

ILFA Newsletter



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

Issue: Autumn 2021

Volume 19 Issue 2

© ILFA 2021

Irish Lung Fibrosis Association
www.ilfa.ie

Dublin Minor Footballers Pedal the Perimeter of Ireland for ILFA

Everyone at ILFA was delighted when the Dublin Minor Footballers and Management Team contacted us to let us know that they would fundraise for our charity. ILFA's patron and former Dublin Senior Footballer, Michael Darragh Macauley, had nominated ILFA to the Dublin Development Squad of 2021 when they said they would like to organise a fundraising activity.

The team decided to cycle the perimeter of Ireland; an impressive 3,171km distance with each team member committing to cycle 50km. The team chose the fundraising target of €3,171 to coincide with the distance they would cycle. The online fundraising page got off to a flying start and within a very short time, the target had been reached, and kind donations continued to be made. There was great excitement in the lead up to the event and David Reynolds kept us informed of all the developments. Ger Lyons, Manager of the Dublin Minor Footballers was interviewed on the Dubs TV channel and did a fantastic job raising awareness of ILFA's work and the charity cycle. The clip was posted on social media and had a huge reach helping to raise awareness and encourage people to donate to the cause. The cycle also featured on the home page of www.dublingaa.ie website which generated great awareness especially among GAA enthusiasts.

The charity cycle took place early on Sunday 25th April 2021 and thankfully the weather was very kind! More than 50 cyclists from all over Dublin enthusiastically set off on their bikes to take on their personal 50km challenge. Social media was buzzing with photos of the cyclists at the start and end of their cycles, and everyone completed the challenge with great times. In the afternoon, the team gathered online via Zoom and ILFA Director, Nicola Cassidy, and ILFA Ambassador, David Crosby, joined Michael Darragh Macauley to convey congratulations to all the participants and express our warmest thanks and appreciation to everyone for raising valuable funds and awareness of lung fibrosis. Nicola, David, and Michael Darragh spoke about their involvement with ILFA and the impact that the fundraising will make to progress ILFA's work.



It was heart-warming to see the young athletes and their management team after their heroic efforts for ILFA.

Ger Lyons said "The "Pedal the Perimeter" cycle was a huge success, and the team raised an incredible €10,600 for ILFA. We were overwhelmed by the generosity of everyone who supported them and donated so generously."

ILFA Chairman Eddie Cassidy and Nicola Cassidy had the pleasure of meeting the Dublin Minor Football Players and Management Team recently for a cheque presentation after one of their training sessions. Eddie took the opportunity to thank everyone for their efforts and helping raise valuable awareness of lung fibrosis. Ger Lyons said "Thanks so much for coming out to meet the boys. The fundraising cycle has been the highlight of our year to date, and I wish you all every success with the great work that is going on with ILFA."

The ILFA committee would like to extend special thanks to David Reynolds, Ger Lyons and Michael Darragh Macauley for their enthusiasm and help with the event. It was a great honour for ILFA to partner with the Dublin Minor Football Team and we're enormously grateful to everyone for the amazing support. Mile, mile buiochas!

Patient Information Day

The next Patient Information Day will take place online on Saturday 11th September from 11am until 1pm. The meeting will take place using the Zoom online platform.

Our speakers will include Professor Killian Hurley (Respiratory Consultant, Beaumont Hospital), Dr Anne Marie Russell (Senior Lecturer & Research Lead, University of Exeter), Dr Anne Marie Doyle (Clinical Psychologist,

Royal Brompton Hospital, London), Dr Kate Devenney (Physiotherapist, School of Allied Health, University of Limerick), and Professor John Baugh (Research Lead, UCD School of Medicine and UCD Conway Institute of Biomolecular and Biomedical Research).

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 on www.ilfa.ie

ILFA held an online World Café workshop on Saturday 12th April with 72 stakeholders; patients, caregivers, healthcare professionals and industry partners. The aim of the event was to determine our stakeholders' experiences around care services for pulmonary fibrosis, both before and during COVID-19, and to capture ideas for future improvements.

Approximately 1,000 people in Ireland are living with pulmonary fibrosis however, ILFA is aware of inadequacies in care delivery for those diagnosed with the condition. It has been proposed that many of the issues around the accessibility and quality of care for pulmonary fibrosis could be resolved by the development of a national clinical care programme for pulmonary fibrosis, as exists for other diseases. The National Clinical Programmes provide a framework for care delivery in the Irish health service, with the stated aim of improving the quality, access and value of healthcare in Ireland. There are currently 31 programmes running across multiple conditions or areas of specialty. Unlike other serious lung conditions, including COPD, asthma and cystic fibrosis, there is no national clinical programme for pulmonary fibrosis. The Irish Thoracic Society (ITS) has previously recommended the establishment of a National Clinical Programme for Idiopathic Pulmonary Fibrosis (IPF) in the 2018 update to the ITS Position Statement on the Management of IPF. Despite the publication of this important document, and from recent ILFA correspondence with the HSE, we are not aware of plans to include pulmonary fibrosis in any national clinical programme, either as a separate disease or under the umbrella of respiratory medicine.

An ILFA stakeholder survey conducted in 2020 showed patients, caregivers and healthcare professionals ranked advocating for a clinical care programme for pulmonary fibrosis as the most important area of ILFA's advocacy work. The "ILFA World Café on Pulmonary Fibrosis Services in Ireland during COVID-19 and Beyond" was developed to document stakeholders' experiences around care access for pulmonary fibrosis, both before and during the COVID-19 pandemic, to better understand the challenges in obtaining and providing high quality pulmonary fibrosis care, and gain insights on priorities for future care. ILFA was enormously grateful to receive funding from The Community Foundation of Ireland/RTE Does Comic Relief Adapt and Respond fund and Roche Pharmaceuticals Ireland to help support this important project.

The programme for the World Café and discussion themes were developed by ILFA in collaboration with Tony Shone (Invisio Ltd), Dr Anne Marie Russell (Senior Lecturer University of Exeter, UK) and Dr Eoin Judge (Respiratory Consultant, Connolly Hospital). To ensure the smooth running of the event, a team of enthusiastic and capable facilitators, note-takers and speakers was put together and they did a superb job.

On 12th April, Eddie Cassidy, ILFA Chairman, welcomed all the participants to the virtual World Café and thanked everyone for their time and willingness to participate. Next ILFA Patron, Michael Darragh Macauley, delivered the shortest yoga class in the history of the world and asked everyone to take part in a series of gentle exercises while focusing on their breathing. After energising the group, he handed the reins over to Dr Anne-Marie Russell who explained the aim and logistics of the event. Dr Eoin Judge delivered a presentation on the current situation of the pandemic and the resumption of healthcare services for pulmonary fibrosis as the COVID-19 vaccination programme accelerates.

Next, the participants were separated into small groups in which they discussed a series of four pre-defined topics for a specified time. Each topic discussion was hosted by a

ILFA World Café on Pulmonary Fibrosis Services in Ireland during Covid 19 and beyond

facilitator and a note-taker, who led the discussions, captured the participants' feedback and then rotated to a different group at the end of the allotted discussion period. The four questions posed for discussion are shown below.

World Café Topics for Discussion

Diagnosis: Thinking about your own experiences, we are interested to know about the barriers you may have encountered in being diagnosed and what you think could be done to make these processes better?

Healthcare supports: Please think about any difficulties you encountered in accessing healthcare supports such as pulmonary rehabilitation, dieticians, social work support, etc. for pulmonary fibrosis, and how patient access to these services can be improved as part of an overall clinical care programme?

Emotional and psychological support: What challenges (if any) did you encounter that prevented you from accessing emotional and psychological support for managing pulmonary fibrosis, and what would you like to see being offered to support those with pulmonary fibrosis and their families, as part of an overall clinical care programme?

Care integration: Is there sufficient integration of care between the hospital and the community for pulmonary fibrosis - what challenges exist that prevent you from easily accessing Integrated (community) care and virtual care. In an ideal world, what would community care integrated with hospital care look like as part of an overall clinical care programme?

