

ILFA Newsletter



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

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Irish Lung Fibrosis Association
www.ilfa.ie

Celebrating ILFA's 15th anniversary

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

ILFA invited individuals and groups to share their experiences and personal perspectives with us and ILFA 15 features articles from patients, doctors, nurses, allied healthcare professionals, clergy, researchers, patrons, professional respiratory bodies including the Irish Thoracic Society and European Lung Foundation, volunteers, family members, fundraisers and support group members.

ILFA 15 was officially launched during IPF World Week on 22nd September by Professor Jim Egan, ILFA Director. Invited guests including patients, family members, healthcare professionals and fundraisers, many of whom had contributed articles to the magazine, gathered at Buswell's Hotel in Dublin to celebrate the launch of ILFA 15. There was great excitement as the bumper 88-page magazine was distributed. A few short speeches were delivered by Nicola Cassidy (ILFA Director and magazine editor), Prof Jim Egan, Matt Cullen (patient, fundraiser and support group leader), and David Crosby (lung transplant recipient and fundraiser) who described their involvement with ILFA.



Dermot King and Joan Doyle at the launch of ILFA 15.

ILFA 15 is dedicated to the memory of Terence Moran, co-founder and former Chairman of ILFA, who sadly passed away suddenly in August. Prof Egan paid special tribute to Terence Moran for his great work on behalf of patients and families affected by IPF. Terence's son, Thomas, attended the launch.

We are very grateful to everyone who contributed articles to the magazine. We would like to extend our deep gratitude and special thanks to Ken Powell, who volunteered his time and gave great help, insights and advice in collating the magazine as co-editor. A selection of photos from the launch is featured on page 4.

ILFA Chairman

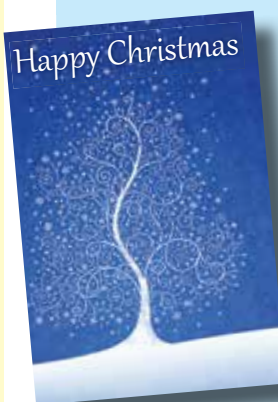


Eddie Cassidy from Dublin is the newly elected ILFA Chairman. Eddie has served as a voluntary member on the ILFA committee for more than 10 years and was appointed as a Director of the charity in 2016. Eddie has also served as ILFA Treasurer for 5 years.

"I am honoured to take on his new role and I hope to continue the great advocacy work of Terence Moran who served as ILFA Chairman from 2002 to 2017. I would like to take this opportunity to express my sincere gratitude to everyone who contacted ILFA to express their condolences following Terence's sudden passing in August. I look forward to progressing the work of ILFA with the great support of ILFA's members and my fellow committee members"

– Eddie Cassidy

Christmas cards



ILFA Christmas cards are now on sale and available to order. Each pack contains 10 cards with 2 cards each of 5 colourful festive designs. The cards are produced in Ireland. One pack of cards costs €6 and two packs cost €10. Cards can be ordered by calling 086 871 5264 or emailing info@ilfa.ie

Please help us raise awareness of lung fibrosis this festive season.

ILFA Service of Prayer and Reflection 2017



The 5th annual ecumenical ILFA Service of Prayer and Reflection took place on Saturday

14th October in the beautiful surroundings of Our Lady of Mount Carmel Whitefriar Street Church, in Dublin. The first ILFA Service of Remembrance and Thanksgiving also took place at this wonderful location in 2012, when many ILFA members from across the country gathered to celebrate our 10th anniversary as a voluntary charity. It was a very special and important ceremony, and significantly it laid the foundation for this event to become an annual and much loved fixture in ILFA's calendar.

Fr Brian McKay O.Carm., Prior of Whitefriar Street Church, warmly welcomed everyone to the Carmelite church and fondly reflected on the various ILFA services that have taken place over the last 5 years. Fr Brian paid tribute to his fellow clergy members; the Reverend Vanessa Wyse-Jackson of Rathgar Methodist Church, and Canon Charles Mullen, Dean's Vicar at St Patrick's Cathedral, who have also participated in each of the ecumenical services, and once again joined us to lead our prayers in 2017.

The 2017 Service was dedicated to the memory of Terence Moran (co-founder of ILFA and Chairman from 2002-2017) who sadly passed away suddenly in August 2017. During the ceremony, ILFA Directors; Eddie and Nicola Cassidy, lit a special candle together in Terence's honour. Eddie Cassidy, who was recently appointed as the new ILFA Chairman, paid special tribute to Terence in his welcome address to the congregation. Later, Canon Charles Mullen also recalled Terence's great work for ILFA in his homily where he described eloquently the power of light over darkness.

