ILFA Newsletter

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

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 2017, ILFA members were invited to nominate a person who showed them or their loved one a special kindness.

ILFA was delighted to receive so many nominations and learn about the great work and kindness shown by our healthcare staff across the country. Sincere thanks to everyone who completed the form and nominated their healthcare hero. All those nominated received a framed Certificate for Excellence in Patient Care from ILFA.

Olivia Mulvaney, staff nurse at the Coronary Care Unit at Cavan General Hospital, was selected as the worthy winner of the 2017 Denise Cassidy Memorial Prize. Olivia was presented with a specially commissioned piece of Dublin Crystal and a framed Certificate for Excellence in Patient Care by Eddie Cassidy (ILFA Chairman) in Dublin on Monday 29th January.

Olivia was nominated by Bridget McEneaney from Mullagh, Co Cavan who said “From our first meeting, Olivia was so sweet, kind and considerate of Dessie and the family. Dessie felt that someone finally listened, heard and understood him. Olivia helped us when our world fell apart. We are thankful to her for all she did to try and make it easier for us.”

Olivia said “I want to express my sincere appreciation to Bridget and 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. I would also like to thank the Irish Lung Fibrosis Association, the chairman Eddie Cassidy, Nicola Cassidy and the extended association members for the award, not forgetting all the hard work you do behind the scenes for this worthy cause improving the lives of patients and families.”

Bridget McEneaney, Eddie Cassidy and Olivia Mulvaney, winner of the Denise Cassidy Memorial Prize for Excellence in Patient Care.

▸ **See page 3 for more coverage of this story.**

Thank you to Nicky Goodbody

Nicky Goodbody set up ILFA in 2002 in memory of her husband, Fergus Goodbody, with her friends the late Terence Moran (former ILFA Chairman), Marie Sheridan (Treasurer) and Professor Jim Egan.

Eddie Cassidy, Nicky Goodbody and Professor Jim Egan.

After an amazing 15-years of voluntary service, hard work and dedication to ILFA, Nicky stepped down from the committee at ILFA’s Annual General Meeting in November 2017. Eddie Cassidy (ILFA Chairman) and Professor Jim Egan formally thanked Nicky for her steadfast contribution, and their thanks and sentiments were echoed by all the ILFA committee.

Patient Information Day

The next Patient Information Day will take place on Saturday 21st April at the Newpark Hotel, Co Kilkenny from 10am until 1pm. We hope you can join us to learn more about pulmonary fibrosis from experts in the field. All are welcome. Our speakers will be;

- **Dr Killian Hurley - Respiratory Consultant at Beaumont Hospital**
- **Paula Ryan - Advanced Nurse Practitioner in respiratory medicine at Limerick University Hospital**
- **Irene Byrne - Senior Respiratory Physiotherapist at the Mater University Hospital**
- **Maria Love - Senior Medical Social Worker at the Mater University Hospital**
- **David Crosby – Double lung transplant recipient.**

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

Patient Information Day

The autumn Patient Information Day took place on Saturday 21st October at the Crowne Plaza Hotel in Santry, Dublin and was very well attended. We had guest speakers of the highest calibre and their presentations were recorded. The videos can be viewed on ILFA's website (www.ilfa.ie) and on ILFA's YouTube channel. Please ask a friend or relative to help you view the videos if you have difficulty using the Internet.

Professor Anthony O'Regan, respiratory consultant at University College Hospital Galway gave a comprehensive overview of Idiopathic Pulmonary Fibrosis. He discussed how fibrosis (scar tissue) develops in the lungs, the risk factors associated with the development of the condition, the tests used to diagnose the condition, and treatment options.

Prof O'Regan discussed the Irish Thoracic Society's IPF Registry that is designed to capture valuable data on the incidence of IPF in Ireland. Approximately 400 new cases of IPF are diagnosed in Ireland each year and approximately 1,000 people are living with the condition. The incidence of IPF is increasing and this may be due to people living longer as IPF is generally diagnosed in older adults. The registry will allow comparisons between Irish data and data from international registries and will enhance our knowledge of IPF.

Irene Byrne, Senior physiotherapist at the National Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital in Dublin spoke about the importance of exercise for IPF patients to maintain their wellbeing, fitness, mobility and quality of life. ILFA have practical resources available to help patients exercise safely within their limits and Irene encouraged everyone to use the 2000 Steps a Day Walking Programme and the ILFA Exercise DVD. Irene also discussed the benefits of using ILFA's hand held fans for managing breathlessness.

When exercising, you should aim to be moderately breathless. If you experience shortness of breath, use the STALL technique to help you recover;

- **Stop** what you are doing
- **Try** to relax and turn up your oxygen if needed
- **Assume** a position of comfort to help your breathing
- **Let** your imagination take you to a safe place
- **Let** your breathing return to normal.

Irene also discussed the benefits of oxygen for IPF patients especially when you are exercising, doing chores, and carrying out your activities of daily living. It is important to be honest with your healthcare team and let them know if you are struggling with breathlessness. Irene advised everyone to speak with their oxygen company representatives to see what equipment and technology is available to suit your needs. Irene finished by encouraging everyone to "Make the days count!"