The essence and emerging themes of the event were captured through the medium of live art with artist Philip Barrett, who created some stunning pieces. After the data gathering discussions, Professor Gaye Cunnane, Director of Health and Wellbeing at the Royal College of Physicians of Ireland, shared her valuable insights on the importance of tolerance, self-compassion, and hope in maintaining wellbeing during the pandemic. This session was followed by a discussion on the emerging themes from the participants that was chaired by Dr Anne Marie Russell, with contributions and insights from the workshop facilitators.

At the closing session, participants were treated to wonderful performances from two talented musicians. Firstly Moya Brennan, singer, and songwriter, lifted us all with her beautiful voice and sang "Down by Sally Garden". Several people joined in (while on mute) and everyone was lifted by Moya's performance. Next Harry Carpendale, harpist, performed a wonderful piece he had composed specifically for ILFA members and friends. It was a beautiful composition that everyone appreciated.

The World Café was a great success, and this is due to the hard work of everyone involved. Thanks to everyone who contributed and to our sponsors.

Findings from World Café Event



The findings of the ILFA World Café event clearly show that a National Clinical Programme for pulmonary fibrosis

is required. There is international concern that post-COVID lung fibrosis (a complication of COVID-19 infection) will place even further pressure on already stretched pulmonary fibrosis services. Urgent engagement between policy makers and other pulmonary fibrosis stakeholders is required to develop and implement a National Clinical Programme for Pulmonary Fibrosis.

High Unmet Care Need

The World Café meeting demonstrated that there are significant unmet needs in the diagnosis and care of people with pulmonary fibrosis. The discussion revealed most patients, and their caregivers, do not have the access to the care or the support services they require for management of their disease.

Inequality in Care Access and Quality

The issue of inequality in care access and the quality of care for pulmonary fibrosis depending on patients' geographical location arose in all discussions. Often referred to as a "postcode lottery" patients described significantly different care experiences depending on which interstitial lung disease (ILD) specialist center they are referred to, and the support services available to them locally.

Similarly, healthcare professionals discussed differences in specialties or services available within their center or multidisciplinary team and the difficulties in referring some patients to healthcare supports in their local area.

Negative and Positive Impact of COVID-19 on Care Access

Discussion on the impact of COVID-19 on care delivery ran throughout stakeholders' conversations. COVID-19 had clearly negatively impacted patients' access to face-to-face care and clinic assessment. However, it was noted there were also benefits arising from the greater use of new alternative models of care - with virtual pulmonary rehabilitation

programmes being very highly regarded by many patients. Preference for face-to-face versus virtual care differed between individuals, and there was general support for a blended or hybrid face-to-face and virtual care model being used for the future.

Feedback on the World Café Event

Fifty-three participants (74%) completed a feedback survey after the event. Over 96% of those who provided feedback agreed or strongly agreed that the World Café was helpful and 92% agreed or strongly agreed that they were able to get their views across during the event. In response to the question "What are the three things you found most useful about the workshop" there was wide agreement that the small group, multi-stakeholder approach of the World Café was a useful way of gaining insights from those on both the "user" and the "provider" side of pulmonary fibrosis services.

Next Steps

The report of the World Café is in progress and will be available shortly. ILFA will work with the Irish Thoracic Society and leading healthcare professionals in advocating for further advances in care for pulmonary fibrosis patients and caregivers. We plan to use the results of this research as evidence for the inadequacies in care delivery for pulmonary fibrosis in our engagements with policy makers and politicians.

Acknowledgments

ILFA would like to thank all stakeholders who participated in this World Café Event.

Special thanks to Tony Shone and Marco Santorini from Invisio Ltd. for supporting the World Café with expert facilitation and state of the art technology.

Warmest thanks to our World Café discussion facilitators and note takers; Dr Eoin Judge, Marie McGowan, Catherine McGeoghegan, Chris Meehan, Professor Killian Hurley, Lynn Fox, Chloe Meehan, Dr Anne Marie Russell, Liam Galvin, Dr Anne Marie Doyle, Carita Bramhill, Nicola Cassidy, Patricia Davis, Annette Cooke, Ciaran Heatley, Lindsay Brown, Marie Sheridan, and Irene Byrne.

This event was made possible with much appreciated funding from the Community Foundation of Ireland / RTE Does Comic Relief Adapt and Respond funding, and an unrestricted grant from Roche Products Ireland.



Rialtas na
hÉireann
Government
of Ireland



★ The Community
Foundation for Ireland



Easter Monday

2000 Steps Extra Challenge

On Monday 5th April 2021, ILFA held our second Easter Monday 2000 Steps Extra Challenge, following on from the success and popularity of last year's event. Patients, carers, family members and healthcare professionals were asked to join the virtual exercise challenge from their home and take at least an extra 2,000 Steps (approximately 1 mile) to raise awareness of pulmonary fibrosis and raise funds to support ILFA's work.

In the lead up to the 2000 Steps Extra Challenge, ILFA Ambassador, David Crosby, posted a great motivational video on Facebook encouraging people to get active, get walking, and get involved. We had great support from around the country and were delighted to receive so many photos and reports from the participants. All those who registered to take on the challenge received a special fundraising pack which included an ILFA T-shirt, a certificate of completion for photos, and some mini-chocolate egg treats to mark the occasion.

Unfortunately, the weather was not particularly nice on the day, but we are thankful to everyone who braved the elements to join in the exercise challenge. It is said that there is no such thing as bad weather, just bad clothing! Our

resilient participants took this advice to heart and were well prepared and dressed for the elements with plenty of layers and waterproofs where necessary.

Here are some photos and reports from our members across the country. Well done and thank you to all the participants! You're an inspiration!

Gerry Fitzgerald from Tipperary was accompanied on his walk by his dog early in the morning. In fact, Gerry was the first participant to compete the challenge on Easter Monday morning.

Mary O'Sullivan said "I did my extra 2000 steps this morning in lovely Rossmore in support of the ILFA Easter fundraising walk and to raise awareness of the wonderful work they do in supporting patients with respiratory illness. Thank you ILFA".

The Coffey Family from Longford all took part in the Easter Monday 2000 Steps Extra Challenge for ILFA and to support their mother, Mary who also joined them.

Lindsay Brown, Respiratory Advance Nurse Practitioner at St Vincent's University Hospital, and ILFA Committee Member, took 9,000 Steps for ILFA on Easter Monday at home in Wicklow.



Seán Ó Sé from Kerry took an impressive 10,591 steps as part of the ILFA 2000 Steps Extra Challenge! A great achievement!

Matt Cullen took 3,700 steps on his walk along the estuary at Swords on Easter Monday morning. Matt said he enjoyed the Easter eggs from ILFA and wished everyone well in their exercise challenge.

Annette Grehan and Nicola Cassidy ran and walked their 2000 Extra Steps for ILFA at St Anne's Park in Dublin. The ladies even donned some Easter headbands to mark the occasion and take a photograph.

JP O'Sullivan was joined by his family members on Easter Monday morning for his walk and sent warm greetings to everyone from a very cold and damp West Kerry.

Eileen Dwyer took part in the 2000 Steps Extra Challenge with her son Denis and sent us in a short report. "I did my extra 2000 step challenge for ILFA today in my local park. My son Denis did the walk with me. Thank you to all the people who donated to ILFA through my GoFundMe fundraiser. And thank you to ILFA for all the help and support you give to fibrosis patients."

Breda Coughlan completed her 2000 Steps Extra Challenge in Newbridge Park and helped raise awareness of lung fibrosis.

Eddie Cassidy, ILFA Chairman, walked the Malahide Estuary to complete his exercise challenge and David Crosby, ILFA Ambassador took his steps in Dun na Ri Forest Park in Co Cavan.

Gemma O'Dowd and James Kavanagh told us that they braved the snow, hailstones, and chilly temperatures in Dublin to take part in the 2000 Steps Extra Challenge for ILFA. Thankfully the sun made a welcome appearance later in the day so they could take their photo!

In all, more than one quarter of a million steps were taken by those who sent in their step counts to ILFA. Well done and thank you to everyone who took part, especially given the chilly and challenging weather conditions! We hope you will join us again next Easter but, in the meantime, keep exercising!

