



Irish Lung Fibrosis Association
www.ilfa.ie

Irish Lung Fibrosis Association Annual Report 2020

Company Details

Irish Lung Fibrosis Association (ILFA)

Company registration number 367940

Registered charity number 20053437

Charitable exemption number CHY 15462

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The appointed auditors for the Irish Lung Fibrosis Association are Whiteside Cullinan, Fleming Court, Fleming's Place, Dublin 4, D04N4X9.

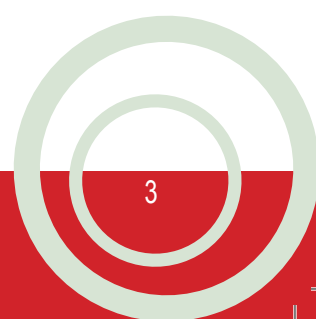
This Annual Report meets the requirement of the Charities Act 2009 whereby every charity registered in the State must provide an Annual Report to the Charities Regulator.



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Foreword from the Chairman

In 2020, ILFA marked 18 years since its foundation. This is a hugely significant milestone and one which would not have been reached were it not for the hard work and vision from our founders, the ongoing work and commitment from our motivated and dedicated committee members, and the amazing support and loyalty from our fundraisers and donors over the years.



In 2020, one significant event impacted on all our lives - the emergence of the Covid-19 pandemic. The first case of Covid 19 in Ireland was declared on February 29th and from that date onwards life changed for everyone in a short time as public health guidelines and lockdown measures were introduced. ILFA had to adapt quickly, and this meant learning all about virtual technology so the committee could meet and decide on plans to continue our advocacy work and reassure lung fibrosis patients that we were here if needed. ILFA campaigned fervently to have pulmonary fibrosis included on the list of “extremely medically vulnerable conditions” at risk from the effects of Covid19 and I would like to acknowledge the assistance of the respiratory consultants who supported ILFA in our advocacy work and submissions to the HSE and HSPC. After much correspondence, pulmonary fibrosis was recognised as an extremely medically vulnerable condition, and this has had positive implications for ILFA and our patients.

ILFA developed a Covid-19 Information Hub on our website that included up to date and trusted information from reputable sources to help our members. The information included HSE advice, practical advice, wellbeing advice and a ‘Creative Cocooning’ space where members could showcase their creative projects from baking, gardening, and painting sheds and masterpieces.

ILFA was delighted to partner with the team at University Hospital Limerick to deliver weekly online exercise classes to pulmonary fibrosis patients. Huge thanks to Gordon Cagney, Niamh Julian, and Paula Ryan for facilitating these classes that helped keep patients fit and motivated while cocooning. ILFA also held online support group meetings and ‘Let’s Talk’ information sessions to offer peer support and clinical expertise to members and we’re grateful to everyone who gave their time and talents to make these virtual events so successful.

The pandemic had a major impact on ILFAs fundraising activities and the decrease in income had major financial implications for the charity. ILFA was fortunate to receive joint funding with the Asthma Society of Ireland and Cystic Fibrosis Ireland from the Community Foundation of Ireland and Bank of Ireland. A series of wellbeing events took place and ILFA also purchased the valuable book entitled ‘Coping with Coronavirus: How to Stay Calm and Protect Your Mental Health’ from Professor Brendan Kelly, Trinity College Dublin. Many people contacted ILFA to express their thanks and appreciation of such a valuable resource during a stressful period.

ILFA applied for COVID-19 Stability Funding from Pobal and the Department of Rural and Community Development announced by the government to support charities providing critical



frontline services to patients and the committee was thrilled to hear that our application was successful and ILFA received €47,031. This crucial government funding ensured that we were able to 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 also successfully applied for The Community Foundation of Ireland / RTE Does Comic Relief: Adapt and Respond funding towards a World Café event planned for 2021.

ILFA conducted a valuable research survey in May 2020 to understand the impact of the Covid-19 pandemic on our stakeholders. Thanks to Danny Sheahan, Invisio Ltd., for all his help with the survey and qualitative interviews of patients, caregivers and healthcare professionals. We are grateful to everyone who participated and shared their perspectives. ILFA commissioned a set of infographics to communicate the results of the research that were sent to all members as an insert with one of the newsletters.

I would 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. The ILFA committee quickly adapted to the virtual world and going online helped us communicate efficiently and collectively. Thank you to everyone who gave up their free time to meet regularly and make important decisions about ILFA's work and response to the pandemic.

I am grateful to everyone who fundraised for ILFA during the year and to those who made kind donations in such challenging times. We are so appreciative of your efforts to support ILFA's work. I warmly acknowledge the support from government and philanthropic agencies to keep ILFA's finances buoyed as fundraising was severely impacted.

2020 was a year like no other and it is amazing to reflect on all that ILFA has achieved in unprecedented times. ILFA will continue to advocate, work for and support lung fibrosis patients, carers and healthcare professionals going forward. In the meantime, take care and stay safe.

Eddie Cassidy, ILFA Chairman



About ILFA

The Irish Lung Fibrosis Association (ILFA) was founded as a charity and company limited by guarantee in 2002 to honour the memory of Fergus Goodbody who died from lung fibrosis. ILFA was set up by Nicky Goodbody, the late Terence Moran, Marie Sheridan, and Professor Jim Egan. The primary aims of the Irish Lung Fibrosis Association charity are to provide a source of information and support to people with the condition, and to promote education and support research. ILFA is funded. The fundraising efforts of our supporters are vitally important to enable ILFA continue our work. ILFA is registered with the Companies Office and the Charities Regulatory Authority. Our financial accounts are audited every year and submitted to the Companies Office following our annual general meeting and are published on the ILFA website.

Directors and Committee Members

ILFA's directors and committee members are all volunteers who have personal experience of lung fibrosis, and healthcare professionals with a special interest in lung fibrosis. In 2020, the ILFA committee members were Eddie Cassidy (Chairman, Director), Liam Galvin (Director), Professor Jim Egan (Director), Nicola Cassidy (Director), Marie Sheridan (Honorary Treasurer), Michael Geoghegan (Secretary), Dr Kate O'Reilly, Marie McGowan, Lynn Fox and Lindsay Brown.

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 for Covid-19, ILFA used Zoom to hold virtual meetings in 2020. In the early months of the pandemic, the committee held online 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.



ILFA Mission Statement

Vision

Our vision is to enhance the quality of life for individuals and families living with lung fibrosis.

Mission

Our mission is to help individuals and families living with lung fibrosis, and the healthcare staff caring for them, by providing evidence-based information, support and practical resources, and to contribute to awareness, education and research in lung fibrosis.

Values

People are at our heart. We promote person-centred care and respect and value every individual.

We promote a positive approach to health and well-being to empower individuals.

We connect people and help build trusted relationships.

Compassion

We help, advise, inform, and support individual's choices and decisions.

We treat everyone professionally and with dignity and empathy.

