



Written Declaration on IPF to be adopted by the European Parliament

ILFA is one of the founding members of the European Idiopathic Pulmonary Fibrosis and Related Diseases Federation (EU-IPFF) which formed in February 2016 when the patient organisations involved in developing the European Patient Charter for IPF joined forces.

The EU-IPFF identified several major projects to tackle in 2016 including the **Written Declaration on Idiopathic Pulmonary Fibrosis (IPF)**. A Written Declaration

of the European Parliament is a principled document that gives direction to the institutions of the European Union and EU Member States. The Written Declaration on IPF is based on the principles of the European Patient Charter for IPF and calls for improvements in diagnosis and treatment, more research to identify the cause and cure for IPF, better access to new medicines approved by the European Medicines Agency, and equal lung transplant eligibility across Europe.

The Written Declaration on IPF was presented to the EU parliament on April 11th and the member EU-IPFF associations, healthcare professionals on the EU-IPFF's scientific advisory board, and other groups had three months to educate, lobby and persuade Members of the European Parliament (MEPs) to sign the document.



Marian Harkin supporting IPF

This was successfully achieved on July 11th with 388 MEP signatories. The Written Declaration on IPF has now been passed to the European Commission and European Council to formally adopt a European strategy for IPF.

The success of the Written Declaration is a major achievement in raising awareness of IPF across Europe and has highlighted the concerns of patients, carers and healthcare professionals to the European policy-makers.

ILFA would like to extend our gratitude to all the MEPs from Ireland and across the EU who supported the Written Declaration 26/2016 on idiopathic pulmonary fibrosis. Marian Harkin, MEP, deserves special thanks as she was one of the co-authors of the Written Declaration. The photo shows Marian Harkin showing her support for the IPF "Breath of Hope" campaign.

The EU-IPFF has also submitted an application to the EU for a **European Reference Network (ERN)** for interstitial lung diseases including IPF. ERNs create a clear governance structure for knowledge sharing and care coordination across the EU. They consist of networks of centres of expertise, healthcare providers and laboratories that are organised across borders. The ERN - LUNG will enable 61 centres of excellence in 12 European countries to receive EU funding to establish a collaborative research network and facilitate exchange of clinical data to ensure that patients with interstitial lung disease receive the best care possible.

ILFA would like to pay special tribute to the great work being done by Liam Galvin (ILFA Director and Secretary of the EU-IPFF) to drive the success of the various EU-IPFF projects.

Welcome to Gemma O'Dowd



ILFA is very pleased to announce that Gemma O'Dowd has recently joined ILFA taking over the reins from Denise Dunne. Gemma joins us with 25 years' experience working in the corporate sector, supporting CEO's and Senior Directors across multinational and financial organisations.

We are delighted to welcome Gemma to the team and look forward to working with her. You can contact Gemma by email info@ilfa.ie or by phone on 086 871 5264.

ILFA Service of Prayer and Reflection



The annual ILFA Service of Prayer and Reflection will take place on Saturday 15th October at 3pm in the Gort Muire Chapel, Balinteer, Dublin 14 (near to the M50, Dundrum Shopping Centre and

Balally Luas station). The ecumenical service will be celebrated by the Reverend Fr Martin Kilmurray (Prior of Gort Muire), the Reverend Vanessa Wyse Jackson (Rathgar Methodist Church), the Reverend Fr Brian McKay (Prior of Our Lady of Mount Carmel, Whitefriar Street Church) and the Reverend Canon Charles Mullen (Dean's Vicar at St Patrick's Cathedral).

A special candle lighting ceremony will take place to remember lung fibrosis patients who have passed away. **If you would like your loved one remembered at the ceremony, please contact ILFA by calling 086 871 5264 or emailing info@ilfa.ie by the 26th September.**



Attending the ILFA Brainstorming Session in Dublin on June 18th are Dermot King, Joan Doyle, Sylvia Ryan and John Doyle.



ILFA Committee members who facilitated and recorded the discussions; Terence Moran, Eddie Cassidy and Liam Galvin (back row). Nicola Cassidy, Nicky Goodbody, and Lindsay Brown with Tony Shone, Director of Invisio Ltd.

ILFA Brainstorming Session

On Saturday 18th June a group of approximately 30 invited guests attended a 'brainstorming session' with ILFA as part of a strategic review. We invited representatives from our various stakeholder groups including patients, caregivers, healthcare professionals, and members from the pharmaceutical industry and oxygen supply companies to attend a 'Word Café' style meeting.

The aim of the gathering was to identify ideas and priority actions needed to advance the six key care areas described in the National Patient Charter for IPF. The topics debated included;

- Early and accurate diagnosis
- Clear and concise information on IPF
- Medicine and oxygen
- Pulmonary rehabilitation and exercise
- Lung transplantation
- Additional supports including counselling, practical supports, patient supports and palliative care.

Using sticky post-it notes, coloured felt-tip markers, poster boards and working in small groups of 4-5 people, the six leaders from the ILFA committee circulated around the room to facilitate and record the discussion about each of the 6 areas described in the charter. The topics were discussed in quick succession over 2 hours. Thankfully everyone fully engaged in the process and ideas and constructive suggestions to improve IPF patient care were flowing.



