

ILFA Newsletter



Patrons: Michael Darragh Macauley, Charlie Bird, Andrea Corr.

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ILFA welcomes the General Scheme of the Human Tissue Bill and an opt-out organ donation system

On 2nd May 2019 the Minister for Health, Simon Harris TD announced the publication of the General Scheme of a Human Tissue (Transplantation, Post-Mortem, Anatomical Examination, and Public Display) Bill. Significantly, this Bill provides for the introduction of an opt-out consent system for organ donation and an associated register. ILFA has long campaigned for the introduction of an opt-out organ donation system and additional resources and infrastructure to support organ donation and transplantation. Following the publication of the Human Tissue Bill, ILFA wrote to the Minister for Health to express our gratitude and hopes for the future in relation to an opt-out consent system.

In a press release on 2nd May 2019, Minister Harris said, "I am really pleased to progress this vital piece of legislation which is a key commitment of mine and of the Government." He acknowledged the great work of staff at Organ Donation and Transplant Ireland (ODTI) and the national transplant centers at Beaumont Hospital, St Vincent's University Hospital, and Mater Misericordiae University Hospital. Minister Harris stated "I strongly believe that this opt-out system could transform organ donation in Ireland. In order for it to be most effective, it will be supported by a series of other measures. It is so important we do everything we can to make organ donation the norm in Ireland when people pass away in circumstances where donation is a possibility." He also stated, "The plan is that the legislation will dovetail with awareness campaigns, enhanced infrastructure, training for medical staff and audit, to ensure that all opportunities for transplantation are followed through."



David Crosby (double lung transplant recipient), Edell Cashman (liver transplant recipient), Minister for Health Simon Harris TD, Martina Goggin (representing organ donor families) and Professor Jim Egan (ODTI) at the announcement of the publication of the Human Tissue Bill general scheme. (Photo courtesy of the HSE and ODTI)

Minister Harris acknowledged the significant and valuable contribution made by Senator Fergal Quinn to progress organ donation and transplantation in Ireland.

The General Scheme of the Human Tissue Bill will introduce a soft opt-out system of consent for organ donation. Under this system, consent will be deemed unless a person has registered that they do not wish to become an organ donor after death. If a person is on the opt-out register, their next-of-kin will not be approached to discuss organ donation and their organs will not be removed. If a person is not registered on the opt-out register, the next-of-kin will always be consulted before any organ is removed. If the next-of-kin objects to the donation, then the donation will not proceed.

Patient Information Day

The next Patient Information Day will take place on Saturday 19th October at the Crowne Plaza Hotel, Northwood, Santry, Dublin from 10am until 2pm. We hope you can join us to learn more about pulmonary fibrosis from experts in the field. Our speakers will include;

- Dr Michelle Murray - Respiratory Consultant
- Petra Grehan - Physiotherapist

- Lindsay Brown – Respiratory Nurse Specialist
- Dr Jennifer Wilson O'Rathaghaille – Clinical Psychologist
- Professor Bernard Mahon – Maynooth University
- Carita Bramhill, Research coordinator
- Sonia Morrison from Air Liquide Ireland and Adrian Sheehan from BOC Healthcare Ireland

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

ILFA Service of Prayer and Reflection

The ILFA Service of Prayer and Reflection will take place on Saturday 12th October at Terenure College Chapel, Terenure, Dublin at 3pm. The ecumenical service will be celebrated by Reverend Fr Brian McKay (Prior of Terenure College), Reverend Vanessa Wyse-Jackson (retired Minister at Rathgar Methodist 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 2019.

Rest in Peace Feargal Quinn

The Irish Lung Fibrosis Association was deeply saddened to learn about the passing of our esteemed and cherished patron Feargal Quinn in April 2019. Feargal was a patron of ILFA for many years and we were honoured to know and work closely with him. Fergal was a true gentleman and was deeply committed to his ILFA role.

Feargal helped launch ILFA's 2000 Steps a Day exercise programme and 'The National Patient Charter for Idiopathic Pulmonary Fibrosis'. He also appeared in the ILFA exercise DVD and encouraged patients to stay motivated and determined. Fergal also attended several ILFA Patient Information Days and spoke at these events sharing his wisdom and insights. Feargal contributed an article to ILFA's special commemorative magazine 'ILFA 15' that was produced in 2017 and his article is reproduced below.

In 2008, Senator Feargal Quinn wrote a Bill entitled the 'Human Body Organs and Human Tissue Bill'. We were delighted when Feargal's pioneering role and vision was acknowledged widely by government officials, the HSE and the Department of Health, and the media when the Human Tissue Bill general scheme was announced. This was a great and fitting legacy to Feargal's tremendous advocacy work. Feargal radiated a special warmth and great kindness and he was always eager to engage with the ILFA committee and patients and learn about their experiences. We have lost a wonderful friend and patron. Please remember Feargal and his family in your thoughts and prayers. May he rest in peace.



The late Feargal Quinn with the late Joan Doyle, and Matt Cuiien at the launch of the National Patient Charter for Idiopathic Pulmonary Fibrosis.



Irene Byrne, Michael Darragh Macauley and the late Feargal Quinn at the launch of ILFA's 2000 Steps a Day Challenge.

Proud to Support ILFA

Former senator Feargal Quinn reflects on his years as an ILFA patron as he looks forward to implementation of the opt-out organ donor system.

The Irish Lung Fibrosis Association was founded back in 2002 and I have been privileged to be a patron of the organisation along with some other key individuals such as Brian O'Driscoll, Andrea Corr, Charlie Bird and Michael Darragh Macauley. My role as patron has required me to offer support, encouragement and publicity for the association and I had the privilege in 2015 to support the organisation with the launch of their Patient Charter in Leinster House.

The work of the ILFA is immeasurable. Approximately 360 people are diagnosed with Idiopathic Pulmonary Fibrosis in Ireland each year and the ILFA acts to support those patients and their families by offering them clear and concise information, access to appropriate therapy and medication as well as connecting them with support groups. All of this is invaluable to families faced with this disease.

The association promotes referrals to the National Lung Transplant Unit. This is an area very close to my heart. Back in 2008 I wrote a Bill entitled the 'Human Body Organs and

Human Tissue Bill'. I am now delighted to see that Minister Simon Harris has taken my Bill on board and announced that he is determined to implement this opt-out system in Ireland by next year. This will hugely increase Ireland's rate of organ donation. In 2016, 35 lung transplants were performed at the National Heart and Lung Transplant Service at the Mater Misericordiae University Hospital. With the implementation of this Bill we will see this figure rise giving a new lease of life to many of those affected.

ILFA also offers very practical ways to adapt to living with this lung condition. One of these initiatives was the launch of the 2000 Steps A Day walking challenge and the ILFA Home Exercise DVD. These initiatives are invaluable as they encourage patients to maintain a level of physical activity which promotes muscle strength, mobility and also good mental health.

I would like to thank the Irish Fibrosis Lung Association for their dedication and hard work. They are a voluntary committee relying on charitable donations and fundraising events. This requires enormous commitment, dedication and hard work. I congratulate you and encourage you to keep up the enthusiasm.

Best wishes, Feargal Quinn, ILFA Patron

(Published in 'ILFA 15' in 2017)



Dr Killian Hurley, Bettina Korn, Maria Love, Anne-Marie Russell, Lynn Fox, Irene Byrne and Dr Irfan Shah.

Patient Information Day, April 2019

ILFA's first information day of 2019 took place at the Hilton Airport Hotel, Malahide, Dublin on 6th April 2019. The focus of this meeting was palliative care and planning for the future for Idiopathic Pulmonary Fibrosis (IPF). The meeting was well attended by patients, family members and healthcare professionals. In opening the meeting, **Eddie Cassidy** (ILFA Chairman) extended a warm welcome to all and gave thanks to the many ILFA volunteers and fundraisers who make events like this possible.

Meeting Chairperson, **Dr Anne-Marie Russell**, Honorary Clinical Research Fellow at the Royal Brompton Hospital London, explained that this information day came about following the ILFA World Café on Palliative Care held in June 2018. Anne-Marie discussed the importance of reframing perceptions of palliative care, a term usually associated with end-of-life-care, to view it as the holistic management of symptoms with the aim of increasing quality of life.

Andrew Cooper, whose mother has IPF, offered a caregiver's perspective on coping with this disease. He explained that the information, knowledge and support he has gained through others by attending ILFA meetings and events has been invaluable in giving him strength as a caregiver.

