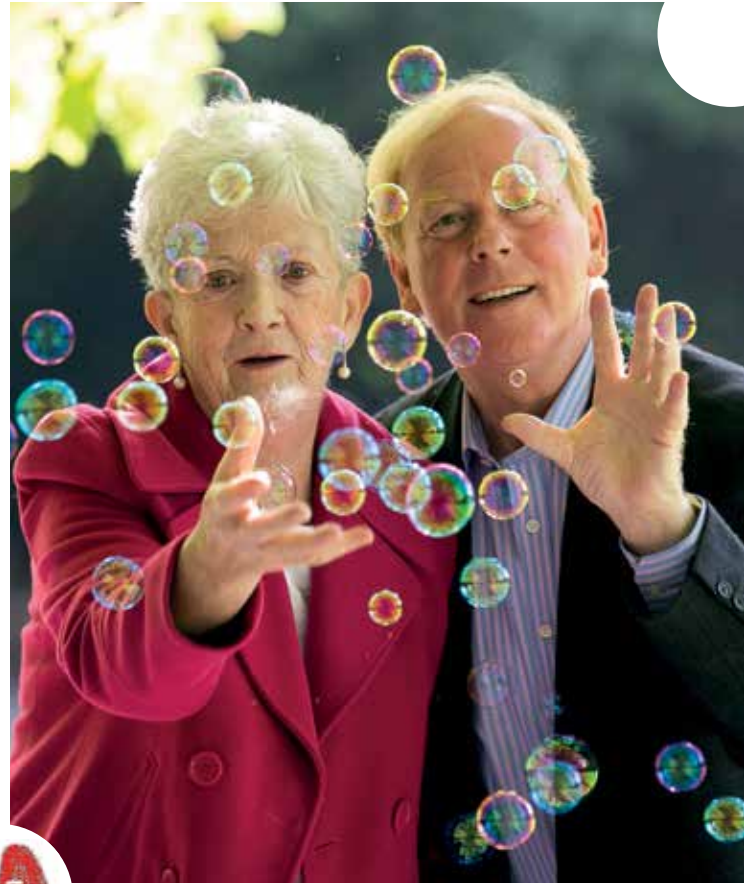


ILFA15



Celebrating the advances in IPF patient care from 2002 to 2017



“Coming together is a beginning;
keeping together is progress;
working together is success.”
— Henry Ford

Front cover, clockwise from top left,

(1) ILFA Exercise Ambassador and Dublin GAA star Michael Darragh Macauley, Mater Hospital physiotherapist Irene Byrne and ILFA Patron Feargal Quinn at the launch of the 2000 Steps A Day exercise programme in 2013;

(2) The 2015 European IPF World Week campaign stars, Matt Cullen and Joan Doyle;

(3) Dolores and Matthew Williams and their grandson Matthew, with Emer Lenehan and the late Brian Lenehan at ILFA's IPF World Week photo shoot in 2016;

(4) IPF patient Dermot King with Minister Finian McGrath at the 2016 'Day In The Life' project.



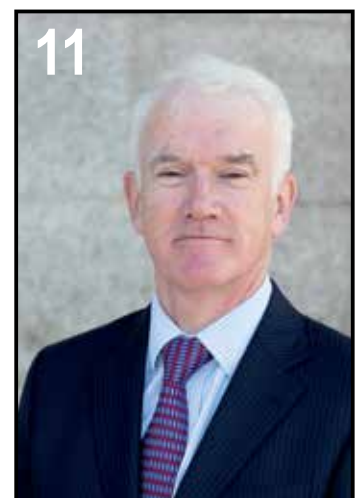
ILFA15

*So much to celebrate and
be thankful for since our
establishment in 2002*

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Irish Lung Fibrosis Association
www.ilfa.ie

A Lasting Legacy



On 22nd August 2017, ILFA's much loved and highly esteemed Chairman of 15 years, Terence Moran, passed away suddenly. The ILFA committee was shocked by this sad news. We have lost a very special friend and our leader.

Back in 2002, Terence was instrumental in setting up the Irish Lung Fibrosis Association with Nicky Goodbody, Marie Sheridan and Professor Jim Egan. Terence was a solicitor by profession and it was great to have a such a talented, competent, knowledgeable, focussed and kind 'legal eagle' to guide the association through its early years and beyond. ILFA has gone from strength to strength, thanks to the hard work and dedication of the volunteers who joined the committee, our inspirational fundraisers, and you - our members.

Throughout our 15-year history, Terence was a constant presence and he was a great and skilled Chairman. He led his team quietly and confidently. He had so many great qualities including; compassion, patience and commitment. Terence was extremely knowledgeable, wise and insightful, and he always knew the right thing to do. He was always respectful of others' opinions and open to new suggestions, even if some of those suggestions were met with a raised eyebrow, a wry smile or an expression of quiet amusement! For example, when the idea of laughter yoga was raised as something different for a Patient Information Day, Terence warily agreed to give it a try. On the day itself, he sat facing the audience and committed himself to participating fully in the various laughter exercises, much to his and our amusement.

Terence was a very modest man who didn't like being the centre of attention. He was always happy to lead quietly and encourage others on the committee to take on new roles and challenges in ILFA's name. Under Terence's expert care and

guidance, ILFA developed and flourished and now the association is considered to be among the leading IPF patient advocacy groups in the world. This is a testament to Terence's great leadership and influence.

Terence was hugely supportive of the idea for the ILFA 15 special edition magazine from the start. This publication, featuring contributions from patients, family members, fundraisers, healthcare staff, professional organisations and committee members, is our way of celebrating the advances in IPF care over the last 15 years and reflecting on ILFA's achievements to date. Terence wrote the foreword for the magazine and a personal article, and he had reviewed many of the contributions. Sadly, he didn't get to see the end result, which is a great shame because all of our achievements and successes over the years were made possible with Terence at the helm, steering us forward. To honour Terence and acknowledge his wonderful contribution to ILFA, we dedicate the ILFA 15 magazine to his memory.

Terence was a true champion for IPF patients and carers, and he would want ILFA to carry on. This will be his lasting legacy and we will endeavour to draw strength, solace and courage from our fond memories of Terence and his outstanding leadership for the last 15 years.

The ILFA Committee:
Eddie Cassidy, Nicky Goodbody, Prof Jim Egan, Liam Galvin, Lynn Fox, Lindsay Brown, Marie McGowan, Dr Kate O'Reilly, Martin Troy and Nicola Cassidy



Foreword

Dear friends,

Welcome to 'ILFA15' - ILFA's special edition magazine to celebrate our 15th anniversary!

We are enormously grateful to you, our friends and supporters who have been so instrumental in helping ILFA grow over the last 15 years. It's incredible to think how much our charity has evolved since its establishment in 2002 when a small group of dedicated people with big aspirations came together determined to make a difference.

The group set themselves an ambitious fundraising target in order to help raise awareness of idiopathic pulmonary fibrosis, facilitate research, and support patients and families affected by the condition. From our humble beginnings we have grown with each passing year. Now, 15 years on, we are proud to recall and celebrate our remarkable journey as a national patient organisation representing those affected by lung fibrosis.

This special edition magazine is an opportunity to celebrate our milestones and achievements, reflect on research breakthroughs and clinical developments in IPF care, and to thank our dedicated fundraisers for their hard work and commitment.

We hope you enjoy reading the wealth and variety of articles contributed by people from all over Ireland and further afield. Thank you everyone for your loyal support and goodwill for ILFA over the years.

Terence Moran
ILFA Chairman (2002 - 2017)



As we celebrate this milestone year for the organisation, ILFA 15 editors Nicola Cassidy and Ken Powell hope readers will enjoy the ILFA 15 magazine half as much as we enjoyed putting it together!

2017 is a landmark year for ILFA as this year the charity reaches its 15th anniversary, and that's certainly worth celebrating! The idea for a special edition magazine started to take shape in April 2017 and the project offered an exciting opportunity to gather stories and reflect on some of ILFA's milestones and the advances in lung fibrosis care.

Back in 2002, ILFA set out to be a voice and advocate for patients diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in order to create awareness about the condition, and facilitate education and research into treatments for IPF. The patient organisation went from strength to strength, thanks to the dedicated volunteers who served on the ILFA committee over the years, ILFA's employees, and the fantastic fundraisers who have worked hard to ensure that ILFA could grow and achieve our aims and objectives. Each passing year has become busier and busier. There is still much work to be done, but as we pause and reflect on our 15 year history, it is important to acknowledge that we have accomplished a lot. ILFA has helped raise awareness of lung fibrosis, supported thousands of patients and families at home and further afield, and made important contributions to lung fibrosis research.

15 years on, we reached out to people from all over Ireland and beyond, and invited them to share their experiences and personal perspectives with us by writing short articles for the magazine. We waited anxiously to see if we would get any response.

Slowly the articles started to arrive. People were so generous to give their time, expertise and great creative talents to share their insights on lung fibrosis and what ILFA means to them. Luckily for us, the job of editing the articles was minimal thanks to the superb compositions we received.

We received contributions from patients, doctors, nurses, allied healthcare professionals, clergy, researchers, patrons, professional respiratory bodies including the Irish Thoracic Society and The European Lung Foundation, volunteers, family members, fundraisers and support group members. These people from every walk of life represent the heart and soul of the ILFA community. Thank you everyone!

We enjoyed reading all the articles; some were factual and medical in nature, some surprised us, some were poignant, some were emotive, but all of them came from the heart. The articles highlight the dedication of healthcare professionals to improving patient care; the energy, loyalty and drive of our fundraisers, and the positivity, determination and courage of patients and families living with lung fibrosis.

It was a pleasure to be part of this ambitious project and we really appreciated everyone's efforts and enthusiasm to contribute to the magazine. Special thanks to Vanessa Randle for the beautiful and colourful illustration of ILFA's milestones, to Niamh Hogan for the design and graphics, and to Ben Brady for the great print production.

It is fantastic to see the end result, which we feel is superb. It is a credit to all the writers involved, that we have been able to produce this inspirational magazine celebrating ILFA's success and advances in patient care. We hope you will enjoy reading ILFA 15.

**Nicola Cassidy and Ken Powell
Editors**



Feargal Quinn with Joan Doyle and Matt Cullen at the launch of ILFA's National Patient Charter for IPF.

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

Positive Vibes

ILFA Exercise Ambassador Michael Darragh Macauley tells how he got involved with the organisation and sends positive vibes to all patients and caregivers.

My name is Michael Darragh Macauley, I am a primary school teacher in Tallaght, a member of the Dublin Senior Football team and I have been an ambassador for the ILFA organisation since 2011. I have very strong links with lung fibrosis on both sides of my family. One happy story, one not so, we'll start with the latter!

My father Michael was diagnosed with IPF in 2005. Up until that point I had no idea about the disease but I, like my whole family would soon become experts on the topic. My dad's situation deteriorated up until the point at which he needed a lung transplant in 2012. To be a candidate for selection you have to meet a number of requirements. He had to lose weight and become smarter with his exercise regime. After a lifestyle change for the better, he managed to get himself on the transplant list. He was called for a possible transplant on three occasions but unfortunately he wasn't the best candidate and it wasn't to be. He passed away on the 31st November 2012. That was nearly 5 years ago and I'm happy to report that the number of lung transplants taking place has increased hugely since then.

My other connection to the disease has a much brighter ending and involves my auntie Edna (on my mam's side). Edna was diagnosed with the condition in 2009. It was particularly tough for Edna as she had been by my dad's side every step of the way and seen with her own eyes the unfortunate ending to that story. She too was placed on the transplant list and managed to be a lucky recipient of a lung in 2015. The progress Edna has made since that date has been



remarkable. She is now enjoying a renaissance with her new respiratory system and looks younger every time I see her.

Having seen both sides of the story through both sides of my family, I know what a difficult condition this disease is for everyone. Initially it can be a very confusing time for patients and families alike trying to adjust to this new way of life and trying to collect all the facts. ILFA was brilliant in helping us as a family to be as best prepared for battling the disease as we could be. Always being available for meetings and at the other end of the phone if we needed a different opinion on a matter, or even just a sympathetic ear to vent at!

ILFA has done incredible work for patients and families of people with this condition and no doubt they will continue to do so for many years to come and I wish them all the best with everything.

I'm sending positive vibes to everyone going through this process at the moment. It's never ideal but positivity is so important throughout the process. Sometimes the patient can find that intrinsically but other times he or she might need a helping hand from their doctors, nurses, families, or even ILFA.

Le grá,

Michael Darragh Macauley
ILFA Exercise Ambassador



Professor Jim Egan with Feargal Quinn, Joan Doyle and Matt Cullen at the launch of The National Patient Charter for IPF in 2015.

15 Years of Medical, Surgical and Advocacy Advances in IPF Care



Professor Jim Egan pays tribute to ILFA, describing the organisation as “a role model for other countries in terms of patient advocacy”.

At the turn of the millennium, the outlook for Irish patients suffering with Pulmonary Fibrosis was regrettably bleak. It is refreshing to reflect on the last fifteen years and see the important developments in both medical therapy and surgical therapy for this condition. Over this fifteen year period with Irish patients actively participating in drug treatment research, we have seen the emergence of two drugs scientifically and financially approved for use.

In parallel, we have seen an extraordinary

increment in the rates of lung transplantation with a particular focus on individuals who suffer with Pulmonary Fibrosis. Consequently, in comparison to other countries, Irish patients have a sophisticated and leading treatment package available to them.

ILFA as an organisation has been central to these developments, providing a voice for patients and also a support for patients. ILFA itself has become a role model for other countries in the context of patient advocacy.

I wish to acknowledge the many patients and their families that we have had the privilege to be involved in their care over the last fifteen years; they provide us with continuing inspiration on a day to day basis.

Professor Jim Egan, Consultant Respiratory Physician, Clinical Director Cardiovascular and Transplant Directorate, Mater Misericordiae University Hospital

Setting up ILFA



The late Fergus Goodbody.

ILFA founder and director Nicky Goodbody explains the background to the organisation and pays tribute to some of its driving forces through the years.

It was hard not to become swept up in the enthusiasm of Professor Jim Egan, in his pioneering efforts to set up a support group for sufferers of lung fibrosis. An initial meeting at Eccles Street (Dublin), attended by several of his patients, some on oxygen, including my late husband, Fergus Goodbody, proved an extraordinary logistical feat in itself. As a group of patients and carers, we ourselves needed support, and did not attempt to meet again.

In May 2002, the disease claimed Fergus as a victim; a sad experience, brightened towards the end by the memorable support of Professor Egan. A respectful lapse of time ensued, and I received a phone call to meet for coffee at St Vincent's Hospital. There, the conversation came around to once again trying to get a support group off the ground. This time it was different; I was no longer a carer and could become more actively involved. Could I get a committee together? Did I know a solicitor and an accountant, who might be prepared to be on the committee? Yes, was the answer, with two very kind friends coming straight to mind: Terence Moran and Marie Sheridan, who would go on to play key roles on the committee. It was thus after the passing of Fergus and over two cups of coffee, that the patient support organisation finally began to take realistic shape.

The first meeting of what was to become known as the Irish Lung Fibrosis Association was held in Clonskeagh in Dublin in September 2002 and friends and family members gave generously of their time. Fundraising was an immediate issue and my niece, Tabby Keane, suggested a swim, which has since developed into an annual event at Sandycove on St Stephen's Day. Subsequent fundraising activities included the Women's Mini Marathon, in which ILFA has participated every year since 2003, and an Over Seventies' Walk in the woods at Clonbur, Co. Galway, which was organised by my late father, Tom Figgis. All of these activities and the generosity of supporters meant that ILFA could do what it had set out to do, which was to inform, educate and support patients and carers.

Patient Information Days were held initially at Donnybrook Hospital and then at St Vincent's Hospital, with Professor Egan and guest speakers providing up to date information on the condition. Equally as important, these events provided an opportunity for patients and carers to socialise. We gradually built up our membership and kept in touch through a four-paged ILFA newsletter.

In 2007, the committee was fortunate to be joined by two of our most stalwart members, Eddie and Nicola Cassidy, who had sadly lost Denise to the disease. Nicola soon put together a Directory of Service with information on Lung Fibrosis for sufferers and carers, which was to raise ILFA to a new level of professionalism.

Since its foundation, many other people have served on the ILFA committee, including patients like Mary O'Connor and Bob Murray; those who have also lost loved ones to the disease, like Liam Galvin and Marie McGowan; as well as healthcare professionals, Lindsay Brown, Lynn Fox, Dr Kate O'Reilly and Professor Jim Egan. In all of our endeavours, we have been ably assisted by our administrators over the years, namely Joanne Coyle, Lorna Murphy, Denise Dunne and Gemma O'Dowd.

As is so clearly reflected in this 15th anniversary magazine, we can all be immensely proud that from our small beginnings, and with the support and dedication of so many people, ILFA has grown into a much more professional body playing an effective advocacy role not only in Ireland but also on the international stage.

Nicky Goodbody
ILFA Director

St Vincent's University Hospital

St Vincent's Hospital clinics embrace a multidisciplinary approach, with strong community links, under Dr Emmet McGrath, Prof Michael Keane and specialist nurse Lindsay Brown.

St. Vincent's University Hospital has offered an Interstitial Lung Disease (ILD) clinic for over 25 years. The emergence of novel anti-fibrotic therapies means we can now offer treatment to patients diagnosed with idiopathic pulmonary fibrosis (IPF). We adopt a multidisciplinary team approach and forge strong links with our community colleagues to optimise support networks for our patient group.

We run a tertiary referral clinical ILD service on alternate Thursdays of the month. Two respiratory physicians with expertise in ILD oversee this clinic; Professor Michael Keane and Dr Emmet McGrath. They are supported by a team of specialist registrars in respiratory medicine, a respiratory nurse specialist - Lindsay Brown, who has a special interest in improving the care available for patients living with IPF, and has completed a post graduate module in Interstitial Lung Disease. Our clinical research nurse, Carita Bramwell, oversees clinical trials and patients may be asked if they would like to be included in novel research.

Professor Michael Keane was the Director of the Interstitial Lung Disease Centre at University of California, Los Angeles Centre from 2000-2003. He returned to Dublin in 2007 to take up



Dr Emmet McGrath

Professor Michael Keane



Lindsay Brown



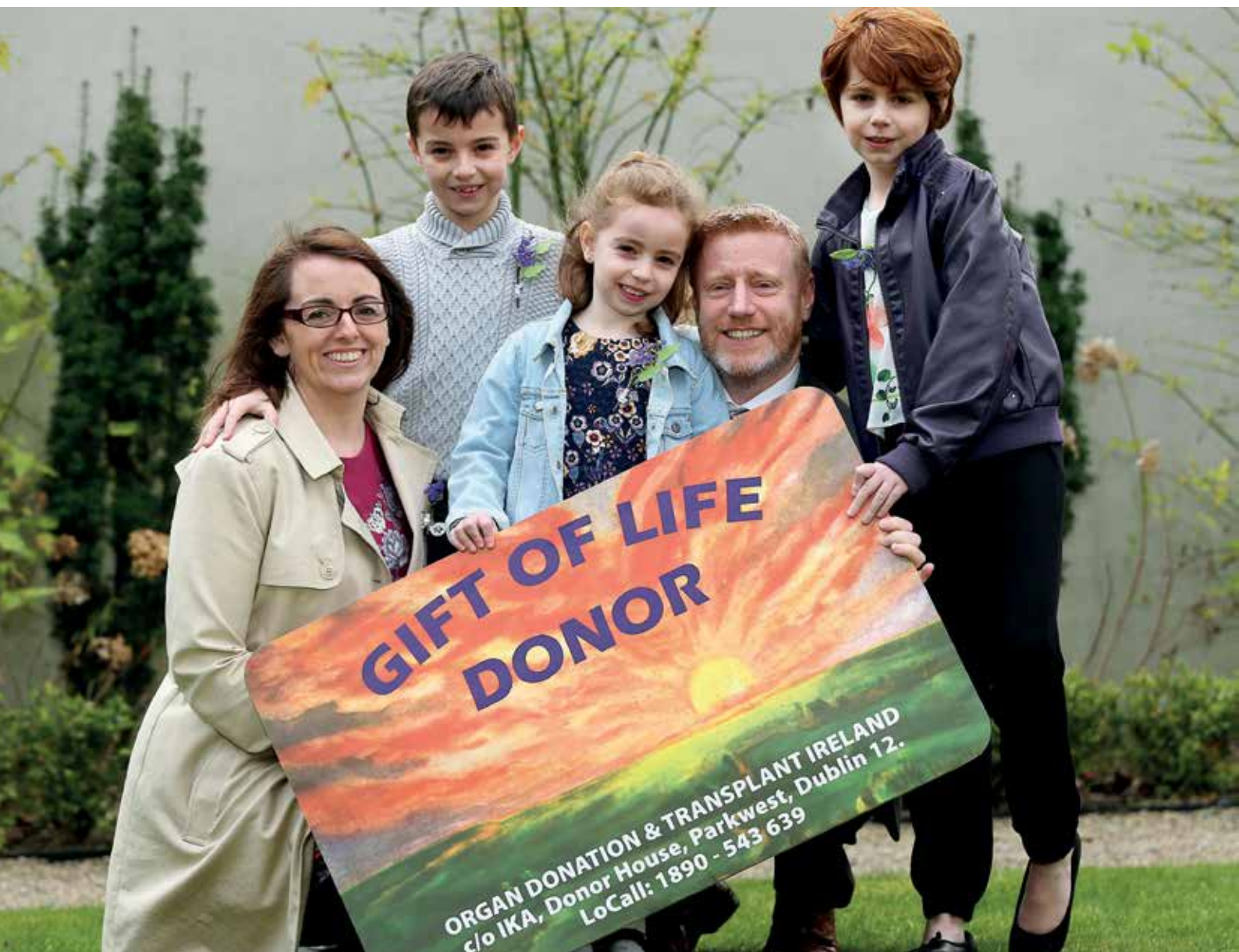
the position of Professor of Medicine at University College Dublin where his research interests focus on molecular mechanisms and treatment of, inflammatory lung diseases; particularly pulmonary fibrosis.

Dr Emmet McGrath graduated from Trinity College Dublin in 1998, joining the Sheffield Respiratory Specialist Registrar Scheme in 2002. He was awarded a prestigious Wellcome Clinical Training Fellowship to investigate inflammatory lung disease in 2005. He took up the role of Senior Lecturer in Respiratory Medicine and Clinical Lead of Interstitial Lung Disease at the University of Birmingham in 2010, prior to his return to St. Vincent's University Hospital in Dublin as a Consultant Respiratory Physician in 2013.

Dr Emmet McGrath, Professor Michael Keane, Lindsay Brown

The Greatness Within

Transplant recipient David Crosby celebrates his new lease of life and channels the 'greatness within' as he prepares for the New York City Marathon.



