

A World Record for Laura and ILFA



On 5th September 2020, Laura Grehan, left, became the first female World Ultra Cycling Association record holder to cycle solo from the most westerly point to the most easterly point of Ireland. Laura took on this challenge to raise funds for ILFA in memory of her aunt, Denise Cassidy. There was great

excitement in the build up to Laura's record attempt as many ILFA members shared words of encouragement via our social media channels.

Family members put the Child of Prague out the night before the cycle to assist with weather on the day and he certainly obliged. On the day of the cycle record attempt, ILFA shared regular updates on Laura's progress as she departed

Kerry at 4.30am and sped through the country to arrive at her destination by late afternoon.

Many supporters followed Laura's progress using a mobile tracker app that showed Laura's location as well as her speed and the kilometres covered, and this added to the excitement. Laura arrived in Wicklow to be met by a surprise welcome party who were thrilled to be there and celebrate her phenomenal success.

Laura earned her World Ultra Cycling Association Record with style and flair and in doing so she raised more than €6,500 for ILFA.

Huge congratulations to Laura and her team on their World Record title. Thank you for raising such a wonderful amount for ILFA and lifting our spirits with your achievement.

Patient Information Day

The next Patient Information Day will take place online on Saturday 28th November from 11am until 1pm. The meeting will take place using the Zoom online platform. Our speakers will include Dr Michael Henry, Respiratory Consultant at Cork University Hospital, Carmel McInerney, Respiratory Nurse Specialist at Ennis Hospital, Debbie Gibbons, Respiratory Physiotherapist at St Francis Hospice, and Sandra Murphy, Dietician at the Mater Misericordiae University Hospital.

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.

Christmas Cards

ILFA's Irish produced Christmas cards are now on sale and available to order. This Christmas will be like no other and we hope you will consider buying ILFA cards to send some festive cheer to family and friends to wish them well. Now more than ever, is a good time to send a card and keep in touch. Each pack contains 10 cards with 2 cards each of 5 colourful festive designs. One pack of cards costs €6 and two packs cost €10. For a limited period, we will include a free pack of cards to those who order 4 packs of cards or more. **Cards can be ordered by calling 086 871 5264 or emailing info@ilfa.ie.** Please help us raise awareness of lung fibrosis this festive season.





A Message from the Chairman

Dear friends,

Welcome to our Winter Newsletter! The ILFA committee hopes you and your families have been staying safe in the current circumstances. It is hard to believe that we are already close to the end of the year, when 2020 has been so difficult for us all.

Despite the daily challenges posed by COVID-19, ILFA has a lot to be grateful for. I am thankful to The Community Foundation of Ireland, Bank of Ireland, Pobal and the Department of Rural and Community Development for generous funding awards that have helped support ILFA's critical work this year.

In April-May, ILFA conducted a research survey on the impact of Covid-19 and we had a great response with over 200 people sharing their experiences with us. The survey results have been incorporated into infographics and are distributed with this newsletter. Thanks to Danny Sheahan, lead researcher with Invisio Ltd. for his help with conducting the survey and analysing the results. Sincere thanks also to Boehringer Ingelheim, Roche Products Ireland and the European IPF & Related Diseases Federation (EU-IPFF) for supporting this valuable research.

Warmest thanks to our amazing fundraisers who used the lockdown months to train and fundraise virtually for ILFA. Their hard work and commitment have raised valuable funds for ILFA, and we have been inspired by their determination. I hope you will enjoy reading their stories in this newsletter.

I am grateful to the ILFA Committee for their willingness to volunteer their time and talents. I am especially grateful to Gemma O'Dowd for her hard work to support our members during the year. I would like to reassure you that the ILFA Team is committed to serving you as best we can. Please remember, if you need us, we are here to help.

**Take care and kind regards,
Eddie Cassidy**

World Café Workshop in 2021

ILFA is planning to host an online World Café-style workshop in March 2021 to establish the unmet care needs of our stakeholders with patients, carers, family members, healthcare professionals and industry representatives. The aim of the interactive meeting will be to discuss specific topics in small groups and share ideas on how best to address the needs and priorities of our stakeholders.

In 2020, ILFA conducted a research survey to understand the impact of COVID-19 on our members and we asked what were their priorities for patient care? Patients, carers and healthcare professionals working in respiratory medicine all selected the need for a dedicated **Clinical Care Programme for Interstitial Lung Disease (Lung Fibrosis)** as their number one priority.

Clinical Care Programmes are already established and operational for Cancer and other respiratory conditions like Cystic Fibrosis and COPD/Asthma. According to the Health Service Executive (HSE) a clinical care programme "brings clinical leadership to the heart of decision-making process with the ultimate aim of improving quality, access and value of healthcare in the country."

ILFA has requested a Clinical Care Programme for ILD but the HSE has refused this on several occasions and meaningful engagement has not happened. We believe this is unfair and our patients deserve equity of care with those diagnosed with other serious health conditions. There is a lack of awareness and understanding of ILD even within health circles and earlier this year ILFA and the Irish Thoracic Society had to lobby the HSE, Department of Health and Health Protection Surveillance Centre (HPSC) for ILD/ Lung Fibrosis to be recognised as an extremely medically vulnerable condition for the Cocooning Guidelines for COVID-19.

ILFA believes that the HSE and Department of Health should introduce a structured clinical care programme for ILD with dedicated funding and benchmarks of care to meet the clinical care needs of patients. This is even more important as there may be an increase in the incidence of ILD given that some patients may develop Lung Fibrosis as a consequence of contracting COVID-19.

If you would like to join the ILFA World Café online event in 2021, please contact ILFA by emailing info@ilfa.ie or calling 086 871 5264. We need patients, carers, healthcare professionals and policy makers to join us and contribute their experiences and ideas. The World Café event will take place online on a Saturday morning and will last approximately 3 hours. The event is likely to take place in March 2021 and the date will be confirmed soon.

COVID-19 Stability Funding awarded to ILFA from Pobal

The ILFA committee is sincerely grateful to Pobal and the Department of Rural and Community Development for COVID-19 Stability Funding that is so welcome and appreciated in a difficult and financially challenging year.

The COVID-19 pandemic has impacted on all our lives and presented us with many challenges; physically, mentally, emotionally, socially, and financially. The upheaval and disruption brought by the pandemic also had major implications for charities in 2020 as they have faced a daunting future with limited fundraising activities taking part and a significant decrease in income expected. Patient organisations, including ILFA, came under immense pressure and had to urgently adapt and consider how to continue to provide services and support to our members under substantial budgetary constraints.

In May, ILFA applied for COVID-19 Stability Funding that was announced by the government to support charities providing critical frontline services to patients. In September, the ILFA committee was thrilled to hear that our application was successful and ILFA received €47,031. This crucial government funding has given us breathing space and ensured that we can continue our work on behalf of lung fibrosis patients and achieve our plans for 2020, while alleviating some of the financial stress of the COVID-19 pandemic.

ILFA's Honorary Treasurer, Marie Sheridan said "In common with many charities, ILFA has had a challenging year in 2020 in terms of fundraising, while at the same time experiencing an increase in demand for our services. We have striven to be proactive in our response to the current situation.