Anne-Marie Russell, clinical research fellow at Imperial College London gave an insightful presentation on communication. Respiratory medicine can learn a lot from the communication models used in cancer care as this area has been widely studied. Receiving a diagnosis of IPF can be difficult and it is ok to feel angry and upset. Feeling distressed and anxious is a normal reaction but if you are struggling, you should ask for help via support groups, GPs and psychologists. Work in partnership with your healthcare team and be honest and open about how you are feeling. If you don't have a good rapport with your clinician, it is ok to ask to see someone else. Patients should aim to informed about IPF to manage the condition as best as possible and good information is available from your healthcare professional and ILFA.

Professor Anthony O'Regan, Anne-Marie Russell, Colin Edwards, Irene Byrne and Ciaran Heatley.

Communication is an active process and the more you put in, the more you will benefit. Prepare for your hospital appointments by writing down any questions you have. If you are unsure about what your clinician has said, ask them to repeat the information in a different way, ask them to draw it or write it down.

Ciaran Heatley, respiratory physiologist at the Mater Misericordiae University Hospital, spoke about Pulmonary Function Tests (PFTs). IPF is a progressive lung disease and over time the lung tissue becomes hard and stiff with scar tissue. This results in loss of flexibility and a decrease in lung volume.

As an IPF patient, you will need to do PFTs regularly, so your healthcare team has a clear picture of how efficiently your lungs are working. PFTs can reveal changes in lung volume and the gas transfer exchange mechanism by monitoring the movement of oxygen and carbon dioxide into/out of your lungs. Having regular tests facilitates comparisons of your results over time to identify changes in lung volume.

Many patients dread having their PFTs done as the procedure is difficult and requires physical exertion. Ciaran stressed that the more effort you put into doing your PFTs, the more accurate the results will be.

Colin Edwards from patientMpower discussed the patientMpower phone and tablet app that helps IPF patients manage their condition via home monitoring and regular measurement of health values. The app has many useful functions, for example daily medication reminders, a diary to record breathlessness, a weekly quality of life survey, and videos.

Bluetooth technology allows the results from a spirometer and a pulse oximeter link in real-time directly to the phone app. It is possible to also to record activity measures (daily step counts), and some patients reported that this feature motivated them to reach their exercise goals. Colin thanked the ILFA patient users who have helped with the development of the patientMpower app to date. The app can be downloaded from Google Playstore and Apple i-tunes.

Thank you to everyone who attended the event, our volunteers, guest speakers, and representatives from the oxygen companies; Air Liquide and BOC Healthcare. Thanks to Roche Products Ireland for sponsoring the event.

The Denise Cassidy Memorial Prize

The Denise Cassidy Memorial Award recognises and celebrates an act of kindness shown by a healthcare worker to a lung fibrosis patient.

Olivia Mulvaney, staff nurse from Cavan General Hospital was the worthy winner of the 2017 Denise Cassidy Memorial Prize. In January 2018, Olivia travelled to Dublin with her husband Tommy and met with Bridget McEneaney who nominated her for the prize, as well as members of the McEneaney family; Phyllis, Leona and Zach, and members of the late Denise Cassidy's Family; her husband Eddie, her daughter Nicola and her sister Annette Grehan.

It was an emotional meeting and the families enjoyed the opportunity to meet Olivia and express their thanks and appreciation for her kindness and gentleness. Certificates for Excellence in Patient Care were also awarded to;

- Bernadette Bowen, respiratory nurse specialist at Cork University Hospital
- Maria Love, medical social worker at the Mater University Hospital
- Carol O'Mahony, physiotherapist at Cork University Hospital
- Lindsay Brown, respiratory nurse specialist at St Vincent's University Hospital
- Sara Winward, advanced nurse practitioner at the Mater Misericordiae University Hospital
- Carol Buckley, respiratory nurse specialist at the Mater Misericordiae University Hospital,
- Sandi O'Reilly - medical receptionist at the Mater Misericordiae University Hospital
- Dr Kate O'Reilly, respiratory physician at the Mater Misericordiae University Hospital
- Lynn Fox, respiratory nurse specialist at the Mater Misericordiae University Hospital
- Zita Lawlor, transplant coordinator at the Mater Misericordiae University Hospital,
- Dr Desmond Murphy, respiratory physician at Cork University Hospital.

Sandi O'Reilly, Lindsay Brown, Eddie Cassidy (ILFA Chairman), Lynn Fox and Carol Buckley.

Maria Love and Eddie Cassidy.

Olivia Mulvaney.

Sara Winward and Eddie Cassidy.

Warmest congratulations to all those nominated and thank you for your great contributions to caring for IPF patients.

patientMpower wins IPF Catalyst Challenge

Eamonn Costello and Colin Edwards (patientMpower) with Elizabeth Estes and Ken Bahk (Three Lakes Partners) and and Steven Collens, CEO MATTER.

patientMpower would like to pass on our sincere thanks to the ILFA volunteers who have worked with us to build and test the patientMpower app. We are delighted to share with you that patientMpower were recently named winners in the IPF Catalyst Challenge and received a prize of $333,333 to further develop our platform.