The event was a great success and the ILFA committee is grateful to everyone for taking part and sharing their ideas, insights, expertise and aspirations for the future. We are currently collating all the ideas gathered during the process and will share the results in the future. ILFA has already started working on some of the excellent suggestions received. Watch his space!

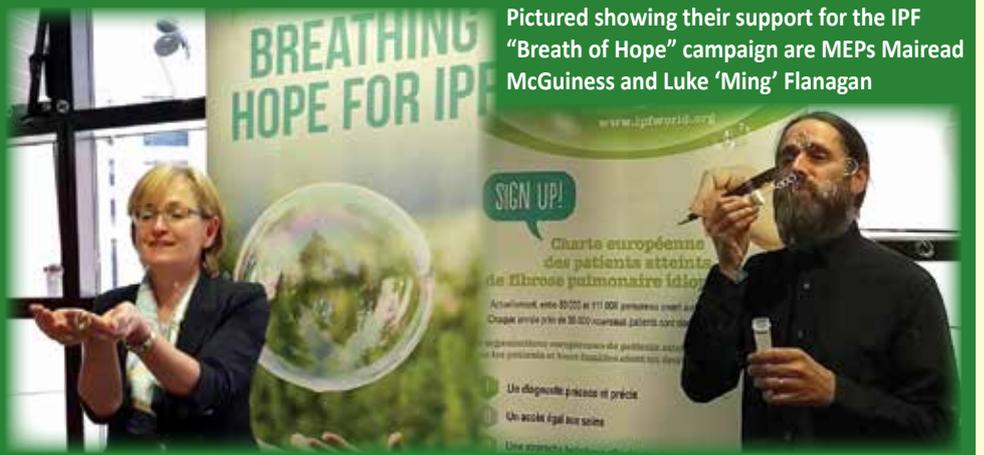
Sincere thanks to Tony Shone, Director of Invisio Ltd., who facilitated the meeting and kindly gave his services and expertise for free. ILFA is extremely grateful to Tony for his generosity and leadership skills as he guided everyone through the invigorating brainstorming process.

Here is a selection of some of the feedback received;

- "It was a great meeting and a pleasure to be able to put our ideas and views across. Thank you and I hope it helps in the future."
- Well done to ILFA for the brainstorming session. I thought it was great the way everyone contributed and the whole process was excellent."
- "Slick, extensive, intensive."
- "It was a pleasure to be there. It was a great session, the best so far."
- "Thank you to the ILFA committee for all your hard work. Everyone enjoyed the meeting and found it interesting and educational. Well done."
- "Professional, informative, social."
- "I think the brainstorming session was excellent because of the very diverse nature of attendees, it was great to get the views of various stakeholders which collectively made it a valuable experience for all concerned."
- "Creative, positive and focused."

Thank you from ILFA

Sincere thanks to the Members of the European Parliament from Ireland and Northern Ireland who signed the EU Written Declaration on IPF; Lynn Boylan, Matt Carthy, Neasa Childers, Deirdre Clune, Luke 'Ming' Flanagan, Marian Harkin, Brian Hayes, Seán Kelly, Mairead McGuinness, Liadh Ní Riada, Martina Anderson (N. Ireland) and Diane Dodds (N. Ireland).



Pictured showing their support for the IPF "Breath of Hope" campaign are MEPs Mairead McGuinness and Luke 'Ming' Flanagan

Interstitial Lung Disease Study Day 2016

Liam Galvin and Nicola Cassidy, ILFA committee members, attended the 2nd Interstitial Lung Disease Study Day for healthcare professionals in Dublin on Friday 5th February. The medical event was organised by Roche Products (Ireland) Ltd.

Nurses, physiotherapists, social workers and pulmonary physiologists from all over the country attended. The event opened with a presentation on the medical aspects of interstitial lung diseases delivered by Dr Kate O'Reilly respiratory consultant from the Mater Misericordiae University Hospital. Dr Emmet McGrath, respiratory consultant from St Vincent's University Hospital, spoke about treatment options for idiopathic pulmonary fibrosis (IPF). Respiratory Nurse Specialists, Bernadette Bowen from Cork University Hospital and Lynn Fox from the Mater Misericordiae University Hospital spoke about the nursing challenges of IPF and managing patients' symptoms.

Irene Byrne, Senior physiotherapist at the Mater Misericordiae University Hospital, spoke about pulmonary rehabilitation for IPF patients and using ILFA's free exercise resources to encourage patients to keep active to maintain their physical strength and improve their quality of life. Patricia Davis, Respiratory Nurse Specialist from St. James' Hospital gave a presentation on

the use of oxygen for IPF patients and the development of Irish oxygen guidelines. Nicola Cassidy spoke about ILFA's involvement with the European Respiratory Society (ERS) Task Force on IPF and the European Lung Foundation (ELF) in the production of a new statement on the diagnosis and management of IPF, incorporating patient's and carer's perspectives. 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 for the future.

Dr Faith Cranfield, Consultant in Palliative Care Medicine at St Francis Hospice, gave a presentation on palliative care and symptom management for IPF patients. The final speaker was Dr Peter Riddell (previously of the Mater Misericordiae University Hospital and now at St Vincent's University Hospital) who discussed lung transplantation for IPF. There were four lively interactive questions and answers sessions spread throughout the day.

