

ILFA Newsletter



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

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Irish Lung Fibrosis Association
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ILFA Celebrates our 18th Anniversary!



On 26th February 2021, the Irish Lung Fibrosis Association (ILFA) celebrated our 18th anniversary as a registered entity.

The initial meetings to establish a charity to support lung fibrosis patients took place in November 2002. ILFA was set up in memory of Fergus Goodbody by his wife Nicky, his friends Terence (a solicitor), Marie (an accountant) and Professor Jim Egan (Fergus's doctor). The group worked hard to organise the first fundraising event – a Christmas Swim. This event was a great success and set the charity on its way. The ILFA team devoted their time and talents to complete the necessary legal and regulatory requirements and ILFA subsequently registered as a company on 26th February 2003. The aims of ILFA are to provide Education, Research and Support for Lung Fibrosis patients, carers and healthcare professionals. It is incredible to think that 18 years have passed. The success of the charity is due to the everyone who has supported us, volunteered their time and talents, and fundraised to ensure we can continue with our important advocacy work for lung fibrosis patients and carers.

ILFA is run by a committee of volunteers who work hard to ensure the charity meets its aims, advocates for the unmet needs of the lung fibrosis community and works towards great awareness and understanding of the condition. We remain committed to doing the best we can to support our members with great help from Gemma O'Dowd, our administrative assistant.



Mary McAleese and David Crosby.

“All Walks of Life” with Mary McAleese and David Crosby

ILFA Ambassador David Crosby, starred in the RTÉ Production “All Walks of Life” with former President of Ireland, Mary McAleese, that aired on RTÉ1 on Friday 12th February 2021. Filming took place in Co Cavan during the summer of 2020, while adhering to public health guidelines. We were sworn to secrecy while the production was taking place and were so excited when the TV programme trailers finally appeared.

David spent a wonderful day chatting with Mary McAleese and the TV crew, and you can read his account of events on pages 3 and 4. On their walk, David shared his touching personal story of growing up in Meath, losing three young siblings to pulmonary fibrosis, and coming to terms with his own shock diagnosis of Idiopathic Pulmonary Fibrosis (IPF) as he reached 40 years of age. David spoke about his life-saving double lung transplant, the generosity of his organ donor and their family, and how the precious gift of life has energised him to run marathons to raise awareness of pulmonary fibrosis and the importance of organ donation and transplantation.

ILFA is enormously grateful to Mary McAleese, David Crosby, Birthe Tonseth, RTÉ and the TV production company and crew for their work on this exciting, beautiful, and touching programme. It was a superb production that helped raise awareness of pulmonary fibrosis and organ donation. You can watch the programme on the RTÉ Player if you missed it.

Celebrating ILFA's 18th Anniversary!

18th

ANNIVERSARY

Irish Lung Fibrosis Association

Chairman's Address

It is a wonderful milestone for ILFA to reach our 18th anniversary! This incredible feat is thanks to the bold, courageous, and ambitious vision of Nicky Goodbody, Terence Moran, Marie Sheridan and Professor Jim Egan who established the patient organisation back in 2002. These leaders were instrumental in creating a firm foundation for the charity and leading us to where we are today.

I took over as ILFA Chairman following the sudden passing of Terence Moran who led the association for 15 years. I think Terence would be proud of what ILFA has achieved, as we have gone from strength to strength. In recent years, ILFA has seen remarkable growth - the association has grown in membership, vision, effectiveness, and standing in the respiratory community. I am confident that ILFA will continue to flourish and make a difference. I would like to extend my sincere thanks to everyone who has volunteered and served on the committee for their valuable time and talents, to those who have worked for ILFA; Lorna Murphy, Denise Dunne and Gemma O'Dowd, to those who have fundraised tirelessly, made donations, volunteered their services, and helped and encouraged us in many different ways over the years.

For the future, we look forward to further growth, meeting our goals, serving our stakeholders, and celebrating many more milestones.

Treasurer's Note on ILFA's 18-year Incorporation Anniversary

"On 26th February 2021, ILFA celebrated 18 years as an incorporated body, i.e. a separate legal entity, under the rules and regulations of the Companies Office in Ireland. Soon after incorporation, ILFA applied for and was recognised as a registered charity.

The Irish Lung Fibrosis Association was the brainchild of Dr Nicola Goodbody, in memory of her late husband, Fergus Goodbody. It was set up by Nicky, myself (my husband and I were good friends and travelling companions of Nicky & Fergus), Fergus' dear friend the late Terence Moran, and Professor Jim Egan. We all brought different skill sets to the table. I'm a qualified Chartered Accountant, so I was the "number cruncher".

The primary purpose of ILFA was to provide information and support to those suffering from Idiopathic Pulmonary Fibrosis (IPF or Lung Fibrosis as it was more commonly known then), and their families. We also aimed to promote education and research into the condition. We have come a long way since and I've been

honoured to work with many amazing, talented and hard-working people over the years.

This last year we've met the unforeseen challenge of Covid-19 and I'm sure, with the help of our wonderful membership, we can continue to work well together into the future."

Marie Sheridan, Honorary Treasurer

Thank you to everyone who sent birthday wishes to ILFA on our 18th anniversary. We were touched by your kind words, some of which are included below:

"Happy anniversary and congratulations ILFA! Thank you all so much for all the incredible work you do. It is testament to the work you do that so much has been achieved over the years. Keep up the excellent work in providing information, help and support to all concerned."

"Congratulations ILFA, giving huge support and understanding of this terrible disease."

"Such a great, well organised organisation that just gets better and better, you fight our corner and are a great support for sufferers and carers alike, well done to everyone for your commitment and dedication. Thank you."

"Congratulations and Happy anniversary ILFA. You provide a wonderful support network which we appreciate so much. Looking forward to celebrating with a cake when we are allowed. Happy anniversary to you all and continued success at what you all do on our behalf. Thank You."

"Congratulations ILFA on your 18th anniversary! You have achieved great success in helping and supporting people throughout Ireland and raising awareness of Lung Fibrosis and organ donation. Thank you all."

"Happy Anniversary ILFA - what wonderful work over the years for patients and their families along with the medical professionals. We are forever in your debt for all the hard work and support."

"Happy Anniversary ILFA, so many amazing people who keep on giving."

ILFA Ambassador David Crosby said: "Happy anniversary ILFA! What an amazing organisation and wonderful people (friends) who run it, so helpful every day and always fighting to put the patients' needs to the front of everything they do, highlighting organ donation to the government and the importance of keeping fit, and having a listening ear. We're not sure where we'd be without them. Thanks so much to every one of you, give yourselves a pat on the back - it's much appreciated."

All Walks of Life



Mary McAleese with David and Katie Crosby and their children; and, right, Mary McAleese and David Crosby.

Hi, my name is David Crosby and as a lot of you may already know I had a double lung transplant in 2016. I have been doing great and have completed 3 major marathons to highlight awareness of Idiopathic Pulmonary Fibrosis (IPF), organ donation, and try to honor my organ donor. I am also hoping to complete 3 more major marathons and become a world record holder in being the first double lung transplant recipient to get a super six marathon medal.

I was honored that ILFA put my name forward to possibly be considered to appear on the RTE program "All Walks of Life" with Mary McAleese, never really thinking that I would be chosen. I was chosen and it was a pleasure to put my story forward.

RTE contacted with me and said that they had chosen a historic graveyard in Cavan for filming the show. I did suggest to them that where I live there are lovely areas that could have worked for the program, Dun Na Rí Forest Park or Newgrange, but the decision was theirs and I think you'll agree they made a good decision when you see the program. The date was set, and I started with lots of preparation as in everything I do. So of course, I was thinking of what to say, and getting my clothes right needed lots of thought. I had no idea what to wear and went through all my wardrobe. In the end it was decided by a democratic family vote, to go simple and relaxed and not wear my football club colours from head

to toe or my marathon outfits.

On the 20th of July 2020, I drove down to Drumgoon graveyard just outside Cootehill in Cavan to a very remote part of the country. Thank goodness for Google maps! At this time, we were living in much different times and social distancing was a big part our daily lives. When I was introduced to Mary, I was greeted with a big welcoming handshake. Luckily from my experience of being a transplant patient and helped by my COVID-19 instinct, I declined the handshake. Mary had a stick with her and said from then on if I got too close, I was going to feel the end of it!