We engage with our stakeholders to understand and prioritise their unmet needs



ILFA Calendar of Key Events 2020

Date	Event	Attended by
January	ILFA Lean White Belt Programme for Respiratory, Healthcare Professionals	ILFA bursary recipients. Course delivered by the Mater University Hospital
February	Roche Study Day - Ashling Hotel, Dublin	Nicola Cassidy (Speaker) & Gemma O'Dowd ILFA
February	ANAIL Day - Midlands Park Hotel, Portlaoise, Co Laois	ILFA /Gemma O'Dowd
March	First online ILFA Patient Support Group meeting – Ongoing	ILFA/ILFA members
April	ILFA 2000 Steps Challenge Fundraiser – Easter Monday	ILFA /ILFA Members
April	ILFA Virtual Yoga Classes commenced – Ongoing	Michael Darragh McCauley (ILFA Patron)/ILFA members
April	ILFA Quantitative and Qualitative Research Project	ILFA in collaboration with Invisio Ltd.
May	ILFA Weekly Online National Rehabilitation Classes for Pulmonary Fibrosis Patients via zoom commenced - Ongoing	ILFA /Respiratory Physiotherapists at University Hospital Limerick
May	ILFA PR Campaign re awareness for 'Critical Care Path' for Pulmonary Fibrosis patients	Hopkins Communications/ ILFA
May	'LET'S TALK' online talks with Healthcare Professionals commenced – Ongoing	ILFA members and healthcare professionals
July	Virtual ILFA Patient Information Day	ILFA members and healthcare professionals
September	Virtual Fergus Goodbody Memorial Lecture and Masterclass, at the Royal College of Physicians (RCPI) ILFA AGM	ILFA members and healthcare professionals ILFA committee and members
October & November	Cognitive behavioural Therapy (CBT) Course for Healthcare Professionals	ILFA bursary recipients. Organised by Pivotal Health UK
December	ILFA Christmas cards	ILFA

Governance

Good governance is essential for charities and involves putting systems and processes in place to ensure that the charity achieves its charitable objectives with integrity and is managed in an effective, efficient, accountable, and transparent way.

The Directors and Committee of the Irish Lung Fibrosis Association (ILFA) are responsible for the running of the charity in a voluntary capacity and to the highest professional standards. The ILFA committee is fully committed to operating the organisation with high standards of good practice and transparency, to delivering the charity's mission statement, its goals and values, to fulfilling our legal requirements, and maintaining the trust, confidence and support of our members, fundraisers, volunteers, donors and other stakeholders. We aim to meet our compliance responsibilities by applying the appropriate policies and procedures necessary to ensure that our organisation is run effectively, efficiently, and transparently.

ILFA is fully compliant with the following voluntary codes, best practice models and statutory obligations:

Charities Regulatory Authority: ILFA is registered with the Charities Regulatory Authority (www.charitiesregulator.ie) and listed on the Charities Regulatory Authority Register of Charities (Charity Registration Number 20053437) in the Republic of Ireland.

The Regulation of Lobbying Act 2015: ILFA is registered on the Register of Lobbying website which is maintained by the Standards Commission (www.lobbying.ie) and provides information to the Standards Commission about our lobbying activities three times a year.

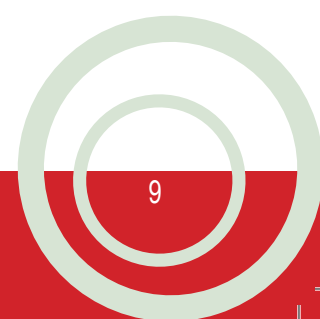
Irish Revenue Commissioners: ILFA is an approved charity with the Irish Revenue Commissioners, registered charity number CHY10456

Good Fundraising Principles: ILFA is compliant with the standards contained within the Statement of Guiding Principles for fundraising (https://www.charitiesinstituteireland.ie/uploads/default/files/5_603292d04d66f.pdf)

Transparent auditing and account reporting: ILFA prepares an annual report and financial statements. We make our annual independently audited accounts available on our website.

Throughout 2020 ILFA has focused on further developing and reviewing our policies and procedures. Governance issues are routinely included on the agenda and discussed at committee meetings. All decisions and actions are recorded in the Minutes. ILFA is committed to undertaking the necessary training and regular review of policies to ensure compliance with governance requirements.

The ILFA Committee met 11 times in 2020 and the majority of the meetings took place virtually.



Finance

Treasurer's Report

Marie Sheridan, B.Comm, M.Litt, FCA

The Irish Lung Fibrosis Association is committed to the utmost transparency and accountability to our members, for whose support we are very grateful. Our annual audited accounts are available on our website as soon as they are signed off by our auditors.

In common with all charities, because of Covid-19, 2020 was a difficult and unusual year. Many of the events from which we receive funds were cancelled or brought online. However, for the first time in our history, we received State Funding; a Pobal, Department of Rural and Community Development, grant of €47,031 to aid with non-pay costs. Apart from that, all of our events and projects are funded by donations, and we are very much appreciative of everyone who raised vital funds to enable us to maintain and increase our services in 2020. Some of our events and projects were sponsored by corporate bodies.

Our latest audited accounts are for the year to 31 December 2020. In this period, we had a surplus of income over expenditure of €28,276.

Last year, in the interests of clarity and comparability, we changed our accounts reporting year end, from 28 February to 31 December, to tie in with the calendar year. This resulted in reporting accounts for ten months to 31 December 2019, following on from the previous accounts for the year to 28 February 2019.

In the ten months to 31 December 2019 our deficit was €23,288.

In the year to 28 February 2019 our deficit was €4,212.

The surplus of €28,276 in the year to 31 December 2020 results from income of €165,970 (including Pobal funding of €47,031) and expenditure of €137,694.

Our balance sheet shows net reserves brought forward as at 31 December 2020 of €306,655.

The deficit in the ten months to 31 December 2019 results from income of €82,584 and expenditure of €105,872.

The deficit in the year to 28 February 2019 results from income of €117,230 and expenditure of €121,442

Apart from the Pobal funding, Income came entirely from corporate and community fundraising. We have no employees; the day to day running of the charity is carried out by an administrative assistant (an independent consultant) with ad hoc help from others. In the year to 31 December 2019, the administrative assistant was paid €51,750; we paid €285 for other administrative help.

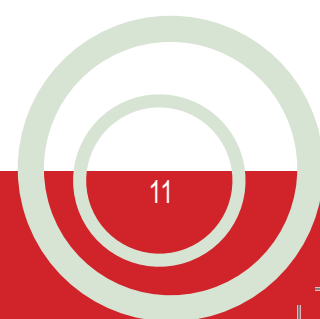
In the ten months to 31 December 2019 the amount paid to the administrative assistant was €35,861. The corresponding amount for the year to 28 February was €40,729.

The day to day running of the charity is done by a committee made up of volunteers and our administrative assistant. We are committed to our aims of Research, Education and Support for patients and families of those with IPF, as well as anyone affected by the condition. All our funds are used to those ends.

In 2020 we commissioned a survey on the impact of Covid-19 on our members. We commissioned infographics and published our findings. We also printed a booklet “Coping with Coronavirus” written by Professor B. Kelly of TCD, and distributed it to our members, along with other leaflets on dealing with aspects of the pandemic. We financed online Yoga and wellness sessions. We provided funding for Lean Belt and CBT training for healthcare professionals, which resulted in them taking useful skills and knowledge back to their IPF patients. To help with day-to-day management of IPF, we provided Therabands to hospital physiotherapy departments and pedometers to patients.

ILFA runs two information days and produces three newsletters a year as well as providing information packs to our members who are recently diagnosed. In 2020, due to Covid-19, we ran these information days online for the first time. In 2020 we commenced a re-vamp of our website, to bring it up to date for the benefit of our members.

We have built up (and added to in 2020) a range of useful leaflets, covering all aspects of dealing with IPF. Support is also provided through our phone line, which is manned by our administrative assistant. ILFA is lucky enough to have built up a loyal following of members who display imagination and commitment to fundraising for us. We look forward to continue working together to ensure that ILFA continues to fulfil our brief to research IPF, educate healthcare professionals and the public, and care for the needs of our members, particularly IPF patients and their carers.



Advocacy work

General Election 2020

The General Election took place in February 2020 and in the lead up to polling day ILFA issued a statement calling on politicians and public representatives to support:

- Fair and fast approval of Medical Cards
- Adequate oxygen supplies
- Opt-out organ donation
- Funding for the National IPF Registry and healthcare inclusivity for IPF
- More health funding for resources to support patients accessing primary care, community care, palliative care services and acute hospitals.

The Irish Lung Fibrosis Association is registered with the Register of Lobbying, maintained by the Standards in Public Office Commission.