It was an excellent educational meeting and a great chance to meet the healthcare professionals who are leading the way in IPF patient care in Ireland.

Photos courtesy of Roche Products Ireland Ltd. show the speakers at the event and Dr Kate O'Reilly from the Mater Misericordiae University Hospital.



Back row: Dr Emmet McGrath (St Vincent's University Hospital), Dr Modestas Jarutis (Medical Manager, Roche Products Ireland). **Front Row:** Bernadette Bowen (Cork University Hospital), Nicola Cassidy (ILFA), Dr Kate O'Reilly (Mater Misericordiae University Hospital), Patricia Davis (St James's Hospital) and Triona Rice (Roche Products Ireland).

Canadian Care Access for IPF patients

In April, the Institute of Health Economics in Alberta Canada and the Canadian Pulmonary Fibrosis Foundation held a joint event entitled "Access to Care for Patients with Idiopathic Pulmonary Fibrosis - Multi-stakeholder National Forum".

30 invited guests including patients, caregivers, healthcare professionals, policy-makers, health system administrators and experts in health technology assessment came together at a roundtable forum to discuss policy recommendations on IPF care for Canada.

Nicola Cassidy from ILFA was invited to address the audience in Toronto via telephone in a session entitled "Healthcare policy and IPF: Values of patients and society – shared interests? Do we need a charter?"



The photo (courtesy of Jim Troy) shows Tom Flynn and Anthony Marnell from the Midlands Support Group with Petra Grehan, Physiotherapist at the Mater Misericordiae University Hospital in Dublin.

ILFA's New Information Leaflet



ILFA launched a revised leaflet entitled "ILFA, Join Us! Get Involved!" at the Patient Information Day in Thurles in April. The leaflet tells you about the work of the Irish Lung Fibrosis Association (ILFA) in supporting patients and families affected by pulmonary fibrosis. It explains how the charity is funded and how it uses this funding. Our financial accounts are independently audited every year, submitted to the Companies Office, and are available on the website. The leaflet also tells you how you can help ILFA and patients with pulmonary fibrosis. We hope you find the leaflet useful.

2016 Autumn ILFA Patient Information Day



The next ILFA Patient Information Day will take place on Saturday 5th November

at the Crowne Plaza Hotel in Santry, Dublin. Registration will take place from 10am and the lectures will start at 10.30am. Speakers will include Dr Kate O'Reilly from the Mater Misericordiae University Hospital. More details will appear on the ILFA website (www.ilfa.ie) nearer to the date.

Patient Information

The first ILFA Patient Information Day of 2016 took place in the Anner Hotel, Thurles, County Tipperary on the 9th April. The event was well attended and the location meant that patients travelled from the surrounding counties and further afield to hear the presentations from the invited speakers. Terence Moran, ILFA Chairman, welcomed everyone to the meeting and introduced the speakers.

Dr Emmet McGrath, Respiratory Consultant from St Vincent's University Hospital in Dublin gave an overview of Idiopathic Pulmonary Fibrosis (IPF). He explained how IPF was largely a neglected medical condition until relatively recently. Thankfully IPF is now being researched more thoroughly and there are two drug treatment options that have been shown to slow down disease progression.

With IPF, the cause of the pulmonary fibrosis is unknown (idiopathic means 'unknown'). IPF is a difficult condition to diagnose and in order to reach a definite diagnosis, all other lung diseases have to be ruled out. The diagnosis is reached when the healthcare members of the multi-disciplinary team reach a consensus after examining the patient's history and results from investigations including lung biopsies (if carried out) and images from high resolution CT scans.

Lung biopsies are not suitable for everyone as there can be risks associated with undergoing a surgical procedure and having a general anaesthetic, especially in older adults. Increasingly, a new technique called cryobiopsy is being used to obtain lung biopsies. This technology is considered to be safer (due to the lower risk) as patients do not have to be put asleep with a general anaesthetic. It also allows for larger pieces of lung tissue (biopsies) to be obtained for examination under a microscope.

IPF is typically diagnosed in adults aged 60-70 although younger patients are sometimes diagnosed. The disease is different for each patient and can progress in 4 ways;

- (1) Patients can remain stable for a number of years
- (2) There is a slow progression with time and patients develop increasing shortness of breath
- (3) There is rapid disease progression, representing severe IPF
- (4) A subset of patients may develop an unexplained acute exacerbation (worsening) of symptoms.

In recent years, there have been many advances in IPF research and a number of successful international clinical trials have taken place. Two anti-fibrotic drugs; Pirfenidone and Nintedanib, have been shown to slow down the rate of disease progression of IPF, although they cannot reverse lung damage that is already present at the time of diagnosis. The two medicines work in different ways but they have similar efficacy. Respiratory doctors must weigh up the benefits and risks associated with each medicine when choosing which one to prescribe. Doctors must also educate patients about the drugs and manage their expectations. It is important to remember that Pirfenidone and Nintedanib will not cure IPF - indeed some patients will not notice significant improvement in their symptoms and unfortunately the health of others will continue to decline. In addition, there is a chance that some patients will experience side effects when taking the



Photo (courtesy of Jim Troy) shows Ciarán Heatley, Petra Grehan and Terence Moran.

medicine and their treatment may have to be stopped for a short time or completely, depending on how serious the adverse effects are.