I met with the editors, producers, and sound people they put microphones on me and explained the order of the day. They said to be as natural as I could and ignore the cameras and drones in the sky around me, which I did, and just start chatting to Mary. After an initial feeling off nervousness, I soon realised that she was such a unique and warm person who put me at ease very quickly by showing so much interest in my story. I had already spoken with the producers and they knew most of my history and were prompting us to speak on different parts of my life. They had a structure laid out for us. It was a beautiful crisp morning and we filmed for a few hours without any stops, just talking about different aspects of my life growing up. I'm sure they could have made a Netflix story out of the amount of information I was giving them. To be honest, I could have kept talking with Mary as she was so full of knowledge and seemed to be able to chat about any subject that was brought up, such as health, sport, travel, religion, importance of family. Mary was very engaging with everything that was mentioned and we both enjoyed long conversations.

Later in the day, a few people from the local community starting to come up and take a look at what was going on. At lunchtime we were greeted with a magnificent picnic feast.

We sat on the grass and I remember thinking to myself, "what am I doing here?", in the middle of Cavan at a graveyard sitting having a picnic with the former President of Ireland. Sometimes you must pinch yourself to realise that you are not dreaming. I mentioned this to Mary because I think it is important not to be shy about telling people how you're feeling, especially a lady who seemed so receptive to your thoughts, it was a beautiful moment.

At the graveyard on a notice board, there was a list of people who were buried within, I found that possibly my ancestors (Crosby) may have been buried here which is kind of poetic. I mentioned this to Mary and because of my strong Meath up-bringing - there was a joke going that maybe

I was originally from Cavan and was playing with the wrong county all along. We got back to filming and I tried to get as much of my story out as I could, but we only had one day- I think it could have taken a week to film. The locals added to the program and gave a beautiful historical account of the graveyard. It was so interesting, and I realised why they picked this place for the show. At the end of the day, my family came along to meet Mary. It was wonderful for the family to be together on this amazing day. We got photos to capture the day, that will forever be a great memory to us as a family. I do realise how lucky I am to be able to do this kind of work that may help somebody down the line.

We all said our goodbyes and expressed how great we thought today was. I will never ever forget my time spent sitting in a graveyard in Cavan, with the former President of Ireland and this day gave me renewed energy to keep doing what I have been doing.

This day was so uplifting because for the few months beforehand I had some rejection with my transplant. I just wasn't my usual self and had to go through some steroid treatment and radiation treatment. This really knocked me back a lot and perhaps it is something that people don't see on Facebook and realise what's going on in the background for transplant patients, and I believe is so important to highlight this. Because not every day is as special as that day in Cavan. There are hard days, but I do know that the hard days are always followed by better ones, and sometimes on the majestic days you need to pinch yourself but also make sure to enjoy them.

I am still planning to complete my super 6 marathons and finish off what I started. I would like to thank ILFA so much for supporting me and putting me forward for that amazing day and to be able to share my story out to a wider audience and hopefully help somebody who isn't feeling the best today. I would also like to take the opportunity to say thank you to all the ILFA members who sent me on good wishes, they are much appreciated and I do read them all, and wish each one of you the very best of health in the future. Having a positive attitude helps so much to keep healthy and its not about finishing a marathon, its about doing what your body will let you do whatever that is. Keep safe and look after each other.

David Crosby,
ILFA Ambassador

World Café Workshop on Pulmonary Fibrosis

An online World Café-style workshop with patients, carers, family members, healthcare professionals and industry representatives will take place via Zoom on Saturday 17th April for approximately 3 hours.

The workshop will allow stakeholders to share ideas on how to address the needs and priorities of the pulmonary fibrosis community. We want to gather this data to help us campaign for a dedicated **Clinical Care Programme for Lung Fibrosis**.



Such programmes exist for other serious health conditions and have dedicated health funding. A structured clinical care programme with a standard

model of care is needed to meet the healthcare needs of our patients. It is even more relevant now, as it is anticipated that there may be an increase in the incidence of pulmonary fibrosis from COVID-19 infection.

If you would like to take part in the online ILFA World Café, please register your expression of interest by emailing info@ilfa.ie or calling 086 871 5264. This event is made possible thanks to funding from the Community Foundation of Ireland and RTÉ Does Comic Relief.

Congratulations on a Remarkable Sporting Career

The ILFA committee would like to send our warmest congratulations to our patron, Michael Darragh Macauley on his retirement from inter-county football following a long, outstanding, and inspiring sporting career.

Michael Darragh achieved great success on the pitch and played for the Dublin Senior Football Team and Ballyboden St Enda's GAA Club. He has won an incredible 8 All Ireland Senior Football Medals, 10 Leinster Senior Football medals, 5 National League honours and 2 All Stars. Michael Darragh was also awarded Footballer of the Year in 2013. Announcing his retirement publicly



Michael Darragh Macauley with Matt Cullen, Pamela Martin and Evelyn Cooper who are the stars of the ILFA Yoga DVD.

Michael Darragh said simply "Sin é uaimse. Míle buíochas ó chroí,"

As ILFA's patron, Michael Darragh has helped us raise awareness of pulmonary fibrosis in the media and has appeared on TV with his aunt Edna (a lung transplant recipient) to share their experiences. Michael Darragh also helped ILFA with the development and filming of our Exercise DVD and Yoga DVDs for Lung Fibrosis Patients and delivered face to face yoga classes and online yoga classes to our members.

Michael Darragh has kindly agreed to continue as patron of ILFA and we are delighted to have his support. We wish him every success in his new endeavours.

The Denise Cassidy

Memorial Prize 2021

Would you like to honour your lung fibrosis healthcare hero?



ILFA is excited to announce the 2021 Denise Cassidy Memorial Prize for excellence in healthcare. This award recognises and celebrates the kindness, compassion and humanity of a hospital healthcare worker to a lung fibrosis patient or their family. Patients and carers are invited to nominate a person who showed you or your loved one a special act of

kindness that helped you cope with your illness better.

If ever there was a year to celebrate our healthcare staff – this is it! Please fill out the nomination form that is included with this newsletter or available on the ILFA website and tell us why your healthcare hero deserves to be honoured. You can nominate a doctor, nurse, physiotherapist, social worker, counsellor, dietician, pharmacist, healthcare assistant, member of the chaplaincy team, clerical worker, catering or cleaning staff - in fact anyone who works in healthcare. The more information you can provide, the better as this helps us make the important decision regarding the overall winner. Everyone who is nominated will receive a certificate of excellence and the winner will receive a special commemorative Dublin crystal award.

The award is named in honour of Denise Cassidy who was diagnosed with IPF at the age of 56 and passed away 3 years later. During her illness, Denise met many kind, friendly, caring, and dedicated healthcare staff and other lung fibrosis patients who helped and supported her enormously. Denise's husband Eddie is Chairman of ILFA and her daughter Nicola is a charity Director. Both have served on the ILFA committee since 2007. Denise's family are loyal fundraisers for ILFA and all are honoured to have this special award dedicated to her memory.

Katie Barry, staff nurse from Cork University Hospital was awarded the inaugural Denise Cassidy Memorial Prize in 2015. Katie was nominated by Vikki Jolly for her outstanding kindness, dedication and compassion when caring for Vikki's father, Martin Erangey. Katie said "To say that I am grateful and honoured is an understatement. Words cannot express how thankful and deeply touched I am. The certificate and award have pride of place in my home. I'm still looking at it with disbelief. I love my job and you never expect to receive anything for the work you do, but to be honoured in such a way is truly amazing and something I will always be proud of and grateful for."

Olivia Mulvaney, staff nurse from Cavan General Hospital was awarded the 2017 prize and was nominated by Bridget



Nelson Gallarin, staff nurse at the Mater Misericordiae University Hospital who was nominated by Peter Gallagher, right, for his "exceptional kindness and compassion".

McEneaney for the outstanding care of her late husband, Dessie McEneaney. Olivia said "I want to express my sincere appreciation to Bridget and all the McEneaney family for taking the time to nominate me for this award at such a difficult time in their lives. To get this recognition, adds to the job satisfaction I get from nursing. I am truly honoured and humbled to have received the Denise Cassidy Memorial Prize for Excellence in Patient Care 2017."

Nelson Gallarin staff nurse at the Mater Misericordiae University Hospital was awarded the Denise Cassidy Memorial Prize for Excellence in Patient Care in 2019 and was nominated by Peter Gallagher for his exceptional kindness and compassion. Nelson was thrilled to learn that he was the winner of the award and said "It is an honour to be granted the award. I am indeed grateful and delighted. It is the small things we consistently do that really give great impact to the lives of others. To live a life of purpose gives life meaning ... a life of service to others that even though they won't be remembering my name long after they have gone home, if they will remember how they felt while they were under my care, then that's good enough for me. I'm happy that Peter remembered my name; that my name is engraved on his heart, like my name is engraved on this trophy, and we both treasure, not only our winnings, but the fond memories of our encounter. Thank you to Peter and ILFA for this award."