Covid-19 Health Communications Stakeholder Support

As part of the national response to Covid-19, the Department of Health, the Department of Rural and Community Development and the HSE set up a national stakeholder group to support patient organisations, community groups and other stakeholders representing some of the most vulnerable and elderly members of society.

ILFA is part of the stakeholder network, and the authorities are keeping in regular email contact with all the stakeholders to provide us with the most up to date information, prevention materials and content for social media posts.

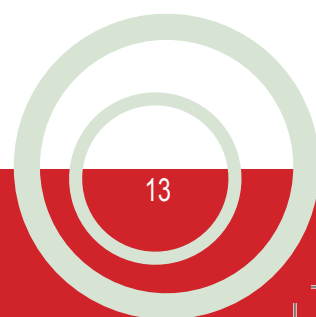
According to the HSE Communications Team, “Our collective efforts are critical, we need to do this together, as one community. We will be asking everyone to play their part, to help each other and we’re here to help you.”

Lung Fibrosis designated an “extremely medically vulnerable” condition

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

Medical Independent

Two articles relating to pulmonary fibrosis were 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.

Respirology

ILFA Director Nicola Cassidy was invited to co-author an editorial for the journal Respirology with Pippa Powell of the European Lung Foundation and Professor Athol Wells of the Royal Brompton Hospital, London. The article was published in Respirology in October 2020.

Patients with idiopathic pulmonary fibrosis: Overcoming 'geographic isolation'.

Cassidy N, Powell P, Wells AU. Respirology 2020;Oct25(10):1019-1020

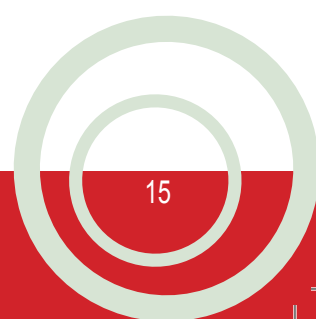


Enhanced Illness Benefit to cocooning patients

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.

National Electronic Patient Summary

A national electronic patient summary provides a 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.



Education

The European IPF & Related Disorders Federation Patient Summit

ILFA awarded educational bursaries to 8 healthcare professionals in Ireland to attend the first European IPF and Related Disorders Federation Patient Summit in Warsaw that was due take place in April. Unfortunately, the conference had to be postponed with the Covid-19 outbreak in Europe and the organisers decided to host a virtual conference in 2021.

IPF Study Day

Gemma O'Dowd, Nicola Cassidy and Lynn Fox from ILFA attended the 6th annual Idiopathic Pulmonary Fibrosis (IPF) Study Day organised by Roche Products Ireland on 7th February 2020 in Dublin. Dr Michael Henry, respiratory consultant at Cork University Hospital and Dr Cormac McCarthy, respiratory consultant at St Vincent's University Hospital, co-chaired the medical education event dedicated to healthcare professionals. Almost 100 respiratory nurse specialists, physiotherapists and respiratory doctors attended the study day.

Nicola Cassidy gave a presentation entitled "ILFA - Patient Organisation Update" which highlighted recent developments in IPF patient care, and ILFA's upcoming events and plans.

Peter Gallagher from Dublin also spoke at the event and shared his personal experiences of being diagnosed with IPF, living with the condition and receiving a single lung transplant in 2019. Peter spoke from the heart and described the challenges he faced, the highs and lows, and the value of friendships made through attending ILFA's Dublin support group.

Anáil Respiratory Nursing Conference

ILFA hosted an exhibition stand at the 7th Annual Anáil Respiratory Nursing Conference in Portlaoise on 28th February 2020 and met with healthcare professionals from all over the country.

Fundamentals of Lean Six Sigma for Healthcare – White Belt Programme

On 8th January 2020, 13 healthcare professionals from across Ireland attended a 'Fundamentals of Lean Six Sigma for Healthcare – White Belt Programme' at the Centre for Nurse Education, at the Mater Hospital in Dublin. This educational activity was funded by ILFA as part of our commitment to supporting healthcare education. By all accounts it was a fantastic day and provided valuable training and tools to those who attended. ILFA hopes this valuable training will facilitate quality improvements at a local level and encourage future healthcare projects to support lung fibrosis patients.

Here are the reports from the successful candidates.

Report from Mary Poland, respiratory nurse specialist at Tallaght Hospital said “Thanks to ILFA for providing the opportunity to attend. The importance of Self-Care for those caring for others was highlighted and I found this both thought provoking and refreshing. We are there when a patient gets the devastating diagnosis of Lung Fibrosis. We can see how it affects, not just the patient, but the family. We try and care for all and can do this more effectively if we are familiar with caring for ourselves. Caring for our patients is not done in isolation, it's a team approach. This day gave us time to reflect on how and why we do the things we do! Our roles are very demanding. It was good to have time to think about ways of making changes ... small changes can sometimes have a great impact and may be cost neutral. They may improve the quality of services that we provide and ultimately improve the patient experience.”

Report from Eilis Gleeson, respiratory nurse specialist at Limerick University Hospital said “Many thanks for allowing me the opportunity for undertake this training. I really enjoyed the day. The presenter gave very beneficial examples of how the lean method was incorporated to make simple, beneficial quality improvements. We are looking at streamlining clinics and ensuring we are providing good quality service to our vulnerable patients.”

Report from Carmel McInerney, respiratory nurse specialist at Ennis Hospital said “I learned that you could evaluate and improve your service with very little resources. I thoroughly enjoyed the group exercise where we had to identify a problem and find the solution. The course has shown me ways to improve the existing services, for example how we can work closely across the sites to avoid duplication of tests/appointments for this group of patients and provide a more streamlined approach. “

Report from Rosaleen Anglim, physiotherapist at South Tipperary General Hospital said “The training day provided a valuable chance to have time out of your busy work-day to look at your own workplace practices. The information about projects already completed using lean principles was very useful in motivating you to consider trying to replicate those successes. Thanks so much to ILFA for the opportunity to attend this training session.”



Report from Carol Doherty, respiratory nurse specialist at Letterkenny Hospital said “I found the white belt lean programme extremely beneficial as it allowed me to reflect on my own practice. It highlighted how on a personal level I could be more productive in my working day. Focusing on time management, in practice a lot of time is spent going through a patient’s medical notes to get information for example, medication, investigations, oxygen prescription, date of referrals etc. The development of a Pulmonary Fibrosis Care Bundle would enable me to document all appropriate information onto one sheet that would be kept in the patient’s medical notes and easily accessed by all health professionals. I would be very interested in pursuing further learning with the LEAN programme.”

Report From Mary Nagle, advanced nurse practitioner at the Bon Secours Hospital, Tralee said “Thank you ILFA so much for giving me the opportunity to attend the lean white belt programme. It was a very interesting day and made me think about different ways of doing things in the length of time you have available. I have already used one of the techniques that was demonstrated to us on the programme - the time and motion skill - that is, how much time do I have in the day? I feel this is a good way to plan out the day and gives a real idea of the time slots we should allocate for each patient interaction.”

Report from Nora McNamara, respiratory nurse specialist at South Tipperary General Hospital said “This was a most enjoyable course. It provided great vision and methods on how to achieve goals and deliver a quality service. It highlighted what can be achieved if we look at things in a different light. I am currently in the process of establishing a clinic for lung fibrosis patients and this has shown me that I can deliver an excellent service even if all the chains of the link are not available in my facility. I would highly recommend the course to other healthcare professionals, and I would very much like to go on and enhance my knowledge of the LEAN programme.”



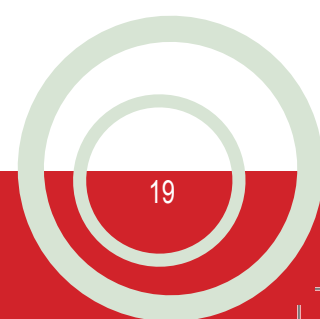
Cognitive Behavioural Therapy (CBT) Training Bursaries



In August 2020, ILFA offered 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, 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 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.



