ILFA Newsletter

Patrons: Michael Darragh Macauley, Charlie Bird, Andrea Corr.
Issue: Summer 2022 Volume 20 Issue 2

Irish Lung Fibrosis Association
www.ilfa.ie

ILFA celebrates our 20th Anniversary!

A message from the Chairman

"The Irish Lung Fibrosis Association (ILFA) was set up in 2002 to provide support to people diagnosed with pulmonary fibrosis, as well as to provide education and research into the condition. The charity was founded by a small group of volunteers with high aspirations including Nicola Goodbody, the late Terence Moran, Marie Sheridan, and Professor Jim Egan.

Over the years, the charity has flourished thanks to the hard work, commitment and dedication of the current and past volunteers who joined the ILFA Board. It takes lots of planning, preparation, organisation, time, and effort to deliver ILFA's aims and mission, and support our stakeholders' needs. I am extremely grateful to the team for their unwavering support, loyalty, and hard work behind the scenes for ILFA. Special thanks to Gemma O'Dowd and Anne Griffin for all their hard work for ILFA.

I also wish to extend my thanks to everyone who works with the charity in a professional capacity to support ILFA's online programmes such as our online exercise classes, virtual Patient Information Days, "Let's Talk" sessions and other activities. We are so fortunate to work with great individuals who want to make a difference to the lives of lung fibrosis patients, and we value this great support.

ILFA's successes would not have been possible without our amazing fundraisers. Each year many of you have supported our work by organising or taking part in fundraising activities that have not only raised vital funds but also raised valuable awareness of lung fibrosis.

We are delighted to reach the important milestone of 20 years (in November 2022) and we look forward to continuing our work into the future with your help and support."

Eddie Cassidy, Chairman of ILFA

ILFA Website

For many people their first interaction with ILFA is via our website and our social media channels. The ILFA website (www.ilfa.ie) was upgraded in 2021/2022 with financial support from the Pobal Covid-19 Emergency Support funding.

The new look website went live in January 2022. The site is packed with information resources for lung fibrosis patients and respiratory healthcare professionals, as well as information on our news and events, fundraising ideas, and information about the charity.

We hope the information will help people understand the condition better and our practical resources and wellbeing advice will help people manage and maximise their health. We have also a dedicated **Donations Page** with the facility to make a direct and secure online donation to ILFA using your debit or credit card, as well as alternative payment options for those wishing to support the charity. The ILFA Board would like to thank everyone involved in this project, especially the patients who helped review the site and contents. Their input was hugely valuable.

Visit www.ilfa.ie

Dr Liam Chawke and Dr Kate O'Reilly.

Terence Moran Memorial Award

The inaugural Irish Thoracic Society Interstitial Lung Disease Education Day for healthcare professionals took place in September 2021. The Irish Lung Fibrosis Association was humbled that the inaugural Terence Moran Memorial Award, named in honour of our esteemed founder and leader for 15 years, was awarded to Dr Liam Chawke, Specialist Registrar at the Mater Misericordiae University Hospital for the best-case presentation at the event.

Dr Chawke was recently presented with the Terence Moran Memorial Award and an education bursary by Dr Katherine O'Reilly, Respiratory Physician at the Mater Misericordiae University Hospital, and Co-Chair of the Irish Thoracic Society Interstitial Lung Disease Group. Many congratulations to Dr Chawke!

Denise Cassidy Memorial Prize for Excellence in Patient Care

The Denise Cassidy Memorial Award recognises and celebrates an act of kindness shown by a healthcare worker to a lung fibrosis patient. The winner of the 2021 Denise Cassidy Memorial Award was **Mary Ward,** pictured, Clinical Nurse Specialist at St Michael's Hospital in Dublin who was nominated by Paula Jacob. Mary was presented with her Dublin Crystal trophy in December 2021.

Ms Grace O'Sullivan - ILD Clinical Nurse Specialist, Dr Mike Henry – Consultant and clinical lead ILD regional service, CUH, Dr Jehangir Khan – Specialist Registrar, Ms Carmel Casey – Specialist Physiotherapist with the ILD service CUH, Ms Bernadette Bowen – Advanced Nurse Practitioner ILD CUH and Dr Moises Olaverria – Locum Consultant at CUH

Dr Michael Henry and his respiratory team (pictured above) at Cork University Hospital (CUH) were nominated for the Denise Cassidy Prize for Excellence in Healthcare by Gerry Redican. Dr Henry contacted ILFA and said "I received a lovely surprise last week – the framed certificate for patient care for me and the team from ILFA. It was such a lovely surprise. Something like this means an awful lot, and me and the team will treasure it. Many thanks."

Congratulations to **Sara Winward**, pictured,Respiratory Advanced Nurse Practitioner in Lung Transplantation at the National Lung Transplant Unit, Mater Misericordiae University Hospital on being nominated for the Denise Cassidy Memorial Prize for Excellence in Patient Care. Sara said "Thank you so much for sharing this wonderful news. I feel very privileged to be nominated. This really means a lot to me."

Kevin McSkeane from Monaghan nominated respiratory nurses Bernie Walsh and Rita Cullen at Cavan General Hospital for the Denise Cassidy Memorial Prize for Excellence in Patient Care. Kevin was invited to participate in the recent photo shoot. Rita has recently retired, and the award was accepted on her behalf by Professor James Hayes, Consultant Respiratory Physician, and Siobhan Lovett, Assistant Director of Nursing. Congratulations to Bernie and Rita!

The following healthcare professionals also were nominated for the award and received framed certificates:

- Catherine McGeoghegan, Clinical Nurse Specialist at Beaumont Hospital
- Dianne Moran, Clinical Nurse Specialist at the Mater Misericordiae University Hospital
- Dr Nicola Ronan at Mater Misericordiae University Hospital
- Folasade Olaosebikan, Registered Nurse at the Mater Misericordiae University Hospital
- Roseanne Kenny, Orla Harnan, Angela Lawlor and the ICU Nursing Team at Connolly Hospital.

ILFA would like to send our sincere thanks to Sandra Stuhli, of Stuhli Design who kindly designed the beautiful, bespoke certificates for the nominees.

Exercise Resources

ILFA's Online Exercise Classes

The virtual exercise classes from ILFA are now in their third year and are increasing in popularity with new participants joining the classes every month. It is great to see so many participants from across the county taking part with such enthusiasm. Between the start of January and the end of April 2022, there have been 763 participant sessions with an average attendance of 27 people at each class.

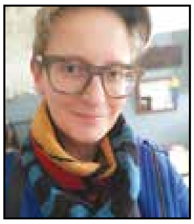
Lung Fibrosis patients are being referred to the classes by doctors, respiratory nurses, and physiotherapists working in public and private hospitals, community integrated care, and hospices. These classes are not intended to replace formal hospital pulmonary rehabilitation programmes but to help keep patients exercising and maintaining their physical activity if their hospital/community programme has ended or while waiting to join a pulmonary rehabilitation programme.

The classes take place on Monday and Thursday at 11am via Zoom and are led by experienced respiratory physiotherapists. The classes last approximately 1 hour and included breathing techniques as well as warm up and warm down exercises. If you would like to join the classes, please contact ILFA by phone or email (see below). We will provide you with information about the classes, safety information, and advice on how to use the Zoom platform if necessary. The classes are provided free of charge to patients registered with ILFA.

ILFA would like to extend our sincere thanks to the physiotherapists who deliver the classes, Eimear Bell (Wexford) and Petra Grehan (Dublin) who do amazing work with the participants.

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.

