ILFA Newsletter

Patrons: Brian O'Driscoll, Charlie Bird, Feargal Quinn, Andrea Corr.
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Irish Lung Fibrosis Association
www.ilfa.ie

ILFA's Patient Charter wins a National Award

ILFA is delighted to announce that The National Patient Charter for Idiopathic Pulmonary Fibrosis won the prestigious 2016 Plain English Award for Best Patient Information Leaflet. Plain English is a style of presenting information that helps you understand it the first time you read or see it. It involves short clear sentences, and using everyday words and imagery.

The award from the National Adult Literacy Agency (NALA) means a lot to ILFA as we have long supported the need for clear and concise health information and effective communication. In fact, one of the six principles of The National Patient Charter calls for clear and concise information about Idiopathic Pulmonary Fibrosis (IPF) in plain language.

The Plain English awards ceremony took place on Thursday 9th February in the beautiful surroundings of the President's Hall at the Law Society in Dublin. The Master of Ceremonies was John Murray, RTE radio presenter and advocate of plain English. ILFA was represented at the event by Matt Cullen, Anne Casey and Nicola Cassidy (ILFA Director). Matt and Anne represented IPF patients and their carers respectively, who are at the heart of The National Patient Charter.

The awards ceremony was very inspiring and uplifting, and it was great to meet so many people who also support effective communication through plain English. The National Patient Charter for IPF was complimented by the judges for its layout, colour coding of chapters, and the clear communication of complex medical information. The judges said "the charter won because it empowers patients to become partners in their healthcare by informing them of available services and supports."

Pictured are Anne Casey, Matt Cullen and Nicola Cassidy receiving the award from Declan Black, Managing Partner at Mason Hayes & Curran, who sponsored the NALA Plain English awards.

Patient Information Day

The next ILFA Patient Information Day will take place on Saturday 22 April at the Clayton Hotel, Clarion Road, Sligo. The speakers will include Dr Emmet McGrath - respiratory consultant from St Vincent's University Hospital, Dublin, Lynn Fox - respiratory nurse specialist from the Mater Misericordiae University Hospital, Dublin, Tara Hannon - respiratory physiotherapist from University Hospital Galway, and Vivienne Vize and Zita Lawlor - lung transplant coordinators from the Mater Misericordiae University Hospital, Dublin. Noreen Carroll, a patient from Tipperary, will also speak at the event.

Registration will start at 10am and the meeting will end at approximately 1pm. Light refreshments will be served afterwards. All are welcome. **Please contact ILFA by phone on 086 871 5264 or email info@ilfa.ie if you would like more details.**

ILFA Celebrating 15 years

The Irish Lung Fibrosis Association (ILFA) was set up in November 2002 in memory of Fergus Goodbody by his wife Nicky Goodbody, along with good friends Terence Moran (ILFA Chairman) and Marie Sheridan (former Treasurer), and Professor Jim Egan from the Mater Misericordiae University Hospital in Dublin and others. The charity was founded to support those affected by lung fibrosis and to facilitate research and education. Since its humble beginnings in 2002, ILFA has gone from strength to strength thanks to the dedication of everyone who has served on the committee over the last 15 years, the clinical, research and administrative assistants who have worked for ILFA, and the many healthcare professionals, fundraisers and members who have supported ILFA so loyally.

ILFA is delighted to be celebrating the remarkable achievement of reaching our 15th anniversary in 2017. To celebrate this important milestone, ILFA will produce a special edition magazine for the autumn that will focus on some of the major achievements in IPF research and patient care over the last 15 years. If you would like to contribute a positive story, a poem, or a few words about your achievements for the special edition magazine, please get in touch. You can call ILFA on 086 871 5264 or email info@ilfa.ie.

Pictured are ILFA Directors; Professor Jim Egan with Professor Jurgen Behr from Munich, Terence Moran (ILFA Chairman) and Nicky Goodbody.

Advancing

The 6th AIR meeting took place in Vienna, Austria on 18th and 19th of November and brought together over 300 respiratory healthcare professionals from across Europe. This unique meeting focussed on recent developments in interstitial lung disease (ILD) and idiopathic pulmonary fibrosis (IPF) and some of the world's leading experts in this field shared their insights. The meeting was chaired by Professor Athol Wells from the United Kingdom and Professor Carlo Vancheri from Italy.

The meeting got off to a great start as **Professor Bruno Crestani** from France discussed recent developments in our understanding of what factors contribute to IPF at a cellular level. The cells in the lungs are particularly susceptible to damage due to breathing in contaminated air, chemicals, particles, cigarette smoke, bacteria and viruses. Lung fibrosis starts when the normal repair mechanism in the lungs goes out of control and scar tissue forms. Recent research has examined the increase of some biological molecules when experiments that physically 'stretch' lung cells are carried out. Going forward, some of these biological molecules could be potential research targets.

Professor Wym Wyts from Belgium discussed developments in oxygen treatment, pulmonary rehabilitation and anti-reflux therapies. Research confirms that these elements are vital to help patients maintain their quality of life and improve symptoms. He concluded his presentation by announcing that hope is on the horizon as more studies on Patient Reported Outcome Measures (PROMS) are being conducted to help assess, improve and maintain quality of life.

Professor Carlo Alberra from Italy described the latest research on the benefits of the anti-fibrotic medicines, Perfinidone and Nintedanib, for patients with IPF. Both medicines can preserve lung function although they work by different mechanisms. He also discussed some of the new drugs being investigated. There are currently 8 IPF drug trials underway and hopefully there will be positive results in the coming years.