Dr Killian Hurley, Respiratory Physician at Beaumont Hospital, gave a presentation entitled 'What is IPF?' Dr Hurley used the analogy of an upside-down tree to describe the structure of the airways and lungs. He explained that the problems with IPF occur down at the 'leaves' (the alveoli, small air sacs) where scarring means that oxygen cannot effectively get into and out of the lungs. Multiple tests are used to diagnose IPF, including chest X-rays, CT scans, possibly a biopsy, along with breathing tests, oxygen saturation measurements and six-minute walking tests. A diagnosis of IPF is made by a multi-disciplinary team comprising the healthcare professionals involved in assessing the patient, including the respiratory consultant,

the pathologist, the nurse specialist, the thoracic surgeon and the radiologist. IPF is a progressive disease, meaning it gets worse with time, but the progression can be fast or slow. Patients are monitored closely to establish their individual rate of progression and decide on their treatment plan.

Lynn Fox, Respiratory Nurse Specialist at the Mater University Hospital, discussed symptom management in IPF. She explained that there is no set process for the management of IPF, and that treatment is individualised with the goal of improving quality life. Breathlessness, the biggest symptom in IPF, can be improved through non-medical interventions such as positioning, relaxation breathing, exercise and the use of a hand-held fan. Medical options for breathlessness include oxygen, small doses of opioid medications and anti-anxiety medications. Patients need a full check-up prior to being started on oxygen, including a six-minute walking test, arterial blood gas tests and assessment to see if you are a nose or a mouth breather (this is important as oxygen concentrators are not triggered by mouth breathers). Fatigue, another common symptom of IPF, affects everyone differently but Lynn's advice for patients was to plan ahead so you have the energy to do the things you want to do. Also, to look after yourself by eating well, drinking enough fluids, exercising and getting enough rest and sleep. Gastric reflux (heartburn) is also common in IPF and may be a side effect of anti-fibrotic medication, and proton pump inhibitor medications (PPIs) can be helpful in treating this symptom. Cough can be a very debilitating symptom in IPF and is difficult to treat. Lynn advised people to keep a diary to help establish cough triggers. Anxiety and depression are also common in IPF and attending support groups, counselling, exercise and medication can be beneficial.

Dr Killian Hurley gave a second presentation and spoke about acute exacerbations of IPF, also called 'flare ups'.

An IPF exacerbation is a sudden unexplained worsening of IPF symptoms in the last 30 days, which includes new changes on a CT scan, with no evidence of infection or other causes for shortness of breath (for example, heart failure). IPF exacerbations can disrupt the progression of IPF, meaning that lung function may not fully recover after an exacerbation. Exacerbations can have long term repercussions and need to be prevented and managed. To help reduce the risk of exacerbations, patients should ensure their vaccinations for influenza and pneumococcal disease are up to date, minimise acid reflux including using PPI medications (as this may be a risk factor for exacerbations), avoid airway irritants, follow good hand-washing practices and avoid contact with people who are sick. There is also research that indicates anti-fibrotic medications may reduce the risk of exacerbations. If you think you are having an exacerbation, it is vitally important to let your GP or nurse specialist know quickly so it can be managed. Diagnosis involves a CT scan or chest x-ray and tests to exclude other causes, and treatment can include oxygen, antibiotics and steroids.

Irene Byrne, physiotherapist at the Mater University Hospital, gave a practical guide to living with IPF. A key theme from Irene's presentation was adapting to the 'new normal' and the importance of accepting offers of help! By taking us through the rooms in the house, Irene gave pragmatic advice on coping with breathlessness, including clearing areas around the front door, placing a stool at the top of the stairs, using a shower chair or a bath stool, and sitting down whilst propping up the elbow to shave or use a hairdryer. Little things like getting a 'picker-up' device or a V-shaped pillow can also help make life easier. Irene advised that stair-lifts require early planning as they can take a long time to arrange. There are many practical aspects to consider with using oxygen, so Irene recommended that people have thorough discussions with their healthcare team regarding the pros and cons of all the oxygen options available to find a solution to suit their lifestyle. To improve mobility, people should consider a rollator (a walking aid with wheels). Irene also advised that as breathlessness makes chewing more difficult and decreases appetite, use moist foods, and eat little and often. Holidays require careful planning and permission to travel from your doctor. For air travel, the European Lung Foundation have information on individual airline's policies around oxygen on their website www.elf.org

Maria Love, social worker at the Mater University Hospital, discussed the psychosocial aspects of living with IPF. Maria presented the biopsychosocial model for IPF, where 'bio' means the biological disease and its symptoms, 'psycho' refers to the depression, anxiety as stress related to IPF, and 'social'; relates to our hobbies, families, friends, career, retirement plans or the isolation that can result from

IPF. These areas can impact on each other and lead to a vicious circle where, for example, breathlessness leads to lack of exercise, which increases social isolation and anxiety, which make breathlessness even worse. Illness affects our mental health and has massive social impacts, limiting daily activities, changing relationships and family structures. Understanding these problems can help us to cope better; as Maria conveyed "It is the medical support that keeps me alive, but the psycho and social support enables me to live". Ways of coping with the psychosocial impacts of IPF include support from professionals, joining support groups, attending pulmonary rehabilitation (not just for the exercise but for the social benefits too), and being honest and open about your emotions whilst recognising that the illness is not your complete identity. Carers play a much under-recognised role, and Maria advised that as a carer it is important to look after your own physical and psychological health and recognise the impact of caring on your lifestyle.

Dr Irfan Shah, medical registrar at St Michael's Hospital in Dublin discussed the considerations for lung transplantation. IPF is now the leading reason for lung

transplantation worldwide. There are several criteria, as set out by guidelines from the International Society of Heart and Lung Transplantation, to assess IPF patients' suitability for lung transplantation. Early referral for transplant assessment is recommended. In Ireland the National Lung Transplant Centre is based at the Mater University Hospital, and Dr Shah spoke about the multiple medical and psychological assessments patients must undergo to assess if they are suitable for a



Tom O'Sullivan, Anne-Marie Russell and Andrew Cooper.

transplant. The assessments determine medical suitability but also gauge if a patient is focused and committed to follow the intensive requirements after surgery. If a patient is considered suitable for transplantation, they are placed on the transplantation waiting list, with the time to surgery being dependent on the availability of a suitable donor organ. In addressing questions on the age of patients considered suitable for surgery, Dr Shah explained that it was not chronological age but physiological age and how otherwise healthy you are (apart from your lung condition) that was important in considering transplantation.

Bettina Korn, the End-of-Life Co-ordinator at St James Hospital, sensitively guided the audience through a discussion on end-of-life preferences. For end of life care, there are several considerations; meeting care needs, the environment where care happens, dignity and respect, communication and care for relatives. Patients' wishes are imperative in end of life care, so having conversations with loved ones and healthcare providers about preferences for end of life care is important. These conversations can obviously be difficult, but Bettina's advice is to create opportunities for these discussions, to



Andy McGrane, Shauna Clarke and Chris Meehan who volunteered on the day and provided excellent support with registration and timekeeping.



Rebecca Lloyd.

recognise that some people may be ready to talk about this topic at different times and to seek professional guidance. Bettina recommended that is never too early to start these conversations, and that lots of small conversations about end of life care may be easier than creating time and space for one big discussion. There are supports available for information and education on end of life: The Irish Hospice Foundation (www.hospicefoundation.ie) has developed a Charter on Death, Dying and Bereavement and its 'Think Ahead' programme has a very practical form to guide people through end of life planning. In addition, the conversation project (www.theconversationproject.org) has information and supports for people to talk about their wishes for their end of life care.

Rebecca Lloyd, Public Engagement Officer at the Irish Hospice Foundation, discussed the legal aspects of planning for the future which you may want to discuss further with your solicitor. Please bear in mind that some forthcoming changes in the law around assisted decision-making capacity may affect the information she discussed at this meeting. Legal considerations for the future include:

- Wills provide instructions on what you would like to happen to your assets after you die. You don't have to make a will but if you don't the state will make these decisions for you. Rebecca shared that 'do-it-yourself' wills can be troublesome; they can be legally challenged and the witness to your will cannot receive anything. Wills can be changed, and it is recommended they are reviewed at certain 'ages and stages'.
- Enduring Power of Attorney gives power to another person to make decisions about your care if you become mentally incapacitated to do so (unlike Power of Attorney which is temporary and is effective once a person loses capacity). These give far reaching powers to another individual and need careful consideration. An Enduring Power of Attorney is made with both a solicitor and a doctor, can be expensive to make and requires a court order to amend it.

