



European Idiopathic Pulmonary Fibrosis and Related Diseases Federation (EU-IPFF)



The EU Patient Charter for IPF was developed by a group of patient organisations and healthcare professionals from across Europe who identified the common unmet needs and optimal care plans for IPF patients in all the countries involved. The EU charter highlights the rights and supports that should be available to IPF patients across the European Union and will be used as a lobbying tool on their behalf. The success of the project led to the realisation that by working together, the voice of IPF patients could be heard at an EU level. The possibility to also help new patient organisations develop with the experience available from established patient groups, led to the formation of the EU-IPFF. The first general assembly of the EU-IPFF took place in Brussels on 21st February 2016 and Carlos Lines Millán from Spain was elected President.

In April 2016, the EU-IPFF in collaboration with fourteen Members of the European Parliament (MEPs) from different countries and political groups will submit a 'Written Declaration on IPF' before the EU Parliament. Marian Harkin, MEP, is a co-author on behalf of Ireland. The Written Declaration is based on the EU Patient Charter and if passed, will send a strong message to the national governments and help raise awareness of IPF among the EU institutions. The EU-IPFF is also working with respiratory



Liam Galvin signing the EU-IPFF Statutes at the European Parliament

doctors to support their application to have a 'European Reference Network' recognised for IPF. If successful, this will allow the transfer of knowledge and treatments across Europe's centres of excellence, and provide opportunities for funding IPF research and the pooling of data and experiences.

The EU-IPFF will work with other EU patient groups to increase IPF awareness, identify lobbying and support opportunities, and help countries who wish to set up new IPF associations. The federation will connect with industry

and healthcare professionals to encourage research and bring information on clinical trials and developments to IPF patients across Europe.

ILFA has been a long-term supporter of this vision and our representative, Liam Galvin, was elected as Secretary of the EU-IPFF. The formation of the EU-IPFF represents a major achievement and a significant milestone in IPF care.

News from the Chairman

Goodbye and thank you to Denise Dunne who will be leaving ILFA after almost two years of service as our Management and Development Officer. The ILFA committee would like to wish Denise every happiness and success for the future.

ILFA would also like to send our good wishes to our patron and friend, Senator Feargal Quinn on his retirement from the Seanad with 23 years of distinguished service. We wish Feargal a long, happy and active retirement and hope to continue working with him in the future in his role as patron.

Liam Galvin, Eddie Cassidy and Nicola Cassidy were appointed as Directors of the ILFA in January 2016 after serving on the committee for a number of years. Marie McGowan, Martin Troy, Lindsay Brown, Dr Kate O'Reilly and Dr Emmet McGrath have recently joined the committee and we look forward to working with them and availing of their experience, ideas, skills and talents.

Congratulations to Liam Galvin who has been appointed Secretary of the European Idiopathic Pulmonary Fibrosis and Related Diseases Federation. **Terence Moran, ILFA Chairman**

Patient Information Day

The next ILFA Patient Information Day will take place on

**Saturday 9th April
in The Anner Hotel,
Thurles, Co Tipperary.**

The speakers will include Dr Emmet McGrath, respiratory consultant and Lindsay Brown, respiratory nurse specialist from St Vincent's University Hospital and other healthcare professionals.

Registration will start at 10am and the meeting will end at approximately 1pm. Light refreshments will be served afterwards. All are welcome.

Please call **086 871 5264** or email info@ilfa.ie if you would like more details.

Patient Information

The 2015 autumn ILFA Patient Information Day took place in the Crowne Plaza Hotel in Santry, Dublin and was well attended. We had a packed programme and were fortunate to have speakers of a very high calibre. Terence Moran, ILFA Chairman welcomed everyone and introduced Professor Jim Egan from the Mater Hospital to get things underway.

Professor Egan explained how ILFA was one of the first charities in Europe to support patients and families affected by Idiopathic Pulmonary Fibrosis (IPF). ILFA was set up in 2002 by Prof Egan, Terence Moran, Nicky Goodbody, Marie Sheridan and a small number of volunteers. Since then ILFA has been leading the way in patient advocacy in Ireland and Europe. In recent years, new patient groups have been established across Europe and the patient organisations are coming together to promote greater awareness of IPF and call for improvements in patient care.

In the last few years, major advances in the field of IPF have included the successful development of two medicines, Perfinidone and Nintedanib, which can slow down disease progression. There are currently a handful of new drugs being investigated as potential treatments for IPF. Lung transplantation has also come a long way and is a very successful treatment option for some IPF patients. Thanks to the skills, dedication and commitment of the surgical, medical, nursing and allied healthcare teams at the Mater Hospital in Dublin, 35 lung transplants were performed to date, in 2015. This significant achievement placed Ireland third in the league of top performing countries in Europe for lung transplantation. Approximately half of the 35 lung transplant recipients had IPF. Professor Egan urged everyone to talk to their families and politicians about the need to push forward the introduction of presumed consent for organ donation.