Collaborative 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 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 Misericordiae University. Maria began by explaining what mindfulness is and discussed the benefits of practicing this type of meditation to reap the benefits.

ILFA would like to offer our sincere thanks to the Community Foundation for Ireland and Bank of Ireland for supporting these important initiatives to support patients with respiratory disease.

Research

Impact of Covid-19 of ILFA Stakeholders

In April-May, ILFA conducted a research survey on the impact of Covid-19 on patients, carers and healthcare professionals and we had a great response with over 200 people sharing their experiences with us. The survey results were incorporated into infographics and distributed to our members. 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

Infographics describing the results of the survey are included in the next pages.



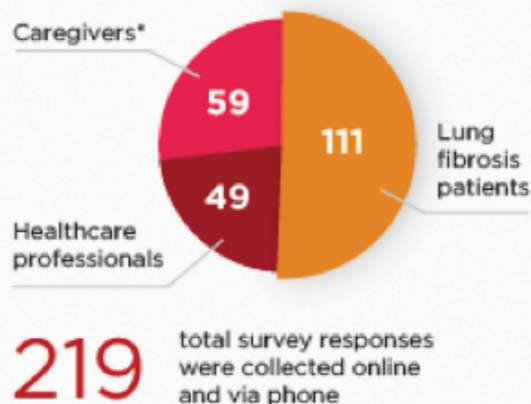
Between April 16th - May 5th 2020, ILFA commissioned a survey of its stakeholders to gain a deeper understanding of how their daily and healthcare needs were being met during the Covid-19 pandemic. The goal was also to gain a deeper understanding of stakeholders concerns, mental wellbeing and future outlook as well as gather suggestions for improving the supports available to lung fibrosis patients.

CONCERNS

On scale of **1 to 10**, how worried are you about the coronavirus?

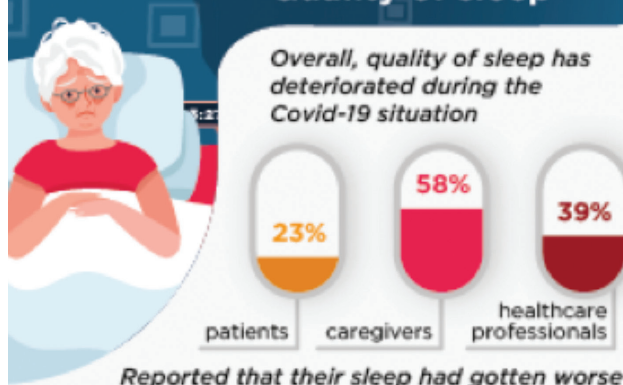


Stakeholder Profile



Quality of sleep

Overall, quality of sleep has deteriorated during the Covid-19 situation



MEDICAL CARE

Most stakeholders are confident in the healthcare service's ability to meet their needs during the outbreak



25% of patients are aware of the Irish Hospice Foundation's "Think Ahead" document but only **3%** have completed it.

ADVOCACY

Stakeholder priorities for how lung fibrosis is managed in the future by the health service



* Caregivers / family members of lung fibrosis patients

I miss my grandchildren, my daughter and my son. They haven't been into the house. My daughter lives too far away to talk in the window and we haven't seen each other in a few weeks

We do the video call but it's not the same as giving someone a hug





ILFA
STAKEHOLDER
SURVEY PATIENTS

Between April 16th and May 5th 2020, the Irish Lung Fibrosis Association commissioned a survey of its stakeholders to gain a deeper understanding of how their daily and healthcare needs were being met during the Covid-19 pandemic.

Patients are coping reasonably well in terms of immediate daily needs and current healthcare requirements. However prolonged restrictions and cancelled tests, appointments and procedures are a cause of grave concern.

CONCERNS



83% of patients were concerned about their ability to safely access hospital care if needed.



EXERCISE

49%

49% of patients use a pedometer to help with exercise.

49%

10%

49% of patients exercise daily, and 10% never exercise.



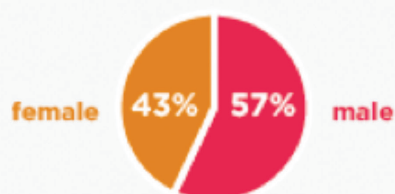
47%

Since Covid-19, 47% indicated that they are exercising less since the COVID-19 lockdown began.

I now realise that being a more active member of this association, (ILFA) will improve my level of knowledge and understanding of the support structures which will help me as this condition progresses.



Patients Profile



QUALITY OF SLEEP

23%

reported that their sleep had gotten worse during the Covid-19 situation.

45%

of patients reported good or very good quality of sleep.

MEDICAL CARE

Health Service and Government Response

39%

of patients who've had medical tests since the coronavirus lockdown had their results delayed

43%

of patients had tests relating to Idiopathic Pulmonary Fibrosis delayed due to the Covid-19 situation

43%

of patients have had to call their GP since the lockdown was put in place

Between April 16th and May 5th 2020, the Irish Lung Fibrosis Association commissioned a survey of its stakeholders to gain a deeper understanding of how their daily and healthcare needs were being met during the Covid-19 pandemic. Caregivers were quite concerned about poor levels of awareness and lack of recognition of Idiopathic Pulmonary Fibrosis (IPF) as a serious condition. Several were experiencing stress and they found the support from ILFA very helpful. They also felt it would be useful for newly diagnosed patients and their caregivers to be pointed to ILFA immediately upon diagnosis.

Caregivers Profile

86%



female

14%



male



QUALITY OF SLEEP

58%

reported that their sleep had gotten worse during the Covid-19 situation.

22%

of caregivers / family members reported good or very good quality of sleep.

QUOTE

Realising the importance of what I have and appreciating life before the pandemic hit

were the most common positives experienced by caregivers / family members.



CONCERNS

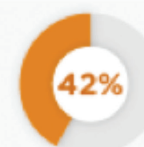
When asked to rank sources of concern, caregivers were most concerned about their patient's access to hospital care as well as their financial situation.



88% of caregivers were concerned about the person they care for being able to safely access hospital treatment.

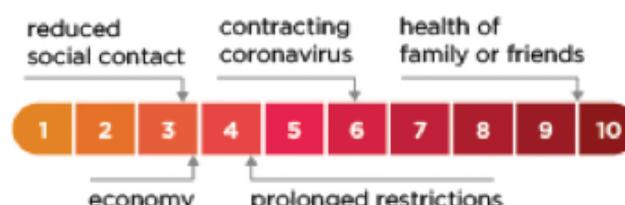
FINANCIAL SITUATION

42% of caregivers reported being financially worse off because of the COVID-19 situation.



SOURCES OF WORRY

Caregivers ranked the health of family or friends as their main source of worry



MEDICAL CARE

Health Service and Government Response

76% of caregivers felt reassured by the government's response to Covid-19.

68% were confident in the ability of the health service to meet society's needs during the outbreak.

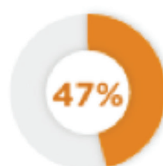
68% of caregivers were confident in the ability of the health service to meet their needs during the outbreak.

Between April 16th and May 5th 2020, the Irish Lung Fibrosis Association commissioned a survey of its stakeholders to gain a deeper understanding of how their daily and healthcare needs were being met during the Covid-19 pandemic.

Healthcare professionals felt that despite personal and professional challenges, they had dealt well with the unprecedented changes that were required of them during the pandemic. They also felt this was largely due to goodwill and a willingness to adapt among healthcare professionals.

CONCERNS

Healthcare professionals main concerns revolved around the mental health implications of the crisis and the clinical implications for their patients who had appointments cancelled and treatments interrupted.