David with his wife Katie and their children (photo courtesy of Irish Kidney Association).

When I was diagnosed with IPF in late 2015, I was devastated. Having lost three siblings to a lung disease in childhood, one of whom was on a heart and lung transplant list, I thought my days were numbered. But being put under the excellent care of the respiratory team at the Mater Hospital gave me the hope and confidence that this was not to be.

With the support of medical staff, family, friends and patient support groups (ILFA), I was able to

find the strength to do my utmost to get up and fight every day. From taking medication, oxygen 24 hours a day and taking on every bit of advice I was given, I was able to live my life as positively as possible.

Shortly after I was given my diagnosis, my doctor discussed lung transplantation as the best option for me, as my IPF was progressing rapidly. I was a 40 year old Dad to three small children, a

husband, and I was afraid for their future and my own.

Everything that was asked of me I did with enthusiasm. I exercised daily, lowered my BMI (I lost 2.5 stone in 8 weeks), attended every appointment and kept a positive attitude as much as possible. I was on the transplant list a short time when I received my double lung transplant.

It is such an overwhelming experience of many emotions. Fear of the unknown, afraid of the outcome, and then afterwards relief and elation, and a sense of gratitude to medical staff, but mostly bittersweet, when you think of your Donor and their family. I think of them every day, when I can breathe easily, walk freely with no oxygen tubes, play with my children and see a brighter future for myself, my wife and family. Without my Donor's wonderful gift of life and the amazing talented medical staff, I would not have had a second chance of life.

My outlook on life has totally changed. I am seizing every opportunity and trying to give back to the many people who have helped and supported me along the way.

I have set myself a challenge of completing the New York City Marathon in November 2017 in honour and memory of my Donor, while raising funds for charity.

I was honoured to speak at the launch of Organ Donation Awareness week in March 2017. I was also given opportunities to speak of my experiences in public, at schools, in newspapers, TV shows and on radio.

I am now looking forward in life knowing that ... **"FAILURE IS NOT AN OPTION".**

And that we all have ... **"GREATNESS WITHIN"**

David Crosby

Lung transplant recipient and fundraiser

Partnerships and Collaborations

Collaboration and partnership with other organisations is a key priority for ILFA that allows the charity to embrace opportunities and share insights, expertise, skills, knowledge and best practice with partners in Ireland, UK, Europe and globally to advance patient care.

ILFA works with;

- ▶ **The Irish Lung Health Alliance** - an alliance of respiratory charities in Ireland.
- ▶ **The Irish Donor Network** - a community of patient organisations dedicated to promoting organ donation and transplantation in Ireland. The group consists of the Alpha One Foundation, Cystic Fibrosis Ireland, the Irish Heart and Lung Transplant Association, COPD Support Ireland, Cystinosis Ireland, the Pulmonary Hypertension Association of Ireland and ILFA.
- ▶ **The European Idiopathic Pulmonary Fibrosis Federation (EU-IPFF)** which consists of 13 lung fibrosis patient organisations from Europe. ILFA was one of the founding members of the EU-IPFF and Liam Galvin, ILFA Director, is the Secretary of the EU-IPFF.
- ▶ **European Respiratory Society Taskforce on IPF.** This project is of special importance as it was the first time leading IPF experts sought patient and carer perspectives to inform, influence and develop new European guidelines for IPF care. Patients and carers from four countries participated; Ireland, Belgium, Italy and the United Kingdom.
- ▶ **European Lung Foundation (ELF)** - ILFA committee members have advised the ELF on patient matters, delivered an online learning module on patient perspectives, and spoken at ELF events and conferences. ILFA's news and achievements regularly feature in the ELF newsletter.
- ▶ **The Irish Thoracic Society, Anail** (the respiratory nurses association) and healthcare professionals across Ireland.
- ▶ ILFA collaborates with **patientMpower**, a technology company based in Dublin, in the development of a phone and tablet app to monitor health parameters for patients with lung fibrosis.
- ▶ ILFA works closely with pharmaceutical companies and oxygen companies to keep up to date with important developments in their industries that impact on patient care.



Dermot King and Finian McGrath.

My connection with ILFA

Minister of State Finian McGrath TD pays tribute to ILFA on its birthday and pledges his ongoing support for the introduction of a soft opt-out organ consent donation system in Ireland.

I am delighted to send my congratulations to the Irish Lung Fibrosis Association as they celebrate their 15th anniversary. I have engaged with ILFA on many of their recent patient advocacy activities. In 2013, I was happy to support ILFA's 'Call to Action' campaign for the licensing of the first anti-fibrotic medication in Ireland to treat the condition. I subsequently attended the launch of ILFA's National Patient Charter for Idiopathic Pulmonary Fibrosis in 2015 to learn more about the care pathway that patients diagnosed with IPF should have access to.

In 2016, ILFA invited me to spend a few hours with a patient to get their perspective on the daily challenges of living with IPF. In late August, I had the pleasure of meeting Dermot King, an IPF patient from Portmarnock, along with his daughter Jennifer and grand-daughter Isabelle, and members of the ILFA committee in Artane. Over tea and cake, we chatted and I learned about some of the difficulties faced by patients in relation

to oxygen prescriptions and access to medical cards. Dermot also told me about the benefits of attending pulmonary rehabilitation classes in Dublin City University, the good work carried out by ILFA, and the support he gets from the local support group in Dublin. ILFA recorded two short videos that day to help raise awareness of IPF.

Recently, I welcomed ILFA committee members to my office in Leinster House in May to discuss the introduction of a soft opt-out organ donation consent system in Ireland. I am happy to support this move as it will mean more life-saving organ transplants can take place.

Congratulations to ILFA on all their work on behalf of IPF patients over the last 15 years and best wishes for the future.

Yours, Finian McGrath

**Finian McGrath T.D., Minister of State,
Social Protection, Justice and Health
with special responsibility for Disabilities**

Marathon man

'Marathon man' Andrew Grehan went the extra 26 miles to raise funds for ILFA, now he has moved on to cycling and triathlons.



Andrew's medals, Andrew after his 2015 marathon and Andrew with his cheerleaders before his 2016 marathon.

I spent my whole life thinking I'd love to complete a Dublin City Marathon, having watched from the sidelines cheering on my mother Annette, and my aunt and uncle, Denise and Eddie Cassidy, as they took on the challenge year after year.

In 2006, I did just that - my inspiration was always my mother but without warning my Auntie Denise suddenly got sick and was diagnosed with Lung Fibrosis. She fought for as long as she could and did so with great dignity, always smiling any time we would see her. She lost her fight just days before my first child was born. On the day my wife gave birth to our daughter, Lily, my family were in the church mourning Auntie Denise.

Three weeks later, I was at the start line of the Dublin City Marathon running for ILFA, originally with the hope of supporting my aunt but now taking part in her memory. Having not been at her funeral, it was my way of saying goodbye to Auntie Denise. An army of followers cheered me around the course including my parents and family, with my wife awaiting my return home with our new born lady.

The marathon didn't go to plan - most probably due to a lack of sleep and poor preparation! I finally made it to the last mile with nearly 6 hours on the clock to be met by my mum, cousin Nicola

and uncle Eddie. Together they walked me home the last mile and together we remembered a sister, a mother, a wife and an amazing Auntie.

After all the pain of that initial marathon, I did the same thing all marathon runners say and vowed to "never go through that again!!!" That didn't happen and I took part again and again and again! I finally decided, after getting through my own illness scare, that 2016 would be my last marathon, making it a total of 8 Dublin City Marathons in aid of ILFA. In that 10 year period, one of my closest friends, Alexander Sayve, also lost his father to Lung Fibrosis and we completed a Dublin City Marathon together to continue to raise money for ILFA. Ours is a friendship that will never be broken.

I will forever remember my marathons with pride and hope that the money I've raised has made a difference to others. My marathon days are over now but my fundraising hasn't finished. I've now turned my attention to cycling and triathlons! The ILFA community is a great family to be part of and to everyone who has helped raise money and raise awareness over the years, I say "Thank you and please keep it going!"

Andrew Grehan
Fundraiser

Advancing patient centred research



Anne-Marie Russell of London's Royal Brompton Hospital highlights the importance of keeping patients and caregivers front and centre for lung disease research.

Growing patient centred approaches in research is a priority for the Interstitial Lung Disease (ILD) research community. At the centre of this community are patients and their significant others, often named 'caregivers'. Several studies have been published exploring the patient and 'caregiver' journey using qualitative methods (structured conversations and group discussions). One study identified that healthcare professionals needed to improve their conversations with patients relating to healthcare; to better adapt to the changing needs of patients and their caregivers at the different stages of the IPF journey.

Patient centeredness is not an abstract concept. It is a dynamic process of engagement, shared learning and shared decision-making between patients and professional. Patient centeredness ".....ensure[s] that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care."

How do we achieve this? Charitable networks play an important role. For example, ILFA provides practical and condition specific information and support. They also promote education and support research, through recruitment, advertisement and funding. Becoming more knowledgeable about ILD, treatment and clinical trial options, is an approach that can empower patients to engage in joint decision-making with their clinicians about their healthcare at an individual level.

Clinicians also have a responsibility to engage in joint decision-making, contributing their valuable medical knowledge. This process can be challenging for some who may perceive a loss of medical power. A European survey presented at the American Thoracic Society meeting highlighted the need for better physician education regarding the benefits of awareness of the needs and wishes of patients newly diagnosed with IPF.

Knowledgeable patients have a powerful voice for self-advocacy. This has contributed to the delivery of several IPF Charters across the world. Whilst the IPF Charter affirms the need for equal access to care it is not always equitable. For example, parameters imposed by NICE (National Institute for Clinical Excellence) prevent the NHS prescribing of anti-fibrotic medication for those at the earlier stages of IPF in the UK. We must critically appraise how this decision impacts patient centred care and the parameters of future studies.

Research is influenced by funding bodies, ethical committees, reviewers and journal editors who guide the ebb and flow, strongly influenced by health and social policy. Increasingly, evidence of working with patients as research co-investigators is being requested by funders. This contributes to embedding patient centeredness in the research design at the outset. The IPF-Patient Reported Outcome Measure (PROM) provides a successful example of working with patients as research co-investigators.

At the output stage, the merits of publishing in open access journals should be seriously considered to enable patients and caregivers to access relevant research. Where research is not published as open access, strategies are needed to disseminate research findings to the very people who have enabled the research to happen – the patient. One approach that strengthens the construct of patient centred research and enriches the research process is including patients in the writing of manuscripts. If you would like to be more involved in the research process ILFA is able to sign post you to the relevant organisations / centres.

Anne-Marie Russell,
NIHR Clinical Research Fellow,
Department of Respiratory Epidemiology,
National Heart and Lung Institute, Royal
Brompton Hospital & Imperial College, London

It Started in a Kitchen...

ILFA Chairman Terence Moran charts the organisation's evolution from idea stage through milestone achievements across the intervening 15 years and looks forward to the future.



For me, ILFA started in a kitchen - it was some months after the death of my good friend Fergus Goodbody, who had been diagnosed with lung fibrosis about three years before he died. His wife Nicky, his physician Professor Jim Egan, and a number of friends met in the kitchen of Nicky's house, determined that we should do something to mark Fergus's passing, but unsure what that something should be.

We recognised that a significant problem for Fergus and Nicky was the lack of information

or support available to patients suffering from lung fibrosis and the sense of isolation that this caused to them and their carers. We also identified the need to contribute towards research into the condition.

Over the next while, and over many cups of tea, four of us worked on a structure and a set of goals. Nicky was very much the patient representative with direct experience of lung fibrosis, Jim Egan brought his broad experience of treating patients to the table while Marie Sheridan contributed financial and accountancy expertise. I assisted on the legal side.

Thus the Association was created – early steps included fundraising events which still feature today such as the annual winter swim at the Forty Foot in Sandycove, Dublin and the Women's Mini Marathon. It took us about a year before the first Newsletter was issued. We produced the first Information Leaflet in 2004 and at around the same time appointed a Research Coordinator, Joanne Coyle, to assist Professor Egan at the Mater Hospital. The first Patient Information Day took place in 2006 at The Royal Hospital in Donnybrook, Dublin.

Over the years, ILFA has grown organically with support and input from such a wide number of people from diverse backgrounds – I am so grateful to all those who contributed to its success. Personally, I feel honoured to have had the opportunity to share in the birth and early years of ILFA. May it continue to thrive.

Terence Moran
ILFA Chairman (2002-2017)

Mater Hospital ILD Service

Specialist nurse Lynn Fox outlines the importance of multi-disciplinary teamwork in looking after Interstitial Lung Disease patients at the Mater Hospital.



Front row: Mairead Fewer (Medical Secretary), Dr Kate O'Reilly (Respiratory Consultant) and Ciaran Heatley (Respiratory Physiologist). Back row: Lynn Fox (Respiratory Clinical Nurse Specialist), Grainne Murphy (Respiratory Physiotherapist), Carol Buckley (Respiratory Clinical Nurse Specialist) and Aoife Kelly (Research Nurse).

The Mater Misericordiae University Hospital (MMUH) in Dublin is one of a handful of Interstitial Lung Disease (ILD) referral centres in Ireland. Established in January 2014, our service team is a multidisciplinary team (MDT) lead by Dr Katherine O'Reilly, Consultant Respiratory Physician, and includes Respiratory Clinical Nurse Specialists (CNSp), Respiratory Physiotherapists and Physiologists. Mairead Fewer and Sandra Reilly make up the administrative team. Our service has strong ties with many interlinked services

within the MMUH including Transplant, Palliative Medicine and Rheumatology.

The consultant clinic provides access to an accurate diagnosis. The gold standard for patient diagnosis is the monthly ILD MDT meeting. Complementing the consultant ILD clinic, is the dedicated nurse-led ILD clinic.

The Respiratory CNSp, Lynn Fox, Carol Buckley, Claire Sheridan, Lavinia McLeod, and Paula Hallahan, are in attendance at the nurse-led clinic. This clinic provides support and education for patients, their families and/or carers about their diagnosis, treatments and symptom management. We discuss prescribed treatments and how to deal with any side effects that patients may experience. We educate patients on ways to manage their breathlessness and assist with cough management. In addition, the patients may be referred to the nurse-led oxygen clinic if they require assessment for oxygen. In between appointments, patients can contact the respiratory nurse service if they have any concerns about their disease or medication.

We also highlight the importance of exercise and where appropriate refer them to our ILD

pulmonary rehabilitation programme. 2017 saw the commencement of the first dedicated ILD pulmonary rehabilitation class. This service is headed by our respiratory physiotherapists, Grainne Murphy and Grainne Casey. It is centred on the needs of patients with ILD, as research has shown that pulmonary rehabilitation and regular exercise positively benefits patients with ILD. The Pulmonary Function Laboratory is essential to helping monitor disease progression. This service is facilitated by Deirdre O'Doherty and Ciaran Heatley, respiratory physiologists.

Our service has a close collaboration with the Irish Lung Fibrosis Association (ILFA). We make use of ILFA literature to help support our patients during education sessions. We feel it is important to give patients and their families the knowledge, skills and confidence to make informed decisions about their care. We will continue to strengthen our links with ILFA to help empower our patients.

Lynn Fox

**Respiratory Clinical Nurse Specialist
Mater Misericordiae University Hospital**

Genetics of Pulmonary Fibrosis



Respiratory Physician Dr Emmet McGrath explains how some risk factors have been identified in relation to development of IPF, but there's still much more research required.

Idiopathic Pulmonary Fibrosis (IPF) by definition has no obvious cause but a number of risk factors have been associated with the disease. These include patient related factors such as male gender, older age, a history of smoking, gastro-oesophageal reflux / acid reflux (which may also be a co-morbidity) and genetic links. A number of environmental risk factors have also been described such as farming, metal dust, livestock work and keeping birds.

Familial pulmonary fibrosis is described in individuals who have two or more direct family members diagnosed with idiopathic interstitial pneumonia (for example; a parent, sibling or offspring). It usually presents between the age of

50 and 70 years. Recent work has shown that a number of genes are associated with the disease but as yet, there is no form of genetic testing available to patients or families. The treatment and progression of the disease is the same in those with the familial form as those with sporadic (non-familial) disease.

Currently there is a lot of research ongoing including the development of National Registries (such as Irish Thoracic Society's ILD Registry in Ireland) to help understand the risk factors and genetic links associated with this condition.

Dr Emmet McGrath

**Respiratory Physician
St Vincent's University Hospital, Dublin**

European Lung Foundation



Dan Smyth

European Lung Foundation chair Dan Smyth underscores the importance of the wider patient organisation network at medical public and policy level.

The European Lung Foundation (ELF) was founded by the European Respiratory Society (ERS) in 2000 with the aim of bringing together patients, the public and respiratory professionals to positively influence lung health. This was a result of ERS looking to better communicate to patients and the public, and recognising the increasing value of patients' expertise in their own conditions and the importance of patient involvement in ERS activities.

Over the years, ELF has supported the growing role of patients within ERS activities, to the point that it is overseen by a patient. In 2014, I became the first Patient Chair of ELF and, when my mandate comes to an end at the ERS International Congress in Milan, in September 2017, I will be succeeded by Isabel Saraiva as the next Patient Chair. I have tremendously enjoyed the past 3 years as Chair of ELF and my role brought many personal highlights for me.

- Sitting on the ERS Executive Committee and having influence at the highest level of ERS as a patient
- Launching the 'Healthy Lungs for Life' campaign in 2014, when taking over as the new ELF Chair, and seeing its continuing successes in Europe and worldwide, the campaign now entering its fourth year
- Working on patient-led guidance through Patient Priorities, a new ELF project in which patients advise on the development of guidance to address the needs of patients and inform healthcare professionals on areas where European patient-centred information is lacking
- Getting more patient organisations involved in the work of ELF/ERS and bringing them together for the first ever ELF patient organisation networking day during the ERS International Congress
- Seeing a growing number of patients attending the ERS International Congress both as representatives of their organisations and as patient speakers, giving the patient perspective during scientific sessions
- Being part of ELF during a time when the number of patients involved in ERS task forces has increased steadily
- Developing further the European Patient Ambassador Programme (EPAP), which helps



The ELF team; Courtney Coleman, Emma Thompson, Irene Ferrario, Jeanette Boyd, Kerstin Morrison and Pippa Powell.

patients gain the skills and knowledge needed to become well-informed and being able to take part in high-level healthcare advocacy activities and contributing in a meaningful way.

As a member of the European patient organisation network, ILFA has a longstanding relationship with ELF/ERS. We really value the contributions ILFA has made to many activities – including the IPF Task Force. ILFA member Matt Cullen spoke about his experience with pulmonary rehabilitation in a symposium during the 2015 ERS International Congress in Amsterdam. He has also, since 2016, been an active member of the patient advisory group of the European Patient Ambassador Programme (EPAP), and has attended a meeting for this at the ELF offices in March this year.

The European patient organisation network is an important tool to widen patient involvement and the reach of empowered and well informed patients. By bringing together patient organisations across Europe, it enables us to speak as one voice for patients with a range of lung conditions, increasing the impact we can all have at a medical, public and policy level. September 2017 will be the second year that patient organisations will be able to attend a dedicated networking day for patient organisations as part of the ERS International Congress - this year including an opportunity to discuss key issues not only among themselves but with primary care professionals from across the world.

I would like to thank ILFA for their contributions and their involvement with us and I would like to congratulate them on their 15th anniversary.

Dan Smyth

Chair of the European Lung Foundation

ILFA in numbers

Set up in **2002**
– 15 years old

3 National Awards

22 Patient
Information
Days

ILFA has over
3,200
Facebook friends
PLUS over 320 Twitter followers

27 Newsletters

6 patient
support
groups



950 patients, family
members, fundraisers
and healthcare
professionals
registered on ILFA's mailing list

The Margaret Maloney Memorial Darts Tournament

Owen Maloney tells how family, friends and supporters gather to remember his late mother and raise crucial funds for ILFA through the Margaret Maloney Memorial Darts Tournament.



Mark Maloney, Michael Maloney, PJ Maloney, Marcella Maloney, Joe Maloney, Owen Maloney, Denise Origan, Declan Maloney.



Mark Maloney, Denise Origan, Joe Maloney, Michael Dooley, Liam Galvin (ILFA), Owen Maloney, Marcella Maloney, PJ Maloney and Joe Lowry (RIP). Missing from the photo are Declan and Michael Maloney.

Our late Mam, Margaret Maloney, was diagnosed with Idiopathic Pulmonary Fibrosis in January 2011. Unfortunately Mam also suffered from other underlying conditions which prevented her from doing some of the advisory things that help prolong your life if you suffer from IPF. Mam was put on oxygen which she thought would be temporary but little did she know it was keeping her alive and she would need it for the rest of her life. In July 2013, Mam started to fail and spent a couple of weeks in Tullamore General Hospital. Mam came home and we celebrated Dad's 65th birthday in August but Mam was fighting hard to keep the good side out. On September 4th, Mam was taken back to Tullamore hospital and unfortunately on the 20th of September, she passed away peacefully with her seven kids and her husband - our Dad, Joe, by her side.

Mam was a great lover of a game of darts in her day and would have been the ladies captain at The Railway Bar in Roscrea town in the early 80s. So we, her family, along with a couple of close family friends, decided to start up what we thought would be a fun and fitting darts tournament in Mam's honour. Little did we know the huge success

the Margaret Maloney Darts Tournament would be. We started off with 48 throwers on the 1st of October 2014, it grew to 74 throwers on the 26th of September 2015, and we reached a whopping 78 throwers on the 24th of September 2016. Who knows how many will turn up on this year on the 30th of September 2017 at The Central Pub in Roscrea!

To date, we have raised almost €12,000 for ILFA and we will add to that total this year. ILFA does a great job making people aware of this disease, which is probably not so rare. Our family and friends are delighted to be playing our part in raising funds to help raise awareness for this disease that broke our hearts.

The Margaret Maloney Memorial Darts Tournament will live on in memory of a great lady who was taken from us far too soon. Hopefully our fundraising will go towards helping make more people aware of IPF, and support patients and their families by informing them what they can do to help themselves or their loved ones deal with it.

**Owen Maloney
Fundraiser**

ILFA15

My second chance

Transplant recipient and mini-marathon fundraiser Edna Powell shares her experience as she makes the most of her second chance at life.

One lunchtime during the autumn of 2015, the call I was waiting for came through. It was my lucky day as I was asked to come immediately to the Mater Hospital in Dublin to check my suitability for a possible lung transplant. Friends brought me to the hospital and my family arrived to await the outcome of the various tests.

