ILFA Newsletter

Patrons: Feargal Quinn, Michael Darragh Macauley, Charlie Bird, Andrea Corr.
Issue: Autumn 2018 Volume 16 Issue 2 © ILFA 2018

Irish Lung Fibrosis Association
www.ilfa.ie

ILFA Visits Áras an Uachtaráin

On St Patrick's Day, Saturday March 17th 2018, a delegation of ILFA members was invited to Áras an Uachtaráin as special guests of President Michael D Higgins and Sabina Higgins in recognition of our work promoting organ donation and transplantation.

ILFA was thrilled to receive this very special invitation. Eddie Cassidy (ILFA Chairman), Nicola Cassidy and Lynn Fox represented the ILFA Committee and were joined by our special guests; Ann and Michael Kennedy, Pamela and Liam Martin, and Edna and Kenneth Powell who have all fundraised for ILFA and whose names were drawn from a hat. Other ILFA members; Val Kennedy and David Crosby were invited to the event by the Irish Heart and Lung Transplant Association.

We were so excited to join our friends and colleagues from other patient organisations, healthcare professionals working in organ donation and transplantation, and families from all over Ireland who were invited to the very special event. The President and Sabina Higgins warmly welcomed everyone to their beautiful home and there were plenty of photos taken, touching words exchanged, and friendly hugs and embraces shared with the guests. Patient groups from the Irish Donor Network including ILFA, Cystic Fibrosis Ireland, the Irish Heart and Lung Transplant Association, Alpha-one Foundation and Cystinosis Ireland also had the pleasure of meeting the President as a group.

The staff at Áras an Uachtaráin were so hospitable, kind and helpful and this added to the special occasion. We were treated to wonderful traditional music, song and dance from talented performers, tasty refreshments and the opportunity to chat with old friends and make new acquaintances.

Eddie Cassidy (ILFA Chairman), Lynn Fox, President Michael D Higgins, Sabina Higgins and Nicola Cassidy at Áras an Uachtaráin.

The President gave a beautiful and heartfelt speech highlighting the wonderful generosity of organ donors and their families at a time of great personal tragedy, and the wonderful gift of life they bestow to those in need of life saving transplants. Professor Jim Egan (Organ Donation and Transplant Ireland) also gave a speech acknowledging the great sacrifice of donors to give renewed life to transplant recipients.

It was such an honour, a privilege and a wonderful treat to meet the President and Sabina Higgins on Ireland's national day. Our treasured memories will be recalled with pride every St Patrick's Day for many years to come.

■ **See page 2 for more photos**

Service of Prayer and Reflection

The **ILFA Service of Prayer and Reflection** will take place on Saturday 6th October at Rathgar Methodist Church, Brighton Road, Dublin 6.

The ecumenical service will be celebrated by the Reverend Vanessa Wyse Jackson (Minister at 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 21st September 2018.**

Patient Information Day

The next Patient Information Day will take place on Saturday 20th October at the Crowne Plaza Hotel, Northwood, Santry, Dublin from 10am until 1pm. We hope you can join us to learn more about pulmonary fibrosis from experts in the field. All are welcome. Our speakers will include;

- Dr Michael Henry, Respiratory Consultant at Cork University Hospital
- Grainne Casey, Physiotherapist at the Mater University Hospital
- Dr Anne-Marie Doyle, Clinical Psychologist at the Royal Brompton Hospital, London
- Sandra Murphy, Senior Dietitian at the Mater University Hospital

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

ILFA Visits Áras an Uachtaráin

Eddie Cassidy, Lynn Fox, Liam and Pamela Martin, Michael and Ann Kennedy, Professor Jim Egan, Nicola Cassidy, Edna and Kenneth Powell.

Pamela Martin, Sabina Higgins, President Michael D Higgins and Liam Martin.

Sabina and President Michael D Higgins greet Michael and Ann Kennedy.

Kenneth and Edna Powell.

Nicola Cassidy, President Michael D Higgins, Lynn Fox, Pamela Martin, Eddie Cassidy and Liam Martin.

Edna Powell, Katie and David Crosby, Lynn Fox and Eddie Cassidy.

Pamela and Liam Martin with Val Kennedy.

Members of the Irish Donor Network meet the President and Mrs Higgins.

David Crosby, Claire Byrne and Val Kennedy *(photo courtesy of the Irish Kidney Association).*

Professor Jim Egan (Director of ODTI), Minister of State Catherine Byrne T.D. and Eddie Cassidy (ILFA Chairman).

Eddie Cassidy (ILFA Chairman), Robert McCutcheon (Chairman of the Irish Heart & Lung Transplant Association), Ken Mulkerrins (heart transplant recipient), Gemma O'Dowd (ILFA), and Val Kennedy (lung transplant recipient).

Vivienne Vize (Transplant co-ordinator, Mater University Hospital) with David Crosby (lung transplant recipient).

Organ Donation Awareness Week 2018

On Tuesday 27th March 2018, Val Kennedy, IPF lung transplant recipient, from Co Laois spoke at the launch of Organ Donation Awareness Week at the Mansion House in Dublin. The event was organised by the Irish Kidney Association. Representing ILFA at the event were Eddie Cassidy (ILFA Chairman), Nicola Cassidy, Gemma O'Dowd and lung transplant recipient David Crosby who spoke at the 2017 event.

Claire Byrne from RTE is the new Ambassador for Organ Donation Awareness Week and she urged everyone to have a conversation with their family and next of kin to let them know their wishes on organ donation.

Val and other transplant recipients who had received lung, kidney, heart, kidney/pancreas and liver transplants shared their touching personal stories and described how their lives had been transformed by the kindness and generosity of organ donors and the families who had consented to organ donation. All the speakers paid tribute to the hospital staff who cared for them and supported them during their ill health, while preparing for transplant surgery, and during their recovery post-transplant. Everyone spoke from the heart and it was emotional to hear such moving and inspiring stories and learn of their deep gratitude and appreciation for the gift of new life that they have received thanks to their donors.

Professor Jim Egan, Director, HSE Organ Donation and Transplant Ireland (ODTI) paid tribute to the medical and surgical staff around the country who have assisted with and facilitated organ donation and transplantation, the staff of the ODTI, the transplant co-ordinators at the three national transplant units at Beaumont Hospital, St Vincent's University Hospital and the Mater Misericordiae University Hospital, and the donors and their families who gave permission for organ donation to proceed at a time of deep personal loss.