47% of healthcare professionals were worried about contracting the Coronavirus

Mental health wise, I think there is support there. However, it is just having the time and the physical and mental space to access it



Usually self-care is at the bottom of the pyramid of things that need to be done



When this is over we'll have to deal with cancellations which is tough, the backlog of patients



SOURCES OF WORRY

Healthcare professionals ranked the health of family or friends as their main source of worry



Healthcare Professionals Profile



29%
male

71%
female



QUALITY OF SLEEP

39%

reported that their sleep had gotten worse during the Covid-19 situation.

41%

of healthcare professionals reported good or very good quality of sleep.

MEDICAL CARE

Health Service and Government Response



84%

of healthcare professionals felt reassured by the government's response to Covid-19.



80%

were confident in the ability of the health service to meet society's needs during the outbreak.



76%

of healthcare professionals were confident the health service would meet their needs during the outbreak.

Patient Support

Embracing Digital Technology



The emergence of COVID-19 in Ireland meant that everyone 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.

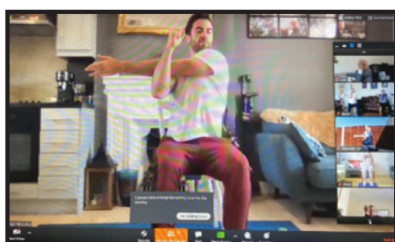
Huge thanks to everyone who has contributed to these events.

Support Group Meetings Online Education Sessions



To meet the needs of our members in 2020, 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 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 ILFA's online activities must register in advance.



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 classes which focus on breathing, stretching, and standing and seated exercises are relaxing but challenging and have been well received.

In December, a special "Christmas Jumper" yoga session took place to help everyone get into the festive spirit.

Online Pulmonary Rehab Classes: Virtual Pulmonary Rehabilitation Classes for Lung Fibrosis patients started in July 2020 and were delivered by Niamh Julian and Gordon Cagney (Respiratory Physiotherapists) and Paula Ryan (Advanced Nurse Practitioner) at Limerick University Hospital. The feedback from patients has been very positive. Noreen O'Carroll from Tipperary said "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."



“Let’s talk” online sessions

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 4-6 weeks 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 patients must contact ILFA to register in advance to join the 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 the 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.

The Let's Talk Series was supported by funding from the Community Foundation of Ireland and Bank of Ireland.

Investing in mental health and wellbeing

In April, ILFA was thrilled and honoured to receive funding from The Community Foundation 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 proportion 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.



ILFA Patient Support Groups across Ireland

As more patients and family members become aware of lung fibrosis, this has encouraged people to seek peer support within their region. Currently there are seven ILFA support groups in existence. The pulmonary fibrosis support groups face-to-face monthly meetings were cancelled from March 2020 however, the support group leaders kindly gave permission for their contact details to be shared in case people would like to contact them by telephone.



Online support group meetings were facilitated by ILFA, and this enabled patients from all over Ireland to join, including people from remote areas where support groups are not established.

- Cavan/Monaghan Support Group
- Clare Support Group
- Cork Support Group
- Dublin Support Group
- Kerry Support Group
- Midland Support Group
- Mid-West Support Group

We are grateful to the leaders of the support groups for their continued help and support in facilitating the monthly meetings



Patient Information Days



ILFA was pleased to be able to host two online patient information days in 2020. These valuable events enable patients and family members to access information and advice from medical professionals and other lung fibrosis patients and caregivers. ILFA is very grateful for the funding and sponsorship that contribute towards the costs of providing the patient information days. We are also grateful to the speakers at the

events for their willingness to take part and share their expertise, and to the volunteers who give their time and talents to help deliver the events

ILFA Patient Information Day Saturday 11 July 2020

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. Speakers at the event were

- Dr Eoin Judge, Respiratory Consultant at Connolly Hospital, Blanchardstown Hospital
- Lynn Fox, Respiratory Nurse Specialist at Mater Misericordiae University Hospital
- Danny Sheahan, Researcher with Invisio Ltd.
- Professor Brendan Kelly, Professor of Psychiatry at Trinity College Dublin
- Niamh Julian, Respiratory Physiotherapist at University Hospital Limerick

ILFA Patient Information Day Saturday 28 November 2020

ILFA's second online Patient Information Day took place on Saturday 28 November 2020 and 140 people registered for this event. Speakers at the event were

- Dr Mike Henry – Respiratory Consultant at Cork University Hospital
- Carmel McLnerney – CNS, Ennis Hospital
- Debbie Gibbons – St Francis Hospice
- Sandra Murphy – Mater Misericordiae University Hospital
- Gerry Redican – Transplant Patient & Fundraiser
- Laura Grehan – Ultracyclist & Fundraiser



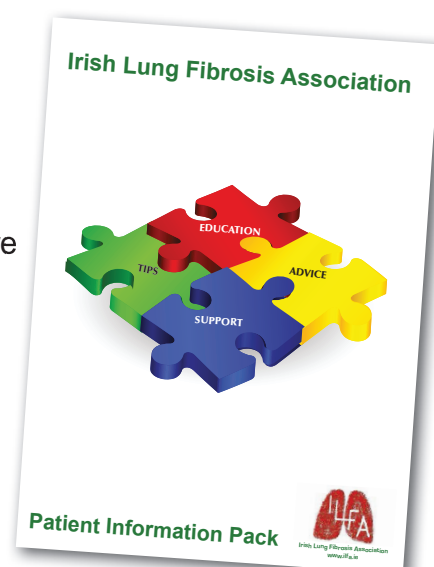
Patient Resources

ILFA has printed leaflets and booklets as well as practical resources available for patients, family members and healthcare professionals caring for lung fibrosis patients.

Some of the resources available are included here:

Information Leaflets

- What is Pulmonary Fibrosis?
- The treatment of Idiopathic Pulmonary Fibrosis
- Oxygen and Idiopathic Pulmonary Fibrosis
- Managing Breathlessness
- Advice for Lung Fibrosis Patients
- Getting the most out of your hospital appointments: Advice for IPF patients
- Advice for carers of people with Idiopathic Pulmonary Fibrosis



Exercise Resources

- ILFA 2000 Steps a Day Challenge
- ILFA Exercise DVD for Lung Fibrosis Patients
- ILFA Yoga DVD for Lung Fibrosis Patients
- Therabands (stretch bands)

Practical Resources

- STALL Breathing Technique Card from ILFA
- ILFA Medical Alert Card
- ILFA handheld fan



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

The emergence of COVID-19 in Ireland meant that everyone had to adapt aspects of their daily lives especially in relation to how we communicate, and the same applies to healthcare delivery. Here is a short report from Gordon Cagney, Respiratory Physiotherapist at University Hospital Limerick.

“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.”

Feedback received from participants

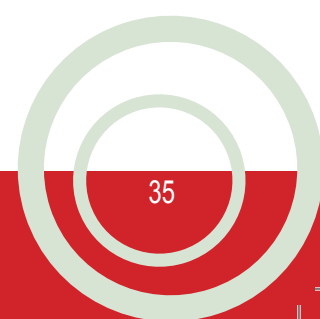
- “The fact that it’s on a Monday is great and a good motivating start to the week. The care, courtesy, and the understanding of all the physios who give the classes is just so beneficial for people like us who may at times struggle. Not forgetting ILFA’s input in organising and coordinating each event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



Publicity Campaign for Pulmonary Fibrosis 2020

In July 2020, ILFA worked with Hopkins Communications to raise awareness of pulmonary fibrosis and highlight the need for a dedicated clinical care programme to ensure patients with pulmonary fibrosis can access the appropriate healthcare supports. Some of the publicity achieved online, in print, and on the airwaves is highlighted below. ILFA is grateful to the individuals who shared their stories to help raise awareness.