We have been working with ILFA since 2016, and it is the fantastic advice and feedback we have received from the ILFA members that has helped us build our current app. patientMpower for Pulmonary Fibrosis is a free download for your phone or tablet. It connects to home monitors to give you spirometry tracking, pulse oximetry tracking and much more, including medication alerts and a health diary.

Keeping track of your Pulmonary Fibrosis is crucial to maintaining your health. It allows you and your doctors to see if your Pulmonary Fibrosis is stable, how well you are responding to treatment, and assess the next steps for your care and treatment, empowering you to live better with IPF.

With the funding we have received through the IPF Catalyst Challenge we are working on the next updates for the patientMpower app. After discussions with lung fibrosis specialists, we will be developing our platform so that doctors with patients using the patientMpower app at home will be alerted to unusual results in their patients' lung health information, hopefully preventing problems before they get worse. We will also be adding air quality alerts to the app, as well as using location services to give people the opportunity to link in with other people with IPF in their area.

We are always looking to evolve our app so we can empower patients to live better with pulmonary fibrosis. If you have ideas, we want to hear from you! Please contact us on: info@patientMpower.com. If you are not already using patientMpower it can be downloaded for free from our website www.patientmpower.com.

Report by Colin Edwards

AIR Meeting 2017

Nicola Cassidy (ILFA) and Professor Venerino Poletti from Italy.

Liam Galvin and Nicola Cassidy at AIR 2017.

The meeting was chaired by Professor Athol Wells from the United Kingdom and Dr Molina-Molina from Spain who presided over a day and a half of excellent presentations, debates, and lively discussions with some of the world's leading experts in the field. Here are some of the highlights from the meeting.

Professor Thomas Geissler from Austria gave an overview of the pathophysiology of IPF and discussed the underlying factors and natural age-related changes that occur at a cellular level in the lung which may influence the development of fibrosis. Lung fibrosis starts when the normal repair mechanism in the lungs goes out of control and scar tissue forms.

Professor Gisli Jenkins from the United Kingdom discussed the interaction between genes and environmental factors that could contribute to IPF. There is no single cause for IPF – multiple factors lead to the development of the condition. And there is no single gene responsible. Going forward, having clinically useful biomarkers (biological measurements that can enhance our understanding of IPF, for example, lung function tests, CT scans, and measurements of biological molecules) may help the development of new drugs that will potentially target the cells in the lung that drive fibrosis. Biomarkers will also help determine if medication is working for an individual.

Dr Simon Walsh from the United Kingdom discussed recent developments in the use of CT imaging to diagnose IPF. Approximately 50% of patients do not have typical findings present on the CT scan of their lungs, which can make a diagnosis more challenging. Radiologists (doctors who read x-rays and CT scans) take the patient's age, pattern of honeycombing (if present) and severity of fibrosis into account when determining if they have an ILD or a different lung abnormality. Computer technology for interpreting CT scans is being developed but this emerging technology will not replace the specific expertise and experience of trained respiratory radiologists.

Professor Athol Wells from the United Kingdom spoke about the diagnostic criteria used by the multi-disciplinary team (MDT) to reach a working diagnosis of IPF. IPF is difficult to diagnose. IPF is only diagnosed once all other interstitial lung diseases have been excluded (there are over 200 different types of ILD). The MDT must use their experience, clinical reasoning and evidence-based medicine to reach agreement on the diagnosis of IPF. Cryobiopsy (taking lung biopsies using a special frozen apparatus) has a useful role to play in supporting a diagnosis of IPF.

Professor Wym Wyts from Belgium addressed the challenges of treating patients with anti-fibrotic medications due to potential side-effects. It is important to educate patients, to manage their expectations, and support and encourage them to continue with treatment especially if they experienced medication side-effects. Patient education should focus on the prevention of side effects, making medication dose-adjustments if required, and the need to persist with the treatment.

Nicola Cassidy (ILFA) was invited to deliver a presentation entitled "Should all patients with IPF be treated immediately on diagnosis?" Nicola spoke about the different domains that are necessary for the optimal treatment of IPF (1) pharmacological treatment with antifibrotic medicines, (2) non-pharmacological treatments for example, pulmonary rehabilitation and oxygen (3) surgical treatments – lung transplantation (4) palliative care which addresses symptom management and end-of-life care. Nicola included several patient stories that highlighted some shocking experiences of poor communication and inadequate treatment reported by patients to ILFA. To ensure optimal treatment, patients must be partners in their care plans. Mutual trust between patients and healthcare staff is essential and must be achieved through good communication, open and honest education and understanding what values are important to patients and their family.

Anne-Marie Russell from the United Kingdom spoke about the cancer-care model of palliative care and whether this should be applied to IPF care. Palliative care aims to support patients and help them manage their symptoms over the course of their illness and not just at the end-of-life. Palliative care is well established for cancer patients but much less so for IPF patients, however this is changing. Discussions on the role of palliative care should be introduced and explained soon after the diagnosis of IPF as it is a progressive condition. Healthcare professionals need to educate patients and their families about the benefits of palliative care and taking a holistic view to their care and symptom management.

Liam Galvin (ILFA and the European IPF Federation (EU-IPFF)) spoke about the role of the EU-IPFF and its work supporting healthcare professionals and patients in Europe and globally.

