ILFA Newsletter

Patrons: Brian O'Driscoll, Charlie Bird, Feargal Quinn, Andrea Corr.
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A Day in the Life...

In June, ILFA invited patients, carers, healthcare professionals and representatives from oxygen and pharmaceutical companies to attend a brainstorming session to set priorities for ILFA's future work and identify ways to raise awareness of IPF. One of the imaginative suggestions put forward was to invite a politician to spend time with a patient to raise awareness and highlight some of the challenges of living with Idiopathic Pulmonary Fibrosis (IPF).

ILFA duly wrote to Finian McGrath T.D,. Minister of State, Social Protection, Justice and Health with special responsibility for Disabilities, and formally invited him to participate in this project. Finian has always been very supportive of ILFA and previously raised parliamentary questions on our behalf and attended the launch of the National Patient Charter for IPF in 2015. Without hesitation, Finian kindly agreed to get involved in the "**A Day in the Life"** project and from the outset he was keen to learn more about IPF and help ILFA to raise awareness. Dermot King from Dublin was diagnosed with IPF in 2012 and is a good friend to ILFA. Dermot attends the monthly Dublin support group meetings and starred in the ILFA Home Exercise DVD in 2015 with his good friends Matt Cullen and Joan Doyle. When approached to participate in this special project, Dermot said "YES" immediately and was 100% committed to the task.

On Tuesday 30th August, Finian travelled to Artane to meet with Dermot, his daughter Jennifer and grand-daughter Isabelle, and ILFA representatives Gemma O'Dowd, Eddie Cassidy and Nicola Cassidy. It was a glorious warm and sunny day and everyone was excited, enthusiastic and keen to make the most of the opportunity of meeting with the Minister. Things got off to a great start with a relaxing cup of tea and some home baking. The conversation flowed and Finian listened intently to Dermot's experience of adapting to life with IPF and asked plenty of questions to get a better understanding of the condition. Dermot shared his positive stories about being part of the support group, attending pulmonary rehabilitation classes in Dublin City University, going on holiday to Kilkenny, and having support and encouragement from family and friends. He also highlighted the many challenges for patients including the impact of breathlessness, the significant financial burden of IPF, and having to constantly look for adequate vital oxygen supplies to enable him to exercise, maintain good health and live life to the full.


Dermot King with Minister Finian McGrath.

Dermot and Finian kindly agreed to be filmed during their meeting and Fergal Murphy our videographer captured beautifully the interaction between the two gentlemen without being intrusive. Two short videos entitled "A day in the life" and "Raising awareness" were subsequently produced and were released to mark IPF World Week, which took place from September 17th to 25th. ILFA is immensely grateful to Minister Finian McGrath and Dermot King for their considerable generosity, time and willingness to engage with ILFA and help us raise awareness for IPF World Week. "A Day in the Life" was a hugely valuable project and ILFA is hopeful that the inspiring videos will help raise awareness of IPF and give hope to patients living with the condition.

Dermot said "The day couldn't have gone better. Finian was so pleasant, down to earth and interested in learning about IPF and my circumstances. I knew from the moment he introduced himself that things would go well. It was fantastic".

News from the Chairman

On behalf of each of us on the ILFA Committee, I wish all of our supporters and friends a very Happy Christmas. I hope that you benefitted from the various activities and initiatives we carried out in 2016. I commit to our determination to continue to work on your behalf in 2017 to improve knowledge and awareness of IPF and to improve access to treatments and services. The members of the Committee are very grateful for the ongoing fundraising and raising of awareness of IPF by so many of you and look forward to your further dedication and work in the future.

Beannachtaí na Nollag.

Terence Moran, Chairman, ILFA.

Christmas cards

ILFA Christmas cards are now available to order. Each pack contains 2 cards each of 5 designs. One pack costs **€6** and two packs cost **€10**. The cards are printed in Ireland. **Cards can be ordered by calling 086 871 5264 or emailing info@ilfa.ie.**Please help raise awareness of lung fibrosis this festive season.

ILFA Service of Prayer and Reflection

Planning for the 2016 ILFA Service of Prayer and Reflection commenced in April and Reverend Canon Charles Mullen suggested holding the service at the Carmelite Chapel at Gort Muire in Balinteer. Telephone calls and emails were exchanged and during the summer Canon Mullen and Nicola Cassidy visited Gort Muire. We received a very warm welcome from the Prior, Fr Martin Kilmurray, and Mairead Hutchinson who showed us around the beautiful grounds and chapel. We were immediately taken with this beautiful and special venue.

Reverend Vanessa Wyse Jackson was invited to deliver the address and we then set about selecting suitable prose, bible readings and prayers to reflect the theme of faith and the importance of prayer and conversing with God. Harry Carpendale kindly agreed to perform the harp once again at the service and Cillian Long, Trinity Scholar, kindly stepped in to help out when we needed an organist.

Our readers; John Donnelly, Professor Gaye Cunnane, Giles Baily, Harry Deegan, Peter Gallagher, Lisa McGowan, Susie Harrison, Alison Maguire, John Doyle, Gemma O'Dowd and Eddie Cassidy all answered enthusiastically when asked to take part in the service, as did our candle lighters Lindsay Brown (Respiratory Nurse at St Vincent's University Hospital), Sheena Minogue (Respiratory Nurse at the Mater Misericordiae University Hospital) and Edna Powell (lung transplant recipient).

On the day itself, 85 people gathered together at Gort Muire and the sun filtered through the windows to fill the chapel with warmth and light. It was another very special occasion and very much appreciated by those present and indeed by many who could not make it in person but sent messages of support. Reverend Vanessa Wyse-Jackson's address informed us about the Methodist tradition and their great love of singing. We were told about the special significance of the hymns chosen for the service; "How Great Thou Art" and "The Lord is My Shepherd". The candle lighting ceremony was poignant but beautiful and comforting to everyone remembering a departed loved one.