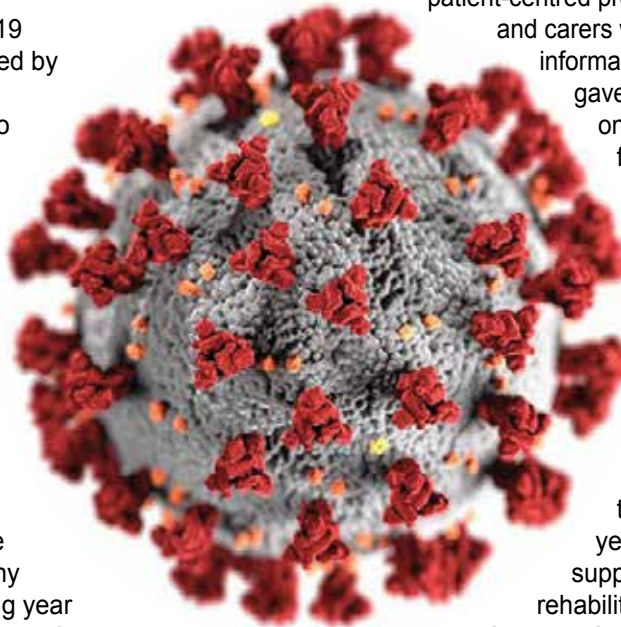
In September, we were delighted to hear that our application to the COVID-19 Stability Fund for Community and Voluntary, Charity and Social Enterprises was successful. This scheme is funded by The Department of Rural and Community Development, along with the Department of Health and the Department for Children, Disability, Equality and Integration.

To date, the scheme has announced four tranches of successful applications, allocating funding of €30,073,923 to 568 organisations. We were awarded €47,031, which will be used to ensure that we can continue to deliver our "critical front-line services to the most at need in our society".

ILFA Chairman, Eddie Cassidy said "ILFA is a voluntary organisation that relies on fundraising activities and charitable donations to conduct our advocacy work. As the impact of the pandemic unfolded, the ILFA committee resolved to reassure our members and carry on with our support activities and patient-centred projects, as well as providing patients and carers with trusted and accurate clinical information on Covid-19. The committee gave up their time to meet more frequently online to assess and manage the financial and human impact of COVID-19 on our charity.

The COVID-19 Stability Funding awarded to ILFA is a blessing and I would like to express my sincere appreciation to Pobal and the Department of Rural and Community Development. This funding has allowed ILFA to continue our work supporting our members. Some of the new activities ILFA undertook this year include the coordination of online support group meetings and pulmonary rehabilitation and yoga classes, and we also increased our printed, email and social media communications to reassure and update members on developments.

I would also like to thank my fellow committee members for their dedication and commitment to ILFA this year. I am especially grateful to Marie Sheridan (Honorary Treasurer), Gemma O'Dowd (Administrative Assistant) and Nicola Cassidy (Director) for their efforts in applying for and managing the financial and practical aspects of ILFA's grant funding."



Together but Apart

Usually in October we have the ILFA Ecumenical Service of Prayer and Reflection to look forward to and we come together as a community. Sadly, this year the ILFA Service could not take place due to the public health restrictions in place to safeguard everyone from the threat of COVID-19. Instead this year ILFA invited people to light a candle at 6pm on Saturday 24th October in support of patients and their families, and to remember loved ones with lung fibrosis who have died. The time of 6pm (18.00hr) was symbolic as ILFA was founded at this time of year 18 years ago.



Candles lighting in support of patients living with pulmonary fibrosis, to remember those who have passed away, and in memory of loved ones.

We were delighted that so many of the ILFA community near and far responded to this impromptu event from the comfort of their own homes. Candles were lit all over Ireland and overseas in support of lung fibrosis patients and in memory of those who are no longer with us.



ILFA's candle lit in memory of organ donors.

Many people posted appreciative comments and shared photos of lighting candles on our Facebook page. Wendy Nobel sent the following message "Thanks to you all at ILFA. We attended the ILFA Ecumenical Service last year which was on our parents' anniversary. It was so special and so beautiful to attend and so uplifting. Hopefully, next year we can be together to give thanks and pray for those we have lost, the fighters and all their families. Not forgetting the amazing people who look after them and all of us."

The candle lighting event proved to be a welcome, uniting, and comforting activity for many people. Thank you all for your support and for coming together, though apart.

ILFA is delighted to share contributions from our resident clergy members who take part in the annual ILFA Ecumenical Service of Prayer and Reflection with you here. The Reverend Canon Charles Mullen and the Reverend Brian McKay have contributed pieces below. The Reverend Vanessa Wyse Jackson who would have given the address at this year's service has shared a reflective story with us on page 5.

How sad we were when we realised that we couldn't hold our annual Service of Prayer and Remembrance this year. Without the comforts of being able to come together to pray and to remember in thankfulness and hope, we're all feeling diminished. Nevertheless, we believe that while God takes us through difficult waters, he never abandons us in the storm. Our loved ones still watch over us faithfully, and we must continue to unite ourselves with them in prayer and faith. Let's look forward together by staying safe and staying hopeful. The Psalmist sang, 'God is our hope and strength: a very present help in trouble.' May God strengthen you in these times.

**The Reverend Canon Charles Mullen
Dean's Vicar, St Patrick's Cathedral, Dublin**



The Reverend Brian McKay, Reverend Vanessa Wyse Jackson and Reverend Charles Mullen (2018).

Since the Covid-19 Pandemic first impacted us in a significant way early in the year I have noticed two details upon which I want to comment. Firstly, the emphasis on numbers. Every day we are being told how many have become infected, how many have died and what the ratio is between numbers of the population and rate of infection etc, etc. As a Christian I find myself wanting to reply that I am not interested in numbers, but in people. Every person is made in the image and likeness of God and is known by God by name. It is personal!

So these days are highlighting for me the infinite value of EVERY human life and the preciousness of this gift of life. This leads me easily into my second point. We are being constantly dragged into the future with concerns about what level of restriction will be imposed next week and will we be free for Christmas etc. Too much emphasis on the future or indeed on the past can literally rob us of the present and we are all called to live TODAY to the full. No point wasting time regretting yesterday or worrying about tomorrow. We are called to live in the now and, literally, the present is all we have.

So let us cherish ourselves and each other, and let us use what we have to live our lives to the full here and now. I will



be remembering all the ILFA departed and all our loved ones in my November Masses. Stay safe, stay well and may God bless you and yours.

The Reverend Fr Brian McKay
Prior of Terenure College, Dublin

Beauty in Brokenness

Our older daughter, Susanna, has started a 2-year Masters programme in stained glass window conservation in York. One of the very first things she and her fellow students were asked to do was to make a stained glass panel. This involved cutting up pieces of different coloured glass and then carefully joining them together using lead and a number of specialized tools.

The students were delighted at their achievements. Imagine their dismay and disappointment when, having produced these spectacular panels, they were then asked to break them up. The purpose, of course, was to learn how to restore and to mend the broken glass. The glass had to be broken in order for the necessary repairs to take place.

Most of us view breakage as a negative thing. We speak of broken promises, broken hopes and broken dreams. Negotiations break down. We can feel heartbroken. We break off a relationship. But breakages don't always have to be seen as entirely bad. There can be a great deal of beauty in brokenness. On holidays to Kerry over the years, I have collected bits and pieces of broken glass and pottery on the

beach. The shards of glass are beautiful, especially in a glass bowl in a place which gets the light. The irregular fragments of multicoloured pottery share another bowl in the living room.

There can be a great deal of beauty in brokenness. Put another way, being broken need not be any impediment to beauty. In Japan, there is a tradition of ceramic repair called kintsugi, which means, literally, 'to join with gold'. The broken pieces of an accidentally smashed pot are carefully picked up, reassembled and then glued together with lacquer inflected with a very luxuriant gold powder. But here's the thing: there should be no attempt made to disguise the damage. The craftsman doing the repairs is not attempting to make the pot look as though nothing has happened. The whole point of kintsugi is to render the fault-lines and the cracks beautiful and strong. The precious veins of gold that are plain for everyone to see are there to emphasise that breaks and cracks have a merit all of their own. How transformative it would be if we were to see our difficulties, not as a negative, but as a positive opportunity to help others also see the merit and beauty that still exist in the world, despite the challenges we all face.

