ILFA Newsletter

Patrons: Michael Darragh Macauley, David Gilna, Charlie Bird, Andrea Corr.
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Irish Lung Fibrosis Association
www.ilfa.ie

David Gilna is ILFA's New Patron

David Gilna and Matt Cullen.

David Gilna, Peter Gallagher, Breda Coughlan, Eddie Cassidy, Matt Cullen and Philo Mullaney.

The Irish Lung Fibrosis Association (ILFA) is delighted to announce that David Gilna, Dublin actor and playwright, is our new patron! We look forward to working with David and we're sincerely grateful to him for his help and support raising awareness of lung fibrosis.

David kindly supported an ILFA fundraising event in 2017 when he acted as Master of Ceremonies for the launch of a highly successful fundraising art exhibition by artist Matt Cullen. Matt was diagnosed with idiopathic pulmonary fibrosis in 2013 and is a great supporter of ILFA.

Matt, his wife Teresa, and David have a great friendship spanning many years after the couple were regular attendees at David's plays. David was aware of Matt's health condition and his amazing acts of volunteerism both in the local Swords community and the ILFA community. The ILFA Board approached David and asked if he would like to join ILFA as a new patron, and we're thrilled that he agreed. David was full of enthusiasm and has already taken part in an interview with the Fingal Independent announcing his new role and shining a light on lung fibrosis.

On 16th September, a photoshoot was arranged with some ILFA members at Swords Castle to celebrate the appointment of our new patron. It was a glorious morning - the sun was shining; the sky was blue and there was a warm, gentle breeze. Present at the photoshoot were David Gilna, Matt Cullen, Eddie Cassidy (ILFA Chair), Breda Coughlan and her husband John, Philo Mulanney, Peter Gallagher, and Nicola Cassidy (ILFA Director). There were great chats and laughter as everyone enjoyed meeting each other and posing for photographs. Breda and John deserve a special mention as they arrived at the photoshoot after renewing their wedding vows on their 50th wedding anniversary. They looked amazing and were in great spirits and delighted to support ILFA on their special day.

We are grateful to David, our willing models, and our photographer Owen for a fun morning. Thanks also to Joan and Paddy for facilitating our request for photos at Swords Castle and looking after us. We had a great time!

See page 2 for more photos and to learn more about David.

Patient Information Day

The next Patient Information Day will take place online on Saturday 5th November from 11am until 1pm. The meeting will take place using the Zoom online platform.

Our speakers will include Dr Liam Chawke (Respiratory Consultant, Kerry University Hospital), Ber Bowen (Respiratory Advance Nurse Practitioner, Cork University Hospital), Eimear Bell (Respiratory Physiotherapist), and Carita Bramhill Ph.D researcher at Trinity College Dublin.

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

ILFA Service of Prayer and Reflection

The ILFA Service of Prayer and Reflection will take place on Saturday 15th October at Our Lady of Mount Carmel Whitefriar Street Church, Aungier Steet, Dublin 2 at 4pm. The service will be celebrated by Reverend Fr Brian McKay and the Reverend Canon Charles Mullen.

A special candle lighting ceremony will take place to remember lung fibrosis patients who have passed away. If you would like your loved one remembered at the ceremony, please contact ILFA by calling **086 871 5264** or emailing **info@ilfa.ie** by the 7th October 2022.

Peter Gallagher, Breda Coughlan, David Gilna, Philo Mullanney, Eddie Cassidy, John Coughlan, Matt Cullen and Nicola Cassidy.

About ILFA's New Patron David Gilna

David Gilna is an award-winning playwright, actor, and screenwriter. He has performed in The West End, Shakespeare's Globe and off-Broadway and most recently has finished his debut sell-out tour of America. Known for his award-winning plays "The Unsung Hero", "My Bedsit Window" and "A Bolt From D'Blue" and films "Ya Clown" and "One For The Ditch". David co-founded Theatre Under The Big Top with Charles O'Brien at Electric Picnic in 2008, and Lightning Comedy in 2018. He is best known for being struck by lightning and never talking about it.

David is honoured to have been chosen as a Patron for the Irish Lung Fibrosis Association (ILFA). For more information, check out David's website www.davidgilna.ie

Here are some more photos from the recent photoshoot involving some ILFA members and David Gilna at Swords Castle.

Matt Cullen, Eddie Cassidy and Breda Coughlan.

Peter Gallagher, David Gilna and Philo Mullanney.

David Gilna.

Breda Coughlan, Nicola Cassidy and Phil Mullanney.

ILFA Service of Prayer and Reflection

The ILFA Service of Prayer and Reflection will take place on Saturday 15th October at Our Lady of Mount Carmel Whitefriar Street Church, Aungier Steet, Dublin 2 at 4pm. We hope you will join us. The service will be live-streamed and available to watch via the church website **www.whitefriarstreetchurch.ie,** for those who cannot attend the church in person.

During the service, we will light candles for those patients whose names have been submitted to ILFA by family members. If you cannot attend, we encourage ILFA members to come together virtually as a community and light a candle in their home at 8pm on the evening of Saturday 15th October to support or remember loved ones affected by lung fibrosis. You can send your photos to info@ilfa.ie if you would like to share your images.

ILFA Patient Information Day

March 2022

Eddie Cassidy, ILFA Chairman, welcomed everyone to the first virtual Patient Information Day of 2022. He thanked the speakers for sharing their knowledge and expertise, the organisers of the event, and Justin Dawson for technical support. Eddie also acknowledged the hard work of ILFA's fundraisers and supporters for their efforts to help the charity. The Patient Information Day was videoed, and the presentations are available to watch on YouTube.

"Perspectives on living well with pulmonary fibrosis" was presented by Elaine Craven, Respiratory Advanced Nurse practitioner at Connolly Hospital.

When we're diagnosed with an illness, it's important to focus on our whole self and our lifestyle and to establish what is meaningful for us? This will vary for everybody. Dr John Travis, speaks of the 'illness/wellness continuum'. When we are ill, we focus on diagnosis, treatment, symptom management. Instead look for other things that help to give meaning, purpose, and enthusiasm to life. Frankel, an Austrian psychiatrist said we must never forget that we may find meaning in life even when confronted with circumstances that can't be changed. 'When we are no longer able to change a situation, we are challenged to change ourselves'. A diagnosis of pulmonary fibrosis challenges us to take an inventory of our life. It can help to focus attention on other areas in your life rather than your illness. You may start to feel better, more motivated, and more inspired.

Often, we don't feel particularly motivated to do something. Mark Manson talks about the two-minute rule - if we commit to do some action for two minutes this will give us the motivation to adopt healthy habits. His two-day rule: where you commit to something and don't miss it for two days, our thoughts influence our emotions and behaviours. But we can influence our thoughts, choose our response.

