

ILFA Newsletter



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

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Irish Lung Fibrosis Association
www.ilfa.ie

#HoldFirm

A message from the ILFA Committee

Dear friends, the ILFA committee sends you our best wishes and we hope that you are managing okay during these unusual and challenging times. Reflecting on recent months, it seems to have been very much a time of contrasts and things that we may have thought were impossible (such as cocooning) became possible (entering a new phase of restrictions). Since the emergence of the coronavirus pandemic, we have all had to adapt to a 'new normal' way of life and this has been both difficult and even rewarding at times. For some, the slower pace of life has allowed us to live in the moment, take delight in the little things that makes us smile, and appreciate what we have. For those cocooning and especially those who have been ill or feeling stressed or anxious, the last few months may have seemed endless and even overwhelming. We have lived day to day and watched the time pass slowly, and yet in some respects, it also feels like the duration of the national lockdown measures have passed relatively quickly, especially now that we are holding firm and embarking on the Government's Roadmap to an economic and societal recovery.

Over the last few months, the ILFA committee has remained active with our advocacy work on your behalf. We embraced digital technology and met online every 2 weeks to keep up to date with the evolving situation so that we could react to key developments, introduce additional supports for patients and caregivers, and continue to campaign on behalf of our members. We hope we have been able to meet your needs and communicate effectively with you through our newsletter, website, and social media channels. Please do not hesitate to contact us if you have any concerns.

We are delighted to announce that our first online Patient Information Day will take place on 11th July and we hope you will join us to learn more about lung fibrosis. Also, keep an eye out for our free online pulmonary rehab exercise classes, yoga classes and support group meetings. Details are available on www.ilfa.ie

The Covid-19 pandemic has hit charities hard as most fundraising activities had to be cancelled. The ILFA committee were apprehensive about the financial outlook for 2020 but committed to carrying on with our work. We were absolutely thrilled to receive very welcome funding from the Community Foundation for Ireland and Bank of Ireland for projects that are Covid-related. This money allowed us to reach out to our members and support their emotional wellbeing. We were also honoured to receive funding from the sales of eco-friendly face masks from RashR in Cork and were delighted with the response to our first virtual fundraiser - the Easter Monday 2000 Steps for ILFA walk/run. We hope you will be able to join



Some of the members of the ILFA committee

us for the upcoming virtual **ILFA Tea Party** fundraiser from the comfort of your own home or garden in the coming weeks. More details are on page 16.

We hope you will enjoy reading more about our activities and advocacy work in this newsletter as well as articles on vaccines, resilience and planning for the future. We encourage you to stay strong, hold firm and to contact ILFA if we can help you in any way.

Finally, we would like to acknowledge the great work of all healthcare professionals, essential service workers, public servants, government officials and volunteers who have cared for us and helped us stay well during the national response to Covid-19. Take care everyone.

The ILFA Committee

Patient Information Day

The next Patient Information Day will take place online on **Saturday 11th July from 11am until 12.30pm**. We hope you can join us to learn more about pulmonary fibrosis from experts in the field. Our speakers will include Dr Eoin Judge, Respiratory Consultant at Connolly Hospital, Blanchardstown; Lynn Fox, Respiratory Nurse Specialist at Mater Misericordiae University Hospital, Niamh Julian, Respiratory Physiotherapist at Limerick University Hospital, Professor Brendan Kelly, Professor of Psychiatry at Trinity College Dublin and Danny Sheahan, researcher with Invisio Ltd. Please call 086 871 5264 or email info@ilfa.ie to register for this free event.



Adapting to the 'new normal'

with **Maria Love**, Senior Social Worker Practitioner, Mater Misericordiae University Hospital

It is an understatement to say that life as we knew it has changed enormously over the last months. Normal daily routines, social interactions, hobbies and ways of living taken for granted, changed overnight and continue to change. The future and impact of Coronavirus or Covid is a destination unknown – we are truly in uncharted waters. We are all affected differently, but everyone has their own worries and struggles, whether seen, noticed or spoken about. Media bombards us with messages of *'being in this together, while staying apart'* – it is common to feel isolated and cut off, however interacting with others and building social connections has never been so crucial. Covid has invited us to consider new ways of being, interacting with each other, living our lives; but it is your choice how you respond and adapt.

Resilience is a word we hear a lot about these days and simply put it means having the ability to deal with and grow from difficult situations. Emotional resilience is an 'inner strength' to be able to deal with the ups and downs that life throws at us and, like a muscle, is it something that needs opportunity, time and effort to grow and flourish. It doesn't

mean accepting the problem, being constantly positive or never having any problems – it means being able to acknowledge a difficulty, look to our inner resources, coping skills or external supports to address and deal with that difficulty and then being able to learn from how you dealt with it, whatever the outcome. It involves being flexible, creative and adaptable in how you think and react to a problem; being aware of how the problem is making you feel, but recognizing the feeling may not last forever and you have choices about how you respond. A lot of different factors influence how we respond emotionally, and the good news is that there are many ways to help ourselves. There is much reputable advice and resources available via various media platforms and having a good routine, eating healthily, a regular sleep pattern and exercise are key components of looking after our physical and mental health. Maintaining relationships with family and friends – in whatever way you can – is vitally important, enjoying nature and maintaining or growing your interests/hobbies is also beneficial. But no matter what you do, you may have some days or times when you feel rotten which simply means you're a human responding to extraordinary times. It is very normal to feel anxious or overwhelmed as Covid is a threat however there are ways to manage these feelings.

In his recently published book **Coping with Coronavirus (2020)**, Professor Brendan Kelly looks at the anxiety resulting from Covid which can range from mild to a profound questioning of one's life and future. His book, amongst other

resources, outlines techniques to “teach ourselves how to keep our anxiety proportionate to the risk, how to live with a certain amount of worry, and how to navigate the uncertainty that coronavirus has brought to our broader lives”. Many of us have a toolkit in our sheds, we equally have a ‘coping skills or psychological toolkit’ with different tools and techniques we can use to help ourselves - I encourage everyone to find what works for them.

“The greatest glory in living lies not in never falling, but in rising every time we fall.”

Nelson Mandela

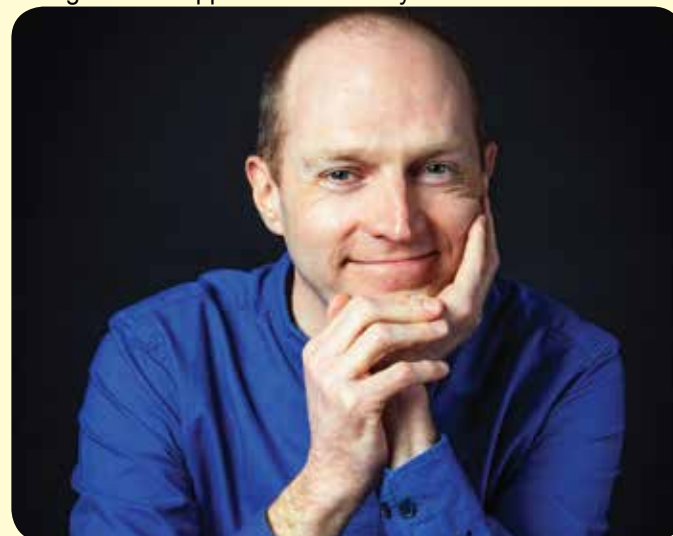
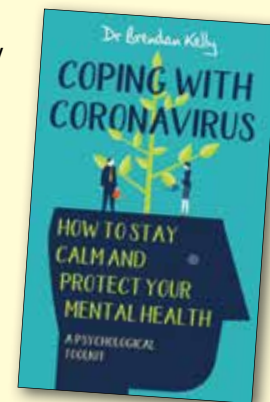
What is in your toolkit? What do you do already do to help yourself when you are having a bad day? And are there any other tools or techniques that you can add to your toolkit to draw on when things are tough? The building blocks of emotional resilience include having a mixture of physical, psychological and social tools in your arsenal which gives you more options to use depending on the situation – i.e. you are not putting all of your eggs in one basket. Examples of ‘tools’ are connecting with other people; exercise; engaging in a hobby; connecting with your breath or meditating; being self-compassionate; connecting with nature; connecting with yourself; problem-shooting to search for solutions; seeking professional help if you need it...the list is endless and unique to everyone. It’s important to avoid negative habits like excessive use of alcohol or drugs, over-eating, social isolation or other destructive behaviors. While it’s important to recognize what tools you have to help you cope, it is equally essential to build these activities in your daily life. Incorporating these “habits of happiness” as Dr Kelly calls them, gives you a good foundation on which you can better deal with stress when exceptional things happen. It is important to find your own pace and if it’s a bad day, don’t ‘beat yourself up’, be compassionate towards yourself as you would to an upset child and remember every day offers an opportunity to start again - “this too, shall pass” (Buddhist saying).