The Revd Canon Charles Mullen, The Revd Vanessa Wyse Jackson and The Revd Fr Martin Kilmurray O.Carm.


Eddie Cassidy, Nicola Cassidy, The Revd Canon Charles Mullen and Terence Moran.


Sheena Minogue, The Revd Canon Charles Mullen and Professor Gaye Cunnane.


Liam and Pamela Martin.

Terence Moran (ILFA Chairman) gave a short address at the end of the ceremony and thanked everyone for their participation. Terence extended ILFA's heartfelt thanks to all our dedicated fundraisers whose vital support helps keep the association going. Terence also praised baby Isabelle (our youngest guest at only 6-months old) who was so well behaved and gleefully joined the congregation singing along to one of the hymns!

After the ceremony we adjourned for tea, coffee, and some delicious cakes and biscuits. Thank you to Mairead and Nadia for looking after us so well and to everyone who helped serve and supply the tasty treats. It was great to see everyone mixing and chatting, as the social gathering is another important aspect to our annual spiritual gathering.

ILFA is extremely grateful to the clergy, musicians, readers and candle lighters for their participation and to everyone who attended the service and those who sent good wishes.

We received some lovely emails after the service. Here are some of the comments;

- Our thanks to all on the committee who organised such a wonderful and moving service.
- Thank you to you for bringing us all together yesterday. It was a very uplifting service.
- The venue and the service were special - thank you.
- Well done, the service on Saturday was wonderful. I find the whole thing very uplifting. Thanks so much for continuing to organise it.

"Our annual service of prayer and reflection took place this year on Saturday 15th October in Gort Muire in Ballinteer. This service, which has taken place every year since 2010, draws together a wide range of people from around the country, and has become an important event in the association's year. Candles are lit as we remember those who have passed away and we also take time to acknowledge the care of the medical staff who have done and continue to do so much to support the patients in their care.

This year the celebrants were Fr. Martin Kilmurray (Gort Muire), Rev. Canon Charles Mullen (St Patrick's Cathedral) and Rev. Vanessa Wyse Jackson (Rathgar Methodist Church) and the beautiful music was provided on the harp by Harry Carpendale and on the organ by Cillian Long. A very warm word of thanks to Fr. Martin Kilmurray and all involved at Gort Muire for their wonderful hospitality."
The Revd. Vanessa Wyse Jackson

International Colloquium on Lung and Airway Fibrosis (ICLAF)

Prof Luca Richeldi (Italy) and Prof Sonye Danoff (USA).

Dr Michael Henry (Cork University Hospital) and Gemma O'Dowd (ILFA).

Eddie Cassidy, Gemma O'Dowd and Nicola Cassidy from ILFA supporting the Canadian Pulmonary Fibrosis Foundation's 'Kiss IPF Goodbye' photo campaign.

Nicola Cassidy (ILFA), Prof Athol Wells (London), Prof Hal Collard (California), Prof Sonye Danoff (New York), Prof Michael Keane (Dublin) and Gemma O'Dowd (ILFA).

The 19th International Colloquium on Lung and Airway Fibrosis (ICLAF) took place in Dublin Castle from 24th to 28th September. Researchers, specialists, scientists, students and clinicians from 24 countries attended this major international conference to learn about the latest research on lung fibrosis.

The event was organised locally by the Conference Co-chairs, Professor Michael Keane from St Vincent's University Hospital and Professor Seamas Donnelly from Tallaght University Hospital, in collaboration with the local steering committee.

The programme was packed with scientific content and 38 expert speakers from all over the world travelled to share the latest exciting and innovative findings on lung fibrosis. In addition, a total of 130 poster presentations showcased the latest research and developments. The conference also provided a unique and lively social programme where the delegates could network with their peers and engage in discussions on current best practices and future directions in research, diagnosis, therapeutic developments and innovations, and treatment.

ILFA had an information stand at the event for 3 days that was manned by Gemma O'Dowd, Marie McGowan, Eddie Cassidy and Nicola Cassidy at different times. We received great feedback from everyone who visited our Irish themed table that displayed all the ILFA literature and resources, as well as shamrock confetti and Irish toffees. We invited everyone who visited our stand to sign our 'Visitors Book'. We welcomed some familiar friends from Ireland as well as international visitors from India, Switzerland, France, Italy, Scotland, England, the Netherlands, Israel, and the USA.

The Canadian Pulmonary Fibrosis Foundation also had an information stand at the event and it was great to meet our Canadian colleagues Robert Davidson and Jennifer Mota and share our patient advocacy experiences.

Some of the world's biggest and best known IPF doctors visited the ILFA stand including Professor Athol Wells (Royal Brompton Hospital, London, UK), Professor Hal Collard (University of California San Francisco Medical Centre, USA), Professor Sonye Danoff (Johns Hopkins Hospital, Baltimore, USA) and Professor Luca Richeldi (University Hospital Southampton NHS Foundation Trust, UK). It was very exciting to meet the 'giants' of medicine who are leading the way in IPF care, and also very humbling to hear their words of encouragement for the work ILFA does in raising awareness and supporting patients and family carers both locally and internationally.

ILFA would like to extend sincere thanks to Professor Michael Keane and Professor Seamas Donnelly for inviting ILFA to be present at this most prestigious conference.

