

ILFA's Online Exercise Class Wins Patient Organisation Project of the Year At The Irish Healthcare Awards

The Irish Lung Fibrosis Association (ILFA) was delighted to be short-listed for the Irish Healthcare Awards on 1st December 2022, in the highly contested Patient Organisation Project of the Year category. The Irish Healthcare Awards have been running for 21 years and celebrate and reward the achievements, innovation, and resilience of the Irish healthcare sector.

ILFA's project entitled 'Online exercise programme for pulmonary fibrosis patients during Covid-19 and beyond' was short-listed with 3 other worthy and exceptional patient-centred projects.



Nicola Cassidy, Gemma O'Dowd and Anne Griffin (left) represented ILFA at the awards ceremony held at the Aviva Stadium in Dublin. The ceremony was expertly compered by Dr Sumi Dunne. The ILFA team was overjoyed to hear ILFA's name called out as the winner of the Patient Organisation Project and there was lots of cheering and excitement. The

beautiful, engraved crystal award means the world to ILFA and is a great endorsement of our patient-centred support and exercise promotion ethos.

ILFA is sincerely grateful to:

- the wonderful and talented respiratory physiotherapists who have delivered our online classes since 2020; Gordon Cagney, Niamh Julian, Petra Grehan and Eimear Bell, and respiratory advanced nurse practitioner Paula Ryan
- Gemma O'Dowd and Anne Griffin who facilitate the classes for ILFA
- the patients who attend the classes with such enthusiasm, camaraderie, and positivity
- the fundraisers who support ILFA with their efforts that enable our work to continue especially in challenging times.



The ILFA Board has dedicated the Irish Healthcare Award to the pulmonary fibrosis patients who have passed away during the pandemic, especially those who were members of the 'ILFA exercise class family'.



Patient Information Day

The next Patient Information Day will take place online on Saturday 25th March from 11am until 1.30pm via the Zoom online platform. Our speakers will include:

- **Professor Kiilian Hurley**, Respiratory Consultant at Beaumont Hospital;
- **Donna Langan**, Respiratory Advanced Nurse Practitioner at Galway University Hospital;
- **Grace O'Sullivan**, Respiratory Clinical Nurse Specialist at Cork University Hospital;
- **Dr Roisin Cahalan**, Lecturer in Respiratory and Cardiovascular Physiotherapy in the School of Allied Health in the Faculty of Education and Health Sciences at University of Limerick;
- **Dr Anne Marie Russell**, Senior Lecturer at University of Exeter Medical School.

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

Easter Monday 2000 Steps Extra Challenge

On Easter Monday 10th April 2023, ILFA will hold our annual 2000 Steps Extra Challenge. Patients, carers, family members and ILFA supporters are invited to join the virtual exercise challenge from around Ireland and beyond 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



ILFA's Ecumenical Service of Prayer and Reflection took place on Saturday 15th October 2022 at Our Lady of Mount Carmel Whitefriar Street Church in Dublin's city centre. It was the first in-person gathering of the ILFA community since the lifting of the Covid-19 pandemic public health restrictions and it was a very special occasion for the lung fibrosis community. A large crowd gathered in the church and thanks to technology, we were delighted to welcome people from across Ireland to the service who joined in via the livestream that was available online. We even had someone join virtually from Cyprus! The service had an extra special element too, as it marked ILFA's 20-year anniversary.

The Reverend Dr Simon Nolan, Prior at Our Lady of Mount Carmel Church, welcomed everyone to the Service and he was joined by the ILFA Chaplains - The Reverend Canon Brian McKay (The Carmelite Priory, Moate, Co. Westmeath) and The Reverend Canon Charles Mullen (Dean's Vicar, St. Patrick's Cathedral, Dublin) to lead the service. We remembered our dearly departed friend and ILFA Chaplain. The Reverend Vanessa Wyse Jackson. Members of the Culwick Choral Society attended the service and performed a beautiful selection of hymns and musical pieces. We were also treated to the musical talents of Dr David O'Shea (organist) and Harry Carpendale (harpist) who performed beautiful musical pieces throughout the ceremony.

The theme of the ILFA Service was 'hope' and we were blessed to have two poets read original and moving compositions during the Service. ILFA's new Patron and playwright David Gilna read his composition entitled "Hope". Later, Pauline Byrne from Dublin read her poem entitled "Future Hopes." It was great to have such talented people to encourage hope and inspire us. We are grateful to our readers, Alexandre Sayve who was visiting Ireland from Switzerland, David Gilna (ILFA Patron), Susan Mullaney, Gerry Redican, Pippa Richards, Oisín Carroll, Anthony Walsh, Breda Coughlan, and Nicola Cassidy.

As always, the candle lighting ceremony is a central part of the ceremony and so important to those who have lost loved ones to lung fibrosis. Special thanks to Catherine McGeoghegan and Deirdre O'Flaherty, Respiratory Nurse Specialists at Beaumont Hospital who lit the candles to remember patients who have passed away. Gerry Fitzgerald, lung transplant recipient, travelled from Tipperary to light the special candle dedicated to organ donors and Gemma O'Dowd read the dedications.

Following the Service, everyone was invited for tea, coffee, and cakes at the Whitefriar Street Community Centre. Thanks to the staff and volunteers who welcomed the ILFA members to the hall and helped serve refreshments. We are grateful to everyone who baked and brought cakes and treats for everyone to enjoy. It was great to see and hear so many people engaged in conversation and being reacquainted after so long. On the evening of 15th October, ILFA asked members to light a candle in support of their loved one or to remember a loved one with lung fibrosis. We were delighted to hear that many people from across Ireland and overseas joined in this special virtual event to honour their loved ones.

The ILFA Board is sincerely grateful to everyone who made the ILFA Ecumenical Service possible, especially the clergy, the musicians and members of the Culwick Choral Society, and of course our amazing fundraisers and supporters who have sustained the charity over the last 20-years.

We hope you will join us in the Autumn of 2023 for the next ILFA Ecumenical Service.



ILFA's Service



Pauline and Austin Byrne.

Future Hopes

composed by Pauline Byrne

**Hold On The Pain Has Eased
This Pandemic Has Brought Us To Our Knees
We Are Not Broken, Just Bent Out Of Shape Resting
Still To Gather Our Strength, Our Will
Take Your Time
There is No Rush
As You Re-Engage With Life On Your Terms
Don't Feel Pushed
We Have Longed To Reconnect With Family,
Community
Loved Ones And Friends
To Hold Them Close Again
Is Our Reward In The End
We Hope And Pray That The Best Is Before Us Now
Even Though Covid Has Not Gone Away
We Have Had To Endure The Past Two Years
Come Face To Face With So Much Of Our Fears
To Get To This Place
Of Resting Grace.**



of Prayer and Reflection 2022



Canon Charles Mullen, Canon Brian McKay, and Prior Simon Nolan.



Niall and Liam Galvin.



Alexandre Sayve and Jila Sayve.



Kevin Mullaney, Philo Mullaney, David Gilna, and the Reverend Canon Charles Mullen.



Eddie Cassidy (ILFA Chair), Canon Brian McKay, and Canon Charles Mullen.