Please send your entries to ILFA, PO Box 10456, Blackrock, Co Dublin or email info@ilfa.ie. The closing date for entries is the end of May.

ILFA Online Activities

Let's Talk ...

How do we manage a pandemic?

- Caring for self
- Caring for others
- Support
 - practical
 - emotional
- Seeking the truth
- Perspective
- Hope



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 every month and feature an invited speaker who discusses topics related to their specialist field and answers questions. The meetings usually last 60 minutes and are lively, interactive, sociable, and light-hearted. Some of the recent sessions that have taken place in 2021 are summarised below. We are grateful to the healthcare professionals who are willing to share their time and expertise with us. 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.



Let's Talk Palliative Care

In February 2021, the guest speaker was Dr Paul Gregan from Our Lady's Hospice, Dublin and he discussed the role of Palliative Care in pulmonary fibrosis. We learned about symptom management, the principles of palliative care and specialist palliative care, and the role of hospice care. Dr Gregan discussed the management of breathlessness, fatigue, anxiety, accessing healthcare and planning for the future. He recommended that people with breathlessness use a hand-held fan to help their symptoms.

ILFA can supply a hand-held fan to members if needed, please call Gemma on 086 871 5264 or email info@ilfa.ie

Let's Talk Health & Wellbeing in Challenging Times"

In March 2021, we had the pleasure of having Professor Gaye Cunnane, Director of Health & Wellbeing at the Royal College of Physicians of Ireland speak to ILFA members. Professor Cunnane gave us great advice and tips to manage life in these challenging times including these useful instructions;

- Get creative
- Be present in the moment
- Step outside, look to the sky, breathe in, feel the air on our skin and notice nature - Practice mindfulness
- Plan a simple highlight in every day
- Set goals and priorities
- Talk about our emotions and express vulnerability

- Practice self-compassion.

Let's Talk Singing for Lung Health

On 24th March, our guest speakers were Ciara Meade, Choir Mistress with Sing Strong, Dr Roisin Cahalan, physiotherapist lead with Sing Strong and Denis Teevan, a patient who attends the Sing Strong for COPD classes. 32 enthusiastic participants joined the meeting to learn about the Sing Strong programme. Ciara discussed the logistics of the class and how the musical goals will progress over the course of the 12-week programme from starting with vocal exercises and chants to singing song verses, while building up the voice muscles. Denis told the group how he loved the classes and found them to be enjoyable and great craic and how they have helped him to feel more relaxed. Roisin described some research around the success and health benefits of the Sing Strong programme and explained that participants will be asked to take an optional survey at the beginning and end of the 12-week course to evaluate it. ILFA is grateful to Ciara and Rosin for collaborating with us to deliver Sing Strong for Pulmonary Fibrosis classes (see below).

Sing Strong for Pulmonary Fibrosis

ILFA is delighted to announce a new online Sing Strong for Pulmonary Fibrosis class for patients and carers. Classes will start on April 20 and will last approximately 60-70 minutes each.

Research has shown that singing for lung health classes that are delivered by a trained specialist provided valuable psychological and social benefits to people living with respiratory conditions. Some of the benefits include;

- improvement breathing control
- better management of breathlessness
- improved posture
- relief of anxiety
- fun, enjoyment and social interaction

You do not need to be a good singer or have singing experience. The classes will take place online and everyone will sing (muted) from the comfort of their home, while training and exercising their breathing muscles under the expert guidance of a choir mistress.

This activity is supported with funding from Air Liquide Healthcare Ireland and BOC Healthcare Ireland. We are enormously grateful for their kind support.

Please contact ILFA on 086 871 5264 or email info@ilfa.ie to register.

Advocacy

ILFA Joins Care Alliance Ireland

ILFA is delighted to have been accepted as a member of Care Alliance Ireland - a national network of voluntary organisations supporting family carers. The alliance aims to raise awareness and ensure the role of family carers is fully recognised and valued by society in Ireland. We look forward to working with Care Alliance Ireland to represent the unmet needs of carers.

Irish Thoracic Society's Interstitial Lung Disease Group

Congratulations to Professor Killian Hurley, Respiratory Consultant at Beaumont Hospital and Dr Kate O'Reilly, Respiratory Consultant at the Mater Misericordiae University Hospital following their appointments as Chair & Vice-Chair of the Irish Thoracic Society's Interstitial Lung Disease Group, respectively. We look forward to working with them to progress the Pulmonary Fibrosis Registry, campaign for a Clinical Care Programme for Pulmonary Fibrosis, and support education for healthcare professionals.

ILFA would like to send our sincere thanks to Professor Anthony O'Regan, Respiratory Consultant at Galway University Hospital and Dr Mike Henry, Respiratory Consultant at Cork University Hospital, for their leadership and energy as they step down from the roles. Nicola Cassidy, ILFA Director, is a member of the group and is delighted to represent pulmonary fibrosis patients and carers at the meetings.

Human Tissue Bill and Opt-Out Organ Donation

The Irish Lung Fibrosis Association is pleased that the Human Tissue Bill that includes legislation on organ donation and transplantation, and an opt-out system of consent for organ donation, is included in the government's Priority Legislation Programme for Spring 2021. ILFA has long campaigned for this legislation and looks forward to its introduction. Organ donation saves lives. It is important to let your loved ones know your wishes on organ donation.

Submission to the National Centre for Pharmacoeconomics

ILFA made a submission to the National Centre for Pharmacoeconomics (NCPE) calling for the reimbursement of Nintedanib (anti-fibrotic medication) for people diagnosed with progressive fibrosing diseases (PF-ILD). This umbrella term represents irreversible fibrotic (scarring) respiratory conditions that are debilitating and life-limiting, and have a poor prognosis (for example Systemic Sclerosis ILD, Rheumatoid arthritis ILD, mixed connective tissue ILD, Polymyositis and Dermomyositis ILD and others).

Antifibrotic medications have become invaluable to patients diagnosed with Idiopathic Pulmonary Fibrosis (IPF).

For some patients, the antifibrotic medicines enable them to maintain their respiratory function and fitness levels for longer, and some will be able to stay well enough to avail of a precious lung transplant. Antifibrotic medications have substantially changed the outlook and expectations for patients and enables them to have hope for their future, continue to function and conduct their activities of daily living for longer, and achieve important and precious family milestones.

Medical Cards for Patients with Terminal Illnesses

On 9th February 2021, the Government introduced a measure that will enable individuals, who have been certified by their treating consultant as having a prognosis of less than 24 months to live, to be awarded a medical card without undergoing a means test. The measure is being introduced on an administrative basis pending legislative change.

From 12th March 2021, a medical card can be awarded (without a means test) to an individual who has been certified by their treating consultant as having a prognosis of 24 months or less and the updated information is available on the HSE website – www.hse.ie

Raising Awareness Through Art



Matt Cullen recently printed some of his art onto cards and sold them to raise money for ILFA. The Respiratory Team at Beaumont Hospital bought some of Matt's cards to support his fundraising and loved them so much they had two sets framed to display in the Respiratory Centre and in the Physiotherapy Department.

The photos show one set of framed cards hanging in the Physiotherapy Department and one with Clinical Nurse Specialists, Catherine McGeoghegan (left) and Deirdre

O'Flaherty (right), with Grace McKee (Senior Respiratory Physiotherapist) in the middle.

Thanks to Grace for sending in this lovely story. It warmed our hearts! Well done Matt!



Education

Cognitive Behavioural Therapy (CBT) Training Bursaries

In 2020, ILFA awarded educational bursaries to 8 healthcare professionals working with lung fibrosis patients to study Cognitive Behavioural Therapy (CBT). The online course started required a minimum commitment of 15 hours e-learning and 10 hours participatory online sessions. The course introduces attendees to the basics of CBT and teaches them how to use basic CBT skills and techniques to help address psychological distress, depression and anxiety in patients under psychological distress. Here is the feedback from the ILFA Educational Bursary Recipients.

Paula Ryan, Advanced Nurse Practitioner at University Hospital Limerick said: "I'm very happy to have had an opportunity to be able to complete the Cognitive Behavioural course that was funded by ILFA. Thank you so much to ILFA for kindly affording me the opportunity to complete this course. I thoroughly enjoyed the course and I especially enjoyed learning how to use CBT as part of my ongoing respiratory work with our patients. It was a wonderful opportunity to link with my fellow colleagues across the country again and get to see how CBT will support IPF patients and their families. I hope to incorporate CBT in my daily practice. I now feel that I am able to deliver a superior quality of care in the treatment of patients with IPF. This course has allowed me to have more structure to how I approach my patients and family. Thank you again in supporting me to gain this certificate and I look forward to applying my CBT knowledge to serve the patients in the mid-west in the near future.