Being organised is essential: Keep an appointment diary, be familiar with medical language, try to understand tests and treatments to help understanding your disease, and regain control. 'Grounding exercises' help anxiety. When we get a life limiting diagnosis, we get future focused and worry about what's going to happen. Thinking of our present abilities can help.

Benefits of exercise: Pulmonary fibrosis results in a reduced exercise capacity and shortness of breath during exercise. Exercise is a key treatment along with medication, oxygen, and supportive care. Rehabilitation classes offer many benefits including;

- improve muscle's ability to use oxygen
- improve cardiovascular fitness
- strengthens muscles
- builds immunity to fight infections
- prepares for lung transplantation
- improves quality of life
- decreases shortness of breath
- increases energy levels and reduces stress
- better sleep and mood

Exercise may become enjoyable and routine: Think about moving more and sitting less.

Type of Exercise	Number of Days/week	Examples
Aerobic (continuous)	3 (150 minutes)	Walking, treadmill, cycling, dancing, swimming
Strengthening	2 non-consecutive days Aim for 10 repetitions of an exercise.	Dumbells, bands, ankle weights, weight machine, Own body weight e.g. sit to stand, press up against a wall, climbing stairs, leg raises whilst sitting, March on the spot.
Flexibility	2-3 times per week	Stretching exercises e.g. ILFA yoga DVD

Monitor your level of breathlessness during exercise using the Borg scale (1 – 10) where zero means there is no shortness of breath and 10 represents maximum breathlessness. When exercising, aim for a Borg level of 3-4 that is equivalent of moderate breathlessness.

Pulmonary rehabilitation programmes are group exercise/education programs run by physiotherapists and nurses over eight-weeks. Classes take place twice a week and can be face-to-face or online via video call. The aims of pulmonary rehabilitation are to improve exercise capacity and walk distance, muscle strength, quality of life and reduce the disease burden and symptoms for example, breathlessness

or fatigue. It is important to continue to exercise otherwise you will lose the benefits of pulmonary rehabilitation after six months. Set goals for example, walk for five minutes daily over 2 weeks, and build on this over time. Write down your exercise goal and commit to it. Build a routine which makes it easier to keep up.

ILFA offers regular online exercise classes that are supervised by a physiotherapist on Monday and Thursday. Other resources from ILFA include exercise videos on YouTube and the ILFA 2000 Steps challenge walking pack.

"Dealing with a chronic disease" was presented by Professor Brendan Kelly, Professor of Psychiatry at Trinity College Dublin, Consultant Psychiatrist at Tallaght University Hospital.

Each of us are bigger than any specific problem in our lives. We often struggle with diagnoses or personal issues, losses, and bereavements. Yet we navigate our way through the most astonishing things. A study about happiness in 130 countries, looked at patterns across populations with ages ranging from 16-88 years. We start out life happy as children but become unhappy aged 20-40. The lowest point is at age 47 regardless of country, indicating the challenges of life become greatest in mid-life. Things tend to improve in later life. Apparently, this is because the kind of things that worry us when we are younger, no longer concern us.

One of the key things is physical health, however seeking perfection is unhelpful. Once we accept, adjust, and engage the best way we can, our mental well-being will be helped.

- Aim for more and better sleep compared to last night
- Eat food, not too much and mostly plants if we can. If we can't, we aim to improve our diet today compared to yesterday
- Improve activity today compared to yesterday

Be mindful not to compare ourselves to others. Just compare yourself to yourself of yesterday.

Mental Health

- The less alcohol we drink, the happier we will be and less likely to be depressed
- Subconsciously comparing ourselves to others on social media can have an emotional impact upon us
- Ask people for help. Social contact is essential when we cannot manage something. Giving someone the opportunity to help, helps their mental well-being way more than it helps us
- Becoming absorbed in an activity such that the world just disappears for a short time such as gardening, walking, yoga, knitting is an exceptionally nourishing state of mind and helps us get through. Meditation and mindfulness are good skills that focus on the moment and letting go of all the worries about the past and the future will encourage you to be more active

Thoreau tells us 'Happiness is like a butterfly, the more you chase it the more it will elude you but if you turn your attention to other things, it will come and sit softly on your shoulder'. The more you become absorbed in an activity, happiness and well-being will follow and help you become better at dealing with difficult times.

"Pulmonary Fibrosis" was presented by Dr Sinead Walsh, Consultant Respiratory Physician at Galway University Hospital and National University of Ireland Galway Medical Lecturer.

In pulmonary fibrosis, the interstitial space, area in between the alveoli (air sacs) and blood vessels which is normally very thin allowing oxygen to pass into our blood stream and carbon dioxide to be exhaled, becomes irregularly thickened. So, gas exchange which is the movement of oxygen and carbon dioxide is hindered and becomes slower.

At rest or when sitting, people may have no symptoms with pulmonary fibrosis, but when they try to walk or move around, their lungs/alveoli are not able to keep up with the increased oxygen demands.

Causes of pulmonary fibrosis include:

- medication exposure (nitrofurantoin, amiodarone, cytotoxic medicine, radiation)
- environmental exposure (dusts, asbestos, bird droppings, silica)
- medical conditions (rheumatoid arthritis, lupus, scleroderma)
- unknown (idiopathic) cause.

The symptoms and signs of pulmonary fibrosis include shortness of breath on exertion for example going up the stairs, chronic dry cough, fatigue, reduced exercise tolerance.

Clinical examination reveals velcro- crackles sounds in the lungs (distinctive sounds heard through a stethoscope) is the commonest sign of pulmonary fibrosis. 30-50% of patients show signs of clubbing (rounding) of their fingertips.

Both men and women can be diagnosed with pulmonary fibrosis, but it is more common in men over age 60. It is more common in ex-smokers, although many people have never smoked and approximately 5% of cases have a genetic component and a family history of the condition.

The investigations used to diagnose pulmonary fibrosis include:

- Chest X ray – the lungs look small and scarring seen around the edges
- Breathing tests
- CT scans that may show thickening, hardening, and a honeycomb appearance.
- Blood tests
- Six-minute walk test

A specialist multi-disciplinary team meet to evaluate cases and form a consensus decision before any case is diagnosed as pulmonary fibrosis. The treatment of pulmonary fibrosis may include giving anti-fibrotic drugs called Pirfenidone and Nintedanib. These medicines can slow down the rate of disease progression, however they do not reverse the existing fibrosis. Side effects may include rash in sunlight, stomach upset and diarrhoea. Regular blood tests are required to check liver function.