Dr Emmet McGrath from St Vincent's University Hospital discussed the medical aspects of IPF. There are more than 300 types of lung diseases that are characterised by scarring or fibrosis. A trigger causes a series of events to occur that results in the excessive formation of scar tissue in the lungs. Sometimes the cause of the condition can be identified for example, some people may have had previous exposure to wood, metal, dust or pollutants in the course of their work. However for some patients, the cause cannot be identified and the word "idiopathic" means that the cause is not known. Dr McGrath expressed his confidence that in time, scientists and doctors will identify the cause and then the name "IPF" will have to change as we understand more about the condition.

The majority of patients diagnosed with IPF are in their 60's or older (although sometimes younger people are diagnosed). Most people have been breathless for months or years before they attend their doctor. Some patients are diagnosed "by accident" while they are being investigated for other medical problems and their x-rays or CT scans reveal lung fibrosis. Most people first experience breathlessness when climbing the stairs and often they become more breathless as their IPF progresses. Other symptoms include a cough that is persistent and difficult to treat, low energy, fatigue and generally feeling unwell.

IPF can be difficult to diagnose and a very detailed personal history is needed. Your doctor will ask you questions about your occupation, hobbies, previous drug use, exposure to pollution, dusts, metals and birds, and your family medical history. A variety of medical investigations are needed including a high resolution

Speakers: Prof Egan, Terence Moran, Petra Grehan, Anne-Marie Russell, Dr Emmet McGrath and Irene Byrne.



CT scan of the chest, x-rays, lung function tests, and rarely a lung biopsy. Usually a diagnosis of IPF is made when the multidisciplinary team, made up of respiratory doctors, nurses, radiologists (who read x-rays and scans) and pathologists (who look at lung biopsies), meet to discuss your symptoms and results. IPF is diagnosed when all other lung conditions have been ruled out.

There is no cure for IPF but there are medications that can slow down disease progression for some patients. The development of new medication and the prospect of new clinical trials offer hope for the future. Dr McGrath finished by encouraging patients to keep well in winter, to speak with their doctor about getting the flu and pneumonia vaccines, to speak with a dietician if worried about their diet and weight, to continue to exercise, and learn about oxygen.

Irene Byrne, senior physiotherapist with the Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital discussed different ways of managing breathlessness. Shortness of breath is a major problem for IPF patients and it is important to learn how to remain calm and know how to manage anxiety and breathlessness. Irene explained that breathlessness is 'contagious' and family members often panic and experience anxiety themselves when they see their loved one struggling for breath. Therefore, it's a great idea to discuss breathlessness with your family and friends so that they know what to do in order to help you rather than make the situation worse.

There are some easy techniques that you can practice to help you manage and control your breathing when you become breathless including;

1) Repeating mantras in your head or aloud, for example,

- "I have survived this before, it will go away"
- "There is nothing to be frightened of, I will be ok"
- "I am fine, I will be fine"
- "In with calm, out with fear".

Day, 7th November, Dublin



John and Anne Tracey with Tom and Eileen O'Sullivan (in the background) enjoying some laughter yoga

2) The STALL breathing technique

S = Stop what you are doing,

T = Try to remain calm. Turn up your oxygen,

A = Assume a comfortable position, for example sitting or leaning,

L = Let yourself daydream and imagine yourself in a safe and relaxing place,

L = Let your breathing return to normal.

3) Positions of ease - Sit down and rest your hands on your knees with your palms turned upwards, lean forward on a wall, or sit upright,

4) A small hand-held fan or an electrical fan that blows cool air over the face can help to improve the sensation of breathlessness for some patients.

Irene also spoke about the importance of oxygen and how we all need oxygen to survive. With IPF, it is important to use extra oxygen when doing activities especially if you become more breathless, for example when you are exercising, walking, getting dressed or having a shower. If you are more breathless than usual, you may need more oxygen, and should speak to your doctor, nurse or physiotherapist.

Anne-Marie Russell is a Clinical Investigator with the Royal Brompton Hospital in London and a leading patient advocate. Anne-Marie works closely with IPF patients and is currently developing a health-related quality of life questionnaire to accurately capture the patient experience. Anne-Marie referred to her questionnaire design as being “a measure from patients for patients” and it will help identify what is important to patients and the positive and negative aspects they experience while coping with IPF. It is hoped that the results of this questionnaire will influence research and the design of future clinical drug trials.

The aim of IPF treatment is to help patients manage their symptoms but there is no “one size fits all” approach. IPF is a chronic condition and can impact on your mood and lead to anxiety and depression. Everyone should expect to have good and bad days. If you feel that your mood is affected, you should seek medical advice for treatment options. Sometimes it can help to talk with a loved one or friend who might be able to help you see things in a different light or even help you solve a problem. Keeping a diary is a good

way to monitor and measure how you are coping. Anne-Marie encouraged everyone to be open to solutions that might help to prevent or manage anxiety including acupuncture, yoga and singing.

Petra Grehan, physiotherapist with the Mater Misericordiae University Hospital spoke about the benefits of exercise for IPF patients. Exercise is essential for patients with lung fibrosis and it is important to exercise every day, even when you are on oxygen. If you do not exercise, your muscles will become de-conditioned and you will lose your strength, independence and ability to do physical activities including standing up, moving around, getting dressed and leaving the house. Exercise will help you to maintain your general wellbeing, mobility, mood and confidence, and can improve your breathing and quality of life.