Professor Martin Kolb from Canada discussed the latest advances in diagnostic techniques. A biomarker is any biological measurement that can enhance our understanding of a medical condition, for example, lung function tests, CT scans, and measurements of biological molecules. In order to be useful, a good biomarker should be involved in the disease mechanism, reflect disease severity (to help inform the prognosis), and the results of the measurements must be reproducible, sensitive and specific. Prof Kolb spoke about some of the genetic biomarkers that are currently under investigation but stressed that biomarkers are not yet ready for use in the treatment or prognosis of IPF.

Professor Sara Tomasetti from Italy spoke about cyro-biopsy as an important and emerging technique for taking lung biopsies. This technique is fast, easy to use and involves freezing samples of lung tissue to minus 80 degrees Celsius. The lung tissue that is taken can subsequently be prepared for examination under a microscope. Major drawbacks to this technology include the lack of a standard protocol for the technique and the number and size of biopsies needed to give a clear picture of the lung architecture. Complications can occur for example, there is a risk of bleeding and infection.

Professor Athol Wells

Dr Simon Walsh from the United Kingdom spoke about the challenges facing radiologists (doctors who read x-rays and CT scans). Radiologists assess images of the lung tissue to identify areas of honeycombing – a distinct pattern, similar to the inside of a 'crunchie' bar, and subtle changes called 'ground glass opacities' that are associated with IPF. New technologies including computer analysis of CT scans are coming and will help the multi-disciplinary team diagnosing IPF, however this technology cannot replace the specific expertise and experience of trained respiratory radiologists.

Professor Vincent Cottin from France spoke about the difficulties of accurately diagnosing IPF. A correct diagnosis is important as it impacts on the patients' treatment, the use of anti-fibrotic medicine, and the disease prognosis. For a significant proportion of patients, a 'working diagnosis of IPF' is given as it is very difficult to classify the disease fully without all the results (for example, if a patient does not have a lung biopsy).

Professor Athol Wells talked about the different stages of IPF – early and advanced disease. He highlighted the need to incorporate a measurement of exercise to help patients as they can struggle to understand the severity of their disease in medical terms. He encouraged the audience to have in-dept discussions with their patients to decide on the best treatment for them. There is no 'one-size-fits-all' approach for IPF.

Professor Jim Egan from the Mater Misericordiae University Hospital in Dublin gave a state of the art lecture on Lung Transplantation. He described the low level of lung transplants across Europe as an unmet patient need. The question he is asked most frequently concerns a patient's age and if they are eligible for a lung transplant. Prof Egan believes that every patient should be considered for a transplant provided that they have good general health (apart from their IPF). Patients should have a strong heart, good kidneys, an acceptable body weight, and a willingness to take part in exercise and pulmonary rehabilitation classes to maximise their exercise tolerance. He challenged the audience of doctors to speak with the local lung transplant centres in their countries and to engage with the transplant surgeons on

in IPF Research (AIR)

as been a busy year in IPF
vances in our understanding of IPF pathology
pe for symptom-centred non-pharmacological therapies
citing new data on pirfenidone, nintedanib and FG-3019

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perience highlights the complexity of making differential diagnoses

ng patients a voice in a consensus documents, and addressing

Professor Geisler, Anne-Marie Russell, Gunter Wanke and Nicola Cassidy.

behalf of their patients. Internationally, 40% of all lung transplants should be performed in IPF patients but some surgeons are nervous about operating on older adults (those aged over 65 years). This mindset needs to change. Lung transplantation is completely life-saving for patients with IPF and the survival outcomes are improving all the time.

Professor Marlies Wesenbeek from the Netherlands spoke about managing patients diagnosed with IPF using the “A-B-C-D-E” approach.

A = assess the patient’s needs
B = back up the patient and give them support
C = comfort care – this term refers to managing patients’ symptoms. For example, the treatment of cough was discussed. Cough can be a very debilitating symptom and one study showed that patients cough on average 60 times every hour. More research on cough is needed.
D = disease modifying drugs for example the medicines Perfinidone and Nintedanib
E = end of life discussions

Professor Wesenbeek told that audience that well informed patients can make realistic choices regarding their care. It is important for doctors to speak openly with patients to help them make decisions that reflect their values.

Dr Toby Maher from the United Kingdom described a study where 50 patients used simple spirometry devices at home to see if this technology could help predict disease progression. Patients received training in how to use the device and they were asked to blow into the machine once a day and record the result in a diary. Patients were asked to contact the hospital if the result had decreased by 10% over 3 days. The results between the home devices and the hospital equipment showed similar patterns although the readings did not match exactly. Some patients could not complete the study due to the development of a problematic cough when using the machine. Overall, the study showed that home monitoring is helpful, however larger studies are needed to verify the findings.

Dr Maria Molina-Molina from Spain described the treatment of familial IPF - when two or more members of the same family have an interstitial lung disease. She also stressed the importance for doctors and nurses to take a detailed medical history from patients and to ask about the health of other family members. It is important to ask about the entire history of family members on a few different occasions in case new information comes to light. Genetic testing to find defective genes is not at a clinically useful stage at the moment but research is ongoing.

Gunther Wanke, an IPF patient from Austria, was invited to share his perspectives on being diagnosed with IPF. He described his symptoms, seeking medical help, being diagnosed with IPF, and how he maintains his health. He also described how the health system in Austria funds specialist nurses who visit patients in their home. Gunther emphasised that now “Life is different but it’s a life worth living”.