The Minister of State for Health Promotion and National Drugs Strategy, Catherine Byrne, T.D., also paid tribute to all those working in the field of organ donation, including the patient organisations working to promote awareness of organ donation and transplantation; ILFA, Cystic Fibrosis Ireland, the Irish Heart and Lung Transplant Association, Alpha-one Foundation Ireland and the Irish Kidney Association. Minister Byrne stated that the Human Tissue Bill that includes the introduction of a soft opt-out consent system for organ donation will come before the Dáil in 2018.

Well done Val and thank you for sharing your story and helping raise awareness of the importance of organ donation.

Transplant Figures for 2017

According to Organ Donation and Transplant Ireland (ODTI), a record number of organ transplant operations took place in Ireland in 2017 thanks to the generosity of organ donors and their families. 99 organ donor families consented for organ donation to take place and 260 transplant recipients received the gift of life.

- The Mater Misericordiae University Hospital carried out 36 lung transplants and 16 heart transplants.
- St. Vincent's University Hospital carried out 62 liver transplants and 5 combined pancreas/kidney transplants.
- Beaumont Hospital carried out 141 kidney transplants from deceased donors and 51 transplants from living donors.

Patient Information

Eddie Cassidy, Pamela Martin, Marie Sheridan, Chris Meehan and Gemma O'Dowd.

The first ILFA Patient Information Day of 2018 took place on Saturday 21st April in Kilkenny. The event was a great success with people travelling from all over the country to attend. Eddie Cassidy, ILFA Chairman, welcomed everyone to the meeting and introduced the speakers.

Dr Killian Hurley, Respiratory Consultant at Beaumont Hospital in Dublin gave an overview of Idiopathic Pulmonary Fibrosis (IPF) and discussed the symptoms, diagnostic pathway and treatment options for the condition. There are many different types of pulmonary fibrosis but IPF is the most common form. The term 'Idiopathic' means the cause is unknown; the term 'Pulmonary' refers to the lungs and 'Fibrosis' refers to scarring and hardening of lung tissue that takes place over time. IPF is typically diagnosed in people over the age of 65 years and is unusual in younger individuals. Approximately 400 people are diagnosed with IPF in Ireland every year and 1,000 are living with IPF.

To help establish your diagnosis, your respiratory doctor will ask you many questions to fully understand your medical background and find out if you have other conditions such as joint or muscle pain. You will be asked about your past medication history, your occupational history and exposure to any respiratory hazards, if you have pets at home, and if any of your family members have ever had pulmonary fibrosis.

Often when patients are seen by a respiratory consultant, they have a history of shortness of breath particularly on exertion, dry cough, fatigue, weight loss and sometimes clubbing (rounding of the nail bed) on the fingers and toes. When the lungs are listened to with a stethoscope, the sound of 'Velcro crackles' – a distinctive sound that resembles Velcro strips being pulled apart – can be heard. The lungs are like a fire bellows and when we breathe, oxygen from the air moves across the lungs and into the blood stream and carbon dioxide is pushed out. With IPF, the thick scarring that occurs causes the lung tissue to become stiff and this prevents the efficient transfer of the blood gases.

Reaching a diagnosis of IPF is based on the results of chest x-rays, high resolution CT scans, and lung function tests that determine your lung capacity, the efficiency of the gas transfer, and your blood oxygen concentrations. Your case is discussed by a group of healthcare professionals at a multi-disciplinary team meeting (MDT) including a respiratory doctor, radiologist and pathologist. If the cause of the fibrosis cannot be identified and all other causes of disease have been ruled out, a diagnosis of IPF is reached.

There are currently two drug treatments for IPF; Pirfenidone and Nintedanib. These medications work in different ways, but both can slow the rate of progression in IPF. Patients prescribed these medicines will need careful monitoring by their clinical team to help them manage the treatments and any adverse side-effects that develop. Patients may not necessarily feel better, but the drugs can prolong life.

The wider clinical team taking care of the IPF patient includes doctors, nurses, surgeons, physiotherapists, palliative care specialists, social workers and others. The team ensures that treatment options are tailor-made for the individual patient depending on their health and the stage of their disease. The importance of pulmonary rehabilitation, exercise and maintaining a positive attitude were highlighted. Dr Hurley also discussed the National Registry for IPF that has is being set up by The Irish Thoracic Society to establish an accurate picture of the incidence and prevalence of IPF in Ireland and management of the condition.

Paula Ryan, Advanced Nurse Practitioner in respiratory medicine at Limerick University Hospital spoke about the role of Respiratory Nurse Specialists and how they can support IPF patients. When a patient is diagnosed with IPF, it can be a daunting and confusing time as there can be a lot of information to take in, in a short time. Respiratory nurses can help educate patients about IPF, talk through their questions and concerns and spend time with them to explain medications and their side-effects. Respiratory nurses can also provide important information on smoking cessation if necessary, diet, exercise, pulmonary rehabilitation and relaxation techniques, IPF treatments including; the use of supplemental oxygen to help reduce shortness of breath, lung transplantation and medication management. Paula recommended that patients attend a local support group to meet others living with the condition and learn from their experiences.

Irene Byrne, Senior Respiratory Physiotherapist at the Mater Misericordiae University Hospital spoke about 'Red Flags' that indicate when you should seek medical advice if you are

Day, April 2018

Irene Byrne, Paula Ryan, David Crosby, Maria Love, Dr Killian Hurley and Eddie Cassidy.

not feeling well. Practical advice to help manage IPF was also discussed and Irene advised that people;

- Have a plan of action and know what to do if you are not feeling well
- Know your medication
- Eat small meals throughout the day
- Rest during the day
- Be open to change
- Exercise daily – use the ILFA 2000 Steps a Day Walking Programme

Irene explained that oxygen is a prescription drug that can help relive breathlessness. Oxygen is essential for our vital organs and providing energy to enable us to perform our activities of daily living. When being assessed for oxygen, you should not have your test done when sitting down and your breathing is easy. Instead move up and down and let your doctor know that you are more breathless on exertion. Speak with your oxygen company to select the best machine to suit your lifestyle.

Irene also spoke about the Lung Transplant Unit at the Mater Hospital. Approximately 200 lung transplants have been performed in Ireland since 2005 and almost 50% of these have been on IPF patients. Lung transplantation is a treatment option for IPF. This procedure will not be suitable for everyone, but patients should ask their doctor about this treatment option and ask for referral for lung transplant assessment. There is no age limit for lung transplantation provided that your general health is good.