To conclude, while Covid has turned our lives upside down, is it important to nurture our own physical and emotional wellbeing – this is your choice and one you can make despite, but within the limits of the current public health advice. Life has changed for everyone, no-one can predict the future and it’s important to focus on our wellbeing in the present. If you are worried about your mood or that of a loved one, seek advice from your GP. Sometimes a new perspective can be helpful to see things differently and professional help may be useful. There is increasing awareness of how this pandemic may negatively impact our mental health – it’s important to address both our mental and physical health needs. Resilience theory reminds us growth can come from adversity, there are ways to help ourselves, and, despite the challenges and pain, perhaps for some there will be positives to come out of this unprecedented situation. Maybe this time is an opportunity to slow down, look at what matters most to us and to appreciate and reconnect with interests and people in a different, but meaningful way.

Investing in mental health and wellbeing

In April, ILFA was thrilled and honoured to receive funding from The Community Foundation for Ireland and Bank of Ireland as part of their charitable Respiratory Covid-19 Funding allocation. This welcome and much appreciated funding must be used for projects that focus on Covid-19 related activities.

The ILFA committee decided to invest a portion of the funding into an initiative that focuses on supporting and optimising the emotional health and wellbeing of our members during the pandemic. Professor Brendan Kelly, Professor of Psychiatry at Trinity College Dublin had written an excellent book entitled ‘Coping With Coronavirus: How to Stay Calm and Protect Your Mental Health’ that was available to purchase as an electronic download. We contacted Professor Kelly to request permission to order printed copies of the book and post them to our members and are grateful to him for his willingness to support our advocacy work.



Professor Brendan Kelly (Pic: Ruth Medjber)

We believe this publication offers valuable practical advice and comfort and is a key mental health/wellness support for the public and especially for lung fibrosis patients who are cocooning. The book will also benefit carers, family members and healthcare professionals.

We have received many appreciative comments from patients and healthcare workers on receipt of Professor Kelly’s book and here is a sample of the messages received.

- “What a brilliant resource - not only in times of coronavirus but such practical information for day to day living with and/or without Pulmonary Fibrosis.”
- “Many thanks for my copy and for all the hard work you are all doing in the midst of this pandemic.”
- “A great resource, thank you.”
- “Wonderful book.”
- “A very useful tool. Thank you.”



**Professor Bernard P. Mahon,
Immunology & Cell Biology
Laboratory, Maynooth University
Biology Dept., Maynooth University,
Co. Kildare.**

When things work well, we tend to forget or ignore them. Over the last 140 years we have developed vaccines against most of the major killer diseases that literally plagued previous generations. Measles, Whooping cough, Polio, Smallpox and many other diseases are now preventable or even eradicated, to the point that some in the developed world have the luxury to doubt their necessity or consider vaccination a lifestyle choice. Some countries even dropped infectious disease research from their national priorities. However, patients with compromised immunity or underlying respiratory diseases have long known the threat of infection, even if it has taken the recent Covid19 pandemic to bring that threat into focus for the wider community.

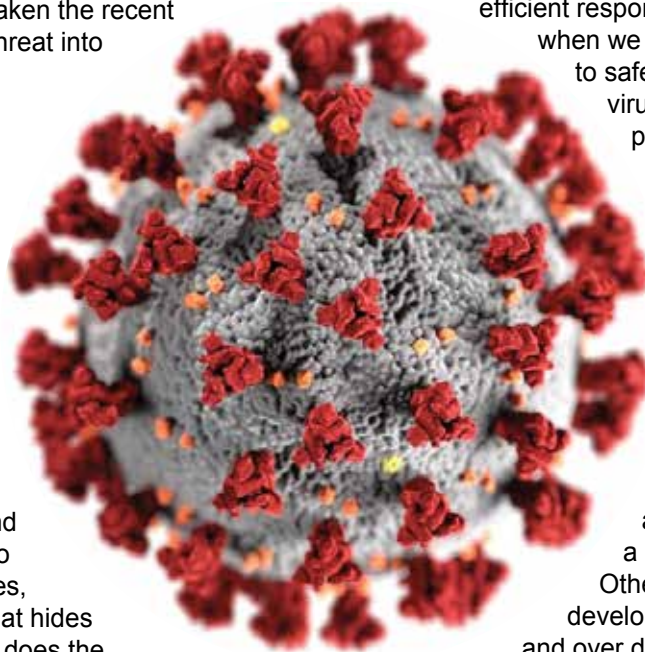
In the midst of the human tragedies of this pandemic there is hopeful news. For most of the population the immune response can halt the virus multiplying, eliminate it and lead to a full recovery. It seems that response is based on two types of white blood cell - the B cell and the T cell. The T cell has the ability to peer inside other cells of the body and kill an infected cell. This is important to stop virus multiplication, to send chemical messages (cytokines) to mobilise the body's other defences, and finally to root out any virus that hides or persists. In contrast, the B cell does the heavy lifting of protection by producing a tailor-made protein called an antibody. Each antibody has two parts. The first is almost infinitely variable; so we can make an antibody against almost any chemical shape we

encounter, it is this part that binds to the virus. Evolution has created a beautiful mechanism that continually improves the binding ability of antibodies during an infection- our bodies learn to do better and better. The other part of the antibody activates other chemical and cell defences of the body to destroy virus at the surface of the airways, in the blood, or in the gut. It is antibody that mops up and destroys the virus. Once we have recovered, virus-specific B and T cells are retained as memory cells so that if we ever encounter the virus again we respond quickly and with a pre-trained, highly efficient response. We exploit these processes when we give a vaccine, exposing the body to safe versions or components of the virus or other microbe so that we are primed and ready when needed.

Unfortunately, as we get older, develop other health conditions, or lose that constant battle with our weight, our immune memory can fade, and our other defences become less productive.

So why don't we have a vaccine now? Some pathogens, like the malaria parasite, can change their coats and become an ever-changing target, making a vaccine very tricky to design.

Others, like the TB bacterium, have developed elaborate counter measures and over decades fight a quiet battle against our defences. Most insidiously, HIV attacks the T cell that normally coordinates the immune response. If untreated, HIV dismantles the T cell response over time and causes the B cell antibody response to become weak.



Vaccines, Covid-19 and hopes for the future

Fortunately most coronaviruses, including SARS-CoV2 the virus that causes Covid19, adopt a more simple strategy - it is a "hit and run" virus, it survives by infecting easily, multiplying to large numbers in respiratory secretions, and quickly moving on to its next host through coughing of droplets or by mouth-to-hand actions. A vaccine should be straightforward, but until we get a vaccine, cocooning, physical distancing and good hand hygiene will remain important.

A Covid19 vaccine will be possible. We are probably all already immune to some other coronaviruses that are close relatives of SARS-CoV2, and laboratory experiments show that we can use part of the virus coat-the spike or S-protein to protect animals against an infectious challenge - so we know theoretically we can be protected. However, those experiments and earlier work on the related SARS virus show that we need to be careful, as antibodies against some parts of the S-protein do not protect; careful vaccine design needs to be followed.

