have submitted after the conference.

- I wanted to learn about patients' perspective so during the poster sessions I visited posters presented by patients' advocates, including ILFA, and paid particular attention to the 'Patients' perspective' often offered as video recordings at the beginning of presentation sessions.

- I have gained knowledge in the field of lung fibrosis and genetic diseases by attending oral presentation and poster sessions. I particularly enjoyed the following sessions: 'Tissue modelling and remodelling', 'Novel treatment options for pulmonary fibrosis' and 'Genetics in paediatric respiratory diseases'.

- I have expanded my network, within my ERS Assembly (Assembly 3). I participated to the Assembly meeting where we learnt how to participate more actively to the ERS activities and really enjoyed the networking event which followed, where we were given the chance to suggest things the Assembly should focus on in the future. At the back of my participation to this session, I nominated myself as member of Assembly 3's long-range planning committee (LRPC), hopefully I'll get elected.



Dr Chiara di Santi and Dr Roisin Cahalan.

- I also really enjoyed the 'Early Career members session'. During this session, we learnt what we can do as scientists to support awareness around climate change and initiatives to slow it down (or maybe stop it completely!). I was particularly interested in this aspect and will follow up with the speaker to organise something in sustainability for next year's conference. We also learnt about social media and how to grow our network and our research opportunities and collaboration using some of the available platforms, and how ERS can help us progress our career. Overall, it was a very enjoyable session, and really focused on early career members so very relevant in terms of career stage where I am.

ILFA ERS Congress Bursary report – Dr Roisin Cahalan

The ERS annual conference took place in early September in Milan and welcomed thousands of delegates from around the world, interested in all facets of respiratory health. There were

multiple sessions of potential interest to ILFA members, and some of the more interesting findings included the following:

- There are promising developments in the differential diagnosis of various types of ILD including existing technologies and more futuristic work. These include various blood markers, home spirometry and even AI to help with earlier diagnosis and treatment.

- A relative decline of FVC of 10% or more is the biggest indicator of disease progression, regardless of the type of condition. This finding supports the importance of serialised assessment and personal care for patients.

- A fantastic talk by Karen Moor on fatigue in ILD discussed how fatigue is the most common problem for people, even considering breathlessness and cough. Fatigue has no common definition, affects physical and mental health, and is an invisible enemy. Moreover, there appears to be no relationship between the level of fatigue and disease severity. Interventions like upper limb strength training and inspiratory muscle training appear to help.

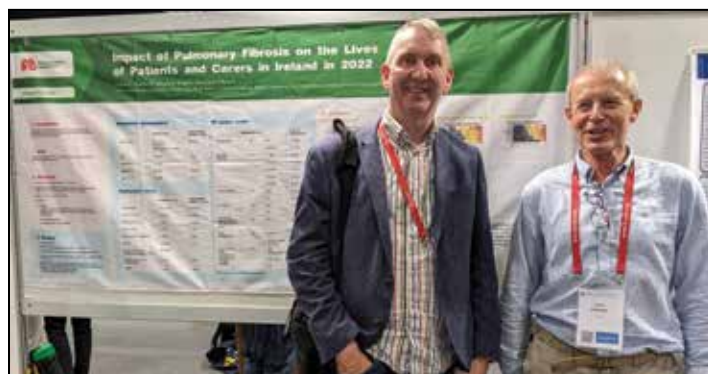
- A wonderful talk by Mr John Solheim, PF patient and advocate provided the following pieces of advice:

- Include other people in your journey – it affects them too.
 - Try to stay positive – it can improve your quality of life.
 - Seek help from experienced health care professionals, patient organisations and peer support.
 - Educate health care professionals by accurately reporting your symptoms and always bring your family with you to meet the consultant. They have parts of the puzzle that you may not have.
 - Ask questions of the consultant.
 - Ask for help – people are happy to give it.
- One of the main takeaways from his talk was "this is not a one-person disease" which underpins the importance of support and community when dealing with these conditions.

Huge thanks to ILFA for funding this wonderful opportunity.