Pulmonary fibrosis is a progressive disease which means it gets worse with time. Some patients progress slowly, others have a rapid decline regardless of treatment, and unfortunately serious ‘acute exacerbations’ (worsening) can occur, and patients have to come to hospital.

“Lung Transplantation for pulmonary fibrosis” was presented by Dr Michelle Murray, Consultant Respiratory/ Lung Transplant Physician at the Mater Misericordiae University Hospital.

Patients with pulmonary fibrosis notice worsening breathlessness on exertion over time. Monitoring your level of breathlessness and your ability to do things can be a useful guide to how severe your pulmonary fibrosis is becoming. You might notice that your walking distance is less, your breathlessness increases, it is difficult to climb stairs, personal care becomes more difficult and doing house chores and hobbies is harder. Using a pulse oximeter can tell you if you have satisfactory oxygen levels while walking. If the level is below 90% when breathing room air, you may need oxygen. Having the right amount of oxygen can help you do some of the things you enjoy, with less work to breathe.

Chest infections can worsen the lung scarring and patients become more breathless because their lung reserve is limited. Swollen ankles/feet can mean the heart is under strain and this will need investigation. Muscle and weight loss is common due to side effects of anti-fibrotic medication, worsening disease due to the effort to breathe, deconditioning due to not walking/exercising, acid reflux and poor appetite. You may be referred to a dietitian and started on medication to reduce acid reflux.

Lung function and six-minute walk tests are checked over time to see how you are doing and the results indicate if your health is stable or worsening. Referral for lung transplant may be offered if you meet the criteria.

Pulmonary rehabilitation is important because people with pulmonary fibrosis lose muscle mass rapidly. You need to keep strong, whether you are being considered for transplant or not. You need to have some reserve to fight infection. A stationary exercise bike and a home exercise program are recommended. Your nurse or physiotherapist can advise on whether oxygen is needed to exercise and how much. Monitoring pulse oximetry and urgently reporting levels into low 80s/70s when you exercise will allow a re-evaluation of your lungs and reassessment of your oxygen needs. Don’t take chances by not using your oxygen, even over short walking distances, as it is important to avoid complications such as an enlarged heart, pulmonary hypertension or brain function being affected.

Local hospital respiratory teams may refer patients being considered for lung transplant to the Mater University Hospital with details of your medical history, test results, and medications. The transplant team will assess your suitability and may see you in the clinic. Many issues impact on the likelihood of a successful transplant including rapidly declining lung function, other life-threatening illnesses: cancer, heart or kidney failure, heart disease and infection, smoking status (you need to stop smoking and vaping and be taking nicotine replacement for at least 12 months beforehand), and alcohol intake. All prescribed medication must be adhered to and monitored at frequent intervals. Patients must have a healthy body weight, good family and friend support, and age-related frailty can lead to complications or poor survival after transplant.

Stage of Transplant Process	
Referral	Initial consultation with transplant physician
Assessment	Every body system is investigated as part of the assessment. Patients meet the Lung Transplant Multidisciplinary Team
Psychiatric evaluation	To ensure adequate support
Medical Social Worker Evaluation	To assess risks
Lung multidisciplinary	Discuss your case in detail
Active wait list	Patients are listed for possible lung transplant if they have a good survival chance after transplant. Await suitable sized organ matched to blood type and antibodies.

The Mater Hospital's duty of care lies with both the transplant recipient and organ donor to correctly match organs for a successful outcome. The Transplant Coordinators will answer any questions you have about the transplant assessment process, and you will still attend clinics at your referring hospital, as your care is shared until after lung transplant.

You may be called in to the Lung Transplant Unit if an organ becomes available but ultimately not go to theatre if the organ is not a suitable match. These "false calls" can happen several times and are stressful. If your health has deteriorated significantly, you may be admitted to the Mater Hospital while waiting for a transplant. Palliative care can help manage breathlessness and if you become too poorly to undergo surgery safely. Lung transplantation is a major operation lasting 6-8 hours. Complications during surgery can interfere with the heart and brain which puts a strain on other organs.

Dermot Rafferty, a 73-year-old retired airline pilot, presented his experience of living with pulmonary fibrosis. Here is Dermot's story "At several GP visits in 2017, crackling sounds were heard in my lungs. After a chest x-ray in August, I was referred to a consultant in St. James's Hospital in June 2018. Routine tests followed including a CT scan, breath tests and bronchoscopy and I was diagnosed with idiopathic pulmonary fibrosis and I started anti-fibrotic medicine. I decided to maintain my general good health, and slow down the disease progress. I enrolled in pulmonary rehabilitation with St James Hospital via Zoom and found it very successful. Then I enrolled for ILFA's virtual exercise classes twice a week which I find excellent. It offers discipline and routine to my exercise program.

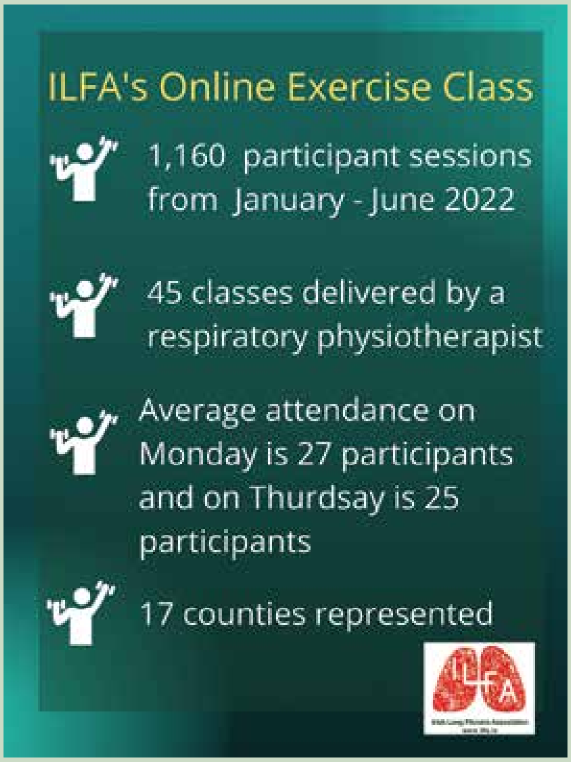
Over the past two years, I've participated in ILFA's Sing Strong program and Patient Information Days and the Carmelite Centre support group. I talk with other people with pulmonary fibrosis and although I am in an early stage of this disease, I can share ideas with them and lend social support. The Clinical Nurse Specialists are available via the telephone, but I've not needed them yet. I'm trying to stay as fit as possible and ILFA provides great backup and information, education, and support. I look forward to staying well, informed, and educated by ILFA."

Thanks to Paula Jenkins for transcribing the text of the presentations for ILFA to edit.