This is an important point, in the 1930s there was huge pressure on scientists for miracle serum or vaccines against polioviruses. Ill conceived trials and poorly designed vaccines back then set back the field many years until the careful work of Jonas Salk and Albert Sabin in the 1950s. This is why most scientists are cautious about predicting when a Covid19 vaccine will be ready. The good news is that modern medical science is a global and collaborative enterprise, we share our findings, and use them to accelerate the pace of discovery. Small scale, phase 1 safety trials of candidate Covid19 vaccines have been completed and already show promise. The lead candidates seem to be safe, and a number are moving to phase 2 trials, but for all their ingenuity, it will be the power of the body's T cells, B cells and antibody that will determine which will be the best to use.

Digital Thermometer Draw

Congratulations to the 30 lucky ILFA members who won state of the art digital thermometers that were kindly donated to ILFA by our friends at patientMpower. We are most grateful to Eamonn Costello, Colin Edwards and all the team at patientMpower for such a generous and thoughtful donation to ILFA for our members. We advertised the draw on the website, Facebook and Twitter and also through the Support Groups network and had lots of entries. 30 names were selected at random to receive a digital thermometer. The winners were extremely grateful, and some got in touch to offer their thanks and messages of appreciation to patientMpower and ILFA.



John Carroll (pictured above) said "A big thank you to ILFA and patientMpower for my prize of a Bluetooth Digital Thermometer that arrived today. Many thanks and stay safe Everyone!"

Margaret Nicholl added "My thermometer arrived, Thank you to all involved. A massive thank you to you all for all your hard work. We'd be lost without your updates and positivity. Stay safe all of you."

Declan Mescall said "Thank you very much indeed ILFA and patientMpower "

Eileen O'Dwyer sent word to say "Thank you ILFA and patientMpower. Delighted with my prize and all your helpful information."

Pauline McGuigan wrote in to say "Thanks very much to ILFA and patientMpower for the thermometer which arrived yesterday for my husband Fergal. We are delighted and grateful for all the friendship and support given by all fellow members. Hope you're all keeping well"

Lynne Lefondre said "A big 'Thank you' to Eamonn and everyone for my thermometer. I am delighted with it. Also to all at ILFA, Take care everyone xxx"

Kevin Pigott said "Thanks a million to everyone in ILFA and patientMpower...its very much appreciated."

Michael Collins said "Thanks for the digital thermometer ILFA it's very much appreciated"

Embracing Digital Technology

The emergence of COVID-19 in Ireland meant that everyone has had to adapt aspects of their daily lives especially in relation to how we communicate. Collectively we have had to be resourceful and innovative in our thinking to try to conduct business and life as a 'new normal' and this meant we had to embrace technology and move online. Here are some of the activities that commenced in March 2020. Huge thanks to everyone who has contributed to these events.

ILFA Committee Meetings

The ILFA committee usually holds face to face meetings in Dublin every month but in response to government advice and social distancing requirements, ILFA had to explore the feasibility of digital video meetings so we could respond to urgent Covid-19 related matters. We nervously but quickly embraced the technology and its benefits. Over the last few months, we have held online committee meetings every two weeks as our workload has increased so much. We decided that our priority was to reassure our members that we are here for them and set to continue our committee and advocacy work. Thankfully, virtual meetings have been hugely successful for us as a committee and will continue for the future.

Support group meetings and online education sessions



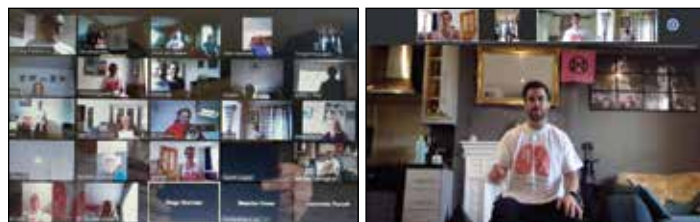
To meet the needs of our members, ILFA invested in an online digital subscription to Zoom (digital platform) and this has provided us with an opportunity to facilitate virtual video meetings for our network of regional support groups around the country. Many support group members have adapted and reacted favourably to this mode of communication and acknowledged the valuable opportunity to connect with their peers. Online meetings mean that patients who live in geographically remote areas, with no local support group can join an online lung fibrosis support group meeting if they would like to. The meetings are held on a private link and therefore those wishing to join all of ILFA's online activities, must register in advance. It is easy to connect to the online activities once you have a laptop, smart phone or digital tablet device.

On 15th May we held a national support group meeting online and had people from all over the country took part. We were delighted to be joined by Niamh Julian (Respiratory Physiotherapist at Limerick University Hospital), Paula Ryan (Advanced Nurse Practitioner at Limerick University Hospital) and Carmel McInerney (Respiratory Nurse Specialist at Ennis Hospital). The ladies answered the group's questions on pulmonary rehabilitation, exercise and maintaining physical activities.

On 22nd May we held an online education session called 'Let's talk Oxygen' to discuss oxygen for lung fibrosis patients. The meeting was expertly led by Patricia Davis, Clinical Nurse Specialist - Respiratory Integrated Care, Nurse Advisor to National Medical Gases Co-Ordination Group for

Covid-19 with support from Adrian Sheehan, BOC Healthcare Ireland. Patricia and Adrian talked us through the indications, practicalities, technicalities and safety issues of oxygen and demonstrated equipment from their home offices in Wicklow and Cork. The discussion was lively, engaging and interactive and participants asked a variety of great questions. It was a fantastic event that was appreciated by everyone who joined the meeting.

Online yoga



A series of online yoga classes with Michael Darragh Macauley (ILFA Patron, Dublin GAA star and qualified yoga instructor) has taken place over the last few months. The first class had an incredible 30 members from all over the country taking part and Michael Darragh took great pleasure in having a Kerry man take instructions from a Dublin man! The classes that focus on breathing, stretching, and standing and seated exercises are relaxing but challenging and have been well received. We hope to continue with this activity and the dates and times will be posted on the ILFA website and Facebook page.

Online Pulmonary Rehab Classes



A weekly Pulmonary Rehabilitation Class for Lung Fibrosis patients takes place online every Monday morning at 11am. The class is delivered by Niamh Julian (Respiratory Physiotherapist) and Paula Ryan (Advanced Nurse Practitioner), pictured, at Limerick University Hospital and has been running since the start of May. Everyone is welcome to join from the comfort of their own home.

The feedback from patients for these activities has been so positive, we thought we would share the quotes with you.

"I'm so delighted ILFA has provided the classes and meetings during Covid - it's been a great way to bring us all together as a group and not only give us the incentive to exercise and keep going but to feel hugely supported by ILFA and not forgotten, a heartfelt thank you to all involved" Noreen O'Carroll.

Education and wellbeing events

The Irish Lung Fibrosis Association, Asthma Society of Ireland and Cystic Fibrosis Ireland joined forces to collaborate on a series of online events to for respiratory patients during the COVID-19 pandemic. The three charities received welcome funding from the Community Foundation for Ireland and Bank of Ireland to support our members during this time.

Although the three respiratory conditions are hugely different in their underlying causes and clinical treatments, all three organisations were acutely aware of the impact of the pandemic on the mental health and emotional wellbeing of our patients.

The shared concerns regarding increasing anxiety levels for all our patients impressed on us the benefits of joining forces to develop and deliver a series of free online events for respiratory patients, to discuss respiratory medicine and wellbeing during the time of Covid-19.

The first event was a free educational webinar entitled “**Respiratory Medicine in the Time of Covid-19**”. The event took place on Thursday 4th June at 5pm via Zoom (online digital platform) and was open to patients, carers, the general public and medical professionals working in the respiratory field. Sarah O’Connor, CEO of the Asthma Society, chaired the event and introduced the main speakers; Dr Anne-Marie Russell, Professor Anthony O’Regan and Professor Richard Costello.