Dr McGrath mentioned the importance of having regular check-ups, bone scans and vaccines. He stressed the importance of stopping smoking and taking medication for stomach acid reflux, and these themes were continued in a later talk by Lindsay Brown.

The next speaker was **Petra Grehan**, physiotherapist with the Mater Misericordiae University Hospital. Petra started her presentation by explaining how the lungs work. She compared the lungs to a tree; the trachea (wind-pipe) is similar to a tree trunk and the alveoli (tiny air-sacs that allow the gas exchange of oxygen and carbon dioxide) are similar to leaves.

With IPF, the thick scar tissue that develops in the lungs prevents the normal gas exchange and patients can develop shortness of breath, a cough and low energy. The fear and anxiety that can sometimes accompany breathlessness can lead to patients avoiding exercise or activity, however a lack of exercise will lead to a decrease in quality of life as patients lose their mobility, strength and independence. To avoid this vicious cycle, it is important to know the benefits of exercise and physical activity for IPF patients.

Daily exercise is essential, even when you are on oxygen. Exercise will help you to maintain your general well-being, mobility, mood and confidence, and can improve your breathing and quality of life. Petra advised everyone to;

- ▶ include exercise in their daily routine
- ▶ start exercising slowly and progress gradually
- ▶ exercise during the TV advertisements
- ▶ exercise at your own pace and do not compare yourself to others or how you used to be
- ▶ keep a diary to record the amount of exercise you do and how you feel.

Petra advised everyone to walk more and use the ILFA 2000 Steps a Day walking challenge to increase their levels of aerobic exercise. It is also important to include exercises that will improve strength and

Day, April 2016



Photo (courtesy of Jim Troy) shows Ciarán Heatley, Petra Grehan, Lindsay Brown, Dr Emmet McGrath and Terence Moran.

flexibility. The ILFA Exercise DVD is an ideal way for patients to take part in a variety of simple exercises that can be carried out at home and performed while standing or sitting.

Petra briefly talked about managing a cough and encouraged patients to talk to their healthcare team if their cough is getting worse. Some simple tips include sipping water (but not if you are breathless), sucking on a sweet, using extra pillows to lift your head when sleeping and medication. Petra also encouraged anyone experiencing urinary incontinence due to coughing to tell their doctor or nurse, as help is available.

Lindsay Brown, respiratory nurse specialist from St Vincent's University Hospital, spoke about some of the treatment options used to help patients with IPF. The topics covered included smoking cessation, weight management, coping with breathlessness, and oxygen therapy. Stopping smoking at any age will result in immediate health benefits. All patients with IPF who smoke should seek medical advice to help them quit their smoking habit and there are many different nicotine-replacement aids available. The HSE National Quit Line can give helpful advice and can be contacted on Freephone 1800 201 203.

Weight management is very important for patients with lung fibrosis. Being overweight can place additional stress on the body and can result in further health complications, for example a higher risk of stroke, diabetes, heart disease and sleep apnoea. In addition, carrying extra eight adds to the work of breathing and impacts on your exercise capacity. Being underweight is also a problem for some patients and can lead to bone disease, fatigue, frailty and increased rates of hospitalisation. If you are underweight, your breathing can be affected due to weakened muscles which can impact on your ability to exercise. Your weight is extremely important if you are being considered for a lung transplant operation.

It is important to have a good diet to;

- ▶ provide energy for breathing
- ▶ have enough protein to help build muscle
- ▶ promote a strong immune system to help you prevent and fight infection

- ▶ help you maintain a healthy weight.

Lindsay encouraged everyone to eat regular small meals and snacks, take small bites, eat slowly and breathe deeply while chewing. You should ask your healthcare team for advice if you need to lose weight or if you notice that you are losing weight without trying.

Next Lindsay discussed some of the treatment options used to manage breathlessness. These include the use of different breathing techniques for example, the STALL breathing technique, pursed-lip breathing, using fans that blow cool air, relaxation techniques and medicine. Supplemental oxygen can help reduce shortness of breath and will also improve your ability to exercise, walking distance, and your ability to do your activities of daily living such as bathing and dressing.

Lindsay finished off by discussing the anti-fibrotic medications Pirfenidone and Nintedanib, both of which can slow down disease progression in patients with mild to moderate IPF.

Ciarán Heatley, respiratory physiologist at the Mater Misericordiae University Hospital, spoke about "Pulmonary function testing". He explained that patients will be asked to do pulmonary function tests (PFTs) regularly following their IPF diagnosis in order to get a clear picture of how the lungs are working. PFTs are like the National Car Test (NCT) where the mechanics of your lungs are tested.

Doing PFTs is hard work but the more effort you put into doing them well, the more accurate the results will be. Ciarán knows exactly how hard it is to do the tests as he has to do them himself several times a week to calibrate the machine and make sure the equipment is working correctly and the results are consistent.