Nicola Cassidy (ILFA) was invited to deliver a presentation entitled “What matters to patients and carers”. Nicola discussed ILFA’s involvement in an international project organised by the European Respiratory Society’s Taskforce on IPF and the European Lung Foundation. Patient organisations from Ireland, Belgium, Italy and the United Kingdom participated. Focus groups of patients and carers were asked for feedback on a number of topics and some of the patient priorities that emerged included quality of life, exercise, end of life care and improved communication. Nicola highlighted some of the communication difficulties experienced by patients. To overcome poor communication, healthcare professionals should use plain language, get to know the patient’s values and what’s important to them and their family, and encourage patients and carers to ask questions.

Anne-Marie Russell from the United Kingdom spoke about patient communication strategies. Anne Marie offered advice to the healthcare professionals on how to structure appointments and consultations with patients, how to start difficult conversations and how to be self-aware. It is important to establish good rapport with patients and help them discuss and understand their treatment options to support them in the decision making process. Anne-Marie described a recent study that showed that patients often used websites that provided incorrect, inaccurate or false information about IPF. Anne-Marie finished by describing new ways of engaging with patients via technological advances including the patientMpower app that is being developed here in Ireland in collaboration with ILFA.

The AIR Vienna Conference was a very special meeting - it was highly educational and superbly organised. Sincere thanks to the Co-chair, Professor Athol Wells, for championing the patients and carers perspectives at the AIR Meetings and inviting ILFA’s participation over the last 4 years.

Patient Information Day, November 2016

Liam Galvin, Laura Grehan, Eddie Cassidy and Marie McGowan.

The second ILFA Patient Information Day of 2016 took place at the Crowne Plaza Hotel, Santry, Dublin on Saturday 5th November. The event was well attended with people travelling from as far away as Cavan, Monaghan, the Midlands and Limerick. Terence Moran, ILFA Chairman, welcomed everyone to the meeting and introduced the speakers.

Dr Kate O'Reilly, Respiratory Consultant at the Mater Misericordiae University Hospital in Dublin gave an overview of pulmonary fibrosis in general and specifically addressed the diagnosis and treatment of Idiopathic Pulmonary Fibrosis (IPF). The word 'pulmonary' refers to the lungs and 'fibrosis' is the name that describes the scarring and hardening of lung tissue that occurs with interstitial lung disease. Usually a diagnosis of pulmonary fibrosis is decided on by the healthcare professionals attending a multi-disciplinary team meeting (MDT), where experts in different fields of medicine including a respiratory doctor, radiologist and pathologist, review all the patient's CT scan results, x-rays, lung biopsies, test results and medical history. If the specific cause of the lung fibrosis cannot be identified and all other causes have been ruled out, a diagnosis of Idiopathic Pulmonary Fibrosis (IPF) is reached. The word 'idiopathic' means unknown.

There are over 200 different interstitial lung diseases (ILD). IPF is the most common form of ILD. With IPF, the amount of scarring gets worse over time. The lungs will become smaller and stiffer as they lose their efficiency and have to work harder, resulting in breathing difficulties for the patient. When we breathe in, oxygen from the air moves across the lungs and into the bloodstream. With IPF, the thick scarring that occurs prevents the efficient transfer of oxygen into the blood and oxygen levels are reduced. Some patients will be prescribed supplementary (medical oxygen) to help improve their breathlessness. Dr O'Reilly encouraged everyone to consider supplementary oxygen as a positive breathing aid. It is beneficial, will improve your quality of life and it should not to be feared. Dr O'Reilly also discussed some of the other conditions that can be associated with lung fibrosis including acid reflux (also called GERD or gastro-oesophageal reflux disease) when acid from the stomach can be inhaled into the lungs. You should tell your doctor if you experience heart burn or acid reflux as you may need medication to control this.

There are two anti-fibrotic drug treatments that slow down disease progression for patients with IPF; these are Pirfenidone (also called Esbriet) and Nintedanib (also called Ofev). These medicines do cure IPF and cannot reverse scarring that is already present in the lungs. At present, only Pirfendone is approved by the HSE in Ireland. Dr O'Reilly finished her presentation by advising everyone to "Keep well, keep active and keep involved".

Petra Grehan, respiratory physiotherapist with the Mater Misericordiae University Hospital, explained how the lungs work and are designed to take in oxygen from the air we breathe in and transfer it to the bloodstream to be pumped around the body. Oxygen is the 'fuel' for our vital organs and provides us with energy to live. Essentially, our lungs are like a car engine. Similar to a good car engine, healthy lungs use less fuel and work efficiently. With IPF, the thick scar tissue that develops in the lungs prevents the normal oxygen transfer and patients may need extra oxygen (supplemental oxygen) to provide more energy.

Petra emphasised the importance of daily exercise for all lung fibrosis patients. A lack of regular exercise will result in the loss of muscle strength, mobility and independence. Petra encouraged everyone to take part in daily exercises that they enjoy. You can exercise anywhere and at any time - there should be no excuses because there is no need for fancy equipment, shoes or sports clothes. Short bursts of exercise are good and there are benefits from exercising for short intervals several times a day. Why not exercise each time the TV advertisements are on ... the benefits will all add up. All you need to get moving is motivation.