Forum for National Clinical and Integrated Care Programmes

Petra Grehan, respiratory physiotherapist at the National Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital attended the National Clinical and Integrated Care Programmes Conference at the Royal Hospital Kilmainham on Tuesday 18th October. The theme for the conference was "The Journey to Person-centred Integrated Care: New Ways of Working".

Petra presented a poster entitled "Information and exercise promotion initiatives for the Irish Idiopathic Pulmonary Fibrosis Population" and described the special collaboration between the Physiotherapy Department at the Mater Hospital and ILFA, and the development of the 2000 Steps a Day Exercise Challenge and the ILFA Exercise DVD for lung fibrosis patients.

European Respiratory

The European Respiratory Society (ERS) Congress took place in London from 3rd to 7th September, 2016 and was attended by almost 24,000 healthcare professionals with an interest in respiratory medicine. Incredibly, there were 560 sessions dedicated to Idiopathic Pulmonary Fibrosis (IPF) with oral presentations and poster presentations taking place each day.

Nicola Cassidy and Liam Galvin represented ILFA and the European Union IPF Federation (EU-IPFF) respectively at a Patient Organisation Networking Day organised by the European Lung Foundation (ELF) on 3rd September. The event consisted of lectures, poster presentations and workshops and 64 individuals representing 45 patient organisations across 25 countries participated. Nicola Cassidy gave an oral presentation entitled “Patient input in the European Respiratory Society taskforces” and described ILFA’s involvement with the ERS taskforce on IPF. Group workshops explored the use of social media, EU funding and the European Patient Ambassador Programme.

On Sunday 4th September, the session entitled “Early Diagnosis of IPF: A Patient Journey” was packed full to capacity. The invited speakers were all from the Royal Brompton Hospital in London, one of the world’s leading IPF specialist centres. The expert panel was made up of Professor Athol Wells, Dr Toby Maher, Anne-Marie Russell, Professor David Hansell and Professor Andrew Nicholson. The multi-disciplinary team described 4 interesting and difficult real cases where the experts were split on whether the patient should be diagnosed with IPF or an alternative interstitial lung disease (ILD).

Nicola Cassidy and Liam Galvin.

IPF can be extremely difficult to diagnose and up to 40% of cases do not meet the criteria needed to reach a definitive diagnosis of IPF. These cases are therefore initially described as ‘unclassifiable’ and are given a ‘working diagnosis’ of IPF until more clinical information comes to light. It is vitally important for the patient and the clinicians to have a correct and definite diagnosis in order to manage the patient well and prescribe appropriate medication and treatments. The four cases were discussed in depth and the experts carefully considered the patients’ signs and symptoms, the results of lung function tests, high resolution CT scans and lung biopsies, and the behaviour of disease progression over time, in order to reach an agreement on the final diagnosis of IPF. The session highlighted the importance of the skilled multi-disciplinary working together to help diagnose the patient correctly and in a timely manner.

On Monday 5th September, another session entitled “Where do we go from here? Personalised medicine and patient focussed care in IPF” was also packed to capacity. The invited speakers in this session came from IPF specialist centres in the UK and the USA and included Professor Luca Richeldi (UK and Italy), Professor Hal Collard (USA), Dr Toby Maher (UK), Professor Sonye Danoff (USA) and Geraldine Burge (UK). Prof Richeldi told the audience about the major advances in our understanding of IPF.

Nicola Cassidy (ILFA) with Professor Athol Wells (Royal Brompton Hospital London) and Sarah Masefield (European Lung Foundation).

Anne-Marie Russell (Heart and Lung Institute, London) with Nicola Cassidy (ILFA).

Last year more than 700 medical articles on IPF were published in medical journals and while this represents enormous growth in the field it also poses a challenge for healthcare professionals to keep up to date with developments. The experts discussed genetic risk factors, bacterial and environmental contributions and biomarkers (biological measurements) associated with IPF.

The presentations by Professor Danoff and Geraldine Burge were particularly powerful as both discussed the need to put patients at the centre of the healthcare process. Both speakers stressed the importance of getting to know the patient as an individual, understanding their values, goals and needs. Knowing what matters to patients is essential to help them respond to and adapt to living with IPF.

On Tuesday 6th September, Nicola Cassidy gave an oral presentation entitled “The Development of a National Patient Charter for IPF” to a packed auditorium at a session called “IPF – Clinical Update”. This was a very prestigious occasion for ILFA and we are very proud that our patient advocacy work was selected to be show-cased with research from the world’s leading IPF doctors and scientists.

Anne-Marie Russell, a clinical researcher at the National Heart and Lung Institute, London, gave an oral presentation entitled “Health status and impact of living with IPF: UK and Ireland Delphi survey.” A special report from Anne-Marie

Society Congress 2016

on her research is included below. Some of the other topics covered during the congress included insights from various IPF registries around the world, an update on the use of cryo-biopsy techniques for taking lung tissue samples, new data on the real life experiences of patients prescribed the anti-fibrotic medicines pirfinidone and nintedanib, and symptom control and quality of life. The 2016 European Respiratory Society Congress was a fast paced, energetic, interesting and educational meeting that provided excellent scientific and clinical updates on the latest research and developments in respiratory medicine. Next year the ERS congress will take place in Milan, Italy.

Patient Reported Outcome Measures

- a report by Anne-Marie Russell

ILFA has been a great supporter of my work to develop a patient centred outcome measure specifically for people with Idiopathic Pulmonary Fibrosis (IPF). Hopefully in the longer term, this measure will also include people with other lung fibrosis conditions.