To understand why PFTs are performed it is important to understand the lung mechanics and the impact of IPF on the lungs. With IPF, the lungs become hard and stiff due to the fibrosis (scarring) and this results in the loss of flexibility (lung compliance) of the lung tissue. As IPF progresses, the lung volume decreases and this is why IPF is classified as a 'restrictive' lung disease. Spirometry is usually one of the first measurements performed during PFTs and this test measures the lung compliance. The Forced Vital Capacity (FVC) value obtained

during spirometry is a direct reflection of your lung compliance.

With IPF, the fibrosis also increases the thickness of the alveoli (air sacs). The alveoli have an extremely thin membrane that enables the transfer of oxygen and carbon dioxide (waste gas) between the lungs and the blood stream when we breathe in and out. However increased thickening of the alveoli due to lung fibrosis makes it harder for the gases to transfer, making the lungs less efficient. The gas transfer measurement is called the DLco (or TLco) value and is extremely important as it is a direct reflection of the efficiency of your alveoli.

Patient Support Groups

Cork Support Group

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 in the Garden Room at the Carmelite Community Centre at Whitefriar Street Church, Aungier Street (South George's Street), Dublin 2. Please call Matt on 086 244 8682, Pam on 086 178 9055 or Paddy on 087 412 8612 for more details.

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at The Fels Point Hotel (previously called the Carlton 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 in the lobby of the Tullamore Court Hotel, Tullamore, Co. Offaly. Please call Tom on 086 150 0970, Mary on 086 160 2482 or Anthony on 087 258 5699 for more details.

New support groups

South East Support Group

Laura and Ruth are hoping to set up an IPF support group in County Wexford, if there is local interest. Please call Laura on 087 285 4509 or Ruth on 085 164 9499 for more information.

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

The values obtained during a PFT are expressed as percentage of the predicted values which mean they are based on reference values for healthy lungs for your age, height, gender and ethnicity. PFTs give your healthcare team a clear picture of the mechanics and efficiency of your lungs.

Here is some advice for when you are due to attend hospital to have your PFTs done;

- ▶ Do not take any inhalers before your tests
- ▶ Let the respiratory physiologist know if you have or recently have had a chest infection
- ▶ Tell the staff about any changes to your health or regular medication
- ▶ Use your oxygen as normal, however you will be asked to remove it during testing and shortly before it, as supplemental oxygen can alter some results
- ▶ Make sure you are well hydrated
- ▶ Plan your journey to the hospital in advance to avoid having to rush
- ▶ Wear loose clothing and avoid wearing jewellery around your neck
- ▶ Try to relax
- ▶ And most importantly ... WORK HARD! And give the tests everything you've got!

After the talks from the invited speakers, there was a lively questions and answers session with good audience participation. Some of the discussions that took place concerned access to medication, familial lung fibrosis, getting a second medical opinion, exercising and managing breathlessness.

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

What you thought ...

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

- ▶ 31.1% of people said they were satisfied with the event while 68.8% indicated they were very satisfied
- ▶ 87.5% felt the programme definitely met their information needs
- ▶ All the speakers scored very highly in the evaluation
- ▶ 93.3% indicated that they would definitely attend another ILFA Information Day
- ▶ 100% said they would definitely recommend the ILFA Patient Information Day to another patient.

Additional comments received included;

"Very informative"

"Great information day"

"Keep up the excellent work"

Farewell to Denise Dunne

ILFA said farewell to Denise Dunne after more than 3 years service. Terence Moran, ILFA Chairman presented Denise with a floral bouquet and a gift voucher as a token of our appreciation. Terence paid tribute to Denise and thanked her for all her help and dedication during her time with ILFA. We wish Denise every success and happiness for the future.



The VHI Women's Mini-Marathon



Some of the members of Team ILFA before the race



The Warren family



Terence, Rose, Nicky and Susie



Sue, Ursula, Edna and Ken



On Monday 6th June 2016, over 40 ladies from all over Ireland took part in the mini-marathon to raise funds for ILFA, making this one of our largest fundraising groups for a number of years. Team ILFA was made up of wives, mothers, daughters, sisters, cousins, friends and colleagues who had a special connection with someone affected by lung fibrosis.

On race day, the weather conditions looked good and a number of ladies left home with sun cream and sunglasses and an expectation of sunshine and warm weather.

The areas around the city centre were filled with colour, excitement, laughing and chatter as over 40,000 ladies met up

with mini-marathon friends before the event.

Team ILFA met at the Mespil Hotel for some photos and words of encouragement from Terence Moran (ILFA Chairman) and ILFA committee members Nicky Goodbody, Marie McGowan and Nicola Cassidy. ILFA was delighted to welcome back some of our loyal supporters including Rosemary Wilson (taking part in her 13th mini-marathon for ILFA) and her friends Rita O'Regan and Margaret McIver. The Kennedy family from Tallaght were represented by Ann and her daughters Fiona, Marianne and Deirdre. We were also joined by Celine Gray and her daughter Ashling, Susie Chatziioannidis and Rose Mellon. Edna Powell was joined by her friends Ursula and Sue and her niece Annajane Cunningham and her friend Caoimhe McConnell.