Petra encouraged patients to attend pulmonary rehabilitation programmes if their doctor refers them to a class in their area. Unfortunately many pulmonary rehabilitation programmes only run for a short period but it is important for patients to carry on exercising after the classes end. If you stop exercising, you will lose any gains that you made. If there is no pulmonary rehabilitation programme available where you live, ILFA can supply you with free exercise programmes that were developed in collaboration with the physiotherapy department at the Mater Misericordiae University Hospital.

- The 2000 Steps a Day Walking Challenge, and;
- Exercise DVD for Lung Fibrosis Patients.

Petra showed the audience some simple strengthening and flexibility exercises and also had everybody marching on the

Speakers at the Patient Information Day: Petra Grehan, Eamonn Costello, Lynn Fox, Terence Moran and Dr Kate O'Reilly.

spot, stretching their arm muscles, and standing up and sitting down repeatedly for short bursts of exercise. (All the exercises are included in the ILFA Exercise DVD). It was a great way to get everyone moving!

Petra also discussed the benefits of using a hand-held fan to help patients manage their breathlessness. Fans generate a flow of air that cools the face and improves the sensation of breathlessness. ILFA has a small, portable, light-weight fan that is easy to use and is available free of charge to members who contact us. Petra encouraged patients to take a free fan and asked that everyone complete a short questionnaire to let ILFA know about the benefits of using the device.

Professor Jim Egan, pictured, Respiratory consultant from the Mater Misericordiae University Hospital spoke about the great success of the lung transplant programme at the national lung transplant unit at the Mater Hospital in Dublin. The number of lung transplants taking place is very encouraging. Prof Egan paid tribute to the generosity of the families who kindly agreed to organ donation to give the gift of life to those in need.

Having a single or double lung transplant involves major surgery and all patients need to meet strict criteria in order to be considered for the operation. Thankfully in Ireland a person's age will not prevent them being considered for a lung transplant if they are otherwise healthy apart from their lung disease. Many patients in their 70's have received a new lung or lungs in Ireland from organ donors. Lung transplantation is an effective treatment for IPF and greatly improves a patients' quality of life and life expectancy post-transplant.

Lynn Fox, respiratory nurse specialist from the Mater Hospital in Dublin kindly stepped in at short notice to give a talk when one of our invited speakers was unable to attend. Lynn spoke about the role of the nurse specialist which involves

- providing education and support and medical advice to patients and families about lung fibrosis
- helping patients to manage the side effects of their medicines
- facilitating access to other services
- liaising with the patient's GP and pharmacy
- running a dedicated clinic for patients with lung fibrosis

Lynn encouraged patients to bring a family member with them to their clinic appointments, write down any questions in advance of the appointment and to call their respiratory nurse specialist between appointments if they have an urgent question about symptoms or side effects they may be experiencing.

Lynn also talked about different ways of managing symptoms of IPF. Breathlessness is common and can be controlled by using a hand-held fan to blow a gentle stream of cool air over the face, breathing techniques, and positions of ease to make you feel comfortable, for example

- Sit on a chair, lean forward and rest your hands on your knees with your palms turned upwards
- Lean against a wall, table, chair or windowsill
- Sit upright in a chair

Lynn also spoke about fatigue which affects everyone differently. Fatigue can be very debilitating for some and can lead to poor concentration, irritability, low oxygen levels in the blood and sleep interruption. In order to manage your fatigue, it is important to plan ahead, prepare lists of what you need to do, for example shopping lists, take regular rests, power nap for 20 minutes when you need it, eat well and exercise.

Eamonn Costello from patientMpower spoke about a new app for smart phones and electronic devices that has been developed to help patients with lung fibrosis. The programme can help patients to monitor their daily health by reminding them when to take their medicine, recording the number of steps they take, any medication side effects, breathlessness scores and even air quality. ILFA and patientmpower are currently recruiting patients to take part in a study to evaluate the latest version of the health app.
If you would like to know more, please contact ILFA.

Cara Ni Fherraigh also spoke briefly about the power of Facebook. Cara has been helping ILFA to raise our profile and awareness of lung fibrosis and ILFA's work via Facebook.

After the presentations, there was a lively questions and answers session with the good audience participation. Some of the discussions that took place concerned access to medication, familial lung fibrosis, getting a second medical opinion, the pros and cons of seeing doctors privately and publicly in the health system, exercising while on oxygen, and managing breathlessness.

Terence Moran concluded the meeting by thanking the audience, the speakers and the representatives from the oxygen companies, Air Liquide Ireland and BOC Healthcare Ireland, for hosting information stands. Refreshments were served after the meeting and everyone had a chance to interact with the speakers and socialise with each other.

What you thought ...

ILFA asked the attendees to fill out a short questionnaire to evaluate the Patient Information Day and give valuable feedback.

- **85.3% said the event was excellent, 11.7% said it was very good and 3% said it was good.**
- **94.3% felt the programme definitely met their information needs.**
- **94.4% said they would definitely attend another ILFA Information Day.**
- **100% said they would recommend the ILFA Patient Information Day to another patient.**

Andy Carroll, John Carroll, Maureen Caroll, Mary Carroll and Val Kennedy.

Hand-held fan to ease breathlessness

You can order your free hand-held fan by calling ILFA on 086 871 5264 or emailing info@ilfa.ie. In return, ILFA would like to know about your experience of using the hand-held fan and to find out if it helped you when you were short of breath. ILFA will send you a questionnaire with your fan and we would be very grateful if you would fill out the questionnaire and return it. An online questionnaire is also available on the website - www.ilfa.ie

Raising awareness via social media

Did you know that ILFA has a Facebook page and a Twitter feed?