Weekly Online Exercise Classes

ILFA would like to extend our sincere thanks to respiratory physiotherapist, Eimear Bell, who delivers the weekly online exercise classes for lung fibrosis patients. The classes are very popular and in the first 6-months of 2022, we had 1,160 participant sessions! Well done to everyone actively and positively engaging in self-management of their chronic respiratory condition!

Classes take place online every Monday and Thursday at 11am via Zoom. All lung fibrosis patients registered with ILFA are welcome to attend these classes that are delivered free of charge.
Email info@ilfa.ie or call 086 871 5264 to register.



ILFA's Online Exercise Class

- 1,160 participant sessions from January - June 2022
- 45 classes delivered by a respiratory physiotherapist
- Average attendance on Monday is 27 participants and on Thurdsay is 25 participants
- 17 counties represented

Exercise is the best medicine

ILFA encourages patients to engage in physical activity and focus on the things you can do rather than the things you can't. ILFA believes that "exercise is the best medicine" and encourages patients to stay positive, get active and stay active. Here is an update of some of our recent online activities.

Yoga

ILFA was delighted to be awarded a grant from Age and Opportunity and Sports Ireland's National Grant Scheme to host an 8-week online yoga programme with our patron Michael Darragh Macauley. The classes took place via Zoom from July to September 2022 and were a great success. The classes featured breath work and gentle seated and standing exercises.

ILFA would like to extend our sincere thanks to Michael Darragh for delivering the classes with great enthusiasm and understanding. We are also grateful to Age and Opportunity and Sports Ireland for the valuable grant towards the cost of the yoga programme.

Following the intervention, ILFA conducted a short survey of the participants, and the feedback was very positive and encouraging. The results revealed that

- 93% of attendees rated the class as very good or excellent
- 93% agreed or strongly agreed they felt more relaxed after the class
- 93% said the breathing exercises were useful
- 100% felt better after taking the class
- 100% enjoyed taking part in the class
- 100% would like to attend more yoga classes
- 100% would recommend yoga to other lung fibrosis patients.

We also asked participants if they would like to provide a personal quote for Age and Opportunity describing their experience of the class. Here are some of the quotes received

- *"The exercises we did are so valuable to people with lung problems"*

- *"Super class"*

- *"The yoga moves are of great benefit to those with respiratory ailments"*

- *"The great advantage of the yoga sessions is that you can do them at your own pace, so age is not a factor, and it provides enjoyable exercises/movements that are very helpful to patients living with lung fibrosis"*

- *"Yoga is good for mind and body"*

- *"I would never have done yoga only for this opportunity and the fact that I could do it online from my own home was brilliant. I really looked forward to it each week, the social interaction equally as much as the yoga. Thank you so much to ILFA and Age & Opportunity. Hopefully we will get to do it again soon"*

- *"Very relaxing, great exercise and you can work to your own ability"*

- *"Excellent teacher"*

Thank you to everyone who took part and contributed their perspectives to the survey. Please keep an eye on the ILFA website for upcoming exercise and yoga opportunities.

Sing Strong Classes Resume

The Irish Lung Fibrosis Association (ILFA) is pleased to announce the start of a new series of 'SingStrong for Pulmonary Fibrosis' classes with Ciara Meade, Choir Mistress, The classes started in September and will take place every Wednesday at 12.30pm for 12-weeks. The online class is free of charge to lung fibrosis patients registered with ILFA, No singing experience or even a good singing voice needed. All are welcome to this fun, sociable and beneficial class.
Email info@ilfa.ie to register.

Raising Awareness and

World Lung Day 25th September 2022

The Irish Thoracic Society in association with members of the Irish Lung Health Alliance hosted an information event for TDs and Senators at Buswell's Hotel in Dublin on 15th September 2022.The Irish Lung Fibrosis Association is a member of the Lung Health Alliance and Eddie Cassidy (ILFA Chair) and Nicola Cassidy represented ILFA at the event.

The Irish Thoracic Society prepared a briefing document for politicians with key messages on access to diagnosis, top tips for healthy lungs and information on the impact of the energy crisis on home oxygen users which is of increasing concern as we head into the Winter months.

ILFA was delighted to speak with Senator Ashling Dolan and T.D.s Danny Healy-Rae, Martin Browne and Ruairi O Murchu to highlight some of the challenges facing lung fibrosis patients. Eddie and Nicola also had the opportunity to meet with representatives from other patient organisations and healthcare professionals. including Aoife Folliard, Chair of Anail (Respiratory Nurses Association of Ireland) and Professor Silke Ryan, Respiratory Consultant at St Vincent's Hospital and Vice President of the European Respiratory Society.

Key Messages for World Lung Day:

1. Access to Timely Diagnosis

Pulmonary function tests (PFTs), or breathing tests, are crucial in the diagnosis and ongoing treatment and care of patients with lung disease and people who may be undergoing surgery, chemotherapy, and bone marrow transplants. The pandemic has exposed the chronic under-resourcing of pulmonary function laboratories over many years, and a severely curtailed service with long waiting times. A survey of pulmonary function laboratories in Ireland took place during August 2022, with 19 laboratories responding out of a total of 33 invited to participate.

Key findings were:

- 68% of the laboratories who responded had vacancies for respiratory physiologists
- the waiting list in nine laboratories was 18 months or more, with four of these indicating a waiting period of three years or more

Dr Marcus Butler, Consultant Respiratory Physician and member of the Irish Lung Health Alliance with Nicola Cassidy and Eddie Cassidy.

Members of the Irish Lung Health Alliance marking World Lung Day.

Professor Silke Ryan, Vice President of the European Respiratory Society and Respiratory Consultant, with Eddie Cassidy, ILFA Chair.

Ruairi O Murchu, Martin Browne with Eddie Cassidy.

Nicola Cassidy, Danny Healy-Rae and Eddie Cassidy.

Advocacy

Senator Ashling Dolan with Nicola Cassidy and Eddie Cassidy.

Aoife Folliard with Eddie and Nicola Cassidy.

2. Cost burden and disruption risk for home oxygen users due to energy crisis

For the 10,000 plus people living with a respiratory condition (such as COPD and Idiopathic Pulmonary Fibrosis) who rely on home oxygen services, the looming energy crisis poses a real threat to their wellbeing. The electricity costs to run a standard oxygen concentrator are estimated to be more than €66 per month in normal times and these are predicted to increase to multiples of this over the coming months. There is also a risk of disruption of service due to power outages which is causing untold anxiety amongst oxygen users.

3. Love your Lungs

The Irish Lung Health Alliance is encouraging people to adopt the following 5-steps to "Love Your Lungs"

1. Quit Smoking. Tobacco smoke is the main cause of many lung conditions. One in two smokers will die of a tobacco-related disease. Check in with your local smoking cessation clinic or call the HSE Quit team on Freephone 1800 201 203.