In 2009, the Federal Drugs Administration (FDA) in the United States issued guidance regarding the development and use of Patient Reported Outcome Measures (also known as PROMs) for research. The IPF-PROM set out to adhere to this ensuring that its history through each stage of development is transparent and accessible. It is important to me that the IPF community including patients, caregivers and healthcare professionals have ownership of the IPF PROM and I therefore selected a methodology that would enable this to happen. A good measure has to be both reliable and meet certain validity criteria. Working closely with the IPF community including IPF charities has ensured that this measure has a high level of face and content validity - i.e. it is relevant and measures what is important to people living with IPF.

Statements about IPF were collected from patients and healthcare professionals working in Interstitial Lung Disease. We started out with over 500 statements 3 years ago which were systematically reduced using consensus methods. Essentially this approach resulted in rounds of voting and discussion by patients who are experts in knowing and understanding their condition and how it impacts upon life; their caregivers who have a unique perspective, and healthcare professionals who contributed an objective understanding.

ILFA members actively contributed to a third round of the IPF PROM Delphi survey either online, via social media or on paper hard copy. Across Ireland and the UK over 500 people accessed the survey and almost 300 people completed this, whilst 70 people completed a portion of the survey.

An update on this work was presented at the European Respiratory Society Congress in London in September. We were able to demonstrate that working with IPF charities such as ILFA is feasible, reliable and an efficient way to gather a large volume of responses across the UK and Ireland in a short period of time (4 months) in IPF, a rare condition. This approach has enabled the volume of responses that I need to apply the appropriate psychometric analysis to these data.

We are now starting to validate the IPF-PROM which has been reduced to less than 10 items. We hope to demonstrate that we have developed a patient centred, user friendly questionnaire that captures succinctly what it is like to live with IPF.

We are working with patientMpower to integrate the IPF PRoM into the IPF phone and tablet app further promoting an approach that works for patients and contributes to shared doctor-patient understanding in the consultation. We will keep you updated and thank you for your continuing help and support.

Raising awareness

Thanks to Lindsay Brown and Lynn Fox, respiratory nurse specialists at St Vincent's University Hospital Dublin and the Mater Misericordiae University Hospital Dublin respectively, who held information stands at their hospitals during IPF World Week. ILFA materials were distributed to staff, patients and hospital visitors to raise awareness of IPF. Well done to Lindsay, Lynn and their colleagues.

Above: David and Bernard. **Top right:** Carol Buckley and Lynn Fox.

Above: Lindsay Brown, Deirdre Donaghy and Patricia Jones.

IPF World Week

Idiopathic Pulmonary Fibrosis (IPF) World Week took place from Saturday, 17th September until Sunday 25th September. IPF World Week aims to create an international network to support patients living with IPF and a number of events took place globally.

On Tuesday 20 September ILFA organised a photo shoot with patients and their spouses to mark IPF World Week. We assembled at Fitzwilliam Square in Dublin city centre and Dolores Williams (IPF patient), her grandson Matthew and husband Matthew attended along with Brian Lenehan (IPF patient) and his wife Emer. Terence Moran (ILFA Chairman), Eddie Cassidy (Treasurer), Gemma O'Dowd and Nicola Cassidy also attended.

Thankfully it was a lovely warm and sunny day - perfect for taking photographs! The theme for IPF World Week was 'Breath of Hope' and lots of fun was had by everyone blowing huge bubbles. Young Matthew was the star of the photo shoot and thoroughly enjoyed himself. The photos taken on the day were lovely and were issued to the national and local press along with a press release announcing IPF World Week. The photos were featured in the Irish Independent and other local publications.

The photo shows Dolores Williams with Matthew Williams Snr. and Matthew Williams and Emer and Brian Lenehan.

ILFA on the airwaves

Interview with Phoenix 92.5 FM

Dermot King, Jim McFadden, Nicola Cassidy, Ann O'Connor and Connor Williams.

Phoenix 92.5 FM invited ILFA to take part in an interview on their weekly programme entitled 'Access All Areas'. On Thursday 22nd September, Dermot King, Nicola Cassidy and Gemma O'Dowd attended the Phoenix 92.5 FM studio at Blanchardstown Shopping Centre in Dublin and were met by Ann O'Connor, Jim McFadden and Connor Williams, the programme producers. We were given a very warm welcome, and relaxed and chatted over a coffee in advance of the radio interview.

The live interview took place at 3pm. We were very excited to see the studio and were impressed with the set up. Although we were slightly nervous, once we had our headphones on and microphones set up, we soon relaxed and enjoyed the experience.

Connor interviewed Dermot and Nicola and asked about IPF and living with and managing the condition. Dermot spoke about his diagnosis, the benefits of exercise, how portable oxygen allows him to leave the house and attend pulmonary rehabilitation classes in Dublin City University and meet with friends in the Dublin support group. Nicola spoke about the impact of IPF on family carers, how ILFA supports patients and caregivers, and also took the opportunity to thank all of the dedicated fundraisers who have worked so hard to fundraise to keep ILFA going for the last 14 years.

ILFA is very grateful to the team at Phoenix Radio for their help in raising awareness during IPF World Week. The radio station has an impressive listenership of 90,000!

TV3 and Ireland AM

ILFA Exercise Ambassador and GAA Star Michael Darragh Macauley and his aunt Edna Powell were interviewed by Laura Woods and Mark Cagney live for Ireland AM at TV3 studios.

Michael Darragh and Edna spoke about their family's personal experience of IPF and the importance of organ donation and lung transplantation. Michael Darragh's father, Dr Michael Macauley - a GP, was diagnosed with IPF in 2006. While on the lung transplant waiting list, he was called for a potential transplant on three occasions. Sadly he was not a match and did not survive to receive a new lung. A few years later, the family was once again faced with IPF when Michael Darragh's aunt Edna was also diagnosed with the condition. Thankfully, Edna received a lung transplant last year thanks to the generosity of an organ donor and Edna went on to complete the VHI Women's Mini Marathon in aid of ILFA in June 2016. Edna and Michael Darragh paid special tribute to the great work being done at the National Lung Transplant Centre in the Mater Misericordiae University Hospital in Dublin and urged everyone to carry an organ donor card. Edna also expressed her gratitude to ILFA for the support she received and indeed we are extremely grateful to Edna and Michael Darragh for raising valuable awareness.