Social media is defined as a group of Internet communication channels that enable sharing of information, interaction and collaboration between groups and individuals.

- **Facebook** is the largest social network in the world. It is a hugely popular free social networking website that allows registered users to create personal profiles, upload text, photos and videos, send messages and keep in touch with friends, family and colleagues. In 2016, Facebook had a mind-boggling 1.79 billion monthly active users.
- **Twitter** is a free service that allows registered users to share short messages called 'tweets'. Incredibly, last year, Tweets about the Rio Olympics in Brazil generated 75 billion impressions.

Facebook is becoming more popular than ever and is a powerful and influential way to raise awareness and disseminate information. The demographics of people who use social media are rapidly changing and increasing numbers of older adults are now using Facebook. When ILFA started using social media in 2012, we had a small number of followers and a small 'reach'.

Thanks to help and advice from Cara Ní Fhearraigh, pictured, we now have over 2,700 followers and have seen our weekly reach increase substantially. Facebook has become an invaluable communication and educational tool especially to help patients, family members and fundraisers learn about ILFA and how we can support those affected by lung fibrosis. The ILFA Facebook page enables our followers to also keep up to date with our work, research findings, and news and events. Our most popular posts regularly feature items on;

- educational videos and links to our leaflets with information on pulmonary fibrosis;
- fundraising events and fundraising achievements;
- lung transplantation and organ donation news items.

As the number of Facebook followers increase, ILFA can reach a larger population, and having more followers will lead to more engagement, more clicks and importantly more awareness.

Now more than ever is the time to embrace social media so why not ask your family members, friends and colleagues to 'like' ILFA and also to help you set up a Facebook account if necessary. It is wonderful to have your support and everyone at ILFA appreciates your 'likes' and 'shares'. We are now working towards a goal of having 5000 followers.

www.facebook.com/ILFAIreland
www.twitter.com/ILFAIreland

Interstitial Lung Disease Inter-Disciplinary Network (ILD -INN)

The inaugural meeting of the ILD-INN took place in Birmingham in October 2016 and it was very well attended by healthcare professionals from all disciplines of respiratory medicine across the UK and Ireland.

The ILD-INN meeting had three aims (1) to deepen knowledge (2) to share knowledge and (3) to allow the attendees to network with each other. The meeting was excellent with great speakers from Great Britain, the Netherlands and Ireland sharing their expertise and experience.

Nicola Cassidy (ILFA Director) was invited to speak about ILFA's work supporting patients and families affected by IPF, and Irene Byrne from the Mater Misericordiae University Hospital spoke about pulmonary rehabilitation and the ILFA 2000 Steps a Day Challenge and Exercise DVD for lung fibrosis patients.

Liam Galvin and Irene Byrne at the ILD INN Conference

Patient and Carer Advisory Group

Would you be interested in joining ILFA's new volunteer patient and carer advisory group? If yes, we would love to hear from you. From time to time, ILFA would like to engage with a group of enthusiastic patients and carers to draw on your personal experiences and insights to help review our printed materials, give feedback on ideas, and help us plan, shape and develop future work projects.

ILFA is looking to recruit a small number of volunteers from across the country with a variety of backgrounds and experiences to support and advise the ILFA committee, as the need arises. Most of the communication will take place by email but occasionally members of the group may be asked to attend a number of face-to-face meetings. You can be involved in as many or as few meetings and activities as you wish, depending upon your health and personal circumstances.

One project that ILFA would like to start developing with input from patients and families is to establish your information needs relating to symptom management, palliative care and planning for the future.

Please contact ILFA if you would like to register your interest in joining the Patient and Carer Advisory Group.
Phone: 086 871 5264
Email: info@ilfa.ie

The Denise Cassidy Memorial Prize

ILFA is excited to announce the 2017 Denise Cassidy Memorial Prize for excellence in healthcare. This award recognises and celebrates the kindness, compassion and humanity of a hospital healthcare worker to a lung fibrosis patient or their family. Patients and carers are invited to nominate a person who showed you or your loved one a special act of kindness that helped you cope with your illness better.

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

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

Denise's husband Eddie and daughter Nicola are members of the ILFA committee. Denise's immediate and extended family have continuously fundraised for ILFA for more than 10 years and all are honoured and humbled to have this special award dedicated to her memory.

Let's get behind our lung fibrosis healthcare heroes and celebrate their great work! The closing date for entries is the end of May.

ILFA's Voice in Europe

ILFA looks forward to continuing its campaign for IPF patients in Europe that started with our contribution to the development of the 2014 European IPF Patient Charter. ILFA worked with 11 other European patient groups and specialist healthcare professionals from nine countries to identify common issues and supports needed for IPF patients across the European Union. The European Idiopathic Pulmonary Fibrosis and Related Disorders Federation (EU-IPFF) was founded to give a stronger voice to patients and to improve awareness of IPF. Liam Galvin (ILFA Director and committee member) serves on the Executive Board of the EU-IPFF and was elected as the first General Secretary of the federation. Liam's hard work and dedication is helping to ensure that Irish patients, along with their fellow European sufferers and families, have a voice among the policy makers, politicians, institutions and health providers of the EU.