It was approaching midnight when we were informed that all was compatible and the team planned to proceed with the surgery within a matter of hours. I was taken to an operating theatre at around 4am. All the way through the experience, my transplant co-ordinator Zita was extremely reassuring to myself and my children, Lorna and Kenneth.

The next thing I remember was waking up in the Intensive Care Unit, where I would stay for the first few days of recuperation. The very next day I was helped to take a few steps and encouraged by everybody there. Pain was negligible due to the amazing care.

After another few days, I was moved to the High Dependency Unit where every need was seen to.

The second weekend I was allowed home

ILFA15



for a few hours and was fully discharged just 16 days after getting my new lung.

I was helped every step of the way, literally. I was given an exercise regime and a medicine routine to stick to, and was followed up frequently at the out-patient clinic.

There were some lifestyle restrictions to get used to but these eased over time. Christmas that year was a very quiet family one but I was back at work by April. By June, I had done fundraising for ILFA and the Irish Heart and Lung Transplant Association and completed the Dublin Women's Mini Marathon.

I would like to take this opportunity to thank my donor and their family for giving me back my life. A big thank you also to my own family and friends and to ILFA for the ongoing support.

Edna Powell
Lung transplant recipient and fundraiser



Petra Grehan and Irene Byrne.

The importance of exercise

Mater Hospital physiotherapists Irene Byrne and Petra Grehan explain the importance of exercise for lung fibrosis patients.

When you have a problem with your breathing, exercise and physical activity can be difficult. But if you learn how to plan and exercise within your ability, you will reap the benefits in many ways. Exercise improves your energy levels and increases your stamina by increasing your confidence and maintaining your independence. Exercise helps you maintain muscle strength, a healthy weight, and increases your bone density.

Lung fibrosis can make it more difficult for the lungs to absorb oxygen. This can lead to shortness of breath, fatigue, and chronic cough which can result in individuals avoiding exercise and even their normal daily activities. Reduced physical activity can lead to muscle weakness and so can increase the symptoms of breathlessness and fatigue. It is vital for people with lung fibrosis to understand that exercise is a very important

Shortness of Breath Modified Borg Dyspnea Scale	
0	Nothing at all
0.5	Very, very slight (just noticeable)
1	Very slight
2	Slight
3	Moderate
4	Somewhat Severe
5	Severe
6	
7	Very Severe
8	
9	Very, very severe (almost maximal)
10	Maximal

component for managing their symptoms.

Breathlessness and the fear of getting short of breath can be one of the greatest barriers to being active and participating in exercise. Learning how to manage your breathlessness during daily activities and your exercise programme is essential.

The **Borg Scale** is a quick and easy way for you to rate your breathlessness - a score of 1 is 'mild breathlessness' and 10 is 'extreme breathlessness'. We all have to get breathless when exercising but this scale will help you monitor and manage your level of breathlessness safely. You should aim to keep your breathlessness at a score of 3-4 (moderate) while you are active.

If breathlessness is affecting your ability to take part in your normal day to day activities, you should speak to your doctor about this. They may recommend a change in your medications, use of oxygen or other therapies to manage this. Your medical team may recommend that you start to use oxygen during rest and exercise depending on your requirements. Oxygen can enable you to be more active. If you have any questions regarding this, you should discuss it with your doctor.

There is some evidence to support the use of a hand held fan to help during breathlessness. ILFA can supply you with a hand held fan if you wish.



through a series of steps to regain control over your breathing.

ILFA has developed, with the support of physiotherapists at the Mater Misericordiae University Hospital, a number of resources to help you start and maintain an exercise programme appropriate to your level of activity.


The 2000 Steps A Day Challenge consists of a pedometer, an exercise diary, and guidance to help you increase your daily step count by an extra 2000 steps (roughly 1 mile) over a period of time, suited to your abilities.

The home-based exercise DVD provides information on how to manage fatigue and breathlessness and takes you through a guided home-based exercise programme. It also contains testimonials from people living with lung fibrosis which can help to encourage and motivate.

Pulmonary rehabilitation programmes can also help you exercise in a supportive class environment. Everyone's level of exercise can vary from hill walking to walking up and down your living room. If you are struggling to find an exercise that suits you or would like more information on exercise classes in your area, speak with your medical team or physiotherapist. Exercise is a vital component to help you live a fuller and better life with lung fibrosis. Every step is a step towards maintaining your well-being and quality of life. If you require more information on any of the ILFA resources, please contact the ILFA team.

STALL Breathing Technique©


for Lung Fibrosis patients



- Breathlessness can cause fear and anxiety.
- If you experience an episode of worsening breathlessness, try the **STALL** method to regain your breathing, composure and confidence.
- Show this card to your carer so that they can support you. It is important that your carer does not panic when you experience breathlessness.

Irish Lung Fibrosis Association www.ilfa.ie

STALL Breathing Technique©



S **Stop** what you are doing.

T **Try** to remain calm. **Turn** up your oxygen.

A **Assume** a comfortable position.
For example, sitting or leaning.

L **Let** your imagination take you to a safe place.
Imagine yourself there, relaxing.

L **Let** your breathing return to normal.

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

The **STALL card** can also be used to help guide you and your carers during episodes of breathlessness. This technique will guide you

Irene Byrne and Petra Grehan
Physiotherapists at the Mater Misericordiae
University Hospital, Dublin



Treasurer's Thoughts

ILFA treasurer Eddie Cassidy charts some of the organisation's achievements to date and looks forward to the next 15 years.

Denise and I went to our first ILFA Patient Information Day, at the Royal Dublin Hospital in Donnybrook. Denise had IPF and was attending Professor Jim Egan at the time, and he spoke that day. Two years later, I and my daughter Nicola were co-opted onto the ILFA committee as volunteers. We wanted to use our experience of caring for our loved one to help others.

I was subsequently elevated to the position of Treasurer. I took on the job with trepidation as it is an important role and a big responsibility. Today I still hold that same position, so I trust that I must be doing something right or else nobody wants to be treasurer!

Marie Sheridan was the first ILFA Treasurer and also a founding member of the association and previous Director of ILFA. Marie handed the reins over to me and I must thank her for having confidence in me and also guiding and advising me. I would also like to thank our auditors Whiteside & Cullinan, and especially David Buggy,

for their assistance with the annual financial accounts over the years.

During my time with ILFA, I have seen many great changes over the years. The voluntary work that is carried out by the committee is superb and their passion and commitment to the work of the charity is second to none.

It is thanks to our amazing fundraisers and those who generously donate to ILFA, that we are in a position to provide practical tools and information resources to patients free of charge. People are so generous and work so hard to fundraise for ILFA and their generosity and kindness have helped keep the charity going, especially through tough financial times. Everyone who has made any contribution to ILFA since our humble beginnings in 2002, has enabled us to support patients and families affected by this terrible condition and hopefully make some small difference to them.

Some of the work that your donations have contributed to include;

- **Research:** There have been many advances in the medical field in the last 15 years. ILFA funds facilitated the research involved with conducting international clinical trials for the medicines Pirfenidone and Nintedanib. Hopefully there will be more advances to come in the future.
- **Information Days:** At present ILFA holds two Patient Information Days per year. One in Dublin and one in the provinces. We try to cover different locations and invest in advertising locally and nationally to keep people informed.
- **Patient resources:** ILFA has developed and produced The National Patient Charter for IPF, many information leaflets, the 2000 Steps a Day exercise pack, an exercise DVD, Stall Cards and hand-held fans. All materials are designed to help patients and indeed the healthcare staff looking after them.

At present, thankfully ILFA is thriving and going from strength to strength. All those on the committee will continue to drive ILFA forward and remain hopeful that with the help of medical science, a cure will be found for our patients.

I would like to thank all those who have served on the ILFA Committee since 2002 our past and present members, my support group friends, our fundraisers, donors and supporters, and the doctors, nurses and healthcare staff who are making a real difference.

Best wishes to all,

Eddie Cassidy
ILFA Treasurer and Director

Interstitial Lung Disease with the University Hospital Limerick Group

University Hospital Limerick Group continues to strive for excellence in offering patients a holistic treatment plan as facilities continue to grow and expand in the Midwest.

As one of the ILD expert centers in Ireland, the University Hospital Limerick Group (ULHG) serves a population of some 400,000 people on its six clinical sites collectively.

With the appointment of two respiratory consultants, an advanced nurse practitioner (RANP) and clinical nurse specialists (CNS), the group provides an expert service for patients with Idiopathic Pulmonary Fibrosis (IPF). Each patient is managed according to standard clinical practice and all pharmacologic or non-pharmacologic interventions are initiated and terminated according to the clinical judgment of our expert respiratory consultants and respiratory team. This is supported by best national and international guideline recommendations where applicable.

Our process within the mid-west group is forever growing and expanding. Once a patient is referred into the consultant, a direct comprehensive health assessment and physical assessment is carried out. The consultant then orders diagnostic tests for patients. These may include CT scan of the chest, a bronchoscopy, full pulmonary function testing, cardiopulmonary exercise testing, oxygen needs assessment, and echocardiogram (ultrasound of the heart). Once results are obtained, each patient is discussed at the multidisciplinary team meeting to decide their future management or treatments.

Our patients have direct contact with the RANP/ CNS once diagnosed and attend the ILD clinic for education and guidance of their disease. We spend time with each patient and family to outline their self-management plan of care, and each patient has our contact details if any

concerns arise outside of the clinic appointment. Each monthly appointment with an ILD patient involves caring for and supporting the patient, and allows opportunities for trust to develop between the patient and the nurse. These patient-nurse interactions are an important aspect of managing patients with ILD symptoms such as cough and breathlessness, and allows the nurse to gain an understanding of how patients are managing their symptoms at home, so any intervention can be started from that appointment. A typical assessment in our clinic will include asking patients about their quality of life, cough, breathlessness, triggers that makes their breathing easier/worse, smoking history, current and past medical history and medications.

Managing symptoms and quality of life is extremely important for this group of patients. We run a very strong pulmonary rehab course, helping to manage their illness and symptoms with a multidisciplinary approach. This offers access to other services that the ILD patient may need such as a dietician or clinical physiology. Our local support group is managed by one of our patients offering continued support in the community.

As our service is growing and expanding, we continue to strive for excellence for our patients and are excited about the future here in the mid-west. We aim now to focus on standardising our plan of care for patients and introduce palliative care at the early stages of diagnosis to ensure our patients receive a holistic treatment plan.

Paula Ryan
Respiratory Nurse Specialist
University Hospital Limerick

My Story

Patient advocate and fundraiser
Matt Cullen explains how
ILFA helped him and outlines
the work he has been doing to
promote sharing of information
and support services.

My first encounter with the Irish Lung Fibrosis Association began in early 2013 when I was going through a very difficult time with IPF. It is a credit of the Irish Lung Fibrosis Association and the patients and carers of the Dublin Patient Support Group who helped me enormously to deal with my health issues.

To explain fully, I was diagnosed with idiopathic pulmonary fibrosis (IPF) in 2010 and in 2013 I was further diagnosed with chronic obstructive pulmonary disease (COPD) and rheumatoid arthritis (RA). The difficulties I experienced were fatigue, breathlessness and hoarseness (for three months approximately). I knew no one with IPF at the time and I was feeling very isolated and somewhat scared. I consider myself to be very fortunate to have been put in contact with ILFA through my initial contact with Paddy O'Mahony (Dublin Patient Support Group) who kindly informed me of the support group and the support that ILFA provided.

That encounter was a turning point which was to have a very positive influence on the way I dealt with my health difficulties. I immediately took part in the ILFA 2000 Steps a Day Challenge which helped improve my fitness and wellbeing. I began to feel well enough to return to my love of gardening, volunteering with



Matt Cullen and his family.



Matt Cullen and former Minister for Health, James Reilly, at the launch of Matt's first solo art exhibition in 2015.

Swords Tidy Towns, DIY and art, although all at a slower pace! On the subject of art, it is worth mentioning that I painted mainly in oils and I was advised to avoid using them as they could cause further damage to my lungs. Fortunately, I learnt of relatively new slow drying acrylic paints which are non-toxic, which meant that I could return to my love of painting. Consequently, I had my first solo exhibition in 2015 and I donated some of the proceeds to ILFA.

The organisation has helped me in other respects too; on IPF patient care, education and especially helping increase awareness of IPF. For example, I was invited by the European Lung Foundation (ELF) to speak at the European Respiratory Society Congress in Amsterdam in 2015. To take part in the ERS Congress was a wonderful experience for me. It was great to be able to convey the patient's perspective to such a wide audience. I was delighted with the help and support from the ELF and ILFA.

Since then, I have volunteered to help ILFA by taking part in an exercise video (ILFA Exercise DVD for Lung Fibrosis Patients) for

patients with a respiratory illness. I have also given talks from an IPF patient perspective at an ILFA Information Day and to a pharmaceutical company. It was great to be involved in the focus group discussions that culminated in the National Patient Charter for IPF and to attend the Plain English Awards where ILFA won an award for the National Patient Charter for IPF booklet.

I became a European Patient Ambassador having completed a European Patient Ambassador Programme (EPAP) which is primarily for patients with a respiratory illness and is run by the European Lung Foundation. Linked with this, I joined the Patient Advisory Group (PAG) which review and promote the programme. Finally, I act as a contact person for patients who have been diagnosed with lung fibrosis to provide information on the ILFA Dublin Support Group. It means a lot to me to be of help, even if it appears miniscule compared to the work of others.

Matt Cullen
Lung fibrosis patient, patient advocate
and fundraiser



Our Lady Of Mount Carmel, Whitefriar Street Church, Dublin.

ILFA Reflections

Canon Charles Mullen of St Patrick's Cathedral, Dublin, reflects on his participation in ILFA's annual ecumenical services.

My first encounter with ILFA was through an invitation to be the priest representing the Church of Ireland at ILFA's 10th anniversary service held in Whitefriar Street Church in 2012. I've had the privilege of keeping that role at the annual service ever since.

What struck me then, and since, was the calm dignity of the ILFA members. The service had – and continues to have – two emphases: to encourage and reassure those who suffer; and to remember in prayer before God those who have departed this life. The candle-lighting ceremony is poignant and thought-provoking: we're not alone in our bereavement, but part of a goodly fellowship brought together and held together by ILFA.

I congratulate you on the way in which you support one another. The ILFA Newsletter is always filled with details of meetings and support days, along with news of how the Association promotes awareness of IPF at home and abroad. You're a strong force: I pray that you'll continue



Canon Charles Mullen, Reverend Denis Campbell, Reverend Vanessa Wyse-Jackson and Fr Brian McKay O'Carm.

to find new strength through your exemplary calmness and dignity.

Canon Charles Mullen
Dean's Vicar
Saint Patrick's Cathedral, Dublin

Comfort Zone!

ILFA fundraiser Margaret McGlynn shares her experiences of honouring the memory of her late father Sean, while following his example of helping other people too.

Here I am again ... doing something that really is completely out of character for me and something that maybe in a previous life, I would have said that I really couldn't do ... because "I just would be no good at that sort of thing" ... a thing like writing an article for a magazine!

Now I couldn't be described as a 'budding author' ... however, I find myself writing these few words for the Irish Lung Fibrosis Association's (ILFA) 15th anniversary special edition magazine.

ILFA had been in existence for almost 8 years before my first encounter with the association in June 2010, when my late father, Sean, was diagnosed with Idiopathic Pulmonary Fibrosis (IPF). This was the start of a truly rapid life changing event for my entire family. Each member of my family found themselves in what can only be described as mirroring an 'outer body experience' and comfort zones knew no bounds. Of course my Dad had the toughest road of all of us to travel, and through it all he bore his illness with great fortitude.

When my Dad passed away on 28 September 2010, I was determined to honour his memory by supporting ILFA, if only in a small way. Throughout his life my Dad always loved to help people and would go out of his way to do so. Therefore I thought it would be fitting to support ILFA which in turn helps and supports so many other people and families affected by lung fibrosis.

Firstly in lieu of flowers at my Dad's funeral, the family suggested donations if desired to ILFA. Next



on the horizon was the Women's Mini-Marathon (WMM) and I saw this as a very good opportunity to raise funds in Dad's memory for ILFA. However taking part in a marathon (even a mini one) was something I had never attempted or even dreamt of attempting – I would never have been of a 'sporty' disposition. I'm sure anyone that knows me raised an eyebrow on hearing that I was seeking sponsorship for taking part in the WMM. I'm happy to report my determination won out and I successfully completed the WMM 2011 and went on to complete 4 consecutive WMMs all in aid of ILFA.

Christmas is universally a special time of year with all those close to us playing a pivotal part. Our senses are heightened to those family and friends who are no longer with us and are greatly missed. Over the last number of years I have sold packs of ILFA Christmas cards in support of the charity. It is a very small gesture but helps keep memories alive and supports a very well deserved cause.

In my opinion ILFA is a marvellous organisation and I really admire the individuals who work so hard in so many areas to keep Research, Education and Support progressing forward. From a personal perspective, I want to particularly mention and pay tribute to ILFA's annual Service of Prayer and Reflection. This commenced in 2012 to celebrate ILFA's 10th anniversary and following its instant success, it became an annual service. It really is a very special event and for any readers who have yet to experience it, I would highly recommend it.

Happy 15th Anniversary ILFA and "Thank You" ... for my ever expanding comfort zone!

Margaret McGlynn
Fundraiser

Therapeutic Advances in IPF



Mater Hospital respiratory consultant Dr Kate O'Reilly outlines benefits of medication

advances, while also highlighting the importance of patients keeping as active as possible.

The development of the oral anti-fibrotic drugs Pirfenidone (trade name Esbriet®) and Nintedanib (trade name Ofev®) has without doubt been the most significant advancement we have seen in the treatment of Idiopathic Pulmonary Fibrosis (IPF). These medicines act in a new and novel way by slowing the rate at which scar tissue replaces normal lung tissue.

The result is that the disease progresses more slowly allowing patients to remain well for longer. Accumulating evidence also suggests that patients on these drugs live longer when compared to patients before treatments were available.

Despite this significant progress, it must be noted that neither treatment reverses or cures the disease.

Therefore specialists treating patients will continue to look for volunteers to participate in clinical trials; a key component in ensuring

that new discoveries will further advance the treatment of IPF in the years to come. As with all medicines, it is important to have access to good and experienced advice when you as a patient or a family member has been diagnosed with IPF.

While both medicines have been shown in clinical trials to be of benefit in certain patients with IPF, there are considerations that may make one or the other more suitable for a particular patient. For example, Nintedanib (Ofev®) is preferred in patients with kidney disease while Pirfenidone (Esbriet®) is generally used in those who are on blood thinning medications.

Both medicines may cause side effects but these can generally be limited and controlled with a number of strategies - some involving other medicines (for example, anti-sickness tablets) and others involving practical changes like how and when the medicine is taken.

Many of the side effects are similar but some are seen more commonly with one or other medicine. Therefore, it is vital to have a discussion with the treating doctor and specialist nurse regarding which medicine is a better choice for you as an individual.

Thankfully patients and doctors in Ireland join those in Europe and North America in having both treatment options available. On June 1st 2017, Nintedanib (Ofev®) joined Pirfenidone (Esbriet®) on the 'High Tech Scheme' for specialist medicines in Ireland.

It is also important to understand that these medicines are not suitable for all patients with IPF. In particular, patients with more advanced disease or those who have fibrosis in combination with another condition such as COPD or Pulmonary Hypertension may benefit from other strategies and other medicines such as oxygen therapy, inhaler therapy, or Sildenafil (Revatio®) to name just a few.

All patients are entitled to specialist advice that takes their particular medical circumstances and their personal preferences into account.

In conjunction with medicines, the benefits of a sensible and sustainable exercise programme cannot be overstated. Improving one's fitness and keeping active will improve overall quality of life to a greater extent than any currently available medicine.

**Dr Kate O'Reilly
Consultant Respiratory Physician
Mater Misericordiae University Hospital**

The Interstitial Lung Disease Service in Galway University Hospital and Saolta University Health Care Group



Professor Anthony O'Regan outlines the services provided at the Interstitial Lung Disease Service in Galway and highlights the need for more resources.

The Interstitial Lung Disease (ILD) service was established in 2013 to provide care for patients with ILD, and in particular Idiopathic Pulmonary Fibrosis (IPF).

The principal aims were to;

- Provide accurate diagnostic pathways supported by multidisciplinary group meetings and by lung biopsy where necessary
- Provide access to and support for established and emerging therapeutics
- Provide appropriate disease supports including end of life care.

The clinic is based at Merlin Park Unit 8 and occurs on a monthly basis with on-going telephone support. Patients are seen on a secondary and tertiary level with, where possible, a multidisciplinary team (MDT) established diagnosis. The service is coordinated and delivered predominantly by a clinical nurse specialist, Donna Langan. The lead respiratory consultant is Anthony O'Regan. The MDT is supported by specialist chest radiology, Dr John Bruzzi and by pathology and rheumatology. It

provides access via video link to other respiratory consultants in the group. The clinic is supported by respiratory physiotherapy, Tara Cahill, and also provides one-stop access to pulmonary function testing, walk testing, and where necessary CT scans.

Pulmonary rehabilitation is available on site and we have run a dedicated IPF programme. The clinic provides educational support relating to lung fibrosis and therapy, in particular anti-fibrotic treatment. A dedicated phone line provides access to online support for patients. The Irish Thoracic Society's ILD registry data is collected and entered on site.

These services have been developed without any additional support from the HSE and the evolution of the service is outstripping the resources available.

Professor Anthony O'Regan
Consultant Physician
Galway University Hospital
Chief Academic Officer
Saolta University Health Care Group



Kevin McSkeane, Michael Cox, Noreen O'Carroll, Evelyn Cooper, John Givens and Malachy Molloy with the titles of some of ILFA's information leaflets.

ILFA's Patient Information Resources

Marie McGowan outlines how ILFA helps patients and works closely with healthcare providers on their behalf.

ILFA is proactive and innovative in researching and developing educational materials and practical patient resources. We source high quality, low cost and effective lifestyle aids and resources to help patients adapt to living with lung fibrosis. All of our resources are provided free of charge to patients and healthcare professionals in Ireland.

Our patient resources include,

► **The National Patient Charter for Idiopathic Pulmonary Fibrosis:** The charter was launched in 2015 and aims to increase awareness of IPF among members of the public, General Practitioners and healthcare professionals. Most people have never heard of IPF and being diagnosed with this condition can be very frightening and

confusing. The charter will help you and your family understand how to access the best IPF treatment, and guide you as you make use of the healthcare system.

- **ILFA Newsletters:** ILFA produces three newsletters annually which are posted to patients, fundraisers, and healthcare professionals throughout the country. There are approximately 950 people on the ILFA mailing list. The newsletters feature information on research and developments in pulmonary fibrosis, fundraising initiatives, updates on ILFA's lobbying and advocacy activities and information on the support groups around the country.