- Advanced Healthcare Directives allow you to make choices about the type and extent of medical treatment you do not want in the future, even if a refusal for treatment may result in your death. They also allow you to appoint a Designated Healthcare Representative. Advanced Healthcare Directives only come into effect if you lose mental capacity to make informed decisions. They can be useful in helping you keep control of your own care and can give loved ones peace of mind. The Irish Hospice Foundation's 'Think Ahead' document gives information on discussing and recording your preferences for treatment in the event of an emergency or serious illness.

After the presentations, Anne-Marie Russell chaired the Questions and Answers session with many questions from the audience and she thanked the speakers for their excellent presentations and Air Liquide and BOC Healthcare oxygen companies for their presence. She then handed over to **Tom Sullivan** who, having cared for his wife Eileen, gave us his personal reflections on palliative care. Tom advised everyone not to fear palliative care programmes, that these offer holistic physical and psychological care for the patient and the family which can be 'turned on and off' as required as the disease progresses. We were fortunate that Tom shared some of his very poignant and equally humorous poetry with us before Maria Love finished up with a session of mindfulness. This exercise reminded us to show ourselves the same compassion during moments of stress and hardship that we would offer to others.

Finally, the ILFA yoga DVD was launched by ILFA Director Nicola Cassidy and she paid tribute to ILFA Patron Michael Darragh Macauley, and three patient volunteers; Pamela Martin, Evelyn Cooper and Matt Cullen for their starring roles in the video. The meeting wrapped up with another form of valuable support; tea, lunch and time for a chat.



Marie Sheridan, David Crosby and Nicola Cassidy.
(Photo courtesy of An Post and ODTI)



David Crosby and Andy Kavanagh.
(Photo courtesy of An Post and ODTI)

Launch of Organ Donation Stamp

Marie Sheridan (Hon. ILFA Treasurer) and Nicola Cassidy (ILFA Director) attended the launch of An Post's new national organ donation postage stamp on 21st March 2019 at the General Post Office in Dublin, along with representatives from other patient organisations, healthcare professionals working in transplant medicine, transplant recipients and donor families. It was a very special occasion and as a bonus it was a lovely sunny day.

The organ donation stamp came about as part of a collaboration between An Post, Organ Donation and Transplantation Ireland (ODTI) and the HSE. The creative design of the stamp features an hourglass timer that represents the precious nature of time and the gift of life passing from one person to another. It is hoped that the stamp will encourage people to have a conversation with their families to let them know about their wishes to be an organ donor and save lives.

Debbie Byrne, managing director of An Post Retail, said the organisation hopes the stamp will help raise public awareness and she gave some impressive figures that will help support this campaign. There are 9,000 An Post staff as well as 3,000 postmasters and their staff who are getting behind donor and recipient families and millions of customers who will send and receive the stamp in Ireland and abroad. The stamp is available in two formats; it can be especially asked for at the post office counter and it is available as Stamps on A Roll, ensuring that the Organ Donor stamp will be printed and posted many millions of times. The stamp will be an ambassador for Organ Donation, travelling around Ireland and all over the world on letters and parcels. Debbie stated that "An Post wants to spark a national conversation in Ireland's post offices, kitchens, cars, playgrounds and wherever families are gathering."

Helping to launch the stamp was Andy Kavanagh and David Crosby. Andy has worked for An Post for 20 years and is the longest surviving heart transplant patient in Ireland, having had the transplant in 1986 and also a subsequent

kidney transplant 12 years later. Andy said "The important message we are trying to get out to people is for people to donate their organs but also to make sure that their family knows what their wishes are if anything was to unfortunately happen to them," David Crosby also shared his story of being diagnosed with Idiopathic Pulmonary Fibrosis (IPF) and undergoing a double lung transplant thanks to the generosity of his organ donor. Both men also featured in two inspirational videos describing the life-changing impact of their transplants.

Professor Jim Egan, Director of ODTI, also addressed the audience and said "I'd like to thank An Post for the creation of this special stamp. It will create more public awareness about organ donation. It is only because of the generosity of the Irish public that patients can receive the life-saving treatment of an organ transplant. Our message is simple: Organ Donation Saves Lives."

ILFA would like to congratulate An Post, ODTI and the HSE on this great initiative to raise awareness of organ donation and help facilitate family discussions on this important topic.



Nicola Cassidy (ILFA Director), Gordon Ryan, Professor Jim Egan, David Crosby, Ciara Quirke and Robert McCutcheon (Chair of the Irish Heart and Lung Transplant Association).

‘The irony of lung fibrosis; a fibroblast to treat IPF’

The Irish Lung Fibrosis Association was delighted and honoured to partner with Maynooth University in welcoming Professor Luis Ortiz, University of Pittsburgh Medical Centre, USA, to the Royal College of Physicians of Ireland for a special lecture. The special educational event took place in the fine and prestigious Corrigan Hall which was packed with healthcare professionals, scientists, students, and patients eager to learn about Professor Ortiz’s work. Prof Ortiz’s inspiring lecture described experimental research on mesenchymal stem cells and their influence on the gene expression and inflammatory actions of lung cells and tissue.

Professor Bernard Mahon of the Immunology and Cell Biology Laboratory at Maynooth University Biology Department wrote the following article which appeared in the Medical Independent. ILFA is grateful to Professor Mahon and to Priscilla Lynch, Clinical Editor of the Medical Independent, for permission to re-produce the article. Photos courtesy of Joshua Shannon (Maynooth University).



Evelyn Cooper, Liam Martin, Pamela Martin, Treasa Brogan, Professor Luis Ortiz, Liam Mullaney, Matt Cullen and Philo Mullaney.



Prof Luis Ortiz.



Prof Paul Moynagh (Head of the Human Health Research Institute at Maynooth University), Prof Jim Egan (Mater University Hospital), Eddie Cassidy (ILFA Chairman), Prof Luis Ortiz (University of Pittsburg), Prof Bernard Mahon (Maynooth University), Prof Michael Keane (St Vincent’s University Hospital).

‘The irony of lung fibrosis; a fibroblast to treat IPF’

– report by Professor Bernard Mahon

The term ‘idiopathic’ is often a refuge for physicians and scientists when we do not understand how a disease is caused. Nevertheless, much has been learned about the mechanisms that underlie Idiopathic Pulmonary Fibrosis (IPF). This was the topic of a special lecture held in the Royal College of Physicians in March where Professor Luis Ortiz from the University of Pittsburgh Medical Centre looked at past and current understanding of lung fibrosis and

scanned the horizon of future therapies. The evening was a co-sponsored event by the Irish Lung Fibrosis Association and the new Maynooth University Human Health Research Institute. In a salute to the history of the disease, Professor Ortiz recalled that the Irish physician, Sir Dominic Corrigan – a former president of the Royal College, made one of the first descriptions of the disease.

However, whilst our understanding of the cells and the biological process of fibrosis have improved, IPF remains a fatal interstitial lung disease of unknown aetiology, characterised by progressive fibrosis of the airways. It



Nicola Cassidy, Professor Luis Ortiz, Eddie Cassidy and Gemma O'Dowd.



Evelyn Cooper, Pamela Martin and Treasa Brogan deep in conversation with Prof Ortiz.



Prof Jim Egan (Mater University Hospital), Prof Muiris Fitzgerald (Emeritus Professor of Medicine at University College Dublin) and Prof Michael Keane (St Vincent's University Hospital).

predominantly affects those over 60 years, and the incidence and prevalence are rising. Whilst lung transplantation affords good prospects for recipients, the limitations of availability and scalability of this approach are well known, and other approaches merely slow what is otherwise a fatal disease. After describing his experiences in Pittsburgh and the processes of disease, Professor Ortiz went on to describe the two medications licensed for use in recent years in the US; Pirfenidone and Nintedanib. These anti-fibrotic medications limit progression but are not curative and certainly in the US context are extremely costly interventions.

In the second half of his presentation, Professor Ortiz focused on the need for more research into IPF and the challenge of reversing fibrosis. He reviewed the latest thinking about how the regular process of cell repair is thought to operate in the distal airways and focused on a cell circuit of three cells and how these communicate. An airway stem cell (the type II alveolar epithelial cell), a supporting cell (the lipofibroblast), and an immune cell (the airway macrophage).