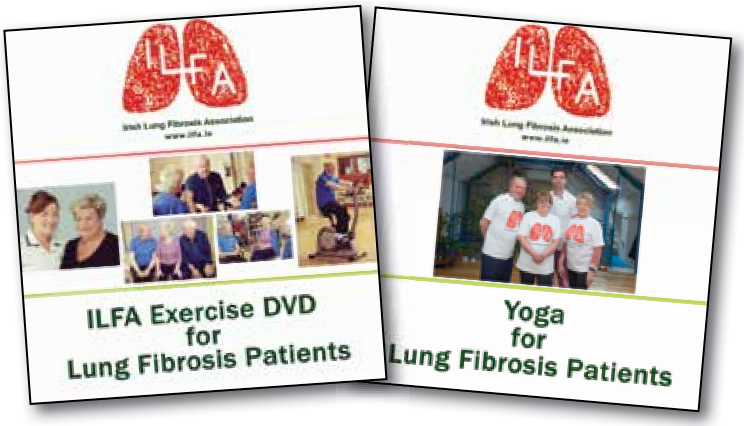
Introducing Eimear Bell



"Greetings to all, my name is **Eimear Bell**. This new year, I joined ILFA in providing twice weekly online exercise classes. Firstly, to introduce myself; I am a Senior Respiratory Physiotherapist and I have worked for approximately 13 years in the acute hospital setting. In my work and my own personal life, I feel the importance of the holistic practice of conscious breathwork and movement/action. This practice helps to create and allow as much presence as possible in our actions; that being thought, word and actions. This can help improve breathing patterns making movement and exercise more enjoyable and beneficial for us holistically.

The pulmonary rehabilitation classes incorporate some conscious breathwork and conscious movement and then a programme of whole body strengthening and aerobic exercise. The strengthening and aerobic exercise can be done at your own pace, taking breaks as needed. I feel the classes offer a wonderful opportunity to participate in exercise in a guided and safe way to maintain and improve your fitness and conditioning. The classes also offer some guidance and tips on improving our presence in our movement and breathing. Lastly and very importantly, exercising as part of a group has the added benefit of the group energy which will help boost our energy and motivation. I have enjoyed providing the initial classes very much and look forward to continuing with these classes in the future."

Eimear Bell, MISCP



Exercise Resources for Respiratory Healthcare Professionals

Exercise is crucial for lung fibrosis patients to maintain their strength, muscle mass and independence. ILFA has a range of exercise resources available to healthcare professionals in respiratory medicine who work with lung fibrosis patients. Our resources include:

- 2000 Steps Walking Packs with a medical grade pedometer and diary to record daily steps counts
- Thera-band stretch bands for exercising
- ILFA Exercise DVD
- ILFA Yoga DVD

Sporting Success for Kevin and Korey

Kevin McSkeane, top left, from Monaghan and his son Korey attended the 2022 IMA Tang Soo Do World Championships in Belfast in April with their club Clontibret Tang Soo Do.

Kevin who is the leader of the Monaghan-Cavan Pulmonary Fibrosis Support club contacted ILFA to say "It was a great weekend with Korey taking home his first-degree black belt and world champion in his division. And myself taking home 1 silver and 1 bronze in my division. So in my eyes that's "Living Life 2 Vs Pulmonary Fibrosis 0"

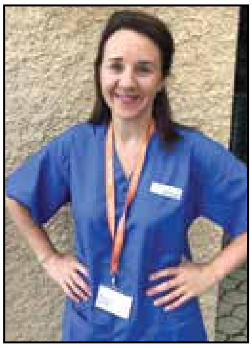
Huge congratulations to Kevin and Korey on their great successes.

Education

Cognitive Behavioural Therapy (CBT) Training Bursaries

In October 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 are their reports after completing the course.

Grainne Murphy, Respiratory Physiotherapist, Mater Misericordiae University Hospital: Thank you ILFA, for providing me with the opportunity to attend the Cognitive Behavioural Therapy (CBT) course run by Pivotal Health. As a respiratory physiotherapist, I work mainly with patients who have lung fibrosis and knew that this training would give me an opportunity to learn a new skill that I could use in my work. This course allowed me to understand the basics of CBT and use CBT skills to help my patients. The course was very well run and had a good balance between theory and practice. I was able to meet with other health care professionals, virtually, working with patients with chronic respiratory conditions, from around the country. CBT helps you manage your problems by thinking more positively, and can be used to support patients in managing breathlessness.



Grainne Coffey, RGN in the High Dependency Unit, University Hospital Kerry: I was very fortunate to be selected by ILFA to complete CBT training recently with Pivitol Health. I thoroughly enjoyed the course; the tutors were excellent and very relatable. It helped immensely that they had years of respiratory nursing experience and were happy to share many clever strategies that they developed over time. Importantly, I have gained a deeper understanding of how mental wellbeing influences physical health. Particularly, this CBT course has taught me practical skills in a stepwise approach of how to really help patients when their ability to self-manage is impaired by anxiety and depression. From the beginning, I was intrigued and motivated to start applying the different techniques learned into everyday practice and am happy to report that these are improving with time, practice, and patience. I am incredibly grateful to ILFA for this fantastic opportunity, I fully intend to tap into the valuable knowledge and skills attained from this programme for many years to come, Thank you ILFA,

Carmel McInerney, Respiratory Advanced Nurse Practitioner, Ennis Hospital: Thanks so much to ILFA for the opportunity to attend the Pivotal Health CBT Course. I thoroughly enjoyed the course and learned so much. While doing the course I realised we are already using various forms of CBT while in clinic, such as breathing techniques and energy conservation, but not in a formalised way. Having completed the course, I am much more aware of listening to the patients and how to support them in their everyday life. I am now much more comfortable talking to patients about their worries and fears. It has been one of the most beneficial courses I have attended in a long time and would highly recommend it to a colleague. Once again thanks to ILFA for providing me with the opportunity to attend and for all the work they do for the Pulmonary Fibrosis patients.

Noelle Ryan, Clinical Nurse Specialist at University Hospital Limerick: “Thank you to ILFA for awarding me the opportunity to complete the Cognitive Behavioural Therapy (CBT) Course. Some of my colleagues here in UHL had completed it previously and found it so beneficial to their areas of practice. This course opened my eyes to a new approach and skill that I can now implement with my IPF patients. The course provided me with the basic principles of CBT and taught me some structured techniques that I can implement into my consultations with patients such as the ‘hot cross bun’ assessment. It provided me with a variety of different questioning techniques that allowed patients to express any worries, concerns, or anxieties they had about their condition or just life in general. Learning from others’ case studies on day 2 allowed us to put what we had learnt into practice and then present it in a safe confidential environment. I continue to apply what I have learnt in my daily work and interactions with patients. Thank you ILFA for the opportunity to complete this very beneficial course.”

Liga Kokina: I would like to say special thank you to the ILFA for an opportunity to participate in CBT course. This course reminded me how important is to stop for a little longer and listen to the patient. Very often I would mostly concentrate on the patient physical symptoms. However, this course emphasised on the importance to listen to patient’s thoughts and feelings. This can be very challenging sometimes in the busy clinic, but very important to them.
I have learned how to use the framework to support the patient through their chronic illness. I continue to use these new gained skills in my professional and personal life. Thank you ILFA!

Cognitive Behavioural Therapy

Olivia Quinn, Respiratory Clinical Nurse Specialist, Nenagh Hospital: I wish to thank the ILFA for providing me with the opportunity to undertake the Cognitive Behavioural Therapy (CBT) course. The course was extremely interesting. The most beneficial aspect for me was that it is so applicable to my day-to-day clinical practice (and dare I say my home life too!).

CBT helps you to recognise unhelpful patterns of behaviour, and gives you tools to assist you in thinking more positively. CBT is based on the idea that the way you think about a situation affects how you feel and how you act. So, it is necessary to change both thinking (cognition) and what you do (behaviour) at the same time. As soon as the course started, I could recognise, and begin to understand, why many patients develop unhelpful patterns of behaviour while trying to live with a chronic respiratory illness.

I could also see how the practice of CBT might help them. For me, this was particularly relevant to dyspnoea and breathlessness management, and the idea that how patients perceived their shortness of breath might determine how they lived with it – was it something that they might control, or would it control them? By using CBT, we were able to tease out the barriers to managing shortness of breath, practice more helpful ways of thinking about breathlessness, and create a more positive plan for self-managing their chronic respiratory illness.

ILFA CBT Bursaries 2022

ILFA will offer a new round of educational bursaries to respiratory healthcare professionals working with lung fibrosis patients to study Cognitive Behavioural Therapy (CBT) in the Autumn of 2022.

Please keep an eye on the ILFA website and on social media for announcements regarding the application process.