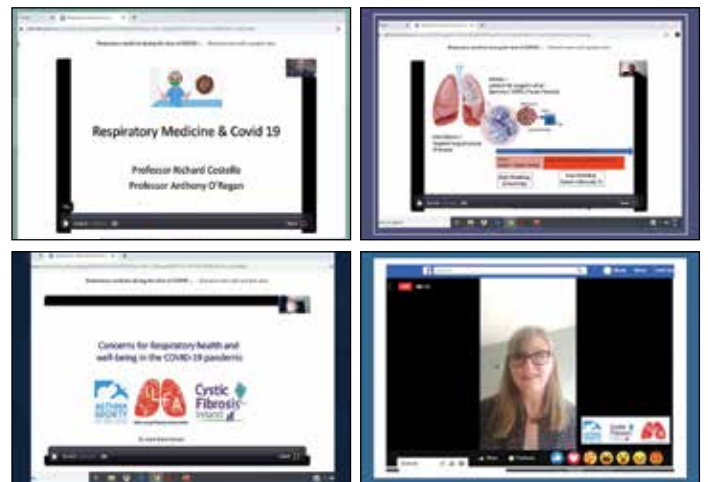
The leading respiratory experts gave an overview of their perspectives of working on the frontline of Covid-19, research on Covid-19, remote monitoring of patients and what the resumption of hospital services may look like with virtual health services, and the use of face coverings (masks).

Three patients also spoke at the event and shared their experiences of how they are managing their lives during the Covid-19 pandemic. ILFA is hugely grateful to David Crosby, ILFA Ambassador, for sharing his story and inspiring everyone to stay positive and exercise daily.

- In total, 281 people joined the live webinar including 116 patients, 27 carers and 84 healthcare professionals.
- 97% said they feel more informed about how respiratory medicine has responded to COVID-19
- 42% rated the event as being excellent, 45% rated it very good and 13% rated it good.
- 95% said they would be interested in attending another webinar hosted by the Asthma Society of Ireland, Cystic Fibrosis Ireland and ILFA.

The second joint initiative was an online wellbeing session held on 18th June via Facebook live. **The Mindfulness Session** was expertly hosted by Maria Love, Senior Social Work Practitioner at Mater Misericordae University. Maria began by explaining what mindfulness is and discussed the benefits of practicing this type of meditation to reap the benefits.

She invited everyone to ‘hit the pause button’, accept what is going on at present, focus on breathing, and be present in the moment as she guided the participants through a mindfulness ‘body scan’. The feedback was very



positive, and many people mentioned how relaxed and chilled they felt after the session.

As of 23/6/20, the mindfulness session was:

- viewed over 1,700 times
- reached 10,060 people
- had 626 engagements

The feedback from participants following the mindfulness session was very positive and here’s a sample of the comments received:

- “Feeling totally chilled now Maria thanks”
- “Thank you it was great”
- “That was amazing- I feel so relaxed and can’t believe the time, it felt like it was only a few minutes. Thank you.”
- “It left me very relaxed. Thank you”

Additional online events that will focus on wellbeing for respiratory patients will be scheduled for the future months. Keep an eye on the ILFA website and Facebook page for details.

ILFA would like to express our sincere thanks to the Community Foundation for Ireland and Bank of Ireland for their kind donation to ILFA, the Asthma Society and Cystic Fibrosis Ireland. This funding has been hugely appreciated and we value the opportunity to work with and learn from colleagues working for other respiratory charities.

Advocacy

Working with Government during Covid-19

ILFA was invited to join the Department of Health and HSE COVID-19 Stakeholder Group in March and since then we have received regular email communications with updates on key developments and public health announcements. We were also able to access to public health information videos and infographic resources that we shared widely on our website and social media channels. The Stakeholder group must be commended for their level of engagement and for also providing the opportunity for stakeholders to give feedback on the resources and highlight our specific requests and concerns to the authorities.

On 27th March 2020, the **'COVID-19 Guidance on cocooning to protect people over 70 years and those extremely medically vulnerable from COVID-19'** document from the Health Protection Surveillance Centre (HPSC) was published. The category of "extremely medically vulnerable" specified people with severe respiratory conditions including cystic fibrosis, severe asthma, and severe COPD. Unfortunately, pulmonary fibrosis/ lung fibrosis/ interstitial lung disease was not included as a severe respiratory disease. Although ILFA had already recommended cocooning to all our patients based on advice from respiratory consultants, we resolved to campaign to have lung fibrosis added to the list of serious respiratory illnesses. A series of correspondence via emails, letters, and social media communications were exchanged between ILFA, the Irish Thoracic Society, Professor Jim Egan, Professor Anthony O'Regan, Dr Aidan O'Brien and Nicola Hurley (patient advocate) with the Department of Health, the HPSC, the HSE, Simon Harris Minister for Health, and Finian McGrath Minister for Health with special responsibility for Disability. We highlighted the complex medical needs of lung fibrosis patients, their decreased capacity to fight a serious infection and the need for special recognition of their condition. We are grateful to everyone who assisted ILFA's campaign. Thankfully, the cocooning guidelines were updated and explicitly listed lung fibrosis/ILD as an extremely medically vulnerable condition. This means that lung fibrosis will be recognised as a serious illness going forward.

Medical publications

It was great to see two articles relating to pulmonary fibrosis published in the Medical Independent's Update Respiratory Medicine (May 2020). The journal is aimed at General Practitioners, specialist nurses, and respiratory physicians at both training and consultant level.

An article from Professor John Baugh (Conway Institute University College Dublin) and Dr Kate O'Reilly (Mater Misericordiae University Hospital and University College Dublin) described the role of microbiota-derived short chain fatty acids in the regulation of lung fibroblast function. Their work is supported by a research bursary from ILFA.

The second article was from ILFA Director Nicola Cassidy and described the charity's response to COVID-19. ILFA is committed to providing information, advice and support to

patients during these challenging times. We were fortunate to have great medical and nursing advisors who reviewed our information and helped us provide factual, evidence-based information to IPF patients and carers.

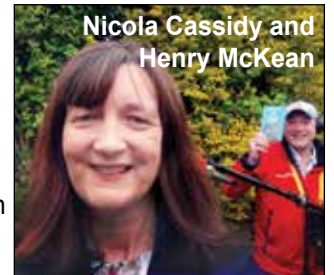
Congratulations to the medical and surgical teams at the Lung Transplant Unit at the Mater Misericordiae University Hospital on the publication of their research paper entitled "Meaningful survival benefit for single lung transplantation in IPF patients over 65 years of age". The article by Dr Peter Riddell, Dr Jana Kleinerova, Ms Donna Eaton, Prof David Healy, Mr Hossein Javadpour, Prof Jim F. McCarthy, Mr Lars Nolke, Prof Karen Redmond, Prof Jim Egan was recently published in the European Respiratory Journal.

Enhanced Illness Benefit to cocooning patients

ILFA joined forces with the Irish Cancer Society and other key organisations to campaign collectively for sustained COVID-19 payments for employees with serious health conditions classified as extremely medically vulnerable. The coalition of organisations signed a joint letter to Government in June to get assurances that medically vulnerable patients should not be pressurised into returning to their place of work while cocooning is still in place, or forced to choose between protecting their health and paying their bills.

Newstalk interview with Henry McKean

Nicola Cassidy, ILFA Director was interviewed by Henry McKean, right, for Newstalk radio on 29th April 2020. ILFA was over the moon to receive funding from The Community Foundation for Ireland and Bank of Ireland to support our work for lung fibrosis patients during the Covid-19 pandemic. We simply cannot thank the sponsors enough for this valuable and much appreciated funding during this difficult time. The interview was pre-recorded in Nicola's garden in the pouring rain whilst following social distancing guidelines. Henry asked Nicola about lung fibrosis, ILFA's work and the funding from The Community Foundation for Ireland and Bank of Ireland. The interview subsequently aired on the Sean Moncrieff show on Newstalk that afternoon. Thanks to Henry and Newstalk for the opportunity to raise awareness of lung fibrosis on the national airwaves.



Nicola Cassidy and Henry McKean

International Year of the Nurse and Midwife

The World Health Organization (WHO) has designated 2020 as the “International Year of the Nurse and the Midwife,” in honour of the 200th anniversary of Florence Nightingale’s birth. Florence Nightingale is perhaps the most famous nurse in history and widely considered to be the founder of modern nursing and a healthcare pioneer for her work championing improved hygiene practices. It is estimated that there are 20 million nurses worldwide and it is fitting that they have a special year of dedication to recognise their vital roles.