His hypothesis is that such a circuit is dysfunctional in IPF but that it might be possible to re-programme it towards a more fibrolytic rather than fibrotic nature. His favoured candidate for achieving this was using a cell-based therapy. His goal is to use a bone marrow stem or stromal cell as a future therapy to perform the reprogramming of the alveolar niche. He described a decade of careful work using the mesenchymal stromal cell in tissue culture, and then in small and large animal models that suggest this approach might be fruitful.

The work has brought him to Ireland to share data with Irish scientists and the team in Maynooth, who study how these stromal cells interact with the immune system. His work has led to some fascinating discoveries about how cells communicate using small sub-cellular particles, and even by exchanging their mitochondrial energy sources. He has now assembled a team from a number of universities and health centres in the US in a bid to begin phase 1 clinical trials of this therapy. However, Prof Ortiz cautioned that research takes time, and that success is not guaranteed. Professor Ortiz also emphasised that while research was necessary it had to be performed in a well-regulated and controlled environment such as in Ireland. He shared his fears about medical tourism and of disreputable and poorly controlled "clinics" that were exploiting regulatory loopholes to make extravagant, unsubstantiated claims. Finishing, he stated that just because IPF was idiopathic, it did not mean we were in the dark. Lung transplantation services and skills were better than ever before, we have new drugs that are an improvement on a decade ago, and we

A Patient's Perspective

We had been alerted that this lecture was for healthcare professionals. The list of the speaker's global awards, honours, trials and publications was formidable. We expected to be dazzled by science. But when we met Professor Luis Ortiz on 13th March, he was an informal, incredibly warm, humble man eager to talk to the patients first, to hear their experiences, as we shared a cup of tea.

The lecture took place in the opulent splendour of The College of Physicians where portraits of eminent past professors adorn the walls. Prof Ortiz delivered his talk under the watchful eye of Dr Dominic Corrigan. Dr Corrigan (1802-1880) an Irishman, of 'Corrigan's Pulse' fame, is also credited for first describing "cirrhosis" of the lungs!

Prof Ortiz began the lecture by first addressing the patients. "Stay active, stay positive" he urged. He described the stem cell research he is doing for the treatment of IPF in layman's terms. He then apologised and said he would have to talk to "the nerds" in the room. The language turned medical and complex but still contained many nuggets of useful information. One intriguing aspect of his talk was when he described spending five years becoming a 'mouse cardiologist' in order to understand how IPF develops.

All agreed this was a brilliant informative evening, delivered with grace and obvious passion. As an IPF patient, it was humbling to know that there is someone in the world trying so hard to find a cure for this rare condition.

- Report by Treasa Brogan

know much more detail of how cell regeneration and repair occur in the healthy and diseased lung, but only with more research and clinical trials will we get to the point where we can repair the fibrotic lung appropriately. Prof Egan (Mater Hospital) then moderated a question and answer session that understandably attracted a great deal of interaction. Patients, supporters, scientists and physicians all contributed to a fascinating discussion that continued long after the formal session ended.

Professor Ortiz is the 2019 Maynooth University Distinguished Visiting Scholar.

Organ Donation Awareness Week 2019

The launch of Organ Donation Awareness Week took place at the Mansion House in Dublin on Tuesday 26th March 2019. The event was organised by the Irish Kidney Association. Representing ILFA at the event were Marie Sheridan (ILFA Honorary Treasurer), Nicola Cassidy (ILFA Director) and lung transplant recipient and ILFA Patient Ambassador David Crosby.

Ray D'Arcy from RTE radio and TV is the Ambassador for the 2019 Organ Donation Awareness Week. In his address, Ray mentioned that he had the honour of being an Ambassador 20 years previously and was very happy to reprise his role. Ray had interviewed David Crosby on radio the day before the launch and described David's incredible return to health and fitness following his double lung transplant as 'miraculous'. Ray paid tribute to David's advocacy work raising awareness about the importance of organ donation and transplantation and he had plenty of further opportunities to marvel at the benefits of organ donation as he introduced the speakers from all over the country.

Garrett French and other transplant recipients who had received kidney, heart, kidney/pancreas and liver transplants told their touching personal stories and described how their lives had been transformed by the generosity of organ donors and families who had consented to organ donation. Garrett was diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in 2010 and received a left lung transplant in 2013. Further health complications meant that Garrett subsequently needed another lung transplant for his right lung. Five years on, Garrett paid tribute to his donors and thanked them for the opportunity to watch his four children grow up. Garrett and his wife Josephine and their 4 children attended the launch and it was wonderful to see the happiness that organ donation has brought to this young family.

Other speakers included Grainne Wyse who described how her family fulfilled her brother's wishes to be an organ donor and how this brought them comfort, and Karen Mason

from ODTI who described eloquently how organ donation can turn loss into hope and grief into blessings for family members who donate.

Professor Jim Egan, Director of Organ Donation and Transplant Ireland (ODTI) acknowledged the talented and dedicated 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 Health, Simon Harris, TD, 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. He also praised Orla Tinsley for raising awareness via her inspiring TV documentary on living with Cystic Fibrosis and waiting on a lung transplant. Minister Harris stated that the Human Tissue Bill that includes provision for the introduction of a soft opt-out consent system for organ donation will come before the Dáil in 2019.

Transplant Figures for 2018

According to Organ Donation and Transplant Ireland (ODTI), 234 transplant recipients received the gift of life thanks to the generosity of 81 organ donors and their families.

- The Mater Misericordiae University Hospital carried out 28 lung transplants and 18 heart transplants.
- St. Vincent's University Hospital carried out 56 liver transplants and 5 combined pancreas/kidney transplants.
- Beaumont Hospital carried out 127 kidney transplants from deceased donors and 40 transplants from living donors.



Robert McCutcheon (Chairman of the Heart and Lung Transplant Association), Marie Sheridan, Garrett French, Ray D'Arcy, Nicola Cassidy and David Crosby.
(Photo courtesy of the Irish Kidney Association).



Ray D'Arcy with Josephine and Garrett French and their children.
(Photo courtesy of the Irish Kidney Association).

Matt Cullen, Pamela Martin,
Michael Darragh Macauley and
Evelyn Copper.

Namaste!

New Yoga Exercise DVD for Lung Fibrosis

Michael Darragh Macauley, Dublin GAA footballer, yoga instructor and ILFA Patron has been central to the production of ILFA's newest patient resource – a yoga exercise DVD for people with lung fibrosis. Yoga has proven benefits for people with lung fibrosis in helping their health and well-being through improved breathing, mobility, flexibility, as well as through the relief of tension and anxiety.

In the video Michael Darragh takes three patient volunteers; Pamela Martin, Evelyn Cooper and Matt Cullen through a series of tailored breathing and meditation techniques, followed by physical exercises. The video was filmed on location in a beautiful yoga studio in Dublin and we are very grateful to everyone involved in the production of ILFA's newest patient resource.

The video features two levels of exercises which are suitable for beginners and those who feel they can progress to a more advanced stage. Before undertaking the exercises, viewers are asked to follow the BORG scale which helps them assess how breathless they should be when exercising and gauge what is the right level of activity for them.

Michael Darragh said *"I was very happy to become involved in this DVD which I hope will make a real difference to the lives of people living with lung fibrosis. I have a deep appreciation of yoga and the holistic benefits it offers across a whole range of areas. In the video we go through a series of exercises that can help people manage their health and cope with the challenges of living with the condition. The great thing is that the exercises can be done whether seated or standing and can be adapted to suit everyone's abilities. People can go at their own pace and no one gets left behind."*

Physical exercise is key to helping people manage their lung fibrosis. Even though many patients experience shortness of breath with physical activity, it is worth remembering that everyone gets breathless when they exercise, even athletes,

but what is important is that lung fibrosis patients know how manage their level of breathlessness. Yoga is beneficial and appropriate as it is suitable for people with varying levels of lung fibrosis, including those who use oxygen. For those on oxygen, we would urge them to speak to their medical team about turning up their oxygen to agreed levels so that they can cope with the activity and exercise comfortably. Positive lifestyle changes and, in particular, physical exercise, is hugely important for people with lung fibrosis. This DVD now means that they can engage safely in a home-based exercise regime.

The production of the ILFA yoga exercise DVD has been made possible thanks to a kind donation from Three Lakes Partners - a philanthropic organisation in the United States. ILFA also offers other exercise tools for people with lung fibrosis and healthcare professionals caring for them, including its 2,000 Steps a Day Exercise Challenge Walking Pack and an Exercise DVD. **To order exercise materials, please call ILFA on 086 871 5264 or email info@ila.ie. The video can also be watched on ILFA's You Tube channel and on ILFA's website, www.ilfa.ie**



Pamela Martin, Matt Cullen and Evelyn Cooper.

