Irish Lung Fibrosis Association
www.ilfa.ie

Irish Lung Fibrosis Association Annual Report 2019

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, Molesworth House, South Frederick Street, Dublin 2.

Foreword from ILFA Chairman

Welcome to ILFA's Annual Report which covers the financial period from March 2019 to December 2019 and encompasses marks the 17-year anniversary since ILFA was founded. This year was our busiest to date and we are grateful to our wonderful fundraisers, corporate donors and kind supporters who have helped ILFA to flourish and go from strength to strength.

ILFA's aims are to support patients and families and promote education and research in lung fibrosis. During this financial period, ILFA continued to support patients and families living with IPF and the healthcare professionals who care for them. We delivered two patient information days and our annual ecumenical service; we supplied printed materials, practical living aids and exercise resources free of charge to numerous individuals and staff working in hospitals, community settings and hospices; we provided educational bursaries to healthcare professionals in the respiratory community and awarded five research bursaries to clinicians and researchers working on various lung fibrosis research projects. Our advocacy work campaigning for the introduction of the Human Tissue Bill continued, and we were delighted to welcome David Crosby as an ILFA Ambassador in recognition and appreciation of his great fundraising and awareness raising activities over recent years.

I am indebted to the dedicated and hard-working ILFA directors and committee members who volunteer their time, talents and experience to help ILFA achieve its aims. The committee is supported superbly by Gemma O'Dowd, ILFA's Administrative Assistant, and we are grateful to her for her commitment, efficiency, and warmth in supporting patients, families, healthcare professionals and the ILFA committee. Warmest thanks to the support group leaders who have kindly volunteered to help coordinate the regional groups and facilitate valuable peer support.

On behalf of the ILFA Committee, I would like to extend our gratitude to David Buggy (Whiteside Cullinan Auditors), to David Phelan and the team at Hayes Solicitors for their professional services and guidance, and to the Irish Thoracic Society for their valuable advocacy work on behalf of respiratory patients and patient organisations. The committee sincerely appreciates the contributions from everyone who has given their time, commitment, fundraising efforts, and donations large and small to ILFA. Your generous support is hugely appreciated and is making a real difference to our work.

Warmest thanks,

Eddie Cassidy, Chairman of the Irish Lung Fibrosis Association

CONTENTS Page

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 solely by donations and fundraising activities. 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 IPF, and healthcare professionals with a special interest in lung fibrosis.

In 2019, 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.

Nicky Goodbody acted as Director until September 2019, when she retired from her role. We would like to thank Nicky for her contribution, dedication, and support to ILFA since it was founded in 2002.

The committee hold regular meetings approximately every 4-6 weeks in Dublin city centre. Nine committee meetings took place in 2019.

ILFA's 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.

Finance

ILFA 2019 Treasurer's Report - Marie Sheridan

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.

We are entirely funded by donations and are very much appreciative of everyone who raised vital funds to enable us to maintain our services in 2019, and going forward. In 2019 we received no government funding. Some of our events and projects were sponsored by corporate bodies. This year we changed our accounts reporting year end, from 28 February to 31 December, in order to tie in with the calendar year.

Our latest audited accounts are for the ten months to 31 December 2019.

In this period we incurred a deficit of expenditure over income of €23,288.

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

The deficit of €23,288 in the ten months to 31 December 2019 results from income of €82,584 and expenditure of €105,872. Our balance sheet shows net reserves brought forward as at 31 December 2019 of €278,379.

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

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, who is an independent consultant. In the ten months to 31 December 2019, she was paid €35,861. In the year to 28 February 2019 the amount paid 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 2019 we provided €25,000 to finance five research projects, which are ongoing. Every year, we also finance healthcare professionals to attend conferences and courses where they can learn about up to date developments in the area of pulmonary fibrosis and network with international colleagues.

ILFA runs two information days and produces three newsletters a year as well as providing information packs to our members who are recently diagnosed. We have built up a range of useful leaflets, covering all aspects of dealing with IPF. Support is provided through our phone line too, which is manned by our administrative assistant.

ILFA is lucky enough to have built up a loyal following of members who continue to surprise and delight us with their imagination and commitment to fundraising. We look forward to 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.

Message from ILFA Secretary - Michael Geoghegan

Shortly after my lung transplant operation I was asked to speak at an ILFA information day. I envisaged a small group, but you can imagine my surprise when I realised the numbers were close to 70. This was my first experience of meeting a broad spectrum of IPF patients and ILFA members and what was immediately apparent is the important role ILFA played in their lives and in the management of their illness.

I had no knowledge of ILFA when I was a patient, even at the stage when I was finally placed on the transplant list. I didn't become aware of the organisation until after my transplant operation. Anyone with knowledge of the disease knows it is a very difficult, stressful and lonely journey for both the patient and their family, but it is especially painful when you are on that journey alone. When I look back now and realise the extraordinary support available from both ILFA and the groups, I can only imagine the difference that support would have meant for me and the family. I sincerely hope that through the work of ILFA and its various support groups there is no other IPF patient and family out there trying to manage the disease alone.

I suppose because I was selected for a transplant, I am acutely aware of the fact that there are so many others who are not as fortunate for whatever reason. It is important that the many obstacles in the way of more transplants are removed. ILFA, has shown remarkable leadership in this area especially in pushing for the implementation of the Human Tissue Bill which should improve organ availability. I am aware that among other obstacles which must be addressed is the limited access to theatre time and availability of additional Consultants. I know that ILFA can continue to play a central role in this area.

Advocacy

- We support change and challenge current practice to improve access to appropriate resources.
- We speak up on people's behalf and lobby Government for adequately resourced services.
- We collaborate with other patient organisations, alliances, and networks to achieve shared goals.

Advocacy – report from Nicola Cassidy, ILFA Director

In 2019, ILFA was committed to continuing our advocacy work on behalf of those affected by lung fibrosis. A summary of our advocacy work is presented below.

The Human Tissue Bill includes the provision for an opt-out organ donation system and is currently under review before being presented to the government in the first quarter of 2019.

The Irish Donor Network (an alliance of patient organisations including Cystic Fibrosis Ireland, Irish Heart and Lung Transplant Association, ILFA, Alpha-One Ireland, Cystinosis Ireland, Pulmonary Hypertension Association of Ireland and COPD Support Ireland) continued to campaign for an opt-out organ donation consent system as well as substantial investment in resources, infrastructure and healthcare personnel, and continuous awareness campaigns to transform and optimise organ donation and transplantation rates in Ireland.

Nicola Cassidy (ILFA Director), Philip Watt (CEO of Cystic Fibrosis Ireland) and Robert McCutcheon (Chair of the Irish Heart and Lung Transplant Association) represented the Irish Donor Network and met with Michael Conroy from the Department of Health and his colleagues James Allen and Helen O'Brien in July and September. The Irish Donor Network also met with Professor Jim Egan of Organ Donation and Transplantation Ireland in August.

ILFA contributed a letter to the Irish Medical Journal entitled 'Opt-out organ donation - a patient organisation's perspective'.

National Heart and Lung Transplant Unit

ILFA was delighted to learn that following many year's campaigning and lobbying for the opening of the full complement of beds at the National Heart and Lung Transplant Programme at the Mater Misericoridae University Hospital (MMUH) in Dublin, the HSE's 2019 Service plan committed to "Progress the opening of transplant service beds for pre, peri and post-transplant related activity in MMUH"

and "Further develop the national organ retrieval service in compliance with the European Working Time Directive."

Pulmonary Fibrosis Awareness Campaign 2019

A successful media campaign took place from April to June 2019 that helped create awareness of Idiopathic Pulmonary Fibrosis in the national and local media, online and on social media. ILFA is grateful to the many people across the country who volunteered to tell their personal stories. The media campaign highlighted the positivity, determination, and courage of patients and families living with IPF as well as the benefits of exercise in managing the condition.

Some of the campaign highlights included;

- Printed and online media coverage included; *Independent.ie, Irish Examiner, RTE Guide, The Mirror, The Star, Irish Daily Mail, Irish Health.com, Senior Times, Irish Sun, RSVP, Mature Living, Dublin Gazette, Echo, Fingal Independent, Northside People.*
- Radio interviews with *East Coast FM, Phoenix radio, South Tipp FM, Dublin South FM, Midlands 103, Shannon side, Clare FM, Near FM, LMFM*
- David Crosby appeared on *The Elaine Show* and shared his story from being diagnosed with IPF, receiving a double lung transplant and subsequent training for the World Super Six marathons. David was also interviewed on the *Ray D'Arcy Show* on RTE Radio 1 ahead of Organ Donation Awareness Week and interviewed on the *Ivan Yates Newstalk Show* in relation to the Cork Marathon Relay Run in June.
- TV coverage: The *Today Show (RTE1).* Carmel McInerney, respiratory nurse specialist at Ennis Hospital and Michael Collins, Ennis Pulmonary Fibrosis Support Group appeared on the RTÉ Today Show with Dáithí Ó'Sé and Maura Derrane in May. Michael nominated Carmel for a special pampering treat for her dedication to pulmonary fibrosis patients. Carmel and Michael had a very special day and Carmel looked radiant when her make-over was revealed. We were delighted when Daithi also mentioned ILFA's Yoga DVD live on air!
- Nicola Cassidy wrote a Letter to the Editor of the Irish Runner that was published in the August edition describing ILFA's participation in the Cork Marathon Relay event.

Educational Opportunities for Healthcare Professionals working in Respiratory Medicine

ILFA believes that education and research are key to understanding more about lung fibrosis and its impact on those diagnosed with Idiopathic Pulmonary Fibrosis (IPF). Over the years, ILFA has supported and funded education and research bursaries.

In 2019, ILFA further supported healthcare professionals by awarding educational bursaries and funding a number of research projects.

The Interstitial Lung Disease Interdisciplinary Network (ILD-IN)

The Interstitial Lung Disease Interdisciplinary Network (ILD-IN) conference took place in Birmingham in October 2019. ILFA awarded educational bursaries to 10 healthcare professionals to support their attendance at the conference.
The bursary recipients were;

John Alickolli (Bon Secours Hospital Cork)

Rosaleen Anglim (South Tipperary Hospital)

Grainne Casey (Mater Misericordiae University Hospital)

Elaine Craven (Connolly Hospital Blanchardstown)

Antoinette Doherty (Letterkenny Hospital)

Carol Doherty (Letterkenny Hospital)

Julie Goss (Harold's Cross Hospice, Dublin)

Donna Langan (Galway University Hospital)

Carmel McInerney (Ennis Hospital) and

Lavinia McLeod (Mater Misericordiae University Hospital).

In addition, Liam Galvin (ILFA Director, EU-IPFF Secretary) and Nicola Cassidy (ILFA Director) attended the conference. Nicola Cassidy gave a presentation entitled 'ILFA's Palliative Care Strategy'.

Attendees at the ILD-INN meeting.

Report from Elaine Craven -
Recipient of an ILFA Educational Bursary

Elaine Craven, Respiratory Advanced Nurse Practitioner: “I would like to express my gratitude to ILFA for their support in affording me the opportunity to attend this year’s ILD–IN Conference in Birmingham. The diversity of the agenda was most impressive with many varied topics delivered by highly esteemed speakers. From science to psychology, radiology to rehab, insights and outcomes, projects and policies; the thought, effort and passion that went into coordinating the two-day conference was apparent.

In addition, networking opportunities with our overseas colleagues allowed for healthy discussions regarding the triumphs and challenges faced in the everyday practicum. This sharing of ideas and practices proved invaluable. The relentless efforts of our wonderful charity (ILFA) who are continuously developing innovative initiatives such as a World Café and a Yoga DVD left everyone inspired. Not to mention the volunteers who are dashing, running, swimming and constantly counting steps to improve the services provided to patients with ILD. Both professionals and patients provided unique perspectives on living well and dying better that were equally heart-breaking as they were heart-warming.

Above all the atmosphere was one of shared enthusiasm among delegates with a demonstrable thirst for knowledge while the patient and their families remained the central focus throughout. It was a fabulous conference and I would highly recommend any HCP with an interest in ILD to attend. Once again, thank you so much to ILFA.”

Report from Julie Goss -
Recipient of an ILFA Educational Bursary

Julie Goss, Advanced Nurse Practitioner Palliative Care: “I would sincerely like to thank ILFA for providing the bursary which enabled me to attend this fantastic conference that was exemplary in providing a wonderful mix of high-quality clinical information, coupled with a very real spotlight on the value of psychological care, interdisciplinary team working, partnership with patients and support bodies and robust clinical research.

A personal highlight of the conference was to hear Dr Havi Carel describe research findings from the ‘Life of Breath’. project which explores the relationship of breathlessness to both illness and wellbeing. It was very hopeful therefore to hear from Dr Karen Marshall on how the use of evidence based practical strategies such as CBT (cognitive behavioural therapy) techniques, that can be learned and utilised by health care professionals to help relieve the distress that can accompany living with chronic illness. This is an area of practice that I would like to develop further for use in our Multidisciplinary Breathlessness Support Service at Our Lady’s Hospice and Care Services.”

Research Funding for Lung Fibrosis

The Irish Lung Fibrosis Association was pleased to award funding of €25,000 for research into lung fibrosis in Ireland. Clinicians and scientists working in respiratory medicine were invited to apply to ILFA for research funding in June 2019. We were delighted to receive so many high-quality applications for innovative and inspiring research projects.

Funding was provided to support five research projects which are described below. ILFA's financial investment in research is made possible thanks to kind donations from individuals and the hard work and dedication of our amazing fundraisers.

1) Elucidation of the Anti-Fibrotic Activity of a Repurposed Drug for IPF

Dr Cian O'Leary, School of Pharmacy, Royal College of Surgeons in Ireland

"We are delighted to receive this funding from ILFA to support our work towards developing new inhalable therapies for Idiopathic Pulmonary Fibrosis (IPF). This support means that we can now explore and understand how a drug candidate in our laboratory operates to reduce fibrosis on a cellular level in the lungs, which is a critical part of research towards our ambition to formulate a new medicine that can improve the well-being of those suffering from IPF or Interstitial Lung Disease."

2) Role of microbiota-derived short chain fatty acids in the regulation of pulmonary fibroblast function.

Dr John Baugh, University College Dublin and Mater Misericordiae University Hospital

"Thanks to ILFA for this great opportunity. This award will allow us to perform experiments that would not otherwise be possible to build on our pilot studies and strengthen translational links with clinical colleagues. We hope to generate definitive data supporting the link between microbiota-derived short chain fatty acids and fibroblast function thereby establishing a link between diet, gut microbes and lung fibrosis."

3) Irish Thoracic Society Interstitial Lung Disease (ITS ILD) Registry

Professor Anthony O'Regan, Irish Thoracic Society and Galway University Hospital

"The Irish Thoracic Society and its lung fibrosis group are committed to enhancing and improving the care of patients with lung fibrosis in Ireland. The ILFA bursary will provide much needed support to clinicians in lung fibrosis clinics around Ireland to move the registry development to the next stage. This work will provide critical information on patients with IPF and enhance our understanding of this disease in Ireland through data collection and research."

4) A longitudinal study of patient self-reported data in IPF

Dr Cormac McCarthy, St. Vincent's University Hospital

"We are delighted with the financial support from ILFA to help conduct this study, in which we will investigate the 'real-world' experiences of persons with IPF. This funding will allow us to understand the experiences of patients at the time of diagnosis and commencement of treatment and how these experiences relate to their condition. Using modern app technology, we will gain insight into this condition through data directly collected by patients."

5) Genetic incidence of telomere related mutations and shortened telomere length among Irish pulmonary fibrosis (IPF) patients

Dr Abhilash Sahadevan (Dr Cormac McCarthy Director), St Vincent's University Hospital

"The research funding will boost our research into characterisation of telomerase related mutations among our Irish pulmonary fibrosis group."

Some of the recipients of the ILFA Research Funding with ILFA committee members.

ILFA Patient Supports

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 and patients and family members meet up every month.

Cavan/Monaghan Support Group

The Cavan/Monaghan Support Group meets in Monaghan

Clare Support Group

The Clare Support Group meets in Ennis, Co Clare

Mid-West Support Group

The Mid-West Support Group meets in Birdhill, Tipperary

Cork Support Group

The Cork Support Group meets in Glounthuane, Cork

Dublin Support Group

The Dublin Support Group meets in the Carmelite Community Centre at Whitefriar Street Church, Aungier Street (South George's Street), Dublin 2

Kerry Support Group

The Kerry Support Group meets in Tralee, Kerry.

Midland Support Group

The Midland Support Group meets in Tullamore, Offaly

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

ILFA Patient Information Days

ILFA was pleased to be able to host 2 patient information days in 2019. 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.

Patient Information Day on 6th April 2019

Speakers at the Patient Information Day, April 2019.

ILFA's first information day of 2019 took place at the Hilton Airport Hotel, Malahide, Dublin on 6th April 2019. The focus of this meeting was palliative care and planning for the future for Idiopathic Pulmonary Fibrosis (IPF). The meeting was well attended by patients, family members and healthcare professionals.

Speakers at the event were;

Dr Anne-Marie Russell, Honorary Clinical Research Fellow at the Royal Brompton Hospital London

Andrew Cooper, Caregiver, Dublin

Dr Killian Hurley, Respiratory Consultant at Beaumont Hospital

Lynn Fox, Respiratory Nurse Specialist at the Mater University Hospital

Irene Byrne, physiotherapist at the Mater University Hospital

Dr Irfan Shah, medical registrar at St Michael's Hospital

Maria Love, social worker at the Mater University Hospital

Bettina Korn, the End-of-Life Co-ordinator at St James Hospital,

Rebecca Lloyd, Public Engagement Officer at the Irish Hospice Foundation

Patient Information Day on 19th October 2019

Speakers at the Patient Information Day, October 2019.

The Autumn Patient Information Day took place at the Crowne Plaza Hotel, Northwood, Dublin and was well attended.

Speakers at the event were;

Professor Jim Egan, Respiratory Consultant at the Mater University Hospital

Dr Michelle Murray, Respiratory Consultant at the Mater University Hospital

Lindsay Brown, Respiratory Nurse Specialist at St Vincent's University Hospital

Carita Bramhill, Respiratory Research Nurse at St Vincent's University Hospital

Professor Bernard Mahon, School of Biology & Immunology at Maynooth University

Dr Jennifer Wilson O'Raghallaigh, Clinical Psychologist at Beaumont Hospital

Petra Grehan, Respiratory Physiotherapist at the Mater University Hospital

Adrian Sheehan, BOC Healthcare Ireland

Sonia Morrison, Air Liquide Ireland

Katie Crosby, family caregiver from Cavan.

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. Our list of some of the resources available is included here:

- 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
- ILFA 2000 Steps a Day Challenge
- STALL Breathing Technique Card from ILFA
- ILFA Medical Alert Card
- ILFA Exercise DVD for Lung Fibrosis Patients
- ILFA Yoga DVD for Lung Fibrosis Patients

Fundraising

ILFA is very grateful to all our volunteers and members of the public who have helped to raise vital funds for the charity. Without their efforts we would not be able to provide support and information to our members.

One of the many events which took place in 2019 was the Pat Casey Memorial Cycle. This incredible event is now in its eight year and has raised thousands of euro for ILFA. The Pat Casey Memorial Cycle 2019 took place on 21st September. We are enormously grateful to the organisers, participants and volunteers who make this event possible.

A report from Daniel Casey

"At 9.30am, just as the rain started, 20 brave cyclists left the Cork City Ford Centre on Forge Hill for the annual 122Km route. They battled cross winds and inclement weather to complete the round-trip in just under 7 hours, returning safely to a hero's welcome at the Ford Centre once again. Speaking on the day, cycle organiser, Anne Casey said "The weather reports were against us but that did not deter the loyal group of cyclists from taking part. We are always so grateful for their dedication. The support we receive from people is always overwhelming and the Cork Pulmonary Fibrosis Support Group are always on hand to help out on the day".

Speaking after completing the cycle Brian Aherne added "The support we get every year for this event means the world to us. Remembering Pat is what it is about. I would like to thank John Nolan from the Cork City Ford Centre and all the collectors from the Cork Pulmonary Fibrosis Support Group for everything they do to help out". Daniel Casey, Pat's son added "Year on year I am always so happy to see the same faces come out in remembrance of Dad. What we are doing - raising awareness and fundraising is something that is near to our hearts and we are so grateful to everyone who helps make this possible".

The organisers would like to thank all those who took part on the day, those who shook buckets on our collection days prior to the cycle and the Cork Support Pulmonary Fibrosis Support Group who give their time and are invaluable to us. Preparations for the 2020 Pat Casey Memorial Cycle are already underway!"

Some fundraising highlights 2019

Swim to Tory Island

Padraig McFadden from the Bloodyforelands on the north west coast of Donegal took on an epic and daunting challenge in June 2019 when he swam from Tory Island to the Donegal mainland in memory of his grandmother Sadie McFadden to raise valuable funds for ILFA. Months of hard work and preparation went into training for the Tory island swim challenge and Padraig provided ILFA with regular updates on his progress. Here is the story in Padraig's own words.

"My name is Padraig McFadden. I recently lost my lovely, beautiful, witty little mate, my grandmother, to Idiopathic Pulmonary Fibrosis (IPF) in November last year. There are not many words I can use that describe this horrible disease - only I wouldn't wish it on anyone. In the months before my grandmother passed, I had it in my head that I would like to raise more awareness about this relatively unknown condition and raise some money for research. I had a chat with her and told her I was going to do the nine and a bit mile swim to Tory Island which we could see in the distance from her kitchen window, in aid of the Irish Lung Fibrosis Association. Of course her first reaction was "Cop on will ya" but after some more talking she said "You know what, if you think you can do it, then go for it".

From then on, I started to plan the swim. I contacted ILFA who have been very helpful and informed them of the swim. I enlisted the help of the Sheephaven Sub Aqua Club who agreed to help and be my crew and support boat on the day and I set up an online fundraising page for ILFA."

On Saturday the 22nd June I managed to swim from Tory Island across to the north west coast of Donegal, a distance of 9 miles in 5 hours and 29 minutes. We all gathered at the pier at 6.30am that morning and met up with the members of the Sheephaven Sub Aqua Club along with my own crew of family members to help out with feeds and prep on the rib for the day. Once we were ready, we headed out towards the island. As we set out and the mainland was getting smaller, Tory island itself didn't seem to be getting bigger and from the looks of faces from some of my crew I started to think "Paddy, 'what are you doing?"

Eventually we got to the rocks to the east of the island and I stripped off, got a good covering of Vaseline and took the plunge into the tropical 13 degrees waters. I swam to the nearest rock that I could stand on, gave the thumbs up and away I went. The first mile I tried to settle in and get a good start.

There were blooms of jellyfish keeping me company but luckily all about one metre below me. The two ladies on the support kayaks soon joined me and kept me headed in the right direction for home. After about 6 miles I got caught up in a current that was dragging me back so I had to up the tempo for a good 30 mins until I got out of it and after that I could just about make out the pier, so it gave me a good lift in spirits to keep going. I eventually got to the pier where I was met with a lovely crowd of family and friends to welcome me in and when my feet touched the ground it was a great feeling. I would like to thank absolutely everyone who helped me through the last 8 months. Especially my wife Dayna for her patience and help even during the winter/ spring months with her doing beach watch when I was training and having my feeds ready during the longer swims. The team at ILFA, the crew from Sheephaven; Sheephaven Sub Aqua Club team; Dearn McClintock (boat pilot); Eddie McFadden (boat pilot); Eileen Coll (kayak) and Bernie Gallagher (kayak), and the coast guard. There is no such thing as a solo swim, it's certainly a team effort."

Cork City Marathon Team Relay

The Cork City Marathon team relay took place on Sunday 2nd June 2019 and ILFA had six teams of 26 runners taking part. The fun, comradery, encouragement and support everyone experienced as part of this special fundraising and awareness raising event was wonderful.

ILFA was fortunate to have one of our teams, ILFA Team 1 - The Patient Journey, profiled by the organisers of the Cork city marathon and this helped raise valuable awareness of pulmonary fibrosis, the team work involved in supporting pulmonary fibrosis patients with their journey, the life-changing impact of organ donation and lung transplantation, and ILFA's role in supporting patients, families and respiratory healthcare professionals. ILFA Team 1 was made up of David Crosby, inspirational double lung transplant recipient, and his support team featuring; Lynn Fox - respiratory nurse specialist at the Mater Hospital, Dr Oisin O'Connell - Respiratory Consultant currently at the Bon Secours Hospital Cork, Professor David Healy - Lung Transplant Surgeon at the Mater Hospital and Nicola Cassidy - ILFA Director.

'HAPPY FEET', an international team featuring Annette Johansson, Heather O'Tuairisg, Emma Cooper, and Captain Yvonne Lynch, was the first ILFA team home with an amazing finishing time of 3 hours 30 minutes. They said they wanted to "raise awareness of the condition and support the great work of ILFA."

The 'ROCHE Team' featured colleagues from the pharmaceutical company Roche Products Ireland. Team captain was Triona Rice and she was joined by Gillian Hession, Ronan Butler and Joe Gleeson. Triona said "The Roche Team is absolutely delighted to help raise awareness and much-needed funds for a great cause in Idiopathic Pulmonary Fibrosis. Anything we can do to help this amazing cause is our pleasure and responsibility - even if the thoughts of a marathon is a very scary prospect!".

The 'BOC HOMECARE'. The oxygen company team was captained by Adrian Sheehan and featured Keith McGrath, Michael Creedon, Mick Dooley and Kieran Hamill. This team said

“We’re taking part and running for a very worthwhile charity; the Irish Lung Fibrosis Association. This organisation gives fabulous support to patients nationwide who are suffering from fibrosis of the lungs. The main objective here is to gain exposure and awareness of the organisation so people can get support and information for those in similar circumstances”.

‘SOUL SISTERS’ led by Katie Crosby said “I am taking part with my three sisters Teresa, Deirdre and Bridget to help raise awareness of Lung Fibrosis. My husband David was diagnosed with IPF at 40 years of age but thankfully he received a life-saving double lung transplant six months later. This devastating disease took an enormous toll on our family and our three young children. David received huge support from family and friends around us. In order to maintain a somewhat stable environment for our children, our families and friends stepped in to keep things running smoothly as David and I navigated our way through everything that IPF brought to our door. From numerous hospital appointments, adjusting our lives to a life of oxygen and medication, trying to remain hopeful that a transplant would save David’s life. I’m also running to give recognition to every carer, who is there for their loved ones and for everybody who helps and supports them along the way. Without our families and friends, I would not have been able to remain as strong as I needed to be to get through a really difficult and life changing time

The ‘WELL WISHERS WALKERS’ team was led by captain Stephen Cassidy and featured his father, ILFA Chairman, Eddie Cassidy (running his 25th marathon), his aunt Annette Grehan (running her 14th marathon), and two amazing nurses from South Tipperary General Hospital in Clonmel; Nora McNamara and Betsy Matthews. The team ran in support of pulmonary fibrosis patients and in memory of a family member, Denise Cassidy. The team members had great fun together and developed a strong bond and team spirit despite only meeting Nora and Betsy on race day.

Women’s Mini Marathon 2019

Over 50 ladies took part in the VHI Women’s Mini Marathon in Dublin, on Sunday 2nd June for ILFA. It was a lovely, warm, sunny day and many ladies gathered before the event for Team ILFA photos and afterwards for well-deserved refreshments. Thanks to Sandra Stuhli, graphic designer at Asavie for designing our lovely photo props. One of the participants, Amy Collins sent in this report.

“I did the mini-marathon on behalf of my dad who received a lung transplant 2 years ago. ILFA does great work and gives great support to my father, therefore I wanted to spread awareness by fundraising for ILFA and to promote them. My team also offered their support and wanted to fundraise for the great cause. The day itself was an amazing experience and we completed the mini marathon in 1 hour 15 mins. The best moment was seeing my dad waiting and cheering us on to the finish line. We took him out of the crowd and had him finish with us”.

ILFA would like to thank all the ladies who took part in the 2019 event. We are grateful for their wonderful support and for sharing photos and special memories of the day.

‘Seeing the Light’ Solo Art Exhibition

It was wonderful to have the kindness and support of so many people in relation to my recent fundraising event for the Irish Lung Fibrosis Association, which was my solo art exhibition ‘Seeing the Light’ in the Atrium, Fingal County Council, County Hall, Swords from 21st to 25th of October 2019.