'Fight IPF' Launch

During the summer, Roche Products Ireland approached ILFA with an idea to produce patient videos to promote a new patient focussed website, www.fightipf.ie. This project was part of a wider global campaign for Roche pharmaceuticals and followed on from the success of the 2015 Irish **'Love Your Lungs'** video campaign featuring Dolores Williams' personal story of IPF.

Three patients kindly and enthusiastically agreed to let a camera crew into their lives for a day to make a short video about how they remain positive while living with IPF. Pamela Martin from Dublin, Noreen O'Carroll from Tipperary and Bob Cooke from Cork allowed us a glimpse of their personal home life and shared their thoughts on how they were diagnosed with IPF and how they continue to live well, stay positive, and fight IPF.

Dr Emmet McGrath, Dr Modestas Jarutis, Nicola Cassidy and Professor Jim Egan (courtesy of Roche Products Ireland).

Noreen O'Carroll and Pam Martin (courtesy of Roche Products Ireland).

The videos were launched in September at a special event held in Dublin. The event was well attended by healthcare professionals, members of the ILFA committee, family and friends, and members of the Dublin and Midland Support Groups who travelled to support the **'Fight IPF'** stars, Pam, Noreen and Bob.

Speakers at the event included Dr Modestas Jarutis, Medical Manager of Roche Products Ireland, Professor Jim Egan (Mater University Hospital), Pam Martin, Noreen O'Carroll and Nicola Cassidy (ILFA Director). The videos were shown to much applause and appreciation.

The videos are featured on the website, www.fightipf.ie and were promoted with a social media campaign on the ILFA Facebook page that reached over 1 million people which is an amazing achievement. The more people who know about IPF, the better.

We are hugely grateful to Roche Products Ireland for their support and partnering with ILFA to deliver this project and to Pam, Noreen and Bob for helping raise awareness of IPF and inspiring us with their positivity.

Dermot King, Pam Martin, Sylvia Ryan, Dolores Williams, Noreen O'Carroll and Trz McHugh.

Anthony Marnell, Noreen O'Carroll and Tom Flynn.

Love Your Lungs

Roche Products Ireland in partnership with Edelman (PR company), ILFA, COPD Support Ireland and the Asthma Society won an Irish Healthcare Award for the Best Pharmaceutical Education Product at a gala awards ceremony held in the Shelbourne Hotel in November.

The 2015 **'Love Your Lungs'** videos featured three patients from the 3 patient organisations, Dolores Williams represented ILFA, Betty Sutton represented COPD Support Ireland and Max and his mum represented the Asthma Society of Ireland. Dolores' video captured the importance of embracing life, and how maintaining a positive outlook and engaging in exercise can help patients manage IPF. All three videos achieved great success online and via social media and helped raise awareness of the importance of good lung health and living well. To our delight, **'Love Your Lungs'** was short-listed for a coveted Irish Healthcare Award. The awards ceremony took place on 10th November and ILFA was represented by Dolores Williams – star of the ILFA video, and Nicola Cassidy. We were joined by our friends Damien Peelo and Erika White from COPD Support Ireland, Averil Power from the Asthma Society and members of the team at Roche Ireland and Edelman.

Nicola Cassidy and Dolores Williams.

There was great cheering, clapping and excitement as Roche and 'Love Your Lungs' was announced as the winner in the Best Pharmaceutical Education category. The award was accepted by Dr Modestas Jarutis, Medical Manager of Roche Products Ireland on behalf of his team, Edelman and the three charities. We are thrilled!!

Fundraising Round Up

Tullamore Golf Classic

The Tullamore Golf Classic fundraiser held in aid of ILFA and the Irish Sarcoidosis Support Network took place on Friday 6th August at Tullamore Golf Club, Brookfield, Co Offaly. The event was expertly organised by Mary and Tim Guiney with the support of the Midlands Lung Fibrosis Support Group.

Thankfully the weather was good and 44 teams and 176 players took part in the event. Everyone had a great time and the fantastic sum of €2750 was raised for each of the two charities.

The photos above shows (1) members of the Midlands Support Group who helped out on the day - Mary Guiney, Anthony Marnell, Paddy Keenaghan and Tom Flynn. (2) Tom Flynn, John Carroll, Mary Guiney, Paddy Keenaghan and Val Kennedy - with the presentation cheque. Thanks to the organisers, supporters and players who participated in the event and to Tullamore Golf Club for their support.

Sadly Mary Guiney passed away in November. This article is printed with kind permission from Mary's husband Tim.

The 2016 Pat Casey Memorial Cycle

- a report by Anne Casey

On Saturday 10th September, a group of cyclists and support crews set out from the Cork City Ford Centre on Forge Hill on a 150k cycle to Limerick via Tipperary and back in aid of ILFA and Cork University Hospital.

The cyclists were led off by piper Theresa Hartnett and drummer Tony Hartnett. An Garda Siochana motorcycle division and vintage cars accompanied the cyclists for the start of the journey. The weather was favourable to the cyclists on Saturday and the support crews were kept busy repairing punctures. All the participants arrived safely and stayed overnight in the South Court Hotel Limerick where they were well looked after by friendly staff.