Alternatively, please register your interest with ILFA by emailing info@ilfa.ie or calling 086 871 5264.

If you are a healthcare professional already registered with ILFA and on our mailing list, please ensure that we have your current email address on file. If you move to a new hospital or have changed your contact email address, please get in touch so we can update your details.

Update your contact details with ILFA

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Patient Information Day

November 2021

Eddie Cassidy, ILFA Chairman, welcomed everyone to the third virtual Patient Information Day of 2021. He thanked the speakers for sharing their knowledge and expertise and acknowledged the organisers of the event.

Dr Aidan O'Brien, Consultant Respiratory Physician at University Hospital Limerick and President of Irish Thoracic Society gave a lecture on 'Idiopathic Pulmonary Fibrosis (IPF)'. IPF is a specific form of chronic, progressive, fibrosing interstitial pneumonia of unknown cause which occurs primarily in older adults and is limited to the lungs. Many other diseases can cause scarring of the lungs leading to progressive fibrosis for example, exposure to asbestos, silicosis, conditions like sarcoidosis, rheumatoid arthritis, or lupus. IPF is more common in males, the median age at diagnosis is 66 years, and IPF can run in families, but this is considered rare.

IPF results from an abnormal response to an injury or insults to the lungs and leads to progressive fibrosis (scarring) that is irreversible. Risks and contributory factors may include (i) environmental exposures: metal dust, wood dust, viral infections (ii) smoking is a risk factor but is not the sole cause (iii) genetics – family history can increase your risk (iv) gastro-oesophageal reflux could aggravate IPF.

Presenting symptoms of IPF include a chronic dry cough or breathlessness, fatigue, clubbing (increased rounding) of fingernails or toenails, low oxygen levels and crackles. Often people present late in the disease process and on average 9 months after symptoms emerge. 5% of people are asymptomatic at the time of diagnosis and it is picked up incidentally on chest x-ray. Lung function tests show reduced lung volumes and diffusion capacity (gas exchange). Radiology forms a vital part of diagnosis and honeycombing of the lungs indicates advanced pulmonary fibrosis.

Treatment options are considered in the context of each individual patient's clinical condition. There are 2 anti-fibrotic mediations, pirfenidone and nintedanib, that appear to slow disease progression, reduce the loss of lung function per year, reduce the number of exacerbations and improve quality of life. Disease progression and treatment are assessed by repeat pulmonary function tests, measuring the lung volumes focusing on the Forced Vital Capacity (FVC) and gas diffusion.

The prognosis varies greatly, some patients slowly progress over years, 5-20% of patients experience a rapid decline following an acute exacerbation (worsening of symptoms) Exacerbations may be caused by infection, lung collapse, or heart failure. Lung transplantation is an option for suitable candidates and early referral for transplant assessment is crucial.

Patricia Jones, Respiratory Clinical Nurse Specialist at St. Vincent's University Hospital gave a presentation on 'Living well with IPF'. Living well with IPF involves adopting and maintaining a healthy lifestyle and behaviours to improve quality of life. Patients should work in partnership with their healthcare team to develop self-management skills and set realistic goals.

It is important to maintain a healthy weight and eat well. Being overweight adds to the work of breathing and hinders exercise capacity whereas being underweight adds to the work of breathing due to weakened inspiratory muscles and weaker limbs (due to loss of muscle) affects mobility and exercise capacity. A balanced nutritious diet is beneficial for energy and improves quality of life, muscle strength, and the immune system.

It is useful to eat small frequent meals and snacks so that you don't feel bloated and expend a lot of energy digesting your meal. Establish regular times for eating, eat slowly, take small bites, eat while sitting up and remain seated for 30 minutes after your meal. Eat a varied diet with vegetables, grains, or starch carbohydrates and complete with a dairy product (yoghurt or glass of milk) or fruit.

Exercise is important to improve and maintain your functional capacities and exercise tolerance to reduce shortness of breath, increase muscle mass and maintain bone mass (thus reducing the risk of bone fractures), improve mood, sleep, and quality of life.

Additional measures to ensure good health include stopping smoking, getting vaccinated against Influenza, Pneumonia and Covid 19, avoiding irritants/triggers that induce cough, screening for other conditions such as acid reflux, obstructive sleep apnoea, heart disease, and recognising an acute exacerbation and seeking early medical advice.

Breathlessness can be managed using advice from a physiotherapist, pacing yourself, using pursed lip breathing or focused breathing, airway clearance techniques and the ILFA STALL Breathing Technique. Palliative care teams run breathlessness clinics where patients can be referred. Oxygen therapy and the use of morphine derivatives can help reduce the perception of breathlessness and cough. In addition, cough can be managed with oral fluids, lozenges, ice-cream, some cough syrups including cough suppressants like simple linctus, codeine linctus or oramorph. Proton pump inhibitors can be useful as they control stomach acid reflux, and nasal sprays that control post-nasal drip.

It is important to recognise and manage stress and emotions. National support groups detailed on www.ilfa.ie can help patients feel supported and connected to others with the same disease. Do things you enjoy and engage in relaxation techniques such as yoga and meditation.

Grainne Murphy, Senior Medical Respiratory Physiotherapist at the Mater Hospital discussed the benefits of exercise in Pulmonary Fibrosis and managing breathlessness. A cycle of Inactivity can occur for patients because breathing feels like hard work, and you can become breathless doing everyday activities like walking. The impact of experiencing breathlessness can lead to inactivity. However, if you are not active, your muscles lose strength: weak muscles use more oxygen and are less efficient and with time you will feel more and more breathless. You can become fearful of activities that make you breathless and avoid those activities resulting in less activity. The aim is to break this cycle and gain the benefits of exercise that include

- Increased muscle strength including breathing muscles
- Muscles use oxygen more efficiently
- Improved breathing and less shortness of breath and tasks are easier
- Improved mobility
- Improved mood due to endorphins being released into the blood stream
- Improved bone density, reducing the risk of osteoporosis

IPF patients should try to include exercise every day and aim for 150 minutes of activity per week. ILFA has several exercise resources to help for example the ILFA Exercise and Yoga DVDs, ILFA 2000 Steps challenge, the ILFA online exercise class.

Dr Cian O'Leary PhD MPSI: Pharmacist and Lecturer in School of Pharmacy and Biomolecular Sciences RCSI discussed his research on 'Inhaled Anti-fibrotic Drug Development for IPF'. He is studying pulmonary fibrosis at the microscopic/cellular level to develop new drugs. Inhaled drugs are advantageous as they are effective for local targeting, smaller doses can be delivered for maximum therapeutic effect, there are less systemic side effects such as gastrointestinal upset and there are less drug-drug interactions. Whereas oral medication is convenient, simple to use and is easy for pharmacists to make and scale up in bulk. However, oral medications can have systemic side effects and drug-drug interactions can be problematic, although sometimes they can bring synergistic benefits.

There are some challenges involved in developing inhalers including

- Utility –It must be beneficial, so a person adheres to treatment
- Practicality – inhalers should be portable and easy to use
- Inhalation capacity –reduced lung function can mean a drug is not delivered effectively to the lungs
- Inhaler Technique – the inhaler device needs a simple technique and education on how to use it
- Drug formulation –medications formulated, can have problems with drug stability for example. if the drug is dissolved for nebulisation

There are clinical trials investigating inhaled medicines in IPF. There is a new inhaled medicine under development that targets a new pathway in IPF. Another trial is ongoing to see if pirfenidone administered via an inhaled route will eliminate or reduce systemic side effects. Treprostinil originally an injectable medicine and converted (repurposed) to an inhaled medicine has been shown to help one condition in the lungs and there is a trial looking at this drug in IPF.

Repurposed drugs are under study at RCSI These drugs have been used safely to treat other diseases and are now being studied for alternative use. This reduces development costs, regulatory hurdles, time to come to market, and as a safety profile has already been established, there is less failure in clinical trials.

Pharmacists think inhaled medicines are very useful and could be the way forward, but the best people who know this are the people who have the condition. IPF patients are the experts on their condition. It's important for patients to have a therapy that is beneficial and not disruptive. Dr O'Leary ended with a series of questions for the audience to consider (1) Do you think inhaled anti-fibrotic medicines are feasible and practical in IPF? (2) What type of inhales are preferred – Nebulisers or dry powder inhalers?