ILFA would like to take this opportunity to thank all nurses who work tirelessly to care for us, improve lives and shape patient-centred care and healthcare systems. We are especially grateful to the amazing nurses who care for lung fibrosis patients and appreciate their professionalism, skills, empathy, drive and commitment especially in this most challenging of years with the emergence of Covid-19. To mark this special year, ILFA asked some nurses to share their stories and we hope you will enjoy their personal reflections. “Happy International Year of the Nurse and Midwife” from all at ILFA!

Why I became a nurse by Lindsay Brown, St Vincent’s University Hospital



In 1983 I embarked on my nursing career as a naïve 17-year old fresh out of school. Over the next 37 years I saw many theoretical and technical advances in Nursing Practice and embraced those challenges with enthusiasm.

I have been privileged to accompany many individuals on their health care journey, from acute episodes of ill health to chronic illness management and

ultimately to end of life care. Difficult journeys that enriched my own life and enabled me to become a tolerant, compassionate, respectful, and trustworthy nurse with the capacity to show humility and empathy towards my fellowmen. A journey that transcended religious, cultural, racial beliefs and allowed me to universally accept individuals in my care. I believe that Nursing allowed me to become a good citizen. I hereby celebrate Nursing and Nurses across the Globe.

What it means to be a nurse by Bernadette Bowen, Cork University Hospital

“Nursing is a school of life” - a quote from my father when I announced that I was applying for a career in nursing. I was his youngest child (of eight) and his third of six daughters to become a nurse. This quote stayed with me and I continue to quote it when asked “what it means to be a nurse”!

I left Cork at 18 and studied nursing science in Kings College, London. My training there gave me a wide, broad perspective into a career in nursing. I experienced a humanistic, holistic and multi-cultural approach to patient care. It was the foundation of my continued nursing and personal approach to life.

I worked in intensive care units for 10 years in Kent, Sydney and around Australia before moving back to Cork University Hospital Intensive care unit. It is hard to put into words the experiences I gained within this time, meeting, working, and caring for people. The personal stories of many flood my mind. The joy of seeing a young guy move a finger or toe after 2-3 weeks on a ventilator post meningitis or brain surgery, a middle age man coming through a difficult aortic aneurysm repair, a lady coming around after taking an overdose and many more stories filled with emotions.

I always found it particularly challenging trying to wean a patient with respiratory disease from a ventilator and found it to be an art of balancing everything to get it right! It entailed giving medications appropriately, nebs etc. at the right times and judging the overall readiness of a patient physically, emotionally, and psychologically.

It was these experiences that led me to become a respiratory nurse specialist. I have been working in this area for 13 years now and still enjoy the complexity of this patient cohort. It gives me great pleasure to build a trusting bond with them and to help in any way I can to support and help meet their needs. This includes advice on medications, co-ordinating pulmonary rehabilitation, oxygen assessments, community care and understanding palliative care needs. I also thoroughly enjoy working as part of a dynamic respiratory team who are supportive, forward thinking and committed to working in the best way for the needs of this patient cohort.

Nursing in 2020 by Grainne Coffey, Kerry University Hospital

It seems oddly fitting to celebrate the Nursing profession during a global pandemic. Never before have we been so significant! Thanks to good leadership and the Irish public, our hospitals weren't hit with the surge of Covid 19 as expected. However, work has still been incredibly stressful. Nurses have had to become inventive and innovative. Planning for Covid 19 has meant that every detail of nursing care had to be carefully considered and adapted. New approaches ensure that safety to patients and staff take precedence, despite this, too many people have sadly lost their lives to this horrendous virus.

I feel proud to be a nurse in these challenging times and particularly proud of the way my hospital's nursing team has led the way in strategically planning and handling this crisis. We were grateful to receive immense support from the local community - this kept our spirits up and really helped us deal with the tougher days. The hardest part for me, is seeing patients missing their loved ones; the "no visiting" rule has been incredibly difficult. The days seem longer and while phone calls and FaceTime helps, it does not replace family contact. We are all trying our best and look forward to a new norm to hopefully return soon.

As my husband is also a critical care nurse, work is not the only challenge our family has faced. The lack of childcare has been a huge concern and managing that by working opposite and longer shifts is exhausting, this takes its toll the longer this situation continues.

In 18 years of Nursing, I had never realised that the profession we are so passionate about could cause us harm. This came true when early in the Pandemic my husband tested positive for Coronavirus. The very thing we had feared, was now in our home. Trying to prevent myself and my sons from catching the virus all whilst trying to look after him was very challenging indeed. Thankfully he turned a corner and slowly made a full recovery. I'd be lying if I said an alternative career didn't cross my mind during those few weeks. However, recalling my brief time in retail and banking I knew that I couldn't imagine doing anything else! In fact, Nursing means more to me now than ever before.

Emerging from this pandemic with a new veil of resilience and vigour is testament to having experienced and survived THE most challenging time of my career. Subsequently, I look forward to continuing my work in HDU, and feel enthusiastic to advance my study in Respiratory Care.

Why I became a nurse by Geraldine Burge, Birmingham, United Kingdom



Forty years ago, I started my nurse training at Westminster Hospital in London. I had always wanted to be a teacher but believe my change in profession was directed by an extraordinary journey to Lourdes in France which shaped my future. Aged 17, I was volunteered to represent my school on a charity trip to Lourdes with the ill and infirmed. We travelled by Jumbalance, a coach converted to ambulance and we carried 6 bed bound patients



2020
INTERNATIONAL YEAR
OF THE NURSE AND
THE MIDWIFE

and 10 disabled folks in chairs. As a young female helper, I very quickly shared basic nursing duties, bed bathing and feeding. It was whilst I was there, I recognised my vocation. The essence of nursing is not in the doing, it is about being open to whatever arises in the interaction with your patients. Understanding the past helps nurses comprehend the current issues.

I trained in cardio thoracic nursing and ran a thoracic medical ward for many years, it was a joy to nurture the juniors always being mindful that it's through care and compassion that we afford dignity, respect, and value.

My career took me to far and wide, most recently to work with inspiring colleges from UK, Ireland, Europe, America and India and latterly setting up a network of interstitial lung disease professions ILD-INN who promote education, influence and support in this field.

So what have I learnt over the forty years and indeed from this pandemic, it has been a huge privilege to nurse; patients want your time not your medicines, a smile and held hand anchors, and lastly compassion heals.

In this the 200th anniversary of Florence Nightingale, she too recognised that distancing beds and hand washing was vital. She was not only the lady with the lamp but the lady with the pie chart, she was a statistical pioneer who gathered scientific evidence to tackle ill health and inequality (and the control of infection)!

Personal perspectives on what it means to be a nurse by Katleen Leceuvre, Belgium



I had never wanted to do a job that involved working with people during my years at school. However, due to some unfortunate circumstances I had to be admitted to hospital. This marked a turning point in my life. A seed was planted and grew in my mind. I wanted to become a nurse. For me nursing equals caring. The definition of caring

is someone that shows kindness and concern for others. Caring for people in the most difficult moments of their life, being near in moments of despair requires compassion and understanding.

Working as a specialised nurse in interstitial lung diseases gives me the opportunity to be part of the patients' journey and to offer guidance in every stage of the illness. During this journey, particularly at points of transition patients have different needs.

Giving information on investigations, diagnosis and therapy is necessary to enable patients to make well informed choices. Supporting and coaching patients during therapy to maximise quality of life is very important, as is facilitating the skills to

cope with advanced care planning and transitions to end of life care.

Yes, being a nurse can be difficult and challenging. However, the gratitude and respect given by patients, families, caregivers and others are nourishment for our professional soul and reaffirm our energy and our dedication.

To ensure patients with rarer conditions receive optimal care, I have taken opportunities to speak about the importance of the role of a specialised nurse in interstitial lung disease on the international stage. This has led to opportunities to build an international network of contacts. In them I find my greatest source of support.

Working with the national and international patient organisations (EU-IPFF) and international networks (ILD-INN) are mutually supportive and enable us to get closer to achieving our goal of optimising care for patients and families affected by interstitial lung diseases.