Maria Love, Senior Medical Social Worker at the Mater Misericordiae University Hospital encouraged everyone to congratulate themselves for attending the event as a first step to learning more about IPF and helping themselves. Every patient is different and receiving a diagnosis of IPF can unleash a roller-coaster of emotions. Anxiety is a normal reaction to getting bad news but it is worth remembering that there is no right or wrong way to react to a diagnosis of IPF and there isn't a time frame to accompany your emotions. IPF can cause poor concentration, irritability, poor sleep, mood change, fatigue and loss of energy. Some people tend to focus on the worst-case scenario and experience fear for living in the present and fear for the future. Try to maintain your independence when possible but do not be afraid to ask for help and acknowledge that things do change, and adjustment is needed. Living with IPF involves a process of change. Coping strategies include talking with healthcare professionals, going to a support group, turning to your faith, exercising, practicing meditation or mindfulness or whatever activity that you like. You can help yourself to regain a sense of control by recognising the impact of IPF has on you and your family, give yourself permission to feel what you feel, have a daily routine, set realistic goals, and practice self-compassion and kindness. Think about what is important to you and what you want to achieve. Ask your GP about counselling if this would be useful to you, find out your entitlements, and plan for the future by looking at your financial and legal affairs. Practicing gratitude in the morning and evening can reinforce a positive outlook and this can make a difference.

David Crosby from Co Cavan was diagnosed with IPF in 2015 and in 2016 he received a double lung transplant. David shared his story with the audience and described his family history, his early symptoms, IPF diagnosis and his journey to transplant and recovery. David said he received good advice from all the healthcare professionals he encountered and encouraged everyone to pay attention to the advice given by their medical team. David exercised daily with a bicycle mounted on a stand and used the ILFA 2000 Steps a Day programme. He lost weight with the help of a dietician to get on the lung transplant waiting list. David gave credit to his healthcare team for saving his life.

After receiving his transplant, David was determined to get fit and train for the New York City Marathon which he ran in November 2017 with a team of 14 family and friends. David encouraged everyone to ask questions – there is no such thing as a silly question, to figure out their own path and to stay positive. He ended by wishing everyone the best of health.

What you thought ...

Attendees were asked to fill out a questionnaire to evaluate the Patient Information Day.

- 86.7% said the event was excellent, 10% said it was very good and 3.3% said it was good.
- 87.1% felt the programme definitely met their information needs.
- 83.9% said they would definitely attend another ILFA Information Day.
- 97% said they would definitely recommend the ILFA Patient Information Day to another patient.

The presentations were videoed and can be viewed on the ILFA website; **www.ilfa.ie** or on ILFA's YouTube channel. Thank you to everyone who came along, our volunteers; Alison Maguire, Pamela Martin and Chris Meehan, guest speakers, and representatives from the oxygen companies; Air Liquide and BOC Healthcare. Sincere thanks to Boehringer Ingelheim Ltd. for sponsoring the event.

Fergus Goodbody

The Irish Lung Fibrosis Association (ILFA) was set up in memory of Fergus Goodbody in 2002 to facilitate research, education and support for Idiopathic Pulmonary Fibrosis (IPF). Every two years since 2010, ILFA has invited an international leader in IPF to deliver an educational lecture to healthcare professionals in Ireland. The 2018 Fergus Goodbody Memorial Lecture on IPF took place on 14th March in collaboration with the Royal College of Physicians of Ireland (RCPI).

170 healthcare professionals registered to attend, making this our largest educational event to date. Dr Diarmuid O'Shea, Registrar of the RCPI, welcomed the speakers and audience to the Masterclass in Respiratory Medicine and was especially delighted to welcome Nicky Goodbody to the event.

Professor Toby Maher from the Royal Brompton Hospital, London spoke on 'Developments in IPF' and discussed the incidence, pathology, and treatment of IPF, and research highlights. The incidence of IPF is increasing and in the UK approximately 1 in 100 deaths are due to IPF, therefore the disease is not as rare as previously thought. The lungs are constantly exposed to substances such as smoke, dust and pollutants that cause repeated micro-injury at a cellular level. Scarring (fibrosis) is part of the normal wound healing process but with IPF, fibrosis goes out of control and is not switched off in susceptible individuals.

In 2014, two successful clinical trials paved the way for the anti-fibrotic medications Pirfenidone and Nintedanib, to be prescribed as IPF treatments. The search for new drug discoveries is ongoing and currently over 20 different compounds are being studied as potential IPF treatments.

Prof Maher spoke about the potential of biomarkers (any test used to measure health, disease or response to treatment; for example, blood tests, spirometry measurements, scans etc.) to help characterise IPF patients. The PROFILE Study followed 600 newly diagnosed patients over 3-years and showed that IPF patients had a distinct blood protein signature compared to healthy individuals. And patients with more progressive IPF appear to have different protein profiles to those with stable disease. These results could help identify patients who may respond to different therapies. Studies investigating the delivery of drugs to the lung by inhalation are also in progress. This is an exciting time for research and evidence is accumulating for compounds that may be effective IPF therapies. At least 3 such compounds are likely to progress to clinical trials in the next year.

Anne Marie Russell, Clinical Doctoral Research Fellow at the National Heart and Lung Institute at Imperial College London spoke on 'Palliative care and end of life management for IPF patients.' The World Health Organisation defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain, and other problems, physical, psychosocial, and spiritual." Much of the learning on palliative care has originated from the cancer-care model.

The disease course with IPF is unpredictable and therefore patients should be informed that palliative care services are available if needed. The assessment of patients' palliative care needs is a dynamic and iterative process and an integrated approach is needed to care for patients holistically and stream-line their care.

In 2017 a major international collaboration produced a review article entitled 'Palliative care in interstitial lung disease: living well' that was published in The Lancet medical journal. The article explained that palliative care focuses on optimising quality of life for IPF patients and managing symptoms effectively. Unfortunately, there are common misperceptions that palliative care is only for end-of-life care however palliative care has an important role in the early course of IPF to improve quality of life. Patients should have access to palliative care and be sign-posted to these services early on following their diagnosis.