Research

The Irish Lung Fibrosis Association had a research poster presentation at the ERS International Congress in Milan in September. The poster was entitled "Impact of pulmonary fibrosis on the lives of patients and carers in Ireland in 2022" and the work was presented by Colin Edwards, ILFA Board Member.



Liam Galvin and Colin Edwards.

Irish Thoracic Society Scientific Meeting

The Irish Lung Fibrosis Association was delighted to have an exhibition stand at the Irish Thoracic Society Annual Scientific Meeting in Limerick in November 2023.

Gemma O'Dowd, Anne Griffin, and Nicola Cassidy represented ILFA at the event and enjoyed meeting healthcare professionals from across Ireland as well as researchers, pharmaceutical and oxygen company representatives, and charity organisation colleagues.

Sincere thanks to everyone who called by our exhibition stand to say hello and have their photo taken. We had a great time and enjoyed meeting old friends and making new friends. A selection of photos from the meeting are included below.



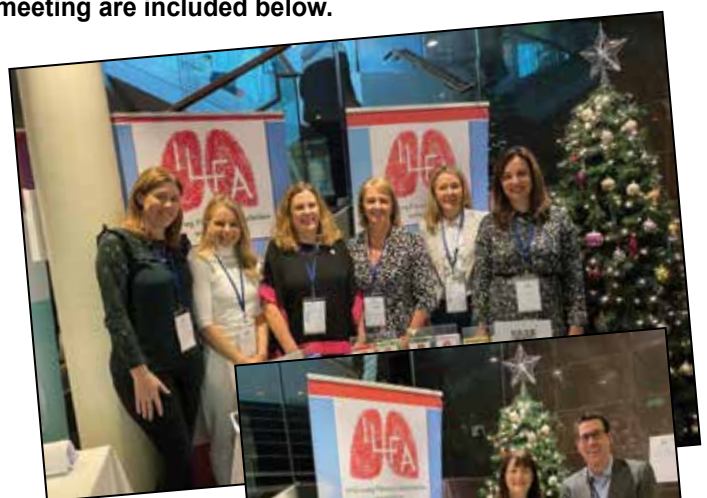
Dr Lucy Power and Professor Killian Hurley

Terence Moran Memorial Award

The Irish Thoracic Society Interstitial Lung Disease Education Day for healthcare professionals took place in February 2023 in partnership with the Irish Lung Fibrosis Association. The event was held as a virtual ILD Multi-Disciplinary Team and Clinical Update with case presentations from trainees in respiratory medicine and contributions from leading clinicians.

The Terence Moran Memorial Award, named in honour of ILFA's late founder and Chairman, was awarded to Dr Lucy Power, Specialist Registrar in Respiratory Medicine at University Hospital Galway, for the best-case presentation. Dr Power was presented with an educational bursary and a crystal award by Professor Killian Hurley, Chair of the ITS ILD Group, at the Irish Thoracic Society Scientific Meeting in November.

Congratulations to Dr Power on her award.



Team Coughlan - run 2km on the hour, every hour for 24 hours



On 29th July, Derek Coughlan from Swords, County Dublin took on an incredible challenge to raise funds for ILFA in memory of his father Ciaran. Derek and his team of supporters completed a 2km run on the hour, every hour, for 24 hours. In doing so, they raised over €8,000 for ILFA and we are enormously grateful to everyone involved. Here is a report from Derek.

“When I first took on this challenge, I honestly thought I’d be tackling it on my own. I knew it’d be tough both physically and mentally, but I wanted to push myself and really make an impact for the ILFA in memory of my Dad, Ciaran. Little did I know just how much support I was in for from all of you – my family and friends. You completely transformed this from a solo mission into a full-blown group effort.

I am so grateful for the ILFA’s unwavering backing throughout this journey. From their branded merchandise to their impactful social media posts and, most importantly, their presence at the event itself, their support has been nothing short of extraordinary. My appreciation goes out to Eddie Cassidy, Nicola Cassidy, and Gemma O’Dowd from ILFA for their relentless dedication to this cause.