Christina Tobin, Respiratory Physiotherapist at Mallow General Hospital, Cork said: "I would like to thank the ILFA and their kind donors for providing me the opportunity to complete 25 hours CPD in Cognitive Behavioural Therapy (CBT). CBT has been a great resource that I have been able to utilise one to one with patients and with our pulmonary rehabilitation group. The outcomes from our first virtual pulmonary rehab group show a hugely significant change in participants anxiety and depression scores.

Being able to practice the techniques that we have learnt and talk through an example on day 2 of the course and get feedback was invaluable. The educators had a wealth of knowledge and experience and shared their resources openly. I found their resources on mindfulness a great personal tool during this stressful time of COVID 19. I would strongly recommend this course to any health professional involved with the care of respiratory patients.

Sarah Cunneen Senior Respiratory Physiotherapist at Tallaght University Hospital said: "Thank you to ILFA for the opportunity to complete Cognitive Behavioural Therapy (CBT) training. I enjoyed participating in the online training with other healthcare professionals from around the country who also work with patients with Pulmonary Fibrosis.

The course provided me with the skills to support patients with Pulmonary Fibrosis who are living with psychological stressors. Learning these techniques has changed my approach with patients who experience symptoms of anxiety and depression. I have also incorporated CBT into how I discuss dyspnoea (shortness of breath) with patients and I have integrated the resources that were shared on the course into the Oxygen Clinic in Tallaght University Hospital. The training was delivered by experts in the area, and I would recommend this course to colleagues involved in the care of patients with respiratory conditions."

Antoinette Doherty, Respiratory Advanced Nurse Practitioner at Letterkenny Hospital said: "Having worked in respiratory nursing for 30 years I often felt helpless in respect of managing the breathless patient. I was fortunate to attend a conference in Birmingham October 2019 funded by Irish Lung Fibrosis Association and there was a particular focus on the healthcare professional's role on breathlessness management, and a new concept for me was the role of cognitive behaviour therapy in breathlessness management.

When ILFA decided to fund educational training

delivered by Dr Karen Heslop-Marshall, I absolutely did not hesitate to apply for this training, and it exceeded my expectations. What I learned on this course has given me the necessary tools to be more effective in my daily practice in the care and management of patients with advanced lung disease.

I have subsequently introduced CBT into breathlessness management with great outcomes for my patients and their family. I am finding it easier to talk and plan care with my new insight. This has improved how I feel. I am confident that things can only get better for our breathless patients with breathlessness management clinics using CBT in practice. Thanks ILFA for your help and support."

Lynn Fox, Advanced Nurse Practitioner, Mater University Hospital said: "I have started the Cognitive Behavioural Therapy (CBT) course, which is facilitated by Dr Karen Heslop, Respiratory Nurse Consultant, and ILFA. It is a very informative and interactive course. Prior to commencing the online sessions, you have to complete some background reading. The techniques introduced on the day can be used in all areas of clinical practice to help patients manage their anxiety levels. Karen also provides



support literature and websites to assist with developing CBT within your practice."

Julie Goss, Advanced Nurse Practitioner at Our Lady's Hospice & Care Services, Harold's Cross, Dublin said:

"Thank you to ILFA for the opportunity to complete the CBT training with Pivotal.

The course has provided me with foundational skills and simple tools that I can use in practice to support patients and family who are living with the psychological challenges that illnesses such as lung fibrosis present.

Both instructors are experienced clinicians and knowledgeable teachers. The live online teaching is supplemented with a great online resource and activities. There was also an opportunity to engage with group learning from colleagues around the country. We were signposted to useful patient information resources – some of which I now use in practice. I would recommend this course to colleagues. It has increased my interest and commitment to continue to develop these skills further."

Catherine McGeoghegan, Respiratory Clinical Nurse Specialist at Beaumont Hospital, said: "I found the ILFA CBT course hugely beneficial in teaching me ways to better support my IPF patients and their families. I also found this course beneficial on a personal level as it has taught me better ways of coping and managing my own thoughts and worries when faced with an ever-climbing workload (specifically this year).

Living with IPF comes with a number of worries and concerns that our patients and their families need to navigate through on a daily basis, and I think this last year has been particularly tough on everyone. CBT can be used to support and empower patients and families to develop their own personal coping strategies to target and overcome their specific concerns.

This course has taught me that although patients may be experiencing similar milestones/ events in their IPF journey, their thoughts, behaviours and coping mechanisms around these events are unique to them. Having some understanding of this means we can tailor a more superior level of support to our patients. I want to thank ILFA for this opportunity and I would highly recommend this course to my fellow colleagues."

Educational Bursaries for CBT Training in 2021

Educational bursaries were awarded to an additional 8 healthcare professionals to study Cognitive Behavioural Therapy in 2021 and we look forward to hearing how they got on. The bursary recipients are:

Niamh Julian, Senior Physiotherapist University Hospital Limerick/ Cashel

Petra Grehan, Senior Respiratory Physiotherapist Heart and Lung Transplant programme at the Mater Misericordiae University Hospital, Dublin

Nora McNamara, Respiratory Advanced Nurse Practitioner, Clonmel General Hospital

Elaine Craven, Respiratory Advanced Nurse Practitioner, Connolly Hospital, Blanchardstown, Dublin

Donna Langan, Respiratory Advanced Nurse Practitioner, Galway University Hospital

Noreen Donoghue, Respiratory Clinical Nurse Specialist, Bon Secours Hospital, Galway

Deirdre O'Flaherty, Clinical Nurse Specialist, Beaumont Hospital, Dublin

Carita Bramhill, Student adviser and PhD student, University College Dublin

Patient Information Day

February 2020

ILFA's Patient Information Day took place on Saturday 27th February and 110 people joined us via Zoom for an excellent programme. ILFA Chairman, Eddie Cassidy welcomed everyone and introduced the speakers. The presentations were recorded and are available to watch online on the ILFA YouTube channel. Here is a summary of the presentations delivered by our panel of speakers to whom we are incredibly grateful.



Dr Kate O'Reilly, Respiratory Consultant at the Mater Misericordiae University Hospital, gave an overview of Idiopathic Pulmonary Fibrosis (IPF) and told us that the incidence of pulmonary fibrosis is increasing globally. Key aspects of care include maintaining physical fitness and good general health, using oxygen

when exercising, avoiding infections (and getting vaccinated especially against Covid19), and maximising quality of life. Exercise is the one aspect of treatment that will benefit patients physically and psychologically. Antifibrotic medicines slow the rate of decline of lung function but do not reverse lung damage. Although side effects can occur, they can be managed. Unfortunately, some patients cannot tolerate the medication. Remote monitoring of patients' health measurements has been introduced during the pandemic as the capacity to see patients in hospital is greatly reduced. Dr O'Reilly discussed the influence of diet on the microbiome (bacteria in the gut). Soluble fibre in the diet influences the levels of short chain fatty acids which in turn may potentially have some antifibrotic and anti-inflammatory effects. Keep a good diet to optimise overall health.



Professor Simon Walsh, Consultant Radiologist at the National Heart and Lung Institute, Imperial College London described how radiologists (doctors who read CT scans and imaging) are central to diagnosing pulmonary fibrosis. Misdiagnosis and misinterpretation of lung CT scans can occur due to the complexity of

reading CT scans, the subtlety of changes and densities, and difficulties visually assessing 3-dimensional patterns and distribution of fibrosis. Artificial intelligence (AI) and deep learning are being developed and used to help radiologists interpret digital images of lungs using computer technology. AI is used to help radiologists (not replace them) by facilitating a more accurate diagnosis, for recruiting patients to clinical trials and in screening programmes to detect early fibrotic changes, called interstitial lung abnormalities, that are significant. AI technology can find patterns in CT scans that can potentially help with predicting disease progression and acute exacerbations, and it has applications for determining the response/lack of response to medication.



Professor Bernard Mahon, Professor of Immunology at Maynooth University, described the development of vaccines. Examples from history tell us that the immune systems of people exposed to pathogens (viruses or bacteria), respond, and remember the exposure. In the body, B cells make antibody proteins that kill free virus in bodily

fluids. T cells can look into other cells to identify and kill hidden viruses and coordinate and amplify an immune response. When the body is exposed to a pathogen, a typical immune response is rapidly initiated but antibody is not measurable for approximately 7 days. As the disease declines, antibody levels fall but do not disappear. A memory is laid down so when you are exposed again, a rapid immune response is mounted. Vaccines are hugely important to individual health and societal health. Vaccines work by exposing people to part of a pathogen or a weakened version of the pathogen, so an immune response is mounted, when we encounter the real pathogen/disease, the body is equipped to mount a powerful response to fight the disease. Prof Mahon described the tools and theory behind the development of vaccines, including the Covid19 vaccines. Prof Mahon told us that we have good reason to be optimistic as we already live with corona viruses (e.g. cold virus), and we are lucky to have vaccines to Covid-19 in such a short time. In response to questions raised on which vaccine to get, Prof Mahon recommended taking the first vaccine you are offered.