The fundraising event was very successful because €2,100 was raised for ILFA as a result of the solo art exhibition. (This amount represented 50% of the proceeds from the show). All 22 artworks were sold! There were three reasons for the fundraising event. First of all, it was to raise much needed funds for ILFA. Secondly, it was to raise awareness of idiopathic pulmonary fibrosis (IPF). Thirdly, it was to highlight another milestone for me - living with IPF. The artwork for the exhibition was influenced from my love of the Fingal area where I live, my love of science and gardening and some of the work was influenced by my medical condition. Art for me is a welcome distraction from thinking too much about my medical condition. It was the culmination of approximately three years’ work (it takes me a long time to do most of the artworks, as some are carried out dot by dot!) so it was a very special, worthwhile and personal event for me.

Fortunately, the response to the fundraising event from family, relations and friends was beyond expectations. It was very helpful to have the Mayor of Fingal Eoghan O’ Brien launch the exhibition and to also have local playwright David Gilna who was a tremendous help to me in launching the exhibition. They both helped in their speeches to increase awareness of IPF, highlighting the importance of the fundraising event and to demonstrate their genuine empathy and kindness shown towards me.

I am very grateful to ILFA and Fingal County Council for their help and support and to all that attended and supported my solo art exhibition. It was great to have the interest and coverage of the event by the news media in the Fingal area and by Phoenix FM. It was an occasion that I will never forget, largely due to the kindness and generosity of all concerned which has continued well after the event.”

Matt Cullen

West Kerry Tractor Run

Where do we start! Another overwhelming outcome to the tractor run weekend. The fun day out at the mart was everything we hoped for with craic, ceol, and an audience to showcase our amazing Irish history. Thank you Brendan Ferris and his crew of helpers for making the threshing happen. Of course I can't go without mentioning our skillful welly throwers as well. Thank you to Neilus, Bridie and mharglann an daingean for allowing us take over the mart and for all their help organising it.

The main event went as well as the year previously. The atmosphere and positivity on the day was electric. A whole peninsula and beyond coming together to raise money for people in need is very special. The auction that followed in the Marina Inn fronted by the talented and hilarious Dónal Ó hAiniféin also went beyond expectation. We are absolutely blown away.

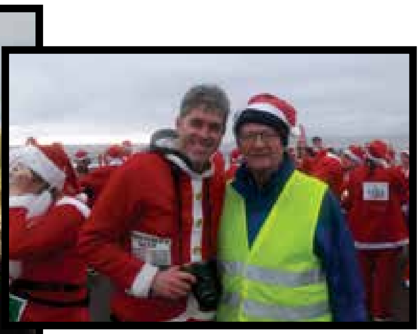
To name just a few who made the weekend possible thank you to John Patrick O Sullivan, Seamus Devane, Sharon Ní Shúilleabháin (who will be mad we mentioned her cause she is very shy but brilliant) and their amazing committee. Macra na feirme Chorca Dhuibhne were also a fantastic addition to the tractor run family this year. Thank you to Dingle chamber of commerce, the gardaí, Kerry co co and the dept of agriculture fisheries and marine for allowing access to the pier.

The Kavanagh family and all staff at The Marina Inn you have so much patience, thank you for all your hard work and generosity again this year.

To everyone who took part in any way big or small, to those who donated, the people who volunteered, the legends who drove their tractors, people who sent good wishes and helped spread awareness about our three important charities we cannot thank you enough.

Donations are still welcome and we will let you know what the final figure is when we do.

The only disappointment over the weekend was that no one sang Foster and Allen's The ole Threshing Mill… how did we leave that one slip… but there is always next year.



Santa Dash 2019

The 11th Santa Dash took place on Sunday 1st December on Dollymount Strand in Dublin and ILFA was thrilled to be the charity partner of this fun festive family 5km and 10km run.

ILFA is enormously grateful to Sean McFadden and the Santa Dash organisers for the valuable opportunity to raise funds and awareness of lung fibrosis at this prestigious event. We are indebted to our team of wonderful, enthusiastic, generous and talented ILFA volunteers who answered the call when we appealed for help with running the event. The ILFA volunteers braved the very early morning start and the cold conditions to help the organisers on race day. The industrious ILFA team helped with running the registration desk, Santa suit collection area, the finish line, medal stations, serving tea, coffee and refreshments to all the finishers, and finally the clean-up operation.

Some of the participants taking part for ILFA included the McSkeane family from Co Monaghan, Daniel Bourke, Sean Duggan, Scott Glenn, Aidan Boyle and Ronan Hennelly from SSA Recruitment Ireland, the Loughrey-Kennedy family from Galway and Dublin, the English family from Co Meath, aunt and niece duo Annette Grehan and Nicola Cassidy (ILFA Director), Gil Hilliard, Stephen Byrne and Rob Farquhar who took part in support of a family member, and members of the Slattery Family from Clare among others. We're very grateful to everyone for their great support and for fundraising for ILFA.

Our fantastic volunteers deserve special praise and our deep gratitude for their hard work, positive energy and endless enthusiasm. Huge thanks to Yvonne Lynch, Stephen Moody, Eamonn Delaney, Philo Mullaney, Rita Callaghan, Mary Ellen English, Deirdre O'Dwyer, Damien Osborne, Laura Grehan, Teresa Barnett, Patricia Swords, Louise Houghton, Eddie Cassidy (ILFA Chairman), Annette Grehan, Nicola Cassidy. Sincere thanks to the Santa Dash organisers for choosing ILFA as their charity partner in 2019. This was a wonderful honour and ILFA is grateful for the media coverage in the lead up to Santa Dash.

In Remembrance

Sincere thanks to all the families who requested donations to ILFA in lieu of flowers at the funerals of their loved ones. We are very grateful for your support and kindness to ILFA at a time of great personal loss.

A New Patient Ambassador for ILFA in 2019

David Crosby agreed to become a Patient Ambassador for ILFA in 2019 and we couldn't be prouder. After receiving a double lung transplant following a diagnosis of Idiopathic Pulmonary Fibrosis, David has devoted his energy, positivity and enthusiasm to raising awareness of pulmonary fibrosis, organ donation and transplantation. He has worked tirelessly sharing his story and giving hope and encouragement to other patients and families, while fundraising for respiratory charities and research foundations.

Post-transplant, David completed the New York City marathon with 14 supporters in 2016 and this amazing achievement set in motion plans to take on the Super Six Marathon Series and earn a place in the record books. David has already run the New York, Berlin and London marathons and will run in Tokyo in 2020 and then Boston and Chicago in 2021 to take on his remaining marathon challenges.

ILFA surprised David with a special recognition award in October for his advocacy work. David was presented with a specially commissioned piece of Dublin Crystal by Lynn Fox, his respiratory nurse specialist at the Mater Hospital. We wish David and his family every success with his ILFA Ambassador role.

A message from ILFA Patient Ambassador David Crosby

Hi my name is David Crosby, I am a very proud patient ambassador for ILFA.

It is a very strange time in which the whole world is living in at the moment. I think everybody has taken a knock from it all. When you have a lung disease it is especially more prevalent and even more worrying.

Listening to all the news reports about how Covid-19 is affecting people with lung problems is worrying. Then you may be wondering whether to go to your healthcare provider to get any issues you may have looked at, maybe you feel apprehensive and don't want to put any extra pressure on your healthcare service provider.

Just remember that your health is the most important thing in your world. It comes first, the health service are professionals and will know how to treat any issues you have. The sooner any symptoms are addressed the quicker they can be treated.

Always try to do the things you have been shown by your health provider. Take your walks, don't put any unnecessary pressure on yourself, talk to someone. Find the triggers that might make you feel breathless or tired and react accordingly.

Stay safe and strong.

Nelson Gallarin awarded the Denise Cassidy Memorial Prize for Excellence in Patient Care

The Denise Cassidy Memorial Award recognises and celebrates an act of kindness shown by a healthcare worker to a lung fibrosis patient. In 2019, ILFA members were invited to nominate a person who showed them or their loved one a special act of kindness. ILFA is delighted to announce that **Nelson Gallarin**, Staff Nurse at the Mater Misericordiae University Hospital in Dublin, is the winner of the 2019 Denise Cassidy Memorial Award for Excellence in Patient Care. Nelson was nominated for the award by Peter Gallagher for his exceptional kindness and compassion.

Peter told us “One night post-transplant surgery I had a lot of discomfort and pain. I had already had my quota of pain relief for that day. Nelson sat with me and talked me through the night. He talked about his country, his family especially his mother and oh! his dog, I know he loves that dog. He also talked about his time in Ireland and his job as a nurse. He sat with me for the duration of my discomfort. I feel Nelson went beyond the call of duty. So what separates Nelson from all the other wonderful young men and women in our hospitals? This was hard to decipher, I narrowed this to two things, his family and his ability to listen intently. I know this because I met Nelson many months later and he still had that familiar warmth and he recalled all our conversation.”

Nelson was thrilled to learn that he was nominated and selected as the overall winner of the award and said “It is an honour to be granted the award I am indeed grateful and delighted. It is the small things we consistently do that really give great impact to the lives of others. To live a life of purpose gives life meaning ... a life of service to others that even though they won’t be remembering my name long after they have gone home, if they will remember how they felt while they were under my care, then that’s good enough for me. I’m happy that Peter remembered my name; that my name is engraved to his heart, like my name is engraved on this trophy, and we both treasure not only our winnings, but the fond memories of our encounter. Thank you to Peter and ILFA for this award.”
Nelson was presented with a specially commissioned piece of Dublin Crystal and a framed Certificate for Excellence in Patient Care at the ILFA Patient Information Day in October. It was very moving to hear Peter’s speech thanking Nelson for his kindness and acknowledging the great impact it had. Warmest congratulations to Nelson from all the ILFA community on your well-deserved award!

A total of 21 healthcare professionals were nominated for the Denise Cassidy Memorial Award for Excellence in Healthcare.

Irish Healthcare Award Commendation for ILFA

Everyone at the Irish Lung Fibrosis Association was over the moon when two of our recent patient-centred projects were short-listed for Irish Healthcare Awards in 2019. Our first project entitled **"Namaste" ILFA's Yoga DVD for Lung Fibrosis"** was shortlisted in the hotly contested **Best Patient Lifestyle Project** category along with 9 other outstanding patient organisation projects. Our second project **"ILFA's World Café on Palliative Care and Planning for the Future with Lung Fibrosis"** was shortlisted in the in the highly competitive **Best Patient Organisation Project of the Year** category with 4 other contenders.

The awards night took place in November 2019 in Dublin and Nicola Cassidy (ILFA Director) and Gemma O'Dowd (ILFA Administrator) were joined by Anne-Marie Russell who expertly helped develop and facilitate the World Café on Palliative Care and Planning for the Future and Pamela Martin, Evelyn Cooper and Matt Cullen who starred in the Yoga DVD along with ILFA Patron and Dublin GAA Star, Michael Darragh Macauley.

ILFA was thrilled when the World Café on Palliative Care and Planning for the Future was awarded a commendation. This collaborative project was developed and delivered in June 2018 and involved patients, carers, healthcare professionals, industry representatives, and leaders in patient care.

2019 ILFA Calendar of Key Events

Date	Event	Attended by
February	Roche ILD Study Day Ashling Hotel, Dublin	Nicola Cassidy (speaker), Lynn Fox (speaker), Gemma O'Dowd
February	Rare Disease Day	Marie Sheridan, Gemma O'Dowd
March	Professor Luis A. Ortiz talk entitled "The irony of lung fibrosis; a fibroblast to treat IPF" In collaboration with Maynooth University, Royal College of Physicians in Ireland, ILFA	Eddie Cassidy, Professor Jim Egan, Nicola Cassidy, Marie Sheridan, Gemma O'Dowd
April	Patient Information Day on Palliative Care and Planning for the Future, Dublin	Eddie Cassidy, Professor Jim Egan, Nicola Cassidy, Marie Sheridan, Gemma O'Dowd
June	VHI Women's Mini-Marathon Dublin	Gemma O'Dowd, Marie Sheridan and participants registered with ILFA
June	Cork Marathon/Relay	Eddie Cassidy, Nicola Cassidy Lynn Fox, David Crosby Healthcare professionals, Roche Products Ireland, BOC supporters
September	European Respiratory Society Congress, Madrid, Spain	Nicola Cassidy, Liam Galvin
October	ILD-INN meeting Birmingham, UK	Nicola Cassidy, Liam Galvin 10 Healthcare professionals awarded an ILFA bursary
October	ILFA Ecumenical Service	Eddie Cassidy, Nicola Cassidy, Lindsay Browne, Michael Geoghegan, Gemma O'Dowd
October	ILFA Patient Information Day, Dublin	Marie Sheridan, Nicola Cassidy, Lindsay Browne, Lynn Fox, Gemma O'Dowd
November	Irish Thoracic Scientific Meeting 2019, Galway	Nicola Cassidy, Gemma O'Dowd
November	Advancing in IPF Research (AIR), Malmo, Sweden	Professor Jim Egan, Nicola Cassidy, David Crosby
December	Santa Dash	Eddie Cassidy, Nicola Cassidy
December	ILFA Christmas Swim	Eddie Cassidy, Nicola Cassidy

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.

Throughout 2019 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. ILFA is committed to undertaking the necessary training and regular review of policies to ensure compliance with governance requirements.

ILFA is registered with the Charities Regulator and the Regulator of Lobbying.

Membership

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

ILFA’s Role in Europe

Report from Liam Galvin,
ILFA Director and EU-IPFF Secretary

Since 2013 ILFA has been working with other Pulmonary Fibrosis Groups across Europe and the World. In 2016 this partnership saw ILFA become co-founders of the European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF).

The EU-IPFF is an International Non-Profit based in Belgium and it provides a collective voice for IPF and PF patients. ILFA is deeply committed to partnering with all those involved in the EU-IPFF and during 2019 took part in both various projects and the annual awareness campaign led by the EU-IPFF.

The EU-IPFF is a group of 21 patient groups from 15 European Countries and since 2016 has had Liam Galvin from ILFA as its General Secretary ensuring that Irish Patients are represented at European level. Details of the work of the EU-IPFF can be found at www.eu-ipff.org

ILFA’s Corporate Partners 2019

The Irish Lung Fibrosis Association would like to thank the following corporate partners supporting for our work in 2019:

Air Liquide Healthcare Ireland Ltd

BOC Healthcare Ireland

Boehringer Ingelheim Ltd

Roche Products Ireland Ltd

Santa Dash 2019

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 2019. Your commitment and contribution are deeply appreciated.

We are indebted to;

- Fundraisers
- Volunteers
- Support Group Leaders & Past committee members
- Hayes Solicitors
- Whiteside Cullinan & Co
- Judita Press
- Boehringer Ingelheim Ireland Ltd.
- Roche Products Ireland Ltd.
- Air Liquide Healthcare Ireland Ltd.
- BOC Healthcare Ireland
- patientMpower
- Irish Thoracic Society
- Anail
- Irish Donor Network
- European Idiopathic Pulmonary Fibrosis and Related Diseases Federation

ILFA Newsletters

Spring 2019

ILFA Newsletter

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

IPF takes centre stage at the Irish Thoracic Society Meeting

The Irish Thoracic Society Annual Scientific Meeting took place in Belfast from 22nd to 24th November 2018. This year the programme for the meeting was particularly exciting and there were many sessions dedicated to Interstitial Lung Disease (ILD) and specifically to Idiopathic Pulmonary Fibrosis (IPF).

One of the keynote speakers at the meeting was **Professor Martin Kolb,** Division of Respirology, Moran Campbell Professor and Chair in Respiratory Medicine, McMaster University, Canada. Professor Kolb delivered a lecture entitled *Demystifying Challenges in the Management of Idiopathic Pulmonary Fibrosis*. He discussed the importance of getting an accurate diagnosis, offering patients choice and control with selecting the best anti-fibrotic medicine to suit their needs, managing patient expectations and treating the patient's symptoms and other co-existing conditions that are often present with IPF including chronic cough, anxiety and depression.

Professor Kolb also attended a meeting of the ILD Respiratory Nurses Group that was chaired by Lynn Fox, Respiratory Nurse Specialist at the Mater Misericordiae University Hospital. Professor Kolb spoke about IPF care in Canada and the many challenges faced by patients who live huge distances from IPF specialist centres. He kindly answered a huge amount of questions relating to his practice that were raised by the audience.

Carita Bramhill, Research Coordinator at the Clinical Research Centre, St. Vincent's University Hospital, also addressed the ILD Respiratory Nurses Group and discussed the background and logistics involved in setting up and managing the Irish Thoracic Society's National IPF Registry. The first annual report of the ITS National IPF Registry was launched at the ITS scientific meeting and is available to read online at the Irish Thoracic Society's website; www.irishthoracicsociety.com

David Crosby (Double Lung Transplant Recipient and Marathon Participant), Professor Karen Redmond (Thoracic and Lung Transplant Surgeon, Mater Misericordiae University Hospital, Dublin), Dr Rory Convery (Craigavon Area Hospital) and Dr Jacqueline Rendall (Belfast City Hospital).

Another inspirational and much anticipated speaker was **David Crosby,** who delivered his presentation entitled *The Greatness Within* to a captivated audience. David shared his touching personal account of losing three siblings to a lung condition in childhood, being diagnosed with IPF aged 42 years old and subsequently undergoing a double lung transplant. Following his life-saving surgery, David set his sights on running the New York City Marathon to honour his donor and help raise awareness and funds to support research into lung fibrosis and organ donation and transplantation.

Ctd overleaf

Patient Information Day

The next Patient Information Day will take place on Saturday 6th April at the Hilton Hotel, Northern Cross, Malahide Road, Co Dublin from 10am until 2pm. We hope you can join us to learn more about Palliative Care and Planning for the Future with Lung Fibrosis. All are welcome.

The topics being discussed will include;

(1) Practical planning for living with Idiopathic Pulmonary Fibrosis (IPF) including home adaptations and oxygen
(2) Palliative care needs and management of symptoms
(3) End of life considerations
(4) Psychological needs and support for living with IPF
(5) Acute exacerbations and transplantation
(6) Legal matters

Please call 086 871 5264 or email info@ilfa.ie to register for this free event.

From page 1:

After completing his first marathon, David set himself a bigger and more ambitious goal of achieving the Super-six – a series of six world class marathons namely; New York, Berlin, London, Tokyo, Boston and Chicago. With New York and Berlin already done, David will head to London in April with his team of 30 family and friends to take part in marathon number three! His determination and enthusiasm have no bounds.

David ended his presentation by thanking his medical team for their help and support and for the honour of addressing the Irish Thoracic Society meeting. He concluded by saying: "From your world crashing down around you, I am here to tell you that there is hope; there's always hope." David's inspiring story and his commitment and determination touched a chord with the entire audience, and he received a standing ovation and a rousing round of applause.

Professor Karen Redmond, Thoracic and Lung Transplant Surgeon, Mater Misericordiae University Hospital delivered a lecture entitled *Lung Transplantation: Beyond the Ordinary* and gave an update from the National Lung Transplant Programme. Professor Redmond emphasised that lung transplantation is a treatment option for patients with certain chronic respiratory conditions and performing single lung transplants enables surgeons to maximise the use of donor lungs. She emphasised that her take home message for the audience was "We can help people, we want to help people and we're able to help people." In Ireland the post-transplant outcomes are comparable and if not better than the international experience and there were no significant differences in post-transplant survival in IPF patients greater than 65 years old compared to those aged less than 65 years old.

Professor Redmond also highlighted the need to improve the clinical pathway for pulmonary fibrosis. The ITS Position Statement on the Management of IPF calls for optimisation of the diagnosis and management of IPF and specifies that all patients should have access to specialist centres and all appropriate treatments without undue delay.

Gemma O'Dowd and Nicola Cassidy represented ILFA at the ITS meeting and hosted an exhibition stand showcasing ILFA's printed materials and exercise resources. Nicola Cassidy delivered two poster presentations; (1) Yoga for pulmonary fibrosis: An exploratory qualitative analysis of patient and caregiver experiences, (2) Evaluation of a World Café Forum on Palliative Care and Planning for the Future.


Professor Martin Kolb (Chair in Respiratory Medicine, McMaster University, Canada), Dr Kate O'Reilly (Respiratory Consultant, Mater Misericoridiae University Hospital) and Nicola Cassidy (ILFA Director).


Gemma O'Dowd (ILFA) with David Crosby (guest speaker) and Nicola Cassidy (ILFA).


Deirdre Donaghy (Respiratory Nurse Specialist, St Vincent's University Hospital), Gemma O'Dowd (ILFA), Lynn Fox (Respiratory Nurse Specialist, Mater Misericordiae University Hospital) and Cherry Wynne (Clinical Nurse Specialist, Respiratory Integrated Care, Cabra, Dublin).


Carita Bramhill (Research Co-ordinator, Clinical Research Centre, St Vincent's University Hospital), Nicola Cassidy (ILFA Director) and Bridget Mulholland (Irish Thoracic Society IPF Registry Data Nurse).

The Denise Cassidy Memorial Prize 2019

Would you like to honour your lung fibrosis healthcare hero?

ILFA is pleased to announce the 2019 Denise Cassidy Memorial Prize for excellence in healthcare. This award recognises and celebrates the kindness, compassion and humanity of a hospital healthcare worker to a lung fibrosis patient or their family. Patients and carers are invited to nominate a person who showed you or your loved one a special act of kindness that helped you cope with your illness better.

Please fill out the nomination form and tell us why your healthcare hero deserves to be honoured. You can nominate a doctor, nurse, physiotherapist, social worker, counsellor, dietician, pharmacist, healthcare assistant, member of the chaplaincy team, clerical worker, catering or cleaning staff - in fact anyone who works in a hospital. Everyone who is nominated will receive a certificate of excellence and the overall winner will receive a special commemorative Dublin crystal award.

The award is named in honour of Denise Cassidy who was diagnosed with IPF at the age of 56. Denise led a happy, busy, healthy, sporty and active life. She loved badminton, running, walking, gardening and socialising. Her symptoms developed out of the blue and she developed increasing breathlessness and a cough. After many difficult and frustrating months of hospital admissions, Denise was eventually diagnosed with IPF and placed on the lung transplant list. During her illness, Denise met many kind, friendly, caring, and dedicated healthcare staff and other lung fibrosis patients who helped and supported her enormously. Denise passed away in 2006.

Denise's husband Eddie is the Chairman of ILFA, and her daughter Nicola has served on the ILFA committee since 2007. Denise's immediate and extended family have continuously fundraised for ILFA and all are honoured and humbled to have this special award dedicated to her memory.

Olivia Mulvaney.

The two previous winners of the award are Katie Barry, staff nurse from Cork University Hospital and Olivia Mulvaney, staff nurse from Cavan General Hospital.

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

Katie Barry with the late ILFA Chairman, Terence Moran.

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

A nomination form is included with the newsletter and will be available on the ILFA website to download (www.ilfa.ie). This award will mean a lot to the eventual winner and indeed to all those nominated. So, let's get behind our lung fibrosis healthcare heroes and celebrate their great work! Please send your entries to ILFA, PO Box 10456, Blackrock, Co Dublin or email info@ilfa.ie. The closing date for entries is the end of May 2019.

Patient Information

ILFA's second Patient Information Day of 2018 took place at the Crowne Plaza Hotel, Santry, Dublin on Saturday 20th October. The event was well attended by patients, family members and healthcare professionals and we were fortunate to have great speakers. Eddie Cassidy, ILFA Chairman, extended a warm welcome to everyone attending ILFA's 25th Patient Information Day.

Professor Jim Egan, Respiratory consultant at the Mater Misericordiae University Hospital congratulated ILFA on their 16th anniversary and paid tribute to the voluntary committee who run the charity, as well as the patients and families who have played an important role in ILFA's success. Professor Egan talked about the advances in recent times with IPF care, particularly the availability of two anti-fibrotic medicines and the tremendous progress being made with lung transplantation at the national lung transplant unit at the Mater Hospital in Dublin.

Lung transplantation is an effective treatment for a highly selected group of IPF patients and can result in improved quality of life and life expectancy post-transplant. The number of lung transplants taking place in Ireland is very encouraging. In some European countries, older adults are not eligible for lung transplantation but in Ireland lung transplants have been performed in individuals aged over 70-years who have good general health apart from their lung condition. Patients being considered for lung transplantation must be physically well enough to undergo major surgery and the subsequent recovery process. Professor Egan paid tribute to the cardiothoracic surgeons at the Mater Hospital who have embraced transplant surgery in IPF patients.

Professor Egan also spoke about the introduction of the Human Tissue Bill which will also legislate for the introduction of an opt-out organ donation system in Ireland. He stressed the need for extra resources, staff and infrastructure to support transplant medicine.

Dr Eoin Hunt, respiratory physician at the Mater Misericordiae University Hospital in Dublin gave an overview of pulmonary fibrosis. Approximately 400 people are diagnosed Idiopathic Pulmonary Fibrosis (IPF) in Ireland each year. Most patients present with shortness of breath on exertion and as IPF progresses falling blood oxygen levels can lead to extreme tiredness, increasing breathlessness and lack of concentration. Other symptoms may include a non-productive cough that can be debilitating and lead to increasing shortness of breath and anxiety and approximately 50% of patients have clubbing (rounding) of their fingernail beds.

IPF can be difficult to diagnose and input from an expert multi-disciplinary team (MDT) is important to help with an early and accurate diagnosis. Local hospitals should be a gateway to recognised respiratory centres with specific expertise in pulmonary fibrosis. All the patient's test results including results from CT scans, x-rays, lung biopsies, blood tests and a detailed medical history will be carefully considered when the MDT work together to reach agreement on a diagnosis. If the specific cause of the lung fibrosis cannot be identified and all other causes have been ruled out, a diagnosis of Idiopathic Pulmonary Fibrosis (IPF) is reached. The word 'idiopathic' means of unknown cause.

IPF is a progressive condition which means that the amount of scarring in the lungs gets worse over time. Lung function monitoring allows healthcare professionals to establish the severity of the disease and rate of decline.

Dr Hunt described the positive benefits of supplementary oxygen (medical oxygen) and how it helps the body cope with breathlessness and fatigue. Oxygen should be used for patients experiencing breathless when doing everyday activities such as bathing and getting dressed. Any amount of oxygen can be prescribed, so it is important to let your healthcare professional know if your breathlessness is getting worse. It is important to exercise and keep physically active. Pulmonary rehabilitation programmes are an ideal way for patients to undertake exercise in a safe and social environment and patients can be advised on managing breathlessness and medication. Dr Hunt discussed some of the other conditions that can be associated with IPF including acid reflux (also called GERD or gastro-oesophageal reflux disease) when acid from the stomach can be inhaled into the lungs. You should tell your doctor if you experience heart burn or acid reflux as you may need medication to control this. There are two approved anti-fibrotic drug treatments that slow down disease progression for patients with IPF; these are Pirfenidone (also called Esbriet) and Nintedanib (also called Ofev). These medicines do not cure IPF and cannot reverse scarring that is already present in the lungs but they have been shown to slow down disease progression.

Lindsay Brown, respiratory nurse specialist at St. Vincent's University Hospital, spoke about the Irish Thoracic Society's Position Statement on the Management of IPF. This important document was launched in 2018 and reinforces the principles of ILFA's National IPF Patient Charter. It provides guidance to healthcare providers on the optimal diagnostic and care pathways for IPF and will empower patients to look for the best care, and describes what personalised care plans entail. The ITS Position Statement on IPF is available on the ILFA website (www.ilfa.ie).

Grainne Casey, respiratory physiotherapist at the Mater Misericordiae University Hospital described the importance of being able to break the cycle of breathlessness that some patients can experience. Grainne encouraged patients to attend pulmonary rehabilitation programmes to engage in exercise safely and learn about managing breathlessness, coping skills, and energy conservation strategies. If patients do not have access to a local pulmonary rehabilitation programme, ILFA can supply free exercise programmes including the 2000 Steps a Day Walking Challenge and the ILFA Exercise DVD for Lung Fibrosis Patients that were developed in collaboration with the physiotherapy department at the Mater Misericordiae University Hospital.

Grainne emphasised the importance of daily exercise for all lung fibrosis patients. Regular exercise will help to improve muscle strength, mobility, mood and independence. She urged

Day, October 2018

Speakers at the Patient Information Day: Back row: Professor Jim Egan, Michael Geoghegan, Dr Eoin Hunt, Eddie Cassidy. Front row: Lindsay Brown, Grainne Casey, Zita Lawlor.

everyone to follow the '3P's rule' which recommends patients to:

- **Prioritise** what is important to them
- **Plan** activities in advance
- **Pace** yourself.

Zita Lawlor, transplant coordinator at the Mater Hospital, provided the audience with some statistics about lung transplantation in Ireland.

- The first lung transplant in Ireland took place in 2005. Prior to that patients had to travel to Newcastle in the United Kingdom.
- Since 2005, over 240 lung transplants have taken place at the National Lung Transplant Centre at the Mater Hospital in Dublin.
- In recent years, approximately 30 lung transplants have been carried out every year.
- Approximately 40 patients are on the lung transplant list at any time.
- 30-50% of all lung transplants are performed in patients with IPF.