In 2016, ILFA and our European friends were proud to see the legal formation of the EU-IPFF as an international non-profit organisation. Furthermore the EU-IPFF achieved three major milestones;

1. the passing of the Written Declaration on IPF at the European Parliament
2. the establishment of the European Reference Network on Rare Respiratory Diseases
3. the expansion of the EU-IPFF to now include 13 groups from 10 countries

In 2017, ILFA as part of the federation, will continue to concentrate on activities to ensure that IPF patients are no longer overlooked on the European stage. These activities will include;

1. the launch of a new EU-IPFF website
2. ILFA will be represented on the board of the EU funded European Reference Network
3. the launch of an EU-IPFF IPF Patient Guide
4. participation in an awareness campaign with global and European IPF patient groups
5. expansion of the EU-IPFF membership with two new patient organisation groups joining
6. working with the EU-IPFF Scientific Board of European IPF Specialists

The EU-IPFF also applied to the European Medicines Agency (EMA) for approved group status which will allow the EU-IPFF to be recognised and contribute on behalf of IPF patients. ILFA was recently represented at the EMA by Liam Galvin as a Patient Expert at a meeting in February.

In 2017, ILFA and the EU-IPFF members will be eagerly awaiting the response from the EU Commission and EU Council to the passing of the Written Declaration on IPF that was supported by 379 Members of the European Parliament. It is hoped that the response and recommendations that result will facilitate the establishment of further links with EU agencies, such as the EMA, and this will raise the possibility of influencing health policy in Ireland and other member states.

ILFA would like to extend our appreciation to Liam Galvin for his hard work and commitment on our behalf at a European level.

Irish Thoracic Society Meeting 2016

The Irish Thoracic Society's Annual Scientific Meeting took place on 18 and 19th November at the Fitzpatrick Castle Hotel, Killiney, Dublin. Gemma O'Dowd and Pamela Martin hosted an information stand for ILFA at the event. It was a busy two days and Gemma and Pam enjoyed meeting the healthcare professionals who called by to learn more about ILFA's work. ILFA's new hand-held fans were very popular and caught the interest and attention of the healthcare professionals.

Petra Grehan, respiratory physiotherapist at the National Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital attended the ITS meeting and a presented a poster entitled "Every breath you take - lung fibrosis breathlessness survey." The research described the results of an ILFA survey where patients were asked to identify the physical and emotional impact of breathlessness, and the practical solutions they used to help them recover their breath.

Above: Pamela Martin and Lorna Murphy

Left: Professor Michael Keane

Nicola Cassidy, Dermot King and Mark Finnegan.

Radio interview with Near FM

On 29th November, Dermot King and Nicola Cassidy were invited to Near FM studios in Coolock, Dublin, to speak live on radio about IPF on the 'Lifeline' programme with Debbie McMahon.

The Near FM Lifeline team, Mark Finnegan, Debbie McMahon and their colleague George Mulcahy extended a warm welcome to Dermot and Nicola and were very interested to learn more about IPF over a cup of tea after the interview. The team also extended an invitation to attend the Near FM studios again in 2017.

The podcast of the interview can be found online at www.nearfm.ie/podcast (search for 'lung fibrosis') and is also available to listen to on the ILFA Facebook page.

Fergus Goodbody Memorial Lecture

The Fergus Goodbody Memorial Lecture took place on 14th February 2017 at the Royal College of Surgeons in Ireland, St. Stephen's Green, in Dublin.

The Irish Lung Fibrosis Association (ILFA) was set up in 2002 in memory of Fergus Goodbody and since 2010, ILFA has invited an international leader in Idiopathic Pulmonary Fibrosis (IPF) to deliver a state of the art lecture to healthcare professionals in Ireland, every two years. Professor Jurgen Behr from Munich kindly accepted ILFA's invitation to deliver the 2017 Fergus Goodbody Memorial Lecture and we were delighted to welcome him to Dublin.

Healthcare professionals from all over Ireland attended the educational meeting that was chaired by Professor Jim Egan (Mater Misericordiae University Hospital). The invited speakers, Dr Emmet McGrath (St Vincent's University Hospital, Dublin), and Professor Jurgen Behr, gave two superb and informative evidence-based medical lectures.

Professor Jim Egan, Dr Emmet McGrath, Professor Jurgen Behr, and Terence Moran.

Dr McGrath spoke about the challenges and difficulties in diagnosing some of the different sub-types of interstitial lung disease (ILD) - there are more than 200 different types. He described the investigative procedures used to obtain clinical and radiological data to help the multidisciplinary team reach a diagnosis. Dr McGrath spoke about the characteristic patterns that are evident on high resolution CT scans, the results of bronchoalveolar lavage procedures, and biopsy findings that can help inform the diagnosis of some ILDs.

Dr Oisin O'Connell, Mr Lars Nolke and Professor David Healy from the Mater Misericordiae University Hospital.

Professor Behr was introduced by Professor Egan as 'a global key opinion leader in respiratory medicine'. Professor Behr's talk was entitled "IPF - Novel Trends in Diagnosis and Treatment" and he discussed how interstitial lung abnormalities are much more frequent than expected in the general population and these changes may represent the development of fibrotic lung disease. He described in depth the benefits and risks and analytic potential of some diagnostic procedures including surgical lung biopsy, transbronchial lung cryo- biopsy and alveolography - an exciting and promising tool that allows doctors to look inside the lungs to visualise scarring.