After a good night's rest, the cyclists and crew set out on the 100 km homeward journey. From the start of day 2, the brave cyclists had to work very hard against the wind but they battled the conditions and arrived home safe but tired to a welcome reception at the Cork City Ford Centre.

The event organisers would like to thank all the participants and volunteers and John Nolan of the Cork City Ford Centre.

Cyclists: Shane Kearney, Tim O' Sullivan, Martin Davies, Robert Sneddon, Maria Tracey, James Wilson, Pat O Connor, John Paul Power, Fergus Madden, Graham Desmond, Dr Mike Henry, Ray Leahy, Brian Aherne and Daniel Leahy.

Drivers and Safety Crew: Mark O'Shaughnessy, Pat Kelly, Martin Casey, Matt Alsford, and Billy O' Connell (paramedic).

Catering: Mary O' Donovan, Anne Casey, Josephine Daly, Christine Lyons, Noreen Aherne, Brian and Margaret Mahar.

A big thank you to all our collectors who turned out for the bucket collection on 9th September despite the 'Yellow Weather Alert Warning': Betty Gamble, Joe Gamble, Sarah Gamble, Lynne Lefondre, Margaret Nichol, Barry Kelleher, Martin and Mary Casey, Rachel Power, Elizabeth Woods, Anne Casey, Mary O' Donovan, Noreen Dwane, Billy O' Connell and Lisa Gamble.

ILFA would like to send special thanks to Anne Casey and Brian Aherne and all those who helped make the 2016 Pat Casey Memorial Cycle a great success. Thank you for all your hard work.

Fundraising raffle in aid of ILFA

Congratulations and thanks to the students of class 3B2, 3rd Year, Coláiste Muire, Realt Na Mara, Crosshaven, Co. Cork who held a raffle in aid of ILFA in October and raised the great sum of €200. Adam Ley kindly nominated ILFA to the class as his personal charity in support of his family members diagnosed with IPF. Anne Casey and Barry Kelleher from the IPF support group in Cork visited the school to tell the students about IPF and highlight the importance of organ donation and transplantation.

We would like to send our sincere gratitude to Adam, his fellow students, and teacher Mr Niall Haydon for organising the event. We are also grateful to the artist Carol Walshe from the United Kingdom who kindly donated one of her beautiful prints as a raffle prize.

The photo shows Erin Long, Jasmine Higgins, Anne Casey, Abbey Fitzgerald, Ivan Hall and Adam Ley with Carol Walshe's beautiful art.

Thank You

Sincere thanks to all the families who requested donations to ILFA in lieu of flowers at the funerals of their loved ones. We are very grateful for your support and kindness to ILFA at a time of great personal loss. ILFA is also grateful to the couples who made a donation to ILFA in lieu of wedding favours on their wedding day. What a kind and thoughtful gesture on your special day.

Limerick Mini-Marathon

Congratulations to Noreen O'Carroll and her family and friends who took part in the Limerick mini-marathon on Sunday 30th October. Noreen is an IPF patient and features in the 'Fight IPF' video. Well done everyone!

Support from the Irish Liverpool Fans

Huge thanks to Pam Martin and the 'You'll Never Walk Alone Irish Reds Club' for fundraising for two charities, ILFA and Team James. €350 was raised for both charities from a raffle held in McGarry's Pub, Harold's Cross. The photo shows Sinead Mooney, Anthony Grendon, Pam Martin and Simon Mooney. During the summer, Pam also kindly donated her prized Liverpool Jamie Carragher framed jersey for auction to raise funds for ILFA and Team James.

The lads from Irish Kop generously clubbed together and bought the jersey for €1000 resulting in €500 being donated to each charity. But, their generosity did not end there, as they decided to present James with the prized jersey. We can only imagine how excited James must be!

The photo shows Vicki Casserly, Pam Martin, James Casserly, Gerry Farrell, Peter Gordon and Mark Lacey.

Thanks to Pam and her friends in Irish Kop for their kindness and support.

Photos (left to right): Andrew Grehan, Dan Morris, ILFA Cheerleaders, Eddie Hogan, Niall Hackett, and Andrew Grehan with Sarah Masefield (formerly with the European Lung Foundation)

Dublin City Marathon

ILFA's 2016 marathon heroes were Laura Byrne, Eddie Hogan, Dan Morris, Niall Hackett and Andrew Grehan who all successfully completed the gruelling 40km race to raise funds to support patients and loved ones, and honour family members.

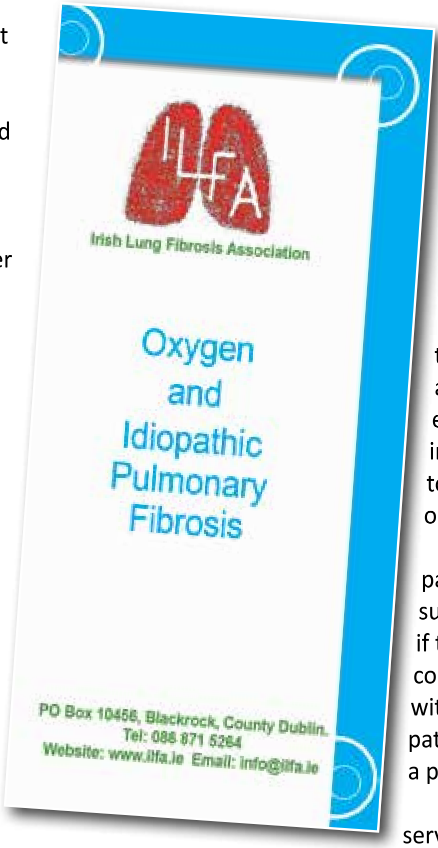
This year the marathon field was bigger than ever with almost 20,000 runners, joggers and walkers taking part, and for the first time in its history, the marathon took place on the Sunday of the October bank holiday. Thankfully the day was dry, the breeze was gentle and the temperatures were mild, and we're told it was a perfect day for running a marathon.