Rather than denying or hiding the "breakages" in our lives, perhaps we ought to treasure them, secure in the knowledge that we are in the hands of the Master Craftsman who takes us as we are, in all of our brokenness and weakness, and who is at work continuously throughout our lives, fashioning each and every one of us into a new and beautiful creation.

The Reverend Vanessa Wyse Jackson

Patient Information Day

ILFA's first online Patient Information Day took place on Saturday 11th July. We were delighted to be able to host a virtual/digital/online meeting and over 120 people registered to join the event. Unfortunately, there were technical issues on the day, and we are grateful to everyone who persevered with us. Some of 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 very grateful.

Dr Eoin Judge, Respiratory Consultant at Connolly Hospital, Blanchardstown gave an overview of Idiopathic Pulmonary Fibrosis (IPF) and described the symptoms associated with the condition including shortness of breath, coughing, clubbing (rounding) of the fingertips, low oxygen concentrations and fatigue. IPF can be difficult to diagnose and it is important to take a detailed medical history including the duration of symptoms, medications, other diagnosed health conditions, and environmental and occupational exposures to dust, wood, and other pollutants. A high-resolution CT scan is the best way to examine the physiology of the lungs and provides useful evidence to help diagnose the condition. A multidisciplinary team (MDT), including a respiratory consultant, a radiologist and pathologist usually decides if a diagnosis of IPF is appropriate and will develop a treatment plan for patients.

Lynn Fox, Respiratory Nurse Specialist at Mater Misericordiae University Hospital described the impact of the COVID-19 pandemic on patient care from a hospital perspective. When the public health restrictions came into force, the healthcare system had to change quickly. Although out-patient clinics and tests were cancelled initially, a lot of planning and work went on behind the scenes. To adapt to the emerging situation, telemedicine (phone consultations) was set up to ensure patient appointments were possible, and this will continue going forward. Face to face hospital clinics are slowly restarting although capacity may be reduced for some time. You may be asked to complete a questionnaire before your clinic visit to determine if you have any symptoms of an infection and you may get a reminder phone call 24-48 hr before your attendance is scheduled. It is important for everyone to wear facemasks, and to practice hand hygiene and social distancing.

Danny Sheahan, researcher with Invisio Ltd. discussed the main results of ILFA's research survey on the impact of COVID-19 on our stakeholders. We had a great response with 111 patients, 59 caregivers and 49 healthcare professionals working in respiratory medicine participating. A further 24 people were interviewed by phone to get a more in-depth understanding of the challenges they were facing. Danny discussed the survey results for levels of anxiety, change in quality of sleep, exercise routines, and priorities for future work that were reported by the respondents. The results are presented in a 4-page



document that is on the ILFA website. We are grateful to Danny and his colleagues for conducting the high-quality research that has helped ILFA understand the challenges faced by our members.

Professor Brendan Kelly, Professor of Psychiatry at Trinity College Dublin described some ways to help ourselves through sustained periods of enhanced anxiety during the COVID-19 pandemic. It is easy to become overwhelmed by information and Prof Kelly suggested that we stay informed with reliable sources of information (check the news once or twice a day) but do not obsess about having up to date information. It is important to focus on the things you can control such as the wearing of face masks, social distancing etc., rather than focussing on apocalyptic scenarios. We should be aware of our feelings but not allow negative emotions to control our lives as they can take over. Prof Kelly encouraged everyone to find an activity that you enjoy doing that will help distract you from concerns on COVID-19, keep in touch with people, be kind and practice compassion for yourself and others.

Niamh Julian, Respiratory Physiotherapist at University Hospital Limerick discussed the importance of exercise for lung fibrosis patients. Niamh started by saying "Exercise is medicine – it's a wonder drug!" Exercise is possible for everyone no matter what their health status is. Research shows that exercise improves the elasticity of lungs, strengthens muscles, helps with the management of breathlessness, improves quality of life and mood, and in time will result in greater exercise tolerance. Niamh encouraged everyone to exercise every day, adopt a positive attitude, have a regular routine, set yourself exercise challenges and factor in relaxation time. Try and do more exercise each time to build up and build your exercise up again if you have a health setback. Remember that pottering around the house is not exercise – you need to engage in regular physical activity.

Niamh, together with her colleague **Paula Ryan** (Advanced Nurse Practitioner) at University Hospital Limerick, have delivered online pulmonary rehabilitation classes for ILFA over the summer months.

The “Let’s Talk” online education sessions started in May 2020 as support groups around the country could no longer meet for face to face meetings. To overcome the difficulties caused by the COVID-19 pandemic and help people keep in touch, ILFA purchased a ZOOM account that enables us 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 60-75 minutes and are lively, interactive, sociable, and light-hearted. The sessions that have taken place to date are summarised below. We are fortunate to have many 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 and all you have to do is contact ILFA to register in advance 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 Oxygen

In May 2020, Patricia Davis, Clinical Nurse Specialist - Respiratory Integrated Care, Nurse Advisor to National Medical Gases Co-Ordination Group for COVID-19 and Adrian from BOC Healthcare Ireland gave a joint presentation on oxygen for pulmonary fibrosis. Patricia and Adrian talked everyone through the indications, practicalities, technicalities, and safety issues of oxygen, and answered a variety of great questions from the participants.

Let’s Talk Pulmonary Function Tests

In August our guest speaker was Ciarán Heatley, Respiratory Physiologist at the Mater Misericordiae University Hospital in Dublin. Lots of questions were submitted in advance and Ciarán worked his way through the enquiries one by one. There was plenty of laughter and learning during the session. Ciarán explained how lung function testing is currently operating in his hospital during Covid-19 pandemic and encouraged everyone to turn up for appointments at their allotted time – not early and not late!

Let’s Talk Lung Transplantation

In September, we were joined by Zita Lawler, Transplant Coordinator at the Mater Misericordiae University Hospital. Zita talked everyone through the journey of lung transplantation including being referred to the National Lung Transplant Centre at the Mater Hospital, undergoing the required tests and assessments, being called for the operation and the recovery process post-transplant. Many lung transplant patients joined the meeting and shared their personal perspectives with the group. It was emotional hearing of the immense gratitude of the lung transplant recipients to their organ donors and families and hear their encouraging messages of hope and courage to fellow lung fibrosis patients.



Let’s Talk Breathlessness

In September, Debbie Gibbons, physiotherapist, St Francis Hospice, Dublin joined the meeting and gave a presentation on managing breathlessness for lung fibrosis patients. Debbie also discussed the benefits of exercise, pulmonary rehabilitation programmes and palliative care for the relief and management of breathlessness. Debbie answered questions that were submitted in advance and during her presentation.

Let’s Talk Exercise Goals

This event took place in late September and the focus of the meeting was the importance of exercise and having exercise goals. To get the conversation started 3 special and inspirational guests were invited to share their stories, exercise goals and challenges; Laura Grehan became the Female World Ultra Cycle Record Holder in 2020 when she completed her solo cycle from the most Westerly point to the most Easterly point; Sleah Head in Kerry to Wicklow Lighthouse.

Kevin McSkeane who has pulmonary fibrosis won a gold and silver medal at the Tang Soo Do National Championships in 2019. David Crosby has completed 3 marathons following his double lung transplant for IPF.