The Barcelona AIR Conference was highly educational. Sincere thanks to the Co-chair, Professor Athol Wells, for championing the patients and carers perspectives and inviting ILFA's participation over the last 5 years.

Raising awareness among General Practitioners

Idiopathic Pulmonary Fibrosis (IPF) is a relatively rare medical condition and on average a General Practitioner (GP) may only treat up to three patients with IPF in their career lifetime. Therefore, education about IPF aimed at GPs and primary care providers is vital.

Towards the end of 2017, ILFA facilitated two important educational activities for GPs and healthcare workers in primary care to raise awareness of IPF and highlight the signs and symptoms of the condition, the tests and investigations needed to help reach a diagnosis, and treatment of the condition.

An educational article entitled ‘Considerations when evaluating the breathless patient: might your patient have Pulmonary Fibrosis?’ featured in the February edition of Forum - the Journal of the Irish College of General Practitioners. The article was co-written by Lynn Fox (Respiratory Nurse Specialist), Dr Alan Kelly (Medical Registrar) and Dr Kate O’Reilly (Respiratory Consultant) at the Mater Misericordiae University Hospital.

Secondly, Dr Emmet McGrath (Respiratory Consultant at St Vincent’s University Hospital, Dublin) filmed a series of video tutorials about IPF that are currently hosted on the GP-Buddy website; an online web-platform for GPs. Over 80% of GPs in Ireland are registered with GP Buddy and the video tutorials will be promoted as an educational activity on the website for one-year. Over 900 GPs watched the videos in the first month of its release.

ILFA is very grateful to everyone who helped us with these important educational activities for general practitioners.

Participants at the IPF Study Day (photo courtesy of Roche Products Ireland).

IPF Study Day

ILFA attended the 4th annual Idiopathic Pulmonary Fibrosis Study Day, organised by Roche Products Ireland, in Limerick on 16th February.

The event was well attended with clinicians and healthcare professionals from the UK and all over Ireland present. There were excellent presentations, clinical case discussions and interactive sessions on the early diagnosis of IPF, treatment of IPF, the management of cough, shortness of breath, fatigue, and the important role of palliative care.

Nicola Cassidy from ILFA gave a presentation entitled ‘The Patients’ Perspective’ which highlighted ILFA’s work, patient priorities in IPF, and the difficulties faced by some patients accessing appropriate IPF treatments.

Irish Thoracic Society meeting

Nicola Cassidy, Professor Paul Cullinan, Imperial College, National Heart and Lung Institute and Royal Brompton Hospital London, and Gemma O’Dowd.

Brian Fitzgibbon (Integrated Care, Kilkenny), Eilis Gleeson (Respiratory Nurse Specialist at Limerick University Hospital) and Paula Ryan (Advanced Nurse Practitioner at Limerick University Hospital).

The Irish Thoracic Society Meeting took place in Limerick on 10th and 11th November 2017. ILFA had an information stand at the event and we had a steady stream of visitors call by.

Nicola Cassidy, ILFA Director, presented two posters at the event. Firstly, the results of ILFA’s research entitled ‘Patient perspectives on the use of a hand-held fan to relieve breathlessness in Interstitial Lung Disease’, and secondly the results of the patientMpower study entitled ‘A longitudinal approach to supported self-management: sustainability of the idiopathic interstitial pneumonia electronic health journal (patientMpower) with integrated home spirometry.’

Thank you to everyone who helped ILFA with this valuable research.

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When I had my double lung transplant after being diagnosed with IPF, I knew immediately that I wanted to do something to give back, and sport came to mind. Three days after my 8-hours operation, I was out of bed and walking the corridors. During my recovery, I asked Irene, my physiotherapist, about getting back to fitness and she gave me good advice. A cousin visited me and said he was going to do a marathon to fundraise for the Mater Hospital. I asked, “why can’t I?” and a seed was planted. I was discharged from hospital after 13 days and remember feeling so thankful, so happy, so cautious and scared.

I spent a few months in isolation around the house to protect myself from picking up infections and I was minded like a king. I started to go to Dun Na Ri, our local forest park, for walks and it felt great. I couldn’t believe that after all my health worries and sleepless nights, I was out and about again. It put a lot of things into perspective for me. Something so simple as to being able to breathe fresh air into my lungs without needing an oxygen tank, being able to walk a few steps and not feel breathlessness, watch my children play, and know that I could look forward to more good days.

Because of my sporting background, I decided to take on one of the hardest challenges - a marathon! All I wanted to do was honour my donor. I felt I could maybe help someone in a similar position and show people what can be done with positivity and hard work. Great things are possible if you really put your mind to it.

My wife and I had lived in New York, so we decided to sign up for the New York marathon - one of the biggest and best in the world. Soon my mum, cousins and friends, inspired by my enthusiasm, asked to join us on this amazing journey. A team of fourteen signed up for the challenge. All the money raised went to charity and all expenses; flights, hotel race entry etc. were paid by the runners themselves. To reach our fundraising target, we organised some fundraising events; we set up a running group for people in our town, held bucket collections at county football games, held a golf classic, and set up cyclathons in local supermarkets. We had amazing support and I knew we would reach our fundraising target due to the goodwill, kindness and generosity shown by everyone.