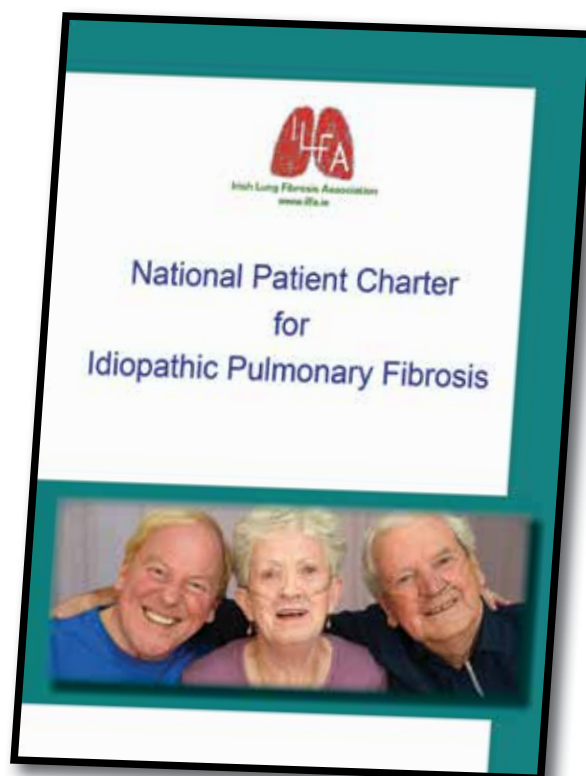
- **Patient Information leaflets:** ILFA develops information leaflets to help patients and their families better understand IPF and also to inform the public about the work we do. The leaflets are developed using plain English guidelines and

reviewed by the National Adult Literacy Agency.

- **ILFA Directory of Services:** The aim of the Directory of Services is to provide patients with accessible information on the resources available to them in order to enhance their activities of daily living and to improve their quality of life. It contains a nationwide listing of companies that provide appliances, products, and services that may be useful to patients with lung fibrosis. We hope that by providing this information in one source, the Directory of Services will save patients and their families' time and effort when trying to access services.

The ILFA Directory of Services was compiled using the shared experiences and knowledge of lung fibrosis patients, along with supplementary research.

- **ILFA STALL Breathing Technique Card:** The ILFA STALL Card is designed to be carried in a wallet, purse or pocket and it has simple instructions on how to control your breathing if you experience breathlessness. Show this card to your caregiver / companion so that they can help you if you have breathlessness.



- **ILFA Medical Alert Card:** Patients who use supplemental oxygen can request an ILFA Medical Alert Card for their wallet, purse, bag or oxygen carrier. The Medical Alert Card should be completed by patients and contains information about your healthcare team and your oxygen company in case this information is needed in a medical emergency.
- **2000 Steps a Day Walking Programme:** The 2000 Steps a Day programme was developed specifically for lung fibrosis patients. The 2000 Steps walking pack includes a pedometer, an information leaflet on the benefits of walking as exercise for IPF patients, a contract for success featuring an inspirational poem, and a diary to record progress.

Additional Resources

ILFA works closely with respiratory nurses and allied healthcare professionals to research and develop patient resources that will help patients to live well with lung fibrosis.

Some of these resources include;

- An exercise DVD for patients with lung fibrosis.
- Hand-held fans.
- ILFA has a website, Facebook page, Twitter page, and educational videos on YouTube.

Marie McGowan
ILFA committee member

In Good Hands

IPF patient Sylvia Cerasi explains how support group meetings have become “a lifeline” for her and gives thanks for the care, advice and treatment from all at the Mater Hospital.

I was referred to a respiratory out patients clinic in May 2009 due to recurrent chest infections, necessitating repeated antibiotic treatment.

A CT scan suggested bronchiectasis and possibly asthma also. I attended this clinic for several years until a High Resolution CT scan diagnosed idiopathic pulmonary fibrosis (IPF) and so began my journey. I knew nothing about this condition and I began my research to find out what this was all about. I was shocked to discover this was a rare and terminal disease and immediately got in touch with ILFA.

The support group meetings on the first Tuesday of the month in Whitefriar Street Community Centre in Dublin became a lifeline for me. I met wonderful people all with varying degrees of pulmonary fibrosis. I listened and learned a great deal from these meetings but most of all I stopped being afraid. It was wonderful to compare notes and I took on board all the information and good common sense offered to me. Soon it became a social and fun event at the meetings and I consider myself very fortunate to

have met such wonderful people.

I particularly enjoy the lectures and visits from experts in the field. I would also like to say that the support from nursing, physiotherapists and other professionals has been excellent and I know how lucky I am to attend the Mater Hospital to receive excellent care, advice and treatment.

Saving the best until last, I feel confident that with the friends I have made including consultants, nurses, physiotherapists and indeed the lovely and very efficient secretaries, that I am in good hands whatever the future holds. I am very fortunate that I am a strong and positive person and have always taken the view that my cup is half-full and I will continue to drink from it so long as it is a vodka and bitter lemon.

“Cheers!”

Sylvia Cerasi
IPF Patient



Happy birthday to ILFA!



Cystic Fibrosis Ireland chief Philip Watt wishes ILFA a happy 15th birthday as the two organisations continue to work closely together on transplant initiatives.

Cystic Fibrosis Ireland has had a long and very positive relationship with ILFA over many years, and together with other patient groups concerned with transplants, we form the Irish Donor Network (IDN).

It has been great to see all the progress in the Irish lung transplant programme since its rejuvenation in 2012/2013. Patient groups have played a key supporting role in this process with the lead taken by the Office for Donation and Transplant Ireland (ODTI), including support for the appointment for specialised transplant surgeons; additional resources for transplants and supporting government policy, and supporting the proposed move to a 'soft opt-out' organ donation system. An additional €2.9million in the HSE service plan for 2014 was dedicated to supporting transplantation and 19 additional posts. This was a key demand of the IDN, that such resources would be provided prior to the introduction of soft opt-out.

According to the Council of Europe, Ireland has risen from 18th place (2010) to 3rd place in 2015 in the league table for lung transplantation in the wider European area. Only Austria (15.3 Patients per Million Population (PMP)) and Belgium (11.4 PMP) exceed Ireland's performance (7.7 PMP) in the European Union. By contrast the UK was only 3.1 PMP in 2015.

IDN and individual patient groups played a key role in the opt-in and opt-out debate. All of the patient groups within IDN adopted the approach of favouring the soft-opt out approach. There were submissions and meetings with the Minister for

Health to convince him that moving to a soft opt-out approach would require significant additional resources.

The best birthday present for all lung transplant patients would be for the government to implement its own commitment to bring in soft opt-out organ donation.

There have been commitments for a soft opt-out system in both the 2011 and 2016 Programmes for Government. In May 2017, Simon Harris T.D., Minister for Health promised that he "plans to bring the proposals [for a soft opt-out policy] to the Oireachtas Health Committee in 2017." This is to be welcomed.

A soft opt-out system has the potential to raise organ donor rates by increasing public participation. A soft opt-out system will close the gap between intent and action because individuals who want to donate their organs, who never get around to opting-in, will automatically be considered donors and their next of kin consulted. According to public surveys, approximately 67% of the Irish population are willing to donate their organs, yet only 29% of respondents carry a donor card. Therefore, if this survey is representative of the public's opinion, the introduction of an opt-out system will increase the number of organ donors.

Cystic Fibrosis Ireland will continue to work closely with ILFA to continue to improve organ donation and transplant rates in Ireland.

Philip Watt
CEO of Cystic Fibrosis Ireland and
Chairperson of the Irish Donor Network

The Kennedy Family



Fiona Kennedy tells how her dad Michael is making every breath count after his lung transplant, aided and abetted by all the family.

We first became aware of the great work that is done by ILFA when our dad, Michael Kennedy, was diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in 2009. 'IPF' was a new term to us and ILFA was a huge support to both Michael and our extended family during this time, providing support and information on IPF, as well as access to other patients and carers through the information days and support groups. They were also very proactive in providing information and updates on new developments on the condition and treatments. In 2011, we completed our first mini-marathon to help raise funds for ILFA and were overwhelmed by the generosity and support from our friends and extended families in supporting both Michael and ILFA. In August 2012 Michael was privileged to receive a lung transplant. Since then we have been delighted to be involved in more fundraising activities to help support ILFA and raise awareness of the condition.

Each year we complete the women's mini-marathon, with Michael and a selection of his ten grandchildren supporting and cheering the walkers/runners along the way. In 2014 when Michael's son Tomás celebrated a 'milestone birthday', he suggested donations to ILFA in lieu of birthday gifts and again we were truly taken aback by the generosity and support of close friends and extended family in supporting this vital cause. Michael's

grandchildren are all growing up rapidly and fully in tune with any fundraising activities to support their Grandad. In recent years, the children who have made their first holy communion have all generously made their own donation to their granny/aunties completing the mini-marathon.

By now, everyone on our Christmas card list is aware of ILFA (the ILFA Christmas cards are an easy way to raise awareness) and even the in-laws have participated in ILFA activities. Michael's son in law, Robert, completed the Pat Casey Memorial Cycle in aid of ILFA last year and plans on attempting it again this September with Tomás in tow.

In May 2017 Ann Kennedy, Michael's wife, upped the ante and walked 80km of the Camino de Santiago (over just 3 days) dragging her daughter Fiona along the route in support of ILFA. Ann also managed to complete the ladies mini-marathon the day after her return from her Camino walk. It has been suggested that perhaps Ann got her events mixed up - the Camino was done at such a pace that more than one pilgrim commented on the two young Irish ladies "running the Camino".

Michael did an important walk of his own in April 2016 when he walked his youngest daughter Deirdre up the aisle on her wedding day. Days like this are hugely symbolic for our family and we are eternally grateful to Michael's donor.

We would like to thank ILFA for their support to our family, as well as the education and information given to us over the years. We also would like to acknowledge our friends and extended family for their continued support and encouragement of both Michael and all of our ILFA fundraising activities.

Those of you who know Michael will agree that he and many people like him are the living embodiment to others on the transplant list to never give up hope. As a family we are truly grateful that Michael has been fortunate enough to be able to do his donor justice in making every breath count. Most of us are looking for inspiration in everyday life, we need look no further than Michael and people like him who have shown us what true inspiration is.

We always look forward to the annual ILFA ecumenical service and the mass organised by the Heart and Lung Transplant Association to remember all organ donors and their families. As a family we will continue to support ILFA in their fundraising activities.

**Fiona Kennedy
Fundraiser**

Cryobiopsy



Dr Michael Henry of Cork University Hospital explains the benefits of a novel diagnostic technique called transbronchial lung cryobiopsy.

Diagnosing Interstitial Lung Disease (ILD) is difficult. Once the presence of ILD is detected, the difficulty and skill lies in differentiating the many different subtypes, which may not have agreed diagnostic gold standards. The multidisciplinary team (MDT) is composed of the specialist ILD respiratory physician, nurse specialist, and a pathologist and radiologist with experience in ILD. The diagnostic tools available include the experienced physician's clinical history and examination, a panel of appropriate blood tests, CT scan of the chest, bronchoalveolar lavage and up to recently, the only available surgical approach was a VATS (Video-assisted thoracoscopic surgery) surgical lung biopsy. Only approximately 25% of patients at best, ever get the benefit of a surgical biopsy to confirm the diagnosis where there is doubt.

The exception may be Idiopathic Pulmonary Fibrosis (IPF), for which diagnostic guidance exists. Yet even this gold standard is flawed, recommending "careful exclusion of alternative aetiologies (causes)" without specific guidance on how to achieve this goal and relying heavily on interpretation of high-resolution CT scans (which has only fair agreement among radiologists) and surgical lung biopsies. More recently, a new biopsy technique called Transbronchial Lung Cryobiopsy has gained popularity in the MDT diagnosis in ILD and particularly IPF.

What is a transbronchial lung cryobiopsy?

Put simply, a cryoprobe is inserted into the lung using a bronchoscope cooled below freezing and then removed along with the lung tissue that has frozen onto it. This tissue is thawed in a saline solution and then processed routinely for histologic evaluation under a microscope. Cryoprobes have been used bronchoscopically for some years for the debulking of lung airway tumours. Because more tissue can be retrieved

than with the usual small bronchoscopic forceps biopsies, cryoprobe-retrieved specimens are larger and have also proven more effective than forceps biopsy specimens for retrieving sufficient tissue for histological diagnosis and allowing a more secure diagnosis. Although, they allow pattern recognition approaching that of a surgical lung biopsy in many cases, the diagnosis rate with cryobiopsies is slightly lower, in the neighbourhood of 80%, versus 90% for surgical lung biopsies

Cryobiopsy is proposed as an alternative to surgical lung biopsy and a technique that may appreciably decrease the number of patients who require surgical lung biopsy for diagnosis. This is important because the mortality from cryobiopsy is very small (0.1% to date) compared with surgical lung biopsy (1.7% for elective procedures). The risks associated with this procedure are bleeding during the procedure and pneumothorax or 'air leak' requiring the patient to remain in hospital for a day or more extra. Otherwise this can be done as a day case procedure under sedation.

At present, Cork University Hospital is the only centre in Ireland carrying out this procedure and to date we have carried out this procedure on 95 patients. The procedure allowed us to make a confident diagnosis in 73% of our patients and thus allowed us to choose the appropriate treatment. 17% of our patients had moderate bleeding or a pneumothorax but only 5 patients required an overnight stay after the procedure.

The diagnostic pathway involved in deciding which form of ILD a patient has, is often complex. Transbronchial Lung Cryobiopsy is a novel diagnostic technique which may allow us to make this diagnosis pathway more secure.

**Dr Michael Henry
Respiratory Consultant
Cork University Hospital**

ILFA in Europe



ILFA director and
EU-IPFF general secretary

Liam Galvin tells how international collaboration and advocacy helped to formulate the first patient-led blueprint for IPF care.

Over the last few years, ILFA has built on its work in Ireland for IPF patients by engaging and working with other patient groups and organisations in Europe and further afield.

Collaborative projects with international organisations like the European Lung Foundation and the European Respiratory Society enabled ILFA to forge links with other European patient advocacy groups, thanks to contributions from Claire Tunissen, Charles Lock and Nicola Cassidy. These interactions laid the groundwork for ILFA to become a founding member of the European IPF and Related Disorders Federation (EU-IPFF).

The EU-IPFF is a registered, non-profit federation that was formed in 2014 as a result of the collaboration of nine patient organisations, with the support of European healthcare professionals. The group jointly developed and launched the European IPF Patient Charter, the first patient-led blueprint of what IPF care should encompass.

Building on our lobbying and advocacy efforts in Ireland, ILFA has helped drive the EU-IPFF in its efforts to become a unified voice for European IPF Patients. ILFA recognised that such a union of IPF patient groups could raise global awareness of IPF and bring about real change to support patients, carers, and healthcare professionals working in the field. The EU-IPFF has grown from an initial informal collaboration between patient groups to becoming a legally established, united Federation of 16 patient organisations from 10 European countries. Last year, the EU-IPFF campaigned at the European Parliament and a Written Declaration on IPF was successfully passed by 388 Members of the European Parliament. The Written Declaration compels



the EU Commission and Council to increase European support to IPF patients. The EU-IPFF also supported and helped fund the establishment of the successful European Reference Network on Rare Respiratory Diseases which facilitates collaboration and sharing of data and research among 61 centres of excellence across Europe.

ILFA hopes that the EU-IPFF can further increase awareness of IPF and the challenges faced by the IPF community among the European policy makers. There is a momentum for change and we are optimistic for positive developments in health policy and IPF care within the EU and Ireland.

Working with the 15 European patient organisations of the EU-IPF Federation, international groups from the USA, Canada, Brazil, Australia, and Israel, and with potential new EU-IPFF members from Eastern Europe, ILFA will continue to share its advocacy experience from the last 15 years. In turn, we will learn from the experience and insights of the other patient advocacy groups.

We wholeheartedly support the EU-IPFF and the collaborative efforts to raise awareness of IPF, influence policy and achieve the implementation of the principles of the European IPF Patient Charter in Ireland and across Europe to further support patients, families and healthcare professionals.

Liam Galvin
General Secretary of the EU-IPFF
and ILFA Director

Enjoy Life!

Patient, advocate and fundraiser Pam Martin shares some tips on coping with an IPF diagnosis, staying positive and enjoying life to the max.

I would personally like to thank ILFA, for the work they do for patients and families who have been hit with a diagnosis of lung fibrosis. It's a blow when you have been given the news that you have a serious lung condition, but ILFA has been with me every step of the way with help, support, and a great support group that provides a wealth of information shared by patients and carers alike. So for this, I thank all those involved with this wonderful organisation.

I would like to share with you some information about myself as a patient living with Idiopathic Pulmonary Fibrosis (IPF). I was diagnosed in December 2009. I considered myself quite fit and was easily able to swim 100 lengths of a standard pool, in one hour. After, I changed gym to a 33 meter pool, I was swimming at least 50 lengths but within 3 months my breathing was not quite right. I also developed a cough and made the excuse that it was probably due to the new swimming pool and maybe the chlorine. When I went on holiday to the Canaries, I could not walk without stopping and coughing, and again I came up with another excuse to explain my symptoms.

I worked in a medical centre and the GP was concerned about me. After 3 lots of antibiotics, I was getting worse and the GP referred me to the Accident and Emergency Department. I was admitted to hospital for 7 weeks and a biopsy confirmed IPF. So within 3 months of being fit to being told that I may need a lung transplant at 51 years of age, having never smoked, was a hell of a shock to me, my family and friends. After a battle with getting the correct medication and pure determination on my part, I started feeling better. I joined a Pulmonary Rehabilitation class which I would recommend to all patients, I know it's hard and sometimes you can't breathe but please fight it as you will feel the benefit.

What I really need to get across is that it's not the end - you can still enjoy life, I still have



Pam Martin, Rafa Benitez, Eddie Cassidy and Stephen Cassidy.

my foreign holidays, I need oxygen on the plane but airlines are pretty good and take good care of you. I use my portable Inogen machine and there are other options available, so please ask your supplier - they will be happy to help you. Aer Lingus and Ryanair allow you to travel with oxygen equipment, just look up the special assistance departments when booking. Both airlines have a form that has to be signed by your GP - usually within two weeks of your travel date. Even cruise ships allow the equipment and your oxygen provider will supply you with a list of companies that will provide you with your specific needs. I cruised from Spain and the oxygen was in my cabin on arrival. You will need to state this when booking, but really it's quite easy so don't be afraid to ask.

Don't be embarrassed about using oxygen, and don't confine yourself to home - get out and enjoy life! Just give yourself that little push to get up and get out. Explain to people that you can't tolerate smoke or heavy perfumes (be honest!), or whatever it is that sets off your cough.

I would like send thanks to all the fundraisers who help ILFA with much needed funds to enable them continue the good work they do. To Irishkop and YNWA Irish Reds, and Rafa Benitez, for supporting me and ILFA through fundraising - a big "THANK YOU!"

Thank you to the ILFA committee and the people who attend the support group - we have had laughs and tears and you all hold a very special place in my heart!

Pam Martin
IPF patient, support group leader and fundraiser

ILFA 15

Start Here ...

2002

- ILFA was set up
- Brian O'Driscoll - Rugby International agreed to be ILFA's Patron
- The first fundraising event was a swim in Dublin on 26th December

2009

- ILFA made a submission to the Organ Donor Review advocating (1) the introduction of a soft opt out organ donation system and (2) the need for a National Transplant Authority to co-ordinate organ transplantation

2016

- A 'brainstorming session' held with 30 invited guests as part of ILFA's strategic review
- 'A Day in the Life' video featuring Dermot King and Finian McGrath, Minister of State for Disability is made to help ILFA raise awareness

- ILFA wins National Plain English Award for Best Patient Information Leaflet
- Nintedanib is licensed for prescribing in Ireland
- Interstitial Lung Disease Registry is set up

2017

- First ILFA Newsletter
- ILFA website launched - www.ilfa.ie
- 50 ladies took part in the Women's Mini-Marathon in Dublin

2003

2008

- The Directory of Services is officially launched

2010

- Inaugural Fergus Goodbody lecture in Mater Hospital with Professor Hal Collard from USA

2015

- The National Patient Charter for IPF developed by ILFA
- The ILFA Exercise DVD for Lung Fibrosis Patients is launched

- ILFA helps develop Patient Charter
- ILFA's 2000 S challenge wins for Best Patient of 2014

2004

- First ILFA information leaflet produced 'What is IPF?'



2005

- First Lung Transplant performed in Ireland



2007

- ILFA participated in 3 International Clinical Trials for IPF



2006

- First ILFA Patient Information Day 24th June in Dublin



2011

- Senator Fergal Quinn agreed to be ILFA patron
- ILFA Committee members met Minister for Health to discuss organ donation and the establishment of Organ Donation & Transplant Ireland

2012

- First ILFA Ecumenical Ceremony of Healing, Thanksgiving & Commemoration to celebrate ILFA's 10th Anniversary; over 300 guests



2013

- Pirfenidone licensed for prescribing in Ireland
- ILFA joins European Lung Foundation & European Respiratory Society Taskforce on IPF
- Michael Darragh Macauley becomes ILFA's Exercise Ambassador
- ILFA 2000 Steps a Day Challenge walking programme launched after a successful pilot study with patients



2014

EU IPF

Steps a Day exercise
Irish Healthcare Award
at Organisation Project



Annual ILFA Swim

Honora Ni Chriogain tells how a Christmas dip by friends and family of the late Fergus Goodbody has become a popular fundraising event for those brave enough to take the plunge!

On May 8th 2002, our lovely friend Fergus Goodbody died, far too young, of lung fibrosis. Shortly afterwards, his widow Nicky, set up a committee with a view to helping fund research being carried out in the area of lung fibrosis under the direction of Professor Jim Egan. These meetings evolved into the Irish Lung Fibrosis Association (ILFA). People were asked to suggest possible fund raising events. It was Nicky's niece, Tabby, who came up with the idea of a winter swim for charity. It was decided that either 26 December (St Stephen's Day) or 31 December (New Year's Eve) at noon, depending on tides, should be the day of the swim at Sandycove, beside the 40 Foot in Dublin.

The first swim took place on 26 December 2002 with Fergus overseeing the weather "from above", it turned out to be a beautiful, sunny, cold and calm day. Nicky's family, friends, colleagues and acquaintances turned up in great numbers. These enthusiastic people, young and old, plunged into the grey/green depths of the sea with much shouting, laughter and shivering. People who had never swum in the Irish Sea before undertook the

swim in memory of Fergus and for the good cause of collecting funds for ILFA. Afterwards most of the crowd adjourned to the Eagle House in Glasthule for soup, sandwiches and glüwein, all organised by Nicky. Sometimes the post-swim meeting alternates with Fitzgerald's Pub in Sandycove. That first swim in 2002 was a great boost to the ILFA funds.