Eddie Cassidy (ILFA Chair), Canon Brian McKay, and Nicola Cassidy.

Education

Interstitial Lung Disease Interdisciplinary Network (ILD-IN) meeting



The Irish Lung Fibrosis Association was delighted to award three educational bursaries to healthcare professionals in Ireland to attend the 2-day Interstitial Lung Disease Interdisciplinary Network (ILD-IN) meeting in Birmingham, United Kingdom on 8th and 9th October.

Here is feedback from the bursary recipients Grainne Coffey, Eimear Bell, and Maria Conlon.

Report from Grainne Coffey, Respiratory Nurse at Kerry University Hospital:

"I was delighted to be selected by ILFA to attend the ILD-IN conference in Birmingham in October. It was wonderful to hear about the advances in the world of ILD and to see the momentum that research in this important area has gained. Dr Pilar Rivera-Ortega opened the session with a talk on Familial ILD, a very interesting talk on the role of genetics and the implications and challenges treating this type of ILD. Dr Conal Hayton discussed the latest developments in ILD associated with connective tissue disease and the benefits of having combined Rheumatology and Respiratory clinics. John Conway, kindly shared his own personal journey which was as poignant as it was informative, highlighting the importance of listening to and learning from the patient.

The workshops on Day 2 were excellent. Virtual care and digital technology in the remote management of patients was a very interesting study with great outcomes. I think there is a place for remote monitoring and care here in Ireland but like anything new, is not without its challenges. Overall, I thoroughly enjoyed the conference, being in a room full of experts sharing their research and knowledge assured me that the future for those living with ILD is encouraging. My sincerest thanks to ILFA for supporting me to attend this important event."

Report from Eimear Bell, Senior Physiotherapist: This was my first year attending the ILD-IN Conference and it was a very worthwhile trip, and I am very grateful for the opportunity to have attended. It was wonderful not only because the content of the talks was so interesting and informative but also because of how inspiring it was to see the care and passion of so many people working in this area and those living with a diagnosis of ILD. So, it was not just an experience of expanding my knowledge, it also inspired me to see all the work being done to help improve the care and health of those who have ILD, and the determination and courage of those living with ILD.

On the first day there were two talks that I found particularly interesting and informative; the first was on

Familial Interstitial Lung Disease by Dr Pilar Rivera Ortega and the second on the management of connective tissue Interstitial Lung Disease by Dr Conal Hayton. These were both great at giving an overview of the complexity of the Multi-Disciplinary Team diagnosis and management. There was also a very nice talk on the concept of creating a thinking environment and this made you stop and think about how you work and improving aspects to create a healthier and more creative thinking environment.

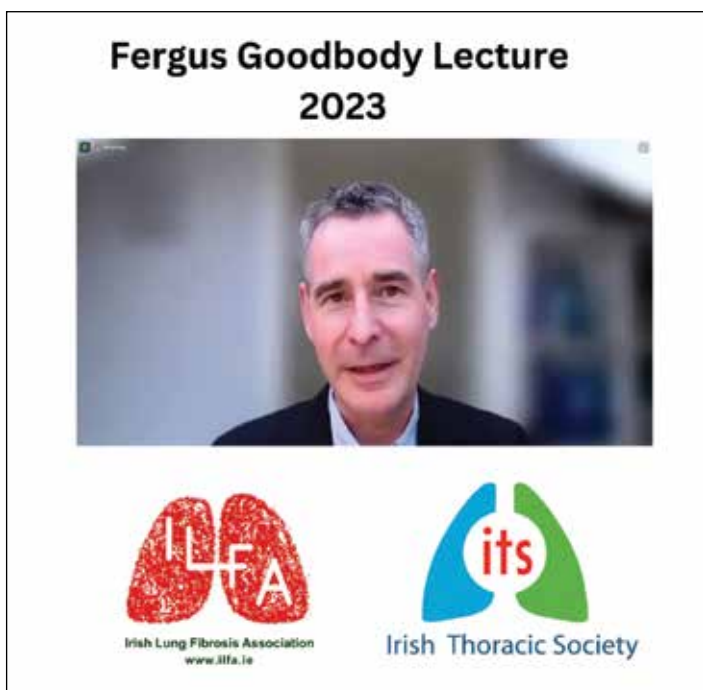
On the second day there were many fantastic talks on lung transplantation. The Patient Story was a wonderful talk and the man's honesty, and openness was remarkable. The talk on transplantation from the medical perspective given by Dr Gerard Meachery, Consultant in Respiratory and Transplant Medicine, was well structured and clear, giving the most up to date information on transplant guidelines and care pre and post transplantation. The talk on a Multi-Disciplinary Approach in Transplantation by Eleanor Johnson, Heart and Lung Transplant Specialist Nurse, brought another perspective giving further insight and understanding into different parts of the journey of lung transplantation. From my perspective as a physiotherapist, these talks emphasised how important exercise and movement is at every stage of the journey. Exercise really is an integral part of patient management both pre and post transplantation.

Over the two days it was lovely to meet others working in ILD and I feel this was inspiring and you could feel the sense of community. I also see this sense of community in ILFA, the power it has and how much good it is doing, I look forward to seeing this growing and helping all those involved. I look forward to continuing providing exercise classes for ILFA and feel even more inspired following this conference to promote how wonderful and powerful exercise is."

Report from Maria Cullinan, Clinical Nurse Specialist at University Hospital Limerick: Thank you, ILFA, for the opportunity to attend the ILD-IN meeting. It was wonderful to attend a conference in person again, to mix with people who all are working with ILD and see how they manage their services. It gave me a great opportunity to assess how we do things and what kind of a service we have and what changes we can make. Some of the highlights included the talk on lung transplantation and the difference between UK and Ireland. It was informative, and the speaker was open to questions. The patient experience was enlightening, and the speaker was brilliant and able to convey the science of his disease with the personal implications for him and his family. The palliative care talk was excellent with such insight. Representatives from patientMpower were present at the event and it was great to meet them. Overall, it was

fantastic meeting and most importantly it gave me and my colleagues lots of ideas for our service which we take great pride in and want only the best for our ILD patients.”

The Fergus Goodbody Memorial Lecture 2023



The Fergus Goodbody Memorial Lecture takes place every 2-years and ILFA invites a leading pulmonary fibrosis expert to deliver a state-of-the-art lecture to healthcare professionals. ILFA was set up in 2002 in memory of the late Fergus Goodbody. This year, ILFA collaborated with the Irish Thoracic Society (ITS) and we were delighted that the Fergus Goodbody Lecture was incorporated into the ITS Interstitial Lung Disease (ILD) Study Day for healthcare professionals.

ILFA was honoured to welcome Professor Michael Kreuter, Director of the Center for Interstitial and Rare Lung Diseases, Heidelberg University Hospital, to deliver the Fergus Goodbody Lecture to healthcare professionals online on 10th February 2023. Professor Kreuter's lecture was entitled "Developments in Idiopathic Pulmonary Fibrosis and Progressive Fibrosis" and he gave an excellent presentation that generated lots of discussion among the panel and audience. Over 100 healthcare professionals attended the event and Professor Kreuter praised the attendees for their excellent and challenging questions.