Maria Love, End of Life Care Coordinator at the Mater Misericordiae University Hospital spoke about 'Palliative Care and Coping with Serious Illness'. Palliative Care is defined by the World Health Organisation as an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

Palliative care aims to improve quality of life for the patient and their family, relieve suffering for patients and families, helps patients manage their symptoms by providing practical support either at home or in hospital, and provides emotional support. Specialist palliative care is available to those suffering from any advanced illness. It is available when the unwell individual or their family decide that a time has come where it is right for them to focus on comfort care only. In this situation, the speciality palliative care team continue to work in partnership with your GP or hospital-based team but will try to manage the person's condition with as little invasive or burdensome treatment as possible.

ILFA's World Café research on palliative care in 2018 informed us that palliative care is fundamental at all stages of the disease however, IPF patients are not getting it when they need it, or at the right time, and are not referred in time. Furthermore, palliative care provision differs across the country.

Referral to palliative care can be made by a GP or a hospital team following discussion with you and family to decide if the time is right. The palliative care team consists of doctors, nurses, and medical social workers. If available there are occupational therapists, physiotherapists, dieticians, chaplains, complementary therapists, household staff, volunteers etc.

Hospices provide care to seriously ill people at the end of life. However, short admissions are possible to improve how people are coping, medically and emotionally, before going home again. Many hospices provide free supports and services and some have day-care programmes with hairdressers, complementary therapists, and classes.

The Irish Hospice Foundation's Think Ahead document can give useful ideas, conversation openers, and questions to help you to think about the future, legal issues, financial issues, and advanced care planning.

Further information is available online at the following organisation's websites

Irish Hospice Foundation
- All Ireland Institute of Hospice and Palliative Care
- St Francis Hospice
- Our Lady's Hospice, Harold's Cross and Blackrock
- Voices4Care

Annette Cremin from Kerry gave her perspective on living with pulmonary fibrosis. Annette's sister Joan was diagnosed with IPF and passed away in 2010. That was the first time Annette had learned of pulmonary fibrosis. In 2017, Annette developed a cough and she approached her GP and asked to be referred to respiratory physician at the Bons Secours Hospital in Tralee for tests. Annette was subsequently diagnosed with pulmonary fibrosis and was prescribed anti-fibrotic medication. She experienced side-effects and her medication was changed to another anti-fibrotic and she reported that "I seem to be doing OK."

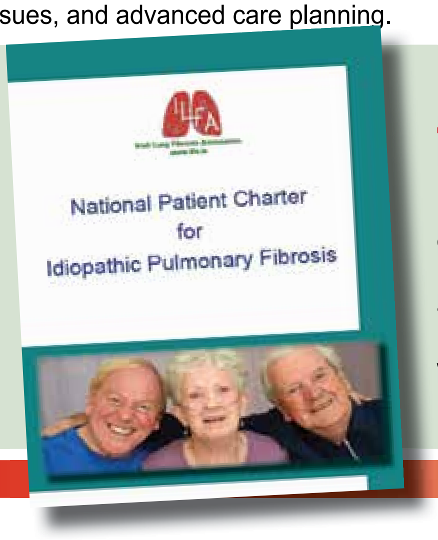
Annette said the speakers at the ILFA Patient Information Day were wonderful, Annette said that she enjoys ILFA's exercise and singing classes and that she is doing everything she possibly can to help her lungs. Annette ended with a special thanks to all the team at ILFA for their help and being at the end of the phone.

Over 100 attendees joined the Patient Information Day from across Ireland, the UK and Spain. Many people submitted interesting and probing questions for the speakers to address at the end of their talks. After 2 hours and 20 minutes of learning, Eddie Cassidy closed the meeting by thanking the speakers, Gemma O'Dowd and Anne Griffin for their work behind the scenes, and Justin Dawson who expertly managed all the technical aspects associated with hosting an online event. Eddie also paid tribute to the volunteers who serve on the ILFA committee and the fundraisers, and thanked Boehringer Ingelheim for supporting the event.

The ILFA Patient Information Day was very well received by attendees, and we are grateful to everyone who sent in positive feedback and words of appreciation.

Sincere thanks to Paula Jenkins for volunteering her services and providing a transcript of the meeting for editing by ILFA. Videos of the presentations are available to view free of charge on the ILFA You Tube channel.

The next ILFA Patient Information Day will take place virtually in November 2022. Please keep an eye on the website (www.ilfa.ie) and ILFA's social media channels for information on the event date and speakers, and instructions on how to join.



National Patient Charter
for
Idiopathic Pulmonary Fibrosis

Useful Information Sources for Lung Fibrosis Patients

ILFA provides a range of information resources, infographics, publications, and educational material on lung fibrosis to help you better understand the condition. Please visit the website, www.ilfa.ie, to see the full range of information leaflets available.

If you are newly diagnosed with lung fibrosis, please register with ILFA and we will send you a free Patient Information Pack and additional resources if needed. Call 086 871 5264 or email info @ilfa.ie

Advocacy Activities

Hospital Professional News features an educational article on IPF

In January 2022, the publication Hospital Professional News featured a great article on Idiopathic Pulmonary Fibrosis (IPF) by Dr Padraig Ridge and Dr Sinead Walsh, respiratory physicians at Galway University Hospital.

In the article written for medical professionals, the authors raise awareness of IPF and referenced the 6 principles of care included in ILFA's National IPF Patient Charter and the support available from ILFA to those affected by the condition. We are grateful to Dr Ridge and Dr Walsh for their support.

Update Respiratory Medicine Journal

Two articles on Pulmonary Fibrosis were published in the Update Respiratory Medicine Journal of the Irish Medical Independent in May 2022 The journal is aimed at General Practitioners, specialist nurses, and respiratory physicians at both training and consultant level.

- Dr Roisin Cahalan, Senior physiotherapy lecturer and researcher at the University of Limerick and Dr Anne Marie Russell, Senior Lecturer, University of Exeter / UK and Senior Clinical Fellow, Royal Devon University Healthcare NHS Foundation Trust wrote an article entitled "SingStrong – singing for Better Lung Health in Pulmonary Fibrosis" and described the benefits of singing for lung health and the collaboration with ILFA to test the feasibility of a singing programme for lung fibrosis patients.

- Nicola Cassidy, ILFA Director wrote an article describing the ILFA online exercise classes that were established to meet patients' unmet exercise needs during the pandemic. The results from a survey of the class participants in 2021 were presented. 53 participants with IPF responded to the survey. 83% were aged over 60-years of age, 51% were male, 36% used oxygen all the time or most of the time, and 6% were lung transplant recipients. 12% of patients were diagnosed with IPF in the last year, 22% between 1-2 years ago, 26% between 2-3 years ago and 24% between 3-5 years ago. 60% of participants were living outside Dublin. A rating of 'excellent' was awarded by 73% of respondents for help in overcoming anxiety about exercising online. 80% stated that the instructions were excellent and 77% found it easy to join the class using Zoom. 64% reported being more active because of the online exercise classes and 68% reported being less fearful about doing exercise since starting the online classes.

ILFA on Social Media - @ILFA_Ireland

In April 2022, ILFA joined Instagram! Instagram is a social networking app with an emphasis on mobile use and visual sharing of images, photos, and videos. There are over a billion registered accounts with Instagram and the social media platform is so much a part of daily life, that there is even an official verb that relates to the activity on Instagram: "Instagramming"!

Instagram is very popular especially with younger people and in 2022, over two thirds of total Instagram audiences were aged 34 years and younger. If you or your family members use Instagram, please follow @ILFA_Ireland and help ILFA raise awareness of lung fibrosis. Too few people know about lung fibrosis and with your help, we can spread the word.

You can also keep up to date with ILFA's news, events, and activities via our other social media channels – Facebook, Twitter, and YouTube. ILFA has over 4,300 Facebook Followers and over 1,400 Twitter Followers and we have lots of information videos that are hosted on our You Tube channel.