Remember you never regret the walk you do, only the walk you don't do!

Exercise Resources

Exercise Equipment for the University Hospital Limerick

The respiratory physiotherapy team at the University Hospital Limerick (UHL) has provided great support to ILFA members since the middle of 2020 when the pandemic put an end to face-to-face pulmonary rehabilitation classes for the immediate future. The respiratory physiotherapists at University Hospital Limerick kindly offered their services to ILFA patients and so the weekly exercise classes commenced on Monday mornings at 11am. The classes were initially delivered by Niamh Julian with her colleague Paula Ryan (Advanced Nurse Practitioner) and later by Gordon Cagney and were a great hit. In fact, the classes were so popular that it was necessary to hold two classes each week to accommodate the demand for places.



Gordon Cagney, respiratory physiotherapist.

To thank the team at UHL for their incredible support and commitment to helping lung fibrosis patients, ILFA made a donation to the physiotherapy department to fund the purchase of vital exercise equipment for patients.

Gordon Cagney, respiratory physiotherapist, is pictured with equipment purchased with the donation from ILFA to the UHL Respiratory Pulmonary Rehabilitation Service. Gordon said "We would like to take this opportunity to thank ILFA wholeheartedly for this generous offer and for the continued support that they have given the UHL Respiratory Service. It is greatly appreciated. The new equipment is being used regularly by myself and my colleagues for a variety of patients including IPF/ILD patients. We hope to continue to use the equipment into the future with hopefully the impending resumption of in-person classes."

Feedback on the online Exercise Classes

During the summer months, we conducted a survey of patients who have participated in ILFA's online exercise classes. The feedback was overwhelmingly positive and some of the comments received are included below.

"I love every minute of the classes. They have been a real game changer for me. It has turned my life around for the better."

"I enjoy the classes and feel I've benefited."

"This regular weekly class makes it more likely for me to exercise more often. The combination of weights and cardio exercises means overall exercise is done in a safe environment with a professional physiotherapist in a hospital setting."

"The value of these classes is not only physical, but there are also enormous psychological and emotional benefits. They

create a sense of wellbeing."

"Having attended a range of pulmonary rehabilitation/exercise classes over the years, the ILFA online pulmonary rehab class excels compared with all of them."

"I enjoy the class. It motivates people to exercise."

"It's just so critical for IPF patients to stay fit and healthy."

"It's extremely useful for people living in isolated areas of the country where there are very few exercise classes available."

"It's excellent, being instructive, supportive and facilitating routine. It encourages participants to take a proactive, involved and self-managed perspective to their condition."

The virtual exercise classes were cancelled for a short period due to the fallout of the cyber-attack on the HSE computer systems in May 2021. However, the classes have now resumed much to the delight of the regular participants. ILFA would also like to thank Petra Grehan, Respiratory Physiotherapist at the Mater Misericordiae University Hospital, who facilitated some classes when Gordon Cagney was unavailable.

If you would like to take part, please call ILFA on 086 871 5264 or email info@ilfa.ie to register and you will receive a link to join the classes on Zoom.

Exercise Resources for Respiratory Patients in Hospital



Rebecca Sweeney and Enya Mulcahy.

Exercise is crucial for lung fibrosis patients to maintain their strength, muscle mass and independence. In 2021, ILFA offered sets of pedal exercisers to the main Interstitial Lung Disease Centres caring for lung fibrosis patients in Ireland.

Rebecca Sweeney, Clinical Specialist Physiotherapist in Critical Care and Surgical Rehabilitation and Enya Mulcahy, Senior Physiotherapist in Critical Care and Cardiorespiratory Practice Educator at St Vincent's Hospital in Dublin are pictured with their pedal exercisers. Rebecca said, "Thank you again for these, they are going to be so valuable for our patients."

Advocacy

ILFA's Research is published in the Irish Medical Journal

In 2020, ILFA conducted a survey to assess the impact of the Covid-19 pandemic on our members. We shared the results with ILFA members in the Autumn 2020 Newsletter but wanted to publish the results in the medical literature to help raise awareness.

The research findings were submitted to the Irish Medical Journal and were accepted for publication following a peer review process. The first paper entitled "Perspectives of Interstitial Lung Disease Healthcare Professionals during Covid19" was published in the May edition of the Irish Medical Journal. The second paper entitled "Perspectives of Interstitial Lung Disease Patients and Carers during COVID-19" was published in the July/August edition of the journal.

We are grateful to everyone who completed the survey and shared their experiences and perspectives. We would also like to thank Amy Bousltridge for help with writing the articles. Please contact ILFA if you would like information on how to access the articles online.

Human Tissue Bill

The Programme for Government includes a commitment to enact the Human Tissue Bill, which will provide the legal basis for an opt-out consent system of organ donation and a public information campaign. The move to an opt-out consent system has the potential to increase the number of organ donors and life-saving transplant operations that can take place.

With an opt-out system, individuals will be considered potential organ donors and their families will be asked for consent to proceed with organ donation unless the individual has opted-out (this means they have officially registered their objection to be an organ donor). Family / next-of-kin consent is paramount and will always be needed for organ donation to proceed. It is therefore important to have family conversations and let your loved ones know your wishes on organ donation.

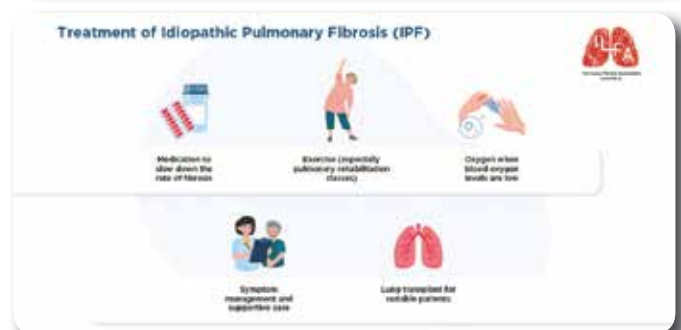
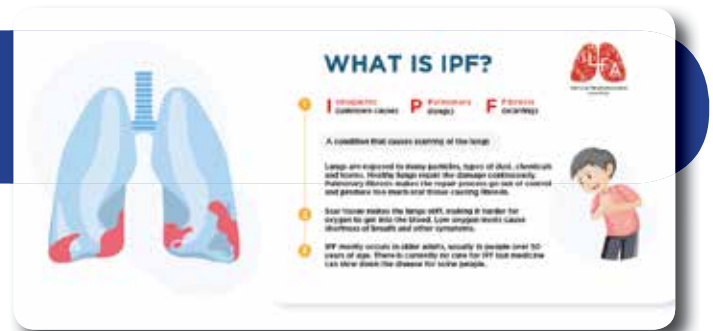
ILFA looks forward to the introduction of an opt-out organ donation consent system after many years campaigning for this in collaboration with the other patient organisations of the Irish Donor Network.

New Information leaflets and Infographics

ILFA has produced 3 new infographics and 2 new information leaflets on Telemedicine and Acute Exacerbations. The leaflets have been awarded the Plain English Mark by the National Adult Literacy Agency to ensure the language used is appropriate and presented in plain English. We are grateful to the patients and healthcare professionals who helped review the leaflets. We hope you will find the information useful.

Telemedicine Phone and video consultations: A guide for patients

Telemedicine is the use of technology by a healthcare



professional to provide medical services and healthcare. It includes telephone and video consultations (appointments) with a doctor or nurse, and even things like online pulmonary rehabilitation classes with a physiotherapist. Knowing how to use telemedicine will help you to continue to receive your healthcare safely from a distance.

Acute Exacerbations of Pulmonary Fibrosis

An acute exacerbation of pulmonary fibrosis is a sudden worsening or 'flare-up' of your disease. It causes:

- a decline in your lung function (your FVC and DLco)
- a rapid worsening of your breathlessness and other symptoms.

When an acute exacerbation occurs, your doctor will be able to see new changes or scarring on your chest scan.

Contact ILFA (call 086 871 5264 or email info@ilfa.ie) or visit the ILFA website (www.ilfa.ie) to read the new information leaflets.