During the ITS ILD Study Day, five respiratory trainees each presented a case that they had encountered in their hospital, and the diagnosis and treatment were discussed by a panel of experts from around Ireland who made up a virtual Multi-Disciplinary Team. The quality of presentations was of an exceptionally high standard and there was lots of discussion, input and valuable lessons learned from the

interactive sessions. The Terence Moran Award (named in honour of ILFA's esteemed founder and leader for 15 years) was awarded to the presenter of the best case presentation. This year, the Terence Moran Award was won by Dr Lucy Power, Specialist Registrar in Respiratory Medicine at Galway University Hospital.

Thank you to the Irish Thoracic Society and the ILD committee for their collaboration and willingness to support ILFA's remit to provide educational opportunities for healthcare professionals.

Cognitive Behavioural Therapy (CBT) Training Bursaries for 2023

ILFA is delighted to announce another round of educational bursaries to respiratory healthcare professionals working with lung fibrosis patients to study Cognitive Behavioural Therapy (CBT) online. The next course will commence in May 2023. There is always a lot of interest in the online course and healthcare professionals can contact ILFA by emailing info@ilfa.ie or calling 086 871 5264 for an application form as soon as possible.



European Respiratory Society Congress Travel Bursaries for 2023

ILFA is delighted to announce three bursaries for respiratory nurses, allied healthcare professionals, researchers, PhD students, and post-doctoral researchers to attend the 2023 European Respiratory Society (ERS) International Congress in Milan in Italy from 9–13th September 2023. The ERS Congress is an annual event that brings together the world's respiratory experts to showcase all the latest advances in respiratory medicine and science. Please contact ILFA by emailing info@ilfa.ie or calling 086 871 5264 for an application form as soon as possible.

Exercise

ILFA's Online Exercise Classes

ILFA's online exercise classes started in 2020 when the Covid-19 pandemic arrived and we were fortunate to have had input from an excellent group of talented respiratory physiotherapists to deliver the classes since then. The classes are growing in popularity and patients who join regularly are experiencing great health benefits. ILFA won an Irish Healthcare Award for Best Patient Organisation Project of the Year 2022 for our online exercise classes.

Many patients are waiting to take part in HSE hospital/community pulmonary rehabilitation classes but unfortunately there can be long waiting lists, and only small patient numbers can attend. Often pulmonary rehabilitation classes are limited to 8-weeks duration and once the course ends, any benefits of the exercise programme could potentially be lost as sometimes patients no longer have a routine or planned activity to maintain their fitness and health. ILFA's classes are not meant to replace formal HSE pulmonary rehabilitation programs but to enhance patient participation in exercise, especially for those on a pulmonary rehabilitation waiting list, and provide ongoing exercise opportunities when HSE courses are unavailable or end. ILFA is committed to continuing the classes once there is demand and you will be reassured to know that demand for the classes is very high!

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.

Eimear Bell is a talented respiratory physiotherapist with expertise, skills and knowledge of lung fibrosis including patients' oxygen requirements who leads the classes. Gemma O'Dowd and Anne Griffin, ILFA's administrative officers, organise the classes, provide support to patients who are not familiar with using Zoom, and actively monitor the class to ensure patient safety. Classes consist of breathing exercises and physical actions.

In February 2023, ILFA asked participants of the exercise classes to complete a short questionnaire. Here are some of the results.

- 87.8% of respondents to the ILFA survey were aged over 61 years.
- 46% were female and 54% were male
- 35% attended one class per week and 65% usually attended two classes per week.
- 98% strongly agreed/agreed that the classes are suitable for them.
- 90% strongly agreed/agreed that they looked forward to attending the class.
- 98% strongly agreed/agreed that they enjoy participating in the online exercise class.



- 100% can do the exercises.
- 100% would recommend the class to another lung fibrosis patient.

Quotations from participants

We asked respondents why they would recommend the class to another lung fibrosis patients and here are some of the comments.

"The exercise classes are ideally suited to pulmonary fibrosis patients coupled with the 'mindfulness' aspect of the sessions makes it quite a unique, enjoyable, and worthwhile experience."

"I am doing the class since July 2022, and I feel it is excellent and beneficial to my condition. Eimear the physiotherapist is excellent and very calm and understanding of the participants. Anne and Gemma are always overseeing the class to ensure smooth running and more particularly to keep an eye on all taking part in case of any mishap."

"I'd recommend the classes because they are modified to suit all abilities and incorporate chair-based and standing exercises depending on your ability. The facilitators are very helpful and friendly and Eimear (the physiotherapist), has a calm, clear approach."

"For people who have difficulty getting out and about, it can give structure to your day."

"The more exercise we do, the better!"

"It is beneficial for the body to combat the progressing disease process by strengthening the muscles. It is also good psychologically to be with fellow patients."

"Good combination of movement and breathing. Well explained. Good variation in activity types."

"The breathing exercises are very helpful in controlling panic. The input of other participants is very beneficial as you don't feel you're alone and the only one having a particular symptom/problem."

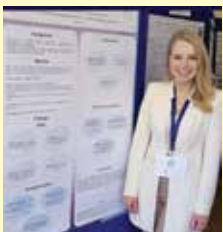
ILFA's online, award winning exercise classes for lung fibrosis patients take place every week and are free of charge to members. Classes take place every Monday, Wednesday and Thursday morning via Zoom. All are welcome to this friendly, supportive, encouraging space.

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 assistance to join the classes.



Irish Thoracic Society Annual Meeting 2022

The Irish Lung Fibrosis Association (ILFA) attended the Irish Thoracic Society Annual Scientific Meeting in Kildare on Friday 2nd December 2022. Gemma O’Dowd was delighted to represent ILFA and meet so many members of the respiratory community once again in person. Thank you to everyone who called by our exhibition stand to say hello and congratulate ILFA on our Irish Healthcare Award for our online exercise classes! A selection of photos of many of the respiratory healthcare professionals and industry representatives who visited the ILFA exhibition stand is included below.



Congratulations to Grace O’Sullivan, pictured left, Clinical Nurse Specialist at Cork University Hospital who was awarded the Jean Norton Award for Best Research Paper on Chronic Restrictive Pulmonary Disease for her presentation “Idiopathic pulmonary fibrosis and palliative care: a qualitative exploration of nurses’ experiences.”



Advocacy

The Human Tissue Bill and Organ Donation

On 29th November, the Human Tissue (Transplantation, Post-Mortem, Anatomical Examination and Public Display) was approved by the Cabinet. This was an important date for ILFA and the other patient organisations that make up the Irish Donor Network who have campaigned for years for the introduction of an opt-out organ donation system. Cabinet approval represents the first stage of this important Bill and includes enabling legislation for a national legislative framework for donation and transplant services in Ireland. The Human Tissue Bill is available to read on the Oireachtas website; <https://oireachtas.ie/en/bills/bill/2022/121/>

Statement from the Irish Lung Fibrosis

Association: "The Irish Lung Fibrosis Association (ILFA) warmly welcomes the publication of the Human



Tissue Bill especially the provision for the introduction of a soft-opt organ donation consent system.