Zita described four important questions that are considered when evaluating a person's suitability for a lung transplant. These include

- Are the lungs sick enough to need a transplant?
- Is the body well enough to survive major surgery?
- Does the patient have adequate support?
- Is there informed consent?

It is important that patients meet strict criteria to be considered suitable candidates for a lung transplant. They must have an ideal BMI (Body Mass Index), have no other life-threatening conditions, be compliant with medication and recommended treatments, and have a realistic understanding of what is involved, and the support needed.

Lung transplantation assessment and surgery is a complex and demanding process and patients will need frequent and careful monitoring pre-transplant and post-transplant to ensure they are in good health. Zita explained that some patients may need to come off the transplant waiting list if they experience poor health. If their health subsequently improves and there are no complications, they may be re-listed.

Zita described what happens when a person receives a call to say that a donor lung has become available. Several potential recipients will be contacted by the transplant coordinator and transferred to the Mater Hospital via ambulance. It is a very busy time and more tests must be done to ensure the donor is a good match and that the donor's lung (or lungs) are in good condition and are suitable for the recipient. Lung transplantation is only possible thanks to the extraordinary kindness and generosity of organ donors and their families.

Michael Geoghegan spoke about his experience of deteriorating health, being diagnosed with IPF, and being assessed for and subsequently receiving a lung transplant in 2018. Michael paid tribute to his donor and thanked the skilled medical and surgical staff at the Mater Hospital for the enormous encouragement and confidence he received from them.

After the presentations, there was a lively questions and answers session with the good audience participation. Eddie Cassidy concluded the meeting by thanking the audience, the speakers and the oxygen companies, Air Liquide Ireland and BOC Healthcare Ireland who supported the event. Refreshments were served after the meeting and everyone had a chance to interact with the speakers and socialise with each other.

Opt-out organ donation consent legislation

ILFA's esteemed patron, Senator Fergal Quinn, first proposed the introduction of an opt-out organ donation system in the Seanad in 2008. Almost all of the EU countries have an opt-out organ donation system in place. Since 2008, ILFA has lobbied for an opt-out consent system and has contributed to two public consultations on Organ Donation in 2013 and the Human Tissue Bill in 2017.

With an opt-out system, individuals will be considered to be potential organ donors and their families will be asked for consent to proceed with organ donation, unless the individual has opted-out (this means they have officially registered their objection to be an organ donor). Family/next-of-kin consent is paramount and will always be needed for organ donation to proceed. It is therefore important to have family conversations and let your loved ones know your wishes on organ donation.

On 31st January, Nicola Cassidy (ILFA Director), Philip Watt (CEO of Cystic Fibrosis Ireland) and Robert McCutcheon (Chair of the Irish Heart and Lung Transplant Association) represented the Irish Donor Network and met with Michael Conroy from the Department of Health and his colleagues James Allen and Helen O'Brien. The Human Tissue Bill includes the provision for an opt-put organ donation system and is currently under review before being presented to the government in the first quarter of 2019.

In February, ILFA wrote to the Department of Health advocating for the introduction of a robust, secure and adequately resourced opt-out registry to record the wishes of individuals who do not wish to be considered as potential organ donors.

National Heart and Lung Transplant Unit

ILFA is delighted to announce that after many year's campaigning and lobbying for the opening of the full complement of beds at the National Heart and Lung Transplant Unit at the Mater Misericoridae University Hospital (MMUH) in Dublin, the HSE's 2019 Service plan commits to;

- "Progress the opening of transplant service beds for pre, peri and post-transplant related activity in MMUH"

and

- "Further develop the national organ retrieval service in compliance with the European Working Time Directive."

The Irish Donor Network (an alliance of patient organisations including Cystic Fibrosis Ireland, Irish Heart and Lung Transplant Association, ILFA, Alpha-One Ireland, Cystinosis Ireland, Pulmonary Hypertension Association of Ireland and COPD Support Ireland) continues to campaign for an opt-out organ donation consent system as well as substantial investment in resources, infrastructure and healthcare personnel, and continuous awareness campaigns to transform and optimise organ donation and transplantation rates in Ireland.

Rare Disease Day 2019

Marie Sheridan (ILFA Treasurer) and Gemma O'Dowd represented ILFA at the Rare Disease Ireland event on 28th February. Marie kindly wrote the following report on the event.

Vicky McGrath of Rare Diseases Ireland opened what was a very interesting morning and we heard from various speakers about bridging health and social care. We heard about the latest developments in the planning for rare diseases in both jurisdictions in Ireland, and how statistics are important for planning. There were many thought-provoking comments and stories from the audience also.

Common threads included the concept that care for people with rare diseases needed to be based on evidence, not just symptoms. Ongoing research is of vital importance and patients would like to be informed by their physicians of what is going on in this area.

Speakers emphasised the need for families of patients to find experts, identify problems and work to eliminate them. Be relentless was the message, which was challenged by other contributors, who questioned why it was always up to the patients and their families and friends to form charities and fundraise. The point was made that this was a health issue, not a charity issue.

Marie Sheridan and Gemma O'Dowd at the Rare Disease Ireland event.

The second session of the morning emphasised how everyone is stronger as part of a bigger whole. Each voice matters and if patients and carers of different diseases join together, then they will make their voice heard. Although every patient is an individual with a need for an individualised care plan, there is enough common ground to work together. People want their stories to be heard and health care professionals should work to ensure this happens and that they learn and improve from the process.

Claire Hudson, a speech and language therapist who project managed the 'Your Voice Matters' survey for the HSE had some interesting points about how families feel after bereavement which brought to mind the ILFA World Cafe process. The morning ended with a panel discussion, chaired by Avril Daly of EURODIS, on what the future holds for rare diseases.

Educational Activities

Update Respiratory Journal

A series of educational articles on Idiopathic Pulmonary Fibrosis (IPF) were published in the Update Respiratory Journal of the Irish Medical Independent in November 2018. The journal is aimed at General Practitioners, specialist nurses, and respiratory physicians at both training and consultant level.

- Nicola Cassidy (ILFA Director) contributed an article describing ILFA's work and the support and information offered to patients and families affected by IPF and why doctors should refer appropriate patients to ILFA.
- Irene Byrne, senior respiratory physiotherapist at the National Heart and Lung Transplant Centre at the Mater Misericoridae University Hospital, wrote an article describing the importance of physical activity and benefits of exercise and pulmonary rehabilitation programmes for patients with IPF.
- Professor Anthony O'Regan, Respiratory Consultant at Galway University Hospital contributed a clinical article on the diagnosis and management of IPF and presented some of the preliminary findings from the Irish Thoracic Society's National IPF Registry.

Respiratory Health of the Nation 2018

Eddie Cassidy (ILFA Chairman), Nicola Cassidy and Matt Cullen represented ILFA at the launch of 'Respiratory Health of the Nation 2018' on Tuesday 18th December at the Royal College of Physicians of Ireland, in Dublin. This research document co-authored by Dr Maire O'Connor (Specialist in Public Health Medicine, HSE East) and Eimir Hurley (Pharmacist and Biostatistician, Centre for Health Policy and Management, Trinity College, Dublin), provides an important epidemiological account of the burden of respiratory disease on the health service and on people's health and quality of life.

Professor Ross Morgan, President of the Irish Thoracic Society, welcomed recent improvements in respiratory patient care and highlighted ongoing challenges including the need for additional respiratory specialists, nurses, physiotherapists, and other allied healthcare professionals; improved access to pulmonary rehabilitation programmes; and properly resourced integrated care and primary care services. The Irish Thoracic Society has called for the establishment of a national taskforce to put respiratory disease on an equal footing with heart disease and cancer where dedicated strategies and care pathways have led to improved health outcomes for patients.

Eimir Hurley, Eddie Cassidy (ILFA Chairman), Matt Cullen, Dr Maire O'Connor and Nicola Cassidy at the launch of 'Respiratory Health of the Nation'.

IPF Study Day

Lynn Fox (Mater Hospital), Nicola Cassidy (ILFA), Dr Kate O'Reilly (Mater Hospital), Professor Anthony O'Regan (Galway University Hospital) and Dr Killian Hurley (Beaumont Hospital).

Gemma O'Dowd, Nicola Cassidy and Lynn Fox from ILFA attended the 5th annual Idiopathic Pulmonary Fibrosis (IPF) Study Day organised by Roche Products Ireland on 8th February. Professor Seamus Donnelly (Tallaght University Hospital), Dr Killian Hurley (Beaumont Hospital) and Lynn Fox (Mater Misericordiae University Hospital) chaired the medical education event dedicated to healthcare professionals.

Professor Seamus Donnelly (Tallaght Hospital), Dr Killian Hurley (Beaumont Hospital), Gemma O'Dowd (ILFA) and Professor Michael Keane (St Vincent's Hospital).

There were excellent presentations from leading respiratory clinicians that focussed on the role of the specialist interstitial lung disease centres in the diagnosis and treatment of IPF, the management of cough, hospitalisations and acute exacerbations, clinical cases, palliative care, and Professor Anthony O'Regan (Galway University Hospital) gave an update on the Irish Thoracic Society's IPF Registry. 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 for the future.

It was an excellent meeting and a great opportunity to meet the healthcare professionals from all over the country.

Collaboration with the European Lung Foundation

The European Lung Foundation (ELF) held a live webinar on 18th January on 'Submitting a research abstract to the European Respiratory Society (ERS) Congress'. Nicola Cassidy from ILFA was invited to share her perspectives with the audience based on her experiences of presenting ILFA's research activities at the ERS Congress from 2014 to 2018. The other speakers taking part were Barbara Johnson from the ELF, Kate Hill (June Hancock Mesothelioma Research Fund) and Liliya Belenko Gentet.

The aim of the webinar was to provide guidance and tips to patient organisations considering submitting an abstract to the ERS scientific meeting for the first time.


Some of the 147 tractors that took part in the West Kerry Tractor Run.

Míle buíochas!

The ILFA committee would like to send our sincere thanks and appreciation to John O'Sullivan, Séamus Devane, the O'Sullivan Family and the organisers of the West Kerry Tractor Run for their passion, dedication, and hard work on this project. The West Kerry Tractor Run was an inspiring and extraordinary event that raised valuable local, national, and international awareness of lung fibrosis, organ donation and transplantation, while also raising a fantastic amount of money for two charities.

The ILFA committee was truly humbled when we learnt about the 147 tractor drivers from across the Kingdom of Kerry and their support teams who descended on Dingle to fundraise on our behalf. The impressive video that captures the true scale and wonder of the event and the beauty of Dingle is superb and well worth a look (available to watch online on You Tube).

ILFA would also like to extend our heartfelt thanks to all the tractor drivers, to those who generously donated goods for the auction, and to the proprietors of The Marina Inn, Dingle, for looking after all the fundraisers so well.

Gemma O'Dowd and Michael Geoghegan from ILFA received a warm welcome from John and Séamus, the O'Sullivan family and community when they visited Dingle on two separate occasions. Gemma was in Dingle in November for the Tractor Run and had a wonderful time and Michael visited in January to attend a cheque presentation. ILFA received €21,000 from the organisers of the West Kerry Tractor Run and we were overjoyed to be bestowed with such a large donation that will make such a difference to our work. **Míle buíochas!**

West Kerry Tractor Run 2018

In the crisp winter sunshine of Sunday 23rd of November 2018, a convoy of 147 tractors followed a 30-kilometre route through the scenic countryside of West Kerry. It was the culmination of a successful fundraising effort in aid of the Irish Lung Fibrosis Association and a local day care centre for the West Kerry elderly, Gáirdín Mhuire.

As a beneficiary of the amazing support of ILFA during his illness with IPF and recovery from a lung transplant, John Patrick O'Sullivan was very eager to help raise awareness of organ donation and raise funds for ILFA. After reading a heartfelt appreciation by a local agricultural contractor, Séamus Devane, in a community news magazine to the staff of Gáirdín Mhuire, for the care they provided for his late wife Noreen, John hit on the idea of a Tractor Run. It was a fundraising method that had never been tried in West Kerry before and Séamus jumped at the idea when John pitched it to him. They gathered a committee around them in September 2018 and set about organising the event.

They set a target of €10 000, which they felt was ambitious but achievable, to be divided equally between the two charities. It quickly became clear though that the novelty of the event and the passion the two chairmen had for their chosen charities had captured the hearts of many in West Kerry and beyond. The Kavanagh family of The Marina Inn provided dinner for all tractor drivers as well as the venue for an auction. West Kerry Men's Shed came on board to donate a bespoke handcrafted table for the auction, a local farmer donated the proceeds from the sale of an in-calf heifer to the cause and hundreds of individuals and businesses donated goods, services and money with incredibly humbling generosity. In addition, the committee were overwhelmed by the positivity and level of support from the local community who gave selflessly of their time to help with bucket collections and stewarding on the day.

Séamus Devane, Michael Geoghegan and John O'Sullivan (Photo courtesy of Declan Malone of The Kerryman).

Members of the O'Sullivan and Devane families with Michael Geoghegan.
(Photo courtesy of Declan Malone of The Kerryman).

Local and national media as well as CNN world news published reports and the video and drone footage from the event, achieving the aim of highlighting the importance of organ donation. The final tally of monies raised came in at an astounding **€43,000** superseding all expectations. There are no words to express the level of gratitude John, Séamus and the committee have towards everyone who helped make the event so successful.

Report by Sharon O'Sullivan

Easy Riders Cycle Club

The Easy Riders Charity Cycle is a charity cycle group from Rathdowney, Co Laois who have been organising charity cycles for the last 16 years and have raised over €400,000 for various charities across Ireland including local charities in the Laois area. What started out as a bit of fun early in 2002, brought forth an annual charity cycle that takes place on the August bank holiday weekend each year. Over the years we have seen old and new faces on bikes and everyone always enjoys the cycle weekend, and more importantly a charity benefits at the end of the annual cycle.

The Easy Riders Charity Cycle organising committee comprising of Sarah Bowe, Kevin Phelan, Colleen Kavanagh, Helen Moynan, Paddy Keyes, Grace Fitzpatrick and Willie Bowe choose ILFA as their charity for 2018. This one was close to their hearts as Kevin's uncle, Tommy Phelan, suffers from IPF and was awaiting a lung transplant. Tommy has since received a transplant from when the 2018 fundraising campaign began and is recovering well. With this in mind, the committee worked tirelessly arranging different fundraising events during the year before the 'big cycle', in order to raise funds for ILFA. Events ranged from 5Km runs to 'Lyric Board' nights, bag packing in supermarkets and games nights. Unfortunately, due to the good spell of summer weather some of the more traditional fundraising events like the annual duck race could not take place in 2018.

Another important decision was what route to choose for the 2-day cycle challenge. After much deliberation, a 220km route from Rathdowney to Clonakilty via Cork City was chosen. 35 cyclists and 15 road crew embarked on the cycle on the August bank holiday weekend. Tommy was at the start line and cut the ribbon to set the cyclists off - it was a sacred moment and one which his family will cherish. Representing Tommy on the cycle was his son Tomas, son-in-law Brian, nephews Kevin, Greg, Paddy and Jason and niece Sabrina. The Phelan family were well represented and did their uncle proud. The 220km cycle to Clonakilty was a tough one with many challenging climbs along the way, but in true Easy Rider spirit they all pulled together, and no one was left behind. The cyclists and crew were greeted by members of the Cork Pulmonary Fibrosis Support Group on the morning of Day-2 in Cork which made the cycle even more special and lifted the spirits of those who were suffering with muscle pains and cramps. The presence of patients and their families who took time out of their Sunday to see the cyclists off on their journey was such a nice touch and one that will not be forgotten. All 35 cyclist and the road crew arrived safely in cycle and to those who helped in anyway throughout the year. It was greatly appreciated, and the annual fundraising events would not be a success without them.

Report by Sarah Bowe

Tommy Phelan, Paddy Keyes, Sarah Bowe, Liam Galvin, Kevin Phelan, Grace Fitzpatrick, Helen Moynan and Colleen Kavanagh.

Andrea Delaney, Grace Fitzpatrick, Kevin Phelan, Tomas Phelan, Tommy Phelan, Colleen Kavanagh, Sarah Bowe, Helen Moynan and Paddy Keyes.

Thank you from ILFA

The ILFA committee would like to extend our sincere appreciation to the Easy Riders Cycle Club for choosing ILFA as their 2018 Charity of The Year. This was a great honour for ILFA, and we are so grateful to Sarah, the organising committee, the cyclists, the Rathdowney community and everyone involved for their amazing commitment, energy and enthusiasm. Their generosity and great fundraising efforts will make a huge difference to the ILFA's work for patients and families.

Members of the Cork Pulmonary Fibrosis Support Group with the Easy Riders cyclists.

Eddie Cassidy, Chris Meehan, Philip Meehan, Emma Treleaven.

Professor Jim Egan and Michael Maguire.

Eddie Cassidy, Evelyn Cooper, Andrew Cooper.

Philip Meehan, Emma Treleaven, Gerard McDonell, Lorna Hogg, Philip Deegan, Chris Meehan.

Philip Meehan, Jack Buggy, Danny Bergin and Hero the dog.

Caroline McErlean, David Buggy, Danny Bergin, Philip Meehan, Emma Treleaven, Chris Meehan and Hero.

Colin Ireland and his supporters.

ILFA Swim December 2018

Sincere thanks to everyone who came along to Sandycove Pier in Dublin on 27th December 2018 to take part and support the annual ILFA Christmas Swim. The 2018 swim was dedicated to the memory of ILFA's loyal supporter Honóra Ní Chríogáin who had organised the swim every year from 2002.

It was a glorious winter's day with blue skies and mild temperatures, and we had a great turnout of brave swimmers and loyal supporters to cheer them on. Some of those taking the plunge into the Irish Sea included Professor Jim Egan, Michael Maguire, Stacia Ireland, Nicky Goodbody, Monica MacLaverty, Philip Meehan, Niall Deegan, Andrew Cooper, Jack Buggy, David Buggy, Iris Bourke, Giles Keane and Barry Prendiville, as well as Colin Ireland, who kindly acted as life-guard.

Supporters included Eddie Cassidy (ILFA Chairman), Marie Sheridan (ILFA Treasurer), Giles Baily, Evelyn Cooper, Emma Treleaven, Chris Meehan, Brenda Lenihan, Averil Paterson, Gerard McDonnell, Lorna Hogg, Moss and Valerie Burris, Danny Bergin, Margaret Lambe, Hero the dog and other canine friends! Marie Sheridan kindly took photographs of the event.

After braving the elements, the swimmers and supporters adjourned to Fitzgerald's Pub for some warm refreshments and friendly banter.

Congratulations, well done and thank you to everyone who took part.

Fundraising Round Up

Thank you from the ILFA committee

The Irish Lung Fibrosis Association was founded in 2002 and is funded solely by the fundraising activities of our supporters and by donations from individuals and corporate donors.

Thanks to you, we have continued to grow and flourish. The ILFA committee would like to extend our warmest thanks to everyone who has supported ILFA over the years. Our amazing fundraisers and volunteers are to be commended for their wonderful enthusiasm, creativity and hard work. It is thanks to the exceptional support, generosity and goodwill of all our fundraisers, event organisers and corporate donors that we can continue our work supporting patients and families living with lung fibrosis.

Christmas Quiz and Raffle

Sincere thanks to Margaret McGlynn and her colleagues at Dublin South County Revenue Office who held a Christmas quiz and raffle on Friday 14 December and raised €629 for ILFA. Margaret (fourth from left), a long-time supporter of ILFA, kindly nominated ILFA as the charity recipient of the funds raised by the festivities. We are very grateful to Margaret and her colleagues for their kindness and generosity.

Margaret McGlynn (4th from left) is pictured with her colleagues at the Dublin South County Revenue Office.

Walk in memory of Dymphna O'Neill

Tom Davitt and his friend Oliver Murtagh from Whitehall, County Westmeath suggested the idea of a fundraising walk, in memory of Dymphna O'Neill, on 25th December 2018. The parish of Whitehall is fortunate to have Ringtown Sports Club, complete with its own purpose-built walking track, located beside the church and school. Every Christmas morning Tom and Oliver open the kitchen and provide tea, coffee, snacks and hot punch to the locals to raise money for a different charity. In 2018 they decided to raise money for ILFA. The community came together in force and raised €765, while honouring the memory of Dymphna O'Neill.

We are very grateful to Tom, Oliver, the Davitt Family and everyone in Whitehall, County Westmeath who contributed so generously to the fundraising event.

Festive Donation

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

Santa Dash 2018

Annette Grehan and Nicola Cassidy.

Back row: Michelle Cregan, Catherine White, Kathleen Evans, Noel Evans, Killian White with Mylo the Dog and Bernadette Bold.
Front row: Sara Bold, Eoin Cregan, Luke Cregan, Daniel White and Isabel Bold.

The Santa Dash Dublin 2018 5km run took place on Sunday 2nd December on Dollymount Strand in Dublin. It was a beautiful balmy morning with blue skies and warm temperatures for the 1,200 Santas and canines that took part running from the North Pole to the South Pole and back again at speed. It was an amazing sight to behold and the atmosphere was certainly festive!

Taking part for ILFA were Annette Grehan and Nicola Cassidy, and members of the Evans family with 'Mylo' the dog. We're very grateful to everyone for their great support.

Team O'Brien

Thank you to all the members of 'Team O'Brien' who organised a collection on Friday 21st December 2018 at Garvey's Supervalu in Tralee in aid of ILFA. We are very grateful to everyone who took part and all who kindly donated to the collection. This was the second fundraising event of 2018 organised by Team O'Brien - in September they also completed a fundraising walk for ILFA to remember and support their loved ones with Idiopathic Pulmonary Fibrosis.

Thanks also to Lorraine Meaney from Dublin who generously donated a hamper of sweets and treats to ILFA. The hamper was put to good use and used as a spot prize for the 'Team O'Brien' event and was won by a lady from Blennerville.

Team O'Brien during their September walk in aid of ILFA.

Liam O'Brien with his grand-niece Erin Moss.

Cormac Coffey with Sam Smith, Esther Coffey and Alannah Moss.

In Remembrance

Sincere thanks to all the families who requested donations to ILFA in lieu of flowers at the funerals of their loved ones. We are very grateful for your support and kindness to ILFA at a time of great personal loss.

Christmas cards

Thank you to everyone who supported the ILFA 2018 Christmas card campaign and helped raise awareness of lung fibrosis at Christmas-time. We are extremely grateful to everyone who also made donations to cover the postage and packaging costs. ILFA would like to extend special thanks to Margaret McGlynn from Co Wicklow and the Evans Family in Dublin who generously took multiple packs of cards to sell to their family and friends.

Halloween Fancy Dress Party

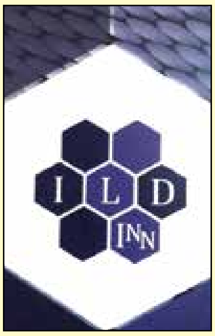
The Rock GAA Club, Mountmellick, County Laois held a Halloween Fancy Dress Charity Party on Saturday 28th October in Turley's Bar, Mountmellick, in memory of Tom Flynn. Tom was one of the founders of the Midlands Pulmonary Fibrosis Support Group and was a dedicated member of The Rock GAA Club. The fancy dress party was a great success and the proceeds were shared by the Irish Lung Fibrosis Association and the Cuisle Cancer Support Centre in Portlaoise.

Val Kennedy and Tricia Conroy accepted a cheque for €2,784.55 on behalf of ILFA on Friday 30th November at The Rock GAA Club. Thank you to everyone who supported this event. A selection of photos is included on pages 12 and 13.


28th October
Horrorgram
4
ROCK GAA CLUB
@ Turleys Bar
1m
CAUTION
1,000,000 HATES
Fancy Dress Charity Party


Horrorgram
ROCK GAA CLUB
@ Turleys Bar
1,000,000 HATES
Fancy Dress Charity Party

ILFA Bursaries for respiratory nurses and allied healthcare professionals



ILFA is pleased to announce that six bursaries (each worth €500) will be made available to respiratory nurses and allied healthcare professionals to attend the Interstitial Lung Disease Inter-Disciplinary Network (ILD-INN) conference in Birmingham on 14th and 15th October 2019.

For more information on the conference please visit **www.ild-inn.org.uk**

What will the bursary cover?

The bursaries will contribute towards the cost of the conference registration including one night's accommodation and dinner, and travel to and from the United Kingdom.

How to apply for an ILFA bursary?

Respiratory Nurses and Allied healthcare professionals working in respiratory medicine can apply for a bursary by completing the application form (available from ILFA and online at www.ilfa.ie) and returning it to **info@ilfa.ie** by 30th May. Please call Gemma on 086 871 5264 if you have any queries.

The winners will be announced by mid-July and the successful applicants will be notified shortly thereafter.

Planning for a National IPF Awareness Day

The Irish Lung Fibrosis Association is hoping to organise a **National Idiopathic Pulmonary Fibrosis (IPF) Awareness Day** in 2019 to raise awareness of the condition among members of the public, healthcare professionals and policy makers. The date is yet to be decided but updates will appear on the ILFA website and on our social media pages (@ILFAIreland).

Unfortunately, too few people know about IPF and this needs to change. For a national awareness day to be successful, ILFA will need your help. Media outlets will look for new personal stories from patients and family members living with IPF from all over Ireland

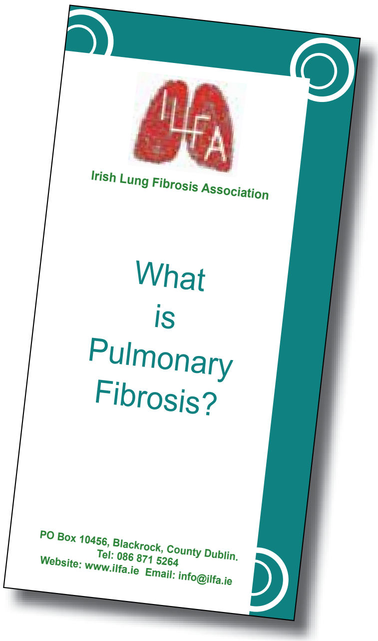
If you have lung fibrosis and are happy to share your story, please get in touch with ILFA by emailing **info@ilfa.ie** or calling 086 871 5264.

We are also looking for healthcare experts who would be willing to provide expert medical opinion and perhaps take part in radio/TV interviews.

ILFA is inviting healthcare professionals from all disciplines and from all over the country to get involved. Please let us know if you would be willing to;

1. Host an information stand in your hospital
2. Act as a spokesperson / respiratory expert and take part in media interviews
3. Identify and approach patients and caregivers who might be willing to share their stories.
4. Visit your local support group

We would also love to hear from you if you have any other ideas please.



ILFA

Irish Lung Fibrosis Association

What is Pulmonary Fibrosis?

PO Box 10456, Blackrock, County Dublin.
Tel: 086 871 5264
Website: www.ilfa.ie Email: info@ilfa.ie

"Together let's make some noise about IPF!"

Cork City Marathon Relay Team

ILFA has a number of teams taking part in the Cork Marathon Relay event on Sunday 2nd June 2019. The first team to register consists of;

- David Crosby - a double lung transplant recipient
- Dr Oisin O'Connell – respiratory consultant
- Lynn Fox - respiratory nurse specialist
- Professor David Healy - cardiothoracic surgeon
- Nicola Cassidy – ILFA representative.

The team was put together to raise awareness of the IPF patient journey and all those involved in patient care. We also have some family teams taking part and a team from Roche Products Ireland.

We would love to have more teams of family members and healthcare professionals participate help raise awareness of lung fibrosis. Contact ILFA on 086 871 5264 or email **info@ilfa.ie** for more information.

EU-IPFF Update

The European Union Idiopathic Pulmonary Fibrosis and related disorders Federation (EU-IPFF) developed a **European Benchmarking Report** that graded the best practices, challenges and short-comings in IPF care and identified where urgent policy action is needed. 16 patient organisations, including ILFA, from 13 EU Member States participated. Representatives of the patient organisations and healthcare professionals were interviewed and completed a detailed questionnaire on national IPF policy, diagnosis and access to specialist care, access to pharmacological and non-pharmacological treatments, and access to palliative care and end-of-life care.

ILFA is grateful to Lynn Fox (respiratory nurse specialist) and Dr Kate O'Reilly (respiratory consultant) at the Mater Misericordiae University Hospital, Deirdre Shanagher at Irish Hospice Foundation, Bettina Korn at St James' Hospital and Maureen Mason of Rare Disease Ireland for their assistance with completing the questionnaire for Ireland.