Even simple stretching exercises and maintaining a good posture while walking, standing and sitting can help to strengthen the muscles around the ribcage, making breathing easier. Petra explained that it is easier to lose fitness than to gain it and encouraged everyone to get moving. The ILFA Home Exercise DVD is an ideal way for patients to take part in a variety of simple exercises that can be carried out while sitting down or standing-up. All the exercises were put together especially for lung fibrosis patients and takes their oxygen needs into account.

The ILFA exercise DVD is available free of charge to patients and can also be watched on the ILFA website, www.ilfa.ie. Petra finished her presentation with great excitement as she proclaimed the famous words ... “and there’s one for everyone in the audience!”

Laughter yoga

The final presentation of the day was kept a secret until the very end. During the course of the morning, our speakers focussed on the benefits of staying positive, engaging in exercise and being open to new ways of managing IPF. So ... we invited Marion and Helen to give us a short class of laughter yoga! The audience was shy at first but soon the room was filled with the sounds of clapping, cheering and contagious laughter. Laughter yoga works by tricking the brain into releasing endorphins, also known as ‘happy hormones’, which make us feel good. Laughter is good for our mental and physical health and can even help our breathing as it gives the muscles a gentle work-out. After 15 minutes of giggling and laughing, most people were flushed, amused and smiling. We received very good feedback after the session and there was a great atmosphere when everyone gathered for refreshments. Sometimes it’s good to try new things! Thank you to Boehringer Ingelheim for supporting the ILFA Patient Information Day.

IPF support groups

If you have been recently diagnosed with lung fibrosis, you may be feeling scared, lost and lonely. You have probably never heard of lung fibrosis or Idiopathic Pulmonary Fibrosis (IPF) before and neither has your family or friends. If you would like to meet people who are also diagnosed with lung fibrosis and find out how they are coping, why not come along to a support group?

Naturally, some people may be nervous of joining a support group but we hope your fears will soon be forgotten when you receive a warm welcome and realise that you are not alone. Support groups can give people a sense of belonging, and connecting with others in a similar position can lead to new hope, new friendships and a new support network. Simply talking, listening to others and sharing your experiences (if you want to) can have a powerful and positive effect on how you cope with your diagnosis, manage your health, engage in exercise, and understand more about your condition.

There are currently 4 IPF support groups that meet once a month around the country and plans to start up a new group in Gorey, County Wexford. ILFA would like to thank all those who give up their time to organise the

support group meetings, keep in touch with all the members, and reach out and help those who call them for more information.

Here is a news round-up from some of the support groups.



Cork support group

A group of people who have lung fibrosis hold an informal meeting at 11am on the last Thursday of every month in the restaurant/bar of The Elm Tree in Glounthaune. Over coffee, we catch up with the month's events and share our stories. Our aim is to provide support in a friendly atmosphere where members will find comfort from talking to people who understand the difficulties faced each day by patients and carers. We are more than a support group, we are friends and new members are always welcome.



Dublin support group

The Dublin support group, pictured above, meets on the first Tuesday of every month at 11am at the Community Centre in Whitefriar Street Church, Aungier Street. Jerry Pouch and his team are very kind and look after us every month when we gather in the Garden Room for tea, coffee and a chat. Recently we celebrated our third anniversary. Each month we have lively discussions and from time to time we invite a healthcare guest to the meeting. We have had physiotherapists and nurses come along for lively and informative 'questions and answers' sessions. Everyone helps each other practically and emotionally and we all enjoy good conversation, many laughs and special friendship.

Midlands support group

The Midlands support group (pictured right) meets on the first Wednesday of every month in the Tullamore Court Hotel, Tullamore. At the moment there are 6

active members, 4 of whom are lung fibrosis sufferers and two former sufferers who have had lung transplants. Our meetings are informal, though we do have an agenda. Our aim is to give help and non-medical information to anyone who wants it. Everyone has a say at the meetings and we



all benefit from the discussion.

Wexford support group

Laura and her sister Ruth are hoping to set up an IPF support group in Gorey, County Wexford, if there is local interest. Laura contacted us to say "Our dad Robert was diagnosed last summer and we have noticed that between hospital appointments, you can be left feeling adrift. With that in mind, we thought a group in the south east might be the answer. We would hope to meet once a month and start by the end of April."

If you are interested, please call Laura on 087 285 4509 or Ruth on 085 164 9499.

Support group voices

"The support group gave me a positive outlook. It's great to talk to others and not burden my own family. It's great to meet up and get out of the house" - Betty

"I became aware of ILFA after my diagnosis in 2011. It was reassuring to find other people with the same condition and the support of fellow sufferers is reassuring. You are guaranteed a great morning of craic at the meetings" - Mags

"I became a new member of the Cork IPF support group last month. I find it very friendly, educational and it really clarifies, in our own language, an understanding of the disease" - Tony

"I feel that it's a great place to meet and talk to people who understand the daily struggle with this illness" - Charlie

"I find the group is a great source of strength to the members. The people there are always ready to help, what I like most is that outside the monthly face to face meeting, everyone is only a phone call or a text away in times of need or just for a chat. This is something that is vital for the morale of carers and family alike" - Dan

Patient Support Groups

Cork

The Cork Support Group meets at 11am on the last Thursday of every month at The Elm Tree, Glounthaune.