Unfortunately just as Team ILFA was leaving for the start line,



Above: Caitriona and Claire

Left: Rose and Nicky



Nicky, Nicola, Terence and Marie



Back row: Deirdre, Fiona, Ann, and Marianne. Front row: Grainne, Ciaran and Keelin.

there was a downpour of torrential rain. Suddenly rain jackets, hats and plastic bin liners were produced and although it was wet and miserable, everyone departed in high spirits. Thankfully by the time everyone sang a rousing “Molly Malone” and the claxon sounded the start of the race, the sun was out again and warmed everyone up as they set out on the 10k route.

After the event, Team ILFA gathered in the Duke Pub for refreshments. There was great excitement as Team ILFA returned and Eddie and Nicola Cassidy, Nicky Goodbody and Marie McGowan from the ILFA committee were there to welcome everyone back. The tea and sandwiches - the best in Dublin! - went down a treat and helped replace lost energy.

ILFA was especially delighted to congratulate Edna Powell on her remarkable mini-marathon success. This event was extra-special for Edna as she recently received a lung transplant at the National Lung Transplant Unit at the Mater Misericordiae University Hospital in Dublin. Edna had great support from her friends and family as they offered support beforehand, cheered her on during the route and celebrated her great achievement

afterwards. Edna was even spotted along the route and cheered on by her respiratory consultant, Professor Jim Egan, and this was a source of great pride to both doctor and patient!

Edna said “Walking the 10km of the VHI Women’s Mini Marathon for ILFA and the Irish Heart and Lung Transplant Association was one of the happiest days of my life. Weather, after a downpour, was perfect. Family and friends were incredibly supportive and ILFA looked after everybody so well. Thanks for a wonderful day.”

Marie McGowan said “It was a great day. This was my 3rd time to take part to raise funds for ILFA. This year’s mini-marathon was different to all the other events as this was my first time to meet an IPF patient who had received a lung transplant and went on to complete the 10k. It was great to see Edna and her friends return to meet with the ILFA group after she had completed the mini-marathon. The day went very well and it was a great opportunity to meet other participants who were taking part in memory or support of a family member or friend diagnosed with IPF. This year my sister Collette and I took part. This year marks 5 years



The Snee family



The Kennedy family



Above: Marie and Collette McGowan



Right: Lisa Kennedy and friends

since our Mum passed away with IPF. For me it's important to keep fit and to look after my health and support those who have been diagnosed with IPF."

It was also a family affair for Fidelma Snee, her daughter Claire Snee, sisters Dorothy Foley and Colette McGettigan, and niece Katie McGettigan. Fidelma said "We had an absolutely amazing day out. I was the only one who had done the marathon before and although it was a good few years ago, I knew what to expect. My sisters and nieces were overwhelmed by the experience as was I. It's such a great day. We are definitely going to take part again."

Another family team taking part was headed by Denise Warren, who was joined by her daughters Sarah and Emily Warren, her sister Martina O'Dowd, her niece Sophie O'Dowd and baby sister Eileen Hynes. Angela Monaghan, Lisa Swift, Leanne McDermott and Niamh Walshe were other members of team ILFA.

Lisa Kennedy and her friends Anndrinna Mooney, Geraldine Graham, Catriona Graham, Barbara McLoughlin, Deirdre Egan, Michelle Barry, Ciara O'Connor and Catriona Daly travelled from

the Midlands to take part in the VHI Women's Mini-Marathon. Lisa's Dad recently received a lung transplant and their friends were a great support. Lisa said "We had a great time on mini-marathon day and look forward to doing more in the future for ILFA. Dad is doing great. We are beyond fortunate."

Ciara Bowe and her cousin Caitriona took part in the Women's Mini-Marathon in Dublin in memory of Ciara's Dad, Eamonn. Ciara told ILFA that she wanted to do something special and positive to mark the 6-month anniversary of losing her Dad to IPF. Ciara and her cousins Caitriona and Lisa's hard work raised over €1200 for ILFA.

Sisters and friends Mary Dillon, Brid Dillon, Aine Dillon, Eilish Dillon, Niamh Gaynor, Kate Lupton, Hannah Lupton and Isabelle Dillon Moloney participated to raise funds for ILFA in memory of Eilish Dillon from Kilkenny.

Heartfelt thanks to all our wonderful ladies and all their sponsors and supporters from everyone at ILFA. Thanks also to everyone who sent in their photos.

We hope to see you all again next year!

Fundraising Round Up



Congratulations to Laura Ryan and Derek O'Donovan from Limerick and their friend, Therese Martin from Kildare for completing the 125km Camino trek from Sarria to Santiago del Compostela in northern Spain, in aid of ILFA. The trio had a good time and enjoyed the challenge while also helping to raise awareness by wearing ILFA t-shirts along the way.

Lorraine Ryan took part in the Great Limerick Run in May 2016 to raise funds for ILFA. Lorraine has been a great ILFA supporter for a number of years and we are very grateful to her for all her fundraising activities.



Farnan Rushe, originally from Sligo but living in Spain, took part in the Rotterdam marathon in April and wore his ILFA t-shirt to support his dad, Jimmy Rushe, an IPF patient. Thanks to Farnan for flying the flag for ILFA across Europe. Last year Farnan took part in the Sligo half-marathon and was cheered on by his supportive family and friends. He finished in an impressive eight place!