Governance – Compliance with Charity Code

The Board of the Irish Lung Fibrosis Association (ILFA) is responsible for the running of the charity in a voluntary capacity and to the highest professional standards. All Trustees are fully committed to operating the organisation with high standards of good practice and transparency, to delivering the charity's mission statement, its goals, and values, to fulfilling legal requirements, and maintaining the trust, confidence and support of our members, fundraisers, volunteers, donors, and other stakeholders.

The ILFA Board meets our compliance responsibilities by applying the appropriate policies and procedures necessary to ensure that the charity is run effectively, efficiently, and transparently. ILFA became fully compliant with the self-assessed Governance Code for community and voluntary organisations as of April 2022.

Research Collaborations

Sing Strong - singing for better health in pulmonary fibrosis: A feasibility study”

Congratulations to Dr Roisin Cahalan, Dr Anne Marie Russell, Ciara Meade, and Grainne Hayes on the publication of their research entitled “*Sing Strong - singing for better health in pulmonary fibrosis: A feasibility study”*. The peer-reviewed research was published in Physiotherapy Practice and Research which is the official journal of The Irish Society of Chartered Physiotherapists.

This patient-centred research included ILFA members who participated in an online singing programme delivered by vocal coach Ciara Meade in 2021. The weekly online programme took place over 12 weeks and was comprised of 45-minute classes of mindfulness, breathing retraining, vocal exercises and singing. People with pulmonary fibrosis were invited to participate and contribute to the research element of the course by giving feedback using the St Georges Respiratory Questionnaire (SGRQ) and Idiopathic Pulmonary Fibrosis Patient Reported Outcome Measure (IPF-PROM).

The results showed statistically significant improvements in self-reported quality of life. There was strong satisfaction with classes and participants reported that they experienced improved efficacy in self-management of their lung health, especially in relation to breathlessness. The authors of the paper concluded that singing programmes are popular and may provide helpful support to existing clinical strategies such as pulmonary rehabilitation.

Dancing for Pulmonary Fibrosis

Dancing for Pulmonary Fibrosis is a new dance exercise and wellness initiative from ILFA in collaboration with Dr. Vikram Niranjan, UCD School of Public Health, Physiotherapy and Sports Science, and Tracey Barnes, Dancing for Health CIC, UK.

The classes started in April 2022 and will take place virtually via Zoom for 8-weeks.

The classes will include seated/standing exercises to music and a social component. 21 participants have signed up for the preliminary course, and we look forward to hearing how they get on.

“Dancing for health and wellbeing: A feasibility study of examining health impacts of dancing among lung fibrosis patients” is funded by an Irish Research Council New Foundation 2021 Award.

ILFA is delighted to collaborate with Dr Niranjan and his team on this novel research project.

Public, Patient and Carer Involvement in Research

Patient and public involvement (PPI) in research is defined by the National Institute for Health Research as “Research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”.

Public, patient, and carer Involvement in research is becoming increasingly important in research planning, development, and design, and is now considered best practice.

Actively involving patients and the public in research activities ensures that the voice of patients and other interested parties is included to influence quality research. This results in research activities that are enhanced, better designed, with clearer and more relevant outcomes, and a faster uptake of new evidence.

ILFA is committed to PPI to ensure patients’ and carers’ perspectives and priorities influence our aims/mission, values, activities, advocacy, and research. This year ILFA would like to set up a PPI Research Advisory Group to inform our research activities, enhance collaborations with researchers and support and influence research relating to lung fibrosis. Ideally, we would like to recruit 15 members.

Role of the PPI Advisory Group

The role of the PPI advisory group is to contribute their perspectives to ILFA’s research activities, to engage with research proposals. meaningfully and actively collaborate in the governance, priority setting and conduct of research, as well as in summarising, distributing, sharing results and knowledge.

Responsibilities

- The group will be asked to meet 2-3 times a year (virtual meetings to start with).
- A commitment to adequate preparation for meetings is required. Members will be asked to read and consider any documents sent in advance of the meeting.
- Members are asked to engage in active, meaningful, and respectful collaboration with other members of the group, ILFA Board Members and research investigators if necessary.

ILFA has prepared Terms of Reference for the PPI Advisory Group that are available on request. If you are interested in joining the PPI Advisory Group, please contact ILFA by the end of June 2022.

Email info@ilfa.ie or call 086 871 5264

Research on the Impact of Covid-19 on People with IPF

Congratulations to Noelle Ryan, Respiratory Clinical Nurse Specialist at University Hospital Limerick on publishing her master's degree research. Noelle has summarised the findings of her research entitled 'To explore the experience of people with idiopathic pulmonary fibrosis living through the Covid-19 pandemic'.

"As part of my Master's Programme in Respiratory Nursing, I opted to undertake a piece of research. Within my daily practice I have a specific interest in the area of Idiopathic Pulmonary Fibrosis (IPF).

After reviewing the literature available, it was evident that prior to the Covid-19 pandemic, people with IPF were an already marginalised and vulnerable group, experiencing social isolation, a limited lifespan trajectory and an underlying respiratory condition that potentially increased their susceptibility to Covid-19 infection. While there was some research conducted on the impact of Covid-19 on people living with chronic illness, it fell short of identifying experiences of people with existing respiratory conditions. I felt it was timely therefore, to consider people with IPF as a particularly vulnerable group whose experiences warranted specific attention to inform the body of evidence around development of interventions to optimise care. My research was entitled 'To explore the experience of people with idiopathic pulmonary fibrosis living through the Covid-19 pandemic'.

I recruited 13 participants with IPF attending the respiratory department of University Hospital Limerick. Data were collected between January 2021 and February 2021 through semi-structured interviews, using an online platform.

Four key themes were identified from participant's experience of living through the Covid-19 pandemic. Included are some of the direct quotes from the interviews undertaken.

(1) Fear of contracting Covid-19 disease

> *'It's been more difficult for us because there's a huge fear of contracting Covid ...it's in your head … if I get this, I'm going to die' P5*
>
> *'No matter where you go or who you see you're trying to avoid everyone … someone might come up behind you … you get paralysed with the fear.' P11*

(2) Living with reduced social interaction

> *'It's not my complaint that's going to kill me, it's the pandemic. My mental health is going to get me because I'm not a person that likes to be confined.' P12*
>
> *'It's really impacted on us and I was feeling really angry, I just feel like there's been a whole year of my life almost gone. … I don't have that time; I can't afford that time. 'I'm missing out on travel, times with my family, my friends… so a lot of anger around that.' P5*

(3) The adjustment in the relationship with healthcare professionals

> *'I'd be praying night and day that there wouldn't be any changes in my condition. I'd be often worried … I wouldn't be able to self-diagnose myself.' P12*
>
> *'There was great support in the knowledge that if I was unwell, I could ring. That message was re-enforced many times, that if I needed a bit of help, someone to talk to.' P3*

(4) Navigating an altered landscape.

Participants used a variety of strategies that helped them to cope with this changing landscape through the pandemic. Many engaged in physical activities; people discussed the importance of exercise in the context of their IPF but also for their mental wellbeing during the pandemic. Physical activity took a variety of routes; some walked every day while others engaged in online exercise classes organised by the Irish Lung Fibrosis Association (ILFA) during the pandemic.

> *'Yoga, meditation, just going out for a walk I mean all of those things definitely helped.' P5*
>
> *'you're using your own supports whether it's your friends, my telephones been burnt out. It's just staying in touch with people, that's kind of what gets you through the day.' P5*

Healthcare professionals have a key role in protecting the physical and psychological health of the person with IPF during this time and into the future. Participants felt compelled to self-isolate due to fear and anxiety of contracting Covid-19. Participants reported increased social isolation with some experiencing anger and resentment at loss of precious time with loved ones.

Participants also felt an increased responsibility for self-monitoring their condition and had concerns about differentiating symptoms of Covid-19 infection from an exacerbation. The results from this study can be used to inform healthcare professionals understanding of the challenges experienced by people with IPF during enforced restrictions, and also underpin decisions regarding interventions to enhance care provision of this vulnerable group in response to the pandemic."