Gordon Cagney, Senior Respiratory Physiotherapist at University Hospital Limerick delivers the weekly online exercise class for ILFA and we are enormously grateful to him. Gordon gave an excellent talk on understanding the importance of exercise especially for patients with pulmonary fibrosis. He explained how our muscle fibres

decrease with age (from 30 years of age) and this impacts on muscle mass and strength. Thankfully, muscles respond well to exercise. Pulmonary rehabilitation programmes are vital to help patients engage in exercise and hear from clinical experts on other educational components for living well. He told everyone about the virtual classes that are available to support patients and develop an exercise routine. He stressed the importance of consulting with your GP / consultant to make sure it is safe for you to exercise. If patients are unable to attend the zoom class, they can watch a video made by the physiotherapy students at University Hospital Limerick (available on the ILFA website).

Paula Ryan, Respiratory Advanced Nurse Practitioner, University Hospital Limerick thanked ILFA for the Educational Bursary she received in 2020 to study Cognitive Behavioural Therapy (CBT). Paula discussed the symptoms and treatment of pulmonary fibrosis, the use of CBT to support patients, and how University Hospital Limerick managed IPF patients during Covid 19 restrictions.



IPF causes shortness of breath, cough, and fatigue/tiredness and impacts on patients' quality of life and for some this can lead to depression and anxiety. CBT is based on behavioural and cognitive psychology and addresses how thoughts impact our feelings and mindset. Paula presented a patient case who responded well

to CBT. His IPF symptoms and thoughts impacted on him. He experienced feelings of isolation, anxiety, tiredness, and developed a fear of going out. CBT can help identify patients' feelings and help them manage better with behavioural changes. Education is key for the management of symptoms and instilling a positive mindset. Paula advised everyone that exercise is vital to maintain lung function and conditioning and reassured us that it is safe to go outdoors for a walk but do not stop to talk with others. She also recommended that patients take part in the ILFA exercise classes and support group meetings.

Covid 19 has impacted on appointments to Outpatient Departments but hospitals are continuing to provide some urgent appointments and to see newly diagnosed patients who need to be assessed and started on antifibrotic medications if appropriate.



Moya Brennan, singer, musician, and composer with Clannad was diagnosed with IPF 3 years ago. She developed symptoms 3.5 years ago that started with a persistent cough. She had a scan in St. Vincent's Hospital which showed scarring on the lungs and she was shocked by the diagnosis. She immediately decided to cancel all her engagements for 6 weeks and rested. Moya follows a healthy diet, exercises regularly, and goes for long walks in the Phoenix Park. She has noticed that her coughing has improved and is problematic mostly in the mornings. In 2020, she was due to go on a world tour which had to be cancelled because of Covid-19. She still sings and is feeling well and doing virtual concerts and singing with others. She is optimistic about future projects and looking forward to singing and touring a lot more. Moya encouraged everyone keep doing all the right things and sing along - Sing in the shower - fill your lungs!

Feedback on the Event

The ILFA Committee was delighted to receive wonderful feedback and comments from so many attendees. Here is lovely email sent by Rhonda for the speakers and organisers.

"Thank you sincerely for organising this event on IPF and related science, information and advice. It was one of the best webinars on any subject I have ever attended! I'm grateful to you all for your efforts to bring information to the fore with such a well-organized event; for your kindness in making yourselves available today (on what might otherwise be a "precious day off"); for your work in preparing slides and providing such good information with engaging presentations. I listened to you all intently and could have listened to you all day!"

Each presentation was well-pitched towards a mixed audience of patients, non-patients, and to scientific, medical, and general interests. The webinar was so nicely introduced by Eddie and very well "mc'd" by Justin (you should have a secondary career in media if you don't already!)

The new research on artificial intelligence in diagnostics, microbiome influence on health, vaccine development, was fascinating and thought-provoking. It's heartening to hear how deep learning technology is helping research and diagnostics to advance, and how a fuller 'holistic' understanding of microbiology and genetic variation is informing personalized medicine and approaches to therapy. The use of CBT, info on exercise, and the lived experience and useful tips from Ms. Moya Brennan were so positive to hear, inspiring and informative. I thank you all for today and wish you all well (and likewise the patients that you treat and support with your care, your scientific research and your advice). I congratulate the ILFA on their great work."

Sincere thanks / Go raibh míle maith agaibh, Rhonda

- "Firstly, I'd like to thank you and the speakers, technicians, facilitators and all involved in presenting Saturday's Patient Information Day. I am truly grateful for the open and generous sharing of knowledge and I know that it will enable me to navigate my disease with greater understanding and confidence. Although I only joined ILFA a few short weeks ago, I have benefitted greatly from the exceptional work of the association. Thank you all."
- "Excellent Patient Information Day, many thanks to all involved, very helpful and informative. Well done!"
- "Great patient information day, really enjoyed listening to the speakers. Very informative and thanks to ILFA for organising everything."
- "Excellent presentations from all involved and hugely informative. Thank you ILFA for all you do!"
- "Thank you and well done to all involved, very helpful and informative. Very interesting to hear how Artificial Intelligence and Machine Learning are helping improve diagnostics in radiography etc."
- "I want to thank you for the excellent webinar on Saturday. This condition takes a lot away from us but projects like that are so helpful and it feels empowering to have access to such presentations."

All of the recording from previous ILFA Patient Information Days are available to watch on the ILFA You Tube Channel.

COVID-19 Vaccine Allocation Strategy

The Irish Lung Fibrosis Association was invited to join an online Stakeholder Briefing meeting for an update on the COVID-19 Vaccine Allocation Strategy with Minister for Health, Stephen Donnelly, Professor Karina Butler (Chair of the National Immunisation Advisory Committee), HSE staff and other patient organisations on 24th February. We were grateful to hear the rationale for the vaccination prioritisation strategy and to have the opportunity to submit questions to the experts. The meeting was valuable and informative.

The development of effective COVID-19 vaccines in such a short time represents major progress in response to the pandemic. The evolving real-world experience of large populations being effectively vaccinated has resulted in a decrease in COVID-19 hospitalisation rates. While this is hugely encouraging and reassuring, we all need to continue to follow public health guidance and adhere to social distancing and hand hygiene measures to ensure we stay safe.

As vaccine supply is currently limited, there is a need to prioritise those groups at greatest risk of illness, hospitalisation, and death due to the coronavirus. The National Immunisation Advisory Committee has issued the updated COVID-19 Vaccine Allocation Strategy based on evidence and an ethical framework to ensure fairness and equity in deciding who should get the vaccine first.

The plan is to target vulnerable groups considered to be most at risk and keep them safe. Patients aged 16-69 years with severe pulmonary fibrosis are included in Cohort 4 and will receive the vaccine directly after those aged over 70 years. ILFA submitted a question regarding the definition of "severe" pulmonary fibrosis as mentioned in the allocation strategy and highlighted the risk of an acute exacerbation for pulmonary fibrosis patients. We await clarification and will update you when possible.

We also asked if carers/spouses of pulmonary fibrosis patients would be prioritised for the vaccine. At this time, priority is given to pulmonary fibrosis patients and other high-risk patients. As the vaccine supply increases, caregivers will be called for vaccinations.

The HSE will be responsible for the implementation of the vaccines (how, when, where). The priority list is under constant review.

You can read more on the Allocation Strategy on www.gov.ie/covid19vaccine

COVID-19 Vaccine AstraZeneca® safety update from the HSE

The European Medicines Agency (EMA) has recommended the AstraZeneca COVID-19 vaccine as safe and effective, whose benefits outweigh the risks, following a review of potential side effects carried out this week.

The National Immunisation Advisory Committee (NIAC), which is the expert group that advises on vaccination in Ireland, has recommended that vaccination with COVID-19 vaccine AstraZeneca should recommence. The HSE has resumed using the AstraZeneca vaccine within the ongoing COVID-19 vaccination programme.

HSE Covid19 Vaccine Community Network

ILFA was invited to join to HSE Covid19 Vaccine Community Network and has been informed that planning and organising for the vaccination of the new allocation Group 4 (aged under 70 years with a serious health condition) has started and is ongoing. It is expected that vaccination of this group will take place throughout April.