'The 40 Foot Swim' is now an annual fundraising event for ILFA. Numbers may not be as high now as they were in the first few years, but the swim has continued without break right up to the swim of winter 2016. It all happens because of Nicky. She organises the event every year and even if some people don't relish the thought of that cold plunge into the Irish Sea, it is an occasion of fun, cheerfulness and catching up for those whom the swim brings together once a year.

Great credit is due to Nicky Goodbody who, with her enthusiasm and organisational skills, has made this annual event such an enjoyable and successful event for ILFA.

Honora Ni Chriogain
Fundraiser

Plain English is the Best Remedy

Claire O’Riordan of the National Adult Literacy Agency on the importance of ‘plain English’ in communications between health practitioners and patients/carers.

Many of us find health information difficult to understand and use. This is particularly true when we have to make decisions about treatment options for ourselves or for others. International research shows that people who are better informed about their health have more effective consultations with their health care provider. They are also more likely to comply with their medication and as a result have improved health outcomes.

Irish research shows that Irish people want healthcare professionals to use less medical jargon. Four out of 10 people (about 40%) called for doctors to use more understandable language and less medical jargon. Almost one in six (17%) people surveyed said they had taken the wrong amount of medication on at least one occasion. But the prognosis isn’t all bad. One step in the right direction is to use plain English.

Plain English is a style of presenting information that the intended reader can understand and act on after a single reading. Using plain English in medicine labels and leaflets, in consent forms and on signs and notices significantly reduces the risk of misunderstandings and distress. Larger print, pictures, shorter sentences and well-known signs and symbols can all contribute to clearer communication. Using everyday words to explain medical terms – for example, by writing ‘blood’ beside ‘haematology’ – can be particularly useful for all patients. As its focus is on everyday language, plain English helps to reduce the mystery and anxiety that surround certain health conditions. This naturally benefits all patients.

Congratulations to ILFA

People working in the healthcare sector play an important role to make sure that the information and services they provide is written in plain English. Many health organisations are now using



plain English writing and design techniques. The Irish Lung Fibrosis Association (ILFA) is one of these organisations. This year, the ILFA won a national Plain English Award for their **National Patient Charter**. The ILFA won this award for empowering patients to become partners in their healthcare by informing them – in plain English – about ILFA’s services and supports.

Other ways to improve health

Health practitioners: The importance of plain English in written information is just one solution. Although time constraints can prevent lengthy consultations, even a few minutes spent talking to patients (or their guardians) through health leaflets, consent forms for treatments and dosage instructions can make a significant difference. One mother who took part in NALA research described an ideal experience of a nurse showing her how to manage her child’s asthma condition. She was shown pictures of lungs to explain what happens during an asthma attack and was asked to breathe out and then try to speak so that she could experience the sensation of an attack.

Patients and carers: Sometimes when we are dealing with health services, it’s difficult to remember everything we wanted to know or ask our doctor or health care worker. One way to avoid sometimes unsatisfactory health consultations is to be prepared. Before a medical appointment, we can make a note of any questions or concerns so we don’t forget to ask important questions. Or, there are three simple questions we should ask our doctor, nurse or pharmacist during every visit. These questions are:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

For more information, see NALA’s plain English website www.simplyput.ie

Claire O’Riordan
National Adult Literacy Agency



My role in the organisation

Since getting involved with the organisation through a workshop last year, ILFA administrative assistant Gemma O'Dowd has enjoyed the many and varied interactions of her role.

Before I joined the Irish Lung Fibrosis Association (ILFA) in 2016, I had not heard of lung fibrosis or ILFA. My first engagement with the charity kicked off with a very interesting and novel 'brainstorming session' with a group of ILFA's stakeholders to get their views and opinions on what matters most to them. This interactive workshop gave me a broad sense of what the organisation was about. It was focused, straight in and getting on with the role of providing support to pulmonary fibrosis patients, their families, carers and healthcare professionals.

After taking up my position with ILFA, the learning curve was rapid but I enjoyed the challenge. The fast pace was evident from the beginning and it has not slowed down and will probably escalate. I enjoy the many and varied interactions I have with people in the course of my work for ILFA including patients, family members, fundraisers, healthcare staff, industry representatives, politicians, and representatives from other patient organisations. The work of the

ILFA committee, the lung fibrosis support groups, and the volunteers and fundraisers around the country is phenomenal. The generosity of these people in terms of their time, their talents, their passion and their commitment to ILFA is evident every day. Patients living with IPF whom I have met are amazing and very positive, and always willing to help others.

I enjoy my work very much and I am inspired by the patients and people associated with ILFA whom I have the privilege to know and work with. ILFA's progress and success appears to me to be due to the great support, commitment and passion of everyone involved.

Ways to contact ILFA:

Address: PO Box 10456, Blackrock, Co Dublin.

Tel: 086 871 5264

Website: www.ilfa.ie Email: info@ilfa.ie.

Facebook and Twitter: ILFAIreland

Gemma O'Dowd
Irish Lung Fibrosis Association

Milestone 200th Lung Transplant in Ireland

Advanced nurse practitioner Sara Winward charts the success to date of the National Heart and Lung Transplant Unit and looks forward to continuing its close relationship with ILFA.

For pulmonary fibrosis patients, lung transplantation is often the best choice for extending life and improving quality of life. Because IPF is a progressive disease with no current cure, the lungs eventually become too scarred to function. A lung transplant can give IPF patients a second chance.

The National Lung Transplant Programme, Mater Hospital, is pleased to have reached another milestone with the 200th lung transplant performed in June this year. A measure of the success of the transplant program is highlighted by our 5 year survival of over 75%, which supersedes many other centres internationally. The Mater Hospital Lung Transplant Programme is recognised as having particular expertise in transplantation for patients with IPF. The proportion of IPF patients receiving lung transplants has steadily increased and represents approximately 40% of all patients transplanted in Ireland. Contributing factors for positive long-term outcomes for IPF patients post transplant can be attributed to continued adherence with life-style changes. This includes taking all medications as prescribed, undertaking regular exercise, good nutrition and achieving and maintaining your recommended weight.

Regular follow-up in the transplant clinic and careful monitoring of self and active participation in your care will help you enjoy the benefits of a lung transplant. Finding and treating problems early, before they become more serious, is important



Members of the Mater Hospital's Lung Transplant Team and ILD Service Team at the Irish Healthcare Centre Awards 2017. The Lung Transplant Team won the Clinical Team of the Year Award.

for your long-term health. Continuing with these good habits will help to improve your quality of life. We are here to help you and to provide support throughout your transplant journey.

Of course, none of this success would be possible without your hard work. We acknowledge the invaluable care and support from your family and caregivers. Social support is recognised as being essential for post-operative follow-up care.

Transplantation is made possible only through the generosity of organ donors and their families. Each year many patients are given a second chance at life through the generosity of organ donors and their families, who are asked to think of others during a time of profound grief for themselves. The entire transplant team offer our heartfelt thanks to the organ donors and their families.

The National Heart and Lung Transplant Unit at the Mater Hospital would like to thank ILFA for all their support over the years and we look forward to continuing to work with you in the future.

Sara Winward, Registered Advanced Nurse Practitioner, Post Lung Transplantation, National Lung Transplant Centre. Mater Misericordiae University Hospital

The Irish Thoracic Society - Developments in IPF



Irish Thoracic Society CEO Suzanne McCormack and Professor Anthony O'Regan detail the work the ITS does in the research, education, advocacy and public health awareness arenas.

The Irish Thoracic Society (ITS) is a national organisation that represents the broad respiratory community in Ireland through its membership which includes physicians, trainee doctors, nurses, physiotherapists, and respiratory physiologists. This means the ITS is centrally placed to shape and promote the highest standards of care for patients with respiratory disease in Ireland through its work in research, education, advocacy and public health awareness.

Through its special interest sub-groups, the ITS can influence and respond to national respiratory issues relating to all major respiratory diseases as well as developing close interactions with chronic disease programmes in the Health Service Executive (HSE). Over the last decade the ITS Interstitial Lung Disease Sub-group has taken a lead on progressing issues relating to Idiopathic Pulmonary Fibrosis (IPF) including the issuing of a position statement on IPF and the development of centres of excellence to allow optimisation of diagnosis and disease management. The increased interest in IPF has also been reflected in topics presented at the ITS Annual Scientific Meeting in terms of invited lectures and original research presented in oral and poster form. In recent years leading international experts such as Prof David Schwartz, Prof Athol Wells and Prof Jim Egan have delivered keynote lectures at the meeting.

There have been significant new developments relating to IPF since the publication of the Interstitial Lung Disease Guideline from the British Thoracic Society in collaboration with the Thoracic

Society of Australia and New Zealand and the Irish Thoracic Society in 2008. These include improved understanding of the nature of the disease and the development of new therapeutic options.

There is also evidence that the genetic risk for IPF is carried at a higher frequency in persons of British and Irish ancestry. Based on these developments, the ITS ILD subgroup recognised an urgent need to develop systems to better understand the prevalence, distribution, and medium to long-term follow up of patients with IPF and other ILD in Ireland in the form of a patient registry.

The Irish Thoracic Society Interstitial Lung Disease Registry is designed to provide a record of ILD in Ireland, at a national level, but also to allow doctors to use the information to support and monitor the care of their patients. The objectives of the registry are to:

- ▶ identify, record, analyse, and store information relating to the prevalence, incidence, and treatment of ILD in the Republic of Ireland. This will allow the ITS to provide data on the long-term prognosis of ILD in the Republic of Ireland, and to compare this information with international data.
- ▶ provide a framework on which to develop strategies in the evaluation of novel treatments in ILD and facilitate treatment of these patients in a fair and appropriate manner.
- ▶ promote and facilitate the use of clinical data

in approved research projects, relating to the causes, distribution, treatment, and outcome of ILD in the Republic of Ireland.

- enhance and develop important dialogue and information streams to the HSE in Ireland that will assist in the planning and management of health services and essential resources for ILD in Ireland.

The web based registry has been developed and piloted in conjunction with specialist IT providers Openapp, and with thanks to support from Boehringer Ingelheim through an unrestricted grant. It is now enrolling patient data from centres in Cork, Galway, Limerick, Tallaght and St Vincent's University Hospital with the Mater Misericordiae University Hospital expected to join shortly. Over 100 patients are currently on this registry and this number is expected to double by November when initial data will be presented at the ITS Annual Scientific Meeting in Limerick.

This model is identical to that used and approved in many hospitals in Ireland for cystic fibrosis. Patients give written informed consent at the hospital site and the consent record is kept at that site. After informed consent, patient data relating to IPF is recorded in the registry. At

each hospital site, the site principal investigator is able to view information for each patient under their care. The data can then be collected and analysed centrally by the Irish Thoracic Society in an anonymised form which means it will contain no identifiers relating to individual patients. The ITS ILD Registry Steering Group oversees the governance of the registry and the Irish Lung Fibrosis Association is represented on the Steering Group by ILFA Director Nicola Cassidy.

The ITS ILD Registry represents an exciting development in the care of patients with IPF. As well as supporting and monitoring the care of individual patients, it will enable a better understanding of the scale of the disease in Ireland and of the standards of diagnosis and care that patients are receiving including the use of new medicines and lung transplantation. In turn, any gaps identified will be brought to the attention of the HSE with the purpose of driving quality improvement.

Suzanne McCormack
CEO of the Irish Thoracic Society

Professor Anthony O'Regan
Galway University Hospital

Three Lakes Partners: Investing in Research and Advocacy

Three Lakes Partners is a US based, venture philanthropy organisation created by a family who lost their matriarch to IPF in July of 2015. Their mission is to accelerate progress in IPF research and advocacy through targeted investments and gifts. Their success will be judged not on financial return, but by improving patient and caregiver quality of life, driving early diagnostic advances and helping to enable meaningful therapeutic discoveries.

"Over the past year, we have traveled all over the world to find the best and brightest scientists, advocates, educators and passionate change agents battling IPF.

After visiting with the ILFA on a trip to Dublin, we were amazed and enthused by the grass roots efforts they've put forward thus far. ILFA's dedication to patients and families through the

'2,000 Steps Campaign' and other educational pieces, is a perfect example

of advocacy at its best. Like many, we are humbled by their output and the progress they've made over the past 15 years. It is our sincere wish, and I know theirs, that 15 more years of advocacy WON'T be needed for IPF, and that a cure is found to stop the suffering of this disease" - Ken Bahk, Managing Director.

Three Lakes Partners is proud to support the ILFA and their mission of educating and advocating for patients and families battling IPF.



National Awards



for ILFA

2014 - ILFA 2000 Steps a Day Exercise Challenge for Lung Fibrosis Patients

ILFA won the 2014 Irish Healthcare Award for the Best Patient Organisation Project of the Year.

Pictured are Pat Campion of sponsors Lundbeck presenting the award for Patient Organisation Project of the Year to Nicola Cassidy and Irene Byrne.



2016 - Love Your Lungs

Roche Products Ireland in partnership with ILFA, COPD Support Ireland, the Asthma Society and Edelman won the 2016 Irish Healthcare Award for the Best Pharmaceutical Education Project.

Pictured are Erica White (representing COPD Support Ireland) with Dolores Williams and Nicola Cassidy from ILFA.



2016 - The National Patient Charter for Idiopathic Pulmonary Fibrosis

ILFA won the 2016 Plain English Award for Best Patient Information Leaflet.

Pictured are Anne Casey, Matt Cullen and Nicola Cassidy receiving the award from Declan Black, Mason Hayes & Curran, who sponsored the National Adult Literacy Agency's Plain English awards.



Novel Technology Increasing Lung Transplantation at the Mater Hospital

The National Lung Transplant team explain the novel EVLP technique that helps them look after more patients and give thanks to organ donors and their families.

Advanced surgical and donor preservation techniques at the Mater Hospital are helping to increase the number of lung transplants being performed each year. A novel technique called Ex-Vivo Lung Perfusion (EVLP), which is similar in concept to renal (kidney) dialysis, allows for prolonged assessment of donated lungs outside of the body prior to transplant. This support platform has provided the team with an additional resource in their aim to increase the conversion of potential lung donors to actual lung transplants.

Frequently, potential donor lungs are not utilised for transplantation as they fall outside specific suitability criteria. However, EVLP provides an opportunity to evaluate and recondition donated lungs. In certain cases, lungs that would otherwise not be used for transplant improve to a point where they meet acceptable lung transplant criteria. This improvement may occur due to several factors, for example reduction in pulmonary oedema (airway fluid) or improved ventilation of collapsed airways.

In the past 12 months, three IPF patients have successfully undergone lung transplant following EVLP assessment of donated lungs. These operations would not have occurred without the benefit of EVLP. This is the first time that EVLP reconditioned lungs have been utilised for IPF patients in Ireland. It is a significant milestone. Our initial experience with EVLP transplantation for IPF patients has been positive. All patients are at home and well. One of these patients described EVLP as “a machine that washed the lungs” ... “giving me a new chance at life”.



**Professor Karen Redmond,
Consultant Thoracic & Lung Transplant Surgeon**

As with any advancement in transplant medicine, it is vital that we express our thanks to both the organ donors and their families, without whom transplantation would not be possible.

**Peter Riddell, Jim Egan, Iain Lawrie,
Lars Nolke and Karen Redmond.
National Lung Transplant Programme
Mater Misericordiae University Hospital**



John and his grand-daughters out on a walk.

Circle of Friends

A year on from her dad's successful lung transplant, Sharon Ní Shuilleabháin explains how friendships from the support group in Kerry helped her family through tough times.

If you or a person you love are unfortunate enough to be diagnosed with a chronic, progressive terminal illness, it is not advisable to use the services of 'Doctor Google' to help answer the 5 million questions you will only think of once you leave the consultant's office. Naturally, though, this is exactly what we did as a family when Dad was diagnosed with IPF.

Fortunately for us and all Irish IPF sufferers, 'Doctor Google' suggests the ILFA website and Facebook page at the top of its search suggestions. The information and advice on this website is extensive, extremely informative and up to date in all its research, links etc. In the early days after his diagnosis, it provided Dad, and us as a family, with a good idea of what to expect in the least alarming way possible considering the nature of this condition. While there are so many wonderful healthcare workers, consultants and nurses that deserve our

heartfelt thanks and praise for their help and advice, ILFA was an invaluable reference guide for all the treatments and services we needed to engage with as his condition progressed. The website, newsletter and Facebook page are a credit to the amazing dedication of the volunteers who update, manage and publish them.

The true value of ILFA, in our experience, is the support groups which are attended by IPF patients and their families. The Kerry Support Group meet in the Rose Hotel in Tralee, at 3 o'clock on the last Saturday of every month.

After attending his first meeting over three years ago, Dad spoke of a relief and about how good it felt to be able to speak with people who knew exactly what it felt like to live with IPF and its symptoms, for the first time ever. They 'understood' and sympathised in a way that we as his family or his healthcare team, never could.

The support of this group came into its own when he became very ill and a lung transplant became the only remaining treatment option. By this stage, Dad no longer considered the support group to be made up of acquaintances with the same condition as himself but rather a group of very good friends whose openness, insight, motivation, positivity and advice navigated him and us through the whole process, and who continue to provide support and friendship now.

We are so unbelievably fortunate that Dad is now almost a year post-transplant and is going from strength to strength. We will forever be indebted to the donor and their selfless family, to the talented and empathetic doctors, nurses and lung transplant team we have met along the way but also to the volunteers, supporters and friends in ILFA.

Breithlá sona ILFA, go mairfidh sibh an céad!

Sharon Ní Shuilleabháin
Family member

The Pat Casey Memorial Cycle Honours ILFA

The Pat Casey Memorial Cycle team explain why they got on their bikes to back ILFA, and remember a very special husband, father and friend.



Eddie Cassidy (ILFA Treasurer) with Anne and Pat Casey, and Brian Aherne.

To those of you who don't know us, we are the organisers of the annual Pat Casey Memorial Cycle. In the beginning there were three of us; Brian Aherne, myself and my remarkable husband Pat.

When writing about the Pat Casey Memorial Cycle and our fundraising for ILFA we first need to tell you about Pat. Pat was a husband and a father who loved his family. A man of many talents; a stone mason by trade, he loved music and gardening, and was one of the most hilarious people you could ever meet. He was fearless and inspiring to those around him. He faced IPF with courage, and even in his lowest moments he would find a way to use it for creating positivity around him.

Our first encounter with ILFA was at a patient information day at Cork University Hospital (CUH) in 2009. Dr. Michael Henry had informed Pat and I about the event, which he felt would be beneficial. Excited but not knowing what to expect we were amazed by this group of volunteers whose lives

had been touched by pulmonary fibrosis, who were there representing ILFA. Their enthusiasm and dedication was infectious and spurred us on in the idea of doing something to help raise awareness and funding for pulmonary fibrosis and ILFA.

Pat had a larger than life personality, which was very helpful when fundraising or raising awareness of IPF, doing interviews for TV3 News, Life FM and Newstalk regarding ILFA's National Campaign for the licensing of Pirfenidone for IPF patients in Ireland, day to day with the Cork IPF support group members, and friends and family.

In 2012 on the 4th of April, the first fundraising cycle was held. With a massive support crew and many volunteer cyclists, we set out from Cork City, stopping overnight in Limerick and finishing the event in Galway. We considered the event a roaring success and we haven't stopped since. In 2014 the cycle was renamed the Pat Casey Memorial Cycle and with 2017 being the 6th cycle, we are once again honoured and delighted to be supporting ILFA and the cause.

When asked why do we fundraise, my mind came up with one answer - ILFA campaigns and fights for patients and their families, they have accomplished so much in the last 15 years and have changed the lives of all the people they come in contact with. Be it the National Patient Charter, the 2000 Steps a Day Program, their tireless efforts in raising awareness of the illness, and all the other work that goes on behind the scenes. With effort like that, how could we not want to join this worthy cause?

With that, we want to congratulate ILFA on 15 years of hard work and accomplishments. We are proud to be associated with you and thank you for all your support and friendship throughout the years. We look forward to many more years working with you all.

Anne Casey, Brian Aherne and Daniel Casey

The National Lung Transplant Programme at the Mater Misericordiae University Hospital

Mater Hospital transplant co-ordinators Zita Lawler and Vivienne Vize detail their work in liaising with patients/carers throughout the process and also donor families.

The word “transplant” can be a daunting one to hear and we hope as a team that we can provide support and information to help each person and their family facing a potential lung transplant.

Anyone referred for transplant assessment needs numerous tests done and also requires review by multiple members of the transplant team. Following these tests, each case is discussed at a Transplant Meeting with all the team present to determine if a lung transplant operation is the best treatment option for this particular person.

The ongoing development of medications for many lung conditions has meant that some people can be treated using medication to improve their symptoms and this is an area which is continuously evolving.

Each person and their family will have different questions and needs during their time being assessed and we endeavour to support them



Mater Hospital Transplant Co-ordinators; Alexia Tierney, Zita Lawler and Vivienne Vize. Elaine Burke is missing from the photo.

from the time they are referred for assessment to when they are placed on an active list and whilst they await a call for a potential transplant. Everyone who is on the active lung transplant list is telephoned each week to see how they are.

For those who are on the active transplant list, we advise not using social media if they receive a transplant, as we attempt to protect the confidentiality of the donor family. There is a need for good social support for people going on a transplant list as they will need care and assistance during their recovery. As part of the assessment each person along with their family meets the Medical Social Worker to discuss and identify the persons who can provide this support.

It is not always possible to be admitted to the Mater Hospital for assessment, therefore many referring consultants will arrange for this assessment to be carried out at a person's local hospital. A system that allows us to view x-rays or scans from most other hospitals around Ireland has helped us to speed up this process. We hope that a similar system for blood tests will be available to further enhance the sharing of results between hospitals.

Finally we acknowledge and appreciate the selfless generosity of each donor family as they consider others at a time of great loss, as “Without the organ donor, there is no story, no hope, no transplant..”(UNOS).

**Zita Lawler and Vivienne Vize
Transplant Co-ordinators
Mater Misericordiae University Hospital**



Irene Byrne, Michael Darragh Macauley and Feargal Quinn at the launch of the 2000 Steps a Day Challenge in 2013.

2000 Steps: The story so far

Physiotherapist Irene Byrne and ILFA committee member Nicola Cassidy explain how the 2000 Steps A Day programme has marched from strength to strength since its inception in 2013.

Croagh Patrick, the Giant's causeway, Mount Kilimanjaro ... all can be conquered if you start with a single step and build from there.