ILFA has campaigned with members of the Irish Donor Network for an opt-out organ donation system, and we look forward to the benefits this legislation will bring with time. We urge the government, HSE and Department of Health to commit adequate resources and investment in infrastructure and personnel to ensure that organ donation and transplantation services in Ireland are maximised to their full potential."

ILFA encourages everyone to have a conversation and let your family know your wishes on organ donation. An organ donor can potentially save the lives of 8 people and organ donation is truly a gift of life for those in urgent need of a life-saving organ transplant.

"Tobacco-Free Europe"

The Irish Lung Fibrosis Association is proud to support the Irish Thoracic Society's (ITS) work on the European Citizens Initiative "Tobacco-Free Europe". We need your support to drive this initiative. Please read more below and sign the online petition.

The ITS has been working with the Tobacco Free Research Institute Ireland and Professor Luke Clancy who is co-ordinating the Irish limb of an important new European Citizen's Initiative (ECI) called Tobacco-Free Europe (TFE) just launched with the following 6 objectives:

1. Promote the first tobacco-free European generation by 2028, ending the sale of tobacco and nicotine products to citizens born since 2010.
2. Create a European Network of beaches and riverbanks, free of tobacco and cigarette butts, making these spaces more healthy and environmentally sustainable.
3. Establish a European Network of National Parks, free of tobacco and cigarette butts, making them healthier and reducing contamination and risk of fires.
4. Eliminate tobacco advertising and presence in audio-visual productions, and social media, especially addressing covert advertising through influencers and product placement.
5. Extend outdoor smoke and vapour free spaces, especially those frequented by minors (parks, swimming pools, sports events, and centres, shows and restaurants terraces).
6. Finance Research & Development projects for diseases caused by tobacco use to improve their prognosis and make them curable.



FIRST EUROPEAN TOBACCO FREE GENERATION

One million signatures are needed across at least 7 EU countries to compel the European Commission to consider this initiative.

In Ireland, the threshold number of signatures required is 9,165 by 15th January 2024.

Signing is quick and easy through the link available on the ILFA website (search News and Events section) or by searching <https://eci.ec.europa.eu/029/public/#/screen/home>

Research

Dancing for Health and Wellbeing

Poster Presentation at the Irish Thoracic Society Annual Scientific Meeting



Professor Vikram Niranja (pictured left) presented a poster at the Irish Thoracic Society meeting entitled “Wellbeing via dance caught my mind: A qualitative study exploring health impacts of online dance classes among patients with pulmonary fibrosis”. Professor Niranja’s research was conducted in collaboration with ILFA and supported by the Irish Research

Council. There was great interest in the use of dance as another potential exercise form to keep patients active and engaged in maximising their physical and mental health. Thank you to all the patients who participated in the pilot study and provided valuable feedback on their experiences.

Publication in the International Journal of Environmental Research and Public Health

Huge thanks and congratulations to Prof Vikram Niranja, Giampiero Tarantino, all the research team, Tracey Barnes (choreographer) and the enthusiastic ILFA patients who participated in this research project funded by the Irish Research Council. It is great to see the research published in the medical literature.

‘Dancing for Health and Wellbeing: A Feasibility Study of Examining Health Impacts of Online Dancing among Pulmonary Fibrosis Patients’ by Vikram Niranja, Giampiero Tarantino, Jaspal Kumar, Nicola Cassidy, Liam Galvin, Gemma O’Dowd, Tracey Barnes, Finola O’Neill, Matthew Cullen, Ray O’Connor, and Andrew O’Regan was published in the International Journal of Environmental Research and Public Health 2022, Volume 19, Issue 20, 13510.

ILFA’s Patient and Public Involvement Advisory Group

ILFA’s Patient and Public Involvement (PPI) Advisory Group was established in 2022 to assist ILFA and researchers undertaking research in pulmonary fibrosis by providing new perspectives, feedback, and suggestions. The core group consists of 15 members who are patients, carers, healthcare professionals and academics/researchers. The Chair of the

PPI Advisory Group is Sean O’Shea and he is ably assisted by two Vice-Chairs Paula Jenkins and Carita Bramhill (PhD Student).

The first virtual meeting of the group took place online on 27th September 2022 and following introductions and governance matters, 2

research projects (one in basic science and one a quantitative/qualitative study) being conducted in Ireland were discussed. The second meeting of the PPI Advisory Group took place on 25th February 2023, and we were delighted to welcome Dr Anne Marie Russell from the University of Exeter as a guest to the meeting and updates on 2 other research projects were provided.

Researchers who wish to include a PPI element in their research are invited to contact ILFA by emailing info@ilfa.ie.



ILFA Survey on the Impact of Pulmonary Fibrosis on Patients (2022)

Thank you to the 102 patients who responded to the 2022 ILFA Survey to determine the personal impact of pulmonary fibrosis including physical symptoms, emotional impact and financial cost. The results showed that;

- 52% of patients were male and 48% female.
- 69% were prescribed supplemental oxygen.
- 42% were unable to work or had to retire due to illness.
- Fatigue / tiredness, shortness of breath, disturbed sleep and coughing were the physical symptoms reported by most patients.
- Most people reported experiencing problems with climbing the stairs, exercising, household jobs, and hobbies/leisure activities.
- Most people reported experiencing feelings of “concerns for family”, “fear of getting an infection”, “anxiety”, “low mood” and “guilt or anxiety over a loved one being a carer”.
- Financial concerns include worries about heating costs, electricity costs, day-to-day living costs, the financial impact of pulmonary fibrosis on their spouse or family and their income.
- The average cost of the most recent electricity bill in July 2022 was €241. Considering varying billing periods, the average monthly electricity cost was €134*. (*Please note this cost is likely to have increased since July 2022 with the rise in energy costs)

Data from the survey is being used by ILFA in our advocacy work and an abstract (summary) has been submitted to the European Respiratory Society International Congress.

Awareness

Kerry Chronic Disease Respiratory Team

Dr Liam Chawke, Respiratory Consultant and the Kerry Chronic Disease Respiratory Team, pictured below, launched the Respiratory Service at University Hospital Kerry on Tuesday 22nd November. Dr Chawke was joined by Grainne Coffey, Clinical Nurse Specialist, and Senior Physiotherapists Julie Cournane and Johnny Crowley. The team helped raise awareness of pulmonary fibrosis and ILFA, as well as COPD. We wish them every success with the respiratory service.



Idiopathic Pulmonary Fibrosis and palliative care: A qualitative exploration of nurses' experiences.

Grace O'Sullivan, Respiratory Clinical Nurse Specialist at Cork University Hospital, has conducted some research into nurses' experience of palliative care for people living with Idiopathic Pulmonary Fibrosis. Grace has kindly agreed to share a summary of her work that was presented at the Irish Thoracic Society Annual Scientific Meeting in December 2022. You can read more below.

Symptom burden in Idiopathic Pulmonary Fibrosis (IPF) is evident and often multidimensional¹. National and international guidelines recommend early palliative care implementation^{2,3}. Despite this, inappropriate referral timing and delayed palliative care implementation in IPF has been identified as a common trend in recent years^{4,5}.