Andrew Grehan took part in his 8th marathon for ILFA in memory of his aunt Denise Cassidy. His cheerleading group was made up of his wife Stephanie, his mother Annette, his sister Laura, and his cousin Nicola who were at the start, half-way mark and at the end of the course carrying the giant ILFA banner and cheering everyone on. Eddie Hogan took part in his second Dublin City Marathon for ILFA in support of his father. Laura Byrne is a physiotherapist and wanted to help raise funds for ILFA in support of patients. She told us she had a "great day!" Dan Morris told us "It was a great experience" - Dan took part in memory of his uncle and God-father, Paddy Morris.

Niall Hackett took part in memory of his dad Gerry who sadly passed away in 2014. Niall told us "I really enjoyed the experience of running my first marathon".

Thank you to Laura, Eddie, Dan, Niall and Andrew - these five are not just heroes; they're superheroes!!!

The National Respiratory Therapies Service Improvement Group



ILFA

Irish Lung Fibrosis Association

Oxygen
and
Idiopathic
Pulmonary
Fibrosis

PO Box 10456, Blackrock, County Dublin.
Tel: 086 871 5264
Website: www.ilfa.ie Email: info@ilfa.ie

In 2015, the National Respiratory Therapies Service Improvement Group was set up as part of the National Community Funded Schemes (CFS) Service Improvement Programme to develop quality services for community funded respiratory products by establishing national standards to ensure equal access, optimal patient safety, and value for money. The HSE currently spends approximately €25 million per year on respiratory therapies.

The Respiratory Therapies Service Improvement Group is developing a list of all the approved respiratory health products available to patients in the community. The future provision of these respiratory products and services will then go to public tender and new contracts will be negotiated to enhance the services provided to patients. The categories of products include;

- oxygen (including oxygen products and services, concentrators and associated consumables)
- nebulisers
- monitoring equipment

On 30th September, patient organisations were invited to meet with Frank Murphy, Head of Primary Care Services in CHO 2, Health Service Executive, and Chair of the National Respiratory Therapy Service Improvement Group, and other members of the National Respiratory Therapies Service Improvement Group including specialist staff from HSE procurement, respiratory nurse specialists, a public health doctor, a community physiotherapist and a respiratory consultant. ILFA was represented by Dermot King (patient representative) and Nicola Cassidy (ILFA Director). The other patient organisations in attendance were COPD Ireland, Cystic Fibrosis Ireland and Muscular Dystrophy Ireland. It was a very productive meeting and the patient organisations were given the opportunity to raise their concerns about the current provision of the oxygen equipment and services and future developments.

Under the new procurement process, the country will be divided into 3 geographical areas of approximately equal size (including a rural and urban mix) and population. Companies that supply respiratory products can submit tenders to the HSE to win a maximum of 2 out of 3 contracts in each region. The new process aims to deliver a high quality service to patients no matter where they live, and will ensure that all patients are given adequate training and support with their oxygen equipment. In addition, the process will lead to improved ordering processes, and will educate staff to ensure they are familiar with the equipment in order to support patients.

The proposed changes will mean that some patients may have to change their existing oxygen supplier (but not necessarily their oxygen equipment if they are happy with it). However, the new contracts will ensure that patients will be provided with the best equipment and service. Existing patients will be transferred to the new contracts over a period of time and will be notified in due course.

Under the new contract, all respiratory therapy service providers will have to;

- meet the required standards set out by the National Respiratory Therapies Service Improvement Group
- provide support staff to the geographical areas they are contracted to cover
- provide a 24-hour support telephone service for patients and caregivers
- repair or replace faulty equipment within 8-hours from the time of notification
- operate a complaints procedure and notify the HSE

ILFA will keep you updated with developments.

Lobbying Activities

ILFA undertook a number of lobbying and patient advocacy activities in 2016. A report has been submitted to The Register of Lobbying, maintained by the Standards in Public Office Commission.

- ILFA invited Minister Finian McGrath (Minister of State with special responsibility for disability) to spend time with an IPF patient to help raise awareness of IPF. Two videos were subsequently produced; 'A Day in The Life' and 'Raising awareness of IPF' featuring Dermot King and Minister Finian McGrath.
- ILFA submitted a pre-budget submission and a transplantation statement describing issues affecting IPF patients to Ministers Finian McGrath, Paschal Donohoe (Minister for Public Expenditure and Reform) and Simon Harris (Minister for Health).
- Liam Galvin (ILFA Director) wrote to the Irish Members of the European Parliament (MEP) seeking their support for the Written Declaration on IPF on behalf of ILFA and the European IPF Federation.
- ILFA wrote to Ministers Finian McGrath and Simon Harris to request a meeting to highlight the challenges faced by IPF patients. The request has been acknowledged and we await further correspondence.
- ILFA wrote to the National Respiratory Therapies Service Improvement Group and Ministers Simon Harris, Finian McGrath, Paschal Donohoe and Leo Varadkar (Minister for Social Protection) with the support of Alpha-1 Ireland, COPD Support Ireland, Cystic Fibrosis Ireland, Irish Cancer Society, Irish Heart and Lung Transplant Association, Irish Hospice Foundation, Irish Lung Health Alliance and the Irish Pulmonary Hypertension Association to highlight the financial burden to patients dependent on oxygen via electrical oxygen concentrators.