Anne-Marie described some of the treatments to manage breathlessness, psychological distress and cough. Unfortunately, the current evidence base is weak, and more research is needed to determine the efficacy of treatments.

If patients are not informed about services available to them, they can feel lost and abandoned especially if they only have a yearly hospital review.

Clinicians in the community have a duty to recognise when patients are deteriorating, to refer patients back to specialist centres for re-assessment, and review patients regularly to ensure appropriate treatment. Symptoms should be measured, managed and adjusted.

Anne-Marie highlighted work called 'The Five Wishes' that helps people consider what is important at the end of life. These questions address;

1. The person I want to make care decisions for me when I can't
2. The type of medical treatment I want / don't want
3. How comfortable I want to be
4. How I want people to treat me
5. What I want my loved ones to know

Professor Edward McKone, St Vincent's University Hospital, spoke about Cystic Fibrosis, and Professor Anthony O'Regan, University College Hospital Galway, gave a lecture entitled 'Alphabet soup' and summarised different types of Interstitial Lung Disease.

The presentations were videoed and are available to watch on the ILFA website and YouTube. ILFA is grateful to the RCPI for their collaboration and to Boehringer Ingelheim Ltd. for supporting this educational event.

Memorial Lecture

Dr Diarmuid O'Shea and Nicky Goodbody.

Eddie Cassidy, Nicky Goodbody, Prof Toby Maher, Anne-Marie Russell, Prof Anthony O'Regan, Prof Jim Egan and Prof Edward McKone.

Dr Colin Edwards (patientMpower) with Irene Byrne and Dr Jana Kleinerova from the Mater Misericordiae University Hospital.

Gemma O'Dowd and Nicola Cassidy (ILFA), Bettina Korn (St James Hospital), John Barron (Boehringer Ingelheim) and Eddie Cassidy (ILFA Chairman).

ILFA's World Café on Palliative Care and Planning for the Future


World Café participants

On 9th June, ILFA held a World Café event on Palliative Care and Planning for the Future with 55 stakeholders including patients, carers, healthcare professionals working in hospitals, hospice settings and the community, and industry representatives. The meeting took place at the Crowne Plaza Hotel in Dublin and participants travelled from Cork, Limerick, Galway, the Midlands and the greater Dublin area to attend.

World Café events follow a tried and tested formula that aims to maximise people's participation and capture ideas and solutions. It is fast paced, interactive and dynamic and allows for a set number of topics to be discussed in a group setting for a defined period. Once the allotted time has passed, the leaders and notetakers for each topic rotate to the next group to capture their perspectives. Time keeping is paramount and Tony Shone did an excellent job in keeping us on track. The topics discussed were;

(1) Practical planning for living with IPF
(2) Palliative care needs and management of symptoms
(3) End of life considerations including home, hospital and hospice care at the end of life, and spirituality needs
(4) Psychological needs and support for living with IPF
(5) Acute exacerbations and transplantation concerns
(6) Legal matters

We were honoured to have two great facilitators guide us through the World Café meeting; Tony Shone (Invisio Ltd.) and Anne-Marie Russell (Nurse Consultant at the Royal Brompton and Imperial College Healthcare Trust London). Also participating in the event were 6 leaders;

Maria Love, Deirdre Shanagher, Irene Byrne, Bettina Korn, Tony Shone, Anne-Marie Russell, Carol Kealy, Anne-Marie Doyle and Lynn Fox.

Chris Meehan, Marie Sheridan, Nicola Cassidy, Tony Shone, Lindsay Brown, Nicky Goodbody and Marie McGowan.

Pamela Martin and the Reverend Vanessa Wyse Jackson.

Andrew Cooper, Noel Evans, Teresa Cullen, Catherine White, Kathleen Evans and Liam Martin.

Joan Doyle, Teresa and Matt Cullen and Peter Gallagher.

Val Kennedy and Rachel Power.

Tom O'Sullivan and Matt Cullen.

Eddie Cassidy, Anne-Marie Russell and Tony Shone.

Lynn Fox (Respiratory Nurse Specialist, Mater University Hospital), Irene Byrne (Respiratory Physiotherapist, Mater University Hospital), Maria Love (Medical Social Worker, Mater University Hospital), Deirdre Shanagher (Development Officer, Irish Hospice Foundation), Bettina Korn (End of Life Co-ordinator, St James Hospital) and Anne-Marie Doyle (Clinical Psychologist, Royal Brompton Hospital, London) who facilitated the lively discussions on various aspects of palliative care and planning for the future. The leaders were ably assisted by six note-takers; Chris Meehan, Marie Sheridan, Marie McGowan, Lindsay Brown, Nicky Goodbody and Nicola Cassidy who recorded the challenges and solutions shared by the participants on giant flipcharts. Carol Kealy from Hayes Solicitors also attended the event and gave a short presentation on the upcoming Advanced Care Directive Legislation. Graphic illustrator Philip Barrett and photographer Ray Lohan were also present to capture the essence of the event creatively. Maria Love, Medical Social Worker at the Mater Hospital, delivered two short mindfulness sessions at the start and end of the event and this worked extremely well.

The World Café event provided a great opportunity for ILFA to collaborate with leaders in the field, engage with our stakeholders in a meaningful way, and tap into the enormous potential of like-minded people. ILFA is very grateful for the opportunity to learn about the experiences and challenges faced by healthcare providers, patients, and families living with IPF, and learn about their ideas, aspirations and care improvement activities to prioritise patients' wellbeing.

The World Café on Palliative Care and Planning for the Future was a hugely successful and exciting event thanks to all the team involved in the preparation and delivery of the event, and largely due to the enthusiasm and open and honest dialogue generated by the participants. We are busy analysing the data generated from the discussions, identifying emerging themes, and deciding on the next steps. We will keep you posted - stay tuned!

Anne-Marie Russell wrote "The ILFA World Café on Palliative Care and Planning for the Future was a truly inspiring and energising event. This approach breaks down the traditional barriers in that all participants contribute equally, and every point of view is valued. Palliative care is an emotive topic for many people but all participants confronted the issues head-on catalysing new ideas. It was no surprise that ILFA created a warm and welcoming environment in which it was possible to feel safe and share thoughts. Working in small groups a lot of information was generated in a short space of time. Patients, caregivers, healthcare professionals and other key stakeholders engaged in dynamic conversations identifying core aspects of palliative care and planning that will inform future work and influence health policy."