Contact Anne at 087 985 4587

Dublin

The Dublin Support Group meets at 11am on the first Tuesday of the month in the Carmelite Community Centre, Whitefriar Street Church, Aungier Street, Dublin 2.

Contact Paddy at 087 412 8612

Kerry

The Kerry Support Group meets at 3pm on the last Saturday of every month in The Rose Hotel, Fels Point, Tralee.

Contact Adrian at 087 241 4004

Midlands

The Midlands Support Group meets at 2.30pm on the first Wednesday of every month in the lobby of the Tullamore Court Hotel.

Contact Tom at 086 150 0970

If you would like information about setting up a patient support group in your area, please contact ILFA on 086 871 5264

Katie Barry with Terence Moran, ILFA Chairman



Sheena Minogue with Terence Moran, ILFA Chairman



Nicola Cassidy (ILFA committee) with Lorna Murphy and Anne Casey (Cork IPF Support Group)

The Denise Cassidy Memorial Prize

In 2015, ILFA asked you to nominate a healthcare worker for a special prize, dedicated to the memory of Denise Cassidy, in recognition of an act of kindness shown to a patient with IPF.

ILFA is pleased to announce that Katie Barry, staff nurse from Cork University Hospital, was the worthy winner of the inaugural Denise Cassidy Memorial Prize. Katie was nominated by Vikki Jolly for her outstanding kindness, dedication and compassion when caring for Vikki's father, Martin Erangey. Katie looked after Martin and his family with great personal care, attention and support.

Vikki told us "We have never seen the commitment to patient care and compassion shown by Katie. Her care allowed my father to pass with dignity and love".

Katie and her family were invited to Dublin in November to attend the ILFA Patient Information Day and receive her award. Katie was presented with a specially commissioned piece of Dublin crystal and a certificate for Excellence in Patient Care.

Katie said "I really enjoyed the patient information day. It was wonderful to be a part of it, to be around such strong, amazing and inspirational people was such an honour. It's such an honour

to have been nominated by a lovely family, let alone me being given the award. Denise must have been truly inspirational, and to receive an award with her name on it, is such an amazing gift.

"To say that I am grateful and honoured is an understatement. Words cannot express how thankful and deeply touched I am. The certificate and award have pride of place in my home. I'm still looking at it with disbelief.

"I love my job and you never expect to receive anything for the work you do, but to be honoured in such a way is truly amazing and something I will always be proud of and grateful for."

Also honoured with a certificate for Excellence in Patient Care were Irene Byrne (Senior physiotherapist with the Heart and Lung Transplant Unit, Mater Misericordiae University Hospital) and the staff of the Heart and Lung Transplant Unit, Mater Misericordiae University Hospital) represented by nurse Sheena Minogue. Lorna Murphy (previously of the Mater Hospital and



Irene Byrne with Terence Moran, ILFA Chairman



Katie Barry and her partner Liam Collins and their daughter Emma

ILFA) was unable to attend the event but was subsequently presented with her award at the Irish Thoracic Society Meeting.

Warmest congratulations to all the winners.

AIR 2015

Advancing in IPF Research

The 5th annual meeting fully dedicated to Idiopathic Pulmonary Fibrosis (IPF) took place in Prague, Czech Republic, from 17-18 November 2015. This was the biggest AIR meeting to date with over 300 respiratory doctors, nurses and healthcare professionals invited to attend. The educational meeting brought together some of the world's leading experts in the field of IPF to discuss recent advances in research and clinical practice.

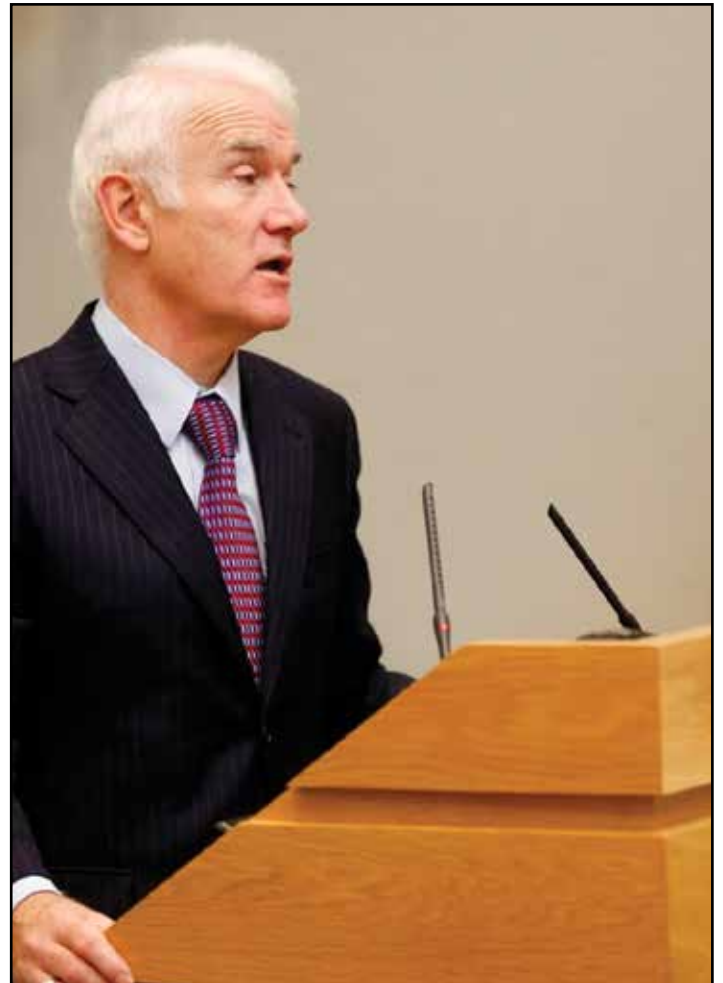
The meeting was chaired by Professor Athol Wells from the Royal Brompton Hospital in London, United Kingdom and Professor Martina Vasakova from Thomayer's University Hospital, Prague, Czech Republic. The programme was exciting and interactive and included lectures, round table discussions, multidisciplinary team presentations, workshops and discussions on the management of challenging real-life cases.