What it means to be a nurse by Lynn Fox, Mater Misericordiae University Hospital



2020 has been dedicated as the Year of the Nurse by the World Health Organisation. In this current climate of the COVID-19 pandemic nurses are showing their compassion, resilience and innovative ways to care for their patients.

I have always wanted to be a nurse. My career guidance teacher at school tried to sway me but I was determined and focused towards nursing. Being a nurse has provided me with so many wonderful opportunities and has introduced me to so many people. It has also allowed me to travel the world and broaden my knowledge to care for patients of different nationalities and faiths.

There has been lots of change to nursing over the years, going from training in hospitals to achieving masters and post doctorate degrees from universities. These opportunities have allowed nurses to specialise in different areas. I have been very lucky to have specialised in respiratory nursing. This has allowed me to meet patients and their families who have been diagnosed with COPD, Asthma and IPF/ILD.

I love being a nurse and I would not change my nursing career.

What it means to be a nurse by Paula Ryan, University Hospital Limerick

Firstly, I am a 'nurse' and have been for over 20 years now. When I first decided I wanted to be a nurse, I believe I did it because I wanted to take care and help sick people. However, through each stage of my life this has evolved and changed. Being a nurse has been fun, frightening and challenging throughout my career. There have been times where I have wondered what area or speciality excited me in nursing, and an opportunity would arise that would change my path/career journey. These life-changing experiences or being involved



in making a person's journey through life better, have all been very different and there isn't a day that goes by that I don't learn something new. People who have saved lives someday are regarded as heroes, but nurses save lives every day. I believe it takes determination, self-will and passion to achieve this, and this is what it means to be a nurse to

me. Today in 2020, I am a nurse who is reviewing how to be a nurse in difficult times with Covid-19.

I find that I am looking at reinventing myself to fit a new system that works for our patients and families, to ensure best practice at all times. However challenging this is, it is certainly not boring and I know that although 'seeing' patients is different currently, I will endeavour to provide an expert service for the respiratory patients with my exceptional respiratory colleagues in the mid-west area.

What it means to be a Nurse by Dr Anne-Marie Russell, London, United Kingdom



2020, the year of the nurse, affords an opportunity to reflect. Florence Nightingale in late nineteenth century was a systemic thinker and passionate statistician; a forerunner of clinical academic practice. I trained in a traditional school of nursing at Addenbrookes Hospital, Cambridge in the 1980's where the founding

principles were to care, to serve, to educate.

The capacity to care for patients and their families remains fundamental element of nursing practice. The concept of self-care was a later addition but of no less importance if one is to consistently deliver excellence in healthcare. Health visiting taught me what good clinical supervision and mentorship is and enabled me to work effectively in challenging environments.

I went on to join the National Institute of Health Research Mentorship Programme during my doctoral programme of study. Inspired by this approach we integrated a mentoring programme for nurses working in the ILD specialist promoting mutually supportive thinking partnerships.

Serving as the chair of the ILD Interdisciplinary network (IN) and on international committees at ERS, ATS and EUIPFF is a privilege. Collectively changing and challenging practice and contributing to improving pathways of patient care. Education in various guises remains at the centre of the nursing profession.

The last decade I have focussed on my own patient centred research programme working with patients as co-researchers. I have learned a great deal and have been humbled by these experiences.

Motivated by making a difference the next decade will take me back to university-based education alongside continuing research to shape the future landscape of nursing practice and patient care.

Planning for the future

Everyone should plan for the future, regardless of illness, age or stage of life they are in. Thinking about and communicating our wishes is important and can have long term benefits for us and our families and friends.

The **Irish Hospice Foundation** would encourage people at every age and every stage of life to talk through options for care and preferences for a time when they might not be able to speak for themselves. Their experience is that it is often easier to think and talk about these things before the need is urgent. You can do this by using the Irish Hospice Foundation's **Think Ahead** booklet. Think ahead is a guide to help you think, discuss and record your preferences of all aspects of your treatment and care. By using Think ahead your wishes will be clear to you, those caring for you and those who manage your treatment and care. It is not a single process. It is easier to manage and think about as a series of tasks and conversations to have over a period of time.

Think about what is important to you. What treatments you would want to have that may prolong your life. What treatments you would not like to have? Where you would like to be cared for?

Talk: your options and your wishes through to the people important to you. Talk to your solicitor about Enduring Power of Attorney and making a Will.

Tell: your family, doctor and other health professionals about any medical or health issues you have. Ask about available treatments and options. Discuss the choices you would like to make about your medical care.

Record your wishes.

Review your preferences. You may change your mind and that is OK.

Think Ahead also has an Advance Healthcare Directive (AHD) this guides you to:

- Make decisions about refusing any medical treatment, including life-sustaining treatment, such as resuscitation, artificial nutrition and hydration, or breathing machines.
- Make decisions about treatment you want from the options offered to you by your doctor or healthcare team. Unlike a refusal of treatment, you don't have the right to request a treatment. This is because no one has the legal right to demand treatment. Your healthcare team will work with you to decide whether a treatment is medically appropriate for your condition and then you decide whether or not you want that treatment.
- Filling in an Advance Healthcare Directive can make things easier for you, your family and friends because it helps them to understand what is important to you.
- The process of planning ahead can also help with conversations with your loved ones or healthcare team about your wishes for the future, helping to initiate what can sometimes be a difficult conversation's.

IMPORTANT: An AHD is only used should you lose your capacity to make your own decisions or become ill in specified circumstances, and be unable to communicate for yourself.



The Irish Hospice Foundation's Think Ahead booklet gives you the opportunity to;

- Keep control over your care
- Receive the care you want but not the treatments that you don't want
- Gives Your Loved Ones Peace of mind, not tough choices
- Give nominated people the necessary information to make the decisions you would want
- Have conversations about what is important to you
- Avoid Family stress and conflict

We would encourage everyone to read the excellent book 'Being Mortal' by Atul Gawande. What is noteworthy is that planning ahead is paramount to ensure our wishes are heard and understood.

Gawande advocates for the difficult conversations, to talk about what you want for yourself, if your treatment and care is at issue.

Being Mortal not only offers sage advice on planning for outcomes that we all face sooner or later, but Gawande manages these topics with humour and transparency that is refreshing and useful.

In his own words;

We (doctors) think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way. Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same:

What is your understanding of the situation and its potential outcomes?

What are your fears and what are your hopes?

What are the trade-offs you are willing to make and not willing to make?

And what is the course of action that best serves this understanding?"

**Atul Gawande,
Being Mortal: Medicine and What Matters in the End**

**For more information on Think Ahead – visit our website
www.hospicefoundation.ie/thinkahead**

The Irish Hospice Foundation is the national charity concerned with all matters relating to dying, death and bereavement in Ireland.

Fundraising Round Up



Easter Monday 2000 Steps Challenge for ILFA

As the country quickly came to terms with the impact of Covid-19 and entered lockdown, ILFA's fundraising activities and most important and valuable source of income came to a sudden stop. The ILFA committee was determined to reassure our members that we were still here for them and had their best interests at heart. We put our thinking caps on to come up with an activity that would be positive, safe and appropriate for lung fibrosis patients, their family members and healthcare professionals. We wanted to lift people's spirits, create awareness and set up a virtual fundraising challenge in aid of ILFA. Of course!!! ... **The 2000 Steps Challenge for Lung Fibrosis Patients** exercise challenge, developed back in 2013, was the perfect solution and it could be easily completed within 2km of home to follow the public health guidelines. We contacted David Crosby, our Patient Ambassador who was cocooning in Cavan for his thoughts and he immediately jumped at the idea. David who is an inspiration to many having run three marathons after his double lung transplant in 2015, made a short video for ILFA encouraging everyone to get involved with the **Easter Monday 2000 Steps Challenge for ILFA**. We announced the event on the ILFA website and social media channels and asked people to sign up, exercise safely within 2km from home, and send us in their photos. We were delighted with the response and we received messages of support from all over the country and fundraising pledges. Easter Monday was a glorious warm, sunny day and we were thrilled that 77 people and at least 3 dogs (Honey, Kevin and Fionn) from all over Ireland took part in the inaugural Easter Monday 2000 Steps Challenge for ILFA. There was great excitement as fabulous

photos came flooding in to ILFA on the day and we were touched by the stories of personal achievement and also by the generous donations made. The ILFA committee would like to express our sincere thanks and congratulations to everyone who supported the Easter Monday 2000 Steps Challenge and helped raise over €2,000 for the charity. ILFA's patron Michael Darragh Macauley sent his congratulations to everyone who took part via a video link and he encouraged us all to keep moving. The challenge proved so popular that we hope to make this an annual event. **Here is a selection of some of the stories and photos of the day.**



ILFA Patient Ambassador David Crosby completed the challenge in his back garden in Cavan on the day and was the first to send in his photo and words of encouragement to everyone taking part. David's wife Katie also took part and did 3,774 steps!!



