ILFA Newsletter

Irish Lung Fibrosis Association
www.ilfa.ie

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

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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.

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.


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

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).

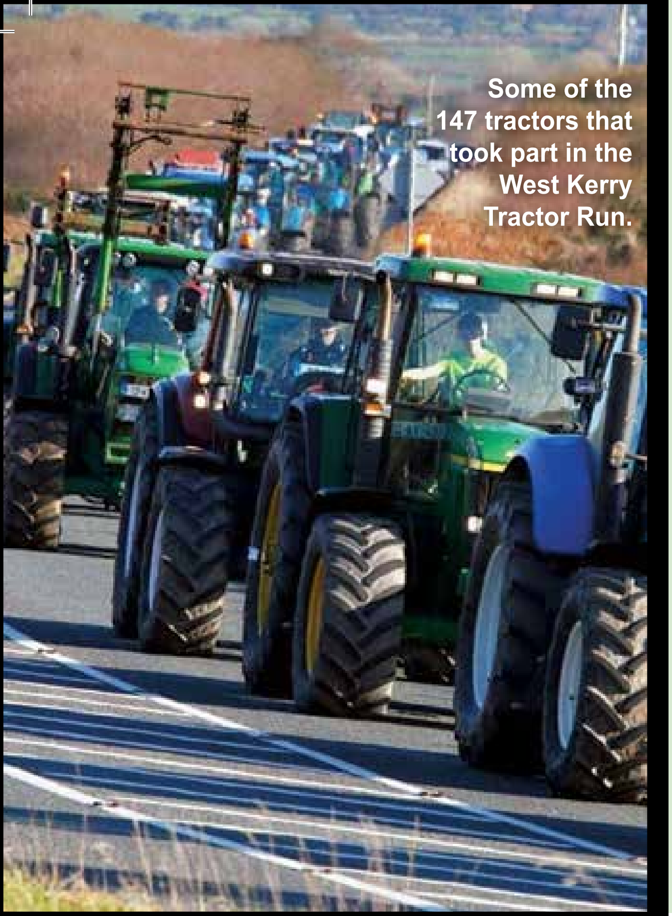
There were excellent presentations from leading respiratory clinicians that focussed on the role of the specialist interstitial lung disease centres in the diagnosis and treatment of IPF, the management of cough, hospitalisations and acute exacerbations, clinical cases, palliative care, and Professor 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.

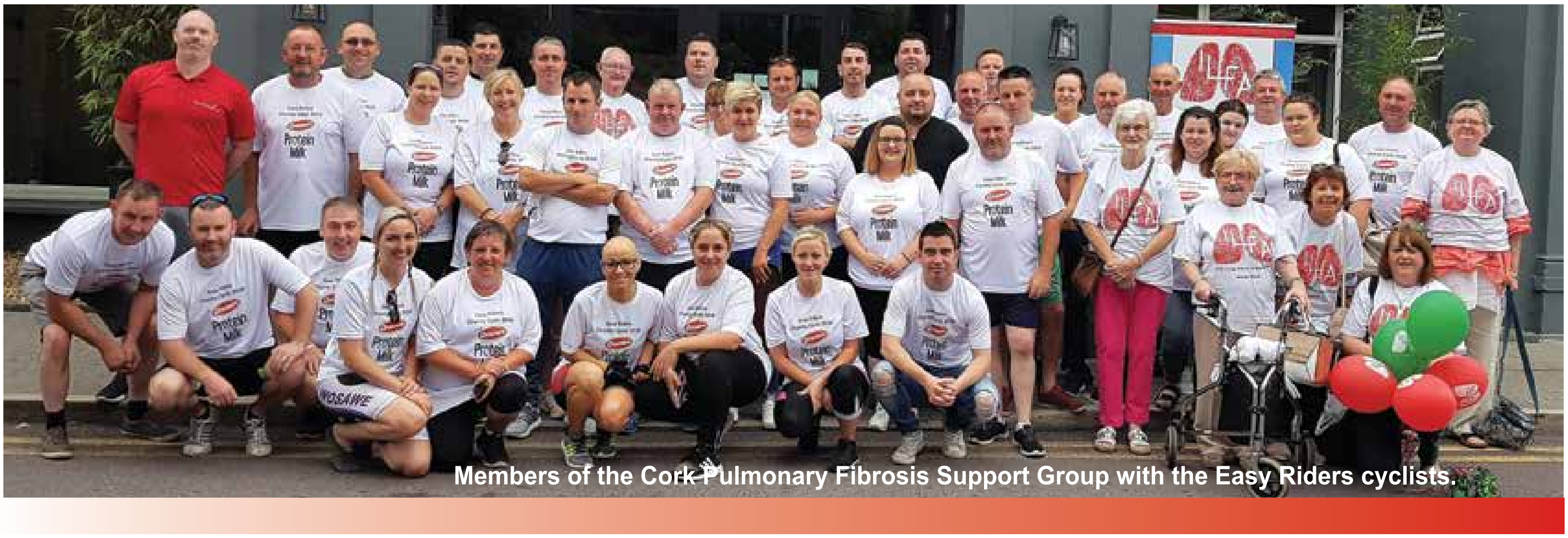

Tommy Phelan, Paddy Keyes, Sarah Bowe, Liam Galvin, Kevin Phelan, Grace Fitzpatrick, Helen Moynan and Colleen Kavanagh.