ILFA Strategic Planning for the Future

The ILFA Committee and several invited guests representing patients and carers took part in two strategic planning meetings in July 2021. The aim of the interactive exercise was to establish where ILFA is now as a charitable organisation whilst reflecting on our objectives and mission, where we want to be in 3-5 years' time and to establish how we will get there. The ILFA Committee is grateful to Tony Shone of Invisio Ltd. for facilitating the meeting.

Sing Strong for Pulmonary Fibrosis



A 12-week **Sing Strong for Pulmonary Fibrosis** online class for patients and carers started in April 2021. The programme was organised by Roisin Cahalan, Physiotherapist at University Hospital Limerick and delivered by Ciara Meade, Choir Mistress.

Research has shown that singing for lung health classes that are delivered by a trained specialist provide valuable psychological and social benefits to people living with respiratory conditions. Some of the benefits include improvement in breathing control and management of breathlessness, relief of anxiety, and fun, enjoyment, and social interaction. A good singing voice is not a requirement to join the class and thanks to the virtual nature of the programme, participants sing (muted) from the comfort of their home, while training and exercising their breathing muscles.

The weekly classes were hugely popular, and Ciara ensured the participants worked hard whilst having great fun. The weeks flew by and on the day of the final class, two soloists performed much to the delight of their peers. Matt Cullen sang 'Tie a yellow ribbon round the ole oak tree' by Irwin Levine and L. Russell Brown. John McCarthy sang 'Yesterday' by the Beatles to much applause. The group finished off in style together all singing 'I'm on the top of the world' by The Carpenters.

ILFA is indebted to Ciara Meade and Roisin Cahalan for their help, expertise, enthusiasm, kindness and help delivering the pilot programme.

The ILFA committee would also like to thank Air Liquide Healthcare Ireland and BOC Healthcare Ireland for generously supporting this patient-centred initiative to help improve breathing.

Here is some of the feedback received from participants.

- "Sincere thanks to ILFA, the sponsors and especially to Ciara for the opportunity to participate in such a worthwhile venture."
- "It was both enjoyable and beneficial and it's wonderful to have the recordings to refer to."
- "Many thanks to ILFA and Ciara for the wonderful Sing Strong for Pulmonary Fibrosis programme, it was excellent, innovative and fun!"
- "Please send my sincere thanks to Ciara. I both enjoyed the classes and benefited from the breathing exercises."
- "Thank you ILFA. Ciara is a tonic just all by herself!!"
- "Ciara has done a terrific job throughout the entire course, I think it has been a great initiative and I am very grateful to all concerned for making it a very enjoyable and fun experience."
- "Thanks to ILFA for organising the sing strong programme. It was very enjoyable. I will miss it!!"

Student-led Health and Wellbeing Programme



In January 2021, six physiotherapy students from the University of Limerick invited people with pulmonary fibrosis from around Ireland to take part in a 12-week online health and well-being programme. Twenty-one participants from all corners of Ireland took part in the holistic programme that was designed and delivered by the students as part of a telehealth placement. The varied programme consisted of a weekly online exercise class and education on relevant topics of interest, including a guided mindfulness and relaxation class. Through collaboration with the MSc Nutrition and Dietetics students at the University of Limerick, participants were also offered one-to-one nutritional assessment and group information sessions on healthy eating



for pulmonary fibrosis. Feedback from the participants was overwhelmingly positive: 100% of participants felt the 12-week programme resulted in both physical and mental benefits for them and 92% would participate in a similar programme in the future. It was an uplifting experience for all involved and demonstrated the positive outputs that can be achieved through partnerships between charity organisations and higher education institutions. It provided students with real life experience in addressing the challenges faced by people living with pulmonary fibrosis and engaged them as lifelong learners and patient advocates as future healthcare professionals.

Dr Kate Devenney, Regional Placement Facilitator, University of Limerick, and Clinical Specialist Physiotherapist in Respiratory at St. James's Hospital

Let's Talk Online Meetings

The "Let's Talk" online education interactive sessions take place every few months via Zoom, an online platform, which enables ILFA to host private and secure online meetings for people around the country. ILFA invites a guest speaker to discuss specific topics related to their specialist field and answers questions submitted by patients. The meetings usually last 60 minutes and are lively, interactive, and informative. Some of the recent sessions that have taken place are summarised below.

Keep an eye out for the "Let's Talk" sessions on the website www.ilfa.ie (News and Events section) and on ILFA's Facebook page. Please contact ILFA in advance to register to attend and you will receive an email link to join the meetings. Please let us know if you have any suggestions for future meetings. We are grateful to the healthcare professionals who are willing to share their time, kindness, and expert advice! Please note, these sessions are not recorded.

"Let's Talk Supportive Care for Pulmonary Fibrosis"

On 13th May 2021, Catherine McGeoghegan and Deirdre O'Flaherty, Respiratory Nurse Specialists, at Beaumont Hospital took part in ILFA's "Let's Talk Supportive Care for Pulmonary Fibrosis" session. 39 people joined online, and all appreciated the information and valuable advice from Catherine and Deirdre.

Here is some of the feedback received;

- "Thanks. Very good presentation from Dee and Catherine and all so supportive"
- "The patients with access to centres of excellence are lucky. My experience with my nurse is that she is so accessible and that gives me confidence and helps with the challenges I have from time to time!"
- "Thank you Dee, Catherine and Gemma. A very knowledgeable and informative session and the references will be great to have."
- "Thank you for a very interesting and educational talk".

"Let's Talk: Lung Fibrosis - Questions and Answers"

On Friday 18th June Dr Abhilash Sahadevan, Interstitial Lung Disease Fellow at St Vincent's Hospital joined ILFA members for a great session entitled "Lung Fibrosis: Questions and Answers" session with patients from all over Ireland.

Participants submitted their questions in advance and Dr Sahadevan answered them during an hour-long conversation. Some of the topics discussed included medication, pulmonary hypertension, emerging treatments, stem cells and the importance of exercise.

Here is some of the feedback received;

"Many thanks for organising such an informative session. I really enjoyed the Q&A and benefited considerably from the issues raised. Please pass on my thanks too to Dr Abhilash."



"Very interesting talk. And very informative questions and answers."

"Thank you. That was very good!"

Let's Talk Exercise

On 21st June, at 11am, Petra Grehan, Respiratory Physiotherapist at the Mater Misericordiae University Hospital discussed the benefits of exercise and encouraged everyone to pace themselves and do what they can. Petra gave lots of sound advice, practical exercise solutions and encouragement to everyone.

Patient Perspectives on the ILD/IPF National Patient Registry

On 20th May 2021, 9 patients from across the country met online with members of the Irish Thoracic Society's Interstitial Lung Disease (ILD) Group. The aim of the meeting was to get stakeholders input on the ILD/IPF national patient registry in relation to its development and key aims and objectives. Valuable discussions on the type of information that should be included in a national patient ILD registry, the collection process for gathering patient information, the use of anonymised data, consent, and ethics, having the opportunity to be included on the registry, and the research considerations of the registry took place. Professor Killian Hurley (ILD lead at the Irish Thoracic Society) and Suzanne McCormack (Irish Thoracic Society CEO) expressed their thanks to the participants for their valuable contributions.

Support Group Meetings online



ILFA hosts online support group meetings every few weeks to enable people to meet in small groups and have a friendly chat over a cuppa. The breakout rooms have proved to be a great success and give people the chance to make new friends, meet old friends, and share lots of information and tips.

Please contact ILFA on 086 871 5264 or email info@ilfa.ie to register to join these online events. All are welcome.

The Redeployed

The automatic doors open, deceptive, inviting
what lies therein is overwhelming, frightening
Ill-prepared, I am glued to the floor
as I process the scene, akin to a war
Not a military zone of conflict and strife
but a united battle to help support life.
The emotions within me instantly seethe
in that moment I forget to breathe,
my heart is racing, my head's in a tizz
And the family enjoy another virtual quiz.