Exercise is essential for lung fibrosis patients and walking is the ideal exercise. The Irish Lung Fibrosis Association has always encouraged patients to exercise and have taken every opportunity to promote exercise as a valuable and important treatment to patients and healthcare professionals. But we needed to provide patients with something to get them started and moving ...

The 2000 Steps Challenge for lung fibrosis patients was based on an original idea from Irene Byrne (Senior Physiotherapist at the Mater Misericordiae University Hospital). Over a cup of tea, after a patient information day in Dublin in October 2012, Irene and Nicola Cassidy (ILFA) came up with an ambitious plan - to build a novel, simple and practical exercise programme specifically for lung fibrosis patients taking their health challenges into consideration. Why 2,000 steps? ... well, the average person takes

approximately 2,000 steps to walk one mile.

Over the next few months, the two ladies discussed, planned, researched and developed the exercise resource. The aim was to deliver a programme that motivated lung fibrosis patients to set attainable goals by supporting them with the basic equipment to get started.

We decided to use tools including a pedometer (step counter), instructions on how to exercise safely and manage set-backs, an exercise diary etc.

The 2000 Steps a Day Challenge is a simple concept suited to patients of all exercise levels because an individual's exercise goal is determined by their baseline step count. This ensures that the exercise programme can be used by those with mild or limited disease who are active and able to engage in exercise, and those with more advanced disease who may be struggling with reduced physical ability.

Patients begin the programme by recording their step count for few days using their pedometer and then aim to add an extra 2000 steps a day to reach a new baseline over the following days or weeks depending on their ability.



Terence Moran, Eileen O'Sullivan, Matt Cullen and Joan Doyle.

The great thing about the 2000 steps challenge is that exercise is recorded over the course of the day and can be carried out indoors or outdoors.

The original prototype was tested in January 2012 by a group of very eager and obliging patients from across Ireland. The January weather was not kind but our willing volunteers took their job seriously and some even did their extra steps in an indoor shopping centre. We checked in with the patients to follow their

progress and they completed an evaluation questionnaire to tell us what they thought of the programme.

The pilot study showed that;

- ▶ 90% of patients said the written materials were clear and understandable
- ▶ 70% said the programme was easy to incorporate into their daily lives
- ▶ 80% were motivated to exercise every day
- ▶ 90% considered the pedometer a good motivational tool
- ▶ 100% felt a sense of achievement after reaching their target
- ▶ 100% would recommend the programme to another patient

IPF patients said the programme was practical and motivational, and helped promote a positive attitude to exercise and increase physical activity despite breathing limitations and oxygen requirements. Here's what some patients said;

- ▶ "Felt very good after walk. The further I can walk, the better I feel."
- ▶ "I felt the programme was overall excellent. The pedometer proved to be a great incentive. Not alone did the programme help physical and mental health but it helped me become more focussed on maintaining a healthy weight."

Following input and feedback from 10 patients who completed the 4-week trial period, the 2000 Steps literature was revised and finalised. We were thrilled with the end result and optimistic that the exercise programme would be embraced by patients and healthcare professionals alike.

The ILFA 2000 Steps a Day walking pack includes;

- ▶ The 2000 Steps a Day leaflet that explains the benefits of walking for lung fibrosis patients and gives advice and tips on how to get started and managing breathlessness.
- ▶ An inspirational poem called "Promises to Yourself" and a Contract for Success for you to sign and commit to the 2000 Steps a Day Challenge.
- ▶ A pedometer and exercise diary to record progress.

The ILFA 2000 steps a Day Challenge was officially launched in June 2013 with a photo



Back row: Fergal Quinn, Paddy O'Mahony, Terence Moran, Michael Darragh Macauley.

Front row: Eileen O'Sullivan, Frank Tierney, Irene Byrne, Eddie Cassidy, Nicola Cassidy.

shoot at Fitzwilliam Square in Dublin with Senator Feargal Quinn (ILFA patron), Dublin GAA star Michael Darragh MacAuley (ILFA exercise ambassador), IPF patients; Eileen O'Sullivan, Frank Tierney and Paddy O'Mahony, Irene Byrne, Nicola Cassidy, Terence Moran (ILFA Chairman) and Eddie Cassidy. Everyone was in great form as we smiled for the camera and had fun with various poses and props as you can see in the photos.

In 2014, ILFA was selected to present the '2000 Steps a Day Exercise Challenge for Lung Fibrosis Patients' at the European Respiratory Society Congress in Munich. The work was presented at an educational session called 'Latest insights in physical activity, exercise testing and muscles' and was a great opportunity for ILFA to showcase our work to an international audience of healthcare professionals working in respiratory medicine. There was great interest from doctors, nurses, physiotherapists, and researchers alike about the 2000 Steps exercise programme.

In November 2014 we were delighted when the 2000 Steps a Day Exercise Challenge was shortlisted for the Irish Healthcare Award for the Best Patient Organisation Project of the Year. Irene and Nicola got dressed up in their best fancy dresses and went to the ball at the Shelbourne Hotel in Dublin. Our category was the penultimate award of the evening and when they called out "And the winner is the Irish Lung Fibrosis Association" ... we couldn't believe it ...

we won!!! We hugged each other with excitement and disbelief, and somehow managed to make our way to the stage to collect our trophy. What an amazing result and a very special honour for ILFA!

This award is wonderful recognition for our hard work and the contribution of the 10 patients who helped with the 2000 Steps a Day pilot study. We dedicated the award to the memory of Pat Casey, Charles Lock, John Glackin, Denis Donaghy, Vincent Foley and Frank Tierney, who were instrumental in the development of the ILFA project and always enthusiastic and supportive.

Since its launch in 2013 the 2000 Steps Programme has gone from strength to strength. Additional practical resources have been added to the pack including the STALL breathing technique card (2014), the ILFA Exercise DVD (2015) and the hand-held fan (2016). The programme is being used by lung fibrosis patients and healthcare professionals all over Ireland and packs are being sent out every week.

We are very proud of the 2000 Steps a Day programme and delighted to know that it is helping lung fibrosis patients to exercise well and safely.

Remember ... "The journey of a thousand miles begins with one step" - Lao Tzu

Irene Byrne and Nicola Cassidy



Irene and Nicola at the ERS Congress - while nobody was looking!!!

Our Centre in CUH, the Services and Staff

Specialist nurse Bernadette Bowen explains the interstitial lung disease treatment and services available for IPF patients at Cork University Hospital.



Dr Michael Henry and Bernadette Bowen from Cork University Hospital.

Having Idiopathic Pulmonary Fibrosis (IPF) makes it harder to breathe and one can become tired easily. It can be harder to do things because of increasing breathlessness. It is important to confirm a diagnosis of IPF as early as possible so treatment can be started straight away. This can help limit the progression of the fibrosis.

In our specialist centre at Cork University Hospital, we have a specialised Interstitial Lung Disease Respiratory Consultant and a specialised multi-disciplinary team to diagnose people with IPF as early as possible.

We have specialised clinics for people with IPF, twice monthly with the Respiratory Consultant, Respiratory Registrar, Respiratory IPF Nurse Specialist and Respiratory Physiotherapist.

At these clinics, patients are given education and information on their disease. They are commenced or continue on their specialised therapies and are given time to raise questions,

and express any fears or worries they might have in relation to their disease.

Patients who may be appropriate candidates for a lung transplant are referred to the National Lung Transplant Unit at the Mater Misericordiae University Hospital. We do full lung transplant work up and assessment at the time of referral.

Many patients are referred to our pulmonary rehabilitation programme to encourage patients to stay as active as possible.

We also refer patients whose disease has progressed significantly for palliative care, support and treatment. The respiratory IPF Nurse Specialist gives all patients her mobile contact number in case they need any help or support with their tablets and/ or disease management.

Bernadette Bowen
Respiratory Clinical Nurse Specialist
Cork University Hospital

Respiratory Integrated Care

Specialist nurse Patricia Davis outlines the aims of the HSE's innovative Respiratory Integrated Care service, launched last year.

The HSE's Respiratory Integrated Care (RIC) service is a new initiative that employs specialist respiratory nurses and physiotherapists in Primary Care, whilst maintaining strong links with Secondary Care. The service aims to improve the diagnosis and management of COPD and asthma patients in the primary care setting by providing spirometry and a programme of care to improve health outcomes and reduce service demand.

As this was an innovative service for respiratory medicine, preparation and planning for it took some time and involved many stakeholders including the National Clinical Programmes, HSE Primary Care and Health and Well-being Divisions, Nursing and Midwifery Planning, clinicians and relevant members of community and hospital Management Teams. The first staff member commenced their role in April 2016.

To date, nine physiotherapists and nine Clinical Nurse Specialists have taken up posts with three nursing posts currently being advertised. The RIC service is now in seven Community Health Organisation (CHO) areas and is linked with 15 acute hospitals. It is hoped that in the coming years the service will be expanded to all CHO areas.

The initial target patient group for the RIC service is patients with or suspected of having COPD or Asthma. As people with IPF often present with cough and/or breathlessness, it is anticipated that RIC staff may assist General Practitioners (GPs) in the earlier identification of IPF. Assessment carried out under RIC involves spirometry, history taking, auscultation and examination, oxygen saturation check and on occasion when indicated, chest x-rays. These

assessments have the potential to facilitate earlier identification of people at risk of IPF. Staff will also provide patients in at risk occupations with harm reduction education, with a strong emphasis on smoking cessation. Specialist Respiratory Nursing and Physiotherapy staff from RIC will be running these clinics in GP practices and Primary Care Centres in the community.

It is hoped that having Specialist Respiratory Physiotherapy staff as part of RIC will increase access to Pulmonary Rehabilitation. According to the COPD National Clinical Programmes Model of Care on Pulmonary Rehabilitation (2010), high levels of scientific evidence have demonstrated improved exercise capacity and health related quality of life and decreased breathlessness, fatigue and health care utilisation following pulmonary rehabilitation. Exercise is a key component of reducing breathlessness and staying well with IPF. These programmes will be facilitated in more community areas where space is available.

One of the key challenges to implementing integrated care services is developing the communication links between primary and secondary care. We are hoping to trial new technologies and to assist the HSE in improving this pathway. The potential and benefits for this service are immense and I hope that in time our numbers will grow and we will be able to offer more and more services for patients in the community.

Patricia Davis, Respiratory Clinical Nurse Specialist, Integrated Care Community Healthcare Organisation (CHO), area 6 Dublin South/Wicklow

No Frontiers

Alexandre Sayve and his family found ILFA's website helpful when his late dad, Pierre, was battling IPF in Lyon, France. Now he runs marathons to raise funds for the organisation.

My first ever attempt to run a marathon was in 2012 when I signed up to take part in the Dublin City Marathon and fundraise for ILFA. I wanted to celebrate the memory of my father, Pierre Sayve, who had pulmonary fibrosis and passed away in November 2007 just before his 52nd birthday. On marathon day, I was lucky enough to be supported by all my friends and family and managed to complete it! Since then I have returned to Dublin to run two more marathons on behalf of ILFA.

When my dad was diagnosed with Pulmonary Fibrosis in 2006, ILFA was the only source of support and advice available. My father was living in France and was treated in Lyon. After his diagnosis, my family consulted the ILFA website for information on pulmonary fibrosis and patient testimonies on how to continue living and managing life with the illness. The work that ILFA does really has no boundaries and no frontiers - it carries a simple and strong message and it does this better than anywhere else in the world!

If it was not for ILFA's work and the support they provide, I would probably never have dreamed or ever considered running marathons! ILFA inspired me to achieve what I considered impossible and allowed me to celebrate the way of life of my dad.

I have been lucky enough to live seven amazing years of my life in Ireland. A part of my heart belongs there, and ILFA is part of my family there. Each challenge that I now think of, wherever I go around the world, is on behalf of ILFA.

I wish ILFA a wonderful 15th year anniversary and many more years of wonderful work for



Alexandre Sayve and his sister Soraya.



patients in Ireland, Europe and all around the world. I will continue to think of many more races to run and challenge to overcome so that I can continue supporting and contributing to your amazing work.

With all my love,

Alexandre Sayve
Fundraiser

The A to Z of IPF

Almost two years on from his mother Edna's successful lung transplant, Ken Powell takes us through the A to Z of the process from an IPF patient family member's perspective ...

A for ADAPTING. Being diagnosed with a respiratory condition will require lifestyle changes, while a modified living environment can help too. Steps and staircases gradually became Mum's enemy, so she was lucky to already have access to her home via a lift. ILFA's Directory Of Services has useful advice on grants for those who need to get work done.

B for BREATHING. None of us give this much thought, it's fair to say, until we're struggling to do it. Mum learnt some useful tips at a pulmonary rehab class in Dublin City University run by former Dublin Gaelic football ace, Noel McCaffrey. Look out for similar opportunities around the country.

C for CLINICS. Personally, I can only vouch for the Mater Hospital service, but I can certainly attest that the after-care there is phenomenally thorough. Initially, Mum was attending once a week following her transplant, but this has been gradually decreased to once every couple of months.

D for DONORS. While drugs, nutrition and keeping active can help to slow down the ravages of lung disease, there's no true long-term hope without these selfless heroes who pass on the gift of life to others as they depart their own.

E for EXERCISE. Ever since Mum's initial diagnosis, exercise was always emphasised to us by the healthcare professionals. Even still, we were amazed how quickly they put their own advice into practice -- I think they had Mum out of her ICU bed taking a few tentative steps within 48 hours of her lung transplant. And she has scarcely looked back since!

F for FAMILY & FRIENDS. We're lucky to have a great support network of pals who, along with extended family members, helped us through all stages of Mum's illness.

G for GROUP support. Mum attended many of the monthly gatherings of the Dublin Support

Group at the Carmelite Community Centre on Dublin's Whitefriar Street, where she picked up nuggets of information and tips that proved very useful.

H for HOPE. We have found the annual ecumenical prayer service organised by ILFA to be particularly uplifting over the years. Special mention to the harpist's sweet music!

I for ILFA. Congratulations and thank you to all concerned for the information, education, love and support that has flowed out of the organisation in its first 15 years. And continued best wishes for the next 15 and beyond.

J for JIM. My mum has been looked after so incredibly well under Mater Hospital respiratory consultant Professor Jim Egan, who's also a co-founder and director of ILFA. Forever grateful!

K for KNOWLEDGE. An IPF diagnosis is so scary initially. Some people will have already heard of 'fibrosis' but 'idiopathic' and 'pulmonary' will have been new to most. As we learn more about it via the professionals and from meeting other patients and caregivers, it becomes less intimidating.

L for LUCK. My late Uncle Michael had Lung Fibrosis and was called in three times as a lung transplant hopeful, but was never lucky enough to receive a matching organ. Like myself, Michael loved a flutter on the horses and the GAA. I sometimes wonder did he use up all his good fortune on them!

M for MATER Hospital. Truly a world leader in the area of managing lung disease. Its lung transplant numbers compare favourably with any medical facilities globally and my family can vouch for the quality of the treatment.

N for NURSES. Couldn't speak highly enough of this body of wonderful people. For the care given to my late Uncle Michael as he too battled IPF, and that received by Mum before, during and after her transplant, thanks to every one of you.

O for OPT-OUT system. It was very encouraging to hear Health Minister Simon Harris recently reaffirm his determination to transform Ireland's organ donation programme. The sooner the better, I say!

P for POSITIVITY. I can truly say Mum's attitude has been inspirational throughout her illness. Support is a two-way street and her mental strength helped all those around her to give her the back-up she needed to keep her show on the road during the hardest days.

Q for QUALITY of Life. Mum's was definitely getting harder as IPF took hold. She was using an oxygen machine for some months before her transplant, but with a little planning -- and the aforementioned positivity -- she could still do almost everything she wanted to.

R for REHAB. ... and also pre-hab! Mum quickly clocked up a Tour de France stage or two on her exercise bike after discharge from hospital. Within a few weeks, she was fully back in circulation and she can now be found marching the piers of Dun Laoghaire most mornings.

S for SUPPORT. I'm beginning to sound like a broken record here, but I really have been so impressed with all the back-up services available via the Mater Hospital -- not just the doctors and nurses but also the dietary advice, physios, medical social workers etc. Nobody is on their own!

T for TRANSPLANT. Unfortunately this is the only successful cure for bringing patients back towards full quality of life. It's a tough process to go through but having emerged on the other side, it's truly amazing what it can achieve. We feel exceptionally fortunate and Mum's definitely making the most of her second chance.

U for 'USEFUL LINKS'. I won't lie, I had to go to the ILFA website to find something for 'U'! Log on to http://www.ilfa.ie/useful_links.asp for a dossier of medical sites, Government bodies, other associations and general information.

V for VIDEOS. Among the helpful footage you'll find on YouTube are 'Nutritional Information for Pulmonary Fibrosis Patients' and the 'ILFA Exercise Video', while there are also clips explaining IPF and other lung conditions in simple terms.

W for WEIGHT management and healthy eating. Mum's lucky in that she has always loved walking and had a nicely varied diet, so when the



Edna and Ken Powell at the 2016 Women's Mini-Marathon.

doctors advised her to lose a few pounds at certain points, it was relatively painless.

X for X-RAY. I struggled on this letter too but I know Mum definitely had her fair share of these over the years. Along with the dreaded bronchoscopies, I think the chest X-rays and scans helped the medics to monitor her lung degeneration initially, then more recently and happily, her progress.

Y for YOGA, recently introduced to the activities mix at the Dublin IPF patient support group by ILFA Exercise Ambassador Michael Darragh Macauley.

Z for ZITA. Transplant co-ordinator Zita Lawler guided us through Mum's transplant over the weekend that changed our lives. Her communication was clear and considered at all times, it really helped so much. And special mention to her colleague Alexia Tierney (which, thankfully, takes us back to 'A'!) for the help and support she too offered us over the years.

Ken Powell
Family member

The Importance of Human Kindness

ILFA committee member Marie McGowan tells how she and her sister Collette have enjoyed volunteering to remember their mother Kathleen and to help others.



2017 will mark 9 years since our mum and immediate family first heard the term 'lung fibrosis'. Our Mum, Kathleen, was diagnosed with lung fibrosis at the end of 2008. Mum visited the Mater Hospital under the care of Professor Jim Egan and also received physiotherapy locally in Co Leitrim.

This was a condition our family had no knowledge of and a few years after Mum's diagnosis we became aware of the Irish Lung Fibrosis Association. We then understood the support and information available to patients and family members.

The condition is so specific that at times we felt that it was difficult to discuss with family and friends. Less than 3 years after Mum was diagnosed, she passed away at the end of March 2011. It was a shock that Mum passed away so soon.

My sister Collette was very determined that there was a need to raise awareness of ILFA and raise funds to support the charity. The closing date for the Women's Mini-Marathon was the end of

April 2011. Collette encouraged family and close friends to join us on the day. A group of 20 entered the mini marathon and by the end of the summer €4,000 was raised.

Over the years my sister and I have volunteered with ILFA in various ways. Now more than ever we understand the importance and value of patient information days and the need to look for ways to improve the lives of lung fibrosis patients.

At the start of 2016, I joined the ILFA committee as I felt I could give additional support to the charity. I am proud to be involved with a dedicated and focused group of volunteers. For me the best experience I have had to date, was meeting two lung fibrosis patients who have successfully undergone lung transplant surgery and have a new lease of life. My involvement with the charity has also taught me the importance of human kindness and the benefit in giving back to society.

Marie McGowan
ILFA committee member and fundraiser

Patient Information Days

ILFA holds two Patient Information Days annually, one in Dublin and one further afield. Events have taken place in Athlone, Belfast, Cork, Galway, Limerick, Sligo and Thurles.

The first ILFA Patient Information Day took place in 2006 in Dublin. It was well attended and success of the day paved the way for the development of future events. Since then, a total of 22 Information Days have taken place in various locations around the country.

The aim of the patient information days are to;

- ▶ provide patients and their families with information about IPF and the best ways of living with the condition,
- ▶ give patients the opportunity to ask the experts questions,
- ▶ allow people interact with each other.

We have been very fortunate to have speakers of the highest calibre talk at these important patient-centred events. We always invite a doctor from one of the Interstitial Lung Disease specialist centres to give a presentation about IPF and provide an update on treatment options for the condition. A physiotherapist is always included on the programme to speak on the importance of exercise for patients to maintain their wellbeing, mobility, confidence and independence. Sometimes (but not always!) the physiotherapist encourages audience participation to get everyone moving and stretching, and also to make sure nobody is drifting off to sleep! We have launched the 2000 Steps a Day Walking Challenge, the ILFA Exercise DVD, the ILFA hand-held fans and numerous information leaflets at Patient Information Days.

Over the years our speakers have included;

- ▶ respiratory consultants
- ▶ respiratory nurse specialists
- ▶ respiratory physiotherapists
- ▶ medical social workers
- ▶ dieticians
- ▶ respiratory physiologists



Liam Galvin, Laura Grehan, Eddie Cassidy and Marie McGowan helping out at a Patient Information Day.

- ▶ transplant coordinators
- ▶ transplant surgeons
- ▶ patients
- ▶ patrons
- ▶ a fire- safety officer with the fire brigade
- ▶ government ministers
- ▶ fundraisers

Although we follow a well established format, we try to keep the content fresh and interesting. Sometimes it is good to try something new and with that in mind we tried laughter yoga with an unsuspecting audience in 2015. Thankfully the audience on that day was very happy to engage with this activity. Our laughter yoga instructors soon had the audience “ooohing and aaaghing”, clapping their hands, laughing out loud, and exercising their lungs and diaphragms. It was funny and therapeutic and there were certainly a lot of endorphins released during the session. One of the audience members said afterwards “I’ve not laughed like that for years!”

After the speaker’s presentations, we always have a ‘Question and Answers’ session where the audience can ask the speakers questions and raise any concerns they may have. There is always lively interaction and debate. Then, everyone has the opportunity to socialise over tea and sandwiches.

Thank you to everyone who attends the events, our volunteers who give their time to help out, the pharmaceutical companies who have sponsored the events, the oxygen companies who have exhibition stands at the events, and the speakers.

We look forward to welcoming you to a future event.

Mini-Marathon Friends

Friends Rosemary Wilson, Rita O'Regan and Margaret McIver tell how they put the 'fun' into fundraising as they take part in the Women's Mini-Marathon for ILFA every year.

Why taking part in the VHI Women's Mini-marathon is important to us by Rosemary, Rita and Margaret.

Taking part in the mini-marathon is one of the highlights of my year – and has been for the past 14 years. (I took one year out due to a knee injury). The late Fergus Goodbody and his wife, Nicky, sang in the same choir as I did for many years. Fergus was a lovely young man and it was tragic to see him fade before our eyes as he succumbed to Lung Fibrosis. He put up a brave fight and I will always remember the last day I saw him when he came to support us in one of our concerts in the National Concert Hall.