2. Breathe Easy by avoiding poor air quality in the environment.

3. Get vaccinated. Protect yourself and others against different diseases, help keep your lungs healthy and help prevent disease from spreading. Talk to your doctor about the vaccines and boosters available and find out which ones are right for you.

4. Keep active. Regular physical activity improves quality of life and fitness and reduces the risk of chronic conditions.

5. You Are What You Eat. Diet plays a role in the development and progress of lung diseases and being either underweight or obese can have harmful consequences for lung health.

Media Coverage of Pulmonary Fibrosis

Thanks Gerry Fitzgerald from Tipperary, Dr Mike Henry, Respiratory Consultant at Cork University Hospital, Marguerite Stafford and her family, for raising awareness of pulmonary fibrosis and organ donation in a great article published in the Irish Examiner in June 2022.

Well done to Finula Rice from Cork for sharing her story about living with pulmonary fibrosis and helping raise valuable awareness of the condition. Finola's story was published by the magazine RSVP in September 2022.

Can you help ILFA rise awareness?

ILFA is always looking for people who are willing to share their lung fibrosis story when media opportunities arise. **If you would like to help raise awareness, please contact ILFA by emailing info@ilfa.ie or calling 086 871 5264.**

Oxygen Advice

Important information for oxygen users:

Register as a priority support customer with your electricity supplier.

When you are prescribed oxygen, you should contact your electricity supplier as soon as possible to register as. 'Priority Support Customer'. If there are planned electricity cuts, the Electric Ireland Network will let you know the date and time of thw cuts.

What to do in case of a power cut:

1. Transfer from home concentrator to your back-up oxygen cylinder.
2. Call Electric Ireland Network customer care centre on 1850 372 999. The sooner you contact them, the sooner they can respond. If the power cut is going to last a long time, you may need to go with your oxygen concentrator to another house that still has an electricity supply or to a hospital that can give you oxygen.

Always be prepared for power cuts.

- Make sure you always have enough oxygen.
- Order your oxygen refills in advance. Don't leave this to the last minute.
- Know how to transfer to your emergency oxygen supply.
- Make a list with telephone numbers for your electricity supplier, oxygen company, doctor, and GP co-op (for night-time and weekends).

Irish Lung Fibrosis Association
www.ilfa.ie

Dancing for Pulmonary Fibrosis

ILFA collaborated with Dr Vikram Niranjan, Assistant Professor in Public Health, University College Dublin, his research team, and choreographer Tracey Barnes from the United Kingdom, to deliver an online dance exercise initiative, as part of a pilot study. This health and wellbeing project was made possible with a grant from the Irish Research Council. The weekly online classes commenced in April 2022 and ran for 8-weeks.

We are grateful to everyone involved with the delivery of this novel exercise initiative. Special thanks to the ILFA members who participated in the study and gave valuable feedback on their experiences of the project. We were delighted to learn of the many health and wellbeing benefits reported by the participants and their enthusiasm in embracing dance as a form of exercise.

A report from Dr Niranjan is included below.

Dancing for Pulmonary Fibrosis Pilot Study

Research has emphasised the importance of exercise to improve the physical and mental health of people living with chronic lung conditions. Exercise improves functional capacity and decreases breathlessness and fatigue. Moreover, it contributes to making people living with lung conditions more engaged in physical activity, creating a beneficial cycle that could deliver enormous advantages to such people.

As the physical and mental health impact of living with chronic lung diseases can worsen over time, exercise becomes increasingly important for health management. Dance has been highlighted as one of the most enjoyable, feasible and low-cost forms of exercise for patients with lung problems. The Covid-19 pandemic brought many challenges and changes that affected all segments of the population, particularly those considered to be extremely medially vulnerable due to certain lung conditions, including lung fibrosis. However, the pandemic helped speed up the adoption of digital technologies, which could be here for the long haul. The increased use of video-conferencing software (such as Zoom) has provided the opportunity to deliver online exercise classes, and a platform where people can socialise with others.

The aim of our project was to provide an online exercise opportunity to people living with chronic lung diseases such as Idiopathic Pulmonary Fibrosis (IPF), in Ireland. The purpose of our pilot study was two-fold;

(1) to understand if the online dance classes were feasible and

(2) to explore the potential impact of online dance classes on people's health and well-being.

Over the course of 8 weeks, dance classes were delivered every Tuesday by an experienced dance teacher and choreographer (Tracey Barnes) via Zoom. On average, the classes lasted 1 hour and a half. The classes started and ended with chitchat sessions, with participants, teacher, and administrative staff sharing their thoughts and ideas, and their suggestions regarding the songs to be used during the sessions. Then, the music would start. The actual dance session would last for one hour, during which participants followed Tracey's instructions.

This initiative was greatly well received among the members of the ILFA and 16 people participated in the pilot study for the dance classes. The sessions were attended by 10 women and 6 men who were living with lung fibrosis. The group helped created a wonderful setting, making the dance sessions enjoyable for all those attending the session including the teacher and research staff.

Before and after the pilot study, we gathered participants' perceptions through questionnaires and interviews to learn about their views on the programme. Overall, people attending the dance classes said that the programme not only met their expectations but also provided an experience as good as the face-to-face exercise programmes that they had previously attended. Most of the participants have been diagnosed with IPF more than 3 years prior to the beginning of the intervention, and therefore had a vast experience in exercise and social activities organised by ILFA and delivered both in person and remotely. There were no major technical issues reported and the group mostly said they would participate in such activities in the future. This is such a valuable finding, considering the extent to which the current pandemic has affected our social interaction with others. Moreover, when considering that most of the participants were either retired or unable to work due to their health condition (only one member was employed at the time of the dance sessions), the social aspect that such an initiative had on the group was reported to be more than beneficial. Results from our pilot study also revealed that females had better emotional function than males, suggesting that women were more aware of their emotions' regulation and expression, and had more awareness of the psychological symptoms related to their lung condition. Women reported, in fact, that they felt less frustrated, upset, discouraged and restless, and more relaxed and satisfied with their life than men. We also found that participants' anxiety levels decreased after the 8-week dance sessions, with women showing lower levels than men both before and after the dance sessions. We found that the mobility capacity (namely, the capability to be independent and carry on the usual activities) increased after attending the dance classes among all participants. Finally, all participants reported that their health self-perception was better after the 8-week dance classes.

We also conducted in-depth interviews with a selection of 8 participants to understand the feasibility, impact, and prospects in detail. Here are some of the comments.

"It struck me that Zoom is a terrific medium for doing exercise and the idea of dance exercise was terrific.'