Let’s Talk Resilience

In October, Dr Jennifer Wilson O’Raghallaigh, Clinical Psychologist at Beaumont Hospital, Dublin was our special guest and she discussed resilience and coping strategies for lung fibrosis patients. The presentation and subsequent discussion with the group focussed on stress control, coping mechanisms, supports for resilience, and the benefits of hope and humour.

Let’s Talk Planning for the Future

This talk featured Rebecca Lloyd from the Irish Hospice Foundation. Rebecca encouraged everyone to have important conversations with loved ones about our wishes for the future, as critical decisions may need to be made as our health declines. Although these conversations can be difficult, we all need to be advocates for ourselves to ensure our wishes are fulfilled when the time comes. Rebecca also discussed the importance of making a will and the practicalities of enduring power of attorney and advanced care directives.

Kindly supported by funding from the Community Foundation of Ireland and Bank of Ireland.

The 7 Cs of Stress First Aid

Recently I had the pleasure of speaking to some ILFA members over Zoom about stress and resilience, and I talked about the Seven C's of Stress First Aid. This comes from work done with the U.S. Navy that was adapted to people working in the front lines of major disasters like fire-fighters and paramedics, and then to health care workers as a way of thinking about how to help people in crisis manage stress. We can use these exact same ideas to help the people around us AND to help ourselves.

The first two C's: **Check** and **Co-ordinate**, have to do with being aware that people can be under severe stress and we need to pay attention to them (check) and figure out resources to help them (co-ordinate). The best advice here is to watch for changes in behaviour like snapping at others, or withdrawing from others, that we wouldn't normally see from them. For example, my husband knows if I'm a bit snappy or irritable that's normal—that's me—but if I stop talking, or pull away from the family, he needs to reach out to me, because that is different than I normally am. We can be alert to changes in ourselves, too. If you notice you aren't making an effort to phone or zoom like you did last week, or two weeks ago, pay attention to that! Maybe you are feeling a bit more down than usual. Like my husband does with me, you need to co-ordinate some action to support yourself. Something like stretching, or watching a comedy, or calling a helpline.

The next C is for **Cover**—that means make sure you have a feeling of safety. That can be so hard at the moment because threat is all around us. Insisting on safe practices, having some time away from threats, or asking for help can give us a sense of safety. Even reassurance can do this in the short term.

The fourth C is for **Calm**. This means making some effort to relax the body and mind. We all know how hard it is to talk sense to someone who is in the middle of a panic. You have to work on calm first—sense comes later! This can mean relaxation exercises like tensing and relaxing your muscles, or a visualisation exercise where you go to a safe place in your mind. Sometimes, when breathing is affected by a medical condition, trying to take a deep breath to calm down can work against us. You might be better off working on dropping your shoulders or loosening the muscles of the back. Other relaxation exercises can be found for free at www.beaumont.ie/marc.

Next comes the C for **Connect**. Linking in with other people is the single most effective resilience tool and stress buster we have. As humans we are social animals and having

people around us, even if it is virtually, helps. Working on your social network is important, and interestingly, helping other people really works to help ourselves. Even though it can feel like we have nothing left in the tank, reaching out to help another person increases our sense of being connected to the world and of how valuable we are. I will add that if you have somebody in your life who is a bit of a laugh, keep that number on speed dial!

The C for **Competence** is next, and that refers to the importance of doing stuff, and doing it well. When we can look at achievements, even if they seem small, it reminds us that we can learn and contribute to the world. We have all seen the elation a child has when they have conquered a new task—as adults we aren't that different. Competence can take a hit

when we are in new circumstances that call for new skills we haven't mastered yet. Some people in the health service and other areas of work found it very stressful to be redeployed to areas they weren't familiar with. I know psychologists who were suddenly doing contract tracing, and feeling totally out of their depth. If you feel like you aren't equal to the task at hand, it is important to figure out what you need to learn to be able for the work. Ask yourself, what help do I need right now? And make sure you get it.

The last of the Seven C's is **Confidence**. This really refers to the idea of hope and self-esteem or self-belief. One way I see that emerging at the moment is people who say to me something like, 'I just can't bear the thought of another lockdown!' If you keep them talking, inevitably they admit that although it was a pain in the rear, they actually managed the first lockdown. They may have been lonely, stressed out, frightened, bored, or whatever, but they rose to the challenge and survived it. Sure, nobody wants to do that again, but it is good for us to know that we CAN. We can have confidence in our ability to manage it, and hope that we have a bit of fun on the other side.

Obviously, the Seven C's don't address every issue or heal every wound. But they give us a way to check in with ourselves and those around us, and to support ourselves in times of crisis. There is one C that is not addressed explicitly in the model, but it does come through implicitly. That is the 'C' of **Compassion**. - being kind to ourselves. Acknowledging that sometimes it is okay to not expect the best of ourselves. The most important message is - be kind to yourselves and those around you. We are all just muddling through.

Dr. Jennifer Wilson O'Raghallaigh
Principal Clinical Psychologist, Beaumont Hospital



Education

Cognitive Behavioural Therapy (CBT) Training Bursaries



In August, ILFA was delighted to offer educational bursaries to respiratory healthcare professionals working with lung fibrosis patients to study Cognitive Behavioural Therapy (CBT). There was a lot of interest in the online course and following their successful applications, educational bursaries were awarded to 8 healthcare professionals.

The successful candidates were

- Paula Ryan, Advanced Nurse Practitioner at University Hospital Limerick
- Julie Goss, Advanced Nurse Practitioner at Our Lady's Hospice & Care Services, Harold's Cross, Dublin
- Deirdre Garvin, Respiratory Nurse Specialist at Mayo University Hospital, Mayo
- Christina Tobin, Respiratory Physiotherapist at Mallow General Hospital, Cork
- Antoinette Doherty, Candidate Advanced Nurse Practitioner at Letterkenny Hospital, Donegal
- Catherine McGeoghegan, Respiratory Clinical Nurse Specialist at Beaumont Hospital, Dublin
- Sarah Cuneen, Senior Physiotherapist at Tallaght Hospital, Dublin
- Lynn Fox, Advanced Nurse Practitioner at Mater University Hospital, Dublin

The online course started recently and requires a minimum commitment of 15 hours e-learning and 10 hours participatory (Teams & skills practice) online sessions.

The course covers;

- * CBT theory
- * Assessing patients using the CBT model

* Cognitive and behavioural techniques

* Case study practice and presentations

After completing this course, the attendees should understand the basics of CBT and why CBT is useful for the treatment of depression and anxiety. It is envisaged that Healthcare professionals will be able to use basic CBT skills and techniques to help address psychological distress and identify patients under psychological distress.

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."

Sarah Cuneen, Senior Physiotherapist at Tallaght Hospital, Dublin recently tweeted her comments on the course and said "Really enjoying studying CBT and putting it into practice with respiratory patients. Great opportunity available to apply for the 2021 course. Thanks to ILFA."

We look forward to receiving more feedback from the healthcare professionals on completion of the course.

ILFA announced another round of educational bursaries for healthcare professionals working in respiratory medicine in November 2020 for a second CBT course commencing in January 2021. If there is demand, further bursaries may be announced. Healthcare professionals who would like to know more and apply for future educational opportunities, should **register with ILFA by calling 086 871 5264 or emailing info@ilfa.ie**

Advocacy

National Electronic Patient Summary



A national electronic patient summary provides a brief summary of a patient's key clinical information, for example health problems and diagnosis,

past medical treatment, prescribed medicines and known allergies. Such a record will help ensure the safe and effective treatment of a patient during an episode of unscheduled care, for example when attending an out-of-hours GP clinic and emergency care. A succinct summary of a patient's health status will help healthcare professionals to make more informed and timely clinical decisions at the point of patient care. The introduction of a national electronic patient summary is a crucial element of Ireland's national eHealth policy. The Health Information and Quality Authority (HIQA) developed draft recommendations for the implementation of a national electronic patient summary in Ireland. The recommendations took the governance structure, patient and public representation and how the patient's clinical information can be incorporated into the electronic patient summary into consideration. A public consultation was launched in August 2020 and ILFA contributed feedback on the draft recommendations.