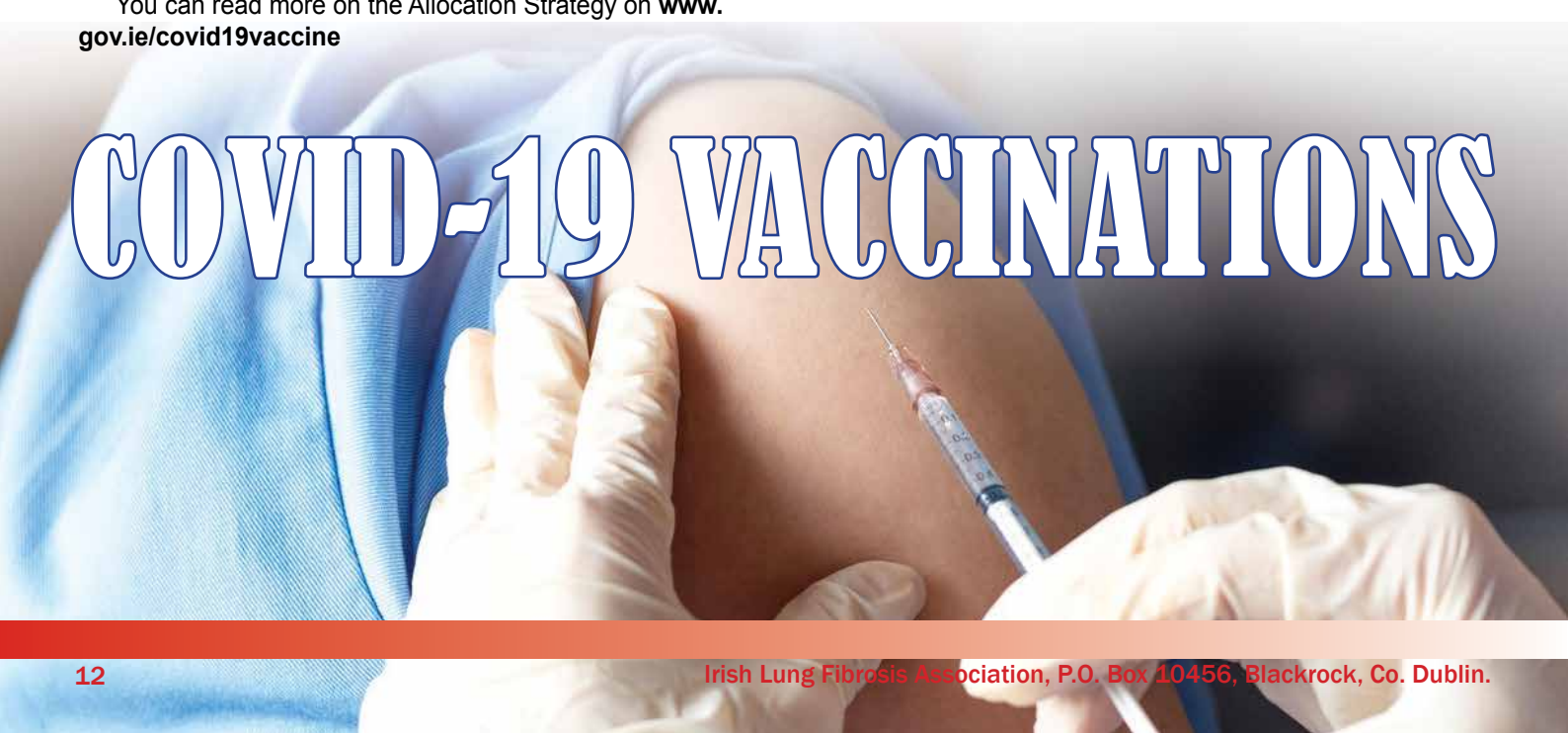
In the first phase, hospitals are working through their lists of people aged under 70 with a serious illness who are currently undergoing care / have regular treatment appointments. The hospitals will plan for these vaccinations. GPs may be contacted in the coming weeks so that they can also help identify people who may be in Group 4 (and aged less than 70 years) but this still has to be agreed (as of 22/3/21)

Many of the people in Group 4 will be vaccinated through their hospital team, or at a vaccination centre connected to a hospital. Some may also be vaccinated through community and primary care services.

The advice is that people in Group 4 (under the age of 70 years) are asked to hold off on contacting their GP for the time being. They expect that most people in Group 4 will be identified through hospitals or their healthcare teams or GPs.

Vaccine supply is an ongoing issue.

Please see www.hse.ie for up-to-date reliable information.



COVID-19 VACCINATIONS

News from the EU-IPFF

In Europe, ILFA continues its membership of the European IPF Federation which now has members from 15 European Countries and links to groups from across the world.

During 2020, the EU-IPFF supported its members including ILFA with financial grants to assist Covid-19 activities, provided supply line statements from medicine manufacturers, and issued joint scientific statements with its scientific advisory board on Covid-19 and Pulmonary Fibrosis and Vaccine Prioritisation.

The EU-IPFF also held its annual awareness campaign during September for Pulmonary Fibrosis Awareness Month which also saw it join forces with ILFA and the US based PF Warriors to host a set of three online events for the Awareness Month.

The EU-IPFF has updated its "Snapshot of IPF Care in Europe" report (which can be found on the website) which highlights the care and support available to patients in 17 countries across Europe.

The various calls to action contained in this important

report also motivated the EU-IPFF to join with the other 8 largest Lung Health Groups in Europe to form the European Lung Health Group, a coalition dedicated to improving health policies and supports at European Level. Launched this January, this group has the support of Members of the European Parliament (MEPs) who support the vision for lung health it has published in its Breathe Vision 2030 paper.

The EU-IPFF will hold its virtual Patient Summit between the 23rd and 25th of April. ILFA encourages all its Irish community to register for this free event at www.eu-ipff.org. The summit will feature a host of experts and interesting topics including a talk by our ILFA Ambassador, David Crosby.

ILFA continues to support the work of the EU-IPFF and looks forward to its summit and the 2021 Awareness Campaign. Liam Galvin of ILFA continues to help lead the EU-IPFF and to ensure that the voice of Irish Patients is heard within this highly active Federation of Patient Groups.

Report by Liam Galvin
CEO of the EU-IPFF

Care Alliance Ireland and Supports for ILFA

Family Carer Support Group

In response to the impact of Covid-19 on Ireland's family carers, Care Alliance Ireland set up an online family carer support group in March 2020. The online support group enables a space for family carers to discuss issues and concerns in a private and supportive environment.

Delivered through a Facebook platform, the group is facilitated and moderated by staff and volunteers of Care Alliance Ireland. Many of these individuals have a professional background in health or social care or a personal background in family caring. The support group consists of group initiatives for family carers to take part in and engage with other family carers. The support group seeks to be a platform to ask questions and access other services such as one-one support if needed.

Feedback from current members

"Hi and thank you all for setting up this group; being a family carer can be a lonely life, great to have support like this."

"Being part of the Carers group on-line has given me so much support and it is a safe place to bring any concerns, anxieties some where you will not be judged, and all questions answered, lots of support."

ONLINE SUPPORT GROUP FOR FAMILY CARERS IN THE REPUBLIC OF IRELAND

FACILITATED AND
MODERATED BY STAFF IN
CARE ALLIANCE IRELAND,
HEALTH AND SOCIAL CARE
PROFESSIONALS AND FAMILY
CARER VOLUNTEERS



The Family Carer Support group is an initiative to bring together the primary aims of the Irish Lung Fibrosis Association and Care Alliance Ireland. As ILFA seeks to provide a source of information and support to people with the condition, placing an equal emphasis on those who care for people with the condition is a fundamental step in achieving such aims.

If you are a family carer and interested in the joining the online support group meeting, please visit the link below:

[https://www.facebook.com/groups/
FamilyCarerOnlineSupportGroupIreland/](https://www.facebook.com/groups/FamilyCarerOnlineSupportGroupIreland/)

STALL Breathing technique



- S** **Stop** what you are doing.
 - T** **Try** to remain calm. **Turn** up your oxygen.
 - A** **Assume** a comfortable position.
For example, sitting or leaning.
 - L** **Let** your imagination take you to a safe place.
Imagine yourself there, relaxing.
 - L** **Let** your breathing return to normal.
- When your breathing has returned to normal, reset your oxygen to normal.
Call for medical help if your symptoms do not settle.



Main photo: Irene Byrne; Top: STALL card;
Bottom: Irene with ILFA Patrons Michael Darragh
Macauley and the late Senator Fergal Quinn.

Happy Retirement to Irene Byrne

Irene Byrne, Senior Physiotherapist at the Heart and Lung Transplant Programme at the Mater Misericordiae University Hospital, and long-term friend of ILFA, retired at the end of 2020 after an outstanding clinical career dedicated to caring for respiratory patients.