And to the incredible bunch who jumped in – Therese Coughlan, Karen Coughlan, Karen Farrell, Lisa Coughlan, Kev Farrell, Tony Clarke, Kev Conlan, Stephen Rafter, Colm Cloake, Joe Clancy, Paul Maguire, Shane Maguire, Stephen Kennedy, Fernando Amatore, Des Maguire, Collette Fox, Sarah Fox, Declan and Bernie, Daniel, Megan Clarke, Harry Clarke and Aoibhe Farrell – Your support was everything and without each of you, this wouldn’t have been possible.

Lastly, I am amazed by the remarkable amount we have raised. To every person who donated, your generosity has truly made this event a success. Thank you for contributing to such a great cause.”

Eddie Cassidy (ILFA Chair) and Nicola Cassidy met the Coughlan family in Swords, Co Dublin for a cheque presentation. Sincere thanks to Derek, his wife Karen, his mother Therese, sisters Lisa and Karen, brother-in-law Kevin and daughter Katie for a warm welcome. Thanks also to all the members of this fantastic fundraising team who completed 48km for ILFA and helped raise awareness and valuable funds.

VHI Women's Mini Marathon 2023

The VHI Women's Mini Marathon took place in glorious sunshine on Sunday 4th June 2023. Thanks to all the ladies who took part on behalf of ILFA.

Congratulations to Ursula O'Hanlon from Dublin who took part in the VHI Women's Mini marathon to raise funds for ILFA in support of her sister. Ursula is pictured below with ILFA member Mary O'Sullivan from Tipperary before the start of the mini-marathon.



Congratulations to Lynda Jackman, her daughter Carrie Jackman, cousin Kathleen Funchion and friend Elaine Lanigan from Kilkenny who took part in the mini-marathon to raise funds for ILFA in memory of Bobby Jackman. Linda said "We had such a great day and was nice to meet up with the group afterwards."



Congratulations to members of the Flanagan Mini Marathon Team who took part in the VHI Women's Mini Marathon to raise funds for ILFA. Linda, the organiser of the group said "Thanks so much for having us back to the Duke Pub on Sunday after the mini-marathon. It was so good to meet up with people who have gone through the same experience as us with our mam. We had a great day and made memories I will never forget."



Congratulations to Mary Greene and Sharon Morrissey who took part in support of their family member Mary O'Sullivan. Mary Greene said "It was a pleasure to meet you all at the event. Mam, Sharon and I had a fabulous day. Glorious sunshine made it so enjoyable for everyone taking part. We were delighted to be part of #TeamILFA. Thanks to generous support from our friends and family we raised over €1,000 this year."



Orlaith Mulligan from Kildare and her cousin Aoife took part in the VHI Women's Mini Marathon to raise funds for the Irish Lung Fibrosis Association. They raised an incredible €1,027 for ILFA with the support of family and friends. Orlaith said "We hope our fundraising will help as I can't explain how much we appreciate all that you do for my dad. A huge thank you to ILFA from my family".



Team ILFA 2023

Running pals

A group of running pals who meet every weekend at St Anne's parkrun in Dublin took on the VHI Women's mini marathon in aid of ILFA. Well done to Birgit Kretschmann, Janet Day, Niamh English, Annette Grehan, Morwenna Quinn, Mary Henry, Mary Fitzgerald, Claire Fitzgerald, and Nicola Cassidy (ILFA Director). The ladies had a great day and enjoyed the 10k run and the get together afterwards. More than €1,600 was raised for ILFA.

Mary Fitzgerald said "What a fantastic experience running 10k for the first time in the women's mini marathon. What made it so special was that I ran it with a group of wonderful running pals and we were raising funds for ILFA. I was so proud to don the ILFA t-shirt along with all the other fundraisers. There was such a buzz on the day and even more so at the celebrations afterwards. I'm looking forward to next year already."

Niamh English said "Myself and my running buddy Nicola and her pals took on the mini-marathon in June. It turned out to be a hot day - 23°C! It was a welcome sight to see the Dublin Fire Brigade at Donnybrook with the water hose on, even though the water was colder than expected. It wasn't the easiest of running conditions for Nicola and I but we ran the entire route and crossed the line together. Thanks to everyone who supported us and cheered us on."