Noelle Ryan, Clinical Nurse Specialist Respiratory, University Hospital Limerick

2000 Steps Extra Challenge on Easter Monday

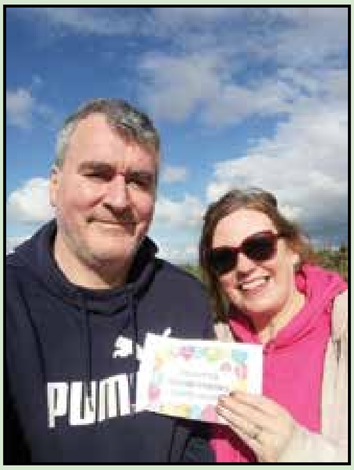
Top, from right: The ILFA Easter bunnies took their extra steps in Dublin; ILFA's Patron Michael Darragh Macauley supported ILFA's 2000 Steps Extra on Easter Monday with ILFA Director, Nicola Cassidy. Below, from right: Breda Coughlan took 2000 Steps Extra for ILFA on Easter Monday in Dublin; Sisters Annette Grehan (Dublin) and Martina Osborne (Carlow) completed their 2000 Steps Extra for ILFA while on holiday in New York. They certainly went the "extra mile" with their costumes. Don't they look great!!; Annette Cremin took her 2000 Steps Extra for ILFA on Inch Strand, Co Kerry. Below: Mary O'Sullivan took part in the ILFA 2000 Steps Extra Challenge and said "Huge thanks to my daughters Mary and Angela and Ben, Fionn and Tilly (the cutest little dog) for their company and support. Many thanks to ILFA for all the great work they do."

On Monday 18th April 2022, ILFA held our third Easter Monday 2000 Steps Extra Challenge. Patients, carers, and family members were asked to join the virtual exercise challenge from their home 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.

Thankfully the country basked in glorious sunshine for most of the day even though there was a chilly wind reported in some counties. We were delighted to have had great support from around the country and were excited to receive photos from participants holding up their ILFA Certificates after bursts of walking and running activities. In total, more than one quarter of a million steps were taken by those who sent in their step counts to ILFA. Sincere thanks to everyone who joined the ILFA 2000 Steps Extra Challenge from across the country and afar. It was great to see and hear about all your efforts to go the extra mile and help raise awareness of lung fibrosis. Thanks also to everyone who kindly donated to the event. Mile buiochas!!!

Here are some photos and reports from our members across the country. Well done and thank you to all the participants! You're inspirational! Keep up the good work and keep exercising!

Frank Boyle, his wife Phil, and family completed their 2000 Steps Extra for ILFA on Easter Monday in Shanganagh Park, Shankill.



Colman and Anne completed in beautiful East Cork.

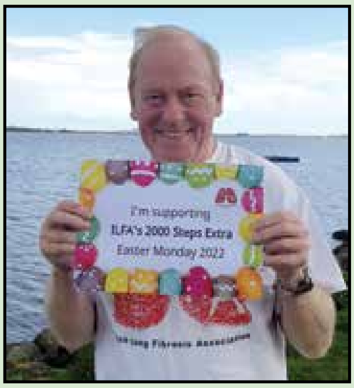
Barry, Hannagh, Reece and Kevin McSkeane from Monaghan supported ILFA's 2000 Steps Extra at the mighty Clontibret O'Neills GFC.

Fionn and Roisin Newman Reid supporting in Malahide.

Morwenna Quinn at Valentia, Kerry to support ILFA.

Freya and Harry Healy from Listellick, Tralee.

Sheila Plunkett took over 15,000 steps through counties Leitrim and Sligo.



Matt Cullen completed his 2000 Steps at the Swords Estuary.

Gemma O'Dowd and James Kavanagh supported in Dublin.

Pip and Gerry Fitzgerald took their dogs Jim and Smit.

ILFA Online Activities

Let's Talk …

The *"Let's Talk"* online education interactive sessions started in 2020 as support groups around the country could no longer gather for face-to-face meetings. To help people keep in touch, ILFA uses the online platform Zoom to host private and secure online meetings for people around the country.

The *"Let's Talk"* meetings take place online approximately every 6-8 weeks and feature an invited speaker who discusses topics related to their specialist field and answers questions from the attendees. The meetings usually last 60 minutes and are lively, interactive, sociable, and light-hearted.

The *"Let's Talk"* sessions are announced on the website www.ilfa.ie (News and Events section) and on Facebook. All you have to do is contact ILFA to register in advance to get an email link to join the meetings. Please keep an eye out for upcoming events and 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 and expertise with us and would love to hear from anyone who would like to work with ILFA on a future *"Let's Talk"* session.

Huge thanks to Gemma O'Dowd and Anne Griffin for coordinating the Let's Talk Sessions and all ILFA's online activities.

Let's Talk Physical Activity

In April 2022, the guest speaker was Dr Orlagh O'Shea, Lecturer at the School of Physiotherapy, Royal College of Surgeons in Ireland. Dr O'Shea told everyone about the benefits of physical activity for lung fibrosis patients and described her research in the area.

Let's Talk Oxygen

In April 2022, we had the pleasure of having Patricia Davis, Clinical Nurse Specialist, Respiratory Integrated Care lead a *"Let's Talk Oxygen"* Questions and Answers session. It was a very informative and engaging session.

Let's Talk Dancing for Lung Fibrosis

On 5th April 2022, ILFA held a *"Let's Talk Dancing for Pulmonary Fibrosis"* session with Dr Vikram Niranjan, UCD School of Public Health, Physiotherapy and Sports Science, and Tracey Barnes, Dancing for Health CIC, UK. The speakers described how the new dance exercise classes running from 8th April to 14th June 2022 will be conducted.

Kind words from Anne in Carlow

We were delighted to receive the correspondence below from Anne, a patient living in Carlow and wanted to share it with you with Anne's consent. Warmest thanks to Anne for such lovely feedback.

"Thank you for all your support over the past year. It has been a tremendous help and I really appreciate it especially the singing, the keep fit classes and information days. The classes keep me focused and I really look forward to them. I find the singing classes loosen my chest up and this helps with my breathing (especially blowing bubbles in a glass of water), as well as being lots of fun.

My life would be very lonely and fretful without the classes given my new situation. I was used to going to the gym and swimming 5 times a week up until last Christmas when I got COVID and was diagnosed with lung fibrosis. I miss going to the gym every day. The ILFA classes have kept me going strong through it all and are good for my wellbeing and keeping me motivated.

I would be lost without these classes. I really enjoy the information days too because my hospital appointments are so far apart, and it gives me a greater understanding of my condition and how best to manage it daily. I can't sing the praises enough of you, and the organisers of the classes and information events. Thank you and all the best for 2022."

Anne

Festive Yoga

Thanks to Michael Darragh Macauley, ILFA Patron, who delivered a relaxing online yoga class in December, ahead of the Christmas mayhem. Michael Darragh joined the class all the way from Sri Lanka!!! It was great for everyone to see the sunshine and hear the birds singing in the background. Well done to all the enthusiastic participants.

Namaste!

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 many sporting and social events have now resumed after the easing of Covid-19 restrictions 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.

Ciara's Christmas Tips

Ciara Slattery came up with a novel and generous way of supporting ILFA at Christmas. Here is a report from Ciara.

"On the 6th of February 2020, my Nanny, Elizabeth Flangan, passed away after many months battling with Pulmonary Fibrosis. While I think Christmas is a time filled with unbelievable joy, I also believe it is a time when people think about loved ones who have passed on. I have worked in my local pub for 2 years now and in past years any tips made in the month of December would be spent on materialistic things. However, this Christmas I found myself thinking about my Nanny and what could be my gift to her this year. My family and I witnessed first-hand the effect Pulmonary Fibrosis has on people and how it can change everything. Seeing what Pulmonary Fibrosis does to a loved one would make anyone want to help in any way they could, that's why this Christmas I have decided to donate any of my tips made in December to the Irish Lung Fibrosis Association.

While there is no cure for Pulmonary Fibrosis, ILFA is constantly supporting families who have loved ones diagnosed with Pulmonary Fibrosis, they spread information about this disease that is not well known by many people and most importantly they are there for the people who have been diagnosed themselves. My Nanny Betty will never be forgotten by anyone who has met her. She was always filled with joy, constantly felt the need to help and care for others and never put herself before anyone.