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

Report by Sarah Bowe

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.


Network
28th October
Horrorgram
4
ROCK GAA CLUB
@ Turleys Bar
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CAUTION
1.000.000 HATES
Fancy Dress Charity Party


Network
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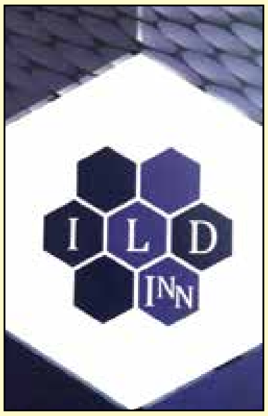
ILFA Bursaries for respiratory nurses and allied healthcare professionals



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

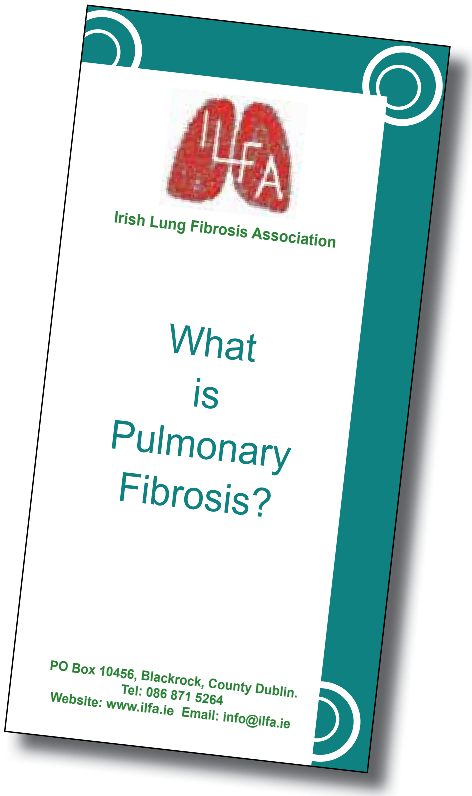
If you have lung fibrosis and are happy to share your story, please get in touch with ILFA by emailing **info@ilfa.ie** or calling 086 871 5264.

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.

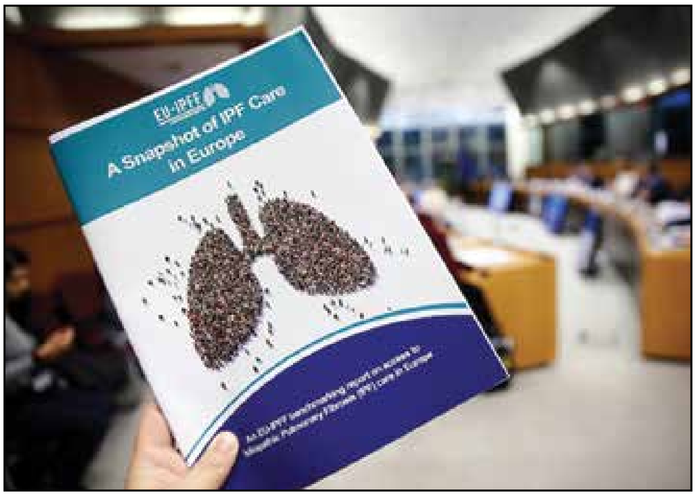
The results of the interviews were collated to produce a European scorecard that enabled comparisons in IPF care to be made. Each country that participated also received a national scorecard that graded their performance. The EU-IPFF hope that the Benchmarking Report will inform policy decision-making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

Members of the EU-IPFF at the European Parliament.



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.

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

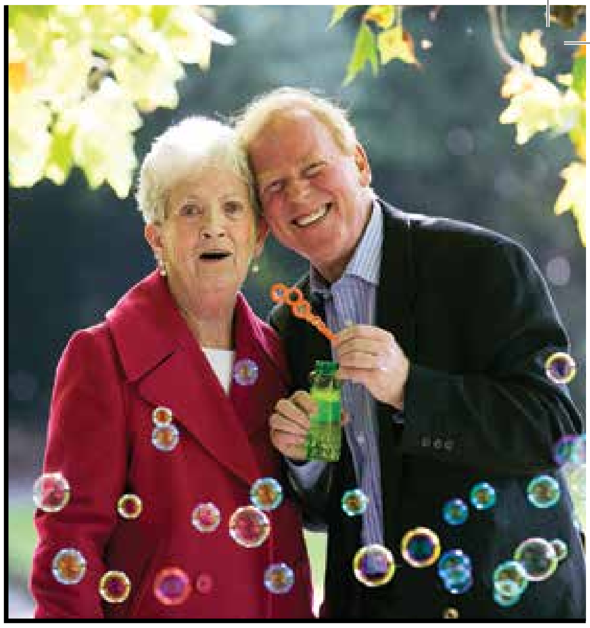
Please contact Michael on 087 637 4068 if you are interested in attending a new support group in Ennis.

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.

Dates For Your Diary

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.

Irish Lung Fibrosis Association
www.ilfa.ie

EU-IPFF