Research and Education

Research Bursaries from ILFA

In May 2019, the Irish Lung Fibrosis Association announced funding of €20,000 for research into Idiopathic Pulmonary Fibrosis (IPF). Healthcare professionals and scientists working in respiratory medicine in Ireland were invited to submit a Research Bursary Application Form.

We are delighted to learn about the fantastic research being conducted in Ireland. ILFA has decided to increase our investment total and will fund several high-quality and diverse research projects that include supporting the National IPF Registry, basic science projects looking at the development and treatment of pulmonary fibrosis, patient experiences, and genetic investigations. Congratulations to those awarded a research bursary. More details will feature in the next newsletter.

ILFA Educational Bursaries

In June, respiratory nurses and allied healthcare professionals were invited to apply to ILFA for an educational bursary to attend the Interstitial Lung Disease Inter-Disciplinary Network (ILD-INN) conference that will take place in Birmingham on 13th and 14th October 2019. The ILFA bursaries will contribute towards the cost of the conference registration including one night's accommodation and dinner, and travel to and from the United Kingdom.

We were delighted to receive many applications from healthcare professionals all over the country. The recipients of the ILFA educational bursaries are; John Alickolli (Bon Secours Hospital Cork); Rosaleen Anglim (South Tipperary Hospital); Grainne Casey (Mater University Hospital); Elaine Craven (Connolly Hospital Blanchardstown); Antoinette Doherty (Letterkenny Hospital); Carol Doherty (Letterkenny Hospital); Julie Goss (Harold's Cross Hospice, Dublin); Donna Langan (Galway University Hospital); Carmel McInerney (Ennis Hospital) and Lavinia McLeod (Mater University Hospital).

Lean White Belt Programme for healthcare professionals

Calling all healthcare professionals ... Do you have an idea that could improve the clinical care and management of pulmonary fibrosis patients at your hospital/clinic?

ILFA is planning to hold a one-day intensive introduction to Lean Six Sigma for Healthcare professionals including nursing, medical and allied health care professionals working in respiratory medicine.

The course will be delivered by two Lean Academy Black Belt Practitioners and will take place at the Mater Hospital in Dublin in January 2020 (date to be confirmed). ILFA is currently seeking expressions of interest from healthcare professionals working with pulmonary fibrosis patients who would like to take part in the programme. ILFA will cover the costs of the course and CPD and CEU points will be awarded to participants.

It is envisaged that a team will then undertake the professional certificate in Lean Six Sigma and develop an improvement initiative for pulmonary fibrosis patients. This quality improvement initiative may be linked to improving referral times, linking patients in with pulmonary rehab, ensuring patients attend an oxygen clinic or what you think is needed in your area for pulmonary fibrosis patients.

For more information, please see the Lean Academy website: www.leanacademy.nmhs.ucd.ie

Please contact ILFA if you would like to attend. Places are limited so please apply early.

Grand Rounds at the Hospice



Professor Anthony O'Regan, pictured, Respiratory Consultant at Galway University Hospital and Chair of the Irish Thoracic Society's Interstitial Lung Disease Group spoke at the Grand Rounds in Our Lady's Hospice & Care Services on 22nd March 2019.

Grand Rounds is a dedicated educational session for doctors, nurses and health and social care professionals working in specialist palliative care. The lecture on Interstitial Lung Disease (ILD) was also screened in satellite sites at Blackrock Hospice, Wicklow Hospice/Community care and Milford Hospice in Limerick.

Bettina Korn, End-of-life care coordinator at St James Hospital reported that Professor O'Regan's lecture was interesting and elegant and very well received. Prof O'Regan provided many examples of how ILD affects people and how different treatments can provide relief from symptoms. He also described how he and his colleagues raise the issue of palliative and end-of-life care in their clinics and how they support and journey with the patient and their family.

Prof O'Regan also mentioned the ILFA Information Day dedicated to palliative care and planning for the future with pulmonary fibrosis. We were delighted to learn that he referred to ILFA's work and the resources we provide for patients and relatives and mentioned our 'forward thinking ways'.

Bettina said, "Although the Grand Rounds session was one hour long, people queued up afterwards to ask questions, indicating their desire to increase their knowledge on ILD and learn how to best provide care for people with the condition. I believe it was a good opportunity for education and conversations across disease specific boundaries that could be repeated elsewhere".

Many thanks to Bettina for the excellent feedback and to Prof O'Regan for helping raise awareness of pulmonary fibrosis among the palliative care community.

Advocacy and Awareness

Pulmonary Fibrosis Awareness Campaign

A successful media campaign took place from April to June 2019 that helped create awareness of Idiopathic Pulmonary Fibrosis in the national and local media, online and on social media. ILFA is grateful to the many people across the country who volunteered to tell their personal stories. The media campaign highlighted the positivity, determination, and courage of patients and families living with IPF as well as the benefits of exercise in managing the condition.

Some of the campaign highlights included;

- Printed and online media coverage included; Independent.ie, Irish Examiner, RTE Guide, The Mirror, The Star, Irish Daily Mail, Irish Health.com, Senior Times, Irish Sun, RSVP, Mature Living, Dublin Gazette, Echo, Fingal Independent, Northside People.



Photo: Peter McLoughlin was interviewed on his experience of living with pulmonary fibrosis on East Coast FM.

- Radio interviews with East Coast FM, Phoenix radio, South Tipp FM, Dublin South FM, Midlands 103, Shannon side, Clare FM, Near FM, LMFM.



- David Crosby appeared on The Elaine Show, above, and shared his story from being diagnosed with IPF, receiving a double lung transplant and subsequent training for the World Super Six marathons. David was also interviewed on the Ray D'Arcy Show, on RTE Radio 1 ahead of Organ



Donation Awareness Week and was interviewed on two occasions on the Ivan Yates Newstalk Show, before and after the Cork Marathon Relay Run in June.

- TV coverage: The Today Show (RTE1). Carmel McInerney, respiratory nurse specialist at Ennis Hospital and Michael Collins, Ennis Pulmonary Fibrosis Support Group appeared on the RTÉ Today Show with Dáithí Ó'Sé and Maura Derrane in May. Michael nominated Carmel for a special pampering treat for her dedication to pulmonary fibrosis patients. Carmel and Michael had a very special day and Carmel looked radiant when her make-over was revealed. We were delighted when Daithi also mentioned ILFA's Yoga DVD live on air!
- Nicola Cassidy wrote a Letter to the Editor of the Irish Runner that was published in the August edition describing ILFA's participation in the Cork Marathon Relay event.



Planning for a National IPF Awareness Day

ILFA plans to hold a National Idiopathic Pulmonary Fibrosis (IPF) Awareness Day in late 2019 to raise awareness among members of the public, healthcare professionals and policy makers.

For a national awareness day to be successful, ILFA needs your help. If you are happy to share your lung fibrosis story, please get in touch by emailing info@ilfa.ie or calling 086 871 5264.

We are also looking for healthcare professionals to get involved. Please let us know if you would be willing to; host an information stand at your hospital, act as a spokesperson / respiratory expert and take part in media interviews, identify and approach patients and caregivers who might be willing to share their stories and/or visit your local support group.

Organ Donation and Transplantation

ILFA contributed a letter to the Irish Medical Journal entitled 'Opt-out organ donation - a patient organisation's perspective'. ILFA continues to work with colleagues in the Irish Donor Network (IDN) to advance issues in relation to organ donation and transplantation.

The IDN Partners welcomed the publication of the General Scheme for the Human Tissue Bill which will allow for an opt-out consent process in relation to organ donation. In addition, Nicola Cassidy (ILFA Director), Philip Watt (CEO of Cystic Fibrosis Ireland) and Robert McCutcheon (Chair of the Irish Heart and Lung Transplant Association) represented the Irish Donor Network at a meeting with Michael Conroy from the Department of Health and his colleagues Helen O'Brien and James Allen in July 2019.

Fundraising Round Up

Pat Casey Memorial Cycle



Members of the Cork Pulmonary Fibrosis Support Group, Dr Mike Henry and participants and organisers of the Pat Casey memorial Cycle.

The ILFA committee would like to extend our sincere thanks to the organisers of the Pat Casey Memorial Cycle; Anne Casey, Daniel Casey and Brian Ahern; for their enthusiasm, hard work and commitment to ILFA over the years. We are also deeply grateful to the cyclists, support crew and all those who have generously donated to the Pat Casey Memorial Cycle and other associated fundraising activities. Mile Buiohas!