- Grainne Coffey, Staff Nurse shared her story about the support ILFA has provided to her family in the Cork Echo and via EchoLive.ie
- Liam Galvin, ILFA Director was interviewed on TippFM.com and Tipp Mid-West Community Radio and called for a clear pathway for people suffering from a rare lung disease.
- Irene McGrath from Cork appealed for more resources and recognition of respiratory diseases. Irene's story featured online on CorkBeo.ie
- Eddie Cassidy, ILFA Chairman put respiratory Health in the spotlight in an article that featured in the Cork Independent.
- The Corkman also featured an article entitled "HSE Urged to provide care programme for lung patients."
- Michelle Clarke's story featured on RSVPLive.ie and she was interviewed by iradio.com
- Dr Aidan O'Brien, President of the Irish Thoracic Society called for a "Critical care pathway for chronic lung disease" that featured on ClareHerald.com
- Gerry Redican from Kerry shared his story of receiving lung transplant and recovering from COVID-19. Gerry was interviewed on RadioKerry.ie and his story appeared in print in The Kerryman.
- Kevin McSkeane from Monaghan shared his story of being diagnosed with Pulmonary Fibrosis in the Irish Daily Mail
- David McCurtin from Cork was interviewed on Cry 104FM and his story featured in The Echo
- John Patrick O'Sullivan, from Kerry was diagnosed with Idiopathic Pulmonary fibrosis and received a lung transplant. His story featured in Kerry's Eye
- Noreen O'Carroll, from Tipperary described her experience of living with Idiopathic Pulmonary Fibrosis and I featured on RSVPLive.ie



Fundraising

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.



Face mask sales raise thousands for ILFA

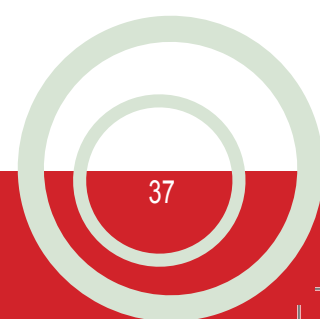
Huge thanks and heartfelt gratitude to RashR for kindly supporting ILFA with the sale of eco-friendly reusable Covid-19 facemasks. The Cork-based company, manufacturing face masks using recycled polyester, wanted to help a lung health charity and kindly decided to donate €2 from the sale of each mask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

Tom Cotter, CEO of RashR 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.

ILFA was thrilled receive €6,500 from RashR and this donation was invested in supporting lung fibrosis patients through the purchase of exercise resources and hand-held fans to help manage breathlessness.

ILFA Tea Party

Over the summer, ILFA asked our members to host a Tea Party for family and friends to help raise awareness of lung fibrosis and fundraise for ILFA. We also provided cake-stands for people to decorate. 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.



Laura Grehan becomes Ireland's First Female World Ultra Cycling Record Holder cycling 386km non-stop in aid of the Irish Lung Fibrosis Association



On 5th September 2020, 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.

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.

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 passers-by 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”, said 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. “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.

“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 raised over €6,500 for ILFA. “The money raised was worth every ounce of energy I burned!” said Laura.

The Virtual VHI Women’s Mini-Marathon 2020

The 2020 VHI Women’s Mini Marathon took place virtually. A small number of fundraisers took part in the 10km event. We are very grateful to ladies who took part in the 2020 event. As the women’s mini marathon was traditionally one of ILFA’s biggest fundraising events, we look forward to safer times when participants can once gather and take on the 10km challenge.

Art Card Fundraiser for ILFA – 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 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.

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

European Pulmonary Fibrosis Federation (EU-IPFF)

Report by Liam Galvin, CEO of EU-IPFF



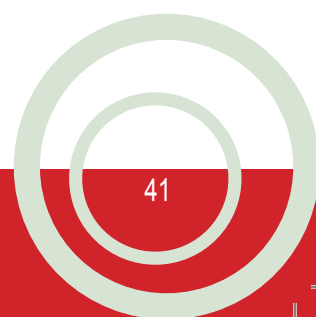
ILFA is an active member of the European Pulmonary Fibrosis Federation (EU-IPFF) whose current General Secretary is also a volunteer director and committee member of ILFA.

2020 saw sadly the EU-IPFF postpone the 1st ever European Pulmonary Fibrosis Patient Summit due to Covid -19 but 2021 will see delegates from 35 countries attend virtually its three-day programme of lectures and presentations. Ireland and ILFA will be well represented with four speakers nominated by ILFA. The EU-IPFF co-funded ILFA's survey into the impact of Covid-19.

The EU-IPFF is a Belgium registered international not for profit of which ILFA is a co-founder. The EU-IPFF has 21 full members from 15 European countries with further close ties to other groups and countries around the world. It is active in European policy, patient Involvement in clinical trials and research as well as supporting an annual awareness campaign. The federation aims to be a unified voice for European pulmonary fibrosis patients, and it works closely with its members and its many international partners to further the cause of those with pulmonary fibrosis.

The federation acts an advocate for its members including ILFA at European level and is currently involved in consultations around varied European legislative measures including the upcoming review of the Rare and Childhood Medicines Legislation. More details on the EU-IPFF and its work can be found on its website

www.eu-ipff.org



Membership and Alliances

ILFA is a member of:

- The Irish Lung Health Alliance
- The Irish Donor Network
- The European Idiopathic Pulmonary Fibrosis and Related Diseases Federation
- The Wheel
- Rare Disease Ireland
- Care Alliance Ireland

ILFA's Funding Bodies and Corporate Partners 2020

The Irish Lung Fibrosis Association would like to thank the following corporate partners supporting for our work in 2020:

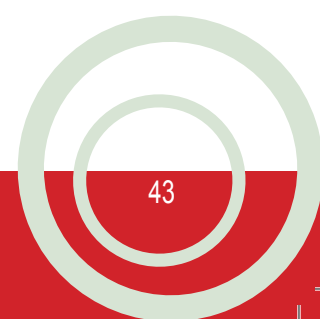
- Air Liquide Healthcare Ireland Ltd
- BOC Healthcare Ireland
- Boehringer Ingelheim Ltd
- Community Foundation of Ireland in association with Bank of Ireland
- Community Foundation of Ireland / RTE Does Comic Relief
- Pobal
- Rashr
- Roche Products Ireland Ltd