The submissions received from stakeholders will be used to inform the work of HIQA and of the Special Advisory Group in the development of Draft Recommendations on the Implementation of a National Electronic Patient Summary in Ireland.

Opt for Life

ILFA Ambassador David Crosby was delighted when his Meath Hill GAA team included the 'Opt for Life' logo on their club jersey. Over 400 sports teams are now using the opt-for-life logo, spreading a valuable message of the importance of organ donation. David received a double lung transplant after a diagnosis of Idiopathic Pulmonary Fibrosis (IPF). David has been actively campaigning to raise awareness of IPF and the importance of organ donation since his life-saving transplant.



Raising Awareness at South Tipperary Hospital

Huge thanks to Nora McNamara, Registered Advanced Nurse Practitioner in Respiratory Medicine at South Tipperary Hospital for hosting an information and awareness stand on Idiopathic Pulmonary Fibrosis (IPF) during IPF Week in September.

ILFA Corresponds with the Minister for Health

In July, ILFA wrote to the Minister for Health, Mr Stephen Donnelly, T.D., to congratulate him on his new appointment and to request a meeting with him to discuss; Clinical Care Programme & National IPF Registry: There is no clinical care programme for pulmonary fibrosis; unlike the model of care that exists for cancer and other serious respiratory illnesses. The Irish Thoracic Society (ITS) and ILFA seek a dedicated clinical care programme for pulmonary fibrosis given the complex clinical needs and unpredictable course of this debilitating lung disease. In addition, resources are urgently needed to support the National IPF Registry facilitated by the ITS. Regarding the Opt-out organ donation consent model: ILFA welcomes the inclusion of the Human Tissue Bill in the programme for government and looks forward to its introduction. ILFA is also seeking (i) additional resources, infrastructure and staff to support organ donation and transplantation services (ii) an ongoing, well-resourced and inclusive public awareness campaign (iii) resources to provide optimal standards of care for patients undergoing pre-transplant assessment and post-transplant care.

Medical Publications from ILFA's Committee Members

Congratulations to ILFA committee members Dr Kate O'Reilly, respiratory consultant and Lynn Fox, Advanced Nurse Practitioner at the Mater Misericordiae University Hospital on the publication of a recent paper entitled "Time taken from primary care referral to a specialist centre diagnosis of idiopathic pulmonary fibrosis: an opportunity to improve patient outcomes?" The paper published in the European Respiratory Journal Open Research in 2020 describes the results from a collaborative study by two

specialist ILD clinics in two countries; University Hospital Southampton, Southampton, UK, and Mater Misericordiae University Hospital, Dublin, Ireland.

ILFA Director Nicola Cassidy, Pippa Powell at the European Lung Foundation and Professor Athol Wells at the Royal Brompton Hospital in London wrote an editorial entitled "Patients with idiopathic pulmonary fibrosis: Overcoming 'geographic isolation' that was published in the Respirology Journal in August 2020.

The Fergus Goodbody Memorial Lecture

The Irish Lung Fibrosis Association was set up in 2002 in memory of Fergus Goodbody by Nicky Goodbody, Marie Sheridan, the late Terence Moran and Professor Jim Egan. In 2010, ILFA held the first biannual Fergus Goodbody Memorial Lecture that was delivered by Professor Hal Collard, San Francisco, USA. In the intervening years, ILFA has invited many international leaders in Idiopathic Pulmonary Fibrosis (IPF) to deliver a state-of-the-art lecture to healthcare professionals in Ireland.

The 6th Fergus Goodbody Lecture on Pulmonary Fibrosis was a virtual event and took place on 23rd September in collaboration with the Royal College of Physicians of Ireland (RCPI). We were delighted that the lecture series was able to take place online as it is such an important event for ILFA and a highlight of our educational programme for healthcare professionals.

The event was chaired by Professor Jim Egan of the Mater Misericordiae University Hospital and our invited speakers were:

Dr Maria Molina Molina, IDIBELL Bellvitge Biomedical Research Institute, Area Inflammatory, Chronic and Degenerative Diseases in Spain who discussed Familial IPF.

Professor Simon Walsh, Consultant Radiologist, NIHR Clinician Scientist, National Heart and Lung Institute, Imperial College, London who gave a Radiological update on Interstitial Lung Disease.

Dr Nazia Chaudhuri, Consultant Respiratory Physician, Clinical Lead in ILD, Deputy Clinical Director Respiratory, Manchester University NHS Foundation Trust; Honorary Senior Lecturer, University of Manchester who discussed Management of Medication.



Dr Maria Molina Molina discussed the importance of taking a good family history to determine the health status of other family members when diagnosing a patient with suspected Interstitial Lung Disease (ILD)/Idiopathic Pulmonary Fibrosis (IPF). Familial IPF, where a close family member has also been diagnosed with IPF, occurs in approximately 20% of cases. IPF is typically diagnosed in adults aged over 60-years, although sometimes younger people are diagnosed, however

this is uncommon. With familial IPF, patients can be younger when they are diagnosed and often are aged less than 45 years old. There are different genetic mutations associated with IPF but not all family members with the defect develop the disease. Routine genetic testing in IPF is not currently recommended. Telomeres are part of our DNA, specifically they are the DNA-protein complexes that are found at the ends of chromosomes. Each time a cell divides, the telomeres shorten naturally as we age but an accelerated process that leads to a shorter telomere length than expected is associated with the development of some chronic health conditions including ILD. Current research analysing telomere length in IPF and familial IPF is ongoing as short telomeres may be associated with a poor prognosis.



Professor Simon Walsh

discussed the use of radiologic data from High Resolution CT scans to help diagnose patients with an Interstitial Lung Disease, The density, pattern (honeycombing, reticulation, ground glass opacification) and imaging biomarkers identified using visual (seen by the naked eye) and computer analysis are taken into account to distinguish

between conditions such as hypersensitivity pneumonitis, IPF and other ILDs. Rapid advances in computer technology in recent times has facilitated the identification of more subtle changes on CT imaging and this will help inform disease behaviour predictions.



Dr Nazia Chaudhuri gave an update on the anti-fibrotic medications used to treat IPF; Nintedanib and Perfinidone and described how they help slow the disease progress, their potential side-effects and how they should be managed and recent clinical trial data on their efficacy in treating other fibrotic lung conditions. Dr Chudhuri also discussed the importance of

oxygen, exercise and pulmonary rehabilitation for IPF patients, palliative care and quality of life issues.

The event was well attended and there was a great variety of questions raised and answered by the speakers. ILFA would like to thank the speakers for their excellent presentations and for their expertise and willingness to participate and RCPI for their help with hosting the lectures series. This was the third collaboration with RCPI for the Fergus Goodbody Memorial Lecture and we are very grateful to them for their support and expertise in hosting the event. ILFA would also like to extend our thanks to Roche Products Ireland for supporting this event.

Embracing technology to support people at home with pulmonary fibrosis from University Hospital Limerick (UHL)



By Gordon Cagney,
physiotherapist

The emergence of COVID-19 in Ireland has meant that everyone has had to adapt aspects of their daily lives especially in relation to how we communicate, and the same applies to healthcare delivery. Collectively we have had to become resourceful and innovative in our thinking to try to conduct business life as a 'new normal' and this means we have had to embrace technology and move online.