The cheque presentation for the 2018 Pat Casey Memorial Cycle took place in the Hawthorn Bar in Cork on Thursday, 4th April 2019. Daniel Casey said "There was a great turn out and a cheque for €4,565 was presented to ILFA. Preparations for the 2019 cycle are well underway and the organisers are aiming for an early September date for the event. We are very grateful to Catherine, owner of the Hawthorn Bar, for her hospitality and the food provided. We look forward to this year's event."

In addition, Anne Casey presented a cheque for €550 from the 2018 Musgrave Cycle held in August in aid of ILFA.

Therese's online fundraising page



Huge thanks to Therese Reddan for fundraising for ILFA Ireland. Therese set up an online fundraising page called 'Mum's Cause: Idiopathic Pulmonary Fibrosis (IPF)' in memory of her mother Annette. The fantastic sum of €1,360 was presented to Marie Sheridan (ILFA Honorary Treasurer) and Eddie Cassidy (ILFA Chairman) by Therese at the ILFA Patient Information Day in April. Sincere thanks to Therese and everyone who supported her fundraising initiative. **Pictured are Marie Sheridan, Therese Reddan and Eddie Cassidy.**

Wexford Half-Marathon

Wendy Noble, pictured right, ran the Wexford half-marathon on Sunday 28 April 2019 in aid of ILFA in memory of her father David Orr. Here's a report from Wendy about her fundraising event.

"Having enjoyed running for many years, it took a back seat for a while as my Dad's (David Orr) health deteriorated

greatly over the course of 2018 due to Idiopathic Pulmonary Fibrosis. He passed away at home on Christmas day, early in the morning. We reckon he took the return flight on Santa's sleigh!



When I returned to running, I was eager to make it worthwhile and decided the Pettit's SuperValu Wexford half-marathon on 28th April was the way to go. Having never run more than 10k, it was challenging but nothing compared to the battle of those with IPF. Dad was very lucky to have stayed at home throughout the final year and that was all down to Mam. She also

had the support of the home help and palliative care team, but mostly her sister Hazel who basically moved in for the weeks leading up to Christmas. The progression of the disease is so difficult, but Dad accepted it at every turn with little complaint. The whole family pulled together to support both Dad and Mam however we could.

While I was running, my head was full of thoughts on how Dad struggled for breath just to move in bed and how Mam worked tirelessly ensuring he was OK. Every mile run meant €100 for ILFA. Count up the money and count down the miles! It was my parents' determination and strength, along with the generosity of all those who sponsored me that got me over the line in just under 2 hours. I can't say I'll be running another half-marathon soon, but I was delighted that I could do something positive to support a worthy cause by raising €1,300. Keep up the good work ILFA!"

Croagh Patrick Climb



Nicola Cassidy, ILFA Director, climbed Croagh Patrick in Murrisk, Co Mayo in April in aid of ILFA. The steep and rocky ascent (746 metres, 2507 feet) was difficult due to poor weather conditions early. Despite the cold temperatures, strong winds and poor visibility, Nicola enjoyed the challenge and was rewarded on the descent with the arrival of sunshine, blue skies and great views of beautiful Clew Bay. This was the first of Nicola's fundraising events for ILFA; she also took part in the Cork City Marathon relay event in June and will run the Great North Run half-marathon in September.

St Patrick's Day walk: Irish Cement Swimming Club



Members of the Irish Cement Swimming Club took part in a fundraising walk on St. Patrick's Day in aid of ILFA. The event was organised by Chris Lycett and he was joined by members

of the swimming club and friends. The fantastic sum of €520 was raised on the day. Additional sponsorship has been added to Annette Grehan's 2019 ongoing fundraising challenges for ILFA including the Cork marathon relay event, the Great North Run half-marathon in Newcastle in September and the Dublin City Marathon in October.

Craft Your Raft at the Muckno Mania Festival



The Muckno Mania Festival took place at Lough Muckno in Co Monaghan from 4th to 7th July. One of the many events taking place was 'CRAFT YOUR RAFT' described as a "high energy high octane team building competition". The winning Under-18 team was made up of Emma McGuigan, Emma Carvill, Molly McGinnity and Méabh Hannon who

received a cheque for €250 following their great success.

The girls kindly presented the cheque to Kevin McSkeane, leader of the Cavan Monaghan Pulmonary Fibrosis Support Group, as one of their grandmothers has pulmonary fibrosis and they wanted to support a charitable cause. The sponsor of the cheque for the event was Shane Tyres Castleblayney. Thank you to Emma, Molly, Meabh and Emma from everyone at ILFA;

Pictured are: Stephen Fitzpatrick - Festival Committee; Niamh Malone - Festival Queen; Kevin McSkeane - Monaghan Cavan Pulmonary Fibrosis Support Group Leader, Finbarr Carvill - Festival Committee; with the winners Emma McGuigan, Emma Carvill and Molly McGinnity. Missing from the photo is Méabh Hannon.

Donation



Following the Mountmellick Drama Festival which took place from 9-17 March, the sum of €230 was presented to Val Kennedy of the Midlands Pulmonary Fibrosis Support Group. Val subsequently presented the

kind donation to Eddie Cassidy (ILFA Chairman) and Marie Sheridan (Honorary Treasurer) at the ILFA Patient Information Day on 6 April 2019. **Pictured are: Val Kennedy, Marie Sheridan and Eddie Cassidy.**

In Remembrance

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



Congratulations and sincere thanks to **Alice Heron and Brian Kane** who were recently married and made a kind donation to ILFA in lieu of wedding favours. Here's a lovely photo of the happy couple. We wish Alice and Brian every happiness for the future.



Congratulations to **Lorraine Meaney and Owen Smith** who married in April 2019. Lorraine and Owen made a kind donation to ILFA in lieu of wedding favours. Lorraine told us "The wedding day was wonderful and the ILFA table cards were great. It has even inspired one of our guests to run the marathon for ILFA in October which I am very happy about. We are delighted to support such a worthy cause." We wish Lorraine and Owen every happiness for the future.

Top left: Bernard Meaney with his daughter Lorraine Meaney-Smith. Top right: Brian Moynagh, Jacqueline Moynagh, Lorraine Meaney-Smith, Owen Smith, David Meaney, Kelsey Hall.



Congratulations and warm thanks to **Ronan O'Sullivan and Eimear Byrne** who got married in June 2019 and made a kind donation to the Irish Lung Fibrosis Association in lieu of wedding favours. Ronan was in touch and said they had a fantastic day! Here is a lovely photo of the happy couple! We wish them every happiness for the future.

London Marathon



Well done and huge thanks to David Crosby who presented ILFA's Chairman, Eddie Cassidy, with a cheque for €3,000 as part of his fundraising proceeds for the London Marathon in April 2019. David received a double lung transplant 3 years ago following a diagnosis of idiopathic pulmonary fibrosis and has

since completed 3 of the super-six world major marathons; New York, Berlin and London. David plans to run the Tokyo, Boston and Chicago marathons in 2020 and 2021 to complete his super-six dream. We're inspired by David's determination and commitment to raising awareness of pulmonary fibrosis and the importance of organ donation and transplantation. Mile buiochas!

Swim to Tory Island

Padraig McFadden from the Bloodyforelands on the north west coast of Donegal took on an epic and daunting challenge in June 2019 when he swam from Tory Island to the Donegal mainland in memory of his grandmother Sadie McFadden to raise valuable funds for ILFA. Months of hard work and preparation went into training for the Tory island swim challenge and Padraig provided ILFA with regular updates on his progress. Here is the story in Padraig's own words.

"My name is Padraig McFadden. I recently lost my lovely, beautiful, witty little mate, my grandmother, to Idiopathic Pulmonary Fibrosis (IPF) in November last year. There are not many words I can use that describe this horrible disease - only I wouldn't wish it on anyone. In the months before my grandmother passed, I had it in my head that I would like to raise more awareness about this relatively unknown condition and raise some money for research. I had a chat with her and told her I was going to do the nine and a bit mile swim to Tory Island which we could see in the distance from her kitchen window, in aid of the Irish Lung Fibrosis Association. Of course her first reaction was "Cop on will ya" but after some more talking she said "You know what, if you think you can do it, then go for it".

From then on, I started to plan the swim. I contacted ILFA who have been very helpful and informed them of the swim. I enlisted the help of the Sheephaven Sub Aqua Club who agreed to help and be my crew and support boat on the day and I set up an online fundraising page for ILFA."