Professor Behr also discussed the pharmacological and non pharmacological options in IPF and focussed on when to start or stop therapy. Professor Behr stated that as IPF is a progressive disease, all patients should be considered for treatment with anti-fibrotic medication. A 'watch and wait strategy' should not be used by doctors as a patient's past medical history does not predict how IPF will behave in the future. Professor Behr also spoke about the need to refer IPF patients for early lung transplant assessment, and he shared some of the treatment approaches for IPF care in Germany.

The meeting ended with a questions and answers session. Professor Egan thanked the audience, the speakers for an enlightening seminar and the sponsors; Boehringer Ingelheim and Roche Products Ireland, who supported the event.

The audience feedback from the meeting was extremely positive and here are some of the comments received;

"Excellent lectures"

"Very informative. Prof Behr was outstanding"

"Interesting to hear a speaker from another country"

"It was fabulous. Prof Behr was a wonderful speaker and the prospect of alveolography was incredible. Thoroughly enjoyed Dr McGrath's talk too."

Interstitial Lung Disease Study Day 2017

The 3rd Interstitial Lung Disease Study Day, organised by Roche Products Ireland, took place in Dublin on 10th February. ILFA committee members; Liam Galvin, Gemma O'Dowd, Lynn Fox, Lindsay Brown and Nicola Cassidy attended the event along with over 100 healthcare professionals from around Ireland. Lindsay Brown, Lynn Fox and Nicola Cassidy were invited speakers at the event and the other speakers included Dr Emmet McGrath (St Vincent's University Hospital), Professor Michael Keane (St Vincent's University Hospital), Dr Dearbhaill O'Driscoll (Mater University Hospital) and Tara Hannon (University Hospital Galway).

Back row: David Ford (Roche), Dr Emmet McGrath, Denise Eggleston (Roche), Prof Michael Keane, Dr Modestas Jarutis (Roche). Front row: Tara Hannon, Lynn Fox, Lindsay Brown, Nicola Cassidy.

Lindsay, a respiratory nurse specialist at St Vincent's University Hospital, spoke about personalised treatment plans for patients. Lynn, a respiratory nurse specialist at the Mater University Hospital, spoke about optimising patient treatment and care. Nicola gave a presentation entitled "What matters to patients and carers" based on the feedback from various ILFA projects.

Dermot King and David Crosby were also invited to give the audience of healthcare professionals an insight into the lives of patients. Dermot and David shared their experiences of being diagnosed IPF and how they exercise to stay well and maintain their fitness levels. Dermot spoke about the Breathe Smart rehabilitation programme at Dublin City University which he attends twice a week, and the benefits of attending the IPF support group in Dublin. David shared his family's story and spoke about receiving a life saving double lung transplant in 2016. David is currently training for the New York Marathon on 5th November to raise funds to support lung transplant research. You can support David's fundraising at https://give.everydayhero.com/ie/the-greatness-within.

Fundraising Round Up

Margaret Maloney Memorial Darts Tournament 2016

The picture shows members of the Maloney family and organising committee presenting a cheque to Liam Galvin, ILFA Director.

The 3rd annual Margaret Maloney Memorial Darts Tournament took place on the 24th September 2016 and the main beneficiary of the funds raised was ILFA. The first tournament started in October 2014 - a year after our mam, Margaret, passed away from Idiopathic Pulmonary Fibrosis. The tournament has grown from strength to strength; in 2014 we had 48 throwers, in 2015 we had 74 throwers and in 2016 we had 78 throwers. Margaret's family and friends are overwhelmed with the support that is given each year. In just 3 years, we have raised over €10,000 for ILFA. Our tournament for 2017 is fixed for the 30th of September in Breretons Bar, Ballybritt, Roscrea. More information will be on the ILFA and Margaret Maloney Facebook pages nearer to the time.

- report by Owen Maloney

Martin Casey, Brian Ahern, John Nolan (Cork City Ford Centre), and Anne Casey.

Pat Casey Memorial Cycle 2016

The Pat Casey Memorial Cycle took place in September 2016 in aid of Cork University Hospital and ILFA. The cycle started at the Ford Centre in Cork , travelled to Limerick for an overnight stay and returned to Cork the following day. Thanks to the organisers, cyclists and support team for their great efforts over the last few years. A cheque was presented to Dr Michael Henry of Cork University Hospital on 16th March 2017.

Jack Nichol, Avril Cooke, Margaret Nichol, Dr Michael Henry, Brian Ahern, Katie Cooke, Betty Gamble, and Anne Casey.

Santa Dash 2016

The 2016 Santa Dash in Dublin was a great event with over 900 Santas of all shapes and sizes taking part in the 5km and 10km. Annette Grehan and Nicola Cassidy took part for ILFA in memory of their sister and mother, Denise Cassidy, who was born on Christmas Day and would have truly loved this event.

It was a gorgeous December morning and although it was a little chilly on Dollymount Strand in north Dublin, once everyone put on their Santa suit, beard and hat, they soon warmed up. There was a lovely festive atmosphere as Christmas songs played in the background and men, women, children and dogs dressed as Sana Claus all got into the Christmas spirit. It was fun to see so many red suits charge down the beach at speed. After the race, Nicola and Annette were interviewed on camera and later appeared in a Denny Sausages online advertisement that honoured volunteers and fundraisers at Christmas! The ladies were proud to display their red and white ILFA badges on their Santa hats.

Here's looking forward to the 2017 event!

Christmas swim

The annual ILFA Swim took place on St Stephen's Day at 11.45 am at Sandycove Pier in Dublin. It was a beautiful sunny day, with a lovely calm sea and the event was well attended by a lot of loyal supporters. The ILFA Christmas Swim has taken place every year since 2002.