I am donned in PPE, now redeployed
in an endeavour to fill the nursing void.
Staff guised in hazmat relentlessly task
I cannot tell the face behind the mask.
I listen and learn on a vertical curve
these alien things I must observe.
Breathing machines, drips, and drains
multiple infusions pumping into veins
Information overload abounds my head
I forget there is a person in the bed.
This realisation, this disconnection
fills my senses with utter dejection,
suppressing my tears, I can feel my
heartbeat
And the neighbours play Bingo out on the
street.

This virus, indiscriminate in its choosing
invades until it seems we are losing,
oxygen levels plummet and
temperatures soar
alarms in the background
constantly roar.
Every cell and organ is under
attack
as modern medicine attempts
to fight back,
monitoring, titrating, adjusting
the plan
working round the clock; it is
virus V man.
Each hour I check, count and
record
And the social isolators are
seemingly bored.

Regardless of circumstance;
No family's the rule,

this aspect of caring seems particularly cruel.
I am handed an I-Pad for a facetime call
I see a wife and two children crumble into a ball.
Virtual comfort, something to clutch,
I choke for this family, denied human touch.
An imposter, a surrogate, I provide the support
while the family and friends are left athwart.
The hazmat suit becomes unbearably warm,
I cannot reconcile this apparent new norm.
My goggles fill up, my lungs constrict
And at home they are having a Netflix binge.

My brain will not quiet, even through night
it is struggling to process this ICU plight,
still all on my desktop, a weight on my shoulders,
refusing to go to the cloud or the folders.
Despite the stress and anxiety, tension, and tears,
the redeployed work on through our fears.

A variety of backgrounds, all out of our field,
contributing to the frontline serves as our
yield.

We toil closely together with hope and
heart

And the good people of Ireland stay
together apart.



Elaine Craven
May 2020

***This incredible poem was
composed by Elaine
Craven, Advanced
Nurse Practitioner at
Connolly Hospital,
Dublin. ILFA would
like to extend
our heartfelt
thanks to all
the healthcare
professionals
caring for
patients and families
during the Covid-19
pandemic.***

EU-IPFF Patient Summit 2021

In April 2021, the first virtual European Union Idiopathic Pulmonary Fibrosis & Related Diseases Federation (EU-IPFF) Summit took place online over three days. The summit brought together patients and caregivers, healthcare professionals, policy makers and industry representatives. The programme consisted of a series of 15 excellent sessions with 52 speakers who shared their experiences of living with Pulmonary Fibrosis and caring for those with Pulmonary Fibrosis. 685 people across the globe registered to attend the event including many from Ireland.

Some of the topics included in the programme were self-management, supporting newly diagnosed patients, palliative care, psychological aspects of living with pulmonary fibrosis, pulmonary rehabilitation, and research.

Several Irish participants spoke at the summit including Liam Galvin (ILFA committee member and EU-IPFF CEO), David Crosby (ILFA Ambassador), Irene Byrne (Respiratory Physiotherapist at the Mater Misericordiae University Hospital) and Paula Ryan (Advanced Nurse Practitioner, University Hospital Limerick).

Here is feedback from some of the presenters and an attendee at the summit to give a flavour of the event.

Healthcare presenter

"I was honoured to be asked to speak about the respiratory nurse perspective at the round table event at the European Pulmonary Fibrosis Patient Summit which took place on the 23rd April. The event was hosted by the EU-IPFF group who were a joy to work with. This was a huge opportunity for respiratory nursing in Ireland and showcase the excellent work being done by all respiratory nurses across the country. The PF Summit was the first virtual European event bringing together patients, healthcare professionals, policy makers and industry representatives.

The event was designed by patients for patients and was a unique platform to discuss Pulmonary Fibrosis and Interstitial Lung Diseases (ILDs). I thoroughly enjoyed speaking at the event and having the opportunity to highlight the experience of working in the respiratory clinics in Limerick and Ennis. It was also a fantastic event to be part of with many very interesting talks and hearing from the patient's perspective."

**Paula Ryan, Advanced Nurse Practitioner,
University of Limerick**

Patient perspective

I attended six of the EU-IPFF Summit sessions and I found all the events to be informative, inspiring, and extremely helpful to me as a patient. I will mention three events which left an

impression on me: On Friday I attended "Self-Management of ILD" which featured Dr Anne Marie Russell providing information on symptom management as well as an interesting discussion from David Crosby.

On Saturday I attended "The psychological aspects of living with chronic disease" which featured two ILD patients, Stefano Pavanello and Joep Welling. They were inspiring in their deliveries, and they emphasised how carers should also be provided with support for the devastating effects of the patient's disease on their own mental health.

On Sunday I attended "What patients want to know about research and how they can be involved". This session provided me with facts about research which I never knew previously. The speakers were marvellous.

Overall, I am delighted that I attended the EU-IPFF Summit. I was inspired by the professionalism, and obvious commitment of the presenters to inform and help patients with IPF and other ILD diseases. I was delighted that it was a virtual event as I would never have attended this summit if it had not been an on-line event.

Seán O Se, Kerry

Patient and advocate presenter

"Hi all, I was privileged to be asked to speak about "Self-Management of ILD" at the EU-IPFF Summit in April 2021. It was the first of hopefully many more of these patient-focussed summits as there were so many great presentations about Pulmonary Fibrosis. It was brilliant to hear the many ways people are helping others to come to terms with living with and hopefully fighting this horrible disease.

There are many wonderful people who care so much about patients.

My co-speakers were Dr Anne-Marie Russell, Dr Lesley Ann Saketkoo and Ron Flewett (moderator). Hopefully our presentations and perspectives were beneficial to patients with Pulmonary Fibrosis.

It is a great platform for anyone who needs any information or questions answered on Pulmonary Fibrosis and it is worth keeping in touch with the EU-IPFF online. I hope everyone is keeping well and safe."

David Crosby, ILFA Ambassador, Cavan

Organiser perspective

As part of the ILFA team, it was great to be one of the organisers for this event. A huge amount of planning went into the summit, beginning in 2019. Whilst it was a disappointment that the face-to-face summit in Warsaw, Poland had to be postponed and then changed to an online event, it was a great testimony to the international co-operation that took place between patients, carers, clinicians, researchers, and companies to make this first summit a reality. The EU-IPFF summit received the endorsement of the European Parliament and other important organisations due to the high quality of its speakers and content, as well as its ground-breaking patient led format. It was very successful, and the recordings of the sessions will be a valuable source of information for patients, clinicians and researchers going forward.

As a ILFA volunteer, it was exciting to have so many Irish speakers selected to speak at the summit and I was honoured to be in the audience to listen to them and the other world class speakers.

Liam Galvin, EU-IPFF CEO and ILFA Director.

Education



Cognitive Behavioural Therapy Training Bursaries

In February 2021, ILFA was delighted to offer educational bursaries to respiratory healthcare professionals working with lung fibrosis patients to study Cognitive Behavioural Therapy (CBT). Educational bursaries were awarded to 8 healthcare professionals and here is what they reported after completing the course.



Petra Grehan, respiratory physiotherapist, Mater Misericordiae University Hospital:

"I recently completed a course in CBT. My place on this course was sponsored by the Irish Lung Fibrosis Association. This course enabled me to learn the fundamentals of CBT while connecting with other professionals around the country working with people who have Lung

Fibrosis. Although I have known about CBT for some time, I have not had the opportunity to study it in-depth until now. This course taught active listening and CBT interviewing skills to identify worrying thoughts that the client may be having which are limiting their participation in things such as climbing the stairs, taking medication, exercising etc. This treatment allows both the client and the care giver to peel away the layers surrounding the thought to expose why they are feeling this way. This allows for appropriate structures and exercises to overcome it to be put into place. Every client, care giver and issue are different and so it can take patience and trust to work through together, but positive outcomes are worth all the effort. Through attending this course, I have realised how beneficial this mode of treatment may be as I continue to work with those with people with Lung Fibrosis. I would like to thank ILFA for affording me the opportunity to participate in this learning."