The results of the interviews were collated to produce a European scorecard that enabled comparisons in IPF care to be made. Each country that participated also received a national scorecard that graded their performance. The EU-IPFF hope that the Benchmarking Report will inform policy decision-making at every level.

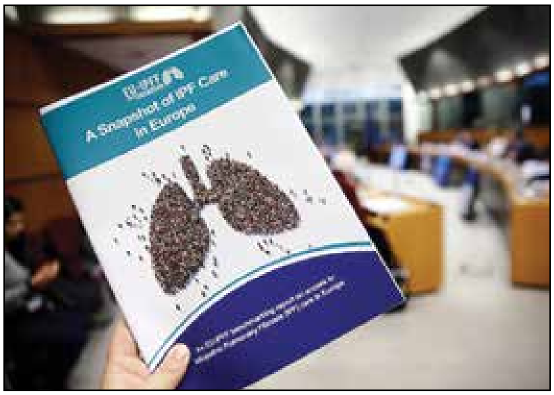
Nicola Cassidy, ILFA Director, said "The Benchmarking Report is an important document and while it appears that Ireland is performing well in some categories, IPF care could be better. National healthcare policies, education and awareness activities and healthcare investment are needed to improve the IPF clinical care pathway and ensure patients have access to an early and accurate diagnosis and treatments, and that healthcare professionals are optimally resourced. ILFA and the Irish Thoracic Society will continue to lobby for improved resources and an ILD Clinical Care Programme for Ireland.

The EU-IPFF Benchmarking Report was presented to the European Parliament at an event on November 20, 2018. The report is available to read online at www.eu-ipff.org

Professor Francesco Bonella, the Chairman of the EU-IPFF Scientific Advisory Board, and Liam Galvin, the EU-IPFF Secretary, co-authored an article, entitled "A call to action for idiopathic pulmonary fibrosis' that was published in Health Europa in December 2018. The article focussed on the key findings and recommendations made by the EU-IPFF Benchmarking Report.

The **inaugural European IPF Patient Summit** will take place from 24th to 26th April 2020 in Warsaw, Poland. This event will be the first European patient-led Summit with a focus on IPF and rare lung diseases. Healthcare experts in IPF, patients and caregivers, industry representatives and policy stakeholders from across Europe will attend and work together to address existing gaps and challenges in IPF care.

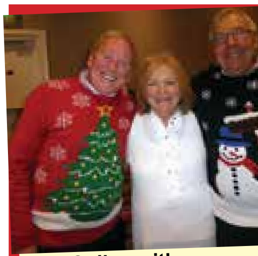
Members of the EU-IPFF at the European Parliament.



The EU-IPFF Benchmarking Report.

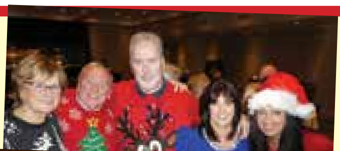
Christmas gathering

On 4th December 2018, the Dublin Pulmonary Fibrosis Support Group held their Christmas Jumper Lunch in Dublin City Centre. 39 people attended the lunch and donned some of the most colourful, bright, 'flashy' and cheerful Christmas jumpers ever seen! The festive get-together was described as being "great fun" with "great food" and "great company"!



Matt Cullen with Dolores and Matthew Williams.

Right: Kathleen and Noel Evans.



Top: Gemma O'Dowd, Matt Cullen, Barney Meaney, Bríd Meaney and Deborah Cullen.

Patient Support Groups

Cork Support Group

The group meets at 11am on the last Thursday of every month at The Elm Tree, Glounthaune. **Please call Anne on 087 985 4587 for more details.**

Dublin Support Group

The group meets on the first Tuesday of every month at 11am at the Carmelite Community Centre at Whitefriar Street Church, Aungier Street, Dublin 2. **Please call Matt on 086 244 8682 or Pam on 086 178 9055 for more details.**

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at The Rose Hotel. **Please call John on 087 280 9801 for more details.**

Midland Support Group

The group meets on the first Wednesday of every month at 2.30pm at the Tullamore Court Hotel, Tullamore, Co. Offaly. **Please call Val on 087 233 2653 for more details.**

Cavan Monaghan Support Group

Kevin McSkeane is hoping to set up a support group in Cavan - Monaghan. **Please call Kevin on 085 243 6828 for more information.**

Mid West Support Group

The group meets on the last Saturday every month at 1pm, at Matt The Thresher, Birdhill, Tipperary. **Please call Noreen on 087 262 7976 for more details.**

Clare Pulmonary Support Group

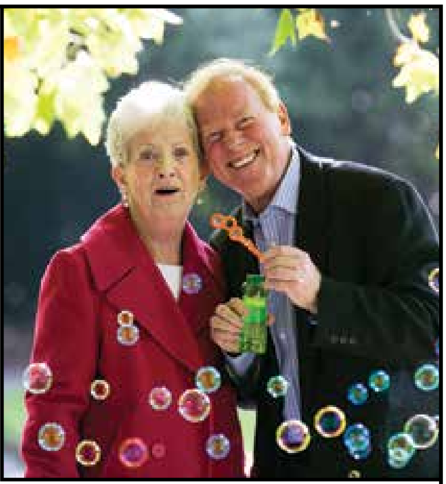
Please contact Michael on 087 637 4068 if you are interested in attending a new support group in Ennis.

ILFA would like to thank the support group leaders for their involvement and organising the groups. It is wonderful to see the groups go from strength to strength and hear about the wonderful peer support available to patients and carers. We wish everyone involved continued success for the future.

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

086 871 5264

Message of Condolence



Joan Doyle and Matt Cullen.

Joan Doyle from Crumlin (and originally from Co Kerry) sadly passed away in January 2019. Joan helped ILFA with many projects and generously volunteered to raise awareness by taking part in the IPF World Week media campaign, the ILFA Exercise DVD for Lung Fibrosis Patients, and the launch of the National Patient Charter for IPF booklet along with Matt Cullen, the late Dermot King and ILFA's patron, Senator Feargal Quinn. Joan was a vibrant, courageous and enthusiastic lady who was always willing to share her experiences and help others. Joan was held in highest regard by all those who knew her and will be greatly missed by everyone in the Dublin Support Group. She was such a positive source of energy, good sensible counsel and great humour. May she rest in peace. We offer our sincere condolences to Joan's husband John and her daughters Deirdre and Siobhan on their great loss.

Diary

Dates For Your

Healthcare Professionals

- **The European Respiratory Society Congress will take place from 28th September to 2nd October in Madrid. Please see www.erscongress.org**
- **The Interstitial Lung Disease Interdisciplinary Network (ILD-INN) Annual Conference will take place on 13th and 14th October in Birmingham, UK. Please see www.ild-inn.org.uk**

Fundraising

- **The Great Limerick Run will take place on Sunday May 5th 2019.**
- **VHI Women's Mini-Marathon will take place on Sunday 2nd of June 2019 at 2pm. Register on-line at www.womensminimarathon.ie**
- **The Cork City Marathon will take place on Sunday 2nd June 2019.**
- **The Dublin City Marathon will take place on Sunday 27th October 2019.**

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

Keep in touch with ILFA

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

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

ILFA Newsletter

Patrons: Michael Darragh Macauley, Charlie Bird, Andrea Corr.
Issue: Autumn 2019 Volume 17 Issue 2

Irish Lung Fibrosis Association
www.ilfa.ie

ILFA welcomes the General Scheme of the Human Tissue Bill and an opt-out organ donation system

David Crosby (double lung transplant recipient), Edel Cashman (liver transplant recipient), Minister for Health Simon Harris TD, Martina Goggin (representing organ donor families) and Professor Jim Egan (ODTI) at the announcement of the publication of the Human Tissue Bill general scheme. *(Photo courtesy of the HSE and ODTI)*

On 2nd May 2019 the Minister for Health, Simon Harris TD announced the publication of the General Scheme of a Human Tissue (Transplantation, Post-Mortem, Anatomical Examination, and Public Display) Bill. Significantly, this Bill provides for the introduction of an opt-out consent system for organ donation and an associated register. ILFA has long campaigned for the introduction of an opt-out organ donation system and additional resources and infrastructure to support organ donation and transplantation. Following the publication of the Human Tissue Bill, ILFA wrote to the Minister for Health to express our gratitude and hopes for the future in relation to an opt-out consent system.

In a press release on 2nd May 2019, Minister Harris said, “I am really pleased to progress this vital piece of legislation which is a key commitment of mine and of the Government.” He acknowledged the great work of staff at Organ Donation and Transplant Ireland (ODTI) and the national transplant centers at Beaumont Hospital, St Vincent’s University Hospital, and Mater Misericordiae University Hospital. Minister Harris stated “I strongly believe that this opt-out system could transform organ donation in Ireland. In order for it to be most effective, it will be supported by a series of other measures. It is so important we do everything we can to make organ donation the norm in Ireland when people pass away in circumstances where donation is a possibility.” He also stated, “The plan is that the legislation will dovetail with awareness campaigns, enhanced infrastructure, training for medical staff and audit, to ensure that all opportunities for transplantation are followed through.” Minister Harris acknowledged the significant and valuable contribution made by Senator Fergal Quinn to progress organ donation and transplantation in Ireland.

The General Scheme of the Human Tissue Bill will introduce a soft opt-out system of consent for organ donation. Under this system, consent will be deemed unless a person has registered that they do not wish to become an organ donor after death. If a person is on the opt-out register, their next-of-kin will not be approached to discuss organ donation and their organs will not be removed. If a person is not registered on the opt-out register, the next-of-kin will always be consulted before any organ is removed. If the next-of-kin objects to the donation, then the donation will not proceed.

Patient Information Day

The next Patient Information Day will take place on Saturday 19th October at the Crowne Plaza Hotel, Northwood, Santry, Dublin from 10am until 2pm. We hope you can join us to learn more about pulmonary fibrosis from experts in the field. Our speakers will include;

- Dr Michelle Murray - Respiratory Consultant
- Petra Grehan - Physiotherapist
- Lindsay Brown – Respiratory Nurse Specialist
- Dr Jennifer Wilson O’Rathaghaille – Clinical Psychologist
- Professor Bernard Mahon – Maynooth University
- Carita Bramhill, Research coordinator
- Sonia Morrison from Air Liquide Ireland and Adrian Sheehan from BOC Healthcare Ireland

Please call 086 871 5264 or email info@ilfa.ie to register for this free event.

ILFA Service of Prayer and Reflection

The ILFA Service of Prayer and Reflection will take place on Saturday 12th October at Terenure College Chapel, Terenure, Dublin at 3pm. The ecumenical service will be celebrated by Reverend Fr Brian McKay (Prior of Terenure College), Reverend Vanessa Wyse-Jackson (retired Minister at Rathgar Methodist Church), and the Reverend Canon Charles Mullen (Dean’s Vicar at St Patrick’s Cathedral). A special candle lighting ceremony will take place to remember lung fibrosis patients who have passed away. If you would like your loved one remembered at the ceremony, please contact ILFA by calling 086 871 5264 or emailing info@ilfa.ie by the 26th September 2019.

Rest in Peace Feargal Quinn

The Irish Lung Fibrosis Association was deeply saddened to learn about the passing of our esteemed and cherished patron Feargal Quinn in April 2019. Feargal was a patron of ILFA for many years and we were honoured to know and work closely with him. Fergal was a true gentleman and was deeply committed to his ILFA role.

Feargal helped launch ILFA's 2000 Steps a Day exercise programme and 'The National Patient Charter for Idiopathic Pulmonary Fibrosis'. He also appeared in the ILFA exercise DVD and encouraged patients to stay motivated and determined. Fergal also attended several ILFA Patient Information Days and spoke at these events sharing his wisdom and insights. Feargal contributed an article to ILFA's special commemorative magazine 'ILFA 15' that was produced in 2017 and his article is reproduced below.

In 2008, Senator Feargal Quinn wrote a Bill entitled the 'Human Body Organs and Human Tissue Bill'. We were delighted when Feargal's pioneering role and vision was acknowledged widely by government officials, the HSE and the Department of Health, and the media when the Human Tissue Bill general scheme was announced. This was a great and fitting legacy to Feargal's tremendous advocacy work. Feargal radiated a special warmth and great kindness and he was always eager to engage with the ILFA committee and patients and learn about their experiences. We have lost a wonderful friend and patron. Please remember Feargal and his family in your thoughts and prayers. May he rest in peace.

The late Feargal Quinn with the late Joan Doyle, and Matt Cullen at the launch of the National Patient Charter for Idiopathic Pulmonary Fibrosis.

Irene Byrne, Michael Darragh Macauley and the late Feargal Quinn at the launch of ILFA's 2000 Steps a Day Challenge.

Proud to Support ILFA

Former senator Feargal Quinn reflects on his years as an ILFA patron as he looks forward to implementation of the opt-out organ donor system.

The Irish Lung Fibrosis Association was founded back in 2002 and I have been privileged to be a patron of the organisation along with some other key individuals such as Brian O'Driscoll, Andrea Corr, Charlie Bird and Michael Darragh Macauley. My role as patron has required me to offer support, encouragement and publicity for the association and I had the privilege in 2015 to support the organisation with the launch of their Patient Charter in Leinster House.

The work of the ILFA is immeasurable. Approximately 360 people are diagnosed with Idiopathic Pulmonary Fibrosis in Ireland each year and the ILFA acts to support those patients and their families by offering them clear and concise information, access to appropriate therapy and medication as well as connecting them with support groups. All of this is invaluable to families faced with this disease.

The association promotes referrals to the National Lung Transplant Unit. This is an area very close to my heart. Back in 2008 I wrote a Bill entitled the 'Human Body Organs and Human Tissue Bill'. I am now delighted to see that Minister Simon Harris has taken my Bill on board and announced that he is determined to implement this opt-out system in Ireland by next year. This will hugely increase Ireland's rate of organ donation. In 2016, 35 lung transplants were performed at the National Heart and Lung Transplant Service at the Mater Misericordiae University Hospital. With the implementation of this Bill we will see this figure rise giving a new lease of life to many of those affected.

ILFA also offers very practical ways to adapt to living with this lung condition. One of these initiatives was the launch of the 2000 Steps A Day walking challenge and the ILFA Home Exercise DVD. These initiatives are invaluable as they encourage patients to maintain a level of physical activity which promotes muscle strength, mobility and also good mental health.

I would like to thank the Irish Fibrosis Lung Association for their dedication and hard work. They are a voluntary committee relying on charitable donations and fundraising events. This requires enormous commitment, dedication and hard work. I congratulate you and encourage you to keep up the enthusiasm.

Best wishes, Feargal Quinn, ILFA Patron

(Published in 'ILFA 15' in 2017)

2 Irish Lung Fibrosis Association, P.O. Box 10456, Blackrock, Co. Dublin.

Dr Killian Hurley, Bettina Korn, Maria Love, Anne-Marie Russell, Lynn Fox, Irene Byrne and Dr Irfan Shah.

Patient Information Day,

April 2019

ILFA's first information day of 2019 took place at the Hilton Airport Hotel, Malahide, Dublin on 6th April 2019. The focus of this meeting was palliative care and planning for the future for Idiopathic Pulmonary Fibrosis (IPF). The meeting was well attended by patients, family members and healthcare professionals. In opening the meeting, **Eddie Cassidy** (ILFA Chairman) extended a warm welcome to all and gave thanks to the many ILFA volunteers and fundraisers who make events like this possible.

Meeting Chairperson, **Dr Anne-Marie Russell,** Honorary Clinical Research Fellow at the Royal Brompton Hospital London, explained that this information day came about following the ILFA World Café on Palliative Care held in June 2018. Anne-Marie discussed the importance of reframing perceptions of palliative care, a term usually associated with end-of-life-care, to view it as the holistic management of symptoms with the aim of increasing quality of life.

Andrew Cooper, whose mother has IPF, offered a caregiver's perspective on coping with this disease. He explained that the information, knowledge and support he has gained through others by attending ILFA meetings and events has been invaluable in giving him strength as a caregiver.

Dr Killian Hurley, Respiratory Physician at Beaumont Hospital, gave a presentation entitled 'What is IPF?' Dr Hurley used the analogy of an upside-down tree to describe the structure of the airways and lungs. He explained that the problems with IPF occur down at the 'leaves' (the alveoli, small air sacs) where scarring means that oxygen cannot effectively get into and out of the lungs. Multiple tests are used to diagnose IPF, including chest X-rays, CT scans, possibly a biopsy, along with breathing tests, oxygen saturation measurements and six-minute walking tests. A diagnosis of IPF is made by a multi-disciplinary team comprising the healthcare professionals involved in assessing the patient, including the respiratory consultant, the pathologist, the nurse specialist, the thoracic surgeon and the radiologist. IPF is a progressive disease, meaning it gets worse with time, but the progression can be fast or slow. Patients are monitored closely to establish their individual rate of progression and decide on their treatment plan.

Lynn Fox, Respiratory Nurse Specialist at the Mater University Hospital, discussed symptom management in IPF. She explained that there is no set process for the management of IPF, and that treatment is individualised with the goal of improving quality life. Breathlessness, the biggest symptom in IPF, can be improved through non-medical interventions such as positioning, relaxation breathing, exercise and the use of a hand-held fan. Medical options for breathlessness include oxygen, small doses of opioid medications and anti-anxiety medications. Patients need a full check-up prior to being started on oxygen, including a six-minute walking test, arterial blood gas tests and assessment to see if you are a nose or a mouth breather (this is important as oxygen concentrators are not triggered by mouth breathers). Fatigue, another common symptom of IPF, affects everyone differently but Lynn's advice for patients was to plan ahead so you have the energy to do the things you want to do. Also, to look after yourself by eating well, drinking enough fluids, exercising and getting enough rest and sleep. Gastric reflux (heartburn) is also common in IPF and may be a side effect of anti-fibrotic medication, and proton pump inhibitor medications (PPIs) can be helpful in treating this symptom. Cough can be a very debilitating symptom in IPF and is difficult to treat. Lynn advised people to keep a diary to help establish cough triggers. Anxiety and depression are also common in IPF and attending support groups, counselling, exercise and medication can be beneficial.

Dr Killian Hurley gave a second presentation and spoke about acute exacerbations of IPF, also called 'flare ups'.

An IPF exacerbation is a sudden unexplained worsening of IPF symptoms in the last 30 days, which includes new changes on a CT scan, with no evidence of infection or other causes for shortness of breath (for example, heart failure). IPF exacerbations can disrupt the progression of IPF, meaning that lung function may not fully recover after an exacerbation. Exacerbations can have long term repercussions and need to be prevented and managed. To help reduce the risk of exacerbations, patients should ensure their vaccinations for influenza and pneumococcal disease are up to date, minimise acid reflux including using PPI medications (as this may be a risk factor for exacerbations), avoid airway irritants, follow good hand-washing practices and avoid contact with people who are sick. There is also research that indicates anti-fibrotic medications may reduce the risk of exacerbations. If you think you are having an exacerbation, it is vitally important to let your GP or nurse specialist know quickly so it can be managed. Diagnosis involves a CT scan or chest x-ray and tests to exclude other causes, and treatment can include oxygen, antibiotics and steroids.

Tom O'Sullivan, Anne-Marie Russell and Andrew Cooper.

Irene Byrne, physiotherapist at the Mater University Hospital, gave a practical guide to living with IPF. A key theme from Irene's presentation was adapting to the 'new normal' and the importance of accepting offers of help! By taking us through the rooms in the house, Irene gave pragmatic advice on coping with breathlessness, including clearing areas around the front door, placing a stool at the top of the stairs, using a shower chair or a bath stool, and sitting down whilst propping up the elbow to shave or use a hairdryer. Little things like getting a 'picker-up' device or a V-shaped pillow can also help make life easier. Irene advised that stair-lifts require early planning as they can take a long time to arrange. There are many practical aspects to consider with using oxygen, so Irene recommended that people have thorough discussions with their healthcare team regarding the pros and cons of all the oxygen options available to find a solution to suit their lifestyle. To improve mobility, people should consider a rollator (a walking aid with wheels). Irene also advised that as breathlessness makes chewing more difficult and decreases appetite, use moist foods, and eat little and often. Holidays require careful planning and permission to travel from your doctor. For air travel, the European Lung Foundation have information on individual airline's policies around oxygen on their website www.elf.org

Maria Love, social worker at the Mater University Hospital, discussed the psychosocial aspects of living with IPF. Maria presented the biopsychosocial model for IPF, where 'bio' means the biological disease and its symptoms, 'psycho' refers to the depression, anxiety as stress related to IPF, and 'social'; relates to our hobbies, families, friends, career, retirement plans or the isolation that can result from IPF. These areas can impact on each other and lead to a vicious circle where, for example, breathlessness leads to lack of exercise, which increases social isolation and anxiety, which make breathlessness even worse. Illness affects our mental health and has massive social impacts, limiting daily activities, changing relationships and family structures. Understanding these problems can help us to cope better; as Maria conveyed "It is the medical support that keeps me alive, but the psycho and social support enables me to live". Ways of coping with the psychosocial impacts of IPF include support from professionals, joining support groups, attending pulmonary rehabilitation (not just for the exercise but for the social benefits too), and being honest and open about your emotions whilst recognising that the illness is not your complete identity. Carers play a much under-recognised role, and Maria advised that as a carer it is important to look after your own physical and psychological health and recognise the impact of caring on your lifestyle.

Dr Irfan Shah, medical registrar at St Michael's Hospital in Dublin discussed the considerations for lung transplantation. IPF is now the leading reason for lung transplantation worldwide. There are several criteria, as set out by guidelines from the International Society of Heart and Lung Transplantation, to assess IPF patients' suitability for lung transplantation. Early referral for transplant assessment is recommended. In Ireland the National Lung Transplant Centre is based at the Mater University Hospital, and Dr Shah spoke about the multiple medical and psychological assessments patients must undergo to assess if they are suitable for a transplant. The assessments determine medical suitability but also gauge if a patient is focused and committed to follow the intensive requirements after surgery. If a patient is considered suitable for transplantation, they are placed on the transplantation waiting list, with the time to surgery being dependent on the availability of a suitable donor organ. In addressing questions on the age of patients considered suitable for surgery, Dr Shah explained that it was not chronological age but physiological age and how otherwise healthy you are (apart from your lung condition) that was important in considering transplantation.

Bettina Korn, the End-of-Life Co-ordinator at St James Hospital, sensitively guided the audience through a discussion on end-of-life preferences. For end of life care, there are several considerations; meeting care needs, the environment where care happens, dignity and respect, communication and care for relatives. Patients' wishes are imperative in end of life care, so having conversations with loved ones and healthcare providers about preferences for end of life care is important. These conversations can obviously be difficult, but Bettina's advice is to create opportunities for these discussions, to

Andy McGrane, Shauna Clarke and Chris Meehan who volunteered on the day and provided excellent support with registration and timekeeping.

Rebecca Lloyd.

recognise that some people may be ready to talk about this topic at different times and to seek professional guidance. Bettina recommended that is never too early to start these conversations, and that lots of small conversations about end of life care may be easier than creating time and space for one big discussion. There are supports available for information and education on end of life: The Irish Hospice Foundation **(www.hospicefoundation.ie)** has developed a Charter on Death, Dying and Bereavement and its 'Think Ahead' programme has a very practical form to guide people through end of life planning. In addition, the conversation project **(www.theconversationproject.org)** has information and supports for people to talk about their wishes for their end of life care.

Rebecca Lloyd, Public Engagement Officer at the Irish Hospice Foundation, discussed the legal aspects of planning for the future which you may want to discuss further with your solicitor. Please bear in mind that some forthcoming changes in the law around assisted decision-making capacity may affect the information she discussed at this meeting. Legal considerations for the future include:

- Wills provide instructions on what you would like to happen to your assets after you die. You don't have to make a will but if you don't the state will make these decisions for you. Rebecca shared that 'do-it-yourself' wills can be troublesome; they can be legally challenged and the witness to your will cannot receive anything. Wills can be changed, and it is recommended they are reviewed at certain 'ages and stages'.

- Enduring Power of Attorney gives power to another person to make decisions about your care if you become mentally incapacitated to do so (unlike Power of Attorney which is temporary and is effective once a person loses capacity). These give far reaching powers to another individual and need careful consideration. An Enduring Power of Attorney is made with both a solicitor and a doctor, can be expensive to make and requires a court order to amend it.

- Advanced Healthcare Directives allow you to make choices about the type and extent of medical treatment you do not want in the future, even if a refusal for treatment may result in your death. They also allow you to appoint a Designated Healthcare Representative. Advanced Healthcare Directives only come into effect if you lose mental capacity to make informed decisions. They can be useful in helping you keep control of your own care and can give loved ones peace of mind. The Irish Hospice Foundation's 'Think Ahead' document gives information on discussing and recording your preferences for treatment in the event of an emergency or serious illness.

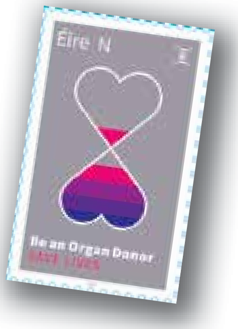
After the presentations, Anne-Marie Russell chaired the Questions and Answers session with many questions from the audience and she thanked the speakers for their excellent presentations and Air Liquide and BOC Healthcare oxygen companies for their presence. She then handed over to **Tom Sullivan** who, having cared for his wife Eileen, gave us his personal reflections on palliative care. Tom advised everyone not to fear palliative care programmes, that these offer holistic physical and psychological care for the patient and the family which can be 'turned on and off' as required as the disease progresses. We were fortunate that Tom shared some of his very poignant and equally humorous poetry with us before Maria Love finished up with a session of mindfulness. This exercise reminded us to show ourselves the same compassion during moments of stress and hardship that we would offer to others.

Finally, the ILFA yoga DVD was launched by ILFA Director Nicola Cassidy and she paid tribute to ILFA Patron Michael Darragh Macauley, and three patient volunteers; Pamela Martin, Evelyn Cooper and Matt Cullen for their starring roles in the video. The meeting wrapped up with another form of valuable support; tea, lunch and time for a chat.

Marie Sheridan, David Crosby and Nicola Cassidy.
(Photo courtesy of An Post and ODTI)

David Crosby and Andy Kavanagh.
(Photo courtesy of An Post and ODTI)

Launch of Organ Donation Stamp



Marie Sheridan (Hon. ILFA Treasurer) and Nicola Cassidy (ILFA Director) attended the launch of An Post's new national organ donation postage stamp on 21st March 2019 at the General Post Office in Dublin, along with representatives from other patient organisations, healthcare professionals working in transplant medicine, transplant recipients and donor families. It was a very special occasion and as a bonus it was a lovely sunny day.

The organ donation stamp came about as part of a collaboration between An Post, Organ Donation and Transplantation Ireland (ODTI) and the HSE. The creative design of the stamp features an hourglass timer that represents the precious nature of time and the gift of life passing from one person to another. It is hoped that the stamp will encourage people to have a conversation with their families to let them know about their wishes to be an organ donor and save lives.

Debbie Byrne, managing director of An Post Retail, said the organisation hopes the stamp will help raise public awareness and she gave some impressive figures that will help support this campaign. There are 9,000 An Post staff as well as 3,000 postmasters and their staff who are getting behind donor and recipient families and millions of customers who will send and receive the stamp in Ireland and abroad. The stamp is available in two formats; it can be especially asked for at the post office counter and it is available as Stamps on A Roll, ensuring that the Organ Donor stamp will be printed and posted many millions of times. The stamp will be an ambassador for Organ Donation, travelling around Ireland and all over the world on letters and parcels. Debbie stated that "An Post wants to spark a national conversation in Ireland's post offices, kitchens, cars, playgrounds and wherever families are gathering,"

Helping to launch the stamp was Andy Kavanagh and David Crosby. Andy has worked for An Post for 20 years and is the longest surviving heart transplant patient in Ireland, having had the transplant in1986 and also a subsequent kidney transplant 12 years later. Andy said "The important message we are trying to get out to people is for people to donate their organs but also to make sure that their family knows what their wishes are if anything was to unfortunately happen to them," David Crosby also shared his story of being diagnosed with Idiopathic Pulmonary Fibrosis (IPF) and undergoing a double lung transplant thanks to the generosity of his organ donor. Both men also featured in two inspirational videos describing the life-changing impact of their transplants.

Professor Jim Egan, Director of ODTI, also addressed the audience and said "I'd like to thank An Post for the creation of this special stamp. It will create more public awareness about organ donation. It is only because of the generosity of the Irish public that patients can receive the life-saving treatment of an organ transplant. Our message is simple: Organ Donation Saves Lives."

ILFA would like to congratulate An Post, ODTI and the HSE on this great initiative to raise awareness of organ donation and help facilitate family discussions on this important topic.