Eddie Cassidy, ILFA Chairman, did his steps locally at home. Eddie said "I completed 5,000 steps this morning for ILFA. I would like to send my best wishes to everyone including patients, carers, nurses, doctors, home helps, and healthcare assistants. Take care everyone." Meanwhile James and Darragh Cassidy did their steps while exercising at home in Kildare to support their grandad Eddie Cassidy, ILFA Chairman, and achieved 3,627 steps!!





Irene McGrath did the challenge at home and said “Just like to thank all my family and friends who have already completed and donated to this worthy cause.” 20,000 steps!! Was this a typo?!



Marie McGowan, ILFA committee member, and her son William took part in the challenge in the Phoenix Park in Dublin. Marie said “It was great that so many people took part in the 2000 Steps Challenge, great motivation!”



Teresa Gogarty said “As part of my run, from our house to the front of Áras an Uachtarain in the Phoenix Park is just over 2,000 steps. I ran the Cork Relay Marathon with my sisters last year, so I had my ILFA vest for this morning. Wishing everyone a happy and safe Easter.” 10,380 steps!!



Niamh English and her daughters Caoimhe, Liath and Cara in Co Meath. Niamh took it in turns to run with the girls around and around a circuit near their home.



Chloe Meehan, Respiratory Physiotherapist at the Royal Brompton Hospital in London, took part after work on the day.

It was great to have support from overseas! Meanwhile back in Dublin, Chloe's

parents Marie Sheridan (ILFA Ireland Treasurer), her husband Chris, and Fionn the dog took part along the seafront in Dublin.



Stephen and Rita Cassidy, left, completed their exercise within 2km from home in Navan, Co Meath. Nicola Cassidy, ILFA Director, ran in Dublin and said “It was a great morning for a run and I even got a salute from the local Gardai!” Deirdre Daly took part in Rathcore, Meath.



Matt Cullen who was cocooning at home in Dublin took part in the challenge. The indoor circuit consisted of the sitting room, hall, kitchen and dining room. Matt completed the challenge at speed without getting too dizzy!!! 2,037 steps!!



Andrew and John Sheehan joined their dad Adrian to take part near their home in Cork and achieved an impressive 4,502 steps!!



Team O'Sullivan was made up of family members of JP O'Sullivan who was cocooning in Lispole, Co Kerry. JP took part in the challenge and followed social distancing guidelines to the letter, so much so that we could barely see JP in his photo! We were told JP did 30,000 steps ... there may be a typo there but that doesn't matter!



Meanwhile Michelle O'Sullivan and her dog Kevin took part at Knock Na How, West Kerry and Dara O'Sullivan, pictured above, got his steps in near the famous Killarney lakes. Doireann and Sinead, left, also took part to support of their grandfather JP and elsewhere Andy, Jack and Aoife took part close to their home in support of their grandfather.



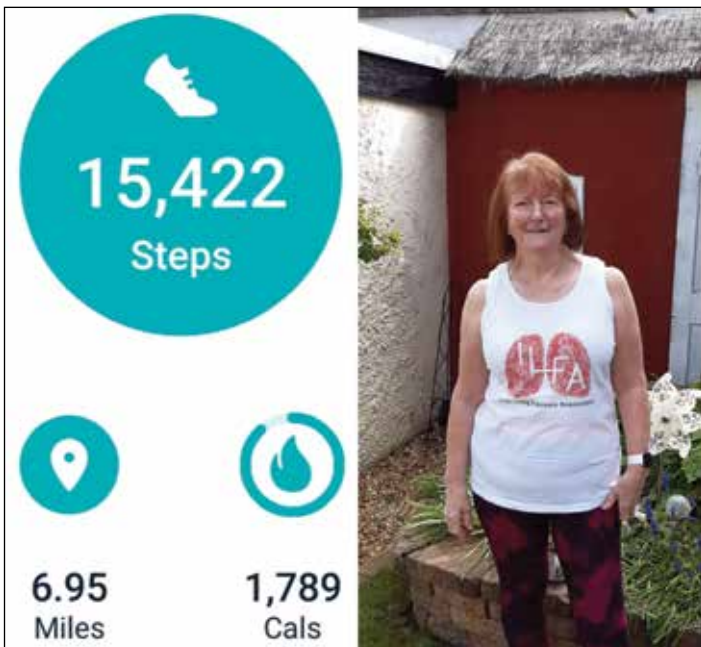
Alison Maguire, left, took part in the Easter Monday 2000 Steps Challenge for ILFA in Mullingar. Alison said “The 2000 step challenge inspired a run within 2km from home. Great idea ILFA!” While

Kevin, Tracey, Corey, Hannah and Reece McKeane, right, completed the challenge in County Monaghan and achieved 7,468 steps each!!





The Collins Team, above, made up of Michael Collins and his family Trevor Collins, Elaine Hogan, Michael, Breda, Amy Collins, Declan and Barbara Folan took part in the lovely Feakle countryside in Co. Clare. "We all had a great time partaking in the challenge from Feakle, Ennis and Connemara!! Thanks to ILFA for all of their excellent work and for some great motivation on this beautiful Easter Monday. Thanks for keeping the SPIRITS high, let's keep the AWARENESS going and let's be sure to keep FUNDING this incredible organisation who work so hard." 11,045 steps!



Annette Grehan in Dublin told us that she "ran around and around and around and around the local park (around the corner from home) to take part in the challenge" and reached a fantastic 15,442 steps for ILFA!!!



Anne and Daniel Casey and Honey the dog, left, took part in the challenge from their home in Cork. Rosemarie Hand and her daughter Emer took part in Co. Monaghan.

Gemma O'Dowd (ILFA's Administrative Assistant) and James Kavanagh



took part in the challenge locally in Dublin.



Marion and Martin Ryan from Dublin took part in the Easter Monday 2000 Steps Challenge for ILFA. They were supported by Carol Ryan and her son Noah who also took part.



Senan, Lily and Nora, left, completed their 2000 Steps Challenge near their home in Tipperary.



Catriona Mc Quillan and her daughters Leah, Clara, Sarah and Keeva took part in memory of their Granny.

Well done and thank you to everybody who supported this event that reminded us that although we are apart, we are united together!

Face mask sales raise thousands for ILFA



Huge thanks and heartfelt gratitude to RashR for kindly supporting ILFA with the sale of eco-friendly reusable Covid-19 facemasks. The Cork-based company, manufacturing face masks using recycled polyester, wanted to help a lung health charity and kindly decided to donate €2 from the sale of each mask to the Irish Lung Fibrosis Association.

Tom Cotter, CEO of RashR, above, said "We chose to donate €2 from every mask sold to the Irish Lung Fibrosis Association given the significant number of members suffering from respiratory diseases at the moment, a lot of their members would suffer from symptoms very similar to COVID-19 constantly and with our masks helping to protect the lungs, it felt like a good fit for us." Tom added.

We were absolutely thrilled to learn that €6,500 was raised for ILFA and this much appreciated funding will be invested in supporting lung fibrosis patients through the purchase of exercise resources and hand-held fans to help manage breathlessness.

Go raibh mile maith agaibh Tom Cotter agus RashR!