Our readers came from all over the country and included patients, family members, fundraisers, healthcare professionals, and Michael Darragh Macauley (ILFA Patron). Everyone read superbly, and the specially chosen prayers and readings took on great meaning. Thanks to Dermot King, Dr Charlene Getty, Maria Love, Michael Darragh Macauley, Peter

Gallagher, Deirdre Donaghy, Robert McCutcheon and Ann O'Flaherty for reading.

The ladies and gentlemen of the Culwick Choral Society, under the musical directorship of Bernie Sherlock, performed two beautiful pieces; *For Unto Us A Child Is Born* (Handel - Messiah), and *Thanks Be To God* (Mendelssohn - Elijah). The choir also joined the congregation in singing a series of much loved hymns. Stuart Nicholson, Master of the Music at St Patrick's Cathedral, accompanied the choir on the organ and performed beautiful solo pieces for reflection during the service.

Candles were lit in remembrance of loved ones with IPF who have passed away by two respiratory nurses; Lorna Murphy (formerly of the Mater Hospital and ILFA) and Mary Poland (Tallaght Hospital), as names were called out from the altar by Eddie and Nicola Cassidy. David Crosby, a double lung transplant recipient from Cavan, lit a special candle in honour of all organ donors. The gentle light and warmth from the candles flickered beautifully on the altar and we remembered our dearly departed with love.

After the service ended, we gathered in Whitefriar Street Church and Community Centre Hall to share tea, coffee, cakes, biscuits and conversation. The hall was packed, and it was a great social occasion. Sincere thanks to Jerry Pouch and the staff at Whitefriar Street Community Centre for looking after us so well. Thanks also to all those who contributed home baking, biscuits and sweets for all to enjoy.

We hope everyone who attended the service found comfort and support through prayer, music, song and fellowship. We are always touched when people get in touch with feedback. Here are some of the comments we received;

- "Absolutely beautiful service"
- "A truly moving and lovely service"
- "Beautiful service. It was extremely moving and dignified and obvious that a lot of planning went into it."

Warmest thanks to the clergy for their great dedication, friendship, guidance and support over the years. We are indebted to Revd Vanessa Wyse-Jackson, Fr Brian McKay for their participation and to Canon Charles Mullen for his help and enthusiasm with planning the service.

The Culwick Choral Society will present their Christmas Concert at the National Concert Hall in Dublin on Monday 11th December. **Please see www.nch.ie for more information.**

Ecumenical Service of Prayer and Reflection

Once again it was my privilege to represent the Church of Ireland at the annual Ecumenical Service, held this year at the Church of Our Lady of Mount Carmel where we received a warm welcome from the Prior, Fr Brian McKay. The Revd Vanessa Wyse-Jackson, representing the Methodist Church,



Robert McCutcheon of the Irish Heart and Lung Transplant Association



Lorna Murphy



Peter Gallagher



Eddie Cassidy



Michael Darragh Macauley



Canon Charles Mullen, Fr Brian McKay and the Reverend Vanessa Wyse-Jackson



The Culwick Choral Society



The Killeen Family



Joan and John Doyle with Brian and Evelyn Cooper

joined him and me in leading the Service.

The Christian faith is lived in the here-and-now, but it points us all in two directions: to the past, in grateful thanks for God's blessings already received; and to the future, in which we will receive Christ's promise of eternal life. We take account of this in the Service: we encourage one another in our friendship by gathering together in

God's house, and we light candles in memory of those who have gone before us to be in God's nearer presence. Many of you have expressed thanks for this special time to find comfort, consolation and hope. It's my firm hope that we will continue to pray together as we journey together.

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

ILFA15

launch



Prof Jim Egan, Petra Grehan, Nicola Cassidy, Maria Love and Prof David Healy



Lynn Fox, Gemma O'Dowd, Prof Jim Egan and Nicola Cassidy



Michael and Ann O'Flaherty, Annette Grehan, Nicola Cassidy and Mick Osborne



Anne Casey, Gemma O'Dowd, Mary O'Donovan and Lorna Murphy



Evelyn and Brian Cooper



Val Kennedy and Kitty Keenaghan



Matt Cullen and Maria Love



Frances Coffey, Patrick Keenaghan and Avril Cooke



Michael Darragh Macauley



Professor Anthony O'Regan



Anne-Marie Russell



Nicola Cassidy and Ken Powell



David Crosby, Prof Egan, Dolores Williams and Peter Gallagher



Prof David Healy, Lynn Fox, Syliva Cerasi and David Crosby

European Respiratory Society Congress

The European Respiratory Society's (ERS) annual congress took place in Milan, Italy from 9th-13th September. Over 220,000 respiratory doctors, nurses, scientists, researchers, pharmaceutical companies and patient representatives from all over the world attended the congress to learn about the latest developments in respiratory medicine. This year there were more sessions dedicated to Interstitial Lung Disease (ILD) and Idiopathic Pulmonary Fibrosis (IPF) than ever before and the venues were all packed to capacity.