Nicola Cassidy (ILFA Director), Gordon Ryan, Professor Jim Egan, David Crosby, Ciara Quirke and Robert McCutcheon (Chair of the Irish Heart and Lung Transplant Association).

‘The irony of lung fibrosis; a fibroblast to treat IPF’

The Irish Lung Fibrosis Association was delighted and honoured to partner with Maynooth University in welcoming Professor Luis Ortiz, University of Pittsburgh Medical Centre, USA, to the Royal College of Physicians of Ireland for a special lecture. The special educational event took place in the fine and prestigious Corrigan Hall which was packed with healthcare professionals, scientists, students, and patients eager to learn about Professor Ortiz’s work. Prof Ortiz’s inspiring lecture described experimental research on mesenchymal stem cells and their influence on the gene expression and inflammatory actions of lung cells and tissue.

Professor Bernard Mahon of the Immunology and Cell Biology Laboratory at Maynooth University Biology Department wrote the following article which appeared in the Medical Independent. ILFA is grateful to Professor Mahon and to Priscilla Lynch, Clinical Editor of the Medical Independent, for permission to re-produce the article. Photos courtesy of Joshua Shannon (Maynooth University).

Evelyn Cooper, Liam Martin, Pamela Martin, Treasa Brogan, Professor Luis Ortiz, Liam Mullaney, Matt Cullen and Philo Mullaney.

Prof Luis Ortiz.

Prof Paul Moynagh (Head of the Human Health Research Institute at Maynooth University), Prof Jim Egan (Mater University Hospital). Eddie Cassidy (ILFA Chairman), Prof Luis Ortiz (University of Pittsburg), Prof Bernard Mahon (Maynooth University), Prof Michael Keane (St Vincent’s University Hospital).

‘The irony of lung fibrosis; a fibroblast to treat IPF’

– report by Professor Bernard Mahon

The term ‘idiopathic’ is often a refuge for physicians and scientists when we do not understand how a disease is caused. Nevertheless, much has been learned about the mechanisms that underlie Idiopathic Pulmonary Fibrosis (IPF). This was the topic of a special lecture held in the Royal College of Physicians in March where Professor Luis Ortiz from the University of Pittsburgh Medical Centre looked at past and current understanding of lung fibrosis and scanned the horizon of future therapies. The evening was a co-sponsored event by the Irish Lung Fibrosis Association and the new Maynooth University Human Health Research Institute. In a salute to the history of the disease, Professor Ortiz recalled that the Irish physician, Sir Dominic Corrigan – a former president of the Royal College, made one of the first descriptions of the disease.

However, whilst our understanding of the cells and the biological process of fibrosis have improved, IPF remains a fatal interstitial lung disease of unknown aetiology, characterised by progressive fibrosis of the airways. It

Nicola Cassidy, Professor Luis Ortiz, Eddie Cassidy and Gemma O'Dowd.

Evelyn Cooper, Pamela Martin and Treasa Brogan deep in conversation with Prof Ortiz.

Prof Jim Egan (Mater University Hospital), Prof Muiris Fitzgerald (Emeritus Professor of Medicine at University College Dublin) and Prof Michael Keane (St Vincent's University Hospital).

predominantly affects those over 60 years, and the incidence and prevalence are rising. Whilst lung transplantation affords good prospects for recipients, the limitations of availability and scalability of this approach are well known, and other approaches merely slow what is otherwise a fatal disease. After describing his experiences in Pittsburgh and the processes of disease, Professor Ortiz went on to describe the two medications licensed for use in recent years in the US; Pirfenidone and Nintedanib. These anti-fibrotic medications limit progression but are not curative and certainly in the US context are extremely costly interventions.

In the second half of his presentation, Professor Ortiz focused on the need for more research into IPF and the challenge of reversing fibrosis. He reviewed the latest thinking about how the regular process of cell repair is thought to operate in the distal airways and focused on a cell circuit of three cells and how these communicate. An airway stem cell (the type II alveolar epithelial cell), a supporting cell (the lipofibroblast), and an immune cell (the airway macrophage).

His hypothesis is that such a circuit is dysfunctional in IPF but that it might be possible to re-programme it towards a more fibrolytic rather than fibrotic nature. His favoured candidate for achieving this was using a cell-based therapy. His goal is to use a bone marrow stem or stromal cell as a future therapy to perform the reprogramming of the alveolar niche. He described a decade of careful work using the mesenchymal stromal cell in tissue culture, and then in small and large animal models that suggest this approach might be fruitful.

The work has brought him to Ireland to share data with Irish scientists and the team in Maynooth, who study how these stromal cells interact with the immune system. His work has led to some fascinating discoveries about how cells communicate using small sub-cellular particles, and even by exchanging their mitochondrial energy sources. He has now assembled a team from a number of universities and health centres in the US in a bid to begin phase 1 clinical trials of this therapy. However, Prof Ortiz cautioned that research takes time, and that success is not guaranteed. Professor Ortiz also emphasised that while research was necessary it had to be performed in a well-regulated and controlled environment such as in Ireland. He shared his fears about medical tourism and of disreputable and poorly controlled "clinics" that were exploiting regulatory loopholes to make extravagant, unsubstantiated claims. Finishing, he stated that just because IPF was idiopathic, it did not mean we were in the dark. Lung transplantation services and skills were better than ever before, we have new drugs that are an improvement on a decade ago, and we know much more detail of how cell regeneration and repair occur in the healthy and diseased lung, but only with more research and clinical trials will we get to the point where we can repair the fibrotic lung appropriately. Prof Egan (Mater Hospital) then moderated a question and answer session that understandably attracted a great deal of interaction. Patients, supporters, scientists and physicians all contributed to a fascinating discussion that continued long after the formal session ended.

Professor Ortiz is the 2019 Maynooth University Distinguished Visiting Scholar.

A Patient's Perspective

We had been alerted that this lecture was for healthcare professionals. The list of the speaker's global awards, honours, trials and publications was formidable. We expected to be dazzled by science. But when we met Professor Luis Ortiz on 13th March, he was an informal, incredibly warm, humble man eager to talk to the patients first, to hear their experiences, as we shared a cup of tea.

The lecture took place in the opulent splendour of The College of Physicians where portraits of eminent past professors adorn the walls. Prof Ortiz delivered his talk under the watchful eye of Dr Dominic Corrigan. Dr Corrigan (1802-1880) an Irishman, of 'Corrigan's Pulse' fame, is also credited for first describing "cirrhosis" of the lungs!

Prof Ortiz began the lecture by first addressing the patients. "Stay active, stay positive" he urged. He described the stem cell research he is doing for the treatment of IPF in layman's terms. He then apologised and said he would have to talk to "the nerds" in the room. The language turned medical and complex but still contained many nuggets of useful information. One intriguing aspect of his talk was when he described spending five years becoming a 'mouse cardiologist' in order to understand how IPF develops.

All agreed this was a brilliant informative evening, delivered with grace and obvious passion. As an IPF patient, it was humbling to know that there is someone in the world trying so hard to find a cure for this rare condition.

- Report by Treasa Brogan

Organ Donation Awareness Week 2019

The launch of Organ Donation Awareness Week took place at the Mansion House in Dublin on Tuesday 26th March 2019. The event was organised by the Irish Kidney Association. Representing ILFA at the event were Marie Sheridan (ILFA Honorary Treasurer), Nicola Cassidy (ILFA Director) and lung transplant recipient and ILFA Patient Ambassador David Crosby.

Ray D'Arcy from RTE radio and TV is the Ambassador for the 2019 Organ Donation Awareness Week. In his address, Ray mentioned that he had the honour of being an Ambassador 20 years previously and was very happy to reprise his role. Ray had interviewed David Crosby on radio the day before the launch and described David's incredible return to health and fitness following his double lung transplant as 'miraculous'. Ray paid tribute to David's advocacy work raising awareness about the importance of organ donation and transplantation and he had plenty of further opportunities to marvel at the benefits of organ donation as he introduced the speakers from all over the country.

Garrett Ffrench and other transplant recipients who had received kidney, heart, kidney/pancreas and liver transplants told their touching personal stories and described how their lives had been transformed by the generosity of organ donors and families who had consented to organ donation. Garrett was diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in 2010 and received a left lung transplant in 2013. Further health complications meant that Garrett subsequently needed another lung transplant for his right lung. Five years on, Garrett paid tribute to his donors and thanked them for the opportunity to watch his four children grow up. Garrett and his wife Josephine and their 4 children attended the launch and it was wonderful to see the happiness that organ donation has brought to this young family.

Other speakers included Grainne Wyse who described how her family fulfilled her brother's wishes to be an organ donor and how this brought them comfort, and Karen Mason from ODTI who described eloquently how organ donation can turn loss into hope and grief into blessings for family members who donate.

Professor Jim Egan, Director of Organ Donation and Transplant Ireland (ODTI) acknowledged the talented and dedicated medical and surgical staff around the country who have assisted with and facilitated organ donation and transplantation; the staff of the ODTI; the transplant co-ordinators at the three national transplant units at Beaumont Hospital, St Vincent's University Hospital and the Mater Misericordiae University Hospital; and the donors and their families who gave permission for organ donation to proceed at a time of deep personal loss.

The Minister of Health, Simon Harris, TD, also paid tribute to all those working in the field of organ donation, including the patient organisations working to promote awareness of organ donation and transplantation; ILFA, Cystic Fibrosis Ireland, the Irish Heart and Lung Transplant Association, Alpha-one Foundation Ireland and the Irish Kidney Association. He also praised Orla Tinsley for raising awareness via her inspiring TV documentary on living with Cystic Fibrosis and waiting on a lung transplant. Minister Harris stated that the Human Tissue Bill that includes provision for the introduction of a soft opt-out consent system for organ donation will come before the Dáil in 2019.

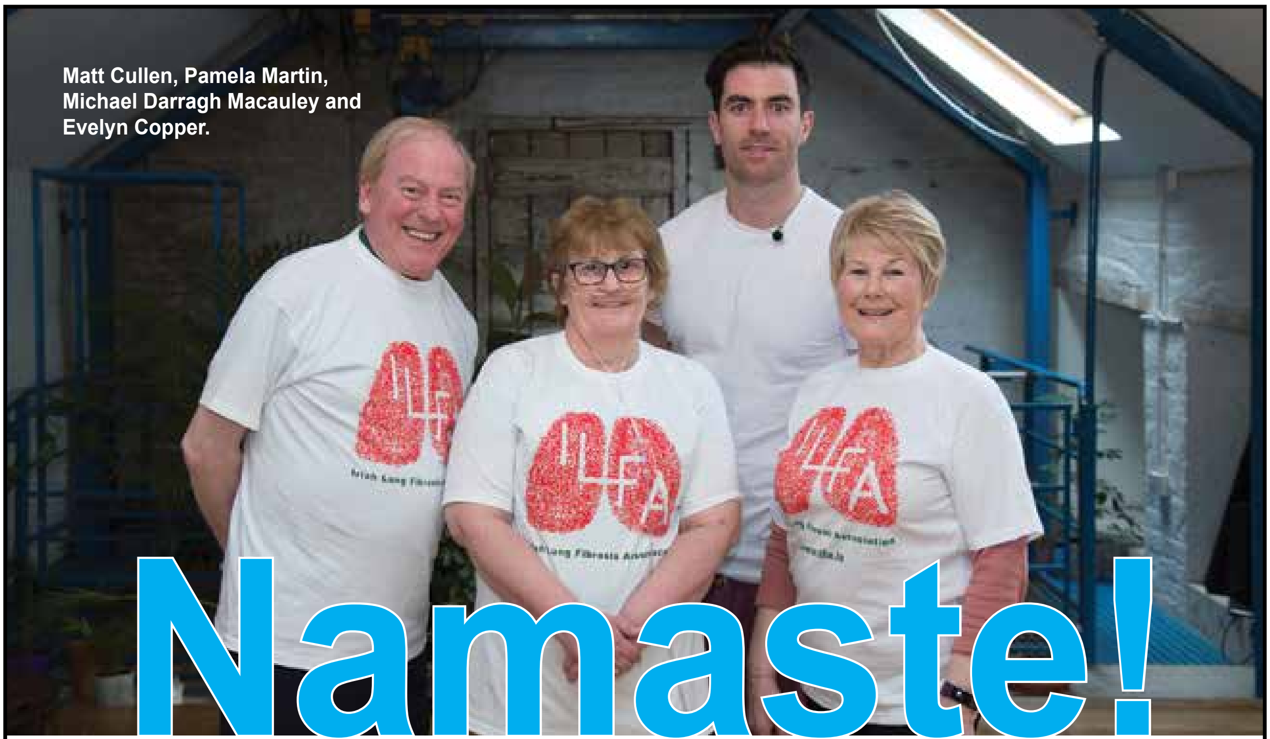
Transplant Figures for 2018

According to Organ Donation and Transplant Ireland (ODTI), 234 transplant recipients received the gift of life thanks to the generosity of 81 organ donors and their families.

- The Mater Misericordiae University Hospital carried out 28 lung transplants and 18 heart transplants.
- St. Vincent's University Hospital carried out 56 liver transplants and 5 combined pancreas/kidney transplants.
- Beaumont Hospital carried out 127 kidney transplants from deceased donors and 40 transplants from living donors.

Robert McCutcheon (Chairman of the Heart and Lung Transplant Association), Marie Sheridan, Garrett Ffrench, Ray D'Arcy, Nicola Cassidy and David Crosby. *(Photo courtesy of the Irish Kidney Association).*

Ray D'Arcy with Josephine and Garrett Ffrench and their children. *(Photo courtesy of the Irish Kidney Association).*



Matt Cullen, Pamela Martin, Michael Darragh Macauley and Evelyn Copper.

Namaste!

New Yoga Exercise DVD for Lung Fibrosis

Michael Darragh Macauley, Dublin GAA footballer, yoga instructor and ILFA Patron has been central to the production of ILFA's newest patient resource – a yoga exercise DVD for people with lung fibrosis. Yoga has proven benefits for people with lung fibrosis in helping their health and well-being through improved breathing, mobility, flexibility, as well as through the relief of tension and anxiety.

In the video Michael Darragh takes three patient volunteers; Pamela Martin, Evelyn Cooper and Matt Cullen through a series of tailored breathing and meditation techniques, followed by physical exercises. The video was filmed on location in a beautiful yoga studio in Dublin and we are very grateful to everyone involved in the production of ILFA's newest patient resource.

The video features two levels of exercises which are suitable for beginners and those who feel they can progress to a more advanced stage. Before undertaking the exercises, viewers are asked to follow the BORG scale which helps them assess how breathless they should be when exercising and gauge what is the right level of activity for them.

Michael Darragh said *"I was very happy to become involved in this DVD which I hope will make a real difference to the lives of people living with lung fibrosis. I have a deep appreciation of yoga and the holistic benefits it offers across a whole range of areas. In the video we go through a series of exercises that can help people manage their health and cope with the challenges of living with the condition. The great thing is that the exercises can be done whether seated or standing and can be adapted to suit everyone's abilities. People can go at their own pace and no one gets left behind."*

Physical exercise is key to helping people manage their lung fibrosis. Even though many patients experience shortness of breath with physical activity, it is worth remembering that everyone gets breathless when they exercise, even athletes, but what is important is that lung fibrosis patients know how manage their level of breathlessness. Yoga is beneficial and appropriate as it is suitable for people with varying levels of lung fibrosis, including those who use oxygen. For those on oxygen, we would urge them to speak to their medical team about turning up their oxygen to agreed levels so that they can cope with the activity and exercise comfortably. Positive lifestyle changes and, in particular, physical exercise, is hugely important for people with lung fibrosis. This DVD now means that they can engage safely in a home-based exercise regime.

The production of the ILFA yoga exercise DVD has been made possible thanks to a kind donation from Three Lakes Partners - a philanthropic organisation in the United States. ILFA also offers other exercise tools for people with lung fibrosis and healthcare professionals caring for them, including its 2,000 Steps a Day Exercise Challenge Walking Pack and an Exercise DVD. **To order exercise materials, please call ILFA on 086 871 5264 or email info@ila.ie. The video can also be watched on ILFA's You Tube channel and on ILFA's website, www.ilfa.ie**

Pamela Martin, Matt Cullen and Evelyn Cooper.

Research and Education

Research Bursaries from ILFA

In May 2019, the Irish Lung Fibrosis Association announced funding of €20,000 for research into Idiopathic Pulmonary Fibrosis (IPF). Healthcare professionals and scientists working in respiratory medicine in Ireland were invited to submit a Research Bursary Application Form.

We are delighted to learn about the fantastic research being conducted in Ireland. ILFA has decided to increase our investment total and will fund several high-quality and diverse research projects that include supporting the National IPF Registry, basic science projects looking at the development and treatment of pulmonary fibrosis, patient experiences, and genetic investigations. Congratulations to those awarded a research bursary. More details will feature in the next newsletter.

ILFA Educational Bursaries

In June, respiratory nurses and allied healthcare professionals were invited to apply to ILFA for an educational bursary to attend the Interstitial Lung Disease Inter-Disciplinary Network (ILD-INN) conference that will take place in Birmingham on 13th and 14th October 2019. The ILFA bursaries will contribute towards the cost of the conference registration including one night's accommodation and dinner, and travel to and from the United Kingdom.

We were delighted to receive many applications from healthcare professionals all over the country. The recipients of the ILFA educational bursaries are; John Alickolli (Bon Secours Hospital Cork); Rosaleen Anglim (South Tipperary Hospital); Grainne Casey (Mater University Hospital); Elaine Craven (Connolly Hospital Blanchardstown); Antoinette Doherty (Letterkenny Hospital); Carol Doherty (Letterkenny Hospital); Julie Goss (Harold's Cross Hospice, Dublin); Donna Langan (Galway University Hospital); Carmel McInerney (Ennis Hospital) and Lavinia McLeod (Mater University Hospital).

Lean White Belt Programme for healthcare professionals

Calling all healthcare professionals … Do you have an idea that could improve the clinical care and management of pulmonary fibrosis patients at your hospital/clinic?

ILFA is planning to hold a one-day intensive introduction to Lean Six Sigma for Healthcare professionals including nursing, medical and allied health care professionals working in respiratory medicine.

The course will be delivered by two Lean Academy Black Belt Practitioners and will take place at the Mater Hospital in Dublin in January 2020 (date to be confirmed). ILFA is currently seeking expressions of interest from healthcare professionals working with pulmonary fibrosis patients who would like to take part in the programme. ILFA will cover the costs of the course and CPD and CEU points will be awarded to participants.

It is envisaged that a team will then undertake the professional certificate in Lean Six Sigma and develop an improvement initiative for pulmonary fibrosis patients. This quality improvement initiative may be linked to improving referral times, linking patients in with pulmonary rehab, ensuring patients attend an oxygen clinic or what you think is needed in your area for pulmonary fibrosis patients.

For more information, please see the Lean Academy website: **www.leanacademy.nmhs.ucd.ie**

Please contact ILFA if you would like to attend. Places are limited so please apply early.

Grand Rounds at the Hospice

Professor Anthony O'Regan, pictured, Respiratory Consultant at Galway University Hospital and Chair of the Irish Thoracic Society's Interstitial Lung Disease Group spoke at the Grand Rounds in Our Lady's Hospice & Care Services on 22nd March 2019. Grand Rounds is a dedicated educational session for doctors, nurses and health and social care professionals working in specialist palliative care. The lecture on Interstitial Lung Disease (ILD) was also screened in satellite sites at Blackrock Hospice, Wicklow Hospice/Community care and Milford Hospice in Limerick.

Bettina Korn, End-of-life care coordinator at St James Hospital reported that Professor O'Regan's lecture was interesting and elegant and very well received. Prof O'Regan provided many examples of how ILD affects people and how different treatments can provide relief from symptoms. He also described how he and his colleagues raise the issue of palliative and end-of-life care in their clinics and how they support and journey with the patient and their family.

Prof O'Regan also mentioned the ILFA Information Day dedicated to palliative care and planning for the future with pulmonary fibrosis. We were delighted to learn that he referred to ILFA's work and the resources we provide for patients and relatives and mentioned our 'forward thinking ways'.

Bettina said, "Although the Grand Rounds session was one hour long, people queued up afterwards to ask questions, indicating their desire to increase their knowledge on ILD and learn how to best provide care for people with the condition. I believe it was a good opportunity for education and conversations across disease specific boundaries that could be repeated elsewhere".

Many thanks to Bettina for the excellent feedback and to Prof O'Regan for helping raise awareness of pulmonary fibrosis among the palliative care community.

Advocacy and Awareness

Pulmonary Fibrosis Awareness Campaign

A successful media campaign took place from April to June 2019 that helped create awareness of Idiopathic Pulmonary Fibrosis in the national and local media, online and on social media. ILFA is grateful to the many people across the country who volunteered to tell their personal stories. The media campaign highlighted the positivity, determination, and courage of patients and families living with IPF as well as the benefits of exercise in managing the condition.

Some of the campaign highlights included;

- Printed and online media coverage included; Independent.ie, Irish Examiner, RTE Guide, The Mirror, The Star, Irish Daily Mail, Irish Health.com, Senior Times, Irish Sun, RSVP, Mature Living, Dublin Gazette, Echo, Fingal Independent, Northside People.

Photo: Peter McLoughlin was interviewed on his experience of living with pulmonary fibrosis on East Coast FM.

- Radio interviews with East Coast FM, Phoenix radio, South Tipp FM, Dublin South FM, Midlands 103, Shannon side, Clare FM, Near FM, LMFM.

- David Crosby appeared on The Elaine Show, above, and shared his story from being diagnosed with IPF, receiving a double lung transplant and subsequent training for the World Super Six marathons. David was also interviewed on the Ray D'Arcy Show, on RTE Radio 1 ahead of Organ Donation Awareness Week and was interviewed on two occasions on the Ivan Yates Newstalk Show, before and after the Cork Marathon Relay Run in June.

- TV coverage: The Today Show (RTE1). Carmel McInerney, respiratory nurse specialist at Ennis Hospital and Michael Collins, Ennis Pulmonary Fibrosis Support Group appeared on the RTÉ Today Show with Dáithí Ó'Sé and Maura Derrane in May. Michael nominated Carmel for a special pampering treat for her dedication to pulmonary fibrosis patients. Carmel and Michael had a very special day and Carmel looked radiant when her make-over was revealed. We were delighted when Daithi also mentioned ILFA's Yoga DVD live on air!
- Nicola Cassidy wrote a Letter to the Editor of the Irish Runner that was published in the August edition describing ILFA's participation in the Cork Marathon Relay event.

Planning for a National IPF Awareness Day

ILFA plans to hold a National Idiopathic Pulmonary Fibrosis (IPF) Awareness Day in late 2019 to raise awareness among members of the public, healthcare professionals and policy makers.

For a national awareness day to be successful, ILFA needs your help. If you are happy to share your lung fibrosis story, please get in touch by emailing info@ilfa.ie or calling 086 871 5264.

We are also looking for healthcare professionals to get involved. Please let us know if you would be willing to; host an information stand at your hospital, act as a spokesperson / respiratory expert and take part in media interviews, identify and approach patients and caregivers who might be willing to share their stories and/or visit your local support group.

Organ Donation and Transplantation

ILFA contributed a letter to the Irish Medical Journal entitled 'Opt-out organ donation - a patient organisation's perspective'. ILFA continues to work with colleagues in the Irish Donor Network (IDN) to advance issues in relation to organ donation and transplantation.

The IDN Partners welcomed the publication of the General Scheme for the Human Tissue Bill which will allow for an opt-out consent process in relation to organ donation. In addition, Nicola Cassidy (ILFA Director), Philip Watt (CEO of Cystic Fibrosis Ireland) and Robert McCutcheon (Chair of the Irish Heart and Lung Transplant Association) represented the Irish Donor Network at a meeting with Michael Conroy from the Department of Health and his colleagues Helen O'Brien and James Allen in July 2019.

Fundraising Round Up

Pat Casey Memorial Cycle

Members of the Cork Pulmonary Fibrosis Support Group, Dr Mike Henry and participants and organisers of the Pat Casey memorial Cycle.

The ILFA committee would like to extend our sincere thanks to the organisers of the Pat Casey Memorial Cycle; Anne Casey, Daniel Casey and Brian Ahern; for their enthusiasm, hard work and commitment to ILFA over the years. We are also deeply grateful to the cyclists, support crew and all those who have generously donated to the Pat Casey Memorial Cycle and other associated fundraising activities. Mile Buiohas!

The cheque presentation for the 2018 Pat Casey Memorial Cycle took place in the Hawthorn Bar in Cork on Thursday, 4th April 2019. Daniel Casey said “There was a great turn out and a cheque for €4,565 was presented to ILFA. Preparations for the 2019 cycle are well underway and the organisers are aiming for an early September date for the event. We are very grateful to Catherine, owner of the Hawthorn Bar, for her hospitality and the food provided. We look forward to this year’s event.”

In addition, Anne Casey presented a cheque for €550 from the 2018 Musgrave Cycle held in August in aid of ILFA.

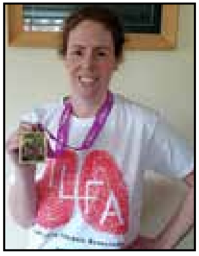
Therese’s online fundraising page

Huge thanks to Therese Reddan for fundraising for ILFA Ireland. Therese set up an online fundraising page called ‘Mum’s Cause: Idiopathic Pulmonary Fibrosis (IPF)’ in memory of her mother Annette. The fantastic sum of €1,360 was presented to Marie Sheridan (ILFA Honorary Treasurer) and Eddie Cassidy (ILFA Chairman) by Therese at the ILFA Patient Information Day in April. Sincere thanks to Therese and everyone who supported her fundraising initiative. **Pictured are Marie Sheridan, Therese Reddan and Eddie Cassidy.**

Wexford Half-Marathon

Wendy Noble, pictured right, ran the Wexford half-marathon on Sunday 28 April 2019 in aid of ILFA in memory of her father David Orr. Here’s a report from Wendy about her fundraising event.

“Having enjoyed running for many years, it took a back seat for a while as my Dad’s (David Orr) health deteriorated greatly over the course of 2018 due to Idiopathic Pulmonary Fibrosis. He passed away at home on Christmas day, early in the morning. We reckon he took the return flight on Santa’s sleigh!



When I returned to running, I was eager to make it worthwhile and decided the Pettit’s SuperValu Wexford half-marathon on 28th April was the way to go. Having never run more than 10k, it was challenging but nothing compared to the battle of those with IPF. Dad was very lucky to have stayed at home throughout the final year and that was all down to Mam. She also had the support of the home help and palliative care team, but mostly her sister Hazel who basically moved in for the weeks leading up to Christmas. The progression of the disease is so difficult, but Dad accepted it at every turn with little complaint. The whole family pulled together to support both Dad and Mam however we could.

While I was running, my head was full of thoughts on how Dad struggled for breath just to move in bed and how Mam worked tirelessly ensuring he was OK. Every mile run meant €100 for ILFA. Count up the money and count down the miles! It was my parents’ determination and strength, along with the generosity of all those who sponsored me that got me over the line in just under 2 hours. I can’t say I’ll be running another half-marathon soon, but I was delighted that I could do something positive to support a worthy cause by raising €1,300. Keep up the good work ILFA!”

Croagh Patrick Climb

Nicola Cassidy, ILFA Director, climbed Croagh Patrick in Murrisk, Co Mayo in April in aid of ILFA. The steep and rocky ascent (746 metres, 2507 feet) was difficult due to poor weather conditions early. Despite the cold temperatures, strong winds and poor visibility, Nicola enjoyed the challenge and was rewarded on the descent with the arrival of sunshine, blue skies and great views of beautiful Clew Bay. This was the first of Nicola’s fundraising events for ILFA; she also took part in the Cork City Marathon relay event in June and will run the Great North Run half-marathon in September.

St Patrick's Day walk: Irish Cement Swimming Club

Members of the Irish Cement Swimming Club took part in a fundraising walk on St. Patrick's Day in aid of ILFA. The event was organised by Chris Lycett and he was joined by members of the swimming club and friends. The fantastic sum of €520 was raised on the day. Additional sponsorship has been added to Annette Grehan's 2019 ongoing fundraising challenges for ILFA including the Cork marathon relay event, the Great North Run half-marathon in Newcastle in September and the Dublin City Marathon in October.

Craft Your Raft at the Muckno Mania Festival

The Muckno Mania Festival took place at Lough Muckno in Co Monaghan from 4th to 7th July. One of the many events taking place was 'CRAFT YOUR RAFT' described as a "high energy high octane team building competition". The winning Under-18 team was made up of Emma McGuigan, Emma Carvill, Molly McGinnity and Méabh Hannon who received a cheque for €250 following their great success.