Thus, the aim of this research was to explore nurses' experiences in relation to the delivery of palliative care in IPF in the hope to improve future care. This qualitative description research design used purposive sampling to recruit nine participants. Inclusion criteria were nurses with a minimum of two years nursing experience, registered with the Nursing and Midwifery Board of Ireland (NMBI) and working within an acute hospital respiratory department. Data was collected over a ten-week period using semi-structured interviews and analysed with thematic analysis.

The results of this study suggested that the stigma associated with the term palliative care is one of the most common barriers to the timely implementation in IPF. This

stigma led by the palliative care misconception created a sense of fear and hopelessness for healthcare professionals, patients and families resulting in palliative care discussion avoidance.

Strategies to counteract such barriers were discussed within this study. Education was deemed as an essential strategy to breakdown this stigma to improve palliative care implementation and overall quality of life (QoL) in IPF. While ambiguity still surrounds the most appropriate implementation timing, it was suggested that palliative care implementation timing should be assessed on an individual basis, provided gradually however implemented at an earlier stage to reduce symptom burden.

This study highlighted that there is hope for change in the current practice of palliative care implementation in IPF. There is hope for greater palliative care understanding and with that improved symptom control and QoL as a result. The nursing profession appeared most proud of their advocacy role to assist with this.

References:

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4. Lindell KO., Liang Z, Hoffman LA, Rosenzweig MQ, Saul MI, Pilewski JM, Gibson KF & Kaminski N. (2015) Palliative care and location of death in decedents with idiopathic pulmonary fibrosis. *Chest*, 147(2), 423-429.
5. Rush B, Wiskar K, Griesdale D. (2016) The use of mechanical ventilation in patients with idiopathic pulmonary fibrosis in the United States: a nationwide retrospective cohort analysis. *Respiratory Medicine*, 111,72-76.

Share Your Story



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

Email info@ilfa.ie or call 086 871 5264



The West Kerry Tractor Run

ILFA is grateful to the organisers of The West Kerry Tractor Run also called 'Mórchúaird Tarracóra Chorca Dhuibhne' that took place in November 2022. We are especially thankful to JP O'Sullivan and family, the enthusiastic participants, and the generous supporters of this fantastic event. A report of the event from Michelle O'Sullivan is included below. We would also like to thank The Kerryman newspaper and Kerry's Eye for helping

raise awareness of lung fibrosis and ILFA's work by publishing two great articles and highlighting the Tractor Run fundraiser. JP O'Sullivan and Annette Cremin from Dingle were interviewed and shared their stories in The Kerryman and Kerry's Eye respectively. Huge thanks to Manuela dei Grandi (Kerry's Eye) and Declan Malone (The Kerryman) for permission to use some of their lovely photos.



Report from Michelle O'Sullivan: "The West Kerry Tractor Run took place on 27th November 2022 and was an enormous success. The 2022 event has so far raised over €16,000 for charity thanks to the exceptional generosity of the local community and supporters of the event. The money will be divided equally between the Irish Lung Fibrosis Association and Gairdín Mhuire day care centre in Dingle, with a donation also going to the West Kerry Mental Health Association.

An incredible 115 tractors from all over Kerry took part in the event that started in Lios Póí and travelled via Dingle, Ventry and Reasc before returning to town. The wonderful staff at the Marina Inn provided free and much appreciated warm food to the participants.

To date, the tractor run has raised over €80,000 since it began, and our main beneficiaries have used these funds to great effect. Gairdín Mhuire (West Kerry Care of the Aged) purchased a Mercedes sprinter minibus helped by monies raised by the West Kerry Tractor Run. It is wheelchair accessible and transports clients from all over the peninsula to the day care centre in town where they can participate in many activities and receive a three-course meal. They have recently opened a brand-new kitchen and are providing a Meals on Wheels service. We hope that funds from this year's tractor run will be able to contribute to running costs of this delivery service.



JP O'Sullivan and his grandchildren.

Improvements in detection and intervention mean that there are over 1,000 people now living with pulmonary fibrosis in Ireland. The Irish Lung Fibrosis Association continues to be an incredible support to these patients, in addition to helping to educate and research this devastating illness.

The success of the tractor run so far would not have been possible if it was not for the generosity of the West Kerry community."

Mayo University Cycle Club take on the Tour de Achill for ILFA

The Irish Lung Fibrosis Association is enormously grateful to the Mayo University Cycling Team for choosing our charity as the recipient of their 2022 cycle. This was a great honour for ILFA, and we would like to extend our warmest thanks and appreciation to all the team and especially to Deirdre Garvin and John Kelly for all their help and drive to make the fundraiser happen. A fantastic sum of €10,568 was raised for ILFA by the team who organised several fundraising events.

Nicola Cassidy, ILFA Director, visited Mayo University Hospital in October to visit the group and attend a cheque presentation. Nicola said "I received the warmest of welcomes at Mayo University Hospital and had enjoyed meeting with members of the cycling team. I loved hearing their stories about their training, the Tour de Achill, and the fun they had with the Staff Turbo Challenge and Bake Sale. It was a real pleasure to meet everyone and to have the opportunity to thank them for their great efforts, enthusiasm, and generosity. This was a very kind, warm and special group of people who clearly love their patients and wanted to make a difference. Everyone at ILFA is enormously grateful to the team and their supporters."

Report by John Kelly, Pharmacist at Mayo University Hospital: "A group of staff members from Mayo University Hospital came together in 2019 to take on the challenge of a fundraising cycle on the Ring of Kerry. Some had extensive cycling experience while others were glad to realise that getting back in the saddle after many years is 'just like riding a bike!' All members rose to the challenge despite a very wet day in the southwest and they succeeded in raising a four-figure sum for the chosen charity.

After a couple of years of lockdown restrictions, the cycling group reformed and expanded. The Irish Lung Fibrosis Association (ILFA) was identified as a very worthy recipient for funds raised. The cycling group thought of the many patients past and present that attended the hospital for management of lung fibrosis. We knew of the great work done by ILFA in the provision of support and advocacy for those with lung fibrosis as well as raising awareness of this debilitating condition, and we were excited by the opportunity to contribute to their efforts.

In 2022, we decided to stay closer to home and signed up to the 'Tour de Achill' on 3rd September 2022 that was hosted by the Achill Wheelers Cycling Club. A magnificent day in Achill ensued with blue skies and calm weather conditions lending to a successful completion of the event by all participants.

Here are some photographs of the participants.

The fundraising efforts of the group were supplemented after the 'Tour' when a cycling Turbo Challenge and Bake Sale were co-ordinated by Colm Keane and Head Porter Peter Grealis in the hospital. We received many generous contributions by hospital staff and visitors as well as from some local businesses to this effort.

In October 2022, we were delighted to welcome Nicola



Tour de Achill Cycling Team.



Nicola Cassidy from ILFA accepting the presentation cheque from the Mayo University Hospital Cycling Team.



Health Care Assistant, Eamon Coyne was warmly greeted at the finish line by his son Eamon Óg.