Women's Mini-Marathon 2020 – Virtual Run



Entries for the VHI Virtual Women's Mini Marathon are now OPEN! This year the event will be run virtually, and you get to choose where, when and how you walk, run or jog! The event

is open from 1st - 10th of October and you can take part at a day and time that suits you. ILFA would be very grateful for your support if you are taking part. You can enter the 2020 VHI Virtual Women's Mini Marathon via the website:

www.vhiwomensminimarathon.ie

Contact ILFA on 086 871 5264 email info@ilfa.ie for your fundraising pack. Thank you for your support!

The ILFA Tea Party



We are delighted to announce our new fundraising event "The ILFA Tea Party". We're hoping you and your family and friends will come together for a cuppa and some treats to help raise funds for ILFA. After all we have been through over the last few months, this will be a wonderful opportunity to make time for tea with the ones you love and have an extra special catch-up chat.

You can organise afternoon tea with all the trimmings, a Zoom/ Skype/Virtual cup of tea online if your pals can't meet in person, a Teddy Bears Party with the little ones in your life, a Mad Hatters Tea Party with everyone dressing up, or a garden party with social distancing.

It's time to get planning, dig out your favourite recipe, look for the tablecloth, dust off the cake stand and decide on when, where and who will be invited! We would love you to send in photos of your favourite mug or cup, tea pot, best china, cake stand, home baking skills etc. Your tea party can take place at a time and date that suits you up until bank holiday Monday on 3rd August. Any donation to ILFA would be hugely appreciated. Please call Gemma on 086 871 5264 to get your fundraising pack.

Thank you for your support.

Thank you

Sincere thanks to everyone who made a personal donation to ILFA over the last few months. We are extremely grateful for your support especially during these challenging times.

Sincere thanks to 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.

Creative Cocooning

As the Covid-19 pandemic emerged in Ireland and patients were advised to cocoon, ILFA created a Health & Wellbeing Information Hub on our website, www.ilfa.ie to collate our information, medical and mental health resources and exercise tools in one place for convenience. ILFA has always emphasised the importance of staying positive especially when facing difficult challenges and in March 2020 we started an online initiative called "Creative Cocooning". We encouraged patients to embrace a positive approach and get creative while cocooning to pass the time. Some of you were very busy while at home and we were delighted to receive so many photos of your works of art, literary prose, culinary prowess, carpentry skills and horticultural mastery!

Your incredible art, poetry, and baking, gardening and DIY talents were regularly showcased on ILFA's social media channels and gave great hope and inspiration.

Well done to our creative cocooners. Unfortunately, we can't include everything here, but we take great pleasure in share some masterpieces with you.

Our featured artistes are clockwise from top left; John Carroll and his grandson (carpentry), Eddie Cassidy (artist), Pamela Martin (confectioner) and Matt Cullen (artist). Our featured poets are Pauline Byrne and Tom O'Sullivan. Thank you to everyone for sharing your talents.



Grace Knows Your Name (2)

You Don't Understand Why I Can't Hold Your Hand and Walk With You
You Are Too Young To Tell The Truth and Reveal What We Living Through
The Fear of The Unknown
When Can We All Move Away From Our Homes
We Hold On With Grace
As We Stay The Pace
We Live Our Lives In A Different Time
In A Different Way
To Save The Day
In We Stay, Living The Best Lives We Can
For All Our Fellow Man
How We Can Grow From Our Core
Mother Nature Can Take No more
By Staying In We Can Go Within
Find Our Way To Live Each Day With A Song in Our Hearts
A Prayer That We Will Never Stray From The Way To Make Us Whole
In Body, Mind and Soul

By Pauline Byrne, April 2020

A wonderful legacy

Eileen left me a wonderful legacy, more precious than the world's gold
Cocooned, each day I walk round it and the fruits of her labour I behold
And in my mind I see her, garden tool in hand as she does toil
With a gleam in her eye and on her face a warm and a loving smile

Eileen gave birth to 5 children and she loved each girl and each boy
And spending time to work in her garden brought to her great joy
Giving birth to the many splendours I see that now do abound
Bringing to me such pleasure as I continue my walk all around

My walk started in springtime as Mother Nature began to awake
With Eileen's vision giving such colours that did my breath take
Each day I looked on with wonder as something new did appear
More colours, more flowers, from an imagination so lucid and clear

In the silver lining of the pandemic cloud such joys to me are shown
Though I walk there by myself, in that garden, I do not feel alone

By Tom O'Sullivan, May 2020



Thank you to everyone in the country who has made life easier for us during a difficult 2020. We have tried to include as many people as possible in the ILFA Roll of Honour but know that we may have missed some valuable people and professions.

A Ambulance staff, advanced nurse practitioners, anaesthetists, ambassadors, Aer Lingus pilots, airport staff

B Bus drivers, bakers, banks

C Carers, caterers, charities, Chief Medical Officer (Tony Holohan), councillors, clergy, cleaners, county councils

D Doctors, Dentists, Deputy Chief Medical Officer (Ronan Glynn), Department of Health staff, dietitians

E Emergency services, epidemiologists, engineers, electricians

F Frontline staff, fire brigade, ferry staff, farmers



G Gardai, GPs, GAA volunteers

H HSE staff, hospital staff, healthcare assistants

I Intensive care staff, immunologists, information technology support staff, infectious disease staff

J Journalists, judges

K Kitchen staff



L Lorry drivers, laboratory staff

M Ministers for Health, Foreign Affairs, Social Welfare, midwives, maintenance staff



N Nurses, news readers, nursing home staff

O Oxygen suppliers, occupational therapists, obstetricians, Ogligh na hEireann (Irish Defence Forces)

P postal workers, pharmacists, physiotherapists, public health doctors and nurses, physiologists, politicians, prison staff, porters, psychologists, psychiatrists

Q Quality controllers

R Retailers, radiographers, researchers, radiologists

S Supermarkets staff, social workers, scientists, surgeons, social welfare workers, student nurses

T An Taoiseach, train drivers, Test Centre volunteers, teachers working from home, telephonists

U Undertakers, U2 rock band

V Virus Reference Laboratory, van drivers, volunteers, ventilator assemblers, vets

W Warehouse staff, ward clerks, World Health Organisation

X X ray department staff

Y YouTubers

Z Zookeepers



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 organising the support group meetings. For safety reasons, the groups will not meet in person during the Covid-19 outbreak but will use mobile phone technology to have virtual meetings and stay connected.

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

086 871 5264

ILFA Survey

Thank you to everyone who completed the ILFA Survey on the impact of Covid-19. We were delighted with the response and over 200 people shared their experiences

Keep Moving with ILFA's Exercise Resources

We hope that you have been able to keep active during the last few months. Exercise is a vital therapy for lung fibrosis patients and helps to maintain lung function, muscle strength, mobility and independence. ILFA's exercise resources are provided free of charge and are tailored to people with lung fibrosis and take into account breathing and lung health challenges. The exercise resources are available to watch on the ILFA website and on YouTube. **If you would like to order your free copy, please contact Gemma on 086 871 5264 or email info@ilfa.ie**



Dates For Your Diary

- **The ILFA Spring Patient Information Day** will take place on Saturday July 11th from 11am to 12.30pm. 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 to get an email ticket to join the event. Details are on the ILFA website and Facebook page or you can call Gemma on 086 871 5264 to register.
- **Pulmonary Rehab online classes** take place every Monday at 11am from the comfort of your own home. These classes are expertly led by Niamh Julian (Respiratory Physiotherapist) and Paula Ryan (Advanced Nurse Practitioner) 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 running events** are taking place throughout the rest of the year 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, please consider raising funds for ILFA.
- **Fergus Goodbody Memorial Lecture** for healthcare professionals will take place online 23rd September in collaboration with the Royal College of Physicians in Ireland. The speaker are Dr Maria Molina-Molina from Spain and Dr Nazia Chaudhuri from Manchester, United Kingdom.
- **ILFA Tea Party:** Taking place at a time and place that suits you! See page 16 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.



with us. This was the biggest response to a survey that we have ever had. Thanks to Danny Sheahan, lead researcher with Invisio Ltd. for his help with developing, delivering and analysing the survey results. We will share the results of the survey in the near future.