Keeping active and staying active is vitally important during these challenging times especially for lung fibrosis patients who in many cases are cocooning at home. With this in mind, a successful collaboration between ILFA and University Hospital Limerick (UHL) was established in April 2020 via the hard work of my colleagues Niamh Julian (Respiratory Physiotherapist), Paula Ryan (Advanced Nurse Practitioner), and the continued support of both Dr. Aidan O'Brien (Respiratory Consultant UHL) and Dr. Brian Casserly (Respiratory Consultant, UHL).

This collaboration led to the delivery of a national weekly online exercise class, organised by ILFA for patients around Ireland, via zoom and these classes have continued every week since May 11th 2020. Enthusiastic participants continue to attend from Limerick, Clare, Tipperary, Kerry, Cork, Mayo, Galway, Sligo, Donegal, Waterford, Wexford, Dublin and

Cavan; which continues to grow. Everyone is welcome to join from the comfort of their own home. The feedback so far from patients has been so positive; we thought we would share a quote with you.

"The fact that it's on a Monday is great and a good motivating start to the week. The care, courtesy and the understanding of all the physios who give the classes is just so beneficial for people like us who may at times struggle. Not forgetting ILFA's input in organising and coordinating each event and dealing with whatever hic-cups may present at these live events - well done Gemma!"

The UHL Respiratory Team are broadening treatment horizons to augment patient care. Working in this specialised area poses unique opportunities to develop new management approaches. As a respiratory physiotherapist I feel my role in this area is rewarding, diverse and fulfilling.

Promoting physical activity and exercise is integral in the management of lung fibrosis patients and one of our key roles as a physiotherapist is prescription of exercise suited to individual needs. Concentrating on what we can do rather than what we can't is a mantra I tell most of my patients and I think now it's even more apt. This is being accomplished by incorporating the use of modern technology in the forms of online video sessions into our range of treatment options. COVID-19 has further accelerated our efforts to use technology to improve the physiotherapy service at UHL. Delivering remote sessions has become a clear priority for the team during the COVID-19 crisis, in an effort to reduce our patient exposure to the hospital setting.

This weekly online exercise class is not a substitute for your local pulmonary rehab programme but more-over a stop gap to create a habit while you are on your local waiting list.

Feedback received from participants

- ▶ "Just finished today's class with Gordon and I wanted to let you know that I think that the classes are fantastic and bring a discipline and direction to my exercise regime which would otherwise would be absent. Long may they continue and keep up the good work."
- ▶ "I have benefited greatly both mentally and physically from the classes. I try to make sure I am available for every class. Please continue them. Gemma, I appreciate your work in organising the communications with us regarding the classes. Well done and thank you very much."
- ▶ "I'm delighted to have the opportunity to show my appreciation to Gemma and Nicola at ILFA for facilitating the zoom rehabilitation exercise class. I find it very beneficial for breathing and flexibility. Many thanks to the amazing physiotherapy team at UHL, Niamh and Gordon."
- ▶ "Huge thanks to ILFA for organizing the weekly Rehabilitation class with UHL and physiotherapists Niamh Julian and now Gordon Cagney. They certainly put us through some hard exercises but so good for our lung function which is the object of the exercise. Looking forward to many more Monday classes."
- ▶ "Mile Buíochas"



Laura becomes Ireland's First Female World Ultra Cycling Record Holder

386km non-stop in aid of the Irish Lung Fibrosis Association



Laura pictured at the finish line at Wicklow Head lighthouse with her crew members (from left): Martina Duignan, Don Samway, Marie Moran, Ian McNally and Aidan O'Neill.

On 5th September, 2020, Dubliner Laura Grehan became Ireland's first female World Ultra Cycling Association record holder by cycling solo from the most westerly point to the most easterly point of Ireland. In so doing, she raised more than €6,500 for the Irish Lung Fibrosis Association (ILFA).

Laura completed the 386km non-stop journey from Sleah Head in Kerry to Wicklow Head in 13 hours 27 minutes. Her only stops during the ride were a quick comfort break at about half-way and a frustrating wait behind a slow-moving herd of cattle in rural Cork!

To the fore of Laura's mind throughout the day was her aunt Denise Cassidy, who died of lung fibrosis in 2006. Denise was an avid sportswoman and a lover of adventure.

"I was delighted that this record attempt gave me an opportunity to raise awareness and funding for ILFA", says Laura. "I've seen first-hand the tremendous work that ILFA does. Thinking that my ride was making a difference for ILFA drove me on. Denise would have loved following my exploits!" Laura's cousin, Nicola Cassidy is one of the directors of ILFA and her uncle, Eddie Cassidy is ILFA Chairman.

Relatively new to cycling, Laura took up the sport in 2015 at the age of 36. She cycled more than 12,500km – much of it indoors during lockdown – in preparation for the record attempt.

The record-making adventure began in darkness at Sleah Head at 4:45am. Members of the public followed Laura via an online tracker as she cycled through Kerry, Cork, Tipperary, Kilkenny, Carlow and Wicklow. She was joined by a support crew, who drove the route and

provided assistance with navigation, mechanics and fuelling.

Clubmates of Laura from Clontarf Cycling Club, Naomh Barróg Cycling Club and Piranha Triathlon Club made up the skilled four-person crew. Aidan O'Neill was Crew Chief, ensuring that the whole logistics behind the attempt ran smoothly. Martina Duignan provided navigation assistance, Don Samway was driver, and Ian McNally coordinated Laura's food and drink handovers – all done while Laura was moving. The crew was joined by World Ultra Cycling Association official, Marie Moran, who verified the attempt.

Also sharing the cross-country adventure were Laura's cousins Frank and Seamus Grehan, who took photos and video and kept Laura's spirits high with their enthusiastic cheerleading along the route.

At just after 6pm, Laura and her crew arrived at their final destination: Wicklow Head lighthouse. They were so far ahead of schedule, it was a rush for friends, family and ILFA supporters to get to the finish line on time to greet them. The excited supporters were joined by somewhat bemused passersby to cheer Laura over the finish line, which was positioned at the top of a steep hill! ILFA banners and balloons added to the sense of celebration.

"The entire attempt, from start to finish, was an incredible experience", explains Laura. "Children cheering from the side of the road, cars tooting in support as we passed by, and the welcome from friends and family at the finish was very special."

Equally special was the support that Laura received from donors and sponsors, including Jones Engineering, Opinions, Windsor Motors, Clontarf Cycling Club and Naomh Barróg Cycling Club.

ILFA supporters also rolled out the red carpet. "I was contacted by John Patrick O'Sullivan of the ILFA Kerry support group", says Laura.



Gemma O'Dowd with Laura Grehan and her parents Annette and Tom



"He organised newspaper and radio interviews for me, ensuring that I was quite the celebrity by the time I arrived in Kerry! Getting ILFA into the media in this way was wonderful". Laura was interviewed subsequently by many other media outlets, including the Alison Curtis Show on Today FM and an ultracycling show in the USA.

Laura was also amazed by the generosity of strangers. The owners of An Portán Guesthouse in Dunquin, Co. Kerry contacted Laura and her crew to say they were refunding the cost of their stay the night before the ride, as they wanted the money to go to ILFA.

Jones Engineering employee Pat Maher (himself an experienced ultracyclist) reached out to offer roadside support from his home on the route in Castlecomer. Pat even had chamois cream on standby in case any saddle sores had set in!