The girls kindly presented the cheque to Kevin McSkeane, leader of the Cavan Monaghan Pulmonary Fibrosis Support Group, as one of their grandmothers has pulmonary fibrosis and they wanted to support a charitable cause. The sponsor of the cheque for the event was Shane Tyres Castleblayney. Thank you to Emma, Molly, Meabh and Emma from everyone at ILFA;

Pictured are: Stephen Fitzpatrick - Festival Committee; Niamh Malone - Festival Queen; Kevin McSkeane - Monaghan Cavan Pulmonary Fibrosis Support Group Leader, Finbarr Carvill - Festival Committee; with the winners Emma McGuigan, Emma Carvill and Molly McGinnity. Missing from the photo is Méabh Hannon.

Donation

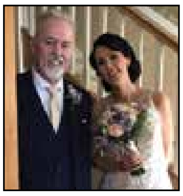
Following the Mountmellick Drama Festival which took place from 9-17 March, the sum of €230 was presented to Val Kennedy of the Midlands Pulmonary Fibrosis Support Group. Val subsequently presented the kind donation to Eddie Cassidy (ILFA Chairman) and Marie Sheridan (Honorary Treasurer) at the ILFA Patient Information Day on 6 April 2019. **Pictured are: Val Kennedy, Marie Sheridan and Eddie Cassidy.**

In Remembrance

Sincere thanks to all the families who requested donations to ILFA in lieu of flowers at the funerals of their loved ones. We are very grateful for your support and kindness to ILFA at a time of great personal loss.

Wedding Favours

Congratulations and sincere thanks to **Alice Heron and Brian Kane** who were recently married and made a kind donation to ILFA in lieu of wedding favours. Here's a lovely photo of the happy couple. We wish Alice and Brian every happiness for the future.



Congratulations to **Lorraine Meaney and Owen Smith** who married in April 2019. Lorraine and Owen made a kind donation to ILFA in lieu of wedding favours. Lorraine told us "The wedding day was wonderful and the ILFA table cards were great. It has even inspired one of our guests to run the marathon for ILFA in October which I am very happy about. We are delighted to support such a worthy cause." We wish Lorraine and Owen every happiness for the future.

Top left: Bernard Meaney with his daughter Lorraine Meaney-Smith. Top right: Brian Moynagh, Jacqueline Moynagh, Lorraine Meaney-Smith, Owen Smith, David Meaney, Kelsey Hall.

Congratulations and warm thanks to **Ronan O'Sullivan and Eimear Byrne** who got married in June 2019 and made a kind donation to the Irish Lung Fibrosis Association in lieu of wedding favours. Ronan was in touch and said they had a fantastic day! Here is a lovely photo of the happy couple! We wish them every happiness for the future.

London Marathon

Well done and huge thanks to David Crosby who presented ILFA's Chairman, Eddie Cassidy, with a cheque for €3,000 as part of his fundraising proceeds for the London Marathon in April 2019. David received a double lung transplant 3 years ago following a diagnosis of idiopathic pulmonary fibrosis and has since completed 3 of the super-six world major marathons; New York, Berlin and London. David plans to run the Tokyo, Boston and Chicago marathons in 2020 and 2021 to complete his super-six dream. We're inspired by David's determination and commitment to raising awareness of pulmonary fibrosis and the importance of organ donation and transplantation. Mile buiochas!

Swim to Tory Island

Padraig McFadden from the Bloodyforelands on the north west coast of Donegal took on an epic and daunting challenge in June 2019 when he swam from Tory Island to the Donegal mainland in memory of his grandmother Sadie McFadden to raise valuable funds for ILFA. Months of hard work and preparation went into training for the Tory island swim challenge and Padraig provided ILFA with regular updates on his progress. Here is the story in Padraig's own words.

"My name is Padraig McFadden. I recently lost my lovely, beautiful, witty little mate, my grandmother, to Idiopathic Pulmonary Fibrosis (IPF) in November last year. There are not many words I can use that describe this horrible disease - only I wouldn't wish it on anyone. In the months before my grandmother passed, I had it in my head that I would like to raise more awareness about this relatively unknown condition and raise some money for research. I had a chat with her and told her I was going to do the nine and a bit mile swim to Tory Island which we could see in the distance from her kitchen window, in aid of the Irish Lung Fibrosis Association. Of course her first reaction was "Cop on will ya" but after some more talking she said "You know what, if you think you can do it, then go for it".

From then on, I started to plan the swim. I contacted ILFA who have been very helpful and informed them of the swim. I enlisted the help of the Sheephaven Sub Aqua Club who agreed to help and be my crew and support boat on the day and I set up an online fundraising page for ILFA."

10 weeks to go …

"With around 10 weeks to go, training is increasing steadily and going very well. An average week is around 4-5 pool sessions with 2-3 sea swims, averaging between 11k to 16k per week. The plan is to swap more pool swims to sea swims once it gets a little warmer, as it's currently only around 9C. Sheephaven Sub Aqua Club will be my support boat and crew on the day of the swim. They have been brilliant with helping to organise the day and I am very grateful to have them on board."

2 weeks to go …

"With under 2 weeks to go, things are coming together very fast. A close eye will be kept on the weather next week as this determines everything on the day. We are in close contact with the lads at Sheephaven Sub Aqua Club who have been amazing with all their help throughout towards this event. Training is up to date with sea sessions from 1 hour plus during the week and up to 4 hours at the weekends and with the water temperature finally coming up to around 12-14C. We're looking good, and no sign of any jellyfish (yet) … so fingers crossed.

I would like to thank everyone who kindly donated for this great cause so far. Thank you again."

Swim Day …

"On Saturday the 22nd June in aid of the Irish Lung Fibrosis Association (ILFA) I managed to swim from Tory Island across to the north west coast of Donegal, a distance of 9 miles in 5 hours and 29 minutes.

We all gathered at the pier at 6.30am that morning and met up with the members of the Sheephaven Sub Aqua Club along with my own crew of family members to help out with feeds and prep on the rib for the day. Once we were ready, we headed out towards the island. As we set out and the mainland was getting smaller, Tory island itself didn't seem to be getting bigger and from the looks of faces from some of my crew I started to think "Paddy, what are you doing?" Eventually we got to the rocks to the east of the island and I stripped off, got a good covering of Vaseline and took the plunge into the tropical 13 degrees waters. I swam to the nearest rock that I could stand on, gave the thumbs up and away I went. The first mile I tried to settle in and get a good start.

There were blooms of jellyfish keeping me company but luckily all about one metre below me. The two ladies on the support kayaks soon joined me and kept me headed in the right direction for home. After about 6 miles I got caught up in a current that was dragging me back so I had to up the tempo for a good 30 mins until I got out of it and after that I could just about make out the pier, so it gave me a good lift in spirits to keep going.

I eventually got to the pier where I was met with a lovely crowd of family and friends to welcome me in and when my feet touched the ground it was a great feeling.

I would like to thank absolutely everyone who helped me through the last 8 months. Especially my wife Dayna for her patience and help even during the winter/spring months with her doing beach watch when I was training and having my feeds ready during the longer swims. Also the team at ILFA, the Sheephaven Sub Aqua Club team; Dearn McClintock(boat pilot); Eddie McFadden (boat pilot); Eileen Coll (kayak) and Bernie Gallagher (kayak), and the coast guard. There is no such thing as a solo swim, it's certainly a team effort."

Padraig McFadden (centre) with his brother Adrian, his father Pete.

Padraig McFadden (centre) with his brother Adrian, his father Pete, his mother Maeve, uncle Michael, and his brother Joseph.

Team ILFA.

Happy Feet - Emma Cooper, Yvonne Lynch, Heather O'Tuairisg and Annette Johansson.

Roche Team - Triona Rice, Joe Gleeson, Gillian Hession and Ronan Butler.

ILFA Team 1 Professor David Healy, Dr Oisin O'Connell, David Crosby, Lynn Fox and Nicola Cassidy.

Cork City Marathon Team Relay

The Cork City Marathon team relay took place on Sunday 2nd June 2019 and ILFA had six teams of 26 runners taking part. The fun, comradery, encouragement and support everyone experienced as part of this special fundraising and awareness raising event was wonderful. There was great excitement in the lead up to race day and the positive vibes were heightened as everyone gathered for group photos on1st June and again on race day.

ILFA was fortunate to have one of our teams, ILFA Team 1 - The Patient Journey, profiled by the organisers of the Cork city marathon and this helped raise valuable awareness of pulmonary fibrosis, the team work involved in supporting pulmonary fibrosis patients with their journey, the life-changing impact of organ donation and lung transplantation, and ILFA's role in supporting patients, families and respiratory healthcare professionals. ILFA Team 1 was made up of David Crosby, inspirational double lung transplant recipient, and his support team featuring; Lynn Fox - respiratory nurse specialist at the Mater Hospital, Dr Oisin O'Connell - Respiratory Consultant currently at the Bon Secours Hospital Cork, Professor David Healy - Lung Transplant Surgeon at the Mater Hospital and Nicola Cassidy - ILFA Director. The team met at 7.15am on race day for official photographs and to be interviewed ahead of the marathon by Dan Linehan of the Irish Examiner and RTE's Jenny O'Sullivan. After exchanging words of encouragement and sharing a morale boosting team hug, the team members went to take up their race positions.

The race started at 8.30am under blue skies and sunshine and the runners set off at speed and smashed their way through stage one of the marathon course with impressive running times. There was little time to relax and never a dull moment as a steady stream of ILFA relay runners positioned themselves at the various relay handover points. News was constantly fed back to the captains by text messages with updates on who was currently running and what location they had reached.

'HAPPY FEET', an international team featuring Annette Johansson, Heather O'Tuairisg, Emma Cooper, and Captain Yvonne Lynch, was the first ILFA team home with an amazing finishing time of 3 hours 30 minutes. The team led from the start and set a blistering fast pace, speeding through the 26.2 mile (42.2km course). This team are family and friends of a person living with IPF and said they wanted to "raise awareness of the condition and support the great work of ILFA."

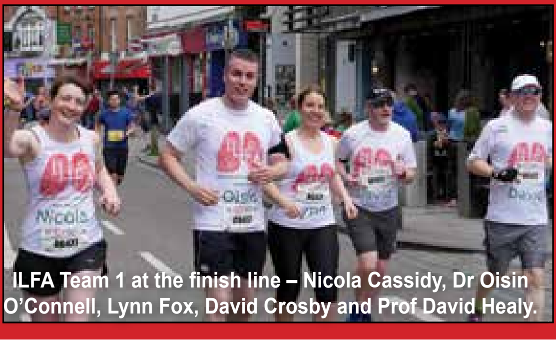
Next home was 'ROCHE Team' featuring colleagues from the pharmaceutical company Roche Products Ireland. Team captain was Triona Rice and she was joined by Gillian Hession, Ronan Butler and Joe Gleeson. Triona said "The Roche Team is absolutely delighted to help raise awareness and much-needed funds for a great cause in Idiopathic Pulmonary Fibrosis. Anything we can do to help this amazing cause is our pleasure and responsibility - even if the thoughts of a marathon is a very scary prospect!". The team had no reason to be scared as they ran well and finished strongly.

Hot on their heels was 'BOC HOMECARE'. The oxygen company team was captained by Adrian Sheehan and featured Keith McGrath, Michael Creedon, Mick Dooley and Kieran Hamill. This team said "We're taking part and running for a very worthwhile charity; the Irish Lung Fibrosis Association. This organisation gives fabulous support to patients nationwide who are suffering from fibrosis of the lungs. The main objective here is to gain exposure and awareness of the organisation so people can get support and information for those in similar circumstances".

Next home was 'SOUL SISTERS' led by Katie Cosby who said "I am taking part with my three sisters Teresa, Deirdre


Soul sisters; The Daly sisters: Deirdre, Bridget, Katie and Teresa


Dr Oisin O'Connell, Adrian Sheehan (Team Captain for BOC Homecare), David Crosby and Lynn Fox.


ILFA Team 1 at the finish line – Nicola Cassidy, Dr Oisin O'Connell, Lynn Fox, David Crosby and Prof David Healy.


Well wishes walkers – Annette Grehan, Eddie Cassidy (ILFA Chairman), Stephen Cassidy, Nora McNamara and Betsy Matthews.

and Bridget to help raise awareness of Lung Fibrosis. My husband David was diagnosed with IPF at 40 years of age but thankfully he received a life-saving double lung transplant six months later. This devastating disease took an enormous toll on our family and our three young children. David received huge support from family and friends around us. In order to maintain a somewhat stable environment for our children, our families and friends stepped in to keep things running smoothly as David and I navigated our way through everything that IPF brought to our door. From numerous hospital appointments, adjusting our lives to a life of oxygen and medication, trying to remain hopeful that a transplant would save David's life. I'm also running to give recognition to every carer, who is there for their loved ones and for everybody who helps and supports them along the way. Without our families and friends, I would not have been able to remain as strong as I needed to be to get through a really difficult and life changing time."

The next team home was ILFA Team 1. From the start of this project, the ILFA Team 1 members wanted to finish together to reinforce their message of teamwork and support. With logistical planning and the local knowledge of Dr Oisin O'Connell, this dream finish was made possible. Nicola Cassidy ran the first leg and handed over to Lynn Fox who ran the second stage. Dr Oisin O'Connell ran stage 3 and handed the baton to Prof David Healy who raced through the fourth leg of the marathon. He continued running and accompanied David Crosby on the fifth and final leg of the race. Meanwhile Lynn, Oisin and Nicola met back at City Hall and made their way to the rendezvous location to join David C and David H. The trio nearly lost their voices shouting excitedly when David Crosby and David Healy ran into view. The five pals reunited and ran the final stages of this amazing journey together. Running the last few metres, the race director announced that "David Crosby, lung transplant recipient, and his healthcare team were approaching the finish line". The cheers from the crowd and the realisation of the team's mission made this a very special end-of-race moment. To make this marathon finish even more exceptional, David Crosby slowed down to allow his team-mates cross the line first as he felt they were the reason he was here. It was a beautiful, poignant and emotional gesture from David that touched the entire group. Once over the line, the fabulous five hugged and congratulated each other on their remarkable achievement. Home in 4 hours 12 minutes and 4 seconds. Job done! Then the team had a series of photographs taken, interviews with various media outlets and reunions with supporters.

Last but not least, the 'WELL WISHES WALKERS' team arrived home to a hero's welcome. The team was led by captain Stephen Cassidy and featured his father, ILFA Chairman, Eddie Cassidy (running his 25th marathon), his aunt Annette Grehan (running her 14th marathon), and two amazing nurses from South Tipperary General Hospital in Clonmel; Nora McNamara and Betsy Matthews. The team ran in support of pulmonary fibrosis patients and in memory of a family member, Denise Cassidy. The team members had great fun together and developed a strong bond and team spirit despite only meeting Nora and Betsy on race day.

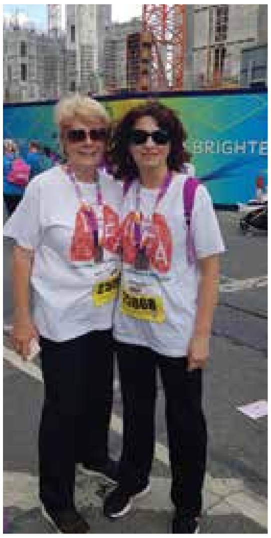
In the evening, some of the team members who were staying over in Cork were joined by family, friends, members of the Cork Pulmonary Fibrosis Support Group and Dr Mike Henry from Cork University Hospital to celebrate the culmination of a very special event and to mark the extraordinary personal and team achievements of the day.

ILFA would like to extend our sincere thanks to the amazing runners for their enthusiasm and commitment to this event and to their families, friends and colleagues for supporting them. Special thanks also to Alan McLoughlin (husband of Lynn Fox) for taking lovely photographs of the occasion, to Sandra Stuhli, graphic designer at Asavie for designing Team ILFA's graphic images, to Fiona Ryan and colleagues at Hopkins Communications for their PR expertise and support on race day, and to Earnest Cantillion of Electric Bar in Cork for his generosity and hospitality.

Women’s Mini Marathon 2019

Captions on this page clockwise from top:

Team ILFA; JP Joggers Team; Amy Collins and friends; Liz Burke, Sue Kenny, Edna Powell and Debbie Cullen; Rachel Alford; Brid and Jacqueline Meaney; Catherine Donoghoe and friends; and Mena Fitzgibbon, Catherine Sherry, Jagoda Dubanik.



Captions on this page from top:
Kim Hanneffy and Deirdre Hyland; James Kavanagh and Chris Meehan; Margaret McIver, Rosemary Wilson, Hazel Griffin, Rita O'Regan; Michelle Clarke, Janice Mitchell, Shauna Clarke; and below: Glenda Murphy Smullen and Edel Collins Hill.
LOGO: Team ILFA by Sandra Stuhli.

Over 50 ladies took part in the VHI Women's Mini Marathon in Dublin, on Sunday 2nd June for ILFA. It was a lovely, warm, sunny day and many ladies gathered before the event for Team ILFA photos and afterwards for well-deserved refreshments.

Shauna Clarke sent us this report. "A team of six ladies representing Hines Ireland recently took part in the VHI Women's Mini Marathon. Our team was proud to have run/walked in aid of ILFA with the runners finishing in just under 1hr 20min and the walkers coming in just behind them. ILFA is a charity close to my own heart - I took part in memory of my Grandad (Paddy Kennedy) who sadly passed away in 2007 after a single lung transplant and in support of my Mam (Michelle Clarke) who was diagnosed with IPF last year. She hasn't let it hold her back though as she completed the marathon as part of our team on the day."

Amy Collins and friends also took part and sent us a report. "I did the mini-marathon on behalf of my dad who received a lung transplant 2 years ago. ILFA does great work and gives great support to my father, therefore I wanted to spread awareness by fundraising for ILFA and to promote them. My team also offered their support and wanted to fundraise for the great cause. The day itself was an amazing experience and we completed the mini marathon in 1 hour 15 mins. The best moment was seeing my dad waiting and cheering us on to the finish line. We took him out of the crowd and had him finish with us".

Brid and Jacqueline Meaney took part in support of their husband and dad Barney Meaney. Jacqueline said "Dad is a member of ILFA and attends the Dublin Pulmonary Fibrosis Support Group meetings. Thank you for all the support you give to him and to all your other members."

Catherine Donoghoe, family members and friends took part and sent this report. "Myself and 4 ladies participated in this years' mini marathon in honour of my mother who is in the palliative care stage of her battle with IPF. Our brother has also been recently diagnosed with IPF and we know he will gain tremendous knowledge and support from ILFA and we wanted to do our bit to help as a small thank you. Myself, my sister Fran, my daughter Ella, our niece Corrine and her friend Ava all felt a tremendous feeling of pride as we crossed the finish line. There were times when you felt exhausted and your legs could go no further, but just the thought of mam at home on her oxygen fighting every single day to be with us, just keeps you going."

Neasa Buchan was in touch and said "The 'JP Joggers' had the best day and were overwhelmed by the generosity of our family and friends all over the country Special mention to John Patrick O'Sullivan in Kerry for inspiring us all to get off the couch to help make a difference! We had the most amazing fun day !"

ILFA would like to thank all the ladies who took part in the 2019 event. We are grateful for their wonderful support and for sharing photos and special memories of the day.

Special thanks to Sandra Stuhli, graphic designer at Asavie for designing our lovely photo props.

Patient Support Groups

Cork Support Group

The group meets at 11am on the last Thursday of every month at The Elm Tree, Glounthaune. **Please call Anne on 087 985 4587 for more details.**

Dublin Support Group

The group meets on the first Tuesday of every month at 10.30am at the Carmelite Community Centre at Whitefriar Street Church, Aungier Street, Dublin 2. **Please call Matt on 086 244 8682 or Pam on 086 178 9055 for more details.**

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at The Rose Hotel. **Please call John on 087 280 9801 for more details.**

Midland Support Group

The group meets on the first Wednesday of every month at 2.30pm at the Tullamore Court Hotel, Tullamore, Co. Offaly. **Please call Val on 087 233 2653 for more details.**

Cavan Monaghan Support Group

Kevin McSkeane is hoping to set up a support group in Cavan - Monaghan. **Please call Kevin on 085 243 6828 for more information.**

Mid West Support Group

The group meets on the last Saturday every month at 11.30am, at Matt The Thresher, Birdhill, Tipperary. **Please call Noreen on 087 262 7976 for more details.**

Clare Pulmonary Support Group

The group meets at 12 noon on the first Wednesday every month at the West County Hotel in Ennis. **Please contact Michael Collins at 087 637 468 for more details.**

ILFA would like to thank the support group leaders for their involvement and organising the groups. It is wonderful to see the groups go from strength to strength and hear about the wonderful peer support available to patients and carers. We wish everyone involved continued success for the future.

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

086 871 5264

VOLUNTEERS NEEDED …

ILFA is delighted to announce our partnership with the 2019 Dublin Santa Dash and we need your help! We need 25 volunteers to help the race organisers on the day for 3-4 hours. The festive 5km and 10km races will take place on Sunday 1st December on Dollymount Strand, Dublin. ILFA will receive a donation from the event organisers for every volunteer who helps. Please contact ILFA if you can volunteer your time to help out (Tel 086 871 5264 or email info@ilfa.ie). We're also looking for as many runners, joggers and walkers to take part in the festive fun. We guarantee that you will love it!!!

And Finally Some Exciting News …

Our good friend David Crosby, left, has agreed to become a **Patient Ambassador for ILFA** and we couldn't be more proud. Over the last 2 years David has devoted his energy, positivity and enthusiasm to raising awareness of pulmonary fibrosis and the importance of organ donation and transplantation. He was worked tirelessly sharing his personal story and giving hope and encouragement to other patients and families, and he has fundraised for respiratory charities and research foundations to help them with their vital work.

David has big ambitions and after receiving a life-saving double lung transplant he is pursuing plans to complete the Super Six Marathon Series and earn a place in the record books. David has already run the New York, Berlin and London marathons and plans to run in Tokyo in 2020 and then Boston and Chicago in 2021. In June, David ran the Cork City Marathon Team Relay with his medical and nursing team, and family and friends to raise awareness about the pulmonary fibrosis patient's journey. David has truly inspired us and ILFA is enormously proud to have David as our new Patient Ambassador and we gratefully acknowledge and celebrate his wonderful and inspirational advocacy work.

Dates For Your Diary

Fundraising

- **The Pat Casey Memorial Cycle** will take place on Saturday 21st September. The cycle will be a circular route of 122km, starting and finishing at Forge Hill, Cork City. For more information please call Anne on 087 985 4587, Brian on 086 088 1064 or email annecasey@live.ie
- **The Dublin City Marathon** will take place on Sunday 28th October. Please contact ILFA if you would like a fundraising pack.
- **Santa Dash 5km and 10km** course will take place on Sunday 1st December on Dollymount Strand, Dublin. Please contact ILFA if you would like to volunteer or take part (Tel 086 871 5264 or email info@ilfa.ie). Register to take part at www.santadash.ie

Keep in touch with ILFA

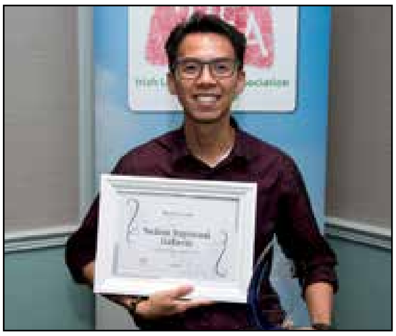
You can keep in touch with ILFA by phone on 086 871 5264 (general enquiries) or 086 057 0310 (fundraising enquiries) by email - info@ilfa.ie on the web - www.ilfa.ie on Facebook - www.facebook.com/ILFAIreland on Twitter - @ilfaireland

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

ILFA Newsletter

Irish Lung Fibrosis Association
www.ilfa.ie

Patrons: Michael Darragh Macauley, Charlie Bird, Andrea Corr.
Issue: Winter 2019 Volume 17 Issue 3 © ILFA 2019



Nelson Gallarin.

Stella Gallagher, Nelson Gallarin and Peter and Gallagher.

Nelson Gallarin awarded the Denise Cassidy Memorial Prize for Excellence in Patient Care

The Denise Cassidy Memorial Award recognises and celebrates an act of kindness shown by a healthcare worker to a lung fibrosis patient. In 2019, ILFA members were invited to nominate a person who showed them or their loved one a special act of kindness. ILFA is delighted to announce that **Nelson Gallarin**, Staff Nurse at the Mater Misericordiae University Hospital in Dublin, is the winner of the 2019 Denise Cassidy Award for Excellence in Patient Care.

Nelson was nominated for the award by Peter Gallagher for his exceptional kindness and compassion. Peter told us "One night post-transplant surgery I had a lot of discomfort and pain. I had already had my quota of pain relief for that day. Nelson sat with me and talked me through the night. He talked about his country, his family especially his mother and oh! his dog, I know he loves that dog. He also talked about his time in Ireland and his job as a nurse. He sat with me for the duration of my discomfort. I feel Nelson went beyond the call of duty. So what separates Nelson from all the other wonderful young men and women in our hospitals? This was hard to decipher, I narrowed this to two things, his family and his ability to listen intently. I know this because I met Nelson many months later and he still had that familiar warmth and he recalled all our conversation."

Nelson was thrilled to learn that he was nominated and selected as the overall winner of the award and said "It is an honour to be granted the award I am indeed grateful and delighted. It is the small things we consistently do that really give great impact to the lives of others. To live a life of purpose gives life meaning ... a life of service to others that even though they won't be remembering my name long after they have gone home, if they will remember how they felt while they were under my care, then that's good enough for me. I'm happy that Peter remembered my name; that my name is engraved to his heart, like my name is engraved on this trophy, and we both treasure not only our winnings, but the fond memories of our encounter. Thank you to Peter and ILFA for this award."

Nelson was presented with a specially commissioned piece of Dublin Crystal and a framed Certificate for Excellence in Patient Care at the ILFA Patient Information Day in October. It was very moving to hear Peter's speech thanking Nelson for his kindness and acknowledging the great impact it had. Warmest congratulations to Nelson from all the ILFA community on your well-deserved award!

A total of 21 healthcare professionals were nominated for the Denise Cassidy Memorial Award for Excellence in Healthcare. See page 2 for more details.

ILFA Christmas Cards

ILFA Christmas cards are now on sale and available to order. Each pack contains 10 cards with 2 cards each of 5 festive designs. The cards are produced in Ireland. One pack of cards costs €6 and two packs cost €10. Cards can be ordered by calling 086 871 5264 or emailing info@ilfa.ie

Please help us raise awareness of lung fibrosis this festive season.

Denise Cassidy Memorial Prize


Annette Grehan, Nelson Gallarin and Nicola Cassidy.


Deirdre O'Flaherty and Marie Sheridan.


Grainne Casey and Marie Sheridan.


Grainne Murphy and Marie Sheridan.


Nelson Gallarin.


Rita Cullen and Brenda Byrne who accepted the award on behalf of Professor Hayes at Cavan General Hospital with Marie Sheridan.

The Denise Cassidy Memorial Award recognises and celebrates an act of kindness shown by a healthcare worker to a lung fibrosis patient. In 2019, ILFA members were invited to nominate their healthcare hero for the award and 21 individuals across the country received a nomination. The ILFA committee was delighted to learn about the great work and kindness shown by healthcare staff to patients and their families. Everyone who was nominated for the award received a framed Certificate for Excellence in Patient Care. The striking certificates were designed by Sandra Stuhli, Graphic Designer at Asavie and we are grateful to Sandra for her creative talents and generous gift to ILFA. Sandra told us "It was a pleasure to create such important certificates for people who devote their lives to such a cause".

Some of the recipients attended the ILFA Patient Information Day on 19th October and were presented with their award by Marie Sheridan, Honorary ILFA Treasurer.

Certificates for Excellence in Patient Care were awarded to **Nelson Gallarin** Mater University Hospital, **Grace McKee** physiotherapist at Beaumont Hospital, **Lynn Fox** respiratory

for Excellence in Patient Care


Veronica Ndah and Marie Sheridan.


Grace McKee with Nicola Cassidy.


Lynn Fox and Marie Sheridan.


Maria Love and Marie Sheridan.


Lindsay Brown with Frank Nugent who nominated her for the award.