Noreen Donoghue, Respiratory Clinical Nurse Specialist, Bon Secours Hospital, Galway: "I am fortunate to have just completed an ILFA sponsored Cognitive Behavioural Therapy course run by Pivotal Health. On reflection, as respiratory nurses, we are using various forms of CBT techniques



(for example, breathing control, relaxation, energy conservation) in our everyday care of respiratory patients. Having completed the course I acknowledge having a better understanding of the basics of CBT which combines cognitive therapy, examining how we think, examining the things we do, and why it is useful in supporting the well-being of patients with physical

conditions. When depression or anxiety is associated with a long-term physical condition such as chronic respiratory disease, and is causing isolation and negative thinking patterns, CBT techniques can help the individual understand and identify potential areas for change."



Niamh Julian, Respiratory Physiotherapist, University Hospital Limerick: "Thanks so much to ILFA for the bursary to attend Pivotal Health Cognitive Behavioural Therapy Course. This was the most enlightening piece of education I have had in a long time. It reminded me to really listen to what my patients are saying, to ask more questions within the

CBT framework and when necessary to challenge unhelpful thoughts and beliefs. This can sometimes take more time in a busy clinic setting but the benefits can be really empowering and long lasting. A lot of the focus was on managing anxiety and breathlessness in a non-pharmacological way and we came away with many useful ways to help our patients with this. We delved into the topic of acceptance of a chronic condition and acceptance of a change which I also found beneficial and learned some tools to try to help with acceptance. I continue to use what I have learned in this course both in work and in my personal life. We have all needed to develop more acceptance and resilience in this past

year and I hope this will stand to us all as we emerge from the shadow of Covid 19. Thanks again to ILFA, Le gach dea ghui.”



Carita Bramhill, PhD candidate, Trinity College Dublin: “Thank you to ILFA for providing me with the opportunity to attend training in CBT. It is a very informative and interactive course. I was very interested to learn CBT skills having previously trained in both Psychology and Psychotherapy. This training gave me a fantastic opportunity to learn a new skill that

I could use in my work with patients. I was delighted to meet with so many healthcare practitioners from around the country who are currently working in the area of Pulmonary Fibrosis. It provided an opportunity to build networks with colleagues while learning CBT skills together. I learned so many new techniques and skills from the workshop and the teachers delivering the training were fantastic. The experienced trainers provided additional resources and supplementary material to help us to develop our understanding of CBT. I gained an awareness about how CBT could be used to support patients in their day-to-day life and in managing breathlessness. I found the course hugely helpful and can see how the many skills could be translated into my work with patients and families by supporting their psychological well-being.”



Deirdre Garvin, Respiratory Nurse Specialist, Mayo University Hospital: “I was very fortunate to be awarded the ILFA bursary to take part in the cognitive behavioural therapy course. It was an area I was very interested in, so I was delighted to be awarded the bursary to complete the course. As nurses we just want to help our patients.

Often, I would feel powerless when patients brought up feelings of anxiety due to the symptoms of breathlessness and their illness. Sometimes though, we can only help by empowering others to help themselves. This course taught me how to really listen to patients, listening to how they feel and how they cope. It then gave us some tools to try and help our patients going forward. It has changed the way I approach topics with my patients, and it has given me the courage to talk more freely. I felt it was one of the most worthwhile courses I have undertaken. I would like to thank ILFA for this opportunity and really feel it will improve my practice going forward.”



Elaine Craven, Advanced Nurse Practitioner, Connolly Hospital:

“I would like to thank ILFA for affording me the opportunity to undertake a course in CBT. The course provided us with the basic principles of CBT and how to structure a session. These included the ‘Hot Cross Bun’ assessment to illustrate how our thoughts, feelings and emotions interact

and can manifest physically. We examined how unhelpful

thinking patterns can be substituted with alternative, more balanced thoughts. We learned specific cognitive techniques to question patients more effectively to help them identify their unique problems or worries. We shared behavioural techniques using Positive Self-talk, Grounding, Three Good Things, Stress Buckets, Worry Trees and many more! Living well with chronic diseases takes courage, perseverance, and acceptance. CBT uses techniques that help build self-management skills, improve relaxation and breathing patterns and promote effective coping strategies. The aim is to facilitate patients to identify unhelpful thinking by challenging their perspective to bring about positive behaviour change. Positive psychology is an integral part of our mental and physical wellbeing and CBT skills provide a means by which patients can overcome debilitating symptoms and enjoy a healthier quality of life. The course was very enjoyable, and I would highly recommend it.”



Nora McNamara, Advanced Nurse Practitioner, Tipperary University Hospital:

“I am delighted to have been given the opportunity to complete the certificate in Cognitive Behavioural Therapy which was funded by ILFA. CBT is an area I have a great interest in and feel the benefits of providing it to the patients attending Tipperary University Hospital are enormous.

Anxiety and depression are two areas that cause great difficulty to patients and families coping with chronic illness and breathing difficulties. It was great to hear and share experiences with colleagues around the country who have implemented CBT into their delivery of care. Carrying out the practical element provided not only me but TUH with an insight into the benefit of providing such a service, showing that psychological input is required to provide holistic care. The hope is that it becomes imbedded into the care bundle for respiratory patients suffering with chronic/acute respiratory conditions. To date I have offered CBT to patients with IPF, and the benefit was felt from the first session, I will continue to incorporate it into my daily practice. For the cohorts of patients whom I provide care it will allow me to improve their quality of life providing awareness and self-management methods for the psychological symptoms/triggers manifested by the illness. Thank you most kindly to ILFA for provided me with this opportunity.”



Donna Langan, Respiratory Advanced Nurse Practitioner, Galway University Hospital:

“Thank you to ILFA for the amazing opportunity to undertake the Cognitive Behavioural Therapy course. It really opened my mind to a different approach in caring for people living with Interstitial Lung Disease. While I was previously doing some cognitive behavioural

techniques with my patients, this course has identified how I can structure my techniques to enable the best outcome for my patients. It has given me a toolbox of approaches that I bring to my patients to help them overcome issues or worries. I would recommend this course to everyone.”

Fundraising Round Up

The ILFA committee and community are extremely grateful to everyone who has fundraised for the charity over recent times. It has been an incredibly challenging time for everyone, and we have been inspired by the innovative fundraising events that have taken place to support our work. Sincere thanks to all of you have made donations, sponsored an event and taken on fundraising challenges in ILFA's name. We appreciate all you have done! Here is a roundup of some of the fundraising events that have taken place in recent months. **If you have a fundraising idea, we would love to hear from you. Please contact ILFA on 086 871 5264 or email info@ilfa.ie**

Donation to the Pat Casey Memorial Cycle



Kieran Prendergast, Tom Hume, Anne Casey, Paul Walsh, and Brian Aherne.

The organisers of the Pat Casey Memorial Cycle were delighted to receive a kind donation from Mr Paul Walsh, Manager of Centra at South Douglas Road in Cork. Paul and the team pictured here raised the outstanding total of €1,125 in lieu of the 2020 Pat Casey Memorial Cycle which could not be held due to the Covid-19 public health restrictions in place.

The organisers of the Pat Casey Memorial Cycle are hopeful that the event can take place again in 2022.

Congratulations to them all!"

Report by Daniel Casey

May Marathon for ILFA

Huge thanks to Karl Johnson who took on a marathon in aid of ILFA over the summer. Here is Karl's story.

"Hello, my name is Karl Johnson. I decided to raise funds for ILFA by running a marathon around my locality on Sunday 2nd May. I wanted to support ILFA for several reasons. I am a member of Longwood/Killyon Macra na Feirme. Some



Marathon Man: Karl Johnson

of our members lost a relative a couple of years ago to pulmonary fibrosis. Since then, this cause has been close to the hearts of everyone in our club. We decided to host a table quiz last March (2020) to raise money and awareness of pulmonary fibrosis, but unfortunately Covid-19 put paid to our plans! That is why, this year, I decided to do what I can to follow up our desire to raise money and awareness for a brilliant cause! Karl completed his marathon locally and received great support from all his friends. Karl said "I recently ran a marathon around my locality to raise money for the ILFA. The run itself was very tough as it was quite a warm day. The lack of crowds or other runners around also made it different to any race I have done before, but it was a fantastic experience overall. I received so many good wishes in the run up (no pun intended!) to the marathon that motivated me to keep going when the legs started to get tired. I was really happy to raise awareness for the cause, and was thrilled to raise €1,400, which was almost six times my original goal! I will definitely look to support the ILFA again in the future"

Huge thanks and congratulations to Karl for all his hard efforts for ILFA!