"I found [it] really beneficial for opening up the chest area and letting in more air and things like that.'

In terms of impact, participants described this dance programme

'Very enthusiastic! Now I wouldn't be a graceful person or very talented in the dancing regard, but I found great fun and joy. I had a feeling of wellbeing but also, I knew exercise for my upper body was going to help.'

'I live alone so for people like me it's a godsend and it's probably that social interaction, not putting this mildly or exaggerating, but it would be the highlight of my day.'

At societal and community level, our study forms a good example that adds to the evidence and promotes good collaboration practices among patients, charity organisations, art performers, and academic researchers to enhance our civic society. To the limited dance-based research interventions, our evaluation shows that dance is a good art form for community engagement and as a valid exercise tool, with potential for implementation on a larger scale. This may encourage dance as a physical activity programme. At clinical and public health level, dance can be an alternative exercise-based rehabilitation activity which can be accepted favourably by patients resulting in higher adherence rates and better health and wellbeing outcomes. A larger scale evaluation involving health care professionals and implementing longer, consistent dance programmes and measurement of clinical parameters may help to form a sustainable programme in future.

Report by Dr Vikram Niranjan, Assistant Professor in Public Health, University College Dublin (On behalf of team Dance for Health and Wellbeing).

"Let's Talk" with ILFA

Thank you to everyone who joined the online "Let's Talk" interactive sessions hosted by ILFA over the summer. Our recent events included "Let's Talk Breathing Techniques" and "Let's Talk Patient and Public Involvement (PPI)". Both events were well attended and very informative.

"Let's Talk Breathing Techniques" took place on Wednesday 27 July 2022 and was facilitated by Eimear Bell, respiratory physiotherapist. Here is some of the feedback received

- "It was an excellent presentation and a terrific information session. Many thanks Eimear and to ILFA."
- "Great informative talk."
- "So much useful information to work on. Thank you Eimear."

"Let's Talk Patient and Public Involvement (PPI)" took place in July 2022 and served as an introduction to the establishment of ILFA's Patient and Public Involvement Research Advisory Group.

We were delighted to invite Dr Michelle Flood and Dr Chiara De Santi from the School of Pharmacy and Biomolecular Sciences at the Royal College of Surgeons in Ireland to discuss PPI for lung fibrosis patients. The first meeting of the newly formed ILFA PPI Research Advisory Group will take place in the Autumn.

Living Beyond a Diagnosis of Idiopathic Pulmonary Fibrosis

A mixed Method Exploration of Patient Related Experience and Unmet Healthcare Needs

Idiopathic pulmonary fibrosis (IPF) is a chronic, progressive lung disease characterised by scarring of the lungs. Patients can experience several symptoms including breathlessness, weight loss, dry cough, and fatigue and some may experience psychological concerns such as anxiety and depression.

The average age of patients with a diagnosis of IPF is around 65–70 years, with incidence increasing with age and higher rates seen in males. It is believed that around 400 people in Ireland are diagnosed with IPF annually, while approximately 1,000 people in this country are living with the condition. We don't currently have comprehensive IPF prevalence and incidence rates from our national ILD patient registry, so these numbers are estimates – It is believed that the numbers living with the condition are even higher. Globally, IPF patient numbers are rising possibly due an ageing population, more awareness of the disease and improved diagnostic tools.

Clinical management of IPF patients includes referring patients for lung transplantation assessment, pulmonary rehabilitation, and supplemental oxygen, which can improve quality of life. Other treatment options, where applicable, include palliative care, symptom management and clinical trial inclusion. A cure for IPF does not currently exist, although there are two approved drugs - pirfenidone and ninetedanib, which slow disease progression but cannot reverse damage already present.

For patients who are diagnosed with IPF they have several needs including physical, psychological and social needs. IPF patient experiences and consequent needs are broad, varied and can differ along the clinical course of the disease. It is understood that many of the anticipated needs of IPF patients remain challenging, with growing evidence of continuing unmet needs for those with the condition. There is a necessity to quantify patients' outstanding requirements to benchmark standards against international best practice clinical care guidelines.

My PhD research, funded by an Irish Research Council Postgraduate Scholarship is focused on investigating the healthcare needs of patients who have a diagnosis of IPF. I am also interested in understanding the reality of patients' experience of access to supportive care and referral and access to healthcare professionals, including physiotherapy, psychology, social work, palliative care and dietetics among others. It is hoped that through this national study, a coherent healthcare needs assessment can be evaluated, based on patients' self-reported needs and experiences of living with IPF. The national patient charter for IPF includes six care areas: (1) early and accurate diagnosis (2) information about IPF (3) access to medicines and oxygen therapy (4) early referral to pulmonary rehabilitation and exercise programmes (5) early referral for lung transplant assessment and (6) access to social, practical, and emotional supports. It is anticipated that the findings from my research can be incorporated into the ongoing work to develop a national ILD clinical care pathway and provide information for the Sláintecare programme for scheduled care through better understanding the needs of patients nationally.

Carita Bramhill, PhD Candidate, Ussher Scholar, Trinity College Dublin.

This mixed methods research study follows two distinct phases:

Phase one involves an anonymous questionnaire involving recruitment at five national hospitals and through social media, such as Twitter and Facebook. Recruitment is open to all patients in Ireland who have a diagnosis of IPF and wish to participate in the study.

Phase Two of the study involves an **optional follow-up interview** and is open to all participants from phase one where a set number of participants will be selected to participate in the interview phase of the study.

I would like to be able to capture as many patients' voices in this research as possible to provide a national picture from the perspective of those living with a diagnosis of IPF.

You can help by reading the participant information leaflet and considering your participation in the study. If you have any questions or wish to participate in this study, please contact the researcher Ms. Carita Bramhill by email bramhilc@tcd.ie or by scanning the QR code below.

To scan the QR code please open the camera function on your phone, then hold the phone screen up to the QR code and when the QR link opens on your screen please click and follow the link which will take you to the participant information form and questionnaire.

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.

Motorcycle Ride Out

Ciaran McCarthy, Gemma O'Dowd (ILFA), Pat Shortt and Noreen O'Carroll.

Mary Hynes (Rally Queen) with Dermot and Noreen O'Carroll.

Huge thanks to the organisers and supporters of this great fundraising event.

Noreen Carroll, her family, and friends held a 100km Motorcycle Ride Out in aid of ILFA on Sunday 15th May 2022. Noreen's husband Dermot and a group of his friends who are keen bikers and who regularly support other charity rides, decided to organise their own event for ILFA.