Advocacy and Awareness Activities

Fight IPF campaign

In December 2017 a series of beautiful videos featuring Noreen O'Carroll from Tipperary, Bob Cooke from Cork and Peter Gallagher from Dublin were produced for the 'Fight IPF Campaign'. This project follows on from the 2017 campaign and aims to raise awareness about Idiopathic Pulmonary Fibrosis (IPF).

Noreen was diagnosed with IPF in 2015, Peter was diagnosed in 2016, and Bob was diagnosed in 2016 and received a lung transplant in 2017. Our three patient advocates spent the day together and shared their advice for coping with their diagnosis and living as well as possible. They all stressed the importance of exercise, peer support and having a positive attitude. Noreen spoke about getting help, Peter told us about his use of the 2000 Steps programme and Bob spoke about the help available from ILFA. The Fight IPF campaign was supported by Roche Products Ireland in collaboration with ILFA and achieved amazing success online, on social media and in the local, national and medical press.

The Fight IPF Campaign also featured on TV3's Sunday AM programme and Noreen O'Carroll and Dr Killian Hurley, respiratory consultant at Beaumont Hospital were interviewed by Anna Daly and Simon Delaney.

We are very grateful to Noreen, Bob and Peter for their willingness and enthusiasm to participate in such inspirational videos that will help others diagnosed with IPF. ILFA also would like to extend our appreciation to Roche Products Ireland and Edelman for supporting and facilitating the video production and promoting the awareness campaign.

Dr Killian Hurley, Noreen O'Carroll, Anna Daly and Simon Delaney at the TV3 studios.

Organ Donation and Transplantation

ILFA continues to work with colleagues in the Irish Donor Network (IDN) to advance issues in relation to organ donation and transplantation. The IDN wants to see the timely introduction of the Human Tissue Bill which will allow for a soft opt-out consent process for organ donation. In July 2018, ILFA wrote to the Minister for Health to request an update on the progress of this potential life-saving legislation. Earlier this year, ILFA wrote to the Minister for Health to request additional funding for the National Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital to support the opening of closed beds in the ward.

HSE National Reform Programme for Community Funded Schemes

Nicola Cassidy (ILFA Director) and Peter Gallagher (oxygen user) represented ILFA at a Patient Information Session with the HSE's National Respiratory Therapies Reform Group on 1st June 2018. The Community Funded Oxygen Scheme is under review and new contracts will be awarded to oxygen supply companies in the coming months. Patient organisations were invited to the meeting to receive an update on the status of the oxygen contracts and had the opportunity to raise patient concerns.

Some of the issues raised by ILFA included;

1. **Reimbursement process.** Non-medical card patients must pay their oxygen supply costs and claim reimbursement under the Drug Payment Scheme. Frequently there is a delay of 4-6 weeks to reimbursement.
2. **Standardisation of the rebate towards the cost of electricity bills.** Although some HSE jurisdictions offer a small rebate towards the cost of electricity bills, this is not a universal practice. ILFA would like a standardised rebate nationally.
3. **Batteries and desk-top charger for portable oxygen devices.** Some patients have had difficulty getting their prescription for a second battery and desk-top charger filled. This is causing great distress to patients and family members. IPF patients have higher oxygen requirements than patients with other chronic respiratory conditions and having a second battery and a desk-top charger are essential to allow patients engage in social activities and attend hospital appointments and pulmonary rehabilitation classes without having to worry about their battery running out. Additional batteries should never be denied if prescribed for a patient.
4. **Communication with oxygen users.** The HSE Respiratory Therapies Group should keep patient organisations and oxygen users updated with information on the timeline and transition process that will accompany the introduction of the new oxygen contracts.

General Data Protection Regulation

General Data Protection Regulation (GDPR) came into effect on May 25th 2018 to update existing data protection law and give you more control over your personal information and how it is used.

The ILFA committee met in May to discuss the implications of GDPR and ensure that we comply with the consent requirements. ILFA collects, stores and uses information such as your name, address, phone number, and email address to send you newsletters and correspondence. We do not share your information with third parties without your consent. ILFA contacted all our registered members to ask everyone to renew their consent for their details to remain on our mailing list.

Please contact ILFA on 086 871 5264 or email info@ilfa.ie if you have any queries. For more information on GDPR, please visit www.gdprandyou.ie

Women's Mini-Marathon

VHI Mini- marathon 2018

Sunday 3rd June 2018 was a glorious summer's day with beautiful, clear blue skies, hot temperatures and the gentlest of breezes. Over 30,000 ladies gathered in Dublin to take part in the world's biggest one day fundraising event, support countless charities and achieve personal health and fitness goals. This year 67 ladies joined Team ILFA and we are very grateful for their amazing support. The ladies kindly took part to support loved ones and friends living with lung fibrosis, and to remember those who have passed away.

Before the race, Team ILFA met at the Mespil Hotel for a group photo on the banks of the picturesque Grand Canal. The ladies and their families were greeted by ILFA committee members, Eddie Cassidy, Nicola Cassidy and Gemma O'Dowd. We welcomed back some of our most loyal fundraisers from the Culwick Choir including Rosemary Wilson, Rita O'Regan, Margaret Ivers, Nicky Goodbody (ILFA Director) and Hazel Griffin. Ann Kennedy and her daughters Deirdre and Marianne took part once again, as did Debbie Cullen, and members of the Healy family; Lynn Healy, Ciara Healy, Helen Forster, Frances Healy, and Geraldine Forster. Nicola Cassidy and her aunt Annette Grehan took part again in memory of Denise Cassidy.

Edna Powell took part in her third mini-marathon post-transplant for ILFA. Edna was accompanied by her good friends Sue Kenny, Ursula Quigley and Joyce Quinn. Some ladies who joined our team for the first time included Bríd Doherty, Ais Gray, Catherine White, Bernadette Bold, Hilary Gaffney, Michelle Evans and members of the Ryan Family and Flynn Family teams.

Thanks to the ILFA cheerleaders; Marie Sheridan and Chris and Philip Meehan who shouted great words of encouragement to everyone at the 4km mark.

After the race, Team ILFA gathered at The Duke Pub for tea, sandwiches and chocolate treats to restore energy! It was great to catch up with everyone and start planning for next year.