It was an extremely busy few days for ILFA Directors, Liam Galvin and Nicola Cassidy as they attended meetings, workshops and lectures, and delivered poster presentations on ILFA's work. On 10th September, many EU-IPF Federation members, global patient organisations, and healthcare professionals met with Elizabeth Estes and Ken Bahk from Three Lakes Partners (a US philanthropy group). Five patient organisations were invited to showcase examples of patient-centred projects and Nicola Cassidy spoke about ILFA's 2000 Steps a Day Exercise Challenge. There was great interest in how this exercise programme could potentially be used by other IPF patient organisations around the world to help benefit patients.

Some of the highlights of the ERS Congress included excellent presentations on developments in the basic science of interstitial lung disease and idiopathic pulmonary fibrosis, new ways to monitor the progression of lung fibrosis using advanced CT imaging techniques and computer simulations, valuable insights from international patient registries, real-life patient experiences of using anti-fibrotic medication, emerging results on the use of potential biomarkers for monitoring disease progression, promising pharmaceutical therapies that have performed well in early clinical trials and much more.

Nicola Cassidy presented ILFA's work at two poster discussion sessions. The first presentation was entitled 'The impact of dyspnoea and strategies used by lung fibrosis patients to relieve breathlessness'. The second poster was called 'Collaborating with stakeholders to advance the National Patient Charter for Idiopathic Pulmonary Fibrosis in Ireland'. Both posters were well received and generated discussion with the audience.



Nicola Cassidy, Elizabeth Estes and Ken Bahk from Three Lakes Partners, and Liam Galvin.



Jeanette Boyd and Pippa Powell (European Lung Foundation) with Liam Galvin.

International Collaboration on Palliative Care for ILD Patients

A paper entitled 'Palliative Care in Interstitial Lung Disease: Living Well' was published in *The Lancet*, one of the world's leading medical journals in September. This paper represents a major international collaborative project that was expertly led by Professor Michael Kreuter from Germany with many of the world's leading experts in Interstitial Lung Disease.

ILFA Director, Nicola Cassidy, was invited to contribute to this paper as a patient advocate and carer. It is great to see this important topic being covered so succinctly and getting the attention it needs and deserves.



Colin Edwards



patientMpower

Connected Health Conference

Colin Edwards from patientmpower presented a poster at the Connected Health conference in Boston, USA in October. The poster entitled 'Pilot study to test the utility and acceptability of an electronic health record (patientmpower) for patients with lung fibrosis' described the experiences of 13 patients in Ireland who used an app on their smart phone or tablet devices to record health measurements. The patients were recruited and supported by ILFA and we are very grateful to everyone involved in this important research.

Lobbying and advocacy activities

Meeting with the Minister for Health

On 21st September, a delegation from ILFA met with the Minister for Health, Simon Harris T.D., and representatives from the Department of Health, and Organ Donation and Transplant Ireland (ODTI) at Leinster House to discuss the move to a soft opt-out organ donation system.

We discussed;

- the timeline, resources, practicalities and benefits of introducing a soft opt-out organ donation system in Ireland, in line with the system in most EU countries.
- the need for additional funding and resources to ensure the timely opening of 7 unopened beds at the National Heart and Lung Transplant Unit at the Mater Hospital, Dublin.
- the need for greater autonomy for ODTI to facilitate a stronger advocacy role allowing it to fully engage with the public, all patient organisations with an interest in organ donation and transplantation, and healthcare professionals. We want the ODTI to be the voice of the donor families, patients on the transplant waiting list and patient organisations who support the move to an opt-out organ donation system.

The Minister was interested in hearing our views and we left feeling optimistic after a positive discussion. Huge thanks to Pamela Martin from Dublin and David Crosby from Cavan for their participation with Nicola Cassidy, ILFA Director. A follow-up letter thanking the Minister for the meeting and expressing ILFA's willingness to engage further was sent to Leinster House.

Submission on the Human Tissue Bill

ILFA made a submission to the Public Consultation on the Human Tissue Bill (including organ donation) calling for the introduction of a soft opt-out organ donation system with additional resources to raise awareness of the importance of organ donation, accelerate organ transplantation operations, and improve after-care for transplant recipients.

In addition, ILFA set up an online petition asking people to sign up with their name and email address to show support for the introduction of an opt-out organ donation consent system. Over 1,000 people have signed the petition. To add your support, please visit the website www.change.org and search for 'ILFA'.