As soon as Nicky became involved with ILFA and asked for volunteers to take part in the mini-marathon to raise funds for the organisation, I jumped at the chance. It was something I was always threatening to do, but never got around to. Here was the perfect reason to get out and do it – a combination of helping the organisation to work towards finding a cure for the disease, remembering Fergus, and finally doing something I wanted to do - so no more excuses!

I'm always nervous setting out on the day and fearful that I might be last, but as I get nearer to the starting line, the pains and aches disappear and the camaraderie (plus the adrenaline!) carry me through to the finish. I'm not the greatest fundraiser as I am now retired and the circle of people I can 'hit on' has diminished considerably, but I do what I can. Mini-marathon day is always a fun day – no matter what the weather - but I never lose sight of the reason why I take part.

My friend **Rita O'Regan** has been taking part for ILFA for the past 13 years: "My other half has hinted from time to time that I'm a hoarder! That's when I get up and leave the room before



Rosemary Wilson, Margaret McIver and Rita O'Regan.

an argument erupts!! From my point of view, I just like to hang on to memories – like the medals from the Ladies Mini Marathon that I've collected over the years. My 2016 medal is still hanging up for all to see, but it will soon be secreted away with the other lot I have amassed since the first Evening Press Ladies Mini Marathon in 1983. Someday soon I'll make a collage from my collection – but that's someday!!!

Each year I look forward to taking part in the Mini Marathon, planning walks ahead of time with my ILFA buddies to build up fitness and stamina for the 10K, enjoying the fresh air, sunshine, wind and rain, exchanging ideas, catching up on the latest fads, family, gardening tips, fashions, comfortable shoes! – the list is endless. Of course, we never forget the reason we participate in the 10K. Our ILFA t-shirts get their annual outing, still looking good after all these years of fundraising, and still full of memories."

Another friend, **Margaret McIver**, has also been taking part for ILFA. This will be her 5th year: "I am a relatively latecomer in participating in the Women's Mini Marathon on behalf of ILFA. It is a wonderful fun day out and I know that whatever contribution I make to the charity will go towards supporting people with the condition and for research into Lung Fibrosis. I sang with the late Fergus Goodbody in the Culwick Choral Society for many years and I am delighted to be involved with fundraising on behalf of ILFA."

Evolving concepts in our understanding of IPF



Professor Michael Keane explains how medical advances in the areas of diagnosis and therapeutic agents mean the future is now brighter for IPF patients.

There has been a revolution in the understanding of the mechanisms underlying the development of Idiopathic Pulmonary Fibrosis (IPF) over the past couple of decades, with a move away from theories solely based on IPF as an immunological disorder involving chronic inflammation of the lower airways which progresses to fibrosis. The view now is that pulmonary fibrosis occurs due to repetitive injury to an ageing lung that is genetically predisposed to fibrosis formation. Part of the shift away from the idea of chronic inflammation as a basis for IPF came with the tighter agreement on the classification of the disease two decades ago, which up to then had included what are now widely accepted as being separate forms of idiopathic interstitial pneumonia such as non-specific interstitial pneumonia and acute interstitial pneumonia, for which anti-inflammatory treatments may show more benefit.

A sentinel event in shaping the current view that immunomodulatory therapies are to be avoided in IPF, came with the findings from the PANTHER study. This showed that a then standard-of-care (though unproven therapy for IPF), the combination of oral corticosteroid, azathioprine and N-acetylcysteine, was not only ineffective in IPF but led to higher mortality and hospitalisation within an average of only 32 weeks of treatment versus placebo. This was followed by the dawn of a new era for what was until then an untreatable disease, with the publication of phase III clinical trial studies of two very different disease modification compounds; pirfenidone

and nintedanib, which both share anti-fibrotic properties.

Nearly all of the compounds currently in development for the treatment of IPF involve mechanisms relating to lung tissue repair, regeneration, inhibition of epithelial cell death and inhibition of collagen deposition, with little interest in an anti-inflammatory / immunosuppressing approach. Within these few years, long-held theories of IPF pathogenesis have been overturned.

We have seen many advances in diagnosis, evaluation and management of IPF over the last decade. We now have global and national networks and well established databases that are helping to further advance our understanding of this disease. There are now two anti-fibrotic medications that have been approved thus bringing viable treatment options to a previously dismal therapeutic landscape. There are other novel agents that are about to enter clinical trials, further enhancing the options available to patients.

Genetic studies will allow us to further improve our diagnosis and evaluation of IPF to allow a more personalised approach to the various therapeutic options and allow us to choose the best therapy for each individual patient. As a result of the progress made, the future is now brighter for patients with IPF.

Professor Michael Keane
Respiratory Physician
St Vincent's University Hospital
Dublin

My Transplant

Transplant recipient Robert Cooke shares his experience as an IPF patient and gives thanks for his second chance.

It all began with a tickly cough that wouldn't go away. After a couple of months, I went to my GP and was referred to a respiratory consultant who carried out tests which seemed to point to asthma. Six months later, I experienced chest pain and tightness across my shoulders when walking, so my GP sent me for a heart stress test and chest x-rays. Pulmonary fibrosis was mentioned for the first time. I was immediately referred to another respiratory physician and diagnosed with Idiopathic Pulmonary Fibrosis. It was a huge shock to learn that it was a progressive illness and the only cure was a lung transplant.

I was immediately prescribed oxygen, initially for 8 hours a day or during physical activity, but then I needed it more and more. Six months later, I was started on Pirfenidone, a drug that can slow down the progress of the disease. After six months, my lung function was still deteriorating, probably less so because of the medication, but I was now using oxygen 24 hours a day and was less able to do things or walk more than a few hundred meters.

On a visit to my consultant in 2016, we asked about the possibility of a lung transplant. He agreed that it was the only hope and admitted me for a week of tests. You can only go on the transplant list if all your other organs are healthy so everything had to be thoroughly checked out. Thankfully, apart from two diseased lungs, I was ok. Next, I was assessed by the transplant team at the Mater Hospital. It was during these meetings with the surgeons, transplant nurses, psychiatrist and social worker that the enormity of what a transplant entails began to sink in. You are given a handbook that explains the procedure, the complications that can occur, the follow-up treatment plan, the life-long drug regime, the changes in lifestyle, and the home support needed – but all so worth it, if it means a second chance at life.

Two weeks later, I was on the transplant list

and the waiting game for a suitable lung began. I packed my bag, had my mobile phone with me at all times, and waited and hoped. One of the transplant co-ordinators rang me every Tuesday to see how I was doing. This call was a huge comfort and once they even recognised a flare up in my IPF from how my breathing sounded over the phone and told me to go straight to my GP.

After 9 weeks on the list, my mobile phone rang. Within an hour I was on my way to the Mater Hospital by ambulance. My wife and son followed by car because if I wasn't a match or I wasn't chosen, they would have to drive me home. We had been warned that this was a very real possibility. I arrived at 11pm and after numerous tests, we were told that my bloods matched and that there was definitely one usable lung and probably a second one but we had an agonising wait because it wasn't until 1.30pm the next afternoon that I got the go-ahead!

The next thing I remember was waking up in ICU attached to lots of tubes and machines. Over the next four or five days, the number of tubes and attachments was reduced and I managed a wobbly walk around the intensive care unit. Once I was steadier on my feet, I was moved to the Heart and Lung Ward where I continued my road to recovery helped by the fantastic care I got from all the Heart and Lung Team.

I had a slight stroke during my operation and this affected my eye-hand co-ordination and eyesight so I had difficulty sorting out the numerous tablets I had to take twice a day. You can't go home until you can do this for yourself so this delayed my discharge by a few days. Just three weeks after my transplant, I was allowed home. It was quite nerve-racking as from now on it was up to us alone to look after this very precious lung.

For the next three months, I couldn't go into



public places without wearing a face mask and had to avoid crowded places. Initially, I had to attend the Mater Hospital clinic every week. The clinic is like a club with people swapping stories and tips but it can be very tiring as some people have to travel long journeys to Dublin for the 3-4 hours it takes to have your bloods taken, pulmonary function tests, and consultations with a transplant nurse and doctor. For the rest of my days, I will have to record my weight, temperature and daily medication in my Transplant Medication Diary so that if a blip occurs, infection can be ruled out as a cause.

Six months after the transplant, my quality of life has improved so much. I can drive again, do the

shopping, visit friends, have a meal out, walk on the beach, and I have lived long enough to see my youngest granddaughter take her first steps and call my name – inconceivable this time last year.

This gift of life selflessly given to me and my family by another family at a time of the most enormous tragedy for them is priceless and I will do my best always to honour and care for that gift. As a family, we cannot thank the donor and their family enough for giving us this second chance. They are in our thoughts and prayers every day.

Robert Cooke
Lung transplant recipient

YES!



**ILFA Director
Nicola Cassidy
shares the
story of her
involvement with
the organisation**

**and give thanks for the enriching
experiences and warm friendships it
has brought.**

My mother, Denise, was diagnosed with IPF at the age of 56. She was fit and healthy and her diagnosis came as a shock to everyone in our family. She loved life and was a very positive, enthusiastic and caring lady. She also had great courage and determination, and said “Yes!” to every opportunity that came her way.

Mam’s health deteriorated steadily and one of the most distressing symptoms for her was a constant, unrelenting cough that meant she struggled to hold conversations, and she loved to talk! Myself and my dad, Eddie, took leave from work to care for Mam as her health got worse. Mam was placed on the lung transplant list but sadly passed away aged 59. I miss her every day.

Dad and I joined ILFA, determined to use our experience to help others. It’s what Mam would have wanted. Within a few years, dad was ‘asked’ to be ILFA Treasurer and I was ‘asked’ to be Fundraising Coordinator - there was no possibility of us being allowed to turn down these roles as no one else wanted them! - so reluctantly we said “Yes” (Mam would have been proud!). I had never done anything like that before and was worried about being out of my depth. However, it was a joy to interact with people who wanted to help ILFA. Our fundraisers are incredible. From the very young to the ‘young at heart’, they work so hard and with such energy and enthusiasm. From table quizzes, tractor-runs, darts tournaments, sky-dives, fancy dress

parties, murder mystery nights, mini-marathons, triathlons, swims, cycles, coffee mornings, talent shows, wedding favours, donations, climbing Croagh Patrick and even Mount Kilimanjaro! – the list of our fundraiser’s activities is endless. Thank you to each and every one of you! “Yes” - you have made a real difference!

Since joining ILFA, my background as a scientist and experience as a carer have presented many opportunities that I would never have dreamt I would have the confidence to say “yes” to. Thanks to Professor Egan and ILFA for believing in me. With their support and encouragement, I have participated in many projects as a patient advocate representing ILFA. I have been fortunate to attend international conferences and have met some of the IPF world leaders who are making a real difference to patient care. I have been inspired by many but particularly by Prof Athol Wells, Anne-Marie Russell, Prof Egan, Sarah Masefield and members of the ERS IPF Taskforce with whom I have had the pleasure of working with and learning from.

Through ILFA I have met some wonderful people, many of whom are now good friends. Thanks to my support group pals around the country for their willingness to always say “Yes” when they get a call, a text message or an email from me looking for help! My ILFA friends are some of the warmest, kindest, and optimistic people in the world. Special thanks to Joanne Coyle, Lorna Murphy, Denise Dunne and Gemma O’Dowd for their support and friendship when they worked for ILFA.

ILFA’s annual Service of Prayer and Reflection is a very special event in the ILFA calendar and one that is close to my heart. Thanks to all those who say “Yes” and help make the service so special; to the clergy; Canon Charles Mullen, Fr Brian McKay and the Reverend Vanessa Wyse Jackson for embracing the ILFA community; to the volunteers who read and light candles; to the talented musicians and singers who perform so beautifully; and to the cake bakers for making sure we are well fed afterwards.

“Yes” is a such a small, powerful and positive word that can make a difference and change the world. Thanks to everyone who has helped ILFA in any way by responding with a resounding “Yes!”

**Nicola Cassidy
ILFA Director**

Patient Support Groups





Dublin Support Group

Messages from the Support Groups

The **Dublin IPF Support Group** wish to offer our congratulations to ILFA on their 15 year anniversary and to thank them for their support and kindness to the patients, carers and family members. Thanks to ILFA for providing uplifting experiences, opportunities to socially engage and to have a bit of banter with each other and learn more about IPF/PF. Thanks also for helping improve patient information and care through Information Days, fundraising, ILFA's Facebook page and newsletters, and the other services provided to IPF patients. We wish you many more years of success in the future.

Dublin IPF Support Group



The **Kerry IPF Support Group**, (above), wish ILFA continued success in the future. Thank you for your achievements in the promotion of the care of sufferers. Best Regards, **Kerry Support Group**

The **Monaghan Cavan Lung Fibrosis Support Group** would like to congratulate the Irish Lung Fibrosis Association on their 15 year anniversary. Your help for patients and their families is out of this world and we are proud to be part of your family. Best wishes for the future, **Monaghan Cavan Lung Fibrosis Support Group**



The **Cork IPF Support Group**, (above), would like to congratulate the Irish Lung Fibrosis Association on 15 years and thank them for their support with encouraging people to attend support groups, keeping an up to date website and all of the tireless work they do. We love seeing the new Inspirational Quotes and Tip of the Week on the Facebook page and website. We congratulate you on all your accomplishments and wish you all the best for the future. Best wishes, **The Cork Support Group**

Michael Cox,
Lynn Fox
and Evelyn
Cooper
launch a new
information
leaflet at
an ILFA
Patient
Information
Day in
April 2017.



Information, Support and the Importance of Patient Information Days

Specialist nurse Lynn Fox highlights the importance of ILFA's Patient Information Days for families coping with an IPF diagnosis.

Receiving a diagnosis of Idiopathic Pulmonary Fibrosis (IPF) can often be a worrying and daunting time for patients and their families and carers. Patients receive a vast amount of information at their appointments, ranging from managing their medications, lifestyle changes, the importance of exercise and managing the symptoms of IPF. In my experience with this condition, I find it beneficial to encourage patients to bring a family member or carer along with them to their appointments. This provides support for the patient and their family, and promotes an honest and open dialogue.

I know that the journey ahead may be difficult for patients and their families, both the physical and emotional impact of the condition. I believe that with support and reassurance patients can go on to have a good quality of life. To assist with the information provided at clinics and to promote self care, I find the information and educational

literature from ILFA to be invaluable for patients. The ILFA leaflets were developed with patients and their relatives to provide information which they deemed necessary. ILFA has also helped facilitate the development of support groups for patients and families. These groups help the patient and their family share personal experiences and offer emotional comfort and moral support. The meetings are also a chance for patients and carers to offer practical advice and tips to one another.

Another important resource for patients and their families is the ILFA Patient Information Days that are held twice a year. I have had the privilege to speak at some of these days, and benefited from hearing some positive and inspiring stories from patients and how they are coping with their condition.

Lynn Fox
Respiratory Nurse Specialist
Mater Misericordiae University Hospital

The Denise Cassidy Memorial Prize

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around"- Leo Buscaglia

The Denise Cassidy Memorial Award recognises and celebrates an act of kindness shown by a healthcare worker to a lung fibrosis patient. In 2015 and 2017, ILFA members were invited to nominate a person who showed them or their loved one a special kindness.

Katie Barry, staff nurse from Cork University Hospital was awarded the inaugural Denise Cassidy Memorial Prize in 2015. Katie was nominated by Vikki Jolly for her outstanding kindness, dedication and compassion when caring for Vikki's father, Martin Erangey. Katie received a specially commissioned piece of Dublin crystal and a certificate for Excellence in Patient Care. Katie said "It's such an honour to have been nominated by a lovely family, let alone me being given the award. Denise must have been truly inspirational, and to receive an award with her name on it, is such an amazing gift. To say that I am grateful and honoured is an understatement. Words cannot express how thankful and deeply touched I am. The certificate and award have pride of place in my home. I'm still looking at it with disbelief. I love my job and you never expect to receive anything for the work you do, but to be honoured in such a way is truly amazing and something I will always be proud of and grateful for."

Also honoured with certificates for Excellence in Patient Care in 2015 were **Irene Byrne** (Senior physiotherapist at the Heart and Lung Transplant Unit, Mater Misericordiae University Hospital), the Staff of the Heart and Lung Transplant Unit, Mater Misericordiae University Hospital) and Lorna Murphy (previously of the Mater Hospital and ILFA).



Terence Moran presents Katie Barry with her award.

Olivia Mulvaney, staff nurse from Cavan General Hospital is the worthy winner of the 2017 Denise Cassidy Memorial Prize and Olivia will be presented with her prize later this year. Olivia was nominated by Bridget McEneaney who said "From our first meeting, Olivia was so sweet, kind and considerate of Dessie and the family. Dessie felt that someone finally listened, heard and understood him. Olivia helped us when our world fell apart. We are thankful to her for all she did to try and make it easier for us." Also nominated in 2017 were;

- ▶ Bernadette Bowen, respiratory nurse specialist at Cork University Hospital
- ▶ Maria Love, medical social worker at the Mater University Hospital
- ▶ Carol O'Mahony, physiotherapist at Cork University Hospital
- ▶ Lindsay Brown, respiratory nurse specialist at St Vincent's University Hospital
- ▶ Sara Winward, advanced nurse practitioner at the Mater Misericordiae University Hospital
- ▶ Carol Buckley, respiratory nurse specialist at the Mater Misericordiae University Hospital
- ▶ Sandi O'Reilly, medical receptionist at the Mater Misericordiae University Hospital
- ▶ Dr Kate O'Reilly, respiratory physician at the Mater Misericordiae University Hospital
- ▶ Lynn Fox, respiratory nurse specialist at the Mater Misericordiae University Hospital
- ▶ Zita Lawlor, transplant coordinator at the Mater Misericordiae University Hospital
- ▶ Dr Desmond Murphy (respiratory physician at Cork University Hospital).

Is there a role for health apps in helping people manage their long-term health conditions?



Colin Edwards, Scientific Director at patientMpower explains how those living with pulmonary fibrosis can use smart-phone apps to take more charge of their healthcare.

Imagine if you could have good information on your health delivered to your phone in real time so that you always have it with you. This could be very useful if you have a long-term condition, as you could monitor your health every day. It could also be handy to always have the right information to hand to discuss with your doctor at clinic visits.

This is now feasible as modern smartphones can collect and store data from suitable devices which measure important properties linked to health (for example, blood sugar, blood pressure, lung air flow). This can turn your phone into a useful health diary to collect information on your medical condition.

As smartphones become more affordable this opens up the opportunity for patients with long term conditions (like lung fibrosis) to take more charge of their healthcare. This can be done by downloading an appropriate healthcare app to your phone and linking it to a device to collect relevant measurements.

For patients with lung conditions, using an app and a portable spirometer can collect long-term information on your lung function. You could share this long-term picture of your lung function which your specialist doctor at clinic visits. Health apps can be used to record a diary of symptoms or possible drug side-effects. Another feature of health apps is that they can be used as a reminder to take your medicines on time.

There is another possible benefit to using health apps with spirometry in lung fibrosis. Long-term data on lung function and symptoms could

be used to create a large database of information which could be a valuable tool for research groups attempting to understand lung fibrosis and find and test new treatments. This means that every patient could be contributing valuable information which could be of benefit to current and future patients.

So far, there are few apps specifically developed for lung fibrosis but the good news is that this is changing. An Irish company, patientMpower Ltd., has developed an app for lung fibrosis and this is now available with home spirometry. patientMpower Ltd. is now conducting user experience surveys and clinical studies. Experience to date suggests that patients with lung fibrosis find this app and home spirometry to be useful.

In summary, the use of health apps is becoming more common. Advances in technology now give patients new tools to monitor their health more closely and hopefully gain a greater sense of control in managing their medical condition. In addition, there is an opportunity for every patient to contribute information to a common pool of data which can be used for research. This will contribute to a greater understanding of lung fibrosis and may help in the development of new treatments.

If you would like to learn more about this topic, please contact the author at colin@patientmpower.com or visit www.patientmpower.com

Colin Edwards
Scientific Director
patientMpower Ltd.

Creating Positivity

Two years on from her own IPF diagnosis, support group leader and fundraiser Noreen O'Carroll advocates staying informed, staying in control and availing of back-up services.

In June 2015, I was diagnosed with IPF. A few months later, I attended an ILFA Information Day in Dublin. It was really useful to get good information from healthcare professionals but I left still never having spoken to another person with this disease. That day, a lady accidentally bumped her oxygen container against my chair. At that point, I was close to tears thinking "is this what's ahead of me? how am I going to cope?" My sister who knows me too well, nudged me in the ribs and whispered "come back, you've gone too far". Those words were a gift. When I have a bad day, I remember those words and remind myself to stay with just today. There is no point in worrying about the future, I'm not there yet, so I can't do anything about it, but today I can try to have the best day I can by creating positivity in my life. This helps me cope with the negative thoughts that have a way of creeping in.

So two years into my diagnosis what has helped me? Three things stand out for me; (1) Being informed (2) Being in control and (3) Support

Thanks to the Internet, it's easy to be informed. When I was diagnosed it was difficult to read the hard facts of this disease. I also realised I needed to know more, so it was useful to find reliable websites with good practical information. I found the ILFA website had good resources and information that's given in a positive way. I was able to recommend it to my family too when I didn't have the energy or words to explain what this disease is about.

Informing myself about IPF helped me to feel more in control and take responsibility for my health with the support of healthcare staff. I now know how important exercise and diet are, I know my test results and what they mean for my health. I know if I reach a certain point, I will need oxygen and I'm ok with that now because I know I won't be putting my other organs under stress. I know the questions I need to ask my consultant when I meet him and if I don't understand something to ask him

to explain it again. I was also able to request an early referral to the transplant clinic at the Mater Hospital.

With regards to support; "No man is an island". If we allow ourselves to be supported by those around us, it is definitely an enriching experience. It took me a long time to be able to tell people about my diagnosis, maybe because I didn't want pity or to be seen in a different light because I am still me and that's something I had to work through. To help me do that, it was invaluable to see a therapist for a couple of weeks and work through all the emotional stuff this diagnosis brought up. It helped me make sense of it all and figure out how I could normalise my life again. I go back for a session or two whenever I begin to feel overwhelmed, but this has become less and less. At least I know that resource is there for me if I need it. Within the primary care service, you can access six free counselling sessions. Your GP can refer you, you just need to ask.

I also discovered that there are IPF specialist centres. My consultant referred me and now that I am linked in with the respiratory clinic, I can access pulmonary rehabilitation and I meet the respiratory nurse on a regular basis. She monitors my medication and is an amazing source of support. I know if I have any concerns, I can call her.