Lynn Fox, Marie Sheridan, Nelson Gallarin, Nicola Cassidy, Gemma O'Dowd and Chris Meehan.

nurse specialist at the Mater University Hospital, **Lindsay Brown** respiratory nurse specialist at St Vincent's University Hospital, **Dr Kate O'Reilly** respiratory consultant at the Mater University Hospital, **Deirdre O'Flaherty** respiratory nurse specialist at Beaumont Hospital, **Bernadette Bowen** respiratory nurse specialist at Cork University Hospital, **Zita Lawler** transplant coordinator at the Mater Hospital, **Catherine McGeoghegan** respiratory nurse specialist at Beaumont Hospital, **Maria Love** social worker at the Mater University Hospital, **Professor James Hayes** Clinical Director, Cavan & Monaghan Hospital, **Grainne Casey** physiotherapist at the Mater Hospital, **Caoimhe Fox** student nurse at the Mater Hospital, **Veronica Ndha** Catering Department at the Mater Hospital, **Deborah Casey** respiratory nurse at Cork University Hospital, **Flavia George Thomas** staff nurse at the Mater University Hospital, **James Dorgan** staff nurse at Cork University Hospital, **Grainne Murphy** physiotherapist at the Mater Hospital, **Noreen Dineen** staff nurse at Cork University Hospital, **Aoife Kelly** research nurse at the Mater University Hospital and **Dr Michelle McNamara** General Practitioner Co Clare.

Eddie Cassidy (ILFA Chairman), John Donnelly, Rev. Canon Charles Mullen, Betsy Matthews, Nora McNamara, and Rev. Vanessa Wyse Jackson.

Rev. Canon Charles Mullen, Peter McLoughlin and Rev. Canon Brian McKay.

Sandymount Gospel Choir.

Gemma O'Dowd, Michael Geoghegan and Lindsay Brown.

Annual Service of Prayer and Reflection

The 9th ILFA Annual Service of Prayer and Reflection took place on Saturday 12th October at Terenure Colleage Chapel in Dublin. It was a beautiful warm day with blue skies and Terenure College looked stunning in the autumnal sun. Reverend Canon Brian McKay O.Carm, Prior at Terenure College, gave a warm welcome to the large congregation and invited everyone to enjoy the service.

The theme for this year's ecumenical service was 'Courage and Strength' and the readings, prayers, music and songs were specially chosen to provide comfort and encouragement to those present. Rev. Canon Charles Mullen gave an enlightened address on resilience and encouraged everyone to stay strong. We were treated to wonderful and inspiring music from the talented harpist Harry Carpendale who performed 'Ave Maria' (an original composition by Harry), 'Brother James' Air' by James Leith Macbeth Bain, a selection of Slow Airs by Turlough O Carolan and 'On Eagle's Wings' by Michael Joncas.

This year we were thrilled to be joined by members of the Sandymount Gospel Choir and their Musical Director Cathy McEvoy. The choir was magnificent and performed a selection of beautiful songs; 'The Storm is Passing Over', 'I Love the Lord', 'Seteng Sediba' and 'He Reigns', with great appreciation from the congregation.

After the service, we adjourned to the college hall for refreshments and delicious treats thanks to generous contributions from the attendees. Refreshments were kindly served by Nicky Goodbody, Mary-Rose Greville, Giles Bailey, Rita Wilson, Margaret McIver and Moss and Val Burns.

The ILFA service is a much-loved annual event and we are immensely grateful to the clergy, musicians, singers, readers, candle lighters and volunteers who contribute their time and special talents. The ILFA committee would like to extend special thanks to Rev. Canon Brian McKay, O.Carm., Rev. Vanessa Wyse Jackson and Rev. Canon Charles Mullen, for their enthusiasm and commitment to the ILFA Ecumenical Service. **ILFA received lovely feedback on the service and some of your comments are included below;**

Feedback

"The service was very uplifting. We all thoroughly enjoyed the day. You certainly arranged a great event from the clergy, choir, harpist, refreshments and even the weather! What a beautiful day for it and so many positive people all around."

"It was a most uplifting service from start to finish - thank you to all who took part, the choir and harpist were excellent, thanks also to those who organised it and those who served the tea and coffee in a most beautiful building, while the sun shone brightly and lifted our spirits."

"Thank you to all those who organised another beautiful service. A special thanks to the musicians and the choir. The last 2 songs were sensational."

"Sincere thanks to everyone for organising the 2019 prayer service. As always it was a privilege to be in attendance yesterday to remember our loved ones. It really is a very special event and is going from strength to strength every year - the choir yesterday deserve a special mention - they were fab!!

Investing in IPF Research

The Irish Lung Fibrosis Association is pleased to announce that funding in excess of €30,000 has been awarded for research into lung fibrosis in Ireland. Clinicians and scientists working in respiratory medicine were invited to apply to ILFA for research funding in June 2019. We were delighted to receive so many high-quality applications for innovative and inspiring research projects. ILFA's financial investment in research is made possible thanks to kind donations from individuals and the hard work and dedication of our amazing fundraisers. The recipients of the ILFA research bursaries are;

1) Dr Cian O'Leary, School of Pharmacy, Royal College of Surgeons in Ireland
Title: Elucidation of the Anti-Fibrotic Activity of a Repurposed Drug for IPF

"We are delighted to receive this funding from ILFA to support our work towards developing new inhalable therapies for Idiopathic Pulmonary Fibrosis (IPF). This support means that we can now explore and understand how a drug candidate in our laboratory operates to reduce fibrosis on a cellular level in the lungs, which is a critical part of research towards our ambition to formulate a new medicine that can improve the well-being of those suffering from IPF or Interstitial Lung Disease."

2) Dr John Baugh, University College Dublin and Mater Misericordiae University Hospital
Title: Role of microbiota-derived short chain fatty acids in the regulation of pulmonary fibroblast function.

"Thanks to ILFA for this great opportunity. This award will allow us to perform experiments that would not otherwise be possible to build on our pilot studies and strengthen translational links with clinical colleagues. We hope to generate definitive data supporting the link between microbiota-derived short chain fatty acids and fibroblast function thereby establishing a link between diet, gut microbes and lung fibrosis."

3) Professor Anthony O'Regan, Irish Thoracic Society and Galway University Hospital
Title: Irish Thoracic Society Interstitial Lung Disease (ITS ILD) Registry

"The Irish Thoracic Society and its lung fibrosis group are committed to enhancing and improving the care of patients with lung fibrosis in Ireland. The ILFA bursary will provide much needed support to clinicians in lung fibrosis clinics around Ireland to move the registry development to the next stage. This work will provide critical information on patients with IPF and enhance our understanding of this disease in Ireland through data collection and research."

4) Dr Cormac McCarthy, St. Vincent's University Hospital
Title: A longitudinal study of patient self-reported data in IPF.

"We are delighted with the financial support from ILFA to help conduct this study, in which we will investigate the 'real-world' experiences of persons with IPF. This funding will allow us to understand the experiences of patients at the time of diagnosis and commencement of treatment and how these experiences relate to their condition. Using modern app technology, we will gain insight into this condition through data directly collected by patients."

5) Abhilash Sahadevan (Dr Cormac McCarthy Director), St Vincent's University Hospital
Title: Genetic incidence of telomere related mutations and shortened telomere length among Irish pulmonary fibrosis (IPF) patients

"The research funding will boost our research into characterisation of telomerase related mutations among our Irish pulmonary fibrosis group."

Dr Cormac McCarthy, Dr Abhilash Sahadevan, Dr Cian O'Leary, Marie Sheridan (Hon Treasurer) and Eddie Cassidy (ILFA Chairman).

Professor Anthony O'Regan, Nicola Cassidy (ILFA), Suzanne McCormack (CEO of the Irish Thoracic Society) and Gemma O'Dowd (ILFA).

Thanks to Lynn Fox Respiratory Nurse Specialist at the Mater University Hospital and her nursing and allied healthcare colleagues for hosting a Pulmonary Fibrosis Information Stand during Pulmonary Fibrosis Week in September. It is great to see everyone giving their time and expertise to help raise awareness. Well done everyone!

Patient Information Day,
October 2019

The Autumn Patient Information Day took place on 19th October at the Crowne Plaza Hotel, Northwood, Dublin and was well attended. **Nicola Cassidy**, ILFA Director, welcomed everyone to the event and thanked the fundraisers and all those who make donations to ILFA for making ILFA's Patient Information Days possible. The first speaker was **Professor Jim Egan**, Respiratory Consultant at the Mater University Hospital. Pulmonary fibrosis used to be described as a 'rare disease' but it is more common than previously thought. Pulmonary Fibrosis occurs more frequently in men and in older adults compared to younger individuals. A diagnosis of pulmonary fibrosis is made by a multi-disciplinary team (MDT) of clinicians who review the results from patients' CT scans, blood results and lung functions tests. Occasionally a lung biopsy may be performed. Prof Egan advised patients to be careful of the quality of information available online; it is best to use a trust-worthy internet site for information. In recent times, there has been good progress with the development and availability of antifibrotic medicines to slow down the rate of progression of idiopathic pulmonary fibrosis. Prof Egan encouraged patients to get the flu vaccination and the pneumonia vaccination and to wash their hands to prevent the spread of infections. **Dr Michelle Murray,** Respiratory Consultant in Transplant Medicine at the Mater University Hospital discussed the clinical signs and symptoms of pulmonary fibrosis including shortness of breath on exertion, coughing, a distinctive 'crackles' noise when their lungs are listened to with a stethoscope, and changes detected in blood tests and lung function tests. Dr Murray described 2 cases of patients diagnosed with idiopathic pulmonary fibrosis (IPF – 'idiopathic' means of unknown cause) who subsequently received a lung transplant. Lung transplantation is a viable treatment option for a select group of IPF patients who meet the strict criteria. It is vital that IPF patients are referred to the national lung transplant centre at the Mater University Hospital early in the course of the condition so they can be assessed and put on the transplant waiting list if they are good candidates for the surgery and recovery. Some contraindications to receiving a lung transplant include obesity, poor exercise tolerance, cognitive impairment and lack of family support. The transplant surgery is demanding and can take up to 12 hours to perform. Afterwards patients will need to take anti-rejection medicine for the rest of their lives and family support is crucial to help patients recover and adjust to their new routine. Dr Murray encouraged everyone to exercise to maintain their health and fitness, to take part in pulmonary rehabilitation classes, take steps to prevent infections and attend their GP if feeling unwell.

Lindsay Brown, Respiratory Nurse Specialist at St Vincent's University Hospital spoke about symptom management. She encouraged patients to read the National Patient Charter for IPF produced by ILFA to know about the services that patients should access. Self-management is a very important component of living with pulmonary fibrosis and ensures that patients know about their condition and stay as well as possible. Lindsay spoke about the need for good nutrition to provide energy and protect the muscles and immune system, weight management for those who are overweight and underweight, psychological strategies to help those struggling with the emotional impact of living with a chronic disease, various ways to manage shortness of breath and cough, and the treatment of other conditions such as gastroesophageal reflux (also known as GORD or heartburn), osteoporosis and anxiety/depression.

Carita Bramhill, Respiratory Research Nurse at St Vincent's University Hospital, gave an update of the Irish Thoracic Society's National IPF Registry. The registry was the vision of Professor Anthony O'Regan and Dr Mike Henry and aims to capture information on the incidence (number of newly diagnosed cases) and prevalence (number of people living with IPF) in Ireland. Several hospitals are contributing data to the IPF Registry already and more will join once ethics approval is obtained from their institutions. The Registry will help clinicians and researchers advance their knowledge of IPF and identify the challenges associated with the diagnosis and treatment of the condition. By collecting anonymous information on cases of IPF in Ireland, important data will be generated that will be used to lobby for more resources to support patients.

Professor Bernard Mahon, School of Biology & Immunology at Maynooth University paid tribute to ILFA for

David Crosby receives a special recognition award from ILFA

David Crosby agreed to become a Patient Ambassador for ILFA in 2019 and we couldn't be prouder. After receiving a double lung transplant following a diagnosis of Idiopathic Pulmonary Fibrosis, David has devoted his energy, positivity and enthusiasm to raising awareness of pulmonary fibrosis, organ donation and transplantation. He has worked tirelessly sharing his story and giving hope and encouragement to other patients and families, while fundraising for respiratory charities and research foundations.

Post-transplant, David completed the New York City marathon with 14 supporters in 2016 and this amazing achievement set in motion plans to take on the Super Six Marathon Series and earn a place in the record books. David has already run the New York, Berlin and London marathons and will run in Tokyo in 2020 and then Boston and Chicago in 2021 to take on his remaining marathon challenges. ILFA surprised David with a special recognition award in October for his advocacy work. David was presented with a specially commissioned piece of Dublin Crystal by Lynn Fox (pictured), his respiratory nurse specialist at the Mater Hospital. We wish David and his family every success with his ILFA Ambassador role and his incredible marathon pursuits.

Speakers at the Patient Information Day. Back row: Dr Michelle Murray, Carita Bramhill, Prof Jim Egan, Prof Bernard Mahon, Adrian Sheehan. Front row: Lindsay Brown, Petra Grehan, Katie Crosby, Dr Jennifer Wilson O'Raghallaigh and Sonia Morrison.

awarding research funding to several academic professionals conducting IPF research in Ireland. Professor Mahon spoke about the science behind lung fibrosis and how the disruption of cellular communication pathways between the different types of lung cells (fibroblasts, macrophages and epithelial cells) leads to an imbalance between tissue regeneration and the formation of scar tissue (fibrosis). The development of anti-fibrotic therapies; Nintedanib and Perfinidone, that slow down the rate of fibrosis has been a major advancement and thankfully these medications are available for clinical use. Unfortunately, lots of promising research projects and clinical trials for potential drug therapies have ended in disappointment and the phenomenon of fibrosis in the lung has proven to be more complex and dynamic than first realised. Research is continuing with the hope of untangling the cellular pathways and discovering new therapies.

Dr Jennifer Wilson O'Raghallaigh, Clinical Psychologist at Beaumont Hospital spoke about living well with a chronic condition. She discussed self-management skills that can help patients and their carers adapt to the emotional challenges of a chronic illness. Sometimes the emotional burden can be overwhelming, and people may struggle. Some hospitals offer a 6-week programme that helps patients to adapt to living with their chronic illness. The course is run by a healthcare professional and a peer leader (a patient with a chronic illness) and the HSE has committed to providing funds to provide generic self-management courses under their Slainte Care programme. Dr O'Raghallaigh encouraged everyone to ask for a referral to the Self-management course and to consider becoming a peer leader.

Petra Grehan, respiratory physiotherapist at the Mater University Hospital, described how breathlessness causes the muscles in your shoulders, neck and chest to become tense. This uses a lot of energy, which makes your breathlessness worse. It is important to relax tense muscles to improve your breathing. Do this by unclenching your jaw, relaxing your neck muscles, letting your shoulders relax and drop down, and finding a comfortable position that helps you to take control and breathe easier. Petra spoke about the benefits of exercise for lung fibrosis patients including increased strength, stamina, and better sleep and mood. She encouraged everyone to look for a referral to a pulmonary rehab programme and to use the ILFA exercise and yoga DVDs for doing exercise at home. Petra encouraged audience participation in some simple exercises with the help of Matt Cullen demonstrating the moves.

Adrian Sheehan, BOC Healthcare Ireland, spoke about the practicalities of medical oxygen in the home environment. Each patient is different and each home is different, and the oxygen companies will work with the individual to best meet their needs. Adrian discussed some common safety issues and their solutions, for example oxygen can promote a fire, so fire-breakers are present on the oxygen tubing to protect patients. Extra long tubing is available to help patients who want to spend time in their gardens so they can use oxygen from a concentrator rather than using their portable oxygen supply.

Sonia Morrison, Air Liquide Ireland, spoke about oxygen allowing people to live their best life. She discussed travelling with oxygen and gave valuable advice on taking short journeys by car or public transport and travelling by plane and boat. It is important to speak with your medical team and oxygen company at least 6-8 weeks in advance to prepare for your oxygen prescription needs. Sonia encouraged people to do some research on their destination and notify the hotel of their oxygen needs.

Katie Crosby shared her personal story of being a caregiver for her husband David (diagnosed with IPF aged 40 years old) as well as being a mother to 3 young children. Kate and David's worlds were turned upside down by the IPF diagnosis and they had to adjust rapidly as David's condition progressed quickly. Thankfully David received a lung transplant and his care needs changed with time. Kate encouraged carers to accept all offers of help made by family and friends and to devote time and energy to looking after yourself and your physical and mental health.

THE ILFA committee is grateful to all the speakers and volunteers who helped make the event so successful.

Interstitial Lung Disease Interdisciplinary Network

The Interstitial Lung Disease Interdisciplinary Network (ILD-IN) conference took in Birminghan in October. ILFA awarded educational bursaries to 10 healthcare professionals to support their attendance at the conference. The bursary recipients were; John Alickolli (Bon Secours Hospital Cork); Rosaleen Anglim (South Tipperary Hospital); Grainne Casey (Mater University Hospital); Elaine Craven (Connolly Hospital Blanchardstown); Antoinette Doherty (Letterkenny Hospital); Carol Doherty (Letterkenny Hospital); Julie Goss (Harold's Cross Hospice, Dublin); Donna Langan (Galway University Hospital); Carmel McInerney (Ennis Hospital) and Lavinia McLeod (Mater University Hospital).

In addition, Liam Galvin (ILFA Director, EU-IPFF Secretary) and Nicola Cassidy (ILFA Director) attended the conference and Nicola gave a presentation on 'ILFA's Palliative Care Strategy'. One of the highlights of the event was the excellent pre-dinner speech by Irene Byrne from the Mater Hospital where she reflected on advances in respiratory physiotherapy.

Elaine Craven, Respiratory Advanced Nurse Practitioner: "I would like to express my gratitude to ILFA for their support in affording me the opportunity to attend this year's ILD–IN Conference in Birmingham. The diversity of the agenda was most impressive with many varied topics delivered by highly esteemed speakers. From science to psychology, radiology to rehab, insights and outcomes, projects and policies; the thought, effort and passion that went into coordinating the two-day conference was apparent.

In addition, networking opportunities with our overseas colleagues allowed for healthy discussions regarding the triumphs and challenges faced in the everyday practicum. This sharing of ideas and practices proved invaluable.

The relentless efforts of our wonderful charity (ILFA) who are continuously developing innovative initiatives such a World Café and a Yoga DVD left everyone inspired. Not to mention the volunteers who are dashing, running, swimming and constantly counting steps to improve the services provided to patients with ILD. Both professionals and patients provided unique perspectives on living well and dying better that were equally heart-breaking as they were heart-warming. Above all the atmosphere was one of shared enthusiasm among delegates with a demonstrable thirst for knowledge while the patient and their families remained the central focus throughout. It was a fabulous conference and I would highly recommend any HCP with an interest in ILD to attend. Once again, thank you so much to ILFA."

Julie Goss, Advanced Nurse Practitioner Palliative Care: "I would sincerely like to thank ILFA for providing the bursary which enabled me to attend this fantastic conference that was exemplary in providing a wonderful mix of high-quality clinical information, coupled with a very real spotlight on the value of psychological care, interdisciplinary team working, partnership with patients and support bodies and robust clinical research. A personal highlight of the conference was to hear Dr Havi Carel describe research findings from the 'Life of Breath' project which explores the relationship of breathlessness to both illness and wellbeing. It was very hopeful therefore to hear from Dr Karen Marshall on how the use of evidence based practical strategies such as CBT (cognitive behavioural therapy) techniques, that can be learned and utilised by health care professionals to help relieve the distress that can accompany living with chronic illness. This is an area of practice that I would like to develop further for use in our Multidisciplinary Breathlessness Support Service at Our Lady's Hospice and Care Services."

John Alickolli, Respiratory Nurse Specialist: "This was a very beneficial conference which encompassed all aspects of patient care where all the presentations and speakers were not only engaging but also current. I thoroughly enjoyed how current research related to patient care in practical terms and how to best support the patient and family. More importantly I learned about the advances being made in the diagnosis and ongoing care of ILD patients, something I will most certainly carry forward and adopt in my practice. It has completely changed my outlook and understanding of what ILD is with particular interest on the IPF component given its often sudden and devastating presentation. The Cognitive Behavioural Therapy (CBT) therapy session was of particular interest as it directly relates to my role in providing patients with the necessary tools in coping with their condition and how to best manage it. This I would like to further explore in the future. I am very grateful to ILFA for this bursary and would like to extend my sincere thanks for enabling this learning opportunity."

Antoinette Doherty, candidate Advanced Nurse Practitioner: "I would like to thank ILFA for my sponsorship to attend the ILD-IN Conference. As a respiratory nurse with 28 years' experience in this speciality, this conference was exceptional in many respects. On day 1, I took the opportunity to visit all the stands; every aspect of the patient's journey was represented in the exhibition hall. This time was well spent meeting the other delegates as well as the dozen or more Irish nurses and physiotherapists. I meet individuals from Belgium, Scotland, Norther Ireland, England and Italy and from this I was able to confirm that Irish patients are receiving care that is internationally recognised as best practice, and when it comes to anti-fibrotic drug therapy, we are able to continue to offer this medication throughout the illness. The pre-dinner speech from Irene Byrne was very special as it documented the past 40 years in patient care with the advancement in treatment and the commencement of lung transplantation at the Mater Hospital. On day 2 every speaker gave me food for thought. Ms Havi Carel from the 'Life of Breath' project at Bristol University was hands down exceptional; living with breathlessness and using Oxygen therapy. I learned so much from this lady. Primarily the language she used to describe breathless has enlightened me and I now understand the patients' experience much more and this will influence my care as I develop my Advanced Nurse Practitioner role in respiratory integrated care."

Some of the Irish delegates attending the ILD IN conference and (inset) Dr Anne-Marie Russell, Irene Byrne and Professor Leslie Saketkoo.

Lavinia McLeod, Respiratory Clinical Nurse Specialist: "Thank you so much for giving me the opportunity to travel to the ILD-INN conference. It was an excellent conference to attend from a nursing perspective. It provided a holistic approach to the management of ILD which included a wide variety of speakers such as consultants, nurses, physiotherapists, occupational therapists, psychologists, radiologists, but most importantly groups such as Action for PF who offered a patient perspective on managing ILD in terms of what they, as patients, deem to be most important in the management of their care. The diversity and motivation of speakers such as Professor Lesley Ann Saketkoo from New Orleans was very inspiring. She specialises in Connective Tissue Diseases and ILD and as well as being very knowledgeable in her speciality, she also incorporates Mindfulness into her practice and did a workshop with us which was very refreshing. This conference took us as through the journey of ILD management, diagnosis, alternative diagnosis, treatment, alternative and additional therapies such as Cognitive Behavioural Therapy and Mindfulness, Pulmonary Rehab, Palliative Care. It was great to see Irene Byrne do a fantastic speech on her years working as a physiotherapist in the Heart and Lung Transplant Unit. It highlighted how far we have come over the years and how staff have managed on limited resources. Lastly Nicola Cassidy (ILFA Director) updated us on ILFA's Palliative Care Strategy and all the fabulous work that was done through the ILFA World Café event. The information concluded that what was most important to patients was hope, empathy and honesty.

Rosaleen Anglim, physiotherapist: "Thank you ILFA for the opportunity to attend a great conference. It was a wonderful opportunity to network with fellow health professionals and hear about the work being done in the UK and Ireland. I was proud listening to Nicola Cassidy and Irene Byrne as great Irish champions of the lung fibrosis patient community. The information I gained from attending will inform my care of lung fibrosis patients. I will share this with my multidisciplinary team colleagues and work with them to provide holistic care to our lung fibrosis patients."

Grainne Casey, physiotherapist: "Thanks so much to ILFA for kindly affording me the opportunity to travel to Birmingham for the ILD - IN conference. I thoroughly enjoyed the conference. I especially enjoyed hearing of the latest research happening in the field of ILD. It was a wonderful opportunity to meet up with other healthcare professionals with an interest and experience in ILD and I hope to incorporate ideas shared into my daily practice."

Carol Doherty, Respiratory Nurse Specialist: "I would like to take the opportunity to express my thanks to ILFA for the educational bursary to attend the ILD-INN conference in Birmingham. This conference hosted an array of topics which were presented by enthusiastic speakers. I have gained a wealth of knowledge that I will bring with me into practice. I particularly found the talk on cognitive behaviour therapy thought provoking and something that I would like to pursue. This was a wonderful opportunity to network with other Health professionals from different counties and indeed countries that also have an interest in ILD"

Carmel McInerney, Respiratory Nurse Specialist: "May I take this opportunity to say thank you to ILFA for the bursary for the ILD-IN conference. It was a brilliant conference this year and I thoroughly enjoyed it. The speakers/ networking was fantastic. Nicola Cassidy did a fabulous presentation and truly put ILFA on the map. Keep up the good work."

Donna Langan, Respiratory Nurse Specialist: "Thank you for giving me the opportunity to attend the ILD-IN conference. It was a wonderful conference and showcased the importance of a multi-disciplinary team approach to the care of patients living with ILD. The wide range of the speakers both national and international spoke so eloquently regarding ILD and the different approaches to help our patients on their own journey. It was also a fantastic opportunity to liaise with both my fellow and international colleagues and learn of their approaches to caring for people living with ILD. This conference is well worth attending for anyone who cares for people who are on their ILD journey".

Joint Oireachtas Health Committee for pre-legislative scrutiny of the Human Tissue Bill

Anne Marie O'Dowd, Professor Jim Egan (Director of ODTI), Nicola Hurley, Philip Watt, Nicola Cassidy and Robert McCutcheon.

On 16th October, members of the Irish Donor Network (IDN) attended the Joint Oireachtas Health Committee for pre-legislative scrutiny of the Human Tissue Bill which includes legislation for an opt-out organ donation consent system. This bill will represent the first piece of Irish legislation in relation to organ donation and transplantation and will bring Ireland in line with the rest of Europe.

The Irish Donor Network consists of 7 patient organisations; Cystic Fibrosis Ireland, the Irish Heart & Lung Transplant Association, COPD Support Ireland, Alpha1 Foundation Ireland, Cystinosis Ireland, Children's Liver Disease Ireland and the Irish Lung Fibrosis Association (ILFA).

Speaking at the Oireachtas hearing were Michael Conroy and Helen O'Brien from the Department of Health, Professor Jim Egan and Fiona Hammond (Organ Donation and Transplant Ireland (ODTI)), Philip Watt and Robert McCutcheon (IDN) and Mark Murphy and John Phelan (Irish Kidney Association). Michael Conroy explained that under the new legislation, consent for organ donation will be deemed unless a person has registered their objection to organ donation by 'opting-out'. The potential donor's next of kin will always be consulted before organ donation can proceed and their wishes adhered to. A robust, secure online, GDPR compliant opt-out registry will be operated by ODTI with appropriate technological and security safeguards to enable people to opt-out of organ donation if this is their wish. A person will be able to revoke their decision online if they chose to do so.

Professor Egan informed the members of the health committee that there are currently 577 people in Ireland on the transplant waiting list. In order to maximise the organ donation rate in Ireland, it is necessary to introduce an opt-out consent system and secure a firm commitment to invest substantial 'new money' into transplant services for much needed additional infrastructure and key personnel. He discussed the situation in other European countries and the need for a robust national awareness programme in advance of the legislation. Professor Egan thanked the families of organ donors for their generosity in agreeing to organ donation thus saving the lives of thousands of people who needed a vital organ transplant.

Philip Watt, Chairman of the IDN and Cystic Fibrosis Ireland, dedicated the IDN's submission to the late Senator Feargal Quinn (former LFA Patron) who championed the call for an opt-out consent system in Ireland. The IDN supports the introduction of an opt-out system for organ donation consent with additional investment in infrastructure and resources to maximise the benefits of the legislation including the recruitment of more organ retrieval surgeons and donor nurse specialists in major hospitals, as well as improved hospital infrastructure and staffing levels at the 3 national transplant centres (Mater Hospital, Beaumont Hospital and St Vincent's Hospital), and sufficient resources for a national public awareness programme.

Public awareness on the proposed legislation changes is crucial and the IDN welcomed the government's commitment to a national public awareness campaign. IDN called for a well-resourced, high-profile, consistent and persistent publicity campaign to enable a more informed public debate. The IDN submissions states that the success of an opt-out system relies upon people knowing about their options and being able, easily and quickly, to opt-out if that is their wish. This change is not about forcing people into donation; it is about making it as easy as possible for an individual's willingness to donate organs after their death to be acted upon. Importantly, regular conversations with family and next of kin on organ donation are crucial to ensure that everyone's wishes are known.

Several questions were raised by the TDs and Senators of the health committee in relation to the infrastructure and personnel resources needed to optimise organ donation, the logistics of an opt-out registry, organ sharing opportunities with Northern Ireland and the United Kingdom, and next of kin involvement in organ donation decisions. Tributes were paid to the organ donors and their families, and to the skilled surgeons, doctors, nurses and healthcare staff who work in transplant medicine.