In a funny coincidence, printer Ciaran Brady of Judita Press recognised a familiar face on the banners commissioned from him by ILFA to mark the start and finish of the record attempt. He and Laura had met on their bikes in north county Dublin a couple of years ago and struck up a long conversation in the saddle. Ciaran very generously provided the banners to ILFA free of charge.

"The constant stream of support and goodwill shown to my crew and me was tremendous", says Laura. "It really highlighted how respected ILFA is and how much people wanted to get behind such a good cause."

In total, the record ride has now raised over €6,500 for ILFA. "The money raised was worth every ounce of energy I burned!" concludes Laura.



Fundraising Round Up

The Virtual VHI Women's Mini-Marathon 2020



Rita O'Regan, Margaret McIver and Roesmary Wilson.

The first trio of ladies to get in touch with ILFA after completing their 10km challenge was **Rosemary Wilson, Rita O'Regan and Margaret McIver from Dublin**. These 3 fantastic ladies and close friends are among our most loyal fundraisers. The pals completed their virtual challenge on 9th October and this occasion marked the 15th mini-marathon for ILFA for Rosemary, while Rita and Margaret have taken part and fundraised for ILFA on 10 and 8 times respectively. Thank you ladies for your support - you're amazing!

Mary Greene completed her 10k challenge on Dursey Island in Cork while on a staycation. In doing so, Mary won a €50 prize for ILFA from the race organisers in recognition of the most original route for her 2020 Virtual Mini Marathon. Well done and thank you Mary!



Above: Annette Grehan after her mini marathon.
Right: Nicola Cassidy after her Virtual 10k for ILFA.



Annette Grehan and her niece Nicola Cassidy (ILFA Director) ran their virtual 10km in beautiful St Anne's Park in Dublin on the anniversary of their loved one, Denise Cassidy. It was a great day for a run and a lovely way to remember their much-loved sister and mother. The ladies were thrilled to finish their run with a final sprint to achieve their personal best times for 2020!

Roisin Breslin also took part in the Virtual Women's Mini Marathon in support of her father, Michael. Roisin completed her 10k challenge in Dublin and raised €386 for ILFA.

Rosaleen Squires completed her Virtual Mini-Marathon in support of family members living with lung fibrosis and raised €210 for ILFA.

This year we certainly missed the excitement and camaraderie of meeting for a group photo pre-race and refreshments post-race and spotting lots of ladies wearing ILFA T-Shirts while running, jogging and walking through the capital city. We are so grateful to the amazing ladies who signed up for the mini-marathon and raised funds for ILFA. Here is looking forward to safer times when the ladies of Ireland can once again participate together and take on the 10km challenge.

Art Card Fundraiser for ILFA – Matt Cullen



Matt Cullen



Art by Matt Cullen

Matt Cullen was very productive during 2020 and produced some fantastic artwork. Matt kindly decided to produce some stationery cards to raise funds for ILFA. The trio of images were of Usher's Lake in Swords, "The Tree" based loosely on a tree seen from Matt's hospital ward when he was in hospital last January, and a set of Spring Tulips. Huge thanks to Matt as always for his inspirational artwork and for raising valuable funds and awareness for ILFA.

The cards were very popular, and Matt shares the story of their success here.

"Thanks to all who purchased art cards to raise funds for ILFA. All art cards sold extremely fast, so I am truly delighted with the kind and generous response from all concerned. I only got a limited amount of art cards printed, so my apologies for not having enough for all those who may have been interested in purchasing the art cards. The cards were prints of paintings I completed since the first lockdown due to Covid-19 in March 2020.

The total amount raised was €1,436, which was far higher than expected. It is very difficult to fundraise in these extraordinary times, so at least this fundraiser was doable from home, and raised some much-needed funds for ILFA, who do wonderful work for all its members."

Report by Matt Cullen

patientMpower Virtual IPF Walk 2020

Sincere thanks to the team at patientMpower for their kind donation to ILFA to mark their fundraising walks across the globe for Idiopathic Pulmonary Fibrosis Awareness Week. What a great staff initiative to raise awareness and benefit patient organisations. Go raibh mile maith agaibh!

Here is a report from Megan Kerr and some photos of her energetic patientMpower colleagues:

At patientMpower we have been working in delivery of remote monitoring solutions for patients with Idiopathic Pulmonary Fibrosis (IPF) for five years and as September was IPF Awareness month, we wanted to show our support for the IPF community. On the 28th of September, the patientMpower team took part in a virtual walk across Ireland, the UK and the U.S. and donated to an incredible selection of IPF support groups.

Report by Meghan Kerr



Clockwise, from top left: Komal Chopra, Dublin; Christina Kenny, Dublin; Keith Fitzsimons & Buddy, Dublin; Amy Boulstridge, Martha & Ted King, Wexford; Rebecca Borton, Kildare; Steve Armstrong & Mariana, Dublin; Serina Fogarty, Kilkenny; Colin Edwards, Dublin; Kevin Doyle (centre, completing a Buddy-shaped track), Dublin.

Would you like to fundraise for ILFA?

It is likely that the fundraising events will remain virtual for the foreseeable future. The beauty of virtual sporting events is that you can take part at a place and a time that suits you and you can even spread the challenge over a few days. It is your chance to do it your way!

If you or your family, friends and colleagues would like to take part in virtual fundraising events, please contact ILFA for a fundraising pack.

Whatever they can do virtually for us to help raise funds and awareness of lung fibrosis, would be a huge help and we would be very grateful.

Santa Dash 2020



The annual Santa Dash 5k and 10k race will be a virtual event in 2020. If you would like to take part, dress up and get into the festive spirit, please register for the event at www.santadash.ie You will receive a Santa suit and a medal and the opportunity to dress up, get active and bring some socially distanced happiness to your area as you take part

in the event on Sunday December 13th at a location of your choice. **To fundraise for ILFA, please call us on 086 871 5264 or email info@ilfa.ie**

Kerry ILFA Friendship Golf Classic & Raffle



ILFA is indebted to the great organisational skills, drive, ambition and generosity of Gerry Redican and JP O'Sullivan from the Kerry Pulmonary Fibrosis Support Group. The two friends along with their team of family, friends and volunteers organised a fantastic raffle and golf classic in aid of ILFA and the Kerry Hospice. Gerry and JP also took to the airwaves in Kerry to share their personal stories and raise valuable awareness of lung fibrosis, lung transplantation, ILFA's work, and to promote their fundraising events.

Their hard work guaranteed that the fundraising events were meticulously well planned and all public health safety measures were in place to protect their team of volunteers, the golfers, and staff at the Beaufort Golf Club. No detail was left to chance and this ensured that the two events were a great success and raised valuable funds for two deserving charities. Full details on the events winners and a reflection on the day from Tom and Gerry are included below! Sincere thanks to Gerry and JP and the people of Kerry for the great support for ILFA. To date, over €15,800 has been raised for ILFA.

Kerry ILFA Friendship Raffle

Thank you to everyone who supported the Kerry ILFA Friendship Raffle in aid of ILFA. The raffle was superbly organised by Gerry Redican and JP O'Sullivan and had some amazing prizes ranging from a stay at a 5 Star Hotel, luxury hampers, vouchers, craft spirits and golfing prizes. The grand draw took place on 26th September via Facebook Live at the Marina Inn in Dingle and all public health guidelines were followed. The 10 lucky winners of the fabulous prizes are;

- 1st Prize - Bernard Redican, Co Roscommon
- 2nd prize - Mary Allen, Ballyduff, Kerry
- 3rd Prize - Mary O'Connor, Baile Ni She, Kerry
- 4th Prize - Amy Mee, Ballinasloe, Galway
- 5th Prize - JF Waldron, Mayo
- 6th Prize - Sean O'Brien, Casttebar, Mayo
- 7th Prize - Mary O'Brien, Lispole, Kerry
- 8th Prize - Martin Carly, Offaly
- 9th Prize - Timothy Kenny, Ballyheigue, Kerry
- 10th Prize - Ciara Healy, Tralee, Kerry

Kerry ILFA Friendship Golf Classic & Raffle

On Saturday 3rd October, the Kerry ILFA Friendship Golf Classic and competition took place at the beautiful Beaufort Golf Club in Kerry in good weather. 20 teams of 4 players took part and set the scene of good competitive scoring.