10 weeks to go ...

"With around 10 weeks to go, training is increasing steadily and going very well. An average week is around 4-5 pool sessions with 2-3 sea swims, averaging between 11k to 16k per week. The plan is to swap more pool swims to sea swims once it gets a little warmer, as it's currently only around 9C. Sheephaven Sub Aqua Club will be my support boat and crew on the day of the swim. They have been brilliant with helping to organise the day and I am very grateful to have them on board."

2 weeks to go ...

"With under 2 weeks to go, things are coming together very fast. A close eye will be kept on the weather next week as this determines everything on the day. We are in close contact with the lads at Sheephaven Sub Aqua Club who have been amazing with all their help throughout towards this event. Training is up to date with sea sessions from 1 hour plus during the week and up to 4 hours at the weekends and with the water temperature finally coming up to around 12-14C. We're looking good, and no sign of any jellyfish (yet) ... so fingers crossed.

I would like to thank everyone who kindly donated for this great cause so far. Thank you again."

Swim Day ...

"On Saturday the 22nd June in aid of the Irish Lung Fibrosis Association (ILFA) I managed to swim from Tory Island across to the north west coast of Donegal, a distance of 9 miles in 5 hours and 29 minutes.

We all gathered at the pier at 6.30am that morning and met up with the members of the Sheephaven Sub Aqua Club



Padraig McFadden (centre) with his brother Adrian, his father Pete.



Padraig McFadden (centre) with his brother Adrian, his father Pete, his mother Maeve, uncle Michael, and his brother Joseph.

along with my own crew of family members to help out with feeds and prep on the rib for the day. Once we were ready, we headed out towards the island. As we set out and the mainland was getting smaller, Tory island itself didn't seem to be getting bigger and from the looks of faces from some of my crew I started to think "Paddy, what are you doing?" Eventually we got to the rocks to the east of the island and I stripped off, got a good covering of Vaseline and took the plunge into the tropical 13 degrees waters. I swam to the nearest rock that I could stand on, gave the thumbs up and away I went. The first mile I tried to settle in and get a good start.

There were blooms of jellyfish keeping me company but luckily all about one metre below me. The two ladies on the support kayaks soon joined me and kept me headed in the right direction for home. After about 6 miles I got caught up in a current that was dragging me back so I had to up the tempo for a good 30 mins until I got out of it and after that I could just about make out the pier, so it gave me a good lift in spirits to keep going.

I eventually got to the pier where I was met with a lovely crowd of family and friends to welcome me in and when my feet touched the ground it was a great feeling.

I would like to thank absolutely everyone who helped me through the last 8 months. Especially my wife Dayna for her patience and help even during the winter/spring months with her doing beach watch when I was training and having my feeds ready during the longer swims. Also the team at ILFA, the Sheephaven Sub Aqua Club team; Dearn McClintock(boat pilot); Eddie McFadden (boat pilot); Eileen Coll (kayak) and Bernie Gallagher (kayak), and the coast guard. There is no such thing as a solo swim, it's certainly a team effort."



Team ILFA.



Happy Feet
- Emma
Cooper,
Yvonne
Lynch,
Heather
O'Tuairisg
and Annette
Johansson.



Roche Team - Triona Rice,
Joe Gleeson,
Gillian Hession
and Ronan
Butler.



ILFA Team 1 Professor David Healy, Dr Oisin
O'Connell, David Crosby, Lynn Fox and Nicola Cassidy.

Cork City Marathon Team Relay

The Cork City Marathon team relay took place on Sunday 2nd June 2019 and ILFA had six teams of 26 runners taking part. The fun, comradery, encouragement and support everyone experienced as part of this special fundraising and awareness raising event was wonderful. There was great excitement in the lead up to race day and the positive vibes were heightened as everyone gathered for group photos on 1st June and again on race day.

ILFA was fortunate to have one of our teams, ILFA Team 1 - The Patient Journey, profiled by the organisers of the Cork city marathon and this helped raise valuable awareness of pulmonary fibrosis, the team work involved in supporting pulmonary fibrosis patients with their journey, the life-changing impact of organ donation and lung transplantation, and ILFA's role in supporting patients, families and respiratory healthcare professionals. ILFA Team 1 was made up of David Crosby, inspirational double lung transplant recipient, and his support team featuring; Lynn Fox - respiratory nurse specialist at the Mater Hospital, Dr Oisin O'Connell - Respiratory Consultant currently at the Bon Secours Hospital Cork, Professor David Healy - Lung Transplant Surgeon at the Mater Hospital and Nicola Cassidy - ILFA Director. The team met at 7.15am on race day for official photographs and to be interviewed ahead of the marathon by Dan Linehan of the Irish Examiner and RTE's Jenny O'Sullivan. After exchanging words of encouragement and sharing a morale boosting team hug, the team members went to take up their race positions.

The race started at 8.30am under blue skies and sunshine and the runners set off at speed and smashed their way through stage one of the marathon course with impressive running times. There was little time to relax and never a dull moment as a steady stream of ILFA relay runners positioned themselves at the various relay handover points. News was constantly fed back to the captains by text messages with

updates on who was currently running and what location they had reached.

'HAPPY FEET', an international team featuring Annette Johansson, Heather O'Tuairisg, Emma Cooper, and Captain Yvonne Lynch, was the first ILFA team home with an amazing finishing time of 3 hours 30 minutes. The team led from the start and set a blistering fast pace, speeding through the 26.2 mile (42.2km) course. This team are family and friends of a person living with IPF and said they wanted to "raise awareness of the condition and support the great work of ILFA."

Next home was 'ROCHE Team' featuring colleagues from the pharmaceutical company Roche Products Ireland. Team captain was Triona Rice and she was joined by Gillian Hession, Ronan Butler and Joe Gleeson. Triona said "The Roche Team is absolutely delighted to help raise awareness and much-needed funds for a great cause in Idiopathic Pulmonary Fibrosis. Anything we can do to help this amazing cause is our pleasure and responsibility - even if the thoughts of a marathon is a very scary prospect!". The team had no reason to be scared as they ran well and finished strongly.

Hot on their heels was 'BOC HOMECARE'. The oxygen company team was captained by Adrian Sheehan and featured Keith McGrath, Michael Creedon, Mick Dooley and Kieran Hamill. This team said "We're taking part and running for a very worthwhile charity; the Irish Lung Fibrosis Association. This organisation gives fabulous support to patients nationwide who are suffering from fibrosis of the lungs. The main objective here is to gain exposure and awareness of the organisation so people can get support and information for those in similar circumstances".

Next home was 'SOUL SISTERS' led by Katie Cosby who said "I am taking part with my three sisters Teresa, Deirdre



Soul sisters;
The Daly
sisters:
Deirdre,
Bridget, Katie
and Teresa



Dr Oisín O'Connell, Adrian Sheehan (Team Captain for
BOC Homecare), David Crosby and Lynn Fox.



ILFA Team 1 at the finish line – Nicola Cassidy, Dr Oisín
O'Connell, Lynn Fox, David Crosby and Prof David Healy.



Well wishes walkers – Annette Grehan, Eddie Cassidy
(ILFA Chairman), Stephen Cassidy, Nora McNamara
and Betsy Matthews.

and Bridget to help raise awareness of Lung Fibrosis. My husband David was diagnosed with IPF at 40 years of age but thankfully he received a life-saving double lung transplant six months later. This devastating disease took an enormous toll on our family and our three young children. David received huge support from family and friends around us. In order to maintain a somewhat stable environment for our children, our families and friends stepped in to keep things running smoothly as David and I navigated our way through everything that IPF brought to our door. From numerous hospital appointments, adjusting our lives to a life of oxygen and medication, trying to remain hopeful that a transplant would save David's life. I'm also running to give recognition to every carer, who is there for their loved ones and for everybody who helps and supports them along the way. Without our families and friends, I would not have been able to remain as strong as I needed to be to get through a really difficult and life changing time."