Sincere thanks to all the families who kindly requested donations to ILFA in lieu of funeral flowers in memory of their loved ones. We appreciate your support and goodwill for ILFA at a very difficult time.

Anniversary celebrations



On 14th May, Patrick and Teresa McSkeane from Castleshane, Co Monaghan were the guests of honour at a party organised by their children to celebrate their 40th wedding anniversary. The party was held in Club Derrynoose and a great night of fun was had by all. Patrick, Teresa and their children Kevin, Patrick Jnr., Malachy, Barry, Eugene and Annie Frances kindly asked for donations to ILFA in lieu of gifts and the fantastic sum of €1600 was raised thanks to the wonderful generosity of their family and friends.

Eddie and Nicola Cassidy from ILFA travelled to Castleblaney on 12th July to meet the McSkeane family for a cheque presentation and to pass on ILFA's congratulations and appreciation for their kindness.

The Pat Casey Memorial Cycle

- a report by Anne Casey



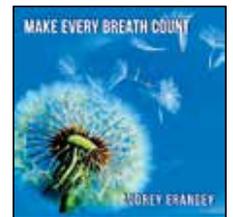
On 15th March 2016, the proceeds of the 2015 Pat Casey Memorial Cycle from Cork-Limerick-Cork were presented to the beneficiaries. Cheques were presented to Dr



Michael Henry, Consultant Respiratory Physician at Cork University Hospital and to Martin Troy of ILFA. There was a great attendance on the presentation night and the event was enjoyed by all. The 2016 Pat Casey Memorial Cycle will take place on the weekend of the 10th and 11th of September and we are looking forward to it. **Anyone interested in participating can contact Anne on 087 985 4587 (or email annecasey@live.ie) or Brian on 086 088 1064**

Make every breath count

Last year Tom Erangey and his wife Audrey from Cork produced a beautiful music CD entitled "Make every breath count". Audrey has an amazing voice and the CD which features 10 well known songs is simply stunning. The CD is dedicated to the memory of Tom's father, Jimmy Erangey, and all the proceeds of the CD sales have been kindly donated to ILFA.



Tom, Audrey, their family and friends have worked very hard promoting and selling the CDs and so far sales have reached €4,560. ILFA is hugely grateful to Tom and Audrey and everyone who has helped support this special project.

The CD can be purchased from ILFA for €10 and would make a lovely gift! Please call ILFA on 086 871 5264 or email info@ilfa.ie to place an order.

Climbing high

Huge congratulations to Edel McDermott and Aoife Stack on their successful climb of Croagh Patrick in July to raise funds for ILFA in memory of Edel's father, John. We're very grateful to Edel and Aoife their great efforts and to all their family and friends who supported them with sponsorship.



Upcoming events

- ▶ The Margaret Maloney Memorial Darts Tournament will take place on Saturday September 24th in Brereton's Bar, Ballybritt, Roscrea, Co. Tipperary. For more information, please contact Owen on 087 241 4475.
- ▶ The Dublin City Marathon will take place on Sunday 30th October.

If you or someone you know would like to take part and raise funds for ILFA, please get in touch by calling 086 871 5264 or emailing info@ilfa.ie

'#Have the chat' is the name of a social media campaign set up by the family and friends of John P. O'Sullivan from Lispolie, County Kerry. The campaign was set up in 2016 to raise awareness of organ donation and the importance of informing your next of kin and family of your wishes to donate your organs and tissue in the event of death.

John, a father of four, suffers from Idiopathic Pulmonary Fibrosis. Following the deterioration of his health at the end of 2015, John was assessed for lung transplantation and placed on the active transplant waiting list. John is currently on oxygen 24-hours a day and his only hope to lead a full and healthy life is lung transplantation.

The #Have the chat campaign highlights that even if you carry an organ donor card, it is your next of kin who will make the final decision regarding the donation of

#Have The Chat



John's grand-daughters Meabh, Doireann and Aine O'Dowd supporting organ donation and the '#have the chat' campaign."

your organs in the event of your death. The campaign urges people to "have the chat" with family members and next of kin about their wishes regarding organ donation.

There are approximately 700 people currently awaiting life saving transplants in Ireland and over 3000 people are enjoying better health and extended life thanks to organ donation and the generosity of donors and their families.

"We set up the campaign because over

35% of eligible organs are not donated as the families of the deceased do not consent to the organs being transplanted - obviously it is a very hard thing to consider given the circumstances in which the decision must be made. Therefore we are urging people to #have the chat with their families now to make the decision easier in the event of an unforeseen death."

You can register to become an organ donor by:

- ▶ texting 'Donor' to 50050 to receive a donor card
- ▶ ticking the box on your driver's licence
- ▶ filling out an organ donor card - available from pharmacies, health centres and hospitals
- ▶ or downloading the Irish Kidney Association's donor e-card to your phone.

Thanks to Sharon Ni Shuilleabhain, Neasa Ni Shuilleabhain, Dara O'Suilleabhain, Michelle Ni Shuilleabhain (John's Daughters), and Elaine Dorgan, Ciara Dorgan, and Grainne O'Sullivan (John's Nieces) for contributing this article to ILFA.