Leading scorers were;

Ladies: (1) Trish Rowland (2) Brid Long (3) Siobhain Murphy.
Gents: (1) Shane Griffin (2) James O Dowd (3) JJ Mc Elligott.
The organisers of the golf classic Gerry Redican and JP O'Sullivan would like to send "A big thanks to the management and staff of the course for the warm welcome and good course, and food on the day."

Reflections on the ILFA Golf Classic

On October the 3rd 2020, I witnessed a gathering of about 80 golfers at my club which is nestled at the foot of the McGillicuddy Reeks approximately 10 kilometres from Killarney, on what was a bright sunny morning.

Tracie and Gerry arrived at 8am, quickly followed by John (JP) and hot on his heels were the first of the day's competitors.

Where necessary, fees were exchanged and a goody-bag with golf card, snack items, and ILFA's Christmas cards along with a tome on how to cope with the present pandemic written by Professor Brendan Kelly.

Players were duly dispatched to the first tee to embark on the day's competition, the mood was friendly, the camaraderie was evident as this was a meeting of friends during a difficult time. A few rogue rain showers dotted the day but failed to dampen the good atmosphere.

The players set out hopeful of a good score as the rewards for such were on display and everyone remarked as to the generous prizes for the lucky winners (electric golf trolleys, a weekend away for two, one hundred-euro vouchers as lady and gent prizes.

I over-heard JP tell Gerry of texts and good wishes from friends and colleagues near and far, and reminders not to get



caught up in the moment and maintain good etiquette in these fraught times.

Four of our teams had to reluctantly withdraw their participation earlier in week due to the shifting sands of Covid-19, as to travel would be a risk.

A team which had won the day out to the competition in the recent raffle contained two notable players - the winning lady on 36 points, Trish Rowland, and our own Val Kennedy. The gentlemen had a very worthy winner in Shane Griffin with 41 points. Photographers came and went picking off unsuspecting diners to stand in. The food and hospitality provided by Helen and staff was exemplary and a huge thanks to them for making the day extra special.

At approximately seven pm, the last of the players having their appetites sated, embarked for home. JP and Gerry also packed up as this was the last hurrah of two events that were in the works for the last two months; there was the Raffle which with the help of our colleagues in their respective ILFA groups, our friends and families spread the word of what this organisation is capable of achieving.

I subsequently heard that JP and Gerry arrived home fatigued but satisfied of a job well done, a substantial amount of money was raised thanks to the generosity of people for two very worthy causes.

Signed, Tom the Cat, also known as Gerry (Redican)!



ILFA TEA PARTY

Over the summer, ILFA asked you to host a Tea Party for family and fiends to help raise awareness of lung fibrosis and fundraise for ILFA. We also provided cake-stands for people to decorate with a €50 voucher awarded for the best one. The public health guidelines introduced to manage the COVID-19 pandemic meant it was difficult to socialise as normal. ILFA is very grateful to everyone who supported this initiative, and we hope we will be able to hold a similar event again in safer times. Here are some of the stories and photos submitted from around the country.



Mother and daughter duo Martina and Louise Osborne sent us in photos of their tea party for ILFA. Martina was busy baking delicious cakes for family and friends in Carlow and they looked delicious!!! (see photo below). Meanwhile Louise enjoyed her well-earned tea party treats after a sea swim in Skerries, Co Dublin.



Breda Coughlan and family held their ILFA Afternoon Tea Party and celebrated with an amazing feast of delicious. Treats.



Another branch of the Osborne family held their tea party in Fethard in memory of Ger's Godmother, Denise Cassidy. Thanks to Ger, Selena and their children for their support.



Mary O'Sullivan in Tipperary sent in photos of her beautifully decorated cake stand that she used for her Tea party in August. Mary decorated her cake stand with decoupage. Mary and her family raised the fantastic sum of €560. Mary said "We supported the ILFA Tea Party 2020 Fundraiser with family and

Eileen O'Dwyer from Thurles sent us a photo of her favourite cup and saucer which are very treasured possessions from her brother whom she lost to Idiopathic Pulmonary Fibrosis (IPF) in 2008. What a special and beautiful memory to have of a dear brother.



friends at the beautiful riverside picnic area in the lovely village of Loughmore, home to the award winning Cottage Tearooms, in memory of my mother Mary Purcell, brother Seamus, sister Carmel Morrissey and cousin Margaret Healy Nolan all of whom the family sadly lost to pulmonary disease."



James Cassidy (aged 6 years old) decorated his ILFA Tea party cake stand with crayons and did a great job. His first family tea-party took place at Donabate beach and a second tea-party was a Zoom call with his grandparents in Wales. Well done James!



Annette Grehan organised a socially distanced swimming-themed Tea Party for her pals in the Irish Cement Family Swimming Circle. Her cake stand was a work of art and featured a swimming pool complete with fast, slow and family lanes as well as swimmers. The group even donned their hats and goggles for a quick photo! Her niece, Nicola Cassidy had a Tea Party for two during a sunny staycation in beautiful Mayo in August.

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

Christmas Message from the ILFA Committee

The ILFA committee would like to extend our warmest wishes to our members for a safe and happy Christmas and a safe and healthy new year. We are indebted to everyone who fundraised for ILFA, volunteered, helped raise awareness of lung fibrosis, and supported our work in the most difficult of years. We send our deep appreciation to the healthcare and frontline service staff throughout the country who have helped keep us safe and cared for in 2020. Stay strong everyone. "Happy Christmas!"



Dates For Your Diary

- **The ILFA Online Patient Information Day** will take place on Saturday November 28th from 11am to 1pm. You can join the meeting from the comfort of your own home. When you join the meeting, you will not be seen or heard but you can watch the presentations live and can submit questions. You need to register in advance by calling Gemma on 086 871 5264 to register.
- **Christmas jumper support group** online meeting will take place on Friday 11th December at 4pm. Why not put on your festive Christmas jumper (the louder the better!), find a Christmas hat, organise a cuppa or a tippie and some mince pies!
- **Pulmonary Rehab online classes** take place every Monday at 11am from the comfort of your own home. These classes are expertly led by Gordon Cagney (Respiratory Physiotherapist) at Limerick University Hospital.
- **Yoga classes and support group meetings** take place online. Dates and times are announced on the ILFA website (www.ilfa.ie) and on the Facebook page.
- **Virtual sporting and fundraising events** are taking place as traditional race meetings with large crowds of people are not possible this year. If you are planning on taking part in a virtual walk, run or jog in 2020/2021, please consider raising funds for ILFA.
- **Santa Dash virtual 5k or 10k race** will take place on Saturday 11th December. See www.santadash.ie for more details.

Keep in touch with ILFA

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

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



Email Correspondence

If you are registered with ILFA and have an email address, we would be grateful if you would send it to ILFA (email info@ilfa.ie) so we can update our records. If you are happy to be contacted via your email address, ILFA can communicate with you more easily if we have upcoming events or important news to share. Rest assured your contact details are stored securely and not shared with other parties as required under GDPR.