Team ILFA

The Healy Family

The Healy Family

This was our second year walking in memory of Martin, a wonderful husband, dad and dear friend. Martin passed way in January 2017 after suffering with lung fibrosis for a few years. To raise the money, we held a fundraising night where all our family and friends gathered together donating very generously for ILFA. On the night we had many lovely raffle prizes that had been donated to the cause. Our fundraising night was a very successful one raising €2,000 for a very worthy charity.

On the morning of the mini marathon we met at the train station as we do every year. Some pictures were taken as we departed and made our way to the starting line. There is always such a great buzz and this year was no different as we stood reading each t-shirt feeling inspired by every person who was taking part for one of hundreds of charities.

We wish ILFA continued success in everything they do and as a family we'll continue to support this great charity in memory of Martin to help raise awareness of lung fibrosis and support the great work being done by everyone involved.

- Report by Frances Healy

The Ryan Family

The Ryan Family

Marion Ryan and her family and friends decided to fundraise for ILFA because of the excellent support Marion and her family received from the organisation. Marion was diagnosed with IPF in 2006. Her condition was stable until June 2017 when she deteriorated quickly and was put on oxygen. As the condition progressed, Marion and her family were able to attend the Support Group in Dublin and access crucial information from ILFA. She also attended the ILFA Patient Information Day and was able to meet people living with IPF and get advice and information from medical professionals. All this support helped Marion and her family cope with the situation at a very difficult time.

In Autumn 2017, Marion was assessed for a lung transplant and was a good candidate. She was put on the list and received a single lung transplant in 2018 at the Mater Hospital. She received excellent care and her recovery is going very well. Marion and her family are very grateful to the family of her donor for this gift of life.

Walking every day has been a large part of Marion's recovery and so it seemed appropriate to do the Women's Mini Marathon to raise funds. Family and friends gathered round to sign up for the event and we received excellent support from ILFA. The mini marathon took place on the 3rd of June 2018. Marion and the gang set off on a lovely sunny and warm day. The mood was good and there was a great buzz. Along the way they linked up with the rest of the ILFA gang who were also fundraising for the organisation. Marion's husband Martin and brother Gerard walked with the group to give them support and encouragement. It got harder as the walk went on, but good humour and determination helped everyone to make it over the line.

Marion would like to thank all the those who did the mini marathon with her and the individuals and groups who sponsored them. The people taking part in the marathon to fundraise for ILFA were; Marion Ryan, Carol Ryan, Viv Ryan, Rose Burke, Frances Kearns, Breda Geoghegan and Bernie Geoghegan.

Sponsorship was provided by; the taxi drivers at Dublin Airport, Hattons Pub - Coole Co Meath, Staff at the European Commission - Kiltale Co Meath, Staff at Moynalvey National School Co Meath, shop keepers in Meath Street, Dublin 8 and family, friends and neighbours of Marion Ryan.

- Report by Carol Ryan

The Flynn Family

"My dad, Tom Flynn, was diagnosed with Pulmonary Fibrosis in May 2005 and subsequently received a transplant a few months later. Sadly, he passed away in October 2017.

It was after his lung transplant that he became involved with ILFA. He was a great advocate and supporter of ILFA and was involved with the Midland IPF Support Group. He was a great man for giving advice, so it was no surprise to us that he became involved with the support group. He would travel the length and breadth of the country to talk to people who had just been diagnosed with pulmonary fibrosis and tell them about his transplant, his recovery and what to expect with the disease. He was quite the regular at the Mater Hospital, and this is where some of you may have met him. It was only after his death, when we received letters from people around the country, telling us what we already knew; that he was a great man - it was then we realised the amount of people he had been a great support to. He would quietly go about it, never divulging any conversations that were had.


Eddie Cassidy (ILFA Chairman), Stasia and Deirdre Flynn, Professor Jim Egan (Respiratory Consultant at the Mater Misericordiae University Hospital).

This year, my mother and I decided to pay tribute to both my father and ILFA and organised a group of 30 friends and family to complete the mini marathon. We recruited my sister-in-law, aunts, cousins, friends, friends of friends and with little or no training we set off for Dublin for the 10km walk.

It was an emotional day and an honour to complete the Women's Mini-Marathon in my dad's memory and in the process, we raised €4,500 for ILFA. I know he would have been proud of the efforts made by each one of us who completed it."

- Report by Deirdre Flynn


The Flynn Family Group

Fundraising Round Up

The 2017 Pat Casey Memorial Cycle

The Pat Casey Cycle organisers and Cork Support Group with Dr Michael Henry.

We, the organisers of the Pat Casey Memorial Cycle, would like to thank all those who attended our cheque presentation on Friday 23rd of March. The event was held at An Spailpin Fanach once again and we would like to thank them for their hospitality. A great night was had and an amazing total of €4,500 was donated to ILFA. We would like to thank Dr Michael Henry (Cork University Hospital) for attending the event, and all those who helped make the 2017 cycle such a success. We are looking forward to the 2018 cycle and once again working with ILFA.

The 2018 Pat Casey Memorial Cycle will take place in Cork on Saturday 29th September.

- Report by Brian Aherne Anne Casey and Daniel Casey.

Musical Bingo Night

Barney Meaney and his family organised a hugely successful and enjoyable Musical Bingo fundraiser in aid of ILFA at Erin's Isle GAA Club in Finglas, Dublin on 9th March. The original event was due to take place on 2nd March but was postponed due to snow. One week later than planned, a superb night of musical fun took place and great prizes were won by almost every person who attended!

Thanks to the generosity of everyone who participated and those who made online donations, the fantastic sum of €1,957.18 was raised for ILFA. Barney, Lorraine and Jacqueline Meaney presented a cheque to Eddie Cassidy, ILFA Chairman, at the Dublin Support Group meeting in April and they received a great round of applause from everyone present. Lorraine said, "We have really enjoyed organising our event and had a lovely day meeting the members of the support group."

Barney Meaney, Lorraine Meany, Bríd Meaney and Liam Mahon.

Lorraine Meaney, Nicola Cassidy, Jacqueline and Barney Meaney and Eddie Cassidy.

Cork City Marathon

Huge congratulations to Jan O' Dwyer and her friend Yvonne Heaney, pictured, who ran the Cork City Marathon in June. It was a very special day for Jan as she ran her first marathon and fundraised for ILFA in memory of her mam, Mary B. Rumley, on what would have been her 74th birthday. Well done Jan and Yvonne!!!

"Hola" from Madrid!