Easter Raffle

In April 2021, Tom Loughrey from Galway held an Easter raffle in aid of ILFA and all his family bought tickets. Tom wanted to donate the money to ILFA to remember his grandad Mick. It was a bit of fun for his family on an Easter Sunday morning in the lockdown.

We're so grateful to Tom for his great fundraising idea and such wonderful support for ILFA. We're sure everyone was delighted with the prizes.



Prepaygo helps raise awareness of ILFA

ILFA is grateful to Prepaygo.ie for partnering with ILFA under their Corporate Citizenship Initiative to help us raise awareness of Idiopathic Pulmonary Fibrosis. ILFA showcased 2 new infographics on the condition; (1) What is IPF? (2) The Treatment of IPF on the Prepaygo site in April.

As well as helping with awareness, Prepaygo made a generous donation to ILFA. Sincere thanks to Aidan Quinn at Prepaygo for his help and support.



Paul Flynn and Michael Darragh Macauley (ILFA Patron), former Dublin Senior Footballers, along with a selection of photos from the Dublin Minor Football team.

Dubs Minor Football team

The Dublin Minor Football Team took to their bicycles and collectively cycled the perimeter of Ireland in aid of ILFA on Sunday 22nd April. Over 50 cyclists set off from their home at the same time. They were joined by their yoga instructor, former Dublin Senior GAA footballer and ILFA Patron, Michael Darragh Macauley, who was instrumental in ILFA being chosen as the charity partner, for which we are extremely grateful.

The fundraiser was a phenomenal success and raised the fantastic sum of €10,600 for ILFA. This amount will have a big impact in supporting our work in 2021 and we are grateful to everyone who donated so generously. The cycle and the publicity associated with it also raised valuable awareness of lung fibrosis and ILFA's work. In fact, Ger Lyons, the team manager told us that several people had approached members of the Dublin Football Management Team to inform them of a personal connection to someone diagnosed with lung fibrosis.

The ILFA committee would like to send our warmest thanks to all the members of the team for their incredible

generosity and enthusiasm for this event. It was such a thrill to be associated with this vibrant, talented team and we're especially grateful to them for their wonderful support in a financially challenging year.

Here is a report from David Reynolds of the Dublin Minor Football Management Team who was one of the event organisers and was in regular correspondence with ILFA during the planning stages.

"It was a complete honour to be involved with ILFA. What ultimately started as a small fundraiser with a target of €3,171 turned into a large fundraiser with plenty of fun with family and friends all involved, raising over €10k while cycling the perimeter distance of Ireland on a Sunday morning around Dublin.

During lock-down, we were lucky to have access to Michael Darragh Macauley's famous yoga sessions and when deciding on running a fundraiser, ILFA was an easy option given how close it is to Michael Darragh's heart. We would like to thank all the ILFA committee and in particular Nicola Cassidy for her work and dedication during running the event."

David Reynolds, Dublin Minor Football Management Team



Half-marathon for ILFA

Michael Irving whose dad passed away with lung fibrosis in 2019 decided to run a half-marathon to raise funds for ILFA. Michael contacted ILFA to say "I am fund-raising for the ILFA on May 9th by doing a half-marathon. I have chosen this charity, as my family were afflicted by pulmonary fibrosis in 2019.



My dad, Pat, was diagnosed with PF in early 2019 and passed away shortly thereafter. We miss him dearly. There is currently no cure for the disease, and it is my hope that in the future with adequate research and development, that may change. Michael was joined by his cousins Fionntann and Fiachra for the half marathon

on May 9th and raised a phenomenal €16,500 for ILFA. Michael said "The support we received from our friends and family was staggering and we raised €16,500 for ILFA."

Congratulations and huge thanks to Michael, Fionntann and Fiachra from all of us for such wonderful support.

Photo: Michael Irving

Connolly Hospital Fundraising

On Saturday 20th March, staff from the Theatre Department at Connolly Hospital held a virtual walk to remember their dear colleague Christine McCarthy on her one-month anniversary. Ann Guy organised the special fundraiser so that Christine's friends and family could unite virtually to celebrate Christine's life and pay special tribute to a cherished member of their team. They raised an incredible €13,762.62 for ILFA and in July, ILFA Chairman, Eddie Cassidy, met Ann and her colleagues for a cheque presentation. Huge thanks to all the team at Connolly Hospital, Dublin and to everyone who supported their fundraising walk and donated so generously.



Eddie Cassidy, Ann Guy and staff at Connolly Hospital.

"Songs I like to Sing" by Mike Joe Fitzgerald

Mike Joe Fitzgerald from Lispolé, Co Kerry achieved a life-time ambition last year and made music CD recording of 15 of his favourite songs. The proceeds of the sales are being

shared between ILFA (a charity with special significance to Mike Joe as his friend JP O'Sullivan received great support from ILFA when he was diagnosed and subsequently received a lung transplant) and the Kerry Cancer Support Group.

Warmest thanks to Mike Joe and his pal JP O'Sullivan for fundraising for ILFA and supporting our work. To order your CD or to make a donation, please contact ILFA on 086 871 5264 or call JP O'Sullivan on 087 280 9801



Facebook Birthday Fundraising

Olwen Brady in Kilkenny raised a fantastic sum for ILFA when she decided to do a Facebook Birthday Fundraiser. We are hugely grateful to Olwen and all her friends who donated so generously. Thank you for this great support and "Happy Birthday" from all of us!

Here is Olwen's story: "I have never run a birthday fundraiser on Facebook, but I regularly donate when my friends do them. This year I decided to run one and I picked a charity that's going to be relevant as my lovely Mam was diagnosed with IPF last summer. I checked with her before I did it, as it would be because of her illness, and she gave her blessing to it. I was absolutely blown away with the response from my Facebook and offline friends and the fundraiser reached €1,334. At the beginning I would have been thrilled if I reached the first goal which was €150 but as I saw the fund growing, I was completely overwhelmed with people's generosity and had to revise the goal many times! Mam hasn't been involved with the ILFA up to now but looking at the fantastic programs that are running she will be from now on. Until Mam was diagnosed with IPF none of us had any idea about this disease. Smaller charities like this deserve our donations just as much as the larger well-known ones and I've been delighted to help."

Roisin McGrath from Dublin set up a Facebook Birthday Fundraiser in April in memory of her dad, Mick Breslin. Roisin told us that her dad loved taking part in the ILFA online exercise classes and she wanted to raise funds as a thank you gesture. Roisin also hopes her birthday fundraising page will inspire other people to fundraise for ILFA. Huge thanks to Roisin for her support and to everyone who has donated to her page. We are very grateful.

Daniel Casey in Cork fundraised with Facebook to celebrate his birthday Daniel said "As my birthday approached, Facebook promoted the ability for me to create a fundraiser for a charity, I was thrilled to see that ILFA was an option available to select. At that point it was a no-brainer, the process to set up the fundraiser was super easy on the site, I was able to do it all on my phone app. Given that fundraising has been very difficult due to Covid19, this option was a welcome and simple method of getting donations to where they need to be. I would really recommend to anyone to give it a try!"

Book Drive in aid of ILFA

Pam Martin from Dublin organised a fundraising Book Drive in association with BookWorld.ie to raise vital funds for the



Clockwise from top: The volunteers at the book drop; Anne Casey and Peter Maguire in Cork; Pam Martin and Nicola Cassidy; and Eddie Cassidy, Liam Martin and Justin Dawson.

Irish Lung Fibrosis Association (ILFA). Pam informed her friends, neighbours, and community in Lucan, of her plans via Facebook, and for weeks she was inundated with thousands of books that were all dropped outside her home. Pam methodically sorted the books and gave over valuable space in a bedroom and the shed to house the books before Michael from Book World arrived to collect them. In fact, Michael had to call to the house a few times, and each time he filled his van with paperback and hardback novels, biographies, autobiographies, classics, fables, and fiction.