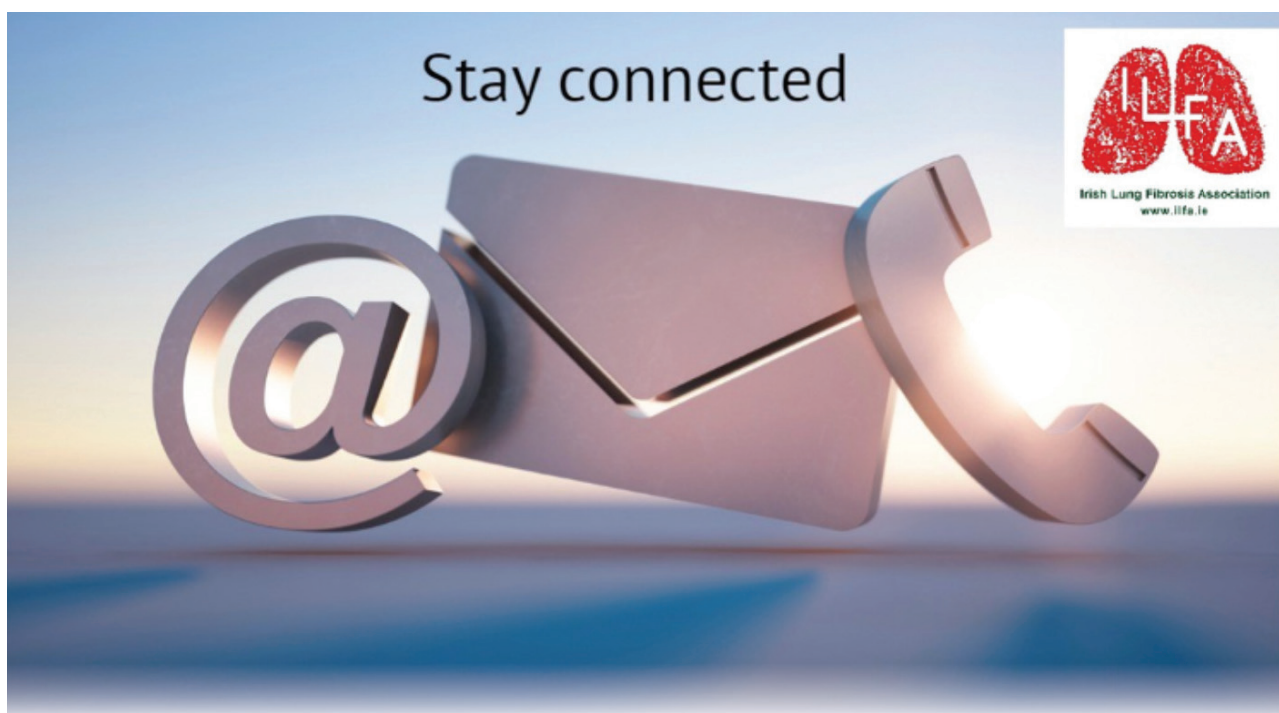
Acknowledgements

The ILFA committee would like to thank all the healthcare professionals who support and advocate for patients diagnosed with IPF. We would also like to express our thanks to our fundraisers, donors and corporate sponsors who have enabled ILFA to conduct our work supporting patients and family members and provide research and educational bursaries in 2020. Your commitment and contribution are deeply appreciated.

We are indebted to;

- Fundraisers
- Volunteers
- Support Group Leaders & Past committee members
- Hayes Solicitors
- Whiteside Cullinan
- Judita Press
- Boehringer Ingelheim Ireland Ltd.
- Roche Products Ireland Ltd.
- Air Liquide Healthcare Ireland Ltd.
- BOC Healthcare Ireland
- patientMpower
- Irish Thoracic Society
- Anáil
- Irish Donor Network
- European Idiopathic Pulmonary Fibrosis and Related Diseases Federation
- Community Foundation of Ireland in association with Bank of Ireland
- Community Foundation of Ireland / RTE Does Comic Relief
- Pobal and the Dept of Rural and Community Development
- Rashr





Irish Lung Fibrosis Association (ILFA)

Registered Address: Lavery House, Earlsfort Terrace, Dublin 2

Postal Address: PO Box 10456, Blackrock, County Dublin

Telephone: 086 871 5264

Email: info@ilfa.ie

Website: www.ilfa.ie

Company registration number 367940

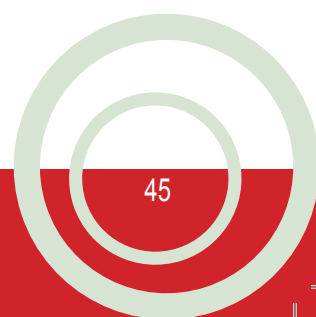
Registered charity number 20053437

Charitable exemption number CHY 15462

The Irish Lung Fibrosis Association CLG
Annual Report and Financial Statements
for the financial year ended 31 December, 2020



Company registration number 367940
Registered charity number 20053437
Charitable exemption number CHY 15462



The Irish Lung Fibrosis Association CLG

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The Irish Lung Fibrosis Association CLG

DIRECTORS AND OTHER INFORMATION

Directors	Edward Cassidy Nicola Cassidy James Egan Liam Galvin
Company Secretary	Michael Geoghegan
Company Number	367940
Charity Number	20053437
Registered Office	Lavery House Earlsfort Terrace Dublin 2
Business Address	PO Box 10456 Balckrock Co Dublin
Auditors	Whiteside Cullinan Registered Auditor and Chartered Accountants Fleming Court Fleming's Place Dublin 4 D04 N4X9
Bankers	Bank of Ireland Montrose Dublin 4
Solicitors	Hayes Solicitors Lavery House, Earlsfort Terrace, Dublin 2

The Irish Lung Fibrosis Association CLG

DIRECTORS' REPORT

for the financial year ended 31 December 2020

The directors present their report and the audited financial statements for the financial year ended 31 December 2020.

Principal Activity

The Irish Lung Fibrosis Association's activities increase the awareness and understanding of idiopathic pulmonary fibrosis. The company is a registered charity, CHY 20053437.

Assets and liabilities and financial position

At the end of the financial year, the company has assets of €334,614 (2019 - €303,867) and liabilities of €27,959 (2019 - €25,488). The net assets of the company have increased by €28,276.

Directors and Secretary

The directors who served throughout the financial year were as follows:

Edward Cassidy
Nicola Cassidy
James Egan
Liam Galvin

The secretary who served throughout the financial year was Michael Geoghegan.

Future Developments

The company plans to continue its present activities and current trading levels. The Directors are hopeful that restrictions imposed due to the Covid-19 pandemic will be eased so that additional fund raising events can be organised.

Auditors

The auditors, Whiteside Cullinan, (Registered Auditor) have indicated their willingness to continue in office in accordance with the provisions of section 383(2) of the Companies Act 2014.

Accounting Records

To ensure that adequate accounting records are kept in accordance with sections 281 to 285 of the Companies Act 2014, the directors have established appropriate books to adequately record the transactions of the company. The directors also ensure that the company retains the source documentation for these transactions. The accounting records are maintained at the company's office at Lavery House, Earlsfort Terrace, Dublin 2.

Signed on behalf of the board

Edward Cassidy
Director

Liam Galvin
Director

27 July 2021

The Irish Lung Fibrosis Association CLG

DIRECTORS' RESPONSIBILITIES STATEMENT

for the financial year ended 31 December 2020

The directors are responsible for preparing the Directors' Report and the financial statements in accordance with applicable Irish law and regulations.

Irish company law requires the directors to prepare financial statements for each financial year. Under the law the directors have elected to prepare the financial statements in accordance with the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council. Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the assets, liabilities and financial position of the company as at the financial year end date and of the profit or loss of the company for the financial year and otherwise comply with the Companies Act 2014.

In preparing these financial statements, the directors are required to:

- select suitable accounting policies for the company financial statements and then apply them consistently;
- make judgements and accounting estimates that are reasonable and prudent;
- state whether the financial statements have been prepared in accordance with applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the company will continue in business.

The directors are responsible for ensuring that the company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the company, enable at any time the assets, liabilities, financial position and profit or loss of the company to be determined with reasonable accuracy, enable them to ensure that the financial statements and Directors' Report comply with the Companies Act 2014 and enable the financial statements to be readily and properly audited. They are also responsible for safeguarding the assets of the company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the directors are aware:

- there is no relevant audit information (information needed by the company's auditor in connection with preparing the auditor's report) of which the company's auditor is unaware, and
- the directors have taken all the steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the company's auditor is aware of that information.

Signed on behalf of the board

Edward Cassidy
Director

Liam Galvin
Director

27 July 2021

INDEPENDENT AUDITOR'S REPORT

to the Shareholders of The Irish Lung Fibrosis Association CLG

Report on the audit of the financial statements

Opinion

We have audited the financial statements of The Irish Lung Fibrosis Association CLG ('the company') for the financial year ended 31 December 2020 which comprise the Income Statement, the Balance Sheet and notes to the financial statements, including the summary of significant accounting policies set out in note 2. The financial reporting framework that has been applied in their preparation is Irish Law and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued in the United Kingdom by the Financial Reporting Council.