Birgit Kretschmann said "On Sunday, 4 June 2023, I took part in my first VHI Women's Mini Marathon which also happened to be my first official 10k run. Sharing this experience with my running pals, this amazing group of ladies who met through running (Parkrun) and who have this wonderful friendship, was a truly special experience which fills my heart with love and joy. From start to finish and beyond, the joy and excitement was palpable among the participants of all ages and running levels. The glorious sunshine was an additional treat. I enjoyed every step of the route and am feeling thankful and proud that by deciding to run and fundraise in aid of ILFA together with my group of



friends, I contributed to a good cause with my own personal achievement. A big thank you to all who have supported our fundraiser."

Cork Mini Marathon



Congratulations to Catriona O'Brien, Kasey O'Brien, and Nadine O'Mahony who took part in the Cork Echo Women's Mini Marathon on Sunday 17 September 2023 to raise funds for ILFA. The ladies said they had a great day! Thank you so much your wonderful support. Mile buiochas!

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.

Anáil Fundraising Walk for ILFA



Congratulations to Anáil (Respiratory Nurses Association of Ireland) on a successful conference in Athlone in March 2023 and their celebrations to

mark their 30th anniversary. The respiratory nurses kindly arranged a fundraising walk in aid of ILFA and there was great excitement in the lead up to the event. Unfortunately, bad weather conditions on 10th March meant that the respiratory nurses planned 5km fundraising walk had to be postponed. The event had to take place virtually the following week and we are grateful to everyone who took part.

Huge thanks to Anáil for their ongoing support for ILFA. Mile buiochas!

Chipping Challenge



Donna Mulholland, Lady Captain Bundoran Golf Club, Donegal had her Captain's Day on 1st July 2023 and raised almost €1,200 for her chosen charity, the Irish Lung Fibrosis Association (ILFA).

The Chipping Challenge entailed chipping golf balls through varying sized tyres. Donna said "It was great fun, even though it was a windy day. People were very generous, and it was a very successful day." Donna would like to thank her volunteers without whom the event could not have happened. Donna's husband Stephen, who has pulmonary

fibrosis, donated a prize for first place. Huge thanks to Donna Mulholland, Stephen Mulholland, and all the volunteers at Bundoran Golf Club for their wonderful support for ILFA.

BOC 32-County Cycle



Massive congratulations to Adrian Sheehan and his colleagues from BOC Healthcare Ireland who completed a phenomenal charity cycle to raise funds for the Irish Lung Fibrosis Association in June 2023. The ambitious cycling challenge travelled through 32 counties covering 1,000km in 4 days.



The team of superheroes faced tough weather conditions, triumphed over hills, and dug deep to achieve their goal. They received great support from family, friends, and colleagues and raised a fantastic

sum of €7,530 for ILFA. Adrian Sheehan from BOC presented a cheque to Eddie Cassidy, ILFA Chairman, in September. Sincere thanks to all the cyclists, support crew, and everyone who sponsored the team for this amazing event.

Niamh and Nicola Run for ILFA

For the second year in a row, loyal fundraisers Niamh English and Nicola Cassidy took on several running challenges to raise money for ILFA - a cause close to their hearts. Niamh and Nicola started their 2023 Running Series for ILFA with the VHI Women's Mini marathon in June, followed by the Irish Runner 10 mile and the Frank Duffy 10 mile in August, the Dublin half-marathon in September, and finally the BIG ONE - Dublin City Marathon on 29th October. The girls wore their ILFA shirts at every run and were even recognised by other runners at subsequent events during the year. They met the legendary exercise guru, Joe Wicks, on one of their training sessions and he wished them well with their marathon challenge. When running the marathon, Niamh and Nicola compiled a list of 26 names and dedicated each mile to someone special. They were delighted with their fundraising total of more than €1,300 and are grateful to everyone who supported them and sponsored them.