It is anticipated that the Human Tissue Bill will be drafted in the first quarter of 2020 and enacted by the third quarter of 2020.

ILFA sent in a pre-budget submission requesting additional resources and support for organ donation and transplant services to the Minister for Health and Minister for Finance.

European Respiratory Society Congress

The European Respiratory Society's (ERS) congress took place in Madrid in September and 22,000 international delegates from all over the world attended. The congress showcased the latest developments in respiratory medicine and there were many sessions dedicated to Idiopathic Pulmonary Fibrosis (IPF). Representing ILFA at the conference were Matt Cullen (as a Patient Ambassador for the European Lung Foundation), Liam Galvin (EU-IPFF Secretary) and Nicola Cassidy (ILFA Director).

Some of the topics covered in the congress included basic science in lung fibrosis, IPF care, lung transplantation, comorbidities (other health conditions) common with IPF, real-life experiences of patients on anti-fibrotic therapies and results from international IPF patient registries. Matt Cullen shared his personal insights and experiences in a session entitled 'Effects of pulmonary rehabilitation other than improving exercise capacity.'

There was great anticipation for the session called 'ALERT: Abstracts Leading to Evolution in Respiratory Medicine Trials: Interstitial lung diseases and pulmonary hypertension', and people queued for 40 minutes to get into the 900 seated auditorium to hear about the latest research. Suzanne McCormack, CEO of the Irish Thoracic Society (ITS) presented a summary of some recent work including; the ITS Respiratory Health of the Nation report, the National IPF Registry, and the IPF Position Statement. It is hoped that the quality data captured by the IPF Registry will help drive improvements in IPF patient care.

ERS Congress: A report from Mark Ward

My name is Mark Ward and I am currently a final year medical student in University College Dublin (UCD). During my studies, I was able to spend one year outside of the normal medical curriculum to undertake a Masters of Science (MSc) by research under the supervision of Dr Katherine O'Reilly from the Mater University Hospital and Professor John Baugh of the Conway Institute in UCD, supported by funding from ILFA.

The MSc programme encourages medical students to get practical experience in medical research and become proficient in scientific techniques needed to perform laboratory-based research. My research primarily focussed on pulmonary sarcoidosis and the mechanisms of fibrosis.

Nicola Cassidy, Liam Galvin, Steve Jones (Chair of Action for Pulmonary Fibrosis, UK), and Dr Anne Marie Russell (Imperial College London).

Dr Aidan O'Brien (Limerick University Hospital, Triona Rice (Roche Products Ireland), Suzanne McCormack (CEO of Irish Thoracic Society) and Nicola Cassidy (ILFA).

My project was concerned with a new technique of studying diseases in vitro (meaning 'in glass' in Latin). In vitro experiments are a quick, easy and relatively cheap way to perform research, especially experiments looking at how diseases happen at a molecular or genetic level. This way of experimenting is not without deficits, as you are limited by the length of time that cells can stay alive in these conditions, and by the fact that the cells grow flat in a plastic dish, in a 2-dimensional (2D) plane. This 2D environment drastically contrasts with the natural environment of cells in human lungs, which are in a 3-dimensional (3D) environment. The new technique that I worked with allowed cells to live in their own 3D environment, which offers a more accurate way of performing in vitro experiments.

I spent three months in the University of Southampton with Professor Donna Davies' research group, who are collaborators and colleagues with Dr O'Reilly, learning how to perform these 3D experiments and analyse the data they produce, spending the rest of my time in UCD working on the experiments.

I was fortunate to be accepted to present my research at the ERS Congress. I was very humbled, as a medical student, to talk about my research to doctors and scientists from all over the world. My two posters were on different days and I was overwhelmed at the interest in my work. To be one of the presenters amongst international experts was a tremendous experience, I hope to continue clinical research work in my career in Irish medicine and to be invited back to speak in the future!

Fundraising Round Up

The Pat Casey Memorial Cycle

The Pat Casey Memorial Cycle 2019 in aid of ILFA took place on 21st September. This incredible event is now in its eight year and has raised thousands of euro for ILFA. We are enormously grateful to the organisers and volunteers who make this event possible.

Here's a report from Daniel Casey: "At 9.30am, just as the rain started, 20 brave cyclists left the Cork City Ford Centre on Forge Hill for the annual 122Km route. They battled cross winds and inclement weather to complete the round-trip in just under 7 hours, returning safely to a hero's welcome at the Ford Centre once again.

Speaking on the day, cycle organiser, Anne Casey said "The weather reports were against us but that did not deter the loyal group of cyclists from taking part. We are always so grateful for their dedication. The support we receive from people is always overwhelming and the Cork Pulmonary Fibrosis Support Group are always on hand to help out on the day". Speaking after completing the cycle Brian Aherne added "The support we get every year for this event means the world to us. Remembering Pat is what it's about. I would like to thank John Nolan from the Cork City Ford Centre and all the collectors from the Cork Pulmonary Fibrosis Support Group for everything they do to help out".

Daniel Casey, Pat's son added "Year on year I am always so happy to see the same faces come out in remembrance of Dad. What we are doing - raising awareness and fundraising is something that is near to our hearts and we are so grateful to everyone who helps make this possible".

The organisers would like to thank all those who took part on the day, those who shook buckets on our collection days prior to the cycle and the Cork Support Pulmonary Fibrosis Support Group who give their time and are invaluable to us. Preparations for the 2020 Pat Casey Memorial Cycle are already underway!"

Coffee Morning in memory of James Maguire

"On 23rd August, my family and I hosted a coffee morning for ILFA to mark my father, James's 10th Anniversary. For obvious reasons, the work of ILFA is very close to my heart and raising awareness and funds is essential because although it will not make a difference to us, it is going towards support for someone else's family member. It is heart-warming to see the services that are on offer to patients and their families, from ILFA Patient Information Days to the Ecumenical Service that brings everyone together each year. IPF affects so many people, yet it seems people know very little about it. My father died at the young age of forty-five. He was a hardworking, active, and positive person and had full faith that he would get a lung transplant.

Unfortunately, it was not to be for him, but it is so encouraging to see the medical advancements that are in progress currently. Hosting the coffee morning was not only a chance to enjoy a slice of cake and a cup of tea, but to raise awareness for all those who have died from lung fibrosis. It's also important to think of those still living with the condition, and all the fantastic doctors, nurses, and carers. It was a privilege to raise €1,400 for ILFA, and it would not have been possible without the kindness and generosity of family and friends." A report by Alison Maguire.

Photograph shows Alison Maguire with her mother Angela and brothers, Kyle and Adam.

Teddy bears gather for ILFA

A report from Sinead O'Sullivan: "Every August Bank Holiday, our village of Lispole becomes a hive of activity for our local festival, Féile Lios Póil. This year the festival celebrated its Forty Year Anniversary - a huge achievement for the community of a small village in the West Kerry Gaeltacht. One event which has proved hugely successful is the Teddy Bear's Picnic. This is a free event, but donations are welcome to the nominated charity, which this year was ILFA. It was a very fitting charity for this year's event as three years ago, our great friend John Patrick O' Sullivan received a lung transplant. He has overcome his illness with immense nobility, and we were delighted that he joined us on the day with his daughters, grandchildren and many friends.

All of our little guests were delighted with the face painting, games and music. We were fortunate enough to be able to interview some of the teddy bears and their special owners and the feedback for this year's event was very positive. The 'Teddy Nurses' were especially busy in their clinic and a surprise visit from our Dancing Dads really added to the party atmosphere! A huge thank you to everyone who came, supported and helped. Without your support this event would not be possible. €400 was raised on the day for this very worthy cause."

Mile Buiochas to Sinead, the teddy bears, their owners and the Lispole community for their wonderful support for ILFA.

Dublin Half Marathon

Jenny Gibson, Annette Grehan and Nicola Cassidy.

“On 21st September, I ran my first half marathon (13 .1 miles) in aid of ILFA. I felt very honoured and privileged to be invited by Nicola Cassidy, a very close family friend of mine to represent ILFA alongside her and her aunt Annette Grehan. Although I hadn’t been training for the event, I was encouraged and motivated by the cause. I really enjoyed the run and felt on top of the world afterwards! It was a fantastic day out and a lovely way to remember Denise Cassidy, who will always have a special place in my heart. Overall it was a very rewarding and fulfilling experience!” A report by Jenny Gibson

‘Seeing the Light’ Solo Art Exhibition

Matt Cullen.

A report by Matt Cullen: “It was wonderful to have the kindness and support of so many people for my solo art exhibition ‘Seeing the Light’ which was held in the Atrium, Fingal County Council, County Hall, Swords from 21-25th October 2019. The fundraising event was very successful and €2,100 was raised for ILFA, representing 50% of the proceeds from the show. All 22 artworks were sold!

There were three reasons for the fundraising event. First, it was to raise much needed funds for ILFA. Secondly, it was to raise awareness of idiopathic pulmonary fibrosis (IPF). Thirdly, it was to highlight another milestone for me - living with IPF. The artwork for the exhibition was influenced from my love of the Fingal area where I live, my love of science and gardening and some of the work was influenced by my medical condition. Art for me is a welcome distraction from thinking too much about my medical condition. It was the culmination of approximately three years’ work (it takes me a long time to do most of the artworks, as some are carried out dot by dot!) so it was a very special, worthwhile and personal event for me.

The response to the fundraising event from family, relations and friends was beyond expectations. It was very helpful to have the Mayor of Fingal Eoghan O’ Brien and playwright David Gilna launch the exhibition. They both helped in their speeches to increase awareness of IPF, highlighting the importance of the fundraising event and demonstrating their genuine empathy and kindness towards me.

I am very grateful to ILFA and Fingal County Council for their help and support and to all that attended and supported my solo art exhibition. It was great to have the interest and coverage of the event by the news media in the Fingal area and by Phoenix FM radio station. It was an occasion that I will never forget, largely due to the kindness and generosity of all concerned which has continued well after the event.”

Matt Cullen, Mayor of Fingal Eoghan O’Brien, and David Gilna.

The Great North Run

Lisa Kane, Nicola Cassidy, Annette Grehan and Lisa Swift.

Annette Grehan and Nicola Cassidy (ILFA Director) ran the Great North Run half-marathon in Newcastle, England on 8th September 2019. The aunt and niece team ran to raise funds for ILFA in memory of Denise Cassidy, a beloved sister and mother. Here’s a report from Nicola.

“Myself and my incredible aunt Annette started running together in 2018. Initially we set ourselves the challenge of running 5k, then10k and then Annette announced it was her lifetime wish to run the Great North Run (20k). We applied separately as there is a lottery system to gain entry to the race but somehow, we both managed to get in. We travelled to Newcastle on 7th September and had plenty of laughs in the 24 hours before our ‘big run’. On race day we were up early and joined 57,000 other runners to line up for the world’s largest half marathon. Along the route we met fellow ILFA supporters Lisa Swift and Lisa Kane who were running in memory of their loved ones; Elizabeth Swift (Lisa’s mother) and Alfie Kane (Lisa’s father), who both had pulmonary fibrosis. We met again at the finish and congratulated each other on completing our first Great North Run. We all agreed that although it was a tough race, it was an amazing achievement and a wonderful day! Thank you to everyone who supported us with kind words, advice and sponsorship."

Dublin City Marathon

Aodan O'Connell, Annette Grehan, Andrew Grehan, Nicola Cassidy and Laura Grehan.

Nicola Cassidy, Laura Grehan, Annette Grehan and Andrew Grehan.

On 27th October 15 heroes took part in the Dublin City Marathon in aid of ILFA making this our biggest marathon group ever. Our marathon heroes are Richie Kavanagh, Caroline Moore, Siobhan Coffey, Donal O'Grady, Adam Moss, Allanah Moss, Ian Moss, Deirdre Moss, Aodan O'Connell, Annette Grehan, Laura Grehan, Andrew Grehan, Nicola Cassidy, Annette Johansson and Heather O'Tuairisg.

Here's a report from Nicola Cassidy, ILFA Director, on her race day experience: "It was a perfect day for a run and me and 3 family members lined up with over 18,000 athletes to take on the iconic 26.2 mile (42km) challenge. I am very proud of my family team consisting of my cousin Andrew Grehan (running his 9th marathon for ILFA), his sister Laura (running marathon #2), his mother Annette (running marathon #13) and me - running my first marathon. Before the start, we met Aodan O'Connell from Kerry who was also running his first marathon and fundraising for ILFA in support of his father.

It was good to get going and the support from the crowds along the route was fantastic. Special thanks to Feargal O'Connor for encouragement at the start, to Niamh, Sean, Caoimhe, Liath and Cara English for their support at Kevin Street and to our family; Tom, Caroline, Stephanie, Lily and Lorna Grehan for their cheers at the James Joyce Bridge. As we ran through the Phoenix Park, we were greeted by screams, cheers and hugs from David and Katie Crosby and their children. David (lung transplant recipient and New York, Berlin and London Marathon finisher) inspired me to start running and has given me great encouragement and advice. We were delighted to meet Dr Sinead Walsh from Galway University Hospital along the way who is doing research in lung fibrosis and described ILFA as "a wonderful charity".

The course was tough at times but enjoyable and there was wonderful camaraderie among the runners who shared stories and words of encouragement with each other. We will never forget the final stage as we ran to the finish line. With the noise our family and friends made to welcome us home, we felt like we had won the race! Huge thanks to Niamh, Caoimhe, Kathleen, Tom, Bernie, Caroline, Stephanie, Lily, Lorna, Tom, Laura and Andrew, Grainne Coffey and family, the ILFA runners who had already finished, and the Crosby Family who cheered us on. As we crossed the finish line, we hugged each other and felt enormously proud of our achievement.

This year Annette and I took on a series of fundraising challenges for ILFA including the Cork Marathon Relay, the Great North Run, Dublin half-marathon and Dublin Marathon. We have received fabulous support throughout the year and are grateful to everyone who has supported us with advice, encouragement and sponsorship."

Donal O'Grady, Alannah Moss, Ian Moss, Adam Moss, Deirdre Moss, Matt Smith and Siobhan Coffey.

West Cork Water Colour Artist supports ILFA

The Cork Pulmonary Fibrosis Support Group was visited by Barry Dawkes, water colour artist, who held two watercolour painting days to raise funds for ILFA. The fantastic sum of €1,000 was raised and Barry presented a cheque to Anne Casey on behalf of ILFA. You can see Barry's work on www.westcorkwatercolour.ie

EU-IPFF 2019 Activities

EU-IPFF
EUROPEAN IDIOPATHIC PULMONARY FIBROSIS
& RELATED DISORDERS FEDERATION

The European Idiopathic Pulmonary Fibrosis & Related Disorders Federation (EU-IPFF) celebrated its 3rd official year as an international non-profit federation in 2019. This organisation represents ILFA at a European level alongside members from another 12 countries. The EU-IPFF works to raise awareness of IPF and similar illnesses, as well as promote research partnerships and better national supports for patients and their loved ones.

This year has been particularly busy in terms of awareness raising with the EU-IPFF supporting specific political campaigns in Malta, France, and Italy as well as being the co-ordinator of the annual IPF Awareness Campaign that takes place in September. This year the campaign continued its theme of #MyIPFstory that was first used in 2018. Events around this were held across Europe and the EU-IPFF used social media posts as well as filming several videos under the #MyIPFstory brand, one of which featured the Irish MEP Sean Kelly, a long-time supporter of ILFA and the EU-IPFF.

In partnership with its Scientific Advisory Board, EU-IPFF members contributed to numerous media articles, scientific publications and national guidelines. The EU-IPFF launched two major publications; (1) the EU-IPFF Benchmarking Report featuring data on IPF support and treatment across 14 European countries including Ireland and (2) A joint Expert and Patient Statement in the European Respiratory Journal. Copies of both articles can be accessed online at www.eu-ipff.org

The EU-IPFF continued its sponsorship of the ILD-IN Conference and Mentoring Programme which supports European nurses and healthcare professionals to learn best practice from recognised experts. It also participated directly or via its members in various research consortiums, taskforces and advisory committees aimed at seeking research funding, improving scientific knowledge and highlighting the patient view.

This year has also seen the EU-IPFF in partnership with other patient groups and European stakeholders finalise the organisation of the first ever European patient led Summit on IPF which will take place in April 2020 in Warsaw, Poland. This unique educational and awareness raising event will bring together patients, carers and healthcare professionals under one roof to discuss the latest research, highlight the disease and the policy changes that need to be addressed, and provide a platform for unprecedented co-operation between all those involved in the European IPF field (for more details please visit www.euipfsummit.org). **ILFA will be offering educational bursaries to healthcare professionals who are Irish Thoracic Society Members to attend the European IPF Summit. Please express your interest in attending this conference via info@ilfa.ie.**

ILFA continues to be a vital contributor to the EU-IPFF having participated in the EU-IPFF Benchmarking Report and other scientific papers. Dr Kate O'Reilly (Mater Misericordiae University Hospital) and Dr Cormac McCarthy, (St Vincent's University Hospital) are the two Irish healthcare professionals who sit on the EU-IPFF Scientific Advisory Board. ILFA Director Liam Galvin was re-elected by the other countries as the EU-IPFF General Secretary again in 2019. Congratulations.

'A History of the Irish Thoracic Society'

Congratulations to the Irish Thoracic Society (ITS) on the launch of their book entitled 'A History of the Irish Thoracic Society' authored by Professor Muiris Fitzgerald, Professor Anthony O'Regan and Suzanne McCormack. Representing ILFA at the book launch on 8th October were Eddie Cassidy (ILFA Chairman), Matt Cullen, David and Katie Crosby and Nicola Cassidy. John Bowman chaired the evening and explained that the ITS is celebrating it's 75th anniversary and is one of the oldest sub-speciality medical societies in Ireland. The ITS has a fascinating history and has been a major influencer of lung health promotion in Ireland. ILFA is grateful to the ITS for their active role in promoting and advancing lung fibrosis care and supporting ILFA's patient advocacy role.

Prof Anthony O'Regan, David Crosby, Matt Cullen, Katie Crosby and Eddie Cassidy.

Photo: Katie Crosby, David Crosby and John Bowman.

Patient Support Groups

Cork Support Group

The group meets at 11am on the last Thursday of every month at The Elm Tree, Glounthaune. **Please call Anne on 087 985 4587 for more details.**

Dublin Support Group

The group meets on the first Tuesday of every month at 10.30am at the Carmelite Community Centre at Whitefriar Street Church, Aungier Street, Dublin 2. **Please call Matt on 086 244 8682 or Pam on 086 178 9055 for more details.**

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at The Rose Hotel. **Please call John on 087 280 9801 for more details.**

Midland Support Group

The group meets on the first Wednesday of every month at 2.30pm at the Tullamore Court Hotel, Tullamore, Co. Offaly. **Please call Val on 087 233 2653 for more details.**

Monaghan Cavan Support Group

Monaghan Cavan Support Group meet at 12 noon on the first Thursday of every month at the Hillgrove Hotel in Monaghan. **Please call Kevin on 085 243 6828 for more details.**

Mid West Support Group

The group meets at 11.30am on the last Saturday every month at Matt The Thresher, Birdhill, Tipperary. **Please call Noreen on 087 262 7976 for more details.**

Clare Support Group

The group meets at 12 noon on the first Wednesday every month at the West County Hotel in Ennis. **Please contact Michael at 087 637 468 for more details.**

ILFA would like to thank the leaders of the support groups for facilitating the group meetings. It is wonderful to see the groups go from strength to strength and learn about the peer support available to patients and family members. We wish everyone involved continued success for the future.

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

086 871 5264

Christmas message from the ILFA Committee

The ILFA committee would like to extend our sincere thanks to everyone who helped raise awareness of pulmonary fibrosis and supported our work in 2019 through volunteering, fundraising, donations and support. ILFA does not receive government funding and therefore must rely on fundraising activities and donations. We are fortunate and blessed to have support from amazing individuals and groups who are deeply committed to fundraising and raising awareness of lung fibrosis so that ILFA can invest in research, education and support activities to help us help patients and families and the healthcare professionals who care for them. Please contact ILFA if you would like to make a donation or set up a standing order to donate regular amounts yearly or monthly. The ILFA committee would also like to extend our warmest thanks and appreciation to Gemma O'Dowd for her invaluable work for ILFA during the year. We wish you and your loved ones, "A very happy and healthy Christmas and New Year."

Dates For Your Diary

Fundraising

- **ILFA Christmas cards** are available to buy. Each pack contains 10 cards with 2 cards each of 5 colourful festive designs. One pack of cards costs €6 and two packs cost €10. Cards can be ordered by calling 086 871 5264 or emailing info@ilfa.ie
- **The ILFA Christmas Swim** will take place on Friday 27th December at 12pm sharp. Refreshments will be served at Fitzgerald's Pub at 12.30pm. Please contact ILFA on 086 871 5264 if you would like to take part and fundraise.
- **The 2020 VHI Women's Mini-marathon** will take place on Sunday 31st May (the Sunday of the June Bank Holiday) 2020. Please see www.vhiwomensminimarathon for more details.
- **The 2020 Cork City Marathon, Half-marathon and Team Relay** will take place on Sunday 31st May (the Sunday of the June Bank Holiday) 2020. Please see www.corkcitymarathon.ie for more details.

Educational Activities

- **ILFA Patient Information Day** will take place on Saturday 4th April at 10am at the Tullamore Hotel, Tullamore, Offaly.
- **Lean White Belt Study Day** for healthcare professionals working with pulmonary fibrosis patients will take place at Mater Misericordiae University Hospital in Dublin on 8th January from 9am to 4.30pm.
- **Fergus Goodbody Memorial Lecture** for healthcare professionals will take place on 23rd September at Royal College of Physicians in Ireland. The invited speaker is Dr Maria Molina-Molina from Spain.
- **The European IPF Patient Summit** will take place from 24-26 April, Warsaw Poland.

Please contact ILFA on 086 871 5264 or email info@ilfa.ie to register your interest in attending any of these events or for a fundraising pack if you would like to fundraise for ILFA.

Keep in touch with ILFA

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

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

Irish Lung Fibrosis Association www.ilfa.ie

The Irish Lung Fibrosis Association CLG

Annual Report and Financial Statements

for the financial period ended 31 December 2019

The Irish Lung Fibrosis Association CLG

CONTENTS

The Irish Lung Fibrosis Association CLG

DIRECTORS AND OTHER INFORMATION

Directors	Edward Cassidy Nicola Cassidy James Egan Liam Galvin Nicola Goodbody (Resigned 1 November 2019)
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 Molesworth House 1-2 South Frederick Street Dublin 2
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 period ended 31 December 2019

The directors present their report and the audited financial statements for the financial period ended 31 December 2019.

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 period, the company has assets of €303,867 (Feb 19 - €311,913) and liabilities of €25,488 (Feb 19 - €10,246). The net assets of the company have decreased by €(23,288).

Directors and Secretary
The directors who served throughout the financial period, except as noted, were as follows:

Edward Cassidy
Nicola Cassidy
James Egan
Liam Galvin
Nicola Goodbody (Resigned 1 November 2019)

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

Future Developments
Since the year end, following restrictions placed on the company and the general public as a result of the outbreak of the Covid-19 pandemic, third party events which would result in funds being raised for the Company temporarily ceased.

The directors believe that once all restrictions have been lifted and third party fundraising events recommence donations will resume. In the intervening period, the company has reduced its cost base in order for them to be able to continue operating as normal, irrespective of the reduced funding.

Post Balance Sheet Events
In the first half of 2020, the Covid-19 virus spread worldwide. In common with many other countries, the Irish government issued guidance and restrictions on the movement of people designed to slow the spread of this virus. In early March 2020, many businesses closed voluntarily and throughout the month more restrictions were placed on people and businesses. On 28th March, all "non-essential" businesses were ordered to close temporarily.

The company reacted to these conditions with the directors and committee members continuing to perform their duties from home, utilising various types of software to meet online.

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

Edward Cassidy

Liam Galvin
Director

1 September 2020

The Irish Lung Fibrosis Association CLG

DIRECTORS' RESPONSIBILITIES STATEMENT

for the financial period ended 31 December 2019

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

Edward Cassidy

Liam Galvin
Director

14 September 2020

INDEPENDENT AUDITOR'S REPORT
to the Shareholders of The Irish Lung Fibrosis Association CLG

Report on the audit of the financial statements

Qualified opinion
We have audited the financial statements of The Irish Lung Fibrosis Association CLG ('the company') for the financial period ended 31 December 2019 which comprise the Income Statement, the Balance Sheet and the related notes to the financial statements, including a 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".

In our opinion, except for the possible effects of the matter described in the Basis for qualified opinion paragraph, the financial statements:

- give a true and fair view of the assets, liabilities and financial position of the company as at 31 December 2019 and of its loss for the financial period 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 qualified opinion
We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are further described 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 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 4 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.

This charity in common with many others of similar size and organisation derives a substantial proportion of its income from voluntary contributions which cannot be fully controlled until they are entered in the accounting records and are not therefore susceptible to independent audit verification.

Conclusions relating to going concern
We have nothing to report in respect of the following matters in relation to which ISAs (Ireland) require us to report to you where:

- the directors' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the directors have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

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.

In connection with our audit of the financial statements, 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 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
Based solely on the work undertaken in the course of the audit, we report that:

- in our opinion, 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
- in our opinion, the Directors' Report has been prepared in accordance with the Companies Act 2014.

We have obtained all the information and explanations which we consider 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. 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 are not made. 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 and for being satisfied that they 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, as 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 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

Mark Hamill
for and on behalf of
WHITESIDE CULLINAN
Registered Auditor and Chartered Accountants
Molesworth House
1-2 South Frederick Street
Dublin 2

14 September 2020

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 period ended 31 December 2019

	Notes	Dec 19 €	Feb 19 €
Revenue		**82,584**	117,230
Gross profit		**82,584**	117,230
Administrative expenses		**(105,872)**	(121,442)
Loss before taxation		**(23,288)**	(4,212)
Tax on loss		**-**	-
Loss for the financial period		**(23,288)**	(4,212)
Total comprehensive income		**(23,288)**	(4,212)
Retained profit brought forward		**301,667**	305,879
Retained profit carried forward		**278,379**	301,667

Approved by the board on 14 September 2020 and signed on its behalf by:

Edward Cassidy
Director

Edward Cassidy

Liam Galvin
Director

The notes on pages 11 to 12 form part of the financial statements

The Irish Lung Fibrosis Association CLG
BALANCE SHEET
as at 31 December 2019

	Notes	Dec 19 €	Feb 19 €
Current Assets			
Debtors	**6**	**4,287**	2,096
Cash and cash equivalents		**299,580**	309,817
		303,867	311,913
Creditors: Amounts falling due within one year	**7**	**(25,488)**	(10,246)
Net Current Assets		**278,379**	301,667
Total Assets less Current Liabilities		**278,379**	301,667
Capital and Reserves			
Income statement		**278,379**	301,667
Equity attributable to owners of the company		**278,379**	301,667

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

Approved by the board on 14 September 2020 and signed on its behalf by:

Edward Cassidy
Director

Edward Cassidy

Liam Galvin
Director

The notes on pages 11 to 12 form part of the financial statements

The Irish Lung Fibrosis Association CLG
NOTES TO THE FINANCIAL STATEMENTS
for the financial period ended 31 December 2019

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 2019 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 period, 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. PERIOD OF FINANCIAL STATEMENTS

The financial statements are for the 10 month period ended 31 December 2019.

4. PROVISIONS AVAILABLE FOR AUDITS OF SMALL ENTITIES

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

5. EMPLOYEES

The Company did not have any employees during the period.

6. DEBTORS

	Dec 19 **€**	Feb 19 €
Other debtors	**2,209**	577
Prepayments	**2,078**	1,519
	4,287	2,09

7. CREDITORS

Amounts falling due within one year	Dec 19 €	Feb 19 €
Amounts owed to credit institutions	**725**	199
Accruals	**24,763**	10,047
	25,488	10,246

8. POST-BALANCE SHEET EVENTS

In the first half of 2020, the Covid-19 virus spread worldwide. In common with many other countries, the Irish government issued guidance and restrictions on the movement of people designed to slow the spread of this virus. In early March 2020, many businesses closed voluntarily and throughout the month more restrictions were placed on people and businesses. On 28th March, all "non-essential" businesses were ordered to close temporarily.

At the time of approving the financial statements, there is uncertainty regarding how the balance sheet may be impacted based on events since the year end and as a result an estimate of its financial effect cannot be made.

9. APPROVAL OF FINANCIAL STATEMENTS

The financial statements were approved and authorised for issue by the board of directors on 14 September 2020.

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

Irish Lung Fibrosis Association
www.ilfa.ie