Professor Jim Egan (Mater Misericordiae University Hospital), Lindsay Brown (Respiratory Nurse Specialist from St Vincent's University Hospital) and Nicola Cassidy (ILFA) were invited to speak at the meeting.

The meeting opened with an update on the most important research findings, advances and achievements in the field of IPF from 2014-2015. Some of the main items discussed included;

Age-related changes - As we get older, the cells in our body naturally 'age' and no longer function at their best. For example, the lungs of a 75-year old do not work in the same way as the lungs in a younger adult. Some of the age-related changes that occur in cells of older adults are also seen in patients with IPF. Research is ongoing to see if these natural age-related biological changes are important for the mechanism of lung fibrosis and if they occur sooner or are more pronounced in individuals with IPF.

The challenges for diagnosis - IPF is a difficult condition to diagnose, even for the respiratory experts. It is a progressive disease that behaves differently for each patient. At the time of diagnosis, the disease has probably been established for a number of years but it is impossible for doctors to know the exact length of time. Unfortunately, many patients delay seeking medical advice when they develop breathlessness because they have a virus or chest infection, a previous smoking habit, or think this is a natural part of



Professor Jim Egan

getting older. 'Early' disease does not always mean that the disease is 'mild'. Therefore the sooner the diagnosis is made the better, as the patient can be started on appropriate treatment.

Opportunities for early diagnosis - Lung health awareness campaigns need to inform the general public that it is not normal to be breathless, get recurrent chest infections or have a chronic (long term) cough, and everyone should seek medical advice if they feel unwell. Family doctors need to pay more attention to the presence of 'crackles' - distinctive sounds that can be heard when listening to the lungs through a stethoscope. If crackles are present, GPs should refer patients to a respiratory consultant for further tests as soon as possible. The presence of finger clubbing (rounding of the fingers and toes around the nail beds) and having another family member with IPF should also prompt GPs to consider the possibility of IPF and refer patients to a respiratory



Nicola Cassidy (ILFA), Lindsay Brown (St Vincent's University Hospital, Dublin) and Dr Huzaifa Adamali (North Bristol NHS Trust, formerly of the Mater Misericordiae University Hospital and St Vincent's University Hospital, Dublin)

specialist as soon as possible. Unfortunately if GPs decide to monitor lung function tests over time rather than referring patients to a specialist, this is a wasted opportunity and prevents patients getting an early diagnosis.

Honey-comb changes in the lung - With IPF, the tiny cells in the lung come under extra stress and energy production falls. This ultimately puts the lungs at more risk of injury and fibrosis because the natural healing process goes out of control and scar tissue forms. It is thought that these changes eventually result in the formation of a typical IPF 'honey comb' pattern that is seen on some CT scans.

The term 'honey-comb' or honey-combing' describes the appearance of the abnormal cell structures in the lung - in simple terms, it looks similar to the inside of a 'Crunchie' chocolate bar when it is snapped in half. If honey-combing is detected in the lungs, it is likely that IPF has been present for a number of years.

Medication - Professor Egan reviewed the evidence for medications that were used to treat IPF. Some of these medications initially showed promising results but are no longer used because large research studies showed they didn't work or caused unexpected harm. For example Azothiaprime, Bosentan and Warfarin are no longer recommended as treatments for IPF. Newer medications, Perfinidone and Nintedanib can slow down the rate of IPF progression and are recommended as treatment options for patients with mild to moderate disease. Further research is needed to study if these medications also have benefits for patients with more advanced and severe disease.

Lung transplantation - This is an effective treatment option for some IPF patients. Worldwide, the numbers of IPF patients who received a lung transplant has increased due to the use of the 'Lung Allocation Score' - a system used by doctors and surgeons to identify which patients need to be assessed early and listed for urgent lung transplant if they meet the criteria. Transplant medicine is rapidly evolving and IPF patients who receive a single lung or double lung transplant are living longer than in the past.