Croagh Patrick Climb

Congratulations to Kathleen, Deirdre and Fionnuala Malone who successfully climbed Croagh Patrick on the 9th of September 2023 to raise funds for ILFA in memory of their dad and husband Fergus.

Fionnuala said "Our dad passed away in December 2022



Dublin half-marathon

Three running superstars Olive McCafferty, Nicola Cassidy, and Niamh English, below, ran the Dublin Half Marathon on Saturday 23rd September 2023 in aid of ILFA. The ladies had a great day and appreciated all the messages of good luck



and encouragement from friends and the ILFA community. Olive, who is a respiratory physiotherapist at the Lung Transplant Unit at the Mater University Hospital, stormed home with a fantastic time and then ran back to cheer on Niamh and Nicola who ran and finished the course together. We're so grateful to our amazing fundraisers for all their support. Mile buiochas!

from lung fibrosis. During his illness and hospital stays, we reached out to the Irish Lung Fibrosis Association. We received great advice and guidance from them which we are very grateful for. When you have a loved one in hospital it can be hard to know how to navigate the medical system and what questions to ask but ILFA helped us to do just that when we needed it most."

The ladies raised over €1,600 for ILFA. Sincere thanks from everyone at ILFA to Kathleen, Deirdre and Fionnuala for their kind words and support, and thanks also to everyone who sponsored the ladies.

Birthday Tea Party

Norah Parkes held a tea party in July to celebrate her birthday and raise funds for the Irish Lung Fibrosis Association. Norah prepared a magnificent feast that looked delicious. Norah is pictured with her daughters Susan and Lisa. Thank you, Norah, for your wonderful support for ILFA on your special day! We are so grateful.



Kinsale Concert in aid of ILFA

The Irish Lung Fibrosis Association was delighted that the concert held by Barry Tierney and Piaras Ó'Lorcáin at St Catherine's Cultural Centre, Ardbrack, Kinsale on 16th June



At the Kinsale COncert in aid of ILFA were Eilís O'Connell, Piaras Ó Lorcáin, Barry Tierney and Áine Tierney.

was a great success. Over €1,100 was raised for ILFA in memory of Finbarr O'Connell. Huge thanks to everyone involved and to those who donated so generously. We are enormously grateful for your support.

Cork City Marathon 2023



Congratulations to marathon heroes Alan Pisani and Paul Carroll who completed the Cork City Marathon on Sunday 4th June under blue skies and scorching heat. Alan and Paul raised over €2,200 for ILFA and their families are very proud of them. Sincere thanks for your support, Alan, and Paul!

Tesco Community Fund



Eddie Cassidy, ILFA Chairman, and Gemma O'Dowd, ILFA Administrator, met Lar Mooney (Tesco Store Manager at Temple Bar Store) in June 2023 for a cheque presentation. Thanks to the Tesco Community Fund, ILFA received €338.

In August, Eddie Cassidy, ILFA Chairman,



met Patrick Kelly (Tesco Store Manager at Jervis Street Store) and Jessica Smith to receive a cheque for €482 raised for ILFA via the Tesco Community Fund Scheme. Thank you to everyone who donated their blue token to raise funds for our charity.

Please consider nominating the Irish Lung Fibrosis Association (ILFA) to your local Tesco Store.

2023 Ballyliffin 10 mile Coastal Challenge

Brother and sister - Brendan and Annmarie Lafferty undertook the 2023 Ballyliffin 10 mile Coastal Challenge to raise funds in memory of their mother Margaret Lafferty from Culdaff, Donegal. They raised a fantastic amount that was divided between 2 charities. A cheque presentation took place at a location very dear to Brendan and Annmarie's mother. The story and photos were published in local papers - the Irish Times

and the Inishowen Independent. Here is a report from Brendan and Anmarie.