In our opinion the financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31 December 2020 and of its profit for the financial year then ended;
- have been properly prepared in accordance with FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland"; and
- have been properly prepared in accordance with the requirements of the Companies Act 2014.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are described below in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of financial statements in Ireland, including the Ethical Standard for Auditors (Ireland) issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), and the Provisions Available for Audits of Small Entities, in the circumstances set out in note 3 to the financial statements, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other Information

The directors are responsible for the other information. The other information comprises the information included in the annual report other than the financial statements and our Auditor's Report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the course of the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2014

Notwithstanding our adverse opinion on the financial statements, we report that:

- the information given in the Directors' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Directors' Report has been prepared in accordance with the Companies Act 2014.

We have obtained all the information and explanations which, to the best of our knowledge and belief, are necessary for the purposes of our audit.

In our opinion the accounting records of the company were sufficient to permit the financial statements to be readily and properly audited. In our opinion the financial statements are in agreement with the accounting records.

INDEPENDENT AUDITOR'S REPORT

to the Shareholders of The Irish Lung Fibrosis Association CLG

Matters on which we are required to report by exception

Based on the knowledge and understanding of the company and its environment obtained in the course of the audit, we have not identified any material misstatements in the Directors' Report. The Companies Act 2014 requires us to report to you if, in our opinion, the disclosures of directors' remuneration and transactions required by sections 305 to 312 of the Act, which relate to disclosures of directors' remuneration and transactions are not complied with by the company. We have nothing to report in this regard.

Respective responsibilities

Responsibilities of directors for the financial statements

As explained more fully in the Directors' Responsibilities Statement, the directors are responsible for the preparation of the financial statements in accordance with the applicable financial reporting framework that give a true and fair view, and for such internal control as they determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the directors are responsible for assessing the company's ability to continue as a going concern, disclosing, if applicable, matters related to going concern and using the going concern basis of accounting unless management either intends to liquidate the company or to cease operation, or has no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an Auditor's Report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is contained in the appendix to this report, located at page 8, which is to be read as an integral part of our report.

The purpose of our audit work and to whom we owe our responsibilities

Our report is made solely to the company's shareholders, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the company's shareholders those matters we are required to state to them in an Auditor's Report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume any responsibility to anyone other than the company and the company's shareholders, as a body, for our audit work, for this report, or for the opinions we have formed.

Mark Hamill
for and on behalf of
WHITESIDE CULLINAN

Registered Auditor and Chartered Accountants
Fleming Court
Fleming's Place
Dublin 4
D04 N4X9

27 July 2021

The Irish Lung Fibrosis Association CLG

APPENDIX TO THE INDEPENDENT AUDITOR'S REPORT

Further information regarding the scope of our responsibilities as auditor

As part of an audit in accordance with ISAs (Ireland), we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the directors.
- Conclude on the appropriateness of the directors' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our Auditor's Report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our Auditor's Report. However, future events or conditions may cause the company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

The Irish Lung Fibrosis Association CLG

INCOME STATEMENT

for the financial year ended 31 December 2020

	Notes	2020 €	2019 €
Revenue		165,970	82,584
Gross profit		165,970	82,584
Administrative expenses		(137,694)	(105,872)
Profit/(loss) before taxation		28,276	(23,288)
Tax on profit/(loss)		-	-
Profit/(loss) for the financial year		28,276	(23,288)
Total comprehensive income		28,276	(23,288)
Retained profit brought forward		278,379	301,667
Retained profit carried forward		306,655	278,379

Approved by the board on 27 July 2021 and signed on its behalf by:

Edward Cassidy
Director

Liam Galvin
Director

The Irish Lung Fibrosis Association CLG BALANCE SHEET

as at 31 December 2020

	Notes	2020 €	2019 €
Current Assets			
Debtors	5	13,025	4,287
Cash and cash equivalents		321,589	299,580
		<u>334,614</u>	<u>303,867</u>
Creditors: Amounts falling due within one year	6	<u>(27,959)</u>	<u>(25,488)</u>
Net Current Assets		<u>306,655</u>	<u>278,379</u>
Total Assets less Current Liabilities		<u><u>306,655</u></u>	<u><u>278,379</u></u>
Capital and Reserves			
Income statement		<u>306,655</u>	<u>278,379</u>
Equity attributable to owners of the company		<u><u>306,655</u></u>	<u><u>278,379</u></u>

The financial statements have been prepared in accordance with the small companies' regime.

Approved by the board on 27 July 2021 and signed on its behalf by:

Edward Cassidy
Director

Liam Galvin
Director

The Irish Lung Fibrosis Association CLG

NOTES TO THE FINANCIAL STATEMENTS

for the financial year ended 31 December 2020

1. GENERAL INFORMATION

The Irish Lung Fibrosis Association CLG is a company limited by shares incorporated in the Republic of Ireland

2. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

The following accounting policies have been applied consistently in dealing with items which are considered material in relation to the company's financial statements.

Statement of compliance

The financial statements of the company for the year ended 31 December 2020 have been prepared on the going concern basis and in accordance with generally accepted accounting principles in Ireland and Irish statute comprising the Companies Act 2014 and in accordance with the Financial Reporting Standard applicable in the United Kingdom and the Republic of Ireland (FRS 102) issued by the Financial Reporting Council

Basis of preparation

The financial statements have been prepared on the going concern basis and in accordance with the historical cost convention except for certain properties and financial instruments that are measured at revalued amounts or fair values, as explained in the accounting policies below. Historical cost is generally based on the fair value of the consideration given in exchange for assets. The financial reporting framework that has been applied in their preparation is the Companies Act 2014 and FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" issued by the Financial Reporting Council.

The company qualifies as a small company as defined by section 280A of the Companies Act 2014 in respect of the financial year, and has applied the rules of the 'Small Companies Regime' in accordance with section 280C of the Companies Act 2014.

Cash flow statement

The company has availed of the exemption in FRS 102 from the requirement to prepare a Cash Flow Statement because it is classified as a small company.

Revenue

Income comprises the amounts received from donations, fundraising activities and deposit interest receivable.

Taxation

The company is a registered charity, CHY 20053437, and has been granted charitable tax exemption under Section 207, Taxes Consolidation Act, 1997. The CHY (Revenue) number is 15462.

3. PROVISIONS AVAILABLE FOR AUDITS OF SMALL ENTITIES

In common with many other businesses of our size and nature, we use our auditors to assist with the preparation of the financial statements.

4. EMPLOYEES

There were no employees during the period under review.

5. DEBTORS

	2020	2019
	€	€
Other debtors	11,216	2,209
Prepayments	1,809	2,078
	<u>13,025</u>	<u>4,287</u>

The Irish Lung Fibrosis Association CLG

NOTES TO THE FINANCIAL STATEMENTS

continued

for the financial year ended 31 December 2020

6. CREDITORS	2020	2019
Amounts falling due within one year	€	€
Amounts owed to credit institutions	9,377	725
Accruals	18,582	24,763
	27,959	25,488

7. State Funding

Agency	Pobal
Government Department	Department of Rural and Community Development
Grant Programme	COVID-19 Stability Scheme 2020
Purpose of the Grant	To assist with the payment of non-pay costs and help maintain financial viability during the COVID19 pandemic to assist the delivery of critical services and supports.
Term	1 January 2020 - 31 December 2020
Total Fund	€47,031
Expenditure	€47,031
Received in the financial year	€47,031
Restriction on use	The grant must be spent on non-pay costs only as listed in the grant agreement.

8. POST-BALANCE SHEET EVENTS

There have been no significant events affecting the company since the financial year-end.

9. APPROVAL OF FINANCIAL STATEMENTS

The financial statements were approved and authorised for issue by the board of directors on 27 July 2021.

Irish Lung Fibrosis Association (ILFA)

Registered Address: Lavery House, Earlsfort Terrace, Dublin 2

Postal Address: PO Box 10456, Blackrock, County Dublin

Telephone: 086 871 5264

Email: info@ilfa.ie

Website: www.ilfa.ie

Company registration number 367940

Registered charity number 20053437

Charitable exemption number CHY 15462





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