Cassidy from ILFA to accept our contribution to the enormous efforts that are ongoing by ILFA for patients and families who were to the forefront of our minds throughout all our activities and preparations. Our final fundraising contribution was more than €10,500."



Novice cyclist and Pharmacy Technician Eimear Callaghan professed not to have been bitten by the cycling bug and has yet to sign up to her local cycling club in Crossmolina. Eimear is pictured with family members Laura, Ian, Enda and Damien.



Dr Colm Keane was the first of the group past the post in the 110k event but unfortunately could not be awarded the prize as it was discovered that he had taken a shortcut on the return from Keem.



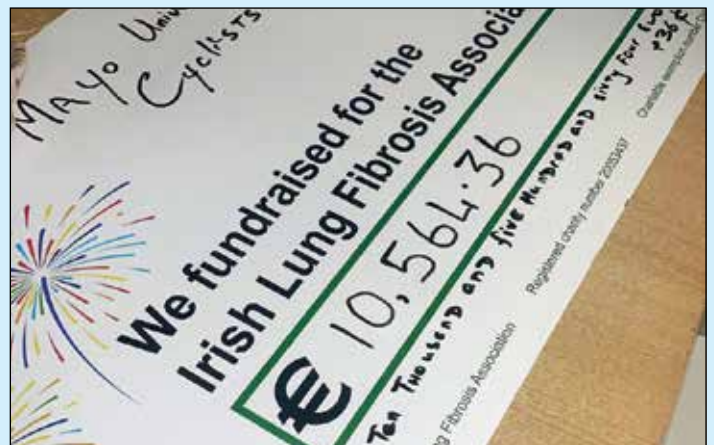
Cyclists from the Stores Department, Keith, Chuck and Seán, revealed their vast cycling experience by opting for the 62km event and finishing the sandwiches before the more conscientious participants completed the longer course.



Physiotherapists, Isaac and Deirdre, took time out to enjoy the spectacular Achill scenery. Keep an eye out for these two in the 'Rás' in the future.



John Kelly, Deirdre Garvin and Eamon Coyne.



Presentation Cheque.



Turbo challenge.



Staff at Mayo University Hospital supporting the Bake Sale and Turbo Challenge.

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. We are delighted that sporting and social events have now resumed after the pandemic and hopefully this means there will be more fundraising opportunities available to ILFA's supporters. 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.

Tea Parties in aid of ILFA

Stella O'Sullivan and her family held a Summer Afternoon Tea Party in August to raise funds for ILFA in memory of their dad Tony Murphy. The family raised €300 for ILFA and we are so grateful for their support.



Anne Oglesby from Carlow held a wonderful tea party for family and friends in aid of ILFA and raised a fantastic amount for ILFA in 2022. There were all sorts of activities organised for the young and the young at heart. Thank you to everyone who donated so generously. Here is a report from Anne.

"Thanks to everyone for their help and support at the garden party. It was a huge success. Everyone said they had a terrific time. It worked out very well. All the young families gathered to the back of the house watching their children and grandchildren have fun on the water slide, zip line, swings,



trampoline, and the age-old game that brings everyone together wherever they come from - football. It was the last day of the heat wave, so all the 'golden oldies' gathered under the tree at the front reminiscing over times past, as we do. A great big thanks to Anne Griffin for announcing the event on the ILFA Facebook page. Thanks also to Kitty Collins for setting up a JustGiving online donation page, to Collette and Jimmy Harper and Liz Kelso for bringing tables, chairs, cups, saucers, tea urns and tea pots from the Presbyterian Church in Carlow with kind permission from Rev Steven Ray. Thanks to Kelly's for lending the field to park cars. I'm grateful to Eilish Murray for setting up tables and tablecloths and to Tina Whelan and all who brought sandwiches, cakes, and finger food. Special thanks to my lovely friends who came all the way from England, Ann, and Catherine. We had a great time especially picking sunflowers for the picnic tables. It wouldn't have been possible without my lovely daughter Jacqueline and my gorgeous grandchildren Miriam, Noah and Caleb - thank you so much for all your help and support, it was greatly appreciated. €1,750 was raised for ILFA, thanks to everyone who donated very generously to this cause."

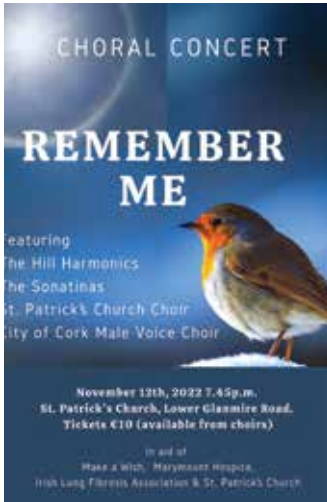
PatientMpower Annual Team Walk for Pulmonary Fibrosis



Thanks to all the team at patientMpower for their kind donation to ILFA, their great support, and help raising awareness of pulmonary fibrosis. The team took part in the patientMpower Annual Team Walk for Pulmonary Fibrosis in September 2022!

Pictured left to right are Eamonn Costello (and this dog Charlie below), Oisín Hayes, Rebecca Bourton, Amy Boulstridge, Joseph Vincent (top) and Cillian O'Brien.

'Remember Me' Choral Concert



William Sisk is a member of ILFA and a pulmonary fibrosis patient who sings with the City of Cork Male Voice Choir. William and his choir kindly selected ILFA as their charity to benefit from fundraising at a concert. On 12 November 2022, a Choral Concert took place in St Patrick's Church, Lower Glanmire Road, Cork. The concert was entitled 'Remember Me' and featured 'The Hill Harmonics', Watergrass Hill, 'The Sonatinas', Glanmire 'St

Patrick's Church Choir', St Patrick's Church, and the City of Cork Male Voice Choir.'

Each choir chose a charity for the proceeds to be shared with. The charities are (1) Make a Wish (2) Marymount Hospice and (3) Irish Lung Fibrosis Association (ILFA). This was the first performance since Covid began and the choir members were very excited to get together for the performance on 12th November.

Sportsworld Running Club



On 6th December, Sportsworld Running Club held a cake sale in their clubhouse at Bushy Park, Terenure, Dublin. This is an annual event which they hold to raise funds for a selected charity.

This year they decided to donate the proceeds to ILFA, in memory of Dorothy Beacom, who sadly passed away last December. Dorothy, was a member of the club in the 90's and regularly took part in the Meet and Train races, and the Sunday morning runs held in Bushy Park, but also developed great friendships which went beyond the sphere of running. On the night, members, and friends, through their generosity raised €1,100, which was presented to Dorothy's husband, Mark, as a donation to ILFA.

We are very grateful to Emily Dowling, and the rest of her team at Sportsworld, for this gesture.

Hell and Back Challenge



Huge congratulations to Shane Cloake and his pals Derek, Alan, and Brian on completing the notorious Hell and Back Challenge for ILFA on Sunday 19th February 2023 at Killruddery Estate in Co Wicklow. The before and after photos of the team showed that the ILFA T-shirts fared quite well considering the many challenges and mucky conditions of the event named "Ireland's Toughest Challenge". We are so grateful to Shane, Derek, Alan and Brian for their bravery, determination and kindness in taking on the challenge to support ILFA's work. Mile buiochas!