This is for you Nanny, Merry Christmas, Love Ciara"

A Night of Dancing

Bobby Jackman hosted 'A Night of Dancing' in aid of ILFA on Friday 8th April 2022 at the Windgap New Community Hall in Kilkenny. The entertainment was provided by Checkers and the Michael Collins Band. In addition, there was a raffle and spot prizes on the night. Huge thanks to Bobby and his team for organising this event which raised the amazing total of €2,440 for ILFA.

Bobby Jackman (pictured right) presented a cheque to Liam Galvin, ILFA Treasurer.

Croagh Patrick Climb

Nicola Cassidy on top of Croagh Patrick.

Nicola Cassidy, ILFA Director, climbed Croagh Patrick in Murrisk in Co Mayo in aid of ILFA on Wednesday 4th May. Nicola said "It's 3 years since I last climbed Croagh Patrick, and it was good to be back. It was a tough climb, but I was delighted to get to the top and back down safely. The views along the way were amazing and well worth the effort to start early and climb the mountain. My climb is dedicated to my mam, special friends lost to pulmonary fibrosis and in support of all those living with pulmonary fibrosis."

Isabel's 100k in December

Isabel Beacom with Eddie Cassidy, Gemma O'Dowd and Mark Beacom.

In 2021 Isabel Beacom decided to undertake a fundraising challenge in support of her mum Dorothy who was diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in 2017. Isabel decided to run 100k during the month of December 2021 while her Mum was awaiting a lung transplant to raise awareness around organ donation and to raise much needed funds for the Irish Lung Fibrosis Association (ILFA), a charity very close to her heart. Dorothy was an active member in the ILFA community at the time and participated in as many online events as she possibly could, even joining the ILFA exercise classes while she was an inpatient in hospital in November and December.

During Dorothy's stay at the Mater Hospital she received great care, especially from the physiotherapists looking after her. Dorothy and her family recognised the need for extra equipment to help IPF patients with their daily exercise which is an essential part of their care and treatment, due to this Isabel and Dorothy decided to donate some of the proceeds from the fundraiser to the Mater Hospital to help towards the purchase of extra equipment to assist other IPF patients.

Isabel Beacom with Mark Beacom and Eddie Cassidy.

Isabel set a target of €2,000 initially for her fundraiser. Within 2 days the target was reached, then surpassed and the amount pledged continued to escalate. Within 1 month Isabel had raised over €15,000! This was truly phenomenal and would not have been possible without the huge generosity of Dorothy and Isabel's friends and relatives. Isabel is extremely grateful and thankful to everyone who donated to and supported her fundraiser for ILFA.

ILFA would like to send our heartfelt thanks to Isabel and her family and friends for their amazing generosity. €5,000 has been donated to the Mater Hospital Foundation for the purchase of exercise equipment for the Heart and Lung Transplant Unit and over €10,000 was raised to support ILFA's work. Isabel and her dad Mark met with Eddie Cassidy (ILFA Chairman) and Gemma O'Dowd (ILFA Administrator) in April 2022 to present them with the proceeds of Isabel's fundraiser in memory of Dorothy. Dorothy was extremely proud and grateful to those who contributed to the fundraiser before she passed away at the end of December. The kindness shown by all of Dorothy's friends and family really showed how loved and cherished Dorothy was. We remember Dorothy with great fondness and affection. She was a remarkable lady and an inspiration to those who knew her. May Dorothy rest in peace.

Camino de Santiago

Huge congratulations and thanks to mother and daughter duo Ann and Emer from Dublin who recently walked the Camino in aid of ILFA. Here is their story.

"After a 2 year delay (due to that which shall not be mentioned), we finally headed off on our first Camino starting in Sarria, Spain on April 22nd. We are Emer and Ann, Goddaughter/niece and sister-in-law of Denise Cassidy who passed away with IPF, which is why ILFA is our chosen charity for the experience.

The plan was to cover 116km in 5 days culminating in Santiago. From 20km to 29km a day, we laughed, hurt, danced, and hobbled our way through beautiful countryside and mostly very rough terrain. When we did arrive in Santiago, the sight of the cathedral was welcoming. Thanks to everyone who supported us along the way xx Ann and Emer"

Canon Brian McKay's Facebook Fundraiser

Canon Brian McKay, Rev Vanessa Wyse Jackson and Canon Charles Mullen.

Canon Brian McKay is a good friend to ILFA and has been an honorary chaplain to the charity since 2012. Recently Fr Brian held a Facebook Fundraiser for ILFA and here is his uplifting story. Warmest thanks to Fr Brian for his wonderful support.

"I was very saddened to learn of the death of John Donnelly earlier in the year. This lovely man endeared himself to many of us associated with ILFA and I felt that I wanted to do something in his honour and memory. Some kind of fundraiser seemed to be most appropriate. As I was drawing close to my 65th birthday, I thought that a Facebook fundraiser might work. I set my target at 1,000 euro and hoped for the best. After a very energetic and enthusiastic few days and with several hundred in the kitty, things began to slow down, and I feared that I had been overly optimistic in my assessment of what could be raised. After all, many people had already contributed large sums to Ukraine and were perhaps feeling that they had done enough. However, as April the 4th approached, there was another surge and I found that I was only 40 euro short of my target on the morning of the 4th. A final appeal brought in another €60 and so I ended up with €1,020 in the pot. I recommend the Facebook fundraiser as all of us have a different line up of friends and so, are not targeting the same people. I was happy to make this small contribution to ILFA and with it, I offer my sincere sympathy to Alice and all of John's family. I must also mention how saddened Canon Charles and myself were to learn of the passing of the Reverend Vanessa Wyse-Jackson. We were the 'Three Amigos of ILFA' and made a great team whenever services had to be organised. To her husband Patrick and to all her family I extend deepest sympathy. John and Vanessa were deeply committed to the work of ILFA and no doubt would encourage us all to continue to 'do our bit' for this wonderful association." ***Canon Brian McKay***

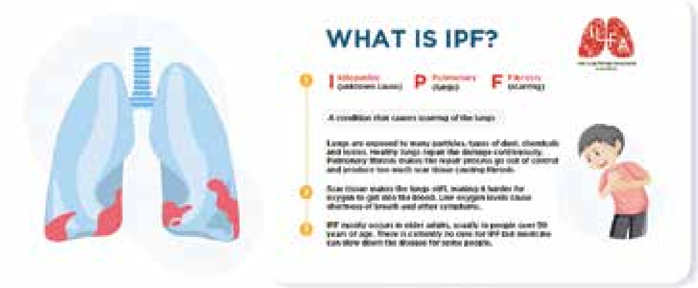
Birthday Fundraising

Thank you to everyone who has set up a Facebook Fundraiser for ILFA recently. We are very grateful for your support and are delighted that so many people have chosen this way to fundraise for ILFA. Early this year, Liam Galvin, ILFA Director, very generously set up a 'matched' Facebook Fundraiser and pledged to donate an equal amount to the amount raised on his fundraising page. What a kind and brave thing to do!

Christmas cards

Sincere thanks to everyone who supported the 2021 ILFA Christmas Card Campaign and helped raise awareness of Lung Fibrosis and ILFA. We are incredibly grateful to everyone who made donations to ILFA in December. Mile Buiochas!

Prepago helps raise awareness of ILFA



ILFA is grateful to Prepago.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 January 2022.

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

Giving in Remembrance

Sincere thanks to all the families who requested donations to ILFA in lieu of flowers at the funerals of their loved ones. We are very grateful for your support and kindness to ILFA at a time of great personal loss. If you would like to make a donation to ILFA in remembrance of someone special, please visit our website **www.ilfa.ie** for a selection of different ways to donate.

Seeking Fundraising Partner Opportunities

If you or one of your family or friends are members of a college, sporting club, organisation, industry group or company who would like to partner with a charity, please consider ILFA as a potential collaborator. ILFA would be thrilled to partner with an organisation large or small that could help us raise awareness and vital funds. We would be very grateful for the opportunity to meet potential collaborators and tell them about our work and future goals.

