



ILFA Newsletter



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

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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 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. 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, **Caomhe Fox** student nurse at the Mater Hospital, **Veronica Ndah** 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 College 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 Birmingham 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 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."

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, Northern 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.

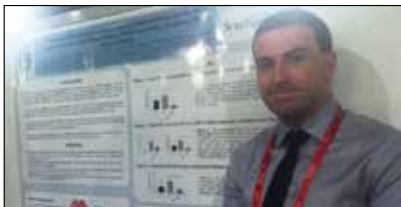
European Respiratory Society Congress

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.

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

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



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

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.”

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, then 10k 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, Allannah 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



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.euipffsummit.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 its 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](https://twitter.com/ilfaireland)

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