I had a training plan for the marathon and set myself 4 goals. My first challenge was a five-mile run in Clontarf which I did eight months after my lung transplant. My second challenge was a 10km run, roughly one-year post transplant. We organised the 10km race in our town. It was an emotional day for all involved. How things had changed in a year! My third challenge was the Rock ‘n’ Roll half-marathon in Dublin. Finally, all that was left was the big one; the marathon - 26.2 miles. My training started in January and progressed from daily walks to easy jogging, gradually increasing the distance.

There was great excitement as marathon day approached. The 14-strong team met on Friday 3rd November at Dublin airport, kitted out in our team tracksuit. Once we landed in the Big Apple, I had to rush from JFK Airport to get to Central Park in New York as I was chosen to be the flag bearer for Ireland. What an amazing feeling; I was so privileged to represent my country at the opening ceremony of the marathon in Manhattan. It was a moment that will always stay with me.

Soon ‘Marathon Day’ was here, and we were ready! Everyone was in high spirits and excited as we travelled by bus, through the streets of Manhattan, over to New Jersey where we got a fantastic view of the New York sky-line. We lined up at the race start, got our photos taken and wished each other good luck. Myself, my wife Katie, my mum Kathleen, cousins, and friends; David Mc Nally and Andy O’Brien all took off together. A large boom from a cannon signalled the start of the marathon, followed by Frank Sinatra singing “New York, New York”. The atmosphere was electric, and my dream was being realised.

Everyone has their own way of completing a marathon; I jogged and walked. I had to listen to my body. I stopped when my breathing felt under pressure and I didn’t run up hills as I felt it was too much for my lungs. I was humbled when my two friends David and Andy said they would complete the marathon alongside me. They gave up their race time to make sure I got mine. Andy kept me positive and reminded

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me of why we were here and what I had achieved. David was beside me with a back-pack of medical supplies; he could have kept a small town healthy! We had our names on the front of our running tops and people were shouting words of encouragement shouting “Go on David” - I felt like a celebrity. Printed on the back of my top was my story – a double lung transplant recipient, running the marathon to honour my donor. Participants along the way gave me high fives, claps on the back, kind words and encouragement. Most were in disbelief that a double lung transplant recipient was running a marathon. When we got to the 8th mile, David asked how I was. In truth, I was finding it tough and feeling sick. Everyone talks about hitting ‘a wall’ when doing a marathon. It’s usually around 18-20 miles but I felt I was hitting mine now. David suggested a cup of tea would might be in order! I looked at him and said, “Where the blazes are we going to get a cup of tea in the middle of a marathon?” But he headed off saying he would catch up. Half a mile later he arrived with a paper cup of herbal tea! I wasn’t sure if should take that kind tea, but as a pharmacist he said one or two sips would be fine to settle my stomach. He was right. I felt better, got a second wind and pushed on.

Seeing my family and friends at 13-miles gave me a huge lift and inner strength. As we progressed, the going was a little harder and my legs were feeling heavy. I did have doubts but I was on a crusade with my team to do something that nobody else in my position had done. I had a finish time in my head - 6 hours and 4 minutes as it was 604 days from my transplant to the marathon. I knew it really didn’t matter. I was struggling but I put my head down and started thinking of all the people who came with me, my family, people in our running group, and those who gave me so much support during the year. It’s overwhelming the strength you get from people’s positivity and encouragement. So, I started to power walk and found that I was walking as fast as many of those running. At 24 miles, we came to Central Park and were greeted by family and friends once again. David Mc Nally had notes that my children had written to give me encouragement if I was struggling. I gave him a look and he quickly said “I know you’re not struggling but take them so the kids will be with you as you cross the line. So, I did, and a half mile later I read them. I will remember forever the feeling I had after reading them - that I was so lucky to have three amazing children and it was they who inspired me to be here.

I also thought of the people I met on my journey, the wonderful doctors, nurses, patients, people at home rooting for me, my donor, my sister, my mam and dad, my two brothers and sister who didn’t make it due to lung disease, my children and the one person who was there with me every step of the way - my wife, Katie. With the finish line in my sights, I looked back on what was an amazing 604 days for me. I wasn’t going to make the time I had in my head, but it didn’t matter. I knew I was doing something more important, I was finishing strong. At last it was there, the finish line. My wife ran to me and gave me a big embrace. Out of somewhere my mother also appeared and hugged me – some things are priceless.

As I received my medal, I bent my head down with such pride. I was smiling because I knew that I had pushed myself as far as my body could go and that my new lungs were the reason for that.

Report by David Crosby

ILD-INN Conference 2017

The Interstitial Lung Disease Inter-Disciplinary Network (ILD-INN) conference took place in Birmingham on 8th and 9th of October 2017 with over 100 respiratory professionals and patient representatives participating.