In addition, Pam organised a book drop for Saturday 7th August at Terenure College in Dublin. We would like to extend huge thanks to Fr Brian McKay, Prior at Terenure College, for kind permission to use the grounds for the book drop. The event was announced by ILFA on our website and social media channels, and on the "Dublin Diary" that features on Sunshine FM104.9 in Dublin.

On the day, there was a steady stream of cars driving by with books to donate. Our volunteers were led by Pam and Liam Martin and included Justin Dawson, Stuart Lee, James

Kavanagh, Eddie Cassidy (ILFA Chairman), Gemma O'Dowd and Nicola Cassidy. Some cars were laden down with boxes of books and the owners all said they were happy to be helping a good cause. Michael and Stuart from Book World were delighted with the quantity and quality of books donated, and with the extra pair of hands helping to load the books into the van.

An impromptu book drive also took place in Cork on Saturday 29th July. Anne Casey, Cork Support Group leader, met Peter Maguire of BookWorld.ie at the book drop location to donate some reading material. Bookworld also offered their clients the chance to raise money for ILFA when purchasing books online. If patrons used the code "ILFA" at the check-out, €5 was donated to the charity.

Bookworld donated €1,350 to ILFA and over €400 was donated directly by kind individuals who wanted to support the event. The ILFA committee would like to send our warmest thanks to Pam and to the team at Bookworld for all their hard work on this fundraising event.



Chloe and Sophie Chatziioannidis.

Garden Sale in aid of ILFA

Huge thanks to Chloe and Sophie Chatziioannidis who held a charity garden sale in aid of ILFA in memory of their granny Patricia Harrison. We're very grateful to Chloe and Sophie for their support.

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.

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.**

Upcoming events

Classic at the Castle

A Golf Classic will take place on Saturday 11th September at Waterford Castle Golf Club. This special fundraiser is being held in memory of an esteemed former member, Carmel Flynn. Carmel was a founder member and trustee at Waterford Castle Golf Club and served selflessly for 25 years in a variety of roles. Sadly, Carmel passed away in May 2020, having been diagnosed with Pulmonary Fibrosis in 2019. All proceeds from the fund raiser will go to The Irish Lung Fibrosis Association and Waterford Hospice, both very worthy charities who cared for Carmel during her illness.



Photo: (left to right): Clare Cotter, Ailish Tierney, Sally Brennan (Lady Captain Waterford Castle Golf Club), Linda Tierney, Tom Joe Power Captain WCGC and Lady President Bernadette Rohan at the launch of the Classic at the Castle event in August.

The format for the classic will be an open four-person team event with any combination of ladies and gents. Entry for the competition is now open to everyone by phoning the pro shop at 051 871 633. The cost is €200 per team which includes food in the clubhouse afterwards. The timesheet is expected to be filled quickly so it is advised to book early.

The prizes on the day are exceptional and include fourballs in some of Ireland's best known golf courses. In conjunction with the golf event, tickets are also being sold for a Mega Draw with some amazing prizes. Tickets are on sale in the pro shop at Waterford Castle or by contacting Sally at 086 839 2503 or ILFA on 086 871 5264.

The Ladies Club at Waterford Castle Golf Club would like to thank Seamus Walsh, owner of Waterford Castle Hotel and Golf Resort, for his generosity in making the golf course available for this very special event.

4 Person Team Event (any combination)

- €200 per Team of 4 (Food is included)
- Handicap Limit: Men 18 – Ladies 28
- Juniors are welcome (maximum of 1 junior per team)

Cork Echo Virtual Mini-Marathon

The Echo 6k Your Way Virtual Mini Marathon will take place in September 2021. Entries are now open, and you register to walk, jog, or run 6k on 19th September 2021 from anywhere in Ireland or further afield! **If you would like to take part and fundraise for ILFA, please call 086 871 5264 or email info@ilfa.ie**
Register for the event at www.echolive.ie/minimarathon/

Virtual VHI Women's Mini-Marathon

The VHI Virtual Women's Mini Marathon will take place on 19th September 2021. Entries are now open, and you register to walk, jog, or run 10k on 19th September 2021 from anywhere in Ireland or further afield!

If you would like to take part and fundraise for ILFA, please call 086 871 5264 or email info@ilfa.ie

Virtual Candle Lighting Ceremony



A virtual candle lighting ceremony in support of lung fibrosis patients and to remember loved ones will take place on Saturday 23rd October (bank holiday weekend). We invite you to light a candle at 6pm in support of patients and their families, and to remember loved ones with lung fibrosis who have passed away.

As we cannot gather as a community at the Annual Ecumenical Service of Prayer and Reflection this year, we hope this activity will bring us together (virtually) as a community. **We invite you to share your photos of your candle via Facebook or by emailing info@ilfa.ie if you would like to.**

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

The Irish Lung Fibrosis Association is the national patient organisation for Lung Fibrosis patients, families and healthcare professionals working in Interstitial Lung Disease. ILFA was founded in 2002 and became a company limited by guarantee in 2003. ILFA is run by a group of dedicated volunteers whose lives have been touched by Lung Fibrosis. The committee is enormously grateful to everyone who fundraises and makes donations to help support our work.

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.

*****Please note**, the Irish Lung Fibrosis Association (ILFA) is not the same charity as the Irish Lung Foundation.***

On-line donations for ILFA:

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 Ireland has been added to 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.

Bank transfer: You can transfer money directly to ILFA's Bank Account. Please contact ILFA by **calling 086 871 5264** or by **emailing info@ilfa.ie** for our bank account details.



Important! When lodging money to the ILFA account, please ensure you include your name or the name of the organisation on the lodgement slip. This will help us know who made the lodgement so we can

Patient Support Groups

The ILFA pulmonary fibrosis support groups monthly meetings remain cancelled for the foreseeable future in the interest of patient safety. We hope that the face to face support group meetings will be able to resume in the future and will update the website with this information. Stay safe everyone.

Cavan Monaghan Support Group

Please call Kevin on 085 243 6828 or 087 762 3485 for more details.

Clare Pulmonary Support Group

Please call Michael on 087 637 4068 for more details.

Cork Support Group

Please call Anne on 087 985 4587 for more details.

Dublin Support Group

Please call Matt on 086 244 8682 or Pam on 086 178 9055 for more details.

Kerry Support Group

Please call John on 087 280 9801 for more details.

Midland Support Group

Please call Val on 087 233 2653 for more details.

Mid West Support Group

Please call Noreen on 087 262 7976 for more details.

ILFA would like to thank the support group leaders for their commitment. For safety reasons, the groups will not meet in person during the Covid-19 outbreak but will use mobile phone technology to have virtual meetings and stay connected.

If you would like information about setting up a patient support group in your area, please contact ILFA on

086 871 5264

ILFA Survey 2021

Thank you to everyone who completed the ILFA Survey to help us understand your experiences of accessing healthcare supports following your diagnosis. 112 patients contributed and the results are being analysed. We will use the data from this survey, the ILFA World Café and our previous surveys on the impact of the first wave and third wave of the COVID19 pandemic, to campaign for a clinical care programme for Interstitial Lung Disease.

If you or a loved one are struggling and would like someone to talk to or a listening ear, please contact ILFA as we have volunteers available to help.

Dates For Your Diary

- **ILFA's Virtual Exercise Class** for lung fibrosis patients takes place every Monday and Thursday 11am via Zoom. The classes are led by Gordon Cagney (Senior Respiratory Physiotherapist) at University Hospital Limerick.
- **ILFA's Patient Information Day** will take place online on Saturday 11th September online via Zoom. See page 1 for details.
- **The VHI Women's Mini-Marathon 2021 & Cork Echo Mini-Marathon** will take place on Sunday 19th September. You can take on the challenge by walking, running or jogging the distance from an area close to your home. Please consider fundraising for ILFA Ireland. Contact ILFA on 086 871 5264 or email info@ilfa.ie for a fundraising pack.
- **Golf classic in aid of ILFA** on 11th September at Waterford Castle will take place on 11th September. Please see page 18 for more information.

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.