Motorcycle enthusiasts gathered at Roundhill Bar, past Birdhill, Co Tipperary, from 11am and the grand departure took place at 1pm. Thankfully the weather was very kind to all those who joined the event. Among those who turned up to take part was well known comedian Pat Shortt and we're grateful to Pat for raising awareness of the event via his Twitter page. Another man who took part was Paddy McNamara from Nenagh who received a lung transplant for pulmonary fibrosis and whose life has been greatly enhanced as a result.

Noreen shared her story and details of the charity fundraiser with the Nenagh Guardian. Noreen and her team of family and friends raised the fantastic sum of €3,698.

Gemma O'Dowd (ILFA Administrator) with Paddy McNamara.

Noreen O'Carroll with Gemma O'Dowd (ILFA Administrator).

Mick's 'Movember' Challenge for ILFA

Mick Connor set up a fundraising page to raise funds for ILFA in support of his sister-in-law Catriona McLoughlin. Mick's challenge was 'to grow a dodgy tash' in November 2021 and in doing so he raised the fantastic sum of €3,901 for ILFA.

Mick and Catriona presented a cheque to Eddie Cassidy (ILFA Chair, left) in the company of Maria (Catriona's sister) and her daughter Rhiannon. Huge thanks to Mick for his epic fundraising efforts and to everyone who sponsored him and supported Catriona. Mile buiochas!
Here's a report from Mick:

"I was inspired by 'Movember' and decided to do my own fundraiser and grow a moustache. Given Catriona

McLoughlin's (my sister-in-law) condition, I asked her to choose a charity for the fundraiser and she choose ILFA.

I completed my fundraiser in November 2021. We started with a target of €1,000 and were impressed with everyone's generosity. It also gave us a platform to highlight Idiopathic Pulmonary Fibrosis (IPF). This was Catriona's motivation also.

Mick and Catriona presented a cheque to Eddie Cassidy (ILFA Chair, left) in the company of Maria (Catriona's sister) and her daughter Rhiannon

I was surprised by the people who were aware of it but also concerned at the volume of people who have never heard of this condition. Early detection can potentially prolong life and prepare the patient with the reality of requiring a lung transplant. Finally, another motivation was the loss of another relation to IPF - Sean Murphy, a first cousin of Catriona's, which indicates that this disease has a genetic component to it, and this makes Catriona and Catriona's family's journey even more difficult."

Oisin's Carrauntoohill Climb

Oisín Carroll from Ballinagar, Tullamore Co. Offaly decided to climb Carrauntoohill, Ireland's highest mountain (1038.6 metres) to raise much needed funds for ILFA in honour of his grandad, John Carroll of Tullamore (*pictured together on the left*). Here is short report from Oisin - "Hi my name is Oisin and I am 14-years old. My grandad was a man who lived life to the max and never let anything get him down, especially after he was diagnosed with IPF in 2008, he continued to enjoy and live life to its fullest. ILFA gave my grandad great support and comfort through his long battle with IPF until he sadly passed away on 1st March 2022 at only 61 years old.

After visiting Kerry in 2021, I decided I would like to climb Carrauntoohill, just for the challenge and spoke of my wishes to do so with my granddad who was as always full of support and encouragement. Now I think it fitting to climb Carrauntoohill in his honour and to give something back to ILFA for all the help and support they gave my grandad and other people over the years. It would also be an opportunity to raise awareness about IPF and ILFA."

On Friday 5th August, Oisin Carroll set off to climb Carrauntoohil with his mam and dad, Pamela and Padraig, and wore his grandad's hiking boots for the climb, and also his cap on the summit for photos. Before starting out, a robin visited Oisin as he was putting on his boots and later another robin appeared at 800m. The Carroll team made great progress up the mountain via the Devil's Ladder route thanks to the help of their local guide. On their return after their epic ascent and descent, they were met by some very proud family members including Oisin's sister Saoirse, his aunt Sinead, his great-uncle Thomas, and his nan Maureen.

Everyone at ILFA was in awe of Oisin's hard work and commitment to fundraise for our charity. What an incredible challenge to take on to honour his much-loved grandad. Huge congratulations to Oisin, Pamela and Padraig!!!

Thanks to the Offaly Independent for featuring the remarkable story of Oisin Caroll's epic fundraising challenge for ILFA Ireland. Thanks also to everyone who kindly donated to and supported Oisin's climb of Carrauntoohil. We are enormously grateful.

M2 Office Interiors

The M2 Office Interiors 21 Day Steps Challenge was won by Rory O'Gorman with an amazing 301,851 steps recorded. Rory kindly nominated the Irish Lung Fibrosis Association for the €500 cheque. We are very grateful to Rory for his great support, and we were thrilled to receive the wonderful donation. Pictured are M2 Office CEO Kieran Maher presenting a cheque to Rory O'Gorman.

"Going Potty" for ILFA

ILFA's resident artist, Matt Cullen from Dublin, recently sold a painting entitled "Going Potty" at the Dunlavin Arts Festival, and kindly donated half of the proceeds (€70) to ILFA. Here's the story behind the lovely artwork from Matt.

"Going Potty!" (During the pandemic!) It was a great bit of fun painting it. The potty person is sitting on a caseload of Jameson Whiskey and Smithwicks, both of which I enjoy in moderate amounts! The topiary plants in the containers in the foreground are those I have in my back garden, so I included them in the artwork. I was delighted that the painting was sold recently and happy to support ILFA with a donation."

VHI Women's Mini Marathon

The 40th VHI Women's Mini Marathon took place on Sunday 5th June 2022 and ILFA had a small but determined group of ladies take part helping to raise funds and raise awareness. Unfortunately, it was a very, very, very wet day in Dublin and the heavy rain never let up. Thankfully, the ladies were happy to brave the elements and it seems that the wet conditions didn't dampen the spirits of our amazing fundraisers. Some even said it was "perfect weather for a run!"

Mary Greene and her cousin Sharon Morrissey took part in support of Mary's mother and in memory of relatives Carmel and Seamus who passed away with Idiopathic Pulmonary Fibrosis. Mary said "We had a great day in Dublin despite the persistent rain." Other ladies who took part were Niamh English, Annette Grehan, Mary Henry, Janet Day, Sheila Plunkett, Yvonne Beacom, Lindsay Browne (Advanced Respiratory Nurse Practitioner at St Vincent's University Hospital, and ILFA Board member) and Nicola Cassidy (ILFA Director).

Well done and thank you to all the ladies for their support and making a difference.

Niamh & Nicola's Running Challenges

Niamh English and Nicola Cassidy, above, ran the Irish Life Frank Duffy 10 Mile Race in aid of the Irish Lung Fibrosis Association (ILFA) in August 2022. This was the second run in a series of events that Niamh and Nicola will undertake in 2022. Their first run was the VHI Women's Mini Marathon in June and on 20th August, the ladies completed their second challenge taking on the 10-mile course through the Phoenix Park in Dublin. They even bumped into Lynn Fox, ILFA Board member and Respiratory Advanced Nurse Practitioner at the Mater Hospital ahead of their run which gave them an added incentive to run as well as possible!