Well done to Martina Osborne, pictured, who donned her customised ILFA T-shirt and did her own 10k mini-marathon in Madrid on 3rd June in solidarity with the ILFA ladies taking part in the Women's Mini Marathon back in Dublin. Martina said, "It was a lovely sunny day and a good one to remember all who are helped by ILFA".

Croagh Patrick Climb

Nicola Cassidy after climbing Croagh Pattick, Westport, Co Mayo.

Nicola Cassidy, ILFA Director, climbed Croagh Patrick in Westport, Co Mayo on a glorious warm and sunny day on 10th May to raise funds for ILFA. The climb was tough, but the weather was great, and the views along the way were amazing.

London Marathon

Congratulations to Daragh Brady who completed the London City Marathon on Sunday 22nd April. Daragh kindly fundraised for ILFA in memory of his father Brendan.

EasyRiders Charity Cycle Group supporting ILFA

Rathdowney Easyrider Charity Cycle group has kindly chosen ILFA as their Charity of the Year 2018. This is a great honour for ILFA and we are so grateful to the group for their support and commitment to raising funds to support lung fibrosis patients and families.

Easy Riders has been in action for 16 years, raising money for different charities around Ireland. The group has been especially busy over the summer months and organised a 5km run/walk in Emo Court, Emo, Co. Laois on Sunday 20th May. In June a charity football match between Iano's Bar and The Brewery took place in Rathdowney at Clover United's grounds. The staff of both Public Houses and some of their regular customers were joined by League and Cup winning Clover United A & B teams. There was a great turnout and a great atmosphere on the day. The game ended 5-all and went to a penalty shootout, where after 10 kicks each there was nothing dividing the two teams and they called it all square on the day!! The group also held a cyclathon at Circle K, Manor Stone at junction 3 on the M8 Motorway on 26th July and a Retro Video Game Night at Jeremiah Grant's Portlaoise on 27th July. The monies raised from the events will be added to the funds raised by the main fundraising event; an impressive 220Km Cycle from Rathdowney Co. Laois to Clonakilty via Cork City on Saturday 3rd and Sunday 4th August 2018.

Killeen Family Fundraiser

Last year the Killeen Family from Ballyfermot in Dublin held a fundraising night for ILFA in memory of Tina Killeen. With the help and support of the Sarsfield Pigeon Racing Club, their family, friends, and the local community, they raised the fantastic sum of €3,480.

On Sunday 22nd April, the Killeen family met with Eddie Cassidy (ILFA Chairman) for a cheque presentation. **Pictured are (back row, from left to right) Michael, Rosanna, Aoife, John, Jodee, Eddie Cassidy, Jade, Lennon and Tanya Killeen, (front row) Demi, Drew, Leon and Evan.**

Well done to all the Killeen Family and thank you for your great support.

Ballybunion Tug of war

Huge thanks to John Horgan and friends who made up the Feale Bar Team and supported ILFA at the inaugural Ballybunion Tug of War competition on Saturday 30th June.

In the true spirit of sportsmanship, both teams in the final agreed pre-match to split the winnings between their respective charities and the fantastic sum of €500 was raised for both teams. Feale Bar Team were the strongest men on the day and won the competition. The patrons of Feale Bar kindly contributed to a further collection to ILFA that evening as they celebrated their team's famous win.

The Feale Bar team (in white): Back row: Philip Julian, Declan O'Connor, Jimmy Mulcahy and Stephen Delaney. Front row: John Cahill. Johnny Mahony, Shane Fogarty, Danny Curran.

Midlands Support Group Table Quiz

Sincere thanks to Val Kennedy and friends of the Midlands IPF Support Group for fundraising for ILFA. A hugely successful table quiz was held in March 2018 and raised the fantastic sum of €1,265. Val Kennedy presented the proceeds of the event to Eddie Cassidy (ILFA Chairman) in July. Thank you to everyone involved in organising and supporting the event.

Pictured are Eddie Cassidy and Val Kennedy.

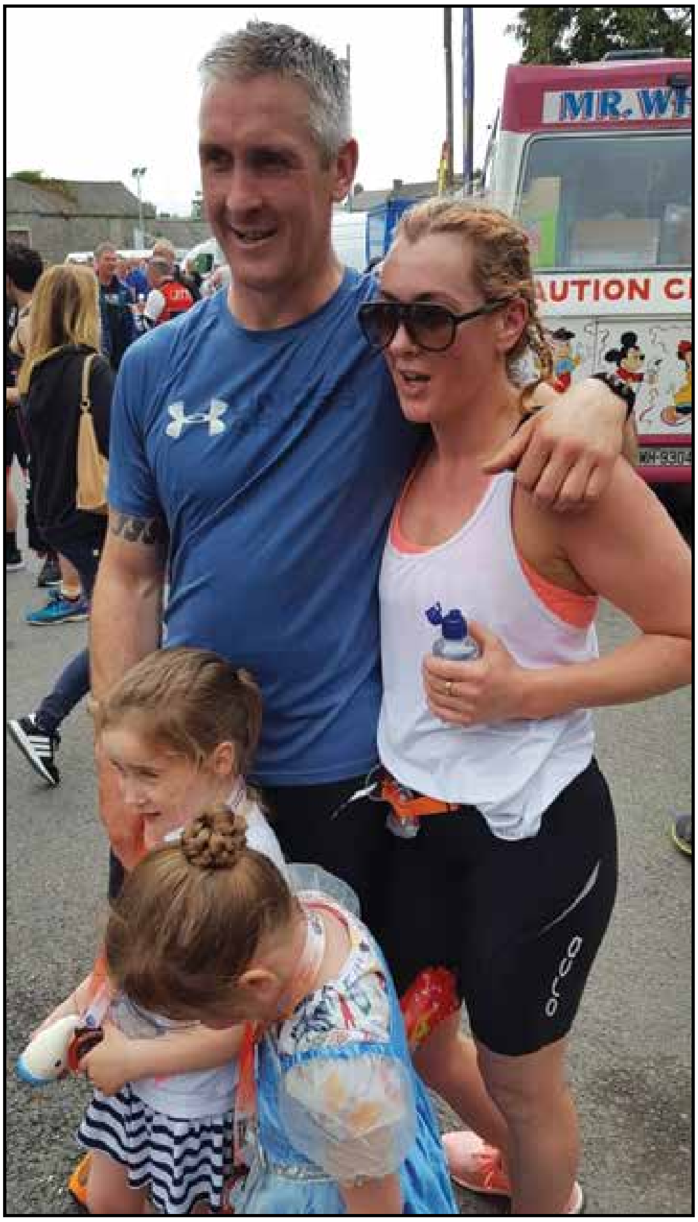
St Patrick's Day Sponsored Walk

Thanks to the Irish Cement Swimming Circle who fundraised for ILFA. Members of the group took part in a sponsored walk on St Patrick's Day and received generous donations from friends to boost their fundraising total.