Patient-centred care - Nicola Cassidy spoke about ILFA's involvement with an international project coordinated by the European Respiratory Society (ERS) Taskforce on IPF and the European Lung Foundation (ELF). Patient groups from Ireland, Italy, Belgium and the United Kingdom participated in this project and shared their experiences and hopes for improvements in patient care.

Some of the priorities highlighted by the patients and carers included the need for better communication, psychological support, and better access to pulmonary rehabilitation and exercise programmes, and palliative care services. The new statement from the ERS Taskforce on IPF and the ELF that incorporates the patient and carer perspectives is expected in 2016.

Case study workshops - Lindsay Brown delivered an excellent presentation on some of the personal and nursing challenges she and her colleagues faced while caring for an IPF patient. Lindsay's talk generated a lot of discussion between the panel of medical experts chairing the session and the audience.

Irish Thoracic Society Annual Meeting 2015

The Irish Thoracic Society Annual Scientific Meeting took place in Cork on 13-14th November 2015 and was well attended by doctors, nurses, physiotherapists, healthcare staff, scientists and patient organisations from across Ireland.

ILFA had an information stand at the event that was looked after by Anne and Daniel Casey from the Cork IPF Support Group and Nicola Cassidy (ILFA committee member). We were kept busy over the two days with plenty of healthcare professionals calling by to get information leaflets, exercise DVDs, and to learn more about ILFA's work. We had a multi-media station with a DVD player and earphones available so that visitors to our stand could watch the 'Love your Lungs' video featuring Dolores Williams from Dublin and a short film about 'The National Patient Charter for IPF' that featured healthcare professionals from different hospitals around Ireland. We also had the opportunity to meet with colleagues and volunteers from other lung health charities who attended the event.

There was a session dedicated to interstitial lung diseases and Nicola Cassidy spoke about some research that was carried out by ILFA. Her presentations were called "The burden of Idiopathic Pulmonary Fibrosis reported by patients and carers in Ireland" and "The Development of the National Patient Charter for IPF". A copy of the national charter was included in the welcome pack for all the delegates who attended the conference, thanks to Suzanne McCormack and the organisers of the ITS conference. Petra Grehan (Physiotherapist at the Mater Misericordiae University Hospital) described the medical evidence for the benefits of exercise and pulmonary rehabilitation programmes for IPF patients. Petra analysed the results from 14 major studies and concluded that IPF patients who took part in physical exercise of low intensity and long duration (for example a home-exercise programme) did better than those who exercised for short duration and at high intensity.

The Irish Guidelines on Long Term Oxygen Therapy in Adults, compiled by Anail (The Respiratory Nurses Association of Ireland), the Irish Society of Chartered Physiotherapists, and the Irish Thoracic Society, were launched at the conference. The aim of the manual is to provide a standardised guideline that healthcare professionals can use when home oxygen is being prescribed for patients. The document is available to read on the Irish Thoracic Society website.

One of the guest speakers at this year's conference was Professor Athol Wells from the Royal Brompton Hospital in London. Professor Wells is a good friend to ILFA and is the Chairman of the ERS Task Force on IPF. His talk was called "Overall approach to interstitial lung disease: the critical importance of clinical reasoning".



Donna Langan (respiratory nurse specialist, Galway University Hospital), Tara Cahill (Respiratory physiotherapist, Galway University Hospital) and Anne Casey (Cork IPF support group).



Grainne Murphy, Nicola Cassidy, Professor Athol Wells, Irene Byrne, Petra Grehan and Laura Grehan.

Professor Wells gave a brief history of IPF and explained the major difficulties that respiratory doctors face when trying to accurately diagnose IPF using the medical guidelines that were published in 2011. He described the guidelines as being "broken" because they did not take into account the significant proportion (40-50%) of patients who do not have a 'typical' IPF pattern on the CT scans of their lungs and therefore cannot be definitively diagnosed with IPF. These patients could be described as having 'probable IPF' or 'possible IPF'. Although surgical biopsies can sometimes be helpful to diagnose IPF when the result of the CT scan is inconclusive, it is unrealistic to consider such a major and potentially risky procedure for everyone, especially older adults, those with advanced lung fibrosis and other co-existing medical conditions. Professor Wells argued that respiratory doctors, histologists (experts in looking at biological tissue under a microscope) and radiologists (experts in reading x-rays and CT scans) must be able to decide on a working diagnosis of IPF based on their knowledge, clinical experience and how the patient's lung disease is behaving, rather than having to rely entirely on strict medical guidelines.

This year the ITS prizes for best poster and best presentation were awarded to Dr Sinead Walsh and her colleagues in the Conway Institute at Trinity College Dublin for research on the cellular mechanisms underlying pulmonary fibrosis.



Dr Modestas Jarutis (Medical Manager, Roche Ireland) with Professor Anthony O'Regan (Galway University Hospital) and Nicola Cassidy (ILFA) at the launch of the 'Love Your Lungs' campaign.

'Love Your Lungs' Video



Dolores Williams, pictured left, from Dublin took part in an uplifting short video describing how exercise and positive thinking help her to manage her IPF. The video was sponsored by Roche Ireland in support of the 'Love Your Lungs' campaign to raise awareness of

lung disease and to encourage people to seek medical help if they are feeling breathless.