ILFA's New Technical T-Shirt

ILFA is pleased to announce that we have a new technical t-shirt especially for fundraisers who are taking part in athletic pursuits in aid of ILFA. The t-shirts are unisex, light weight, quick drying and available in sizes small, medium, large, and extra-large. We also have our regular cotton t-shirts for event organisers and ILFA supporters. If you would like to fundraise for ILFA, please call 086 871 5264 or 086 057 0310 and we will send you a fundraising pack and assist you in whatever way we can.

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!

The ILFA Tea Party

Would you like to host a tea party for ILFA this summer? We hope so!!!!

We would love if you would consider throwing a tea party, coffee morning, or a posh picnic and inviting your family and friends around to your garden, home, the local park, or another outdoor location to enjoy an afternoon of yummy treats, a warm cuppa and flowing conversation. It's the perfect opportunity to reconnect with friends, dust off the cake stand, and get your best China cups out!

The first step is to select a date, venue, and time, then decide what will be on the menu, look up your favourite recipe, and send out your invitations.

We would love to receive photos of your favourite mug or cup, tea pot, cake stand, home baking skills and you with your pals etc. Your tea party can take place at a time and date that suits you up.

Any donation to ILFA would be hugely appreciated.
ILFA has a limited number of craft cake stands available for fundraisers to decorate. Please call Gemma or Anne on 086 871 5264 or 086 057 0310 to get your fundraising pack. Thank you for your support.

Ways to Donate

Sincere thanks to everyone who has generously supported the work of the Irish Lung Fibrosis Association. The generosity and kindness of our amazing fundraisers and those who make donations has sustained the charity for almost 20 years. As we look forward, we want to continue our advocacy work and fulfil our aims of facilitating "Education, Research and Support" for the lung fibrosis community. If you would like to fundraise for ILFA or make a donation, **please give us a call on 086 871 5264 or email info@ilfa.ie**

Making a donation

You can donate easily and securely to ILFA directly using your debit or credit card via the ILFA website www.ilfa.ie or online via the website www.justgiving.com and searching for 'ILFA'. A direct link to the online platform is available on **www.ilfa.ie**

ILFA Ireland is set up for Facebook Fundraising making fundraising campaigns and secure donations available for ILFA's Facebook friends and followers. You can make a direct donation or set up your own fundraising page. Visit https://www.facebook.com/ILFAIreland/

All donations made on-line go directly to the ILFA bank account.

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

Upcoming Events

Please keep an eye on the ILFA website, **www.ilfa.ie** and social media channels for upcoming events.

ILFA's Virtual Exercise Classes

Exercise is the best medicine! ILFA's virtual exercise classes take place every Monday and Thursday at 11am via Zoom. The classes are free for pulmonary fibrosis patients registered with ILFA and are led by a respiratory physiotherapist.
Email info@ilfa.ie or call 086 871 5264 for more details.
We can help you set up Zoom if you need assistance to join the classes. ILFA is grateful to Eimear Bell and Petra Grehan, respiratory physiotherapists, for leading the exercise classes in 2022. The classes are going from strength to strength and between the start of January and the end of April 2022, there have been 763 participant sessions.

Online Support Group Meetings

Online Support Group Meetings take place every few weeks via Zoom. Participants can meet in small groups for a social chat and to exchange tips and experiences. People join from all over the country, and this helps greatly to reduce feelings of isolation and enables new friendships to be established.

Sing Strong for Pulmonary Fibrosis

Sing Strong classes with Ciara Meade, Choir Mistress will resume in the Autumn. The classes are great fun with many participants reporting improvements in breathing, wellbeing, and impact of their disease. Please keep an eye on the ILFA website (www.ila.ie) and our social media channels for the return date. If you would like to know more or to register for future classes. You can contact ILFA by emailing info@ilfa.ie or calling 086 871 5264 to register your interest in this event.

EU-IPFF announcements

The European Idiopathic Pulmonary Fibrosis and Related Disorders Federation (EU-IPFF) is a non-profit organisation established in 2016 that brings together European national patient associations committed to working together to gain access to treatment and care for all pulmonary fibrosis patients, regardless of geography, socio-economic status or age. The 2nd European Pulmonary Fibrosis Patient Summit will take place virtually from 3rd to 5th of November 2022. More information will be available closer to the time. Keep an eye for activities from the EU-IPFF including

- The EU-IPFF Webinar Series that is taking place on a regular basis up to November 2022
- The launch of two new guides; one for patients and carers, and one for healthcare professionals. **See www.eu_ipff.org**

ILFA Celebrating 20 years

The Irish Lung Fibrosis Association (ILFA) was set up in November 2002 in memory of Fergus Goodbody by his wife Nicky Goodbody (nee Figgis), along with friends Terence Moran (the late ILFA Chairman) and Marie Sheridan (former Treasurer), Professor Jim Egan and others, to support those affected by lung fibrosis and to facilitate research and education. Since its humble beginnings in 2002, ILFA has gone from strength to strength thanks to the dedication of the committee members who served on the board at different times, our administrative assistants and volunteers, and the many healthcare professionals and fundraisers who have supported the charity. ILFA is delighted to be celebrating the remarkable achievement of reaching our 20th milestone anniversaries in 2022 and 2023. To celebrate, we will;

1. Produce a special edition magazine, ILFA 20, that will be launched in early 2023. We would love to have your input. If you would like to contribute a positive story, a poem, or a few words, please get in touch. You can call 086 871 5264 or email info@ilfa.ie
2. The **ILFA Ecumenical Service** will return this year and takes place at Our Lady of Mount Carmel Church, Whitefriar Street, Dublin 2 at 4pm on Saturday 15th October. All are welcome. If you would like your loved one remembered at this special service, **please email info@ilfa.ie.**
3. We are currently developing a **Patient and Carer Survey** to understand the physical, emotional, and financial impact of living with pulmonary fibrosis in 2022. ILFA will use this information to campaign for greater awareness of pulmonary fibrosis. Please keep an eye on the ILFA website and social media channels for information on how to access the ILFA Survey of patients and carers.

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.

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 committment. Stay safe everyone and keep in touch. Please contact ILFA if you need help to join our virtual events.

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

086 871 5264

Thanks and Appreciation

The Board of the Irish Lung Fibrosis Association would like to send our warmest thanks and appreciation to Marie Sheridan on her retirement from the role of Honorary Treasurer. Marie, an accountant by profession, helped set up ILFA in 2002 and oversaw all financial matters for two terms of office from 2002- 2015 and 2018-2021. Marie went above and beyond by giving her time and expertise to ILFA to ensure the charity operates to the highest financial standards and committing fully to ILFA's values and aims. A heartfelt thanks to Marie for all her work.

Message of Condolence

The ILFA Board would like to extend our deepest sympathies to the families of John Donnelly and the Reverend Vanessa Wyse Jackson who passed away recently. John was a lung transplant recipient, fundraiser, and kind and loyal friend to many in the ILFA community over the years. Reverend Vanessa, formerly of Rathgar Methodist Church, was one of three ILFA Chaplains and a joy to know and work with. Both John and Vanessa were great supporters of ILFA and contributed to the ILFA Ecumenical Services from 2010 to 2019. We shall miss them.
May they rest in peace.

Dates For Your Diary

- **ILFA's Virtual Exercise Class for lung fibrosis patients takes place every Monday and Thursday at 11am via Zoom. The classes are led by a respiratory physiotherapist.**
- **Sporting and fundraising events have now resumed which will help with fundraising activities. If you are planning on taking part in a virtual walk, run or jog or another sporting event in 2022 for charity, please consider raising funds for ILFA.**
- **ILFA's Ecumenical Service will take place on Saturday 15th October 2022 at Our Lady of Mount Carmel Church, Whitefriar Street Church, Aungier Street, Dublin 2 at 4pm.**
- **Upcoming events for healthcare professionals in the Autumn include the Fergus Goodbody Memorial Lecture with Professor Michael Kreuter, University Hospital Heidelberg, Germany, in collaboration with the Royal College of Physicians of Ireland, and CBT training.**

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

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

Irish Lung Fibrosis Association
www.ilfa.ie

EU-IPFF

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.