IPF World Week

IPF World Week will take place from 17th to 25th September 2016. This initiative started in 2012 and unites IPF patient associations, healthcare professionals and industry and helps to raise awareness of IPF. Some of the hospitals around Ireland will have information stands to help raise awareness during IPF World Week. If you would like to help raise awareness among your friends and local community why not;

- ▶ tell someone you know about IPF,
- ▶ 'like' and 'share' ILFA's posts and tweets on Facebook and Twitter if you use social media,
- ▶ hold a coffee morning to raise awareness.

Please contact ILFA by emailing info@ilfa.ie or calling 086 871 5264 if you would like more information.



Public Attitudes to Organ Donation

In 2015, Organ Donation and Transplant Ireland (ODTI) commissioned a telephone survey of 1000 people to determine 'Public Attitudes to Organ Donation'.

The key findings were;

- ▶ More than 8 in 10 people stated that they would be willing to donate their own organs or donate the organs of a close family member (85%). However, only 50% of respondents have discussed organ donation with their family.
- ▶ One third of the general population currently carry an organ donor card. While just 44% of those who stated that they would donate their organs currently carry one.
- ▶ The statement "one organ donor can save 5 lives" was considered the most effective media communication by 83% of respondents.

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International Colloquium on Lung and Airway Fibrosis

Dublin Castle will host the prestigious 19th International Colloquium on Lung and Airway Fibrosis (ICLAF) from 24th to 28th September, 2016. Researchers, scientists, students and clinicians from all over the world will attend this major international conference to learn more about the latest research findings in lung fibrosis.





tool for people with lung conditions

patientMpower, a digital health company based in Dublin is developing a tool for people with lung conditions to record information on their symptoms, breathlessness, use of medicines and other issues related to their lung health. The information will be recorded on your smartphone or other device (for example, iPad or Android tablet). Collecting this information on a regular basis might be useful in helping people and their medical teams to better manage their lung health.

patientMpower has developed similar tools for people with other medical conditions (for example, after kidney transplantation) and these are now being used in real life. We hope that a similar tool will also be useful for people with lung conditions.

patientMpower is looking for volunteers to try out the first version of this tool so that we can get your feedback and improve it. If you are interested in trying out this new tool now please contact Gemma O'Dowd at the Irish Lung Fibrosis Association on 086 871 5264 for further information, or contact patientMpower. Tel 01 903 8558 or email info@patientmpower.com

Lung Facts

Did you know ...

- ▶ The left lung is smaller than the right one, to allow room for the heart. The right lung has three lobes, while the left has only two.
- ▶ The alveoli are the tiny air-sacs in the lung where gas exchange occurs. There are about 600 million of these spongy, air-filled structures in an adult's lung and they are covered by a thin membrane that allows oxygen and carbon dioxide to pass between the lung and the blood stream. If the alveoli were flattened, the surface area would be roughly the same size as a tennis court.
- ▶ An average healthy adult lung weighs approximately 500g. Lung fibrosis causes the lungs to become stiff and hard with scar tissue. With advanced lung fibrosis, the lungs can weigh as much as 2kg each. Therefore, some patients will have to carry an extra 3kg (approximately 7 lbs) in their chest, making breathing even harder.
- ▶ It is 200 years since Dr Renee Laennec, a French doctor, invented the stethoscope. This simple instrument transformed our understanding of how the lungs work and two centuries later, the stethoscope is still used every day in modern medicine. With IPF, doctors can hear crackles when they listen to a patient's lungs using a stethoscope. New stethoscopes that use sound wave technology are being developed to help diagnose IPF earlier and more accurately.

Raising awareness of IPF among GPs

ILFA has recently registered with GPBuddy.ie - an online service for General Practitioners (GP). The site helps GPs find medical professionals and services they require when making referrals for their patients. It also provides GPs with the opportunity to learn more about different health conditions via educational articles and videos.

Over 2,600 GPs have signed up to GPBuddy.ie which represents more than 85% of the total number of GPs in Ireland. Over 300 GPs visit the site every day and 1,400 GPs visit the site every month.

In June 2016, ILFA commissioned a short survey with GPBuddy.ie and asked the question;

"As a GP, which one of the following would be your preferred method for learning more about idiopathic pulmonary fibrosis?"

1. Direct mail (receiving a letter or

leaflet posted to the GP surgery)

2. Online learning module / video tutorial

3. Seminar / GP study day
4. Clinical education article in a medical newspaper

5. Other

316 GPs responded to the survey and 49% said they wanted to learn more about IPF by watching an educational video. The next most common answers were attending a GP seminar (28%), and reading an educational article in a medical newspaper (11%).

To best meet the information needs of GPs, ILFA plans to produce a short educational video with a respiratory consultant to raise awareness of the diagnosis, symptoms and treatment of IPF over the coming months. We will keep you posted with developments.

Why not ask your GP to contact ILFA if they would join ILFA's mailing list to receive our newsletters?

Dates For Your Diary

- ▶ World IPF Week will take place from 17th -25th September
- ▶ The ILFA Service of Prayer and Reflection will take place on Saturday 15th October at 3pm in Gort Muire, Balinteer, Dublin
- ▶ ILFA Patient Information Day will take place on Saturday 5th November at 10am in the Crowne Plaza Airport Hotel, Santry, Dublin

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.