Irene has been an enormous support to ILFA from the beginning and has volunteered her talents, time, and expertise to help ILFA with many important projects over the years. We are enormously grateful to Irene for her warmth, friendship, and willingness to help. Let's take a look at some of Irene's amazing contributions to ILFA over the years.

Irene spoke at the first ILFA Patient Information Day in 2006 and has presented at many more events over the years. Her talks are always full of sound advice, laughter, fun and

inspiration. Irene has a special skill that makes us all want to embrace exercise, get moving and really enjoy life. She exudes happiness is a champion of common sense. Irene has words at will, a quote for every occasion (usually from her hero Muhammad Ali), tales that make us laugh at ourselves and realise the absurdities of life, and the ability to make us adopt a "can-do" attitude. Irene has always been so obliging, kind, and generous with her advice and always eager to participate in ILFA's activities.

In 2012, over a cup of tea following a Patient Information Day, Irene and Nicola Cassidy (ILFA Director) came up with an ambitious plan to develop a walking challenge specifically for lung fibrosis patients. And so, the 2000 Steps a Day Challenge came into being. The critical number "2000" has special significance as the average person takes approximately 2,000 steps to walk one mile.

The 2000 Steps a Day Challenge is a simple concept suited to patients of all exercise levels because an individual's



Clockwise, from top left: Irene with flowers from the ILFA Committee; The ILFA committee sends their best wishes to Irene via Zoom; 2000 Steps talk at the European Respiratory Society Congress in Munich 2014 (when nobody was looking!); Launch of ILFA's 2000 Steps with ILFA's patrons and patients and at the Irish Healthcare Awards in 2014. The ILFA 2000 Steps A day Challenge was awarded first prize for the Best Patient Organisation Healthcare Project.

exercise goal is determined by their baseline step count. This ensures that the exercise programme can be used by those with mild or limited disease who are active and able to engage in exercise, and those with more advanced disease who may be struggling with reduced physical ability.

The ILFA 2000 Steps a Day Challenge was officially launched in June 2013 on a beautiful sunny day with a photo shoot with ILFA's patrons and patients at Fitzwilliam Square in Dublin. In 2014, ILFA presented the '2000 Steps a Day Exercise Challenge for Lung Fibrosis Patients' at the European Respiratory Society Congress in Munich. This represented a great opportunity to showcase our work to an international audience of healthcare professionals working in respiratory medicine. In November 2014, the 2000 Steps a Day Exercise Challenge won the Irish Healthcare Award for the Best Patient Organisation Project of the Year. What an incredible achievement and a very special honour for ILFA!

Since its launch, the 2000 Steps Programme has gone from strength to strength, and it is being used by lung fibrosis patients and healthcare professionals all over Ireland. 2000 Steps packs that include a pedometer (step counter), exercise diary, high vis vest, and information leaflets are requested and sent every week.

Irene also helped ILFA with the development of the STALL Breathing Technique Card (2014) and the ILFA Exercise DVD (2015). Irene and her colleague Petra Grehan helped us develop another fantastic patient resource and both ladies were naturals in front of the camera! Filming took place in the Mater Hospital with three patients and great fun was had. ILFA is thrilled to have so many practical and beneficial exercise

resources for patients and thankfully these have been embraced by patients and healthcare professionals alike with great enthusiasm.

As the date of Irene's retirement approached, her colleagues at the Mater Hospital's Physiotherapy Department organised a socially distanced party with video contributions from her friends and colleagues who could not attend. The ILFA committee was delighted to be able to be there in spirit by contributing a video message and photos that were enlarged, printed, and displayed on walls in the hospital for Irene's retirement do. The ILFA Committee met online one evening full of enthusiasm and giggles to record our video thanking Irene for her valued support and friendship over the years. Amazingly we got the video done and dusted in one take and no retakes were needed! Some patients and family members also sent in personal video contributions to thank Irene for the difference she has made to their lives and indeed the lives of so many people in the lung fibrosis community.

In December, the ILFA committee presented Irene with a token of our appreciation to thank her for her wonderful support and many, many contributions to ILFA. It has been a real honour for the ILFA committee to work and laugh with Irene over the years and we cannot thank her enough. ILFA is delighted to report that Irene will continue to help ILFA in whatever way she can, and we can say with confidence that we will be calling on her!

With enormous gratitude and appreciation, we wish Irene and her husband Robert, the happiest future on their retirements from work. Now the fun begins!



Virtual Walk to Remember Christine

On 20th February 2021 our friend and colleague Christine McCarthy Ormsby (58) passed away. This came much quicker than anyone would have expected and led to widespread shock within her family, friends and colleagues. Christine a native of Kenmare in Kerry, and never forgot her roots. She lived in Co Meath and worked as a scrub Nurse in Theatre in Connolly Hospital. She worked there for the past 25 years and was working fulltime up to five weeks before her sad passing. She was a wonderful person, a diligent and caring nurse who was loved, respected and treasured by everyone who knew her.

With the restrictions Covid has placed upon us, we were unable to mourn and grieve in the usual Irish way... you have to hand it to the Irish we do funerals well!!!. As a group we decided that as we couldn't express our condolences normally, we would use the occasion of Christine's months mind (20th March) to do something special and raise some money. Her family had asked for donations for Irish Lung Fibrosis Association (ILFA) instead of flowers at her funeral. We therefore chose ILFA as our charity and set up a gofundme page. The expectation was that it would be a small fundraiser within our hospital department but it very quickly grew from there. The €500 target was reached in a few hours and it grew steadily. Christine's colleagues, family and friends were quick to react and very kindly donated.

For the day itself, we made the decision to do a virtual

walk in our little groups within our own 5kms and release some balloons to remember our friend. We got everyone to send photographs from where they were. Christine's family and friends also joined in. All the photos were put together to remember the day along with a short video which was truly emotional.

The true intention of the walk was to honour Christine, support her family and to raise money for and awareness of Pulmonary Fibrosis, but interestingly in doing this it has been very therapeutic for our little theatre family. It has helped us recognise and realise the support, encouragement, and comradery, present in our department. We came together as a group, united in our loss of this remarkable woman.

We are overwhelmed at the monetary support the page has received. The generosity shown has warmed our hearts. Christine would be so shocked and surprised - she was quite humble. After a very tough year in nursing, we as a team have been lifted by the kindness of people and thank you all so very much.

Rest in Peace Christine - treasured forever in our hearts.

**Report by Ann and Orlaith,
Theatre Department,
Connolly Hospital.**



Fundraising Round Up

Wedding congratulations



Paul and Jean on their wedding day

Warmest congratulations to Jean and Paul who married in November 2020 and made a kind donation to the Irish Lung Fibrosis Association in memory of Jean's loving father, Leslie Knight. We are very grateful for their thoughtfulness and wish the beautiful couple every happiness for their future.

Christmas Surprise



Celine with her children Simon, Conor and Abby.

We were very touched to hear from Celine McCarthy-Beckitt in Canada about her special Christmas gift - a donation to ILFA - from her three children. Here is a short report from Celine.

"On Christmas morning I was very touched to open part of my gift from

my three adult children that included a donation to ILFA in memory of their Granny May. Due to Covid-19, my two boys Simon and Conor weren't willing to risk a family gathering and stayed in their homes in Ottawa, Ontario and Vernon, British Columbia. It was just my hubby, our daughter Abby and myself for Christmas.

"This time of year, is difficult for many and I'm no stranger to losing loved ones during this season. My Mam was on the lung transplant list in 2007 but succumbed to her illness in early 2008.

"My three kids were her only grandchildren and she adored them all. It was very nice to see the three of them remember their Granny in this way. Thanks to ILFA for all the work and time you dedicate to this worthwhile health cause. A gift of giving truly made a difference in my life. Rest in peace Mam and Dad." Celine.

Virtual Santa Dash

Thanks to Annette Grehan and Nicola Cassidy who took part in the virtual Santa Dash 5km run on Saturday 20th December in Dublin in aid of ILFA. The ladies were joined by their equally festive friends Birgit, Morwenna and Mary for a fun, socially distanced run that brought a smile to the faces of many of those strolling through the park!



Mary Henry, Morwenna Quinn, Annette Grehan, Nicola Cassidy and Birgit Kretschmann.

Christmas cards

Sincere thanks to everyone who supported the 2020 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!

Festive Donation

Thank you to everyone at Air Liquide Ireland for their kind and generous festive donation to ILFA. This was very much appreciated.

"Songs I like to Sing" by Mike Joe Fitzgerald

As a young person living in Lispolie, Co Kerry, while attending national school Mike Joe loved singing. An early ambition was to sing with and lead a band. Over the years, he continued singing and always in the back of his mind was his dream and lifetime ambition to make a CD. In 2020 Mike Joe decided it is 'Now or Never' and so he chose the year of Covid-19 to produce his CD. Thankfully, with the support and encouragement of his team, he achieved his dream. Delighted to have completed the recording of 15 of his favourite songs, Mike Joe now wants to use his music and CD to help two charities.