The next team home was ILFA Team 1. From the start of this project, the ILFA Team 1 members wanted to finish together to reinforce their message of teamwork and support. With logistical planning and the local knowledge of Dr Oisín O'Connell, this dream finish was made possible. Nicola Cassidy ran the first leg and handed over to Lynn Fox who ran the second stage. Dr Oisín O'Connell ran stage 3 and handed the baton to Prof David Healy who raced through the fourth leg of the marathon. He continued running and accompanied David Crosby on the fifth and final leg of the race. Meanwhile Lynn, Oisín and Nicola met back at City Hall and made their way to the rendezvous location to join David C and David H. The trio nearly lost their voices shouting excitedly when David Crosby and David Healy ran into view. The five pals reunited and ran the final stages of this amazing journey together. Running the last few metres, the race director announced that "David Crosby, lung transplant recipient, and his healthcare team were approaching the finish line". The cheers from the crowd and the realisation of the team's mission made this

a very special end-of-race moment. To make this marathon finish even more exceptional, David Crosby slowed down to allow his team-mates cross the line first as he felt they were the reason he was here. It was a beautiful, poignant and emotional gesture from David that touched the entire group. Once over the line, the fabulous five hugged and congratulated each other on their remarkable achievement. Home in 4 hours 12 minutes and 4 seconds. Job done! Then the team had a series of photographs taken, interviews with various media outlets and reunions with supporters.

Last but not least, the 'WELL WISHES WALKERS' team arrived home to a hero's welcome. The team was led by captain Stephen Cassidy and featured his father, ILFA Chairman, Eddie Cassidy (running his 25th marathon), his aunt Annette Grehan (running her 14th marathon), and two amazing nurses from South Tipperary General Hospital in Clonmel; Nora McNamara and Betsy Matthews. The team ran in support of pulmonary fibrosis patients and in memory of a family member, Denise Cassidy. The team members had great fun together and developed a strong bond and team spirit despite only meeting Nora and Betsy on race day.

In the evening, some of the team members who were staying over in Cork were joined by family, friends, members of the Cork Pulmonary Fibrosis Support Group and Dr Mike Henry from Cork University Hospital to celebrate the culmination of a very special event and to mark the extraordinary personal and team achievements of the day.

ILFA would like to extend our sincere thanks to the amazing runners for their enthusiasm and commitment to this event and to their families, friends and colleagues for supporting them. Special thanks also to Alan McLoughlin (husband of Lynn Fox) for taking lovely photographs of the occasion, to Sandra Stuhli, graphic designer at Asavie for designing Team ILFA's graphic images, to Fiona Ryan and colleagues at Hopkins Communications for their PR expertise and support on race day, and to Earnest Cantillon of Electric Bar in Cork for his generosity and hospitality.

Women's Mini Marathon 2019



Captions on this page
clockwise from top:

Team ILFA; JP Joggers
Team; Amy Collins and
friends; Liz Burke, Sue
Kenny, Edna Powell and
Debbie Cullen; Rachel
Alford; Brid and Jacqueline
Meaney; Catherine
Donoghoe and friends; and
Mena Fitzgibbon, Catherine
Sherry, Jagoda Dubanik.





Captions on this page from top:
Kim Hanneffy and Deirdre Hyland; James Kavanagh and Chris Meehan; Margaret McIver, Rosemary Wilson, Hazel Griffin, Rita O'Regan; Michelle Clarke, Janice Mitchell, Shauna Clarke; and below: Glenda Murphy Smullen and Edel Collins Hill.

LOGO: Team ILFA by Sandra Stuhli.



Over 50 ladies took part in the VHI Women's Mini Marathon in Dublin, on Sunday 2nd June for ILFA. It was a lovely, warm, sunny day and many ladies gathered before the event for Team ILFA photos and afterwards for well-deserved refreshments.

Shauna Clarke sent us this report. "A team of six ladies representing Hines Ireland recently took part in the VHI Women's Mini Marathon. Our team was proud to have run/walked in aid of ILFA with the runners finishing in just under 1hr 20min and the walkers coming in just behind them. ILFA is a charity close to my own heart - I took part in memory of my Grandad (Paddy Kennedy) who sadly passed away in 2007 after a single lung transplant and in support of my Mam (Michelle Clarke) who was diagnosed with IPF last year. She hasn't let it hold her back though as she completed the marathon as part of our team on the day."

Amy Collins and friends also took part and sent us a report. "I did the mini-marathon on behalf of my dad who received a lung transplant 2 years ago. ILFA does great work and gives great support to my father, therefore I wanted to spread awareness by fundraising for ILFA and to promote them. My team also offered their support and wanted to fundraise for the great cause. The day itself was an amazing experience and we completed the mini marathon in 1 hour 15 mins. The best moment was seeing my dad waiting and cheering us on to the finish line. We took him out of the crowd and had him finish with us".

Brid and Jacqueline Meaney took part in support of their husband and dad Barney Meaney. Jacqueline said "Dad is a member of ILFA and attends the Dublin Pulmonary Fibrosis Support Group meetings. Thank you for all the support you give to him and to all your other members."

Catherine Donoghoe, family members and friends took part and sent this report. "Myself and 4 ladies participated in this years' mini marathon in honour of my mother who is in the palliative care stage of her battle with IPF. Our brother has also been recently diagnosed with IPF and we know he will gain tremendous knowledge and support from ILFA and we wanted to do our bit to help as a small thank you. Myself, my sister Fran, my daughter Ella, our niece Corrine and her friend Ava all felt a tremendous feeling of pride as we crossed the finish line. There were times when you felt exhausted and your legs could go no further, but just the thought of mam at home on her oxygen fighting every single day to be with us, just keeps you going."

Neasa Buchan was in touch and said "The 'JP Joggers' had the best day and were overwhelmed by the generosity of our family and friends all over the country Special mention to John Patrick O'Sullivan in Kerry for inspiring us all to get off the couch to help make a difference! We had the most amazing fun day!"

ILFA would like to thank all the ladies who took part in the 2019 event. We are grateful for their wonderful support and for sharing photos and special memories of the day.

Special thanks to Sandra Stuhli, graphic designer at Asavie for designing our lovely photo props.

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 10.30am at the Carmelite Community Centre at Whitefriar Street Church, Aungier Street, Dublin 2. **Please call Matt on 086 244 8682 or Pam on 086 178 9055 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 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 11.30am, at Matt The Thresher, Birdhill, Tipperary. **Please call Noreen on 087 262 7976 for more details.**

Clare Pulmonary Support Group

The group meets at 12 noon on the first Wednesday every month at the West County Hotel in Ennis. **Please contact Michael Collins at 087 637 468 for more details.**

ILFA would like to thank the support group leaders for their involvement and organising the groups. It is wonderful to see the groups go from strength to strength and hear about the wonderful peer support available to patients and carers. We wish everyone involved continued success for the future.

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

086 871 5264

VOLUNTEERS NEEDED ...

ILFA is delighted to announce our partnership with the 2019 Dublin Santa Dash and we need your help! We need 25 volunteers to help the race organisers on the day for 3-4 hours. The festive 5km and 10km races will take place on Sunday 1st December on Dollymount Strand, Dublin. ILFA will receive a donation from the event organisers for every volunteer who helps. Please contact ILFA if you can volunteer your time to help out (Tel 086 871 5264 or email info@ilfa.ie). We're also looking for as many runners, joggers and walkers to take part in the festive fun. We guarantee that you will love it!!!

And Finally Some Exciting News ...



Our good friend David Crosby, left, has agreed to become a **Patient Ambassador for ILFA** and we couldn't be more proud. Over the last 2 years David has devoted his energy, positivity and enthusiasm to raising awareness of pulmonary fibrosis and the importance of organ donation and transplantation. He has worked tirelessly sharing his personal story and giving hope and encouragement to other patients and families, and he has fundraised for respiratory charities and research foundations to help them with their vital work.

David has big ambitions and after receiving a life-saving double lung transplant he is pursuing plans to complete the Super Six Marathon Series and earn a place in the record books. David has already run the New York, Berlin and London marathons and plans to run in Tokyo in 2020 and then Boston and Chicago in 2021. In June, David ran the Cork City Marathon Team Relay with his medical and nursing team, and family and friends to raise awareness about the pulmonary fibrosis patient's journey. David has truly inspired us and ILFA is enormously proud to have David as our new Patient Ambassador and we gratefully acknowledge and celebrate his wonderful and inspirational advocacy work.

Dates For Your Diary

Fundraising

- **The Pat Casey Memorial Cycle** will take place on Saturday 21st 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 Dublin City Marathon** will take place on Sunday 28th October. Please contact ILFA if you would like a fundraising pack.
- **Santa Dash 5km and 10km** course will take place on Sunday 1st December on Dollymount Strand, Dublin. Please contact ILFA if you would like to volunteer or take part (Tel 086 871 5264 or email info@ilfa.ie). Register to take part at www.santadash.ie

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.