Digital Health Diary

Invitation to take part in user testing of patientMpower platform

Would you like to take part in a survey of a new digital health diary which has been specially designed for people with lung fibrosis?

This digital health diary has recently been developed by patientMpower Ltd., an Irish company, who have developed similar digital health diaries for people with other medical conditions such as kidney transplantation, now in use by people all over Ireland.

The patientMpower digital health diary works on any Apple or Android smartphone (like an iPhone or other touchscreen phone) or tablet device (like an iPad or Galaxy tablet).

The patientMpower digital health diary is an “app” that you download to your mobile phone or tablet device. The idea is that you can use your phone to keep a diary of various symptoms and other factors related to your lung health. For example, you can keep track of activity each day or record your level of breathlessness. If you usually keep track of your blood pressure or temperature regularly you can also use the digital health diary to record these. This digital health diary can also be used as a reminder to take your medicines each day and you can record when you take them. If you have symptoms you can keep a note of these on a regular basis.

When visiting for clinic appointments, it may be useful to have this type of information to hand so that you can tell the doctor or nurse about issues that may have been troubling you in the weeks before your appointment.

patientMpower want to find out how useful people with lung fibrosis find this health diary and are looking for volunteers to take part in a survey. They would like participants to use the health diary for one month and then answer a questionnaire to give your opinions on the digital health diary. This information will be useful in refining the design of the health diary to make it more useful and easier to use and this might benefit people in the future. If you have any technical questions on the patientMpower platform, feel free to contact them at 01 903 8558 or by e-mail at **info@patientmpower.com.**

The good news is that it is all free and if you like the patientMpower health diary you can keep using it for as long as you wish.

So if you have a smartphone or tablet device and you would like to take part in this survey of a new digital health diary for people with lung fibrosis please contact the Irish Lung Fibrosis Association at 086 871 5264 or by e-mail at **info@ilfa.ie** for an information pack.

Hand-held fans for managing shortness of breath

Shortness of breath is a common problem for lung fibrosis patients that can result in distress, fear and anxiety. There is some evidence that using a hand-held fan that blows cool air over the face can help to improve the sensation of breathlessness for some patients. The movement of air can help relax the nerves in your face which makes breathing easier. Concentrating on holding the hand-held fan also focuses the mind and this distraction can help your breathing.

ILFA has been looking for a suitable hand-held fan for patients to see if this simple technology can help improve the sensation of breathlessness. After months of searching for a suitable fan, we found it !!! Its small, light-weight, and easy to use. You could even say it’s **Fantastic!**

You can order your hand-held fan by calling ILFA on 086 871 5264 or emailing info@ilfa.ie

Please remember that the fans are not toys; they contain batteries, plastic blades and small parts that may detach. The fans should not be given to children to prevent accidental injuries.

ILFA would like to know about your experience of using the hand-held fan and find out if it helped you when you were short of breath. We will send you a questionnaire when you order a fan and would be very grateful if you would fill out the questionnaire and return it to ILFA. An online questionnaire is also on the website - www.ilfa.ie

Patient Support Groups

Cork Support Group

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

Dublin Support Group

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

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at the Rose Hotel. **Please call Adrian on 087 241 4004 for more details.**

Midland Support Group

The group meets on the first Wednesday of every month at 2.30pm at the Tullamore Court Hotel, Tullamore, Co. Offaly. **Please call Tom on 086 150 0970 or Anthony on 087 258 5699 for more details.**

Southeast Support Group

Please call Laura on 087 285 4509 for more information.

Cavan Monaghan Support Group

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

Mid West Support Group

Noreen O'Carroll is hoping to set up a support group in Limerick - Tipperary. **Please call Noreen on 087 262 7976 for more information.**

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

086 871 5264

Christmas Swim

The annual ILFA Christmas swim will take place on Monday, 26th December at 11.45am at Sandycove Pier, Sandycove, Co. Dublin.
Refreshments will be served afterwards at Fitzgerald's Pub, Sandycove. All are welcome. Please call 086 871 5264 or email info@ilfa.ie for a fundraising pack.

Matt Regan at the ILFA 2015 Christmas Swim

Dates For Your Diary

- The Fergus Goodbody Memorial Lecture for healthcare professionals will take place on Tuesday 14th February at the Royal College of Surgeons in Ireland, St Stephen's Green at 5.30pm. ILFA was set up in memory of Fergus Goodbody and every two years, ILFA invites an international expert to deliver a state of the art lecture to healthcare professionals in Ireland. Professor Jeurgen Behr from Munich will deliver the keynote address entitled "IPF - Novel Trends in Diagnosis and Treatment." Please contact ILFA for more information.
- Next year ILFA will celebrate our 15th anniversary. Watch this space!

Message of Condolence

The ILFA committee would like to extend our sincere condolences to the families and friends of Mary Guiney and David Mulcahy who passed away recently. Mary and David made significant contributions to ILFA and their local communities and they will be greatly missed. May they rest in peace.

Mary was a lung transplant recipient, one of the leaders of the Midlands Support Group in Tullamore, and a dedicated fundraiser for ILFA over the last few years. In August, Mary and her husband Tim organised a hugely successful golf tournament at Tullamore Golf Club and raised the fantastic sum of €2750 each for ILFA and Sarcoidosis Ireland.

David was a lung transplant recipient. David, along with Pat and Anne Casey and Shelley Fennelly, set up the Cork IPF Support Group, the first IPF support group in Ireland. Raising awareness about IPF was important to David and he helped and encouraged the leaders of the Kerry, Midlands and Dublin Support groups to set up monthly meetings. These groups continue to support those in the IPF Community and their families. David and his daughter Sancha served as members of the ILFA committee in the past.

Keep in touch with ILFA

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

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