“When Mam was diagnosed with Idiopathic Pulmonary Fibrosis, she was referred by Dr Olga (Respiratory Consultant) to Antionette Doherty (Respiratory Advanced Nurse Practitioner) who visited Mam at home. Antionette advised us to contact the Irish Lung Fibrosis Association, for both Mam and us as family and carers to optimise our understanding of the condition and maximise quality of life for Mam. When we contacted the organisation, we were very impressed by the speed of response and within a few days Mam was participating in a breathing and exercise programme which not only helped her physical symptoms but also gave her a psychological boost. Those early days were the most difficult for her and us in coming to terms with the condition and the support of ILFA was invaluable. Sadly, the disease progressed within a few short months, but ultimately, we were able to achieve Mam’s wish to be cared for at home throughout her illness and this has sustained us in these months since her death. So, thank you ILFA for your contribution to that achievement!”



Brendan Lafferty presented a cheque for €1,100 to Lisa Sheridan, Community Nurse on behalf of Irish Lung Fibrosis Association and Mary Mc Laughlin, Community Palliative Care Nurse was presented with a cheque for €2,500 to Donegal Hospice by Anmarie Lafferty.



Oonagh McCarthy from Cork also ran to raise funds for ILFA in memory of her dad. Well done to all the athletes on #TeamILFA on a magnificent achievement. Sincere thanks from all at ILFA.

Dublin City Marathon

The Dublin City Marathon took place on Sunday 29th October 2023 and the weather was particularly bad for the almost 20,000 participants. Amazingly, ILFA had 9 athletes wearing an ILFA t-shirt and taking on the iconic 26.2mile course through the streets and suburbs of Dublin to fundraise for our charity. Aoife Quigley (pictured on the left) travelled from Limerick to run the marathon in memory of her uncle Ger Brady and her friend’s dad Eamonn McGrath. Aoife attached 2 ribbons to her running bib in their honour, so the men were with her every step of the way. Aoife met with Nicola Cassidy (ILFA Director) and Niamh English before the start of the marathon for a #TeamILFA photo and to wish each other the best of luck.

Cousins - Paul Giles, and Nicola Cassidy, ran the iconic 26.2-mile course in memory of their loved one Denise Cassidy, and were joined by their friends and running buddies, Niamh, and Stephen, for a photo before the event.

Arlene Bates ran the Dublin City Marathon in support of a good friend diagnosed with lung fibrosis. The weather was awful with lashing rain for most of the morning, but Arlene was smiling before and after completing the 26.2mile course. Arlene sent us some photos and said “Job done. Marathon finished and I’m delighted.”

Half-marathons



Orla Rolland took on the Edinburgh half marathon in May 2023 and had a fantastic run. Orla said “All done and dusted, delighted with myself. It was a brill morning and I got myself a PB, so I’m super pleased!!! My dad is new to this journey, but he is grateful to have you guys there.” Well done Orla!



Ciara Quinn from Tipperary ran the Limerick Half Marathon on 30th April 2023 to raise funds for the Irish Lung Fibrosis Association in support of a family member who has recently been diagnosed with Idiopathic Pulmonary Fibrosis.

Santa Dash

Caoimhe, Liath and Cara English from Trim, Co. Meath took part in the Santa Dash 5km run at St. Anne's Park on Sunday 3rd December and raised funds for the Irish Lung Fibrosis Association (ILFA). The girls took part with their mum, Niamh, who is a loyal supporter of ILFA. Everyone had a great time! Warmest thanks from everyone at ILFA to Caoimhe, Liath, Cara and Niamh for their great support.



Clare Light the Way tractor run



The Clare 'Light the Way' Tractor Run took place on Saturday 16th December 2023 and combined a festive Christmas Light Tractor and Truck Run in aid of the Irish Lung Fibrosis Association and Pieta House. A great night was had by all and Scanlan Agri won the best tractor (see photo above). Thank you from everyone at ILFA to the organisers, volunteers, participants, and spectators for making the event such a wonderful success.

West Kerry Tractor Run 2023



The West Kerry Tractor Run raised an amazing €7,500 for ILFA in 2022 and ILFA Chair Eddie Cassidy travelled to Dingle to accept the cheque from JP O'Sullivan and friends. The 2024

event has raised an incredible €8,000 for ILFA and we are enormously grateful.