Liam Galvin, Gemma O’Dowd and Nicola Cassidy from ILFA attended the conference. In addition, ILFA awarded four educational bursaries to allied healthcare professionals in Ireland to attend the event. The recipients of ILFA bursaries were Petra Grehan and Irene Byrne (senior physiotherapists at the National Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital, Dublin), Eimear Griffin (physiotherapist at Portiuncula Hospital, Galway), and Maria Love (medical social worker at the Mater Miseridordiae University Hospital, Dublin).

Feedback from Maria Love

Maria Love, Eimear Griffin, Petra Grehan and Irene Byrne.

I would like to sincerely thank ILFA for awarding me a bursary to attend the ILD-INN conference which was highly informative. I was especially interested in the research presented on supporting patients and families, and the role of palliative care.

Palliative care was described by one speaker as ‘living as well as possible, for as long as possible’; she later acknowledged that while most ILD patients may have palliative care needs associated with managing symptoms or psychosocial distress at some stage during their illness, specialist palliative care input for all may not be necessary. Many speakers discussed the importance of social support, social interactions, support groups and self-care for patients, carers and professionals working in ILD, and all acknowledged that anxiety is common and important to manage.

Another interesting lecture discussed the role of spirituality in coping with ILD. While the speaker acknowledged that spirituality or religion may have different meanings for different people, she described it as ‘about living the way you want and not just about the way you die’. She approached spirituality as a framework of values by which to understand life, a way of expressing what’s important to the person and a source of comfort. She posed two interesting questions – “What are your sources of comfort and hope? What helps you in difficult times?” – questions for us to ponder and perhaps provide solutions or insight in difficult times.

It was a privilege to attend this conference on a professional and personal level. It was educational and inspiring to meet so many people passionate about advancing care for patients and families.

Thanks from Eimear Griffin

“ILFA, thanks very much for the opportunity to attend the conference in Birmingham. It was a valuable occasion to meet with fellow colleagues working in this area. The information sharing was excellent.”

A Report from Petra Grehan

Thanks to the bursary awarded by ILFA, I attended the ILD-INN conference in Birmingham. It was two days packed with information, experience sharing and networking among a great group of devoted healthcare providers.

All the speakers were extremely experienced and shared with us enthusiastically what they were doing in their centres. Dr Kathleen Lindell travelled from the USA to speak about a patient-centred support group established where she works and how it functioned as a learning and social support to individuals with pulmonary fibrosis. It struck me how similar the group is to the local ILFA support groups and demonstrated how people are living full and active lives despite their diagnosis. I found the patient stories inspiring. I hope that I can use what I’ve learned to contribute to ILFA and their members in the future.

Thanks from Irene Byrne

I am very grateful to ILFA for the opportunity to attend the excellent ILD-INN conference and learn from, meet and liaise with a wide range of professionals working in interstitial lung disease. This conference facilitates practical education and valuable peer interactions and helped me broaden my understanding of patient care, symptom management and end-of-life care, and share the excellent work being done here in Ireland.

New General Data Protection Regulations (GDPR)

New European wide legislation on GDPR will be introduced on May 25th, 2018. Under GDPR, all organisations and businesses must ensure they meet their obligations for processing and safeguarding personal data and follow good data privacy practices.

Personal data is defined as any information that can be used to identify an individual, for example, if you receive ILFA’s newsletter by post, you will have registered to join our mailing list. ILFA keeps a record of your name, address, email address and telephone number on file for the purposes of sending newsletters and occasional correspondence about ILFA’s activities, news and events. ILFA does not share your personal data with any third party.

Gemma O’Dowd and Nicola Cassidy from ILFA attended a training course entitled ‘Get ready for GDPR’ on 20th November at Carmichael House in Dublin to learn more about the process and ILFA’s obligations. ILFA is working to ensure we meet our data protection responsibilities, are GDPR compliant, and our policies and procedures relating to data processing activities are up to date. If you would like your personal data removed from our mailing list, please contact ILFA and we will arrange this for you.

Please call 086 871 5264, email info@ilfa.ie or write to ILFA, PO Box 10456, Blackrock, Co Dublin.

Fundraising Round Up

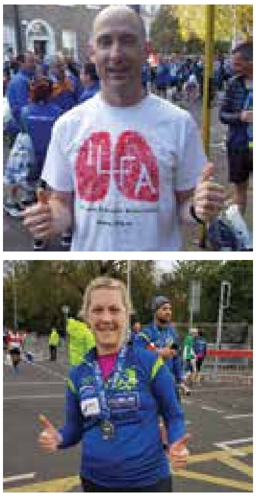
'A Taste of Salamanca' Book Launch

Congratulations and thank you to Caroline Boyle (Salamanca Tapas Bar) in Dublin, who launched her new book 'A Taste of Salamanca' in December 2017. Caroline generously donated €3 from every book sold on the night to ILFA and this amount was matched by their sister restaurant - Mexico to Rome - in Temple Bar, Dublin. The fantastic sum of €1,000 was raised for ILFA.

Gemma O'Dowd and Nicola Cassidy from ILFA were invited to attend the book launch and enjoyed great company and delicious food, and had the opportunity to meet Caroline, her colleagues, friends and family including her brother, Mayo GAA All Star Colm Boyle. Caroline chose ILFA as her charity partner after losing her beloved dad, Edward Boyle, to IPF.