Dolores spent the day with a camera crew filming in her home, at the gym and walking in the local park with her husband Matthew and her grandson Matthew. The video was launched in November 2015 at the Irish Thoracic Society Conference. It is available to watch on the ILFA website and Facebook page and has been very popular with over 160,0000 people viewing it in the first few weeks. We are very grateful to Dolores for helping to raise awareness about IPF and lung health.

Decade of the Lung

The Forum of International Respiratory Societies met at the European Respiratory Society Congress in 2015 to launch the 'Decade of the Lung' campaign. The group called for political commitment, improved prevention and management strategies, and further education of healthcare professionals to drive improvements in lung health around the world. They also specified that patients should have access to effective, affordable and high-quality medicines. These principles are reflected in the key points of ILFA's National Patient Charter for IPF.



Professor Jim Egan, Senator Feargal Quinn, Joan Doyle and Matt Cullen at the launch of The National Patient Charter for IPF

Organ Donation and Transplantation News

Congratulations to all the team at the National Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital in Dublin for performing a record number of lung transplants in 2015.

Figures from the National Organ Donation and Transplantation Office revealed that 36 lung transplants, 16 heart transplants, 61 liver transplants and 120 kidney transplants were performed in 2015 thanks to the generosity of 81 organ donors and their families.

Organ Donation Week will take place from 2nd April to 9th April 2016.

Nintedanib

Nintedanib is an anti-fibrotic drug that can slow down the rate of IPF progression in patients with mild to moderate disease. The medicine was approved by the European Medicines Agency in 2015.

On 27th January 2016, the National Institute for Health and Care Excellence (NICE) in the United Kingdom issued guidance recommending Nintedanib as a treatment option for Idiopathic Pulmonary Fibrosis.

In Ireland, the National Centre for Pharmacoeconomics (NCPE) is currently considering whether to license Nintedanib and reimburse the cost of this high-tech medicine.

The NCPE will carry out a detailed analysis of the clinical benefits, side effects and cost effectiveness of the drug to reach their decision. ILFA has written to the NCPE to request an update on the current status of Nintedanib.

Everyday Hero fundraising site

ILFA has used the mycharity.ie website for many years as our on-line fundraising site. In 2016, mycharity.ie will change its name and be known as 'Everyday Hero'. This fundraising site is simple to use and allows you to set up your own online fundraising page and email the link to your family, friends, and colleagues in Ireland and abroad. People can donate money securely and directly to ILFA using their debit or credit cards. All donations are automatically acknowledged and funds are transferred to ILFA's bank account at the end of each month. A small fee is deducted for each transaction. ILFA will update our sponsorship cards and donation cards with details of the new website,

www.everydayhero.com/ie

Fundraising Round Up

Coffee Morning

Congratulations and thanks to Siobhan Ryan (Respiratory and Acute Medical Clinical Nurse Manager, Mater Private Hospital) for organising an impressive and irresistible cake sale in the Mater Private Hospital in December in aid of ILFA. Siobhan's enthusiasm, hard work and baking talents paid off as she raised the fantastic sum of €1410. Thank you to all the staff, patients and hospital visitors who supported the cake sale so generously.

The photos show Siobhan Ryan and Jimmy Rushe at the cake sale in December and Terence Moran (ILFA Chairman) with Professor Jim Egan (Respiratory Consultant at the Mater University Hospital), Kathryn Holly (Chief Operations Manager of the Mater Private Hospital) and Siobhan Ryan.

ILFA Annual Christmas Swim

a report from Nicky Goodbody

Although it was unseasonably warm on St Stephen's Day 2015, there was a higher than usual tide and strong swell, so only the very brave swimmers ventured into the water. They included Niall Deegan and Matt Regan, who put the rest of us to shame by diving in three times! Honora and Colin Ireland, who both swam, are to be thanked especially for their help with the organisation and the refreshments afterwards.

We had a good turn-out of loyal supporters and are especially grateful to Giles Bailey for shaking the ILFA bucket with such successful results. After the swim, we all adjourned to a local hostelry for warming mulled wine and post-Christmas relaxation. In spite of the weather, a great time was had by all.

Gerard Osborne's sky-dive

Gerard Osborne from Athy, Co Kildare did a sky-dive for ILFA in October in memory of his aunt and God-mother, Denise Cassidy. Gerard was disappointed when the jump was cancelled a few times due to bad weather conditions but he eventually took to the skies in October, and the date of his jump coincided with Denise's anniversary. Gerard's family like to think that Denise pushed him gently out of the plane! Gerard was cheered on by his family and friends and everyone at ILFA is very grateful to him for his bravery and sense of adventure.

Thank you

Sincere thanks to all our fundraisers for all your hard work, dedication and enthusiasm. ILFA relies on your generosity and fundraising talents to support our work. We are very grateful for all your support.

Thank you everyone who supported ILFA's Christmas card campaign and to the families who made donations to ILFA in memory of their loved one.