West Kerry Tractor Run 2024



On Sunday 26th November, the 5th Mórchuard Tarracóra Chorca Dhuibhne / West Kerry Tractor Run took place and once again the organisers pulled out all the stops to put on a great show and raise funds for the Irish Lung Fibrosis Association (ILFA) and the Palliative Care Unit at Kerry University Hospital. Here are some wonderful



photos of the organisers and participants. Huge thanks from everyone at ILFA to all involved in the organisation and delivery of this fantastic spectacle including JP O'Sullivan his family and friends, all the participants, staff at the Marina Inn and the wonderful community of West Kerry. Mile buiochas!

Upcoming Events Donate to ILFA

Patient Information Day

The next Patient Information Day will take place online on Saturday 13th April from 11am until 1.30pm via the Zoom online platform. Speakers will be confirmed soon and will be announced on the ILFA website.

We hope you can join us to learn more about pulmonary fibrosis from experts in the field. Please call 086 871 5264 or email info@ilfa.ie to register for this free online event. You can also register directly via the Zoom link available on www.ilfa.ie

Did you know that ILFA's Patient Information Days are recorded and available to watch on the ILFA YouTube channel. Thank you to all the guest speakers who have contributed to these valuable educational sessions over the years.

HSE Living Well Programme

ILFA is delighted to announce that the HSE Living Well Programme will be available for lung fibrosis patients from Tuesday, 28th May - Tuesday, 9th July. The programme takes place online and will run over 7 weeks.

The first week is 1 hour duration and the following weeks are 2.5 hours duration.

For more information about the course, visit www.hse.ie/LivingWell

To register to take part, please email info@ilfa.ie or call 086 871 5264.

Please support ILFA

On-line donations to ILFA: You can donate easily and securely to ILFA directly using your debit or credit card via the ILFA website, www.ilfa.ie and via the following platforms.

- Just Giving
- Facebook Fundraising
- Paypal Giving Fund

Giving in Remembrance

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

Giving in Celebration

Celebrate your special occasion by asking family and friends to donate to ILFA instead of buying you gifts. Enjoy your birthday, wedding or special anniversary celebrations knowing you're supporting ILFA's work. Please contact ILFA if you would like information on how we can help you to support us.

Legacy Giving

A legacy gift or a charitable legacy is a donation left to a charity in an individual's will. If you are making your will or updating it, please consider leaving a legacy gift to ILFA after you have looked after your loved ones. All amounts would be greatly appreciated and will be used to help ILFA continue our work supporting lung fibrosis patients. As an added benefit, all legacy gifts are excluded from inheritance tax. If legacy giving is something you would like to do, please update your will to reflect your decision and ensure that your wishes are carried out in the future. Thank you.

Easter Monday 2000 Steps Extra Challenge



On Easter Monday 1st April 2024, ILFA will hold our annual 2000 Steps Extra Challenge. Patients, carers, family members and ILFA supporters are invited to join the virtual exercise challenge and take at least an extra 2,000 Steps (approximately 1 mile

more) to raise awareness of lung fibrosis and raise funds to support ILFA's work.

Please contact ILFA by emailing info@ilfa.ie or call 086 871 5264 or 086 057 0310 for more information and to receive a fundraising pack. Online

donations can be made via the website www.ilfa.ie

Here are some of the participants from the 2023 Easter Monday 2000 Step Challenge. Thank you to everyone who took part from many locations across the country and overseas.

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.

Mid-West Support Group

meets on the first Tuesday of the month at the Castle Oaks Hotel, Castleconnell, Limerick at 3pm. Please call Noreen on 087 262 7976 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's Patient Information Day** will take place online on Saturday 13th April 2024 online via Zoom. See the website for more information closer to the time.
 - **ILFA 2000 Steps Extra Virtual Fundraising Walk** will take place on Easter Monday 1st April 2024. Contact ILFA for your fundraising pack and remember to send us in your photos for our social media channels.
 - **VHI women's mini-marathon** on Sunday 2nd June 2024.
 - **Cork mini-marathon, half-marathon, marathon** on Sunday 2nd June 2024.
 - **Dublin City Marathon** on Sunday 29th October 2024.
- 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.