Picture shows: Colm Boyle, Gemma O'Dowd, Caroline Boyle and Nicola Cassidy at the launch of 'A Taste of Salamanca.'

Dublin City Marathon



From top: Anthony Walsh and Joanne Smith

Huge congratulations to Joanne Smith and Anthony Walsh who ran the Dublin City Marathon at the end of October to raise funds for ILFA. Joanne took part to raise funds in memory of Tina Killeen and said "It was a pleasure to run my first Dublin City Marathon for ILFA". We are also extremely grateful to Anthony for once again fundraising for ILFA and taking on the 26 miles and 385 yards running challenge to raise valuable funds to support IPF patients.

Well done and thank you both for all your hard work!!!

ILFA Annual Swim

The annual ILFA Swim took place on New Year's Day at Sandycove Pier in Dublin. There was a superb turnout at the event despite the chilly temperature. Thankfully the winter conditions didn't deter the loyal swimmers who were cheered on by lots of supporters. The swimmers included Professor Jim Egan, Michael Maguire, Andrew Cooper, Giles Keane, and Tabby and Barry Prendiville.

The supporters included Valerie and Morris Burris, Helen, Joe and James O'Connor, Karen and Peter Keeley, Chris Meehan, Gerard McDonnell, Guy Prendiville, Avril Paterson, Evelyn Cooper, James Kavanagh, Honora Ni Chrioghain, Giles Bailey and Vera Murtagh. ILFA representatives included Nicky Goodbody, Marie Sheridan and Gemma O'Dowd. After the swim, everyone adjourned to Fitzgerald's Pub in Killiney for some welcome soup, teas and coffees!

Well done and thank you to everyone who took part.

Photos, clockwise from top: Marie Sheridan, Chris Meehan, Avril Paterson, Andrew Cooper, Evelyn Cooper, James Kavanagh and Nicky Goodbody; Barry Prendiville; and Honora Ni Chrioghain and Giles Bailey.

Analog Devices International

Pictured are Denis Doyle (Vice President & General Manager, Manufacturing, Analog Devices), Martin Troy (ILFA), Mary Lou Flynn (Manufacturing team member) and Leo McHugh (Vice President, Industrial Business Units).

In December, Analog Devices International, Raheen, Limerick presented ILFA with a cheque for €1,000 as part of their Community Awards Programme. Mary-Lou Flynn kindly nominated ILFA for the award, in memory of her late father, John Walsh. Martin Troy (ILFA committee member) visited the home of Analog Devices in Limerick on 21 December to receive the cheque. Thank you to Mary-Lou and everyone at Analog Devices for this wonderful donation.

A Christmas surprise for Noreen

Steven and Noreen Carroll and Nicola Hurley.

In December, Steven O'Carroll and Nicola Hurley set up a Facebook fundraising campaign to raise funds for ILFA. Steven's Mum, Noreen was diagnosed with IPF in 2015 and she has been a great friend to ILFA since then. Noreen is a great advocate of positive thinking, has taken part in a mini-marathon to fundraise for ILFA and spoke at ILFA's Patient Information Day in Sligo in 2017. Noreen is also the leader of the Mid-West IPF Support Group and starred in a 'Fight IPF' video in 2017.

Steven and Nicola shared Noreen's video on social media to raise awareness of IPF. They set an initial fundraising target of €500 but were delighted to raise the amazing total of €5,842.94 - more than 10 times their original target, thanks to the amazing generosity of their friends and family!!!

Noreen was completely taken by surprise when Steven and Nicola told her of their fundraising project and presented her with a giant cheque at Christmas.

Noreen, Steven and Nicola travelled to Dublin in January to present the cheque and additional donations to Eddie Cassidy, ILFA's Chairman. Thank you to Steven, Nicola, Noreen and everyone who donated so generously.

Eddie Cassidy (ILFA Chairman) with Noreen and Steven O'Carroll and Nicola Hurley.

Santa Dash 2017

The annual Santa Dash race took place on Sunday 3rd December on Dollymount Strand in Dublin. It was a great day and over 1,000 Santas of all ages gathered together to have fun while raising money for worthy causes. Annette Grehan and Nicola Cassidy (aunt and niece duo) took part for ILFA in memory of their sister and mother, Denise Cassidy. The weather was perfect, and everyone had a great time running first to the South Pole, then dashing to the North Pole and sprinting to the finish line.

Nicola Cassidy and Annette Grehan

Coffee Morning and Cake Sale

Huge thanks to the Meaney Family from Co Clare who held a very successful coffee morning and cake sale in aid of ILFA in memory of their uncle Gary Baker.

The family went to amazing lengths to bake delicious cakes and sweet treats and organised a beautiful display for their cake sale. Sincere thanks to all the Meaney family and their supporters!

Pictured are Susan Lordan, Rory Meaney, Oscar Lordan, Maria Meaney and Monica Flannery.

Thank you

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.

Margaret Maloney Memorial Darts Tournament

The fourth annual Margaret Maloney Memorial Darts Tournament took place on Saturday 30th September 2017 at The Central, Roscrea, Co Tipperary. Thank you to the Maloney Family and the organising committee for once again hosting another hugely successful and entertaining fundraiser in aid of ILFA. The fantastic sum of €2,800 was raised and a cheque was presented to Martin Troy from the ILFA committee.