"My Eileen" – A Collection of Poems by Tom O'Sullivan



Tom O' Sullivan from Malahide, Dublin has produced a beautiful booklet of his poems written in memory of his wife Eileen and in tribute to her many skills. Tom describes how his poems represent his reflections on the life he shared with Eileen. Tom's grand-daughter has also written a lovely poem entitled "Poem for Gran" that is included in the booklet. Please contact Tom on 087 285 3031 if you would like to receive a copy his beautiful poetry collection. Tom would like

to raise funds for ILFA and has set up an online fundraising page for donations. The fundraising link is <https://www.justgiving.com/fundraising/tom-o-sullivan5>

2000 Steps Extra for ILFA!

Join ILFA for our Easter Monday 2000 Steps Extra virtual walk/run on Monday 10th April. We want patients, carers, family members, healthcare professionals, and our supporters to exercise and take at least an Extra 2000 Steps (approximately 1 mile) to raise awareness of lung fibrosis and raise funds to support ILFA's work.

You can take part from anywhere - near to home, out and about, and while on holiday! The important goal is to challenge yourself and step it out for health!

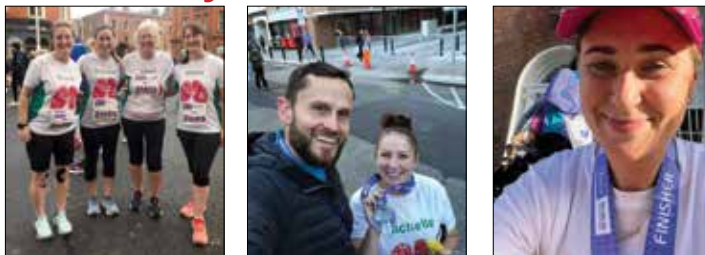
Donations can be made online if you would like to support ILFA's 2000 Steps Extra Challenge. See the Donation Page at www.ilfa.ie for a range of options.

If you would like to take part, please contact ILFA, and we will send you a fundraising pack. Remember to take a photo and log your step count with us! We'll have fun counting the total steps taken to see how far we reach! Contact ILFA on 086 871 5264, 086 057 0310 or email info@ilfa.ie



We would also appreciate if you would nominate ILFA as a charity to your local Tesco Store or to another supermarket chain that supports good causes in the future. Nomination forms for the Tesco Community Fund are available online at www.tesco.ie/communityfund

Dublin City Marathon 2022



The Dublin City Marathon took place on Sunday 30th October 2022. A full report of the marathon is included on pages 18 and 19. Here are some additional photos of the 11 ILFA superheroes who took part.

Raheny 5 Mile Road Race



The AXA Raheny 5 Mile Road Race took place on 29th January 2023 and a group of running pals took part wearing their ILFA T-shirts. Well done and thank you to Birgit Kretschmann, Janet Day, Nicola Cassidy, Helen Leahy, Morwenna Quinn and Sheila Plunkett for raising awareness for ILFA. The distinctive ILFA t-shirts were easy to spot, and the ladies got lots of encouragement and support from the spectators.

Christmas Cards

Thank you to everyone who supported ILFA's Christmas Card campaign in 2022 and helped raise awareness and valuable funds for the charity. Your generous support was very much appreciated.



Birthday Fundraising

Thank you to everyone who has set up a Facebook Fundraiser for ILFA to support our work. We are very grateful for your support and the donations from your friends and family.

Tesco Community Fund



We're thrilled that the Irish Lung Fibrosis Association was included in a round of the Tesco Ireland Community Fund in Temple Bar Metro Store and Jervis Store supermarkets in Dublin. We're grateful to everyone who voted for ILFA with their community fund blue tokens! As Tesco say, "Every little helps!"

VHI Women's Mini Marathon and Cork Marathon



Calling all ladies - grandmothers, mothers, daughters, aunts, cousins, sisters, and friends. please consider running/jogging/walking the VHI Women's Mini-Marathon on Sunday 4th June in aid of the Irish Lung Fibrosis Association. Register via www.vhiwomensminimarathon.ie

and contact ILFA for your fundraising pack. Email info@ilfa.ie or call 086 871 5264. We would love to welcome you to #TeamILFA. The Cork marathon, half-marathon and mini-marathon will take place on Sunday 4th June. Please consider fundraising for ILFA if you are taking part. Register at www.corkcitymarathon.ie

Please support ILFA

The Irish Lung Fibrosis Association (ILFA) was established in November 2002 to provide education, research and support to patients and families affected by lung fibrosis. The charity has thrived thanks to the generosity of people who have supported us with volunteering, fundraising, sponsorship, and donations. ILFA relies on the generosity of our supporters to fund our advocacy work, research initiatives and patient-centred activities.

We would appreciate your support to help the charity continue to provide education, research and support to lung fibrosis patients, caregivers and healthcare professionals working in respiratory medicine. Rest assured, no donation is too small and all donations are gratefully received. Thank you!

Making a Donation to the Irish Lung Fibrosis Association (ILFA)

If you would like to help, there are several ways to make a secure donation to the Irish Lung Fibrosis Association (ILFA) and we hope you will find a method that is convenient for you. Please ensure you use the correct name for our charity to guarantee that ILFA receives your donation.

On-line donations for ILFA

You can donate easily and securely to ILFA directly using your debit or credit card via the ILFA website, www.ilfa.ie

Just Giving: You can donate easily and securely to ILFA directly using your debit or credit card via the online site www.justgiving.com and searching for 'ILFA'. A small percentage fee is applied when using this platform, but donors can choose to pay this to ensure ILFA benefits from 100% of the donation.

Facebook Fundraising: ILFA uses Facebook Fundraising making fundraising campaigns easy and secure for ILFA's Facebook friends and followers. 100% of donations go to ILFA.

www.facebook.com/fund/ILFAIreland/

Paypal Giving Fund: ILFA Ireland has been added to Paypal Giving Fund. When you donate to PayPal Giving Fund through this page, 100% of your donation will go to ILFA -

<https://www.paypal.com/ie/fundraiser/charity/4043546>

Standing order

Why not consider making a regular contribution of your choice to ILFA using a standing order? A standing order form is available from ILFA or can be downloaded via the website www.ilfa.ie for your convenience. Once completed, the form can be returned to ILFA and forwarded to your bank for processing.

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 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 support 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.

Partnering with ILFA

There are many ways your company, business, society, sporting body, school, college, or club can be involved in supporting the work of ILFA. We would be delighted to work with organisations of all sizes seeking a charity partner through corporate social responsibility or simply giving back to society to help raise awareness and valuable funds. In return, we will support your campaign with ILFA branded merchandise and fundraising assistance, and will gratefully acknowledge your support online, in print and via social media to recognise your commitment to charity. Please consider ILFA as a potential partner for the future and help make a difference. Contact ILFA on 086 871 5264 or email info@ilfa.ie for more information. If your local supermarket has a scheme for donating to a charity, and have time to nominate ILFA, we would be delighted to help you with the process.