In September, the running duo took on the Dublin half-marathon wearing their ILFA t-shirts to help raise awareness and support Pulmonary Fibrosis Awareness Month. The course through the Phoenix Park was tough with lots of hills but the weather was perfect and there was great camaraderie with other runners. Here's some of their photos!

Dooley Family 100k

The Dooley family, consisting of siblings Moira, Edward, Marguerite, and Pat decided to put on their walking shoes and fundraise for ILFA in memory of their mother Kathleen. Each sibling committed to take on 100k in June. The siblings and their father John launched their fundraising event in the beautiful but breezy Lough Gur in Co Limerick.

It certainly was a family event with the siblings' husbands and wives lending support, along with Kathleen's special grandchildren Katie, Ellie, Lucy, Charlie, Jack, Harry, Will and Dáithí.

The family's online fundraising page got phenomenal support and raised an amazing sum of €12,420 for ILFA!

This fantastic sum will enable ILFA to deliver our ongoing services and support to those affected by lung fibrosis.

The Dooley family story also featured in the Irish Examiner in June helping raise awareness of pulmonary fibrosis.

Liam Galvin (ILFA Director) met with Moira Maher, Will, Harry and Jack during the summer and was presented with a cheque for €12,420 on behalf of the Dooley family.

Mile buiochas!!!

Achill cycle

Huge thanks to Deirdre Garvin, John Kelly and members of the Mayo University Hospital Cyclists for taking on the Tour de Achill to fundraise for ILFA Ireland.

We are delighted to have such amazing support from our healthcare professionals. ***More information will be included in the next ILFA newsletter.***

Kilimanjaro Climb for ILFA

Owen and Keeley Connolly, a father and daughter duo, decided they would like to climb Mount Kilimanjaro in Tanzania in aid of ILFA. Here is a report from Owen describing their inspiration for this ambitious challenge.

"My Dad, Keeley's grandad, has recently been diagnosed with advanced lung disease. Something we knew very little about. Seeing what my dad has gone through so far, how he has had to adapt his life and his reliance on oxygen from a tank has been hard. Keeley and I will climb Kilimanjaro in July 2022 to raise much needed funds for the Irish Lung Fibrosis Association (ILFA). ILFA provides research, education and support to patients and their families living with lung fibrosis. Climbing Kilimanjaro is at high altitude and reduced oxygen. This will be a challenge for myself and Keeley for a few days however for my dad and many others this challenge is daily."

Owen and Keeley shared their progress on their Instagram page and described the training they undertook to prepare and get in shape. Some of the preparations included getting travel vaccinations, taking part in training weekends, plenty of hiking and walking, doing strength and conditioning exercises, and equipment checks ahead of their departure.

Owen and Keeley set out for the climbing adventure in July 2022 and had a successful climb to reach the peak of Mount Kilimanjaro. We salute them for their bravery and determination in facing such an epic challenge. Here are some photos from their trip. Warmest congratulations to Owen and Keeley and thanks to everyone who supported their fundraising challenge.

Coffey Family 100k in July Challenge

Chloe Coffey and her family took part in a 100k Challenge in July in memory of their mother, Mary. The family wanted to mark the first anniversary of Mary's passing by raising awareness of Pulmonary Fibrosis and raising funds for the Irish Lung Fibrosis Association.

ILFA Tea Party

Stella O'Sullivan and her family held an Afternoon Tea Party to raise funds for @ILFA_Ireland in memory of their dad Tony Murphy. Thanks to Stella and her guests for their kind donation.

Blackbush Golf Club Fundraises for ILFA

Peggy Duffy, Lady Captain of the Blackbush Golf Club, kindly selected ILFA as her chosen charity for the Lady Captain's Charity Day on August 9th, 2022. The event was a great success and the amazing sum of €6,000 was raised for ILFA. Lynn Fox (ILFA Board Member) attended a cheque presentation with Peggy Duffy, Lady Captain, and expressed ILFA's heartfelt appreciation to everyone who supported the fundraising event at Blackbush Golf Club.

Picture shows Lynn Fox with Peggy Duffy.

patientMpower Annual Team Walk

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

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

Please support ILFA

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

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

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

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

On-line donations for ILFA

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

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

Facebook Fundraising: ILFA uses Facebook Fundraising making fundraising campaigns easy and secure for ILFA’s Facebook friends and followers.100% of donations go to ILFA.
www.facebook.com/fund/ILFAIreland/

Paypal Giving Fund: ILFA Ireland has been added to Paypal Giving Fund. When you donate to PayPal Giving Fund through this page, 100% of your donation will go to ILFA - **https://www.paypal.com/ie/fundraiser/charity/4043546**

Standing order

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

Giving in Remembrance

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

Giving in Celebration

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

Legacy Giving

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

Partnering with ILFA

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

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

Would you like to join the ILFA Board?

ILFA is run by a small group of dedicated volunteers who want to make a difference to those affected by lung fibrosis. This year ILFA celebrates our 20th anniversary, and we are grateful to everyone who has helped us reach this milestone. As we enter the next phase of ILFA's growth, the ILFA Board would like to hear from experienced people who have skills in Finance, Legal Matters, Governance and Fundraising to help the charity grow further. If you have the required skills, time to commit to attending 10-12 virtual meetings every year and can commit fully to the role of ILFA Board member, please contact ILFA with an expression of interest by emailing info@ilfa.ie or calling 086 871 5264. We would love to hear from you.

ILFA Christmas Cards

ILFA's Christmas cards will be available to purchase from October. Please consider sending an ILFA Christmas card this year to help raise awareness of lung fibrosis and our charity. The cards are available in packs of 10 with 2 cards each of 5 designs. One pack will cost €6 and 2 packs cost €10. We would appreciate a small donation to cover the costs of post and packaging if you are in position to help.

Dates For Your Diary

- **ILFA's Virtual Exercise Class for lung fibrosis patients takes place every Monday and Thursday at 11am via Zoom.**
- **ILFA's Ecumenical Service will take place on Saturday 15th October at 4pm at Our Lady of Mount Carmel Church, Whitefriar Street Church, Aungier Street, Dublin 2.**
- **ILFA's Patient Information Day will take place online on Saturday 5th November online via Zoom. See page 1 for details.**
- **The Irish Life Dublin City Marathon 2022 will take place on Sunday 30th October. Please consider fundraising for ILFA Ireland if you are taking part. Call 086 871 5264 or email info@ilfa.ie for a fundraising pack.**

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.

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.