News headlines!

ILFA members Lynn Fox, Marie McGowan, Eddie Cassidy, Gemma O'Dowd, Pam and Liam Martin and Nicola Cassidy arrived at Dublin airport at 4am on 9th November to surprise David Crosby and his 14-strong marathon team home after taking part in the New York Marathon. Eleanor Mannion from RTE News also came to the airport to cover the amazing story.

ILFA members surprise David Crosby at Dublin airport; Nicola Cassidy, Lynn Fox, Gemma O'Dowd, David Crosby, Eddie Cassidy, Pam Martin and Marie McGowan.

Gemma O'Dowd, Prof David Healy, Nicola Cassidy, David Crosby, Katie Crosby and Eddie Cassidy.

Prof David Healy, Katie Crosby, David Crosby and Prof Jim Egan.

David was diagnosed with IPF in 2015 and received a double lung transplant in 2016. After his transplant surgery David set himself the incredible challenge of training for the New York marathon and fundraising to honour his donor and support research and patient charities. The coverage at Dublin airport featured on the 7.30am, 1pm, 6pm and 9am RTE News programmes and helped create great awareness.

David and Team Crosby raised an amazing total of €60,700 for their marathon efforts. On 5th February, David and Katie presented cheques to ILFA, Cystic Fibrosis Ireland and the Mater Foundation at the National Lung Transplant Unit at the Mater Misericordiae University Hospital.

We are so grateful to David for helping raise awareness of IPF and organ donation and are inspired by his wonderful achievements, positive attitude and enthusiasm. Mile buiochas!

The Marina Inn, Dingle

Martin Troy from the ILFA committee was presented with a cheque for €2,850 from the proprietors of the Marina Inn (Dingle, Co Kerry), Maurgerite and Jackie Kavanagh, and their family and staff.

The Marina Inn is a very popular spot on the food trail of the Dingle Food and Wine Festival which takes place on the first weekend of October and each year the Kavanaghs generously donate the proceeds from their involvement to charity.

As neighbours and close family friends of lung transplant recipient John P. O'Sullivan, Maurgerite and Jackie were aware of the great work ILFA does and chose it as the 2017 beneficiary.

Back row: Micheál Kavanagh, Tom Kavanagh and Karina Kavanagh (The Marina Inn), John P. O'Sullivan and Joan O'Sullivan, Martin Troy (ILFA)
Front Row: Áine and Méabh Ní Dhúbhda

Killeen Family Fundraiser

Thank you to the Killeen Family and the Sarsfield Racing Pigeon Club who organized a fundraiser in memory of Tina Killeen who passed away in 2017. All funds were donated to ILFA and the fantastic sum of €3,480 was raised.

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, Pam on 086 178 9055 or Paddy on 087 412 8612 for more details.**

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at the Fels Point Hotel. **Please call Adrian on 087 241 4004 or 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.**

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

086 871 5264

Messages of condolences

ILFA would like to offer our sincere condolences to the families and friends of two great patient advocates, Dermot King and Anthony Marnell, who positively affected the lives of those with whom they came in contact.

Dermot King from Portmarnock, Dublin sadly passed away in February 2018. Dermot was a very special, modest, gentle man with a warm smile, who will be greatly missed by his Dublin support group pals. Dermot was always willing to share his experiences and help others, especially those coming to terms with their illness. Dermot generously volunteered to help ILFA raise awareness of IPF on many occasions; he starred in two information videos with the Minister of State Finian McGrath T.D., he featured in the ILFA Exercise DVD for Lung Fibrosis Patients, and the National Patient Charter for IPF booklet. Dermot spoke at an IPF Study Day, he was interviewed on two radio shows and he met with the HSE's Respiratory Therapies Group to highlight the difficulties faced by IPF patients dependent on oxygen.

Anthony Marnell from Mountmellick, Co Laois sadly passed away in December 2017. Anthony was one of the co-founders and leaders of the Midlands Support Group. Anthony was a great source of strength and support to everyone in the support group and to the many people he met at various ILFA events around the country. Anthony also helped with the many fundraising events organised by the Midlands support group over the years. Anthony was held in highest regard by all those who knew him.

Our friends Dermot and Anthony will be greatly missed. May they rest in peace.

Dates For Your Diary

Healthcare professionals

- **The European Respiratory Society Congress will take place from 15th to 19th September in Paris. Please see www.erscongress.org**
- **The Interstitial Lung Disease Interdisciplinary Network (ILD-INN) Annual Conference will take place on 7th and 8th October in Birmingham, UK. Please see www.ild-inn.org.uk**

Fundraising

- **VHI Women's Mini-Marathon will take place on Sunday 3rd of June at 2pm. Register on-line at www.womensminimarathon.ie**
- **The Great Limerick Run will take place on May 6th 2018.**
- **The Cork City Marathon will take place on Sunday 3rd June 2018.**
- **The Dublin City Marathon will take place on Sunday 28th October 2018.**

Contact ILFA on 086 871 5264 or email info@ilfa.ie to request your fundraising pack.

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.