#Team ILFA at the Dublin City Marathon 2022

The Dublin City Marathon took place on Sunday 30th October 2022 and ILFA was delighted to have the support of so many marathon superheroes taking part and raising awareness and funds, wearing their ILFA t-shirts with their names proudly displayed!

Huge congratulations to Deirdre Moss, Michelle Digan, Deirdre Kennedy, Janet Day, Steven Lacey, Simon House, Keith Whelan, Paul Giles, Sinead Doyle, Niamh English, and Nicola Cassidy (ILFA Director) on crossing the finishing line after 26.2 miles! What an inspiring bunch of people!



Running in Memory of Dad

By Deirdre Kennedy, pictured above

I ran the Dublin City Marathon in October 2022 in memory of my Dad, Michael Kennedy, and to fundraise for the Irish Lung Fibrosis Association (ILFA), a charity close to my heart. My Dad suffered from pulmonary fibrosis and ILFA was a huge support to my Dad and our family as we navigated our way through his diagnosis and subsequent transplant journey.

My Dad was blessed to receive a lung transplant in 2012 and this gave him 7 more years of living. This was a gift my dad never took for granted and he was so grateful to his donor. His post-transplant journey came with many challenges but his determination and "keep going" attitude never faltered. He battled daily to do things most of us take for granted and as a family we were always in awe of his strength and determination.

My dad would have celebrated his 80th birthday in September this year and I wanted to do something to mark this significant birthday. It wouldn't have been a fitting tribute to my dad if it didn't involve hard work and a challenge,

so I decided to do the marathon. As the marathon date approached, I could feel the nerves building. Running in memory of my Dad and knowing that people had given so generously to my fundraiser brought some additional pressure but also I was delighted to be back running after several years and thankful to have made it to the start line. The morning of the marathon I met up with some other ILFA runners, it was lovely to see some familiar faces and to see others wearing their ILFA t-shirts. The support around the marathon course was amazing and as it was the first year the marathon was back on since Covid I think people really came out in force. Of course, I had my own band of supporters with my Husband, my siblings, my mum, and all of Michael's twelve grandchildren all out cheering me on.

It was a privilege to be able to complete the 26.2 miles in memory of my Dad and all of those who have been and continue to be affected by lung fibrosis. ILFA are a great source of support both for patients and families and continue to remember those who have died from lung fibrosis. ILFA host a beautiful Ecumenical Service of Prayer and Reflection each year for those who have died from lung fibrosis and these events offer an opportunity for those who are grieving to come together and remember their loved ones. As a family we met so many lovely people through ILFA and I know my Dad would be pleased that we continue to fundraise for ILFA so that they can continue to support all those who need it. Thank you so much to everyone who donated so generously, I was delighted to have raised €3,011.49 for ILFA.

Team work

Three members of staff from the National Poisons Information Centre at Beaumont Hospital ran the Dublin City Marathon on Sunday 29th October 2022. Niamh English, Sinead Doyle, and Nicola Cassidy trained for months and shared many, many conversations about mileage, nutrition, sore feet and running tactics. In fact, it was non-stop running talk for quite a few months! The 3 work pals ran the iconic 26.2 mile course to raise funds for the Irish Lung Fibrosis Association. They were thrilled with their achievement and are grateful to everyone who sponsored them. The ladies raised over €3,000 for ILFA between them.

Niamh English said "My first marathon took place last October in Dublin. What an amazing experience. I am very lucky to call Nicola and Sinead great friends, so I was delighted to join them supporting ILFA. Nicola and I trained together. We trained hard, we committed to running milestones that I had never reached before, and were both



Marathon effort: Niamh English, Sinead Doyle, and Nicola Cassidy from the National Poisons Information Centre at Beaumont Hospital.

very happy with our progress. On marathon day, we knew we were well prepared. It was tough. And it wasn't that we weren't expecting it to be tough, but we had trained so well that when I 'hit the wall' at 13 miles, I was kind of stunned. Nicola pulled me through, and we soldiered on for the second half! It was thinking of ILFA patients, families, and friends and that got me through to the end. And we got there. We made it! And boy were we so proud of our achievement! So proud in fact that we're going to do it again next October!"

Sinead Doyle said "In 2022 I won the marathon lottery ... Having had a gentle nudge from my good friend and colleague Nicola Cassidy, I decided to enter the competition to compete in the Dublin City Marathon 2022. In January, my entry was guaranteed, and I set to training with great encouragement and advice from Nicola and Niamh. In the lead up to race day, the support from everyone at ILFA was amazing, but that was just the start. Race day arrived and celebrity status soon kicked in. With my name printed on my ILFA T-shirt, the cheers from the crowds of "Go Sinéad" and "Go ILFA" really spurred me on. It is my proudest accomplishment to date, and I was honoured to represent ILFA on the day."

Nicola Cassidy said "I was delighted and humbled when my 2 lovely colleagues said they would run the marathon and fundraise for ILFA. It meant the world to me to have them on #TeamILFA raising funds for the charity that is so close to my heart. It was great to have Niamh's company on the course and we encouraged each other constantly. As we ran, we dedicated each mile to someone special and this gave us added determination to keep moving especially when we encountered so many tough hills! Around mile 25, we spotted another ILFA t-shirt and managed to catch up with Michelle Digan. The three of us crossed the finish line together feeling energised by the wonderful encouragement from the crowds and having strength in numbers. We were so proud of our achievement and so grateful to our supporters for their kindness and generosity."

My First Marathon

"The Dublin City Marathon in 2022 was my first marathon and I ran with my friends Keith, Housey, and Stephen. Having our names printed on our ILFA T-shirts was great as we got lots of encouragement and cheers from spectators and supporters all along the 42km route. I thought of my auntie Denise



Paul Giles, third from left with his running buddies, Keith, Stephen and Housey.



Cassidy when running and was delighted to raise awareness for ILFA. My cousin Nicola also took part, and the family were tracking us as we ran the course causing great excitement and commentary in the family WhatsApp group!!! Thanks to everyone for their encouragement and support. My first marathon will always hold a special place in my heart."

Paul Giles, Dublin



"Running and completing the Dublin City Marathon in 2022 was a wonderful experience and I loved every minute of it! The atmosphere was electric, and some highlights included 'high fiving' nearly every child in the city, being spurred on by the cheering crowds, and meeting some lovely people along the way. I was particularly happy and proud to wear my personalised ILFA t-shirt along with the rest of the group."

Janet Day, Dublin

Patient Support Groups

ILFA is delighted to announce that our support groups are resuming their face-to-face meetings around the country, and they look forward to reacquainting with old friends and welcoming new members. For more information, please contact the leader in your area (details are included below). ILFA asks that support group members do not attend the face-to-face meetings if feeling unwell in order 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

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 committment. 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 25th March 2023 online via Zoom. See page 1 of the newsletter for more information.
- **ILFA 2000 Steps Extra Virtual Fundraising Walk** will take place on Easter Monday 10th April 2023. 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 4th June 2023.
- **Cork mini-marathon, half-marathon, marathon** on Sunday 4th June 2023.
- **Dublin City Marathon** on Sunday 29th October 2023.

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.