Pictured are; Brian, Jim, Annette, Tom, Chris and Paul. Missing from the photo are Audrey, Simon and Frank.

Tri-Athy Success

Congratulations and warmest thanks to the amazing Aoife O'Grady who completed the famous Tri-Athy event (consisting of a run, swim and cycle), in Athlone on Saturday 2nd June in aid of ILFA. Aoife is a close family friend of Anthony and Maria Hackett from Dublin and wanted to show her support for Anthony, Maria and their family by talking on the challenge and fundraising for ILFA.



Pictured are Oisin, Aoife, Ellen and Ava after event.

Thank you

Sincere thanks to all the families who requested donations to ILFA in lieu of flowers at the funerals of their loved ones. We are very grateful for your support and kindness to ILFA at a time of great personal loss.

Wedding favours

Huge thanks to the happy couples who make donations to ILFA in lieu of wedding favours for their wedding day celebrations. We are very grateful for your support and helping raise awareness among your wedding guests. We wish you every happiness for the future.

Marta Almagro (Spain), Matt Cullen (Ireland) and Pippa Powell (European Lung Foundation).

ERS Presidential Summit 2018

I was invited by the European Lung Foundation (ELF) to take part in the European Respiratory Society (ERS) Presidential Summit in Athens, Greece on June 19th and 20th, arising from an article I had written on the patientMpower app that was published on the ELF/ERS website. The ELF/ERS thought that technology such as the patientMpower app would be appropriate for the summit's theme - 'Redesigning the Future of Patient Care'.

My presentation focused on how the patientMpower app is helping me to better manage my pulmonary fibrosis. During my presentation I demonstrated the app on my mobile phone. It records FVC measurements, oxygen levels, breathlessness, journal entries and hosts videos such as the ILFA Exercise DVD. There was great interest and positive feedback following the presentation. The programme also included discussions on how multidisciplinary and specialist care should be managed to improve patient outcomes.

Professor Mina Gaga (ERS President) wanted the summit to give patients a platform to share their experiences. Other patients talked about their experience of living with cystic fibrosis, COPD, bronchiectasis and lung cancer. The result was a highly emotional, inspiring and incredibly positive experience. It was wonderful that the views of the patients took centre stage, and those involved in discussions were lung health experts, patients, policymakers, and representatives from the pharmaceutical and medical technology industry. It is fitting to quote Prof. Gaga; "Knowing the scientific data and clinical guidelines is imperative, but it is patients who put a face to disease, give us a new perspective and allow us to get the true measure of the problems and impact of the solutions. They give us the empathy we need to try harder and to get better."

Between the genuine empathy shown during the summit and emotion generated by patient speakers, there is every reason to be positive concerning the future care.

- Report by Matt Cullen (patient advocate)

Patient Support Groups

Cork Support Group

The group meets at 11am on the last Thursday of every month at The Elm Tree, Glounthaune. **Please call Anne on 087 985 4587 for more details.**

Dublin Support Group

The group meets on the first Tuesday of every month at 11am at the Carmelite Community Centre at Whitefriar Street Church, Aungier Street, Dublin 2. **Please call Matt on 086 244 8682, Pam on 086 178 9055 or Paddy on 087 412 8612 for more details.**

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at The Rose Hotel. **Please call John on 087 280 9801 or Joan on 086 353 0310 for more details.**

Midland Support Group

The group meets on the first Wednesday of every month at 2.30pm at the Tullamore Court Hotel, Tullamore, Co. Offaly. **Please call Val on 087 233 2653 for more details.**

Cavan Monaghan Support Group

Kevin McSkeane is hoping to set up a support group in Cavan - Monaghan. **Please call Kevin on 085 243 6828 for more information.**

Mid West Support Group

The group meets on the last Saturday every month at 1pm, at Matt The Thresher, Birdhill, Tipperary. **Please call Noreen on 087 262 7976 for more details.**

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

086 871 5264

Messages of condolences

ILFA would like to extend our sincere condolences to the family and friends of **Adrian Murphy** from **Killarney, Co Kerry** who passed away recently. Adrian set up the Kerry IPF Support Group in Tralee and provided great encouragement and advice to patients diagnosed with IPF. Adrian was a quiet, gentle man and a great patient advocate. He helped raise valuable awareness of IPF by taking part in radio interviews, telling his story to the local press and volunteering his time during IPF World Week to host an information stand at University Hospital Kerry. Adrian made history by being the oldest lung transplant recipient in Ireland and he was a source of inspiration to all the healthcare professionals involved in his care, his support group friends, the wider ILFA community, and all those who knew him. May he rest in peace.

Diary
Dates For Your

Upcoming ILFA Events

- **The National Ploughing Championships will take place at Screggan, Co Offaly from 18th-21st September. Please contact ILFA if you would be able to volunteer to help us at the Ploughing Championship.**
- **The ILFA Service of Prayer and Reflection will take place on Saturday 6th October at Rathgar Methodist Church, Brighton Road, Dublin 6 at 3pm.**
- **The next Patient Information Day will take place on Saturday 20th October at the Crowne Plaza Hotel, Northwood, Santry from 10am to 1pm.**

Upcoming Fundraising Events

- **The Pat Casey Memorial Cycle will take place on Saturday 29th September. The cycle will be a circular route of 122km, starting and finishing at Forge Hill, Cork City. For more information please call Anne on 087 985 4587, Brian on 086 088 1064 or email annecasey@live.ie**
- **The Margaret Maloney Memorial Darts Tournament will take place on Saturday 29th September at The Central in Roscrea and promises to be great fun. Please contact Owen Maloney on 087 241 4475 for more information.**
- **The Dublin City Marathon will take place on Sunday 28th October. Please contact ILFA if you would like a fundraising pack.**

Keep in touch with ILFA

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

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

Irish Lung Fibrosis Association
www.ilfa.ie

EU-IPFF