Upcoming fundraising events

2016 VHI Women's Mini-Marathon

The VHI Women's Mini-Marathon will take place in Dublin on



Debbie Cullen Hezam and Teresa Cullen before the 2014 mini-marathon

Monday 6th 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 online to take part in the mini-marathon at www.vhiwomensminimarathon.ie or use the entry form printed in the Evening Herald. The closing date for entries is 29th April or whenever the maximum number of entries is reached. Once you have registered, please contact ILFA for your fundraising pack.

Don't delay, register today.

Camino Walk

Good luck to Laura Ryan, Derek O'Donovan and Therese Martin who will take part in a 5-day, 125km Camino trek from Sarria to Santiago del Compostela, in Northern Spain, in aid of ILFA. The intrepid trio will start their walking adventure in April. We hope they will enjoy the experience and look forward to hearing how they get on.

Golf Classic

The Midlands ILFA Support Group is running a Golf Classic in aid of ILFA in Tullamore Golf Club on Friday 5th August. The price per team of four is €160 which includes a meal. Tullamore Golf Club is near the M6 and only an hour from Dublin. Your support would be appreciated. **Please call 086 160 2482 for further information.**

Dates for your diary

The Great Limerick Run - 1st May 2016

The VHI Women's Mini-Marathon - 6th June 2016

The Cork Marathon - 6th June 2016

The Dublin City Marathon - 30th October 2016

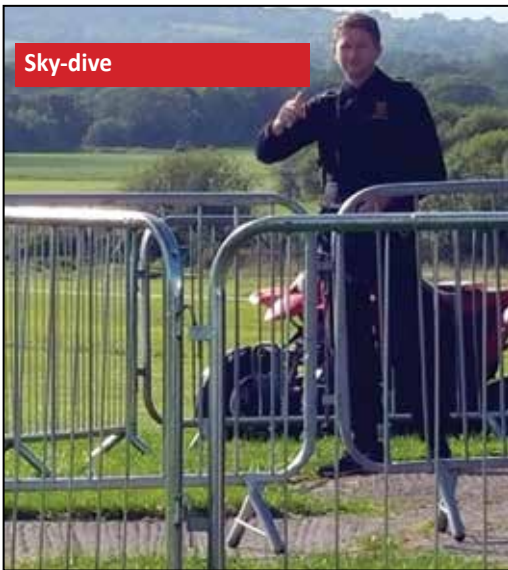
Coffee morning



Coffee morning



Sky-dive



Charity Swim



Sky-dive



Sky-dive



Charity Swim



ILFA breathlessness survey

ILFA would like to find out more about your experiences of breathlessness and how you manage your symptoms. We would be very grateful if you would fill out the enclosed questionnaire and return it to ILFA by the 30th April 2016.

There is no problem if you would prefer not to complete the survey. The questionnaire is anonymous and there are no right or wrong answers. The survey is also available to fill in online on the ILFA website, www.ilfa.ie.

Thank you for sharing your experiences.

Patient resources

Our patient information packs include a wide range of useful patient information leaflets about IPF. Our exercise resources include the 2000 Steps a Day walking pack and the ILFA home-exercise DVD. All our materials are free. Please call 086 871 5264 to request an information pack or exercise materials.



STALL Breathing technique

- S **Stop** what you are doing.
- T **Try** to remain calm. **Turn** up your oxygen.
- A **Assume** a comfortable position. For example, sitting or leaning.
- L **Let** your imagination take you to a safe place. Imagine yourself there, relaxing.
- L **Let** your breathing return to normal.

When your breathing has returned to normal, reset your oxygen to normal.
Call for medical help if your symptoms do not settle.



ITS Interstitial Lung Disease Registry

A disease registry aims to collect important information about specific medical conditions over a wide geographical area, in an anonymous manner. Idiopathic Pulmonary Fibrosis (IPF) is a relatively rare disease that affects people all over Ireland and indeed the world. The Irish Thoracic Society (ITS) has developed an Interstitial Lung Disease (ILD) registry for Ireland to improve our knowledge and ability to treat people with IPF.

The registry will allow us to collect and analyse information relating to the health and wellbeing of people with IPF. Information relating to the prevalence (how common the condition is), incidence (the number of new cases each year), symptoms, and treatment of IPF will be stored on the registry. Using this data, we will be able to measure the disease impact, clinical progression and treatment of IPF across Ireland, and advance education and research into ILDs.

At present, the registry is piloting in Galway University Hospital and will

shortly roll out to centres in Dublin, Cork, and Limerick. It is hoped that by using a network system, patients all over the country can be involved in the registry if they wish. All information is anonymous and a registry committee in the ITS will closely regulate use of the information. If you would like to take part in the registry you will be given an information leaflet and asked to sign a consent form. There is no risk to taking part in the IPF registry and you can refuse to participate at any time.

We are very pleased to have the opportunity to develop this registry and wish to acknowledge the support of the ITS and financial support from Boehringer Ingelheim. This is one of the first disease registries in Ireland and matches international trends in developing such resources to help people with IPF into the future.

This report was compiled by Donna Langan, Respiratory Nurse Specialist, and Professor Anthony O'Regan, Consultant in Respiratory Medicine, Galway University Hospital.

Keep in touch with ILFA

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

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



Irish Lung Fibrosis Association
www.ilfa.ie