JP O'Sullivan, 'a rogue and gentleman', from Lispolie, is a special and lifetime friend of Mike Joe, who he says "never does what he is told". Mike Joe wants to share the proceeds of his CD to support his chosen charities; ILFA, due to their great work and support as a patient organisation for those living with Pulmonary Fibrosis. JP has shown great dedication to ILFA for the help and support they gave him and other patients and families with pulmonary fibrosis. Mike Joe has travelled JP's journey with him. Secondly for the Kerry Cancer Support Group for the great work they do in Kerry for cancer patients, and because Mike Joe is a Kerry man after all.

Congratulations to Mike Joe on achieving his ambition and warmest thanks to Mike Joe and JP O'Sullivan for fundraising for ILFA and supporting our work.



10,000 Steps a Day for January in aid of ILFA



Eva Ni Bhriain, left, who lives in Tipperary made history and became ILFA's first Facebook Fundraiser when she set up her fundraising campaign at the start of January 2021. Eva's initial fundraising target was €100 but this became a moving target of €500, then €800, then €1,000 as the donations came rolling in. Each night Eva posted a photo of her step count to show how she smashed her daily step goal.

Here's Eva's story.

"I set myself the challenge to walk 10,000 steps a day for the month of January for ILFA as I wanted to support a cause that means so much to my family. I lost both of my grandads (Grandad Joe and Grandad Aiden) to lung related illnesses, so I'm doing this in their memory. We were all in lockdown again for the month of January and this motivated me every day, while raising money for an amazing cause. The generosity and support I've received with my Facebook fundraiser was overwhelming. With COVID-19, donations are needed now more than ever." Congratulations and well done to Eva on this great challenge.

Paul and Abbie's Running Challenge for ILFA



Paul Goodman and his daughter Abbie decided to run 120km in February as a fundraising challenge in aid of ILFA. They set up a Facebook Fundraising page to collect donations and told us of their fundraising and fitness plans. We enjoyed following their progress online and were delighted when they successfully achieved their goals. Huge thanks and congratulations to Paul and Abbie. What a team!

Here is a report from Paul.

"This is me and Abbie who ran 120km for Abbie's grandad who passed away a year ago on Monday. Abbie wanted to do something in his memory, so it was 120km in a month, which we completed. We're all so proud of Abbie, who's only 13, to do something so challenging and complete it with ease. I'm sure her grandad Willie would be so proud of her. Over €700 was raised. Thanks lot."

Photo: Paul and Abbie Goodman

20,000 Steps a Day for ILFA

Jacinta Pollard set herself the mighty challenge of taking 20,000 Steps a Day in February to raise funds for ILFA Ireland in memory of her mother, Ann French. Jacinta contacted us and said "I'd like to do 20,000 steps a day in February for ILFA. I lost my mother on 1st September 2019 and had planned to do the mini marathon last year, but it was obviously

cancelled with everything that's going on at the moment. I know this is what my mam would want me to do." We were so impressed with Jacinta's exercise goal and delighted to say she smashed it. Sincere thanks and congratulations to Jacinta and everyone who supported her fundraising campaign to raise over €1,000 for ILFA.

Birthday Fundraising



Fr Brian McKay

We are delighted when Fr Brian McKay became ILFA's first Birthday Facebook Fundraiser. Fr Brian has been a great friend and supporter of ILFA since we held the first ecumenical service in 2012 to celebrate ILFA's 10th anniversary.

Here's what Fr Brian said on his personal fundraising page.

"Myself, Charles Mullen and Vanessa Wyse-Jackson are the chaplains to this amazing organisation which helps countless numbers who contract lung fibrosis in significant numbers every year. ILFA is a relatively recent organisation founded to give holistic support to sufferers and their loved ones. It is an organisation that is close to my heart and I'm fundraising ahead of my 64th birthday which fast approacheth! All monies go directly towards practical help for those afflicted."

Fr Brian raised over €1,500 for ILFA and we are hugely grateful to him and everyone who donated so generously.

Birthday Fundraising

Thank you to Nicki Teeling Barry who recently set up a Facebook Fundraiser for ILFA in memory of her Grandad Patrick Teeling. We are very grateful to Nicki for her kindness and to everyone who supported her birthday fundraising page.

2000 Steps Extra for ILFA!

Join ILFA for our Easter Monday 2000 Steps Extra virtual walk/run on Monday 5th April. We want patients, carers, family members, healthcare professionals, industry supporters to exercise and take at least an Extra 2000 Steps (approximately 1 mile) to raise awareness of pulmonary fibrosis and raise funds to support ILFA's work.

You can take part from anywhere - in your garden, indoors from your house and within 5km of your home while following public health guidance. The important goal is to step it out for health!

Please contact ILFA we will send you a special fundraising pack. Remember to take a photo and log your step count with

us! We'll have fun counting the total steps taken to see how far we reach!

Contact ILFA on 086 871 5264 or email info@ilfa.ie

An Egg-cellent Fundraiser



We were eggstatic to hear that Micheál Loughrey from Galway kindly donated the fantastic sum of €120 to ILFA in memory of his grandfather.

Micheál who is 8 years old, raised the money from selling eggs laid by the hens his family got during the lockdown in 2020. Micheál's mother Miarianne told us "We remember ILFA because of my dad, Michael Kennedy (RIP), who had

wonderful support from ILFA over many years."

We just love this story and want to send our warmest thanks and best wishes to Micheál, his family and of course the hens!

Micheál is pictured with one of his egg-cellent hens.

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.

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.

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 18-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**

On-line donations and fundraising

- 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 direct link to the online platform is available on www.ilfa.ie
- ILFA is set up for **Facebook Fundraising** making fundraising campaigns and secure donations available for ILFA's Facebook friends and followers:
<https://www.facebook.com/fund/ILFAIreland/>
- All donations made on-line go directly to the ILFA bank account.



Patient Support Groups

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

Cavan Monaghan Support Group

Please call Kevin on 085 243 6828 for more details.

Clare Pulmonary Support Group

Please call Michael on 087 637 4068 for more details.

Cork Support Group

Please call Anne on 087 985 4587 for more details.

Dublin Support Group

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

Kerry Support Group

Please call John on 087 280 9801 for more details.

Midland Support Group

Please call Val on 087 233 2653 for more details.

Mid West Support Group

Please call Noreen on 087 262 7976 for more details.

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

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

086 871 5264

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.

ILFA needs your help please!

Pulmonary Fibrosis Week will take place in September 2021 and aims to raise awareness locally, nationally and globally. ILFA is looking for patient volunteers to help raise awareness by sharing your story with the media. Please get in touch if you would be interested in highlighting the personal challenges that you face.

You can contact ILFA on 086 871 5264 or by emailing info@ilfa.ie

ILFA Survey 2021

Thank you to everyone who took the ILFA Survey to help us understand the impact of the third wave of the COVID19 pandemic on patients, carers, family members and healthcare professionals. The survey has closed, and we are currently analysing the results. We will keep you posted.

The winners of the All for One Vouchers whose names were drawn at random from the list of survey participants are (1) Finbar O'Connell who won a €100 voucher (2) Annette Grehan who won a €50 voucher.

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

Dates For Your Diary

- **ILFA's Virtual Exercise Class** for lung fibrosis patients takes place every Monday and Thursday 11am via Zoom. The classes are led by Gordon Cagney (Senior Respiratory Physiotherapist) at University Hospital Limerick.
- **ILFA's 2000 Steps Extra virtual walk/run** on Easter Monday 5th April. Take part within 5km of your home, donate if you wish, but please send us in your photos and steps counts for the day!
- **ILFA's World Café on Pulmonary Fibrosis Services in Ireland During Covid-19 and Beyond** will take place online on Saturday 17th April online.
- **Patient Information Days** will be held in August and November 2021. Keep an eye on the ILFA website and social media for announcements.
- **The VHI Women's Mini-Marathon 2021** will be a virtual event. Please consider fundraising for ILFA Ireland. Contact ILFA on 086 871 5264 or email info@ilf.ie for a fundraising pack. if you would like to fundraise for ILFA.

Keep in touch with ILFA

You can keep in touch with ILFA by phone on 086 871 5264 (general enquiries) or 086 057 0310 (fundraising enquiries) by email - info@ilfa.ie on the web - www.ilfa.ie on Facebook - www.facebook.com/ILFAIreland on Twitter - [@ilfaireland](https://twitter.com/ilfaireland)

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