This disease is isolating and the chances knowing somebody with it is slim but it was really important for me to connect with others. In January 2017, I started the Midwest IPF support group. Support groups aren't for everybody but I can honestly say I really enjoy meeting the men in our group and we learn from each other. One member has had a lung transplant and this makes me feel positive and hopeful for my future.

Last October, the Limerick Ladies Mini-marathon took place and I decided to fundraise for ILFA. Anyone who knows me, knows that I am allergic to walking (I'm so lazy) so this was a big deal for me. I was asking people to support me so I had to tell them why I was doing this. Before



I knew it, my family decided they were doing the mini-marathon too, even my 83 year old mother was getting in on the act, I had to call that one and tell her she was the official tea lady on the day. My son Steven was renamed 'Stephanie' and was given a wig to wear. That day showed me that I don't have to do this on my own - my husband, children and family are my biggest source of support. They will always be there for me and for that I am grateful every single day.

I read an article online where the author talked about the importance of having something positive to look forward to, however big or small, it's a chance to reclaim some control over life. I really believe the value of this because initially when

you have been diagnosed, you are in shock. With time you will realise, that you do have a future and having something to look forward to and making plans are what keeps us going.

So this year I am planning to learn how to build dry stone walls - completely random, I know! I plan to buy a poly-tunnel and grow fruit and veggies, and go to Indonesia to help my daughter realise her dream of setting up yoga retreat courses, I might be her best customer yet. These plans will keep me moving forward and positive about my life despite IPF - and when you're ready you will find what works for you.

Noreen O'Carroll
IPF patient, support group leader and fundraiser

Working with People and Families Living with Pulmonary Fibrosis: A Medical Social Worker's perspective



Mater Hospital social worker Maria Love explains how illness impacts patients and families emotionally as well as physically - and shares some tips for coping through the tough times.

Pulmonary fibrosis (PF) can have an enormous impact on a person's life and their families lives, including their physical, emotional, social wellbeing and expectations for the future. For many people, a diagnosis of PF can be devastating and challenging, particularly as the disease progresses. As a medical social worker, I understand illness from a holistic perspective and can provide support and assistance. This article presents some of the common experiences of people with PF whom I have encountered, and offers their advice on what may be useful.

Emotional Impact

All illnesses can have an emotional impact on a person and their family and it is important to remember there is no 'right way' or 'wrong way' to feel. Give yourself time and permission to feel what you feel. Sometimes it may be helpful to speak with someone close to you to understand the emotions you are experiencing. It can take time to adjust or 'get your head around' a diagnosis of PF – this is normal and understandable.

Many struggle to accept the disease – acceptance does not mean that you are 'ok' with PF, it means you understand you have to learn to live with it, look after yourself and understand the affect it may have on you and your loved ones.

Mood is like Irish weather – it can change frequently, however if you find yourself 'stuck'

in a low mood for longer than is normal for you, seek help from your family, friends or healthcare professionals. Talking to someone or joining a support group may be useful and help you feel like you are not the only one dealing with this disease. Mental health is as important as physical health, and it is not a sign of weakness to seek help or admit you are struggling. Your GP or healthcare team can refer you for counselling if you feel this would be useful. Some people prefer not to talk about their illness – occasional questions from family or friends like "how are you coping with this?", "would you like to talk about anything?" or "is there anything that would be helpful?" can show the person that help is available if they need it.

Remember PF is not your identity and you have a choice in how you respond to it . You should continue to do activities that you enjoy or, if needed, adapt how, when, and where you do those activities. There are lots of ways to improve coping skills while having fun – local community centres or newspapers are full of ideas.

Physical and Practical Impact

The physical symptoms of PF may be annoying, distressing, debilitating and restricting. It can be difficult to take in information about PF, treatment options or disease progression. When we are in shock or unwell, it can be difficult to understand new information so it's useful to have someone

with you when you attend hospital appointments. They will help you remember this information. Beware of going to the Internet for information – ask your healthcare team for reliable information sources.

Exercise has a positive effect on the mind and the body so ask your healthcare team for recommendations – there are lots of fantastic exercise resources available. Try an activity that you enjoy or adapt the activity to your ability.

As PF progresses, you may become more restricted in physical activities, particularly looking after your personal care, grooming and dressing. There are practical aids available that can help you maintain your independence. Sometimes you may need practical assistance from a family member or community care services to help you. Contact your GP, public health nurse or health centre for information on how to access community services. There are limited services available from the HSE (home help or home care packages); however you may be on a waiting list for some time.

Social and Family Impact

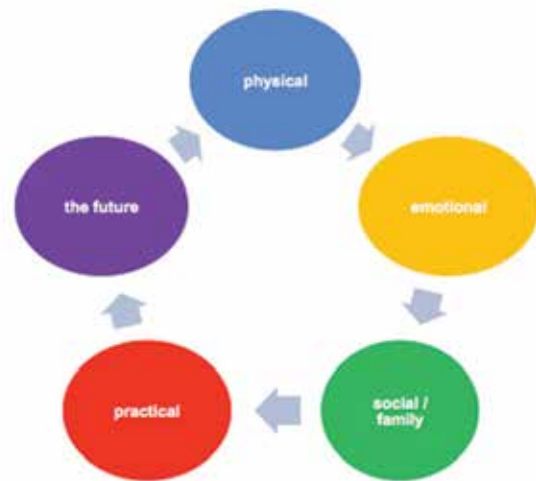
As a social worker, one of my primary roles and privileges is supporting the person and their family. How PF affects people and their family, friends, work and community varies enormously.

One thing I am regularly stuck by is how some people with PF, their family and friends try to hide their true feelings or 'protect' each other from sadness, fear, anger and upset about the disease and the future. It is important, in your own time, to acknowledge the disease and the impact this will have on your family unit and recognise that PF impacts on the emotional and practical aspects of your life and the people in it. Giving yourselves permission to 'feel' and talk to each other about these issues can be healing and worthwhile.

It can be empowering to look at the practical impact of PF and see how you could adapt or change daily routines to support you. It is normal to worry about money, work, and the impact on spouses and children – there are many organisations that can help you with information and practical advice. It may be useful to attend ILFA support groups, carer support groups or community services.

If you are caring for someone with PF, it is important that you are supported and have time to recharge your batteries with your own interests or time off. Many people say that while they hate the disease, it often helps them to appreciate the good things in their lives and they learn to prioritise

Areas of life affected by illness



people and experiences, big and small, that are important to them.

The Future

PF often shatters a person's expectations for the future – plans for an event, career, family growing up or retirement. When these plans seem to be pulled away from you suddenly and unexpectedly, this is a significant loss and this can result in a type of grief that brings up difficult emotions for the person and their family. It is very easy to become overwhelmed when trying to juggle everything and accept our mortality and fragility but this may be a little easier with support. Work out what's important to you and prioritise these things. You will have good days and bad days. It is important to be realistic and informed but also to enjoy and be grateful for the good moments and people we have in our lives.

Conclusion

To conclude, I have discussed briefly how different aspects of our lives may be influenced by PF using examples from the people I have the privilege of working with. This experience is humbling. There may be a wild storm of anger, fear and anxiety present, however I am constantly moved by people's bravery and strength, and inspired by their resilience.

*May I have the courage today
To live the life that I would love,
To postpone my dream no longer
But do at last what I came here for
And waste my heart on fear no more.
~ John O'Donohue ~*

Maria Love
Senior Medical Social Work Practitioner
Mater Misericordiae University Hospital



The Troy Trotters.

The Troy Family

Liam Galvin - husband of the late Phyl Troy, and Martin Troy - brother to Phyl, Peggy and Daniel who all died of IPF, describe why they volunteer with ILFA and their family fundraise for the organisation.

Our motivation to support ILFA by fundraising and through our work with the committee comes from our experiences with Phyl and Daniel Troy from Thurles, Co Tipperary. After being diagnosed with IPF, Phyl and Daniel's lives were greatly improved by the information, support and comfort they received from the volunteers with ILFA. Both were great supporters of ILFA and the work it does.

As the remaining nine siblings of twelve, all three deceased members of our family having died of IPF, we are honoured to support ILFA in any way we can to further their work on behalf of patients and their families.

We have fundraised for ILFA with many events over the years including; a Murder Mystery Night, a fancy dress party, a car boot sale, a magician show, the Highland Games, and in 2015 the 'Troy Trotters' took part in the Women's Mini-Marathon

in Dublin. ILFA is a well run and voluntary organisation and we are beholden to it not only for the care and support it gave to our loved ones but because we attend Patient Information Days, read the newsletters, and especially see the good work the committee members and support groups do.

We also know the difference the association is making to patients.

We take comfort in the annual ILFA Service of Prayer and Remembrance, and like the many families who have been touched by IPF and who support ILFA, we pray for its volunteers and continued existence.

Liam Galvin,
ILFA Director and Secretary of the
European IPF Federation
Martin Troy, ILFA Committee Member

From Kildare to Kilimanjaro

Fundraiser Saileóg O'Keeffe tells how her family and friends remember her late dad Mick while supporting ILFA and promoting organ donation.



Caroline Rawdon, Angela Lyon, Saileóg O'Keeffe, Mairead Diviney on top of Mount Kilimanjaro in Tanzania in 2011.

Around 100 people took part in a fundraising golf classic in aid of the Irish Lung Fibrosis Association (ILFA) at the Liffey Valley Par 3 course on the 25th March 2017. €6,000 was raised for the charity at the event, which was organised to encourage organ donation. The golf classic was organised as a fitting memorial to my father, the late Mick O'Keeffe. My father sadly died in March 2016 aged 60 years old, as a result of this disease. He received four lung transplant calls within the space of three months, however, regrettably no lungs were suitable at the time. He rapidly deteriorated within a week, upon admission to hospital, and passed away soon after.

Nowadays, my mam Caít and I, and extended family members are promoting the importance of becoming an organ donor to everyone. Over the last few years, I have raised over €20,000 for ILFA through numerous fundraising events including church collections, table quizzes and Run Amuck, with the help of wonderful family and friends. In 2011, I climbed Kilimanjaro for ILFA, an experience that I will never forget.

The most recent fundraising event proved a most enjoyable day out for all who participated in the golf classic. There was live music and prizes later that night in Celbridge GAA, as many of Mick's family and friends from Lixnaw, Kerry and Dublin came to honour his memory. My father was



Saileóg O'Keeffe, Con O'Keeffe and Cait O'Keeffe.

a keen golfer and hurler and he played hurling well into his 50's with Celbridge GAA and New Ireland's hurling club. Also attending the night, were some of his Garda colleagues, along with many neighbours who all paid tribute to a wonderful, courageous and amazing gentleman.

I would like to express my sincere gratitude to all my family, friends, neighbours, ILFA and all local businesses who have sponsored and helped me throughout the various charity events over the last seven years.

**Saileóg O'Keeffe
Fundraiser**

The Fergus Goodbody Memorial Lecture

The Irish Lung Fibrosis Association was set up in 2002 in memory of Fergus Goodbody and since 2010, ILFA has invited an international leader in Idiopathic Pulmonary Fibrosis (IPF) to deliver a state of the art lecture to healthcare professionals in Ireland.

The Fergus Goodbody Memorial Lectures have been delivered by:

- ▶ Professor Hal Collard, San Francisco (2010)
- ▶ Professor Ron du Bois, London (2012)
- ▶ Professor Luca Richeldi, Southampton (2014)
- ▶ Professor Jurgen Behr, Munich (2017)



Prof Hal Collard with Prof Jim Egan at the inaugural Fergus Goodbody Lecture at the Mater University Hospital.



Prof Jim Egan, Prof Anthony O'Regan, Prof Ron du Bois, Dr Vera Keatings and Prof Michael Keane at the Royal College of Physicians in Ireland.



Dr Michael Henry, Prof Jim Egan, Prof Luca Richeldi, Ms Donna Eaton and Dr Eoin Murtagh at the Royal College of Physicians in Ireland.



Prof Jim Egan, Dr Emmet McGrath, Prof Jurgen Behr and Terence Moran at the Royal College of Surgeons in Ireland.

ILFA's Academic Achievements

Publications

- 1) An overview of Idiopathic Pulmonary Fibrosis. Cassidy N and Egan JJ. *Forum* [Journal for the Irish College of General Practitioners], 2015
- 2) An overview of Idiopathic Pulmonary Fibrosis. Cassidy N and Egan JJ. *Irish Pharmacist*, 2015.
- 3) Potential Organ Donor Audit in Ireland. Cassidy N, Murphy L and Egan JJ. *Irish Medical Journal*, 2011.

Conference presentations

European Respiratory Society Congress

2017 - Milan, Italy

- 1) Collaborating with stakeholders to advance the National Patient Charter for Idiopathic Pulmonary Fibrosis in Ireland. N. Cassidy, L. Galvin, G. O'Dowd and JJ Egan [poster discussion]
- 2) The impact of dyspnoea and strategies used by lung fibrosis patients to relieve breathlessness. N. Cassidy, P. Grehan, I. Byrne, O. O'Connell and JJ Egan [poster discussion]

2016 - London, United Kingdom

- 1) Development of a National Patient Charter for Idiopathic Pulmonary Fibrosis. Cassidy N, Galvin L, Dunne D, and Egan JJ. [platform presentation]
- 2) Health status and Impact of living with Idiopathic Pulmonary Fibrosis: UK & Ireland Delphi Survey. Anne-Marie Russell, Georgina Jones, Ruth Sabella. Nicola Cassidy et al. [platform presentation]

2015 - Amsterdam, The Netherlands

The burden of Idiopathic Pulmonary Fibrosis reported by patients and carers in Ireland. Cassidy N, Dunne D, Liam Galvin, and Egan JJ [poster discussion]

2014 - Munich, Germany

The Irish Lung Fibrosis Association's 2000 Steps a Day Challenge: A pilot study to evaluate a novel home exercise programme for Lung Fibrosis patients. Byrne I, Cassidy N, Egan JJ [poster discussion]

Irish Thoracic Society Meeting

2016 - Dublin, Ireland

Patient breathlessness survey. Grehan P, Cassidy N, Byrne I, McConnell O, Egan JJ [poster discussion]

2015 - Cork, Ireland

Development of the National Patient Charter for Idiopathic Pulmonary Fibrosis. Cassidy N, Galvin L, Dunne D, Egan JJ [poster discussion]

2014 - Galway, Ireland

The Irish Lung Fibrosis Association's 2000 Steps a Day Challenge: A pilot study to evaluate a novel home exercise programme for Lung Fibrosis patients. Cassidy N, Byrne I, Danaher D, Egan JJ [poster discussion]

Eurodis Conference

2014 - Geneva, Switzerland

Web-based learning to support patient advocacy in rare diseases: The European Patient Ambassador Programme. S Masefield (European Lung Foundation), N Cassidy (Irish Lung Fibrosis Association), P Powell (European Lung Foundation). [poster presentation]

British Thoracic Society Meeting

2014 - London, United Kingdom

The Irish Lung Fibrosis Association's 2000 Steps a Day Challenge: A pilot study to evaluate a novel home exercise programme for Lung Fibrosis patients. Cassidy N, Byrne I, Egan JJ [poster presentation]

Advancing in IPF Research European Meetings

2016 - Vienna, Austria

What matters to patients? Nicola Cassidy, Sarah Masefield, Athol Wells [platform presentation]

2015 - Prague, Czech Republic

Patient centred issues for the ERS/ELF Statement on IPF. Nicola Cassidy, Sarah Masefield and the ERS Taskforce on IPF [platform presentation]

2014 - Copenhagen, Denmark

IPF: Through the eyes of the patient – a summary of patient concerns. Sarah Masefield and Nicola Cassidy [platform presentation]

2013 - Nice, France

Patient associations: how can we work together better? Nicola Cassidy and Jim Egan [platform presentation]

Advancing in IPF Research UK and Ireland Meetings

2017 - Manchester, United Kingdom

IPF: The patient's perspective. Liam Galvin [platform presentation]

2015 - London, United Kingdom

Bringing together the perspectives of patients and professionals on IPF diagnosis, treatment and management priorities in Europe. Nicola Cassidy [platform presentation]

International Experience Exchange for Patient Organisations

2017 - Madrid, Spain

Turning data into clinical evidence for effective lobbying. Liam Galvin

Best practice examples: The EU Written Declaration for IPF. Liam Galvin [platform presentation]

Scottish IPF Update

2017 - Sterling, Scotland

IPF: The patient's perspective. Liam Galvin [platform presentation]

Acknowledgments

The ILFA committee is deeply grateful to everyone who has helped the organisation since 2002. It is thanks to your help and kindness, no matter how large or small, that we are able to mark this important milestone in our history and celebrate the many advances in patient care over the last 15 years. Sincere thanks to everyone who has contributed to our story so far.

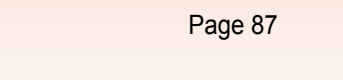
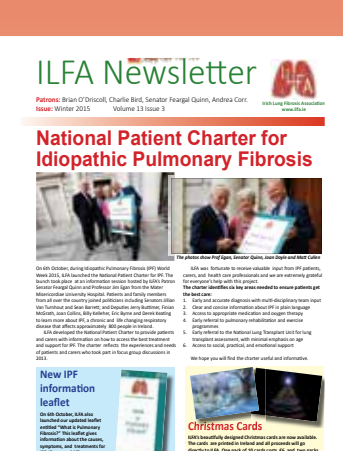
- ▶ Patients
- ▶ Carers
- ▶ Doctors
- ▶ Nurses
- ▶ Allied healthcare professionals
- ▶ Fundraisers
- ▶ Volunteers
- ▶ Past committee members
- ▶ Politicians and Members of the European Parliament
- ▶ Patrons
- ▶ Clergy
- ▶ Hayes Solicitors
- ▶ Whiteside Cullinan & Co
- ▶ Irish Lung Health Alliance
- ▶ Irish Donor Network
- ▶ Irish Thoracic Society
- ▶ Anail
- ▶ European Idiopathic Pulmonary Fibrosis and Related Diseases Federation
- ▶ European Lung Foundation
- ▶ European Respiratory Society IPF Taskforce
- ▶ Corporate donors
- ▶ Three Lakes Partners, Illinois, USA
- ▶ Boehringer Ingelheim Ireland Ltd.

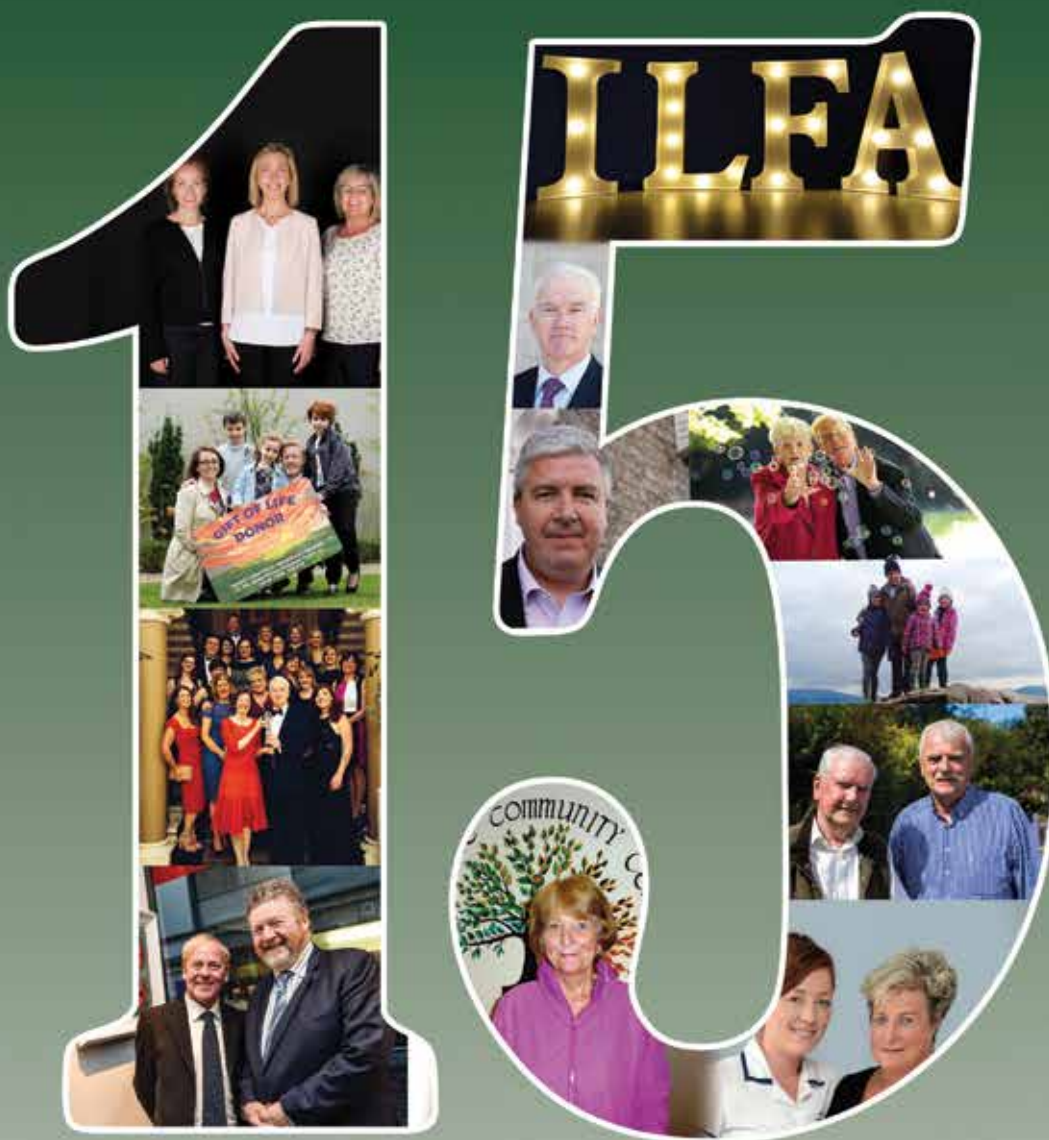


Irish Lung Fibrosis Association
www.ilfa.ie

- ▶ Roche Products Ireland Ltd.
- ▶ Air Liquide Healthcare Ireland Ltd.
- ▶ BOC Healthcare Ireland
- ▶ patient Mpower
- ▶ National Adult Literacy Agency
- ▶ Cara Ni Fhearraigh
- ▶ Niamh Hogan, designer
- ▶ Ben Brady, printer
- ▶ Elevate PR
- ▶ Ray Lohan
- ▶ Fergal Murphy
- ▶ Ken Powell

*“Alone we can do so little,
together we can do so much”
– Helen Keller*





Irish Lung Fibrosis Association

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Registered charity number: 20053437

Company registration number: 367940