This year, ten swimmers bravely participated. First in was Honora Ni Chrioghain, followed by Chloe Meehan and Colin Ireland. Next in was Professor Jim Egan, whose swim was accompanied by great cheers.

Later arrived Giles Keane, all the way from Brussels. He was followed by Christopher and Colin Lock, who were supported by Claire Tunissen and her dog Lottie.

Last but certainly not least were Michael Darragh Macauley (ILFA Exercise Ambassador), and his cousin Ken Powell and brother in law John Sheridan. They were cheered on by family members Edna Powell, and Margaret, Rebecca, Ciara and Daniel Sheridan.

Thanks to Edna for providing a box of Heroes (very apt!) later at Eagles House, where the group warmed up after their heroic swims. The event was a great success, with Giles Bailey shaking the ILFA bucket once more. The collection raised around €650.

- report by Nicky Goodbody (ILFA Director)

Pictured clockwise are: Chris Meehan, Nicky Goodbody, Chloe Meehan and Avril Paterson, Ken Powell and Michael Darragh Macauley, the Sheridan Family - Margaret, Daniel, Ciara, John and Rebecca, and Michael Darragh Macauley and his aunt Edna Powell.

Christmas jumper auction in aid of ILFA

Thanks to Fabio Molle and all the team at Funky Christmas Jumpers who organised a special online auction of a unique and highly colourful Connor McGregor Christmas Jumper in aid of ILFA.

Fabio's father passed away at the young age of 59 with Pulmonary Fibrosis in 2016 and Fabio wanted to raise awareness with his novel fundraising idea. A great total of €360 was raised for ILFA.

Christmas cards

Thanks to everyone who supported the ILFA 2016 Christmas card campaign and helped raise awareness of lung fibrosis at Christmas time. We are extremely grateful to everyone who also made donations to cover the postage and packaging costs. ILFA would like to extend special thanks to Margaret McGlynn and Alison and Angela Maguire who generously took multiple packs of cards to sell to their family and friends.

Thank you

Thank you to all our fundraisers and those who make donations to ILFA. Your hard work and generosity enables ILFA to carry out our work to support patients and families affected by lung fibrosis.

Thanks to Katie O'Gorman from Thurles, Co Tipperary who undertook a number of adventurous fundraising activities during 2016 to raise money for some of her favourite charities including ILFA.

Thanks to Sharon Cassidy who took part in the Dublin City Marathon in October 2016 to raise funds in support of her dear friend Miriam Stone, who sadly passed away in January 2017.

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.

Team ILFA 2016

2017 VHI Women's Mini-Marathon

The VHI Women's Mini-Marathon will take place in Dublin on Monday 5th June at 2pm. We would love if you and your female family members, friends and colleagues would join us to raise valuable funds to support ILFA's work.

You can register to take part in the mini-marathon on-line at www.womensminimarathon.ie

Entries will close once the maximum number of participants has been reached. Don't leave it too late ... 'Don't delay, register today!'

Once you have registered, please contact ILFA for your fundraising pack. We look forward to welcoming you to Team ILFA.

Fundraising dates for your diary

- **The Great Limerick Run** will take place on April 30th 2017.
- **The Cork City Marathon** will take place on Sunday 4th June 2017.
- **The VHI Women's Mini Marathon** will take place on Monday 5th June 2017. Remember to register early to avoid disappointment
- **The Dublin City Marathon** will take place on Sunday 29th October.

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

Patient Support Groups

Cork Support Group

The group meets at 11am on the last Thursday of every month at The Elm Tree, Glounthane. **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 Rose Hotel. **Please call Adrian on 087 241 4004 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 Tom on 086 150 0970 or Anthony on 087 258 5699 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

Noreen O'Carroll is hoping to set up a support group in Limerick - Tipperary. **Please call Noreen on 087 262 7976 for more information.**

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

086 871 5264

ILFA Christmas Lunch

The tree degrees - Eddie Cassidy, Teresa Cullen and Matt Cullen.

The Dublin Support Group held a Christmas Jumper Lunch in early December at the Gresham Hotel in Dublin city centre. Everyone was in great spirits and threw themselves into the Christmas spirit by wearing colourful jumpers and festive hats. Thanks to Pam Martin for organising a very special lunch. Here's hoping it will become an annual event.

The Midland Support Group also shared a festive lunch in December at the Tullamore Court Hotel, Co Offaly.

Members of the Tullamore Support Group and Dublin Support Group.

Dates For Your Diary

- The Sligo Patient Information Day will take place on Saturday 22nd April at the Clayton Hotel Sligo.
- The ILFA Service of Prayer and Reflection will take place on Saturday 14th October at Our Lady of Mount Carmel Church, Whitefriar Street, Dublin 2 at 4pm.
- The Dublin Patient Information Day will take place on Saturday 21st October.

Raising Awareness of IPF

Well done to Lauren Kenny and Aishling Morrissey, second year students at Laurel Hill FCJ Secondary School in Limerick, who showcased their project on 'Lung Fibrosis' at an exhibition stand at their school. Lauren's grandfather has lung fibrosis and the girls wanted to help raise awareness of the condition. We are very grateful to Lauren (pictured on the right) and Aishling for their support.

Thanks also to David Crosby and Dermot King for sharing their experiences and helping raising awareness on behalf of ILFA.

Keep in touch with ILFA

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

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