During the summer, ILFA wrote to all the elected TDs to seek their support for the introduction of a soft opt-out organ donation system. Over 40 politicians responded and pledged their support. Please ask your local public representatives to support this move to an opt-out consent system to save more lives.

Irish Donor Network

The Irish Donor Network (IDN) is an alliance of patient organisations dedicated to promoting organ donation and transplantation in Ireland. The group consists of the Alpha One Foundation, Cystic Fibrosis Ireland, Irish Heart and Lung Transplant Association, COPD Support Ireland, Cystinosis



Nicola Cassidy, Pamela Martin, Simon Harris T.D. and David Crosby.



Prof Jim Egan (ODTI), Helen O'Brien (Department of Health), Nessa Lynch (ODTI), Pamela Martin and David Crosby.

Ireland, the Pulmonary Hypertension Association of Ireland and ILFA. The IDN held several meetings over the summer to discuss support for the introduction of a soft opt-out organ donation system. The IDN also made a submission to the Public Consultation on the Human Tissue Bill and written to all the TDs, Senators and Local Councillors to request their support for an opt-out organ donation system. The IDN has also requested a meeting with Simon Harris, T.D., Minister for Health.

Forum on the End of Life 2017

Gemma O'Dowd and Nicola Cassidy represented ILFA at the Irish Hospice Foundation's Forum entitled "Your Life, Your Death, Your Say" on 10th October 2017. The event took place in Dublin Castle and was attended by over 350 people. There were excellent presentations on planning for the future using the Irish Hospice Foundation's 'Think Ahead' document, palliative care, the importance of conversations about care preferences, and Advanced Care Directives. 'The Peoples Charter on Dying, Death and Bereavement' was launched at the event.

National Ploughing Championship 2017

ILFA hosted an exhibition stand at the National Ploughing Championship (NPC) in Scraggan, Tullamore, Co Offaly, from 19-21 September. This important outreach activity took place during World IPF Week (16-24 September) and was a great opportunity to raise awareness. This was ILFA's first time to attend the NCP and it arose following a suggestion, advice and encouragement from the Midlands IPF Support Group.

Gemma O'Dowd and Lindsay Brown from ILFA and our team of volunteers enjoyed welcoming everyone who visited our stand, located in the Health and Wellness section, over the three days.

Queues of people extended all around Scraggan from early morning each day and for hours before the official time of entry. The number of attendees at this year's NPC event was approximately 300,000.

Thank you to everyone who called by to visit our stand and learn more about IPF. Some visitors learned about lung fibrosis for the first time, and some were patients or had loved ones diagnosed with the condition. It was also a good way to inform the masses about ILFA and our work as a patient support organisation.

Overall ILFA's participation at the NPC was a massive success!

Huge thanks to our wonderful volunteers for helping us out and giving so generously of their time and talents. Their energy, passion and dedication to helping create awareness of pulmonary fibrosis saw no boundaries during the NPC.

Go raibh mile maith agaibh to Val Kennedy, Trish Conroy, Paddy and Kitty Keenaghan, Frances Coffey and David Crosby.



Val Kennedy, Patrick Keenaghan and Cllr. John Leahy.



Frances Coffey.



Val Kennedy, David Crosby and Gemma O'Dowd.



David, Val and Myra at the ILFA stand.

New security measures and back-pack restrictions

Following the introduction of new security measures and rucksack/back-pack restrictions for those attending public events and concerts, ILFA wrote to the major event promoters in Ireland to establish what these new controls mean for patients using supplemental oxygen.

A letter written by ILFA and co-signed by other patient organisations; Alpha One Ireland, COPD Support Ireland, Cystic Fibrosis Ireland, Irish Cancer Society, Irish Heart and Lung Transplant Association, Irish Hospice Foundation, Irish Lung Fibrosis Association, Irish

Lung Health Alliance, and the Irish Pulmonary Hypertension Association, was sent to the GAA, FAI, IRFU, Aiken promotions and MCD promotions.

All the event promoters responded positively, and the following guidelines were agreed;

- 1) In advance of the event, anyone using medical oxygen should contact the event organisers by email or telephone stating that they plan to attend the event, they are prescribed medical oxygen, and will have a portable oxygen medical device with them.
- 2) On arrival at the venue, you

should make yourself known to the event security and explain your circumstances and the nature and necessity of your oxygen device.

- 3) Ideally, you should bring along a letter, an e-mail or an official notification that states that you have a lung condition and are prescribed oxygen via a portable device.

All the event promoters are happy to support and assist clients using medical oxygen.

Please let us know if you encounter any difficulties with your portable oxygen whilst attending a public event.



Support group friends at the Savoy Hotel in Limerick.

IPF World Week 2017

Support Group Lunch

On Friday 15th September, 40 people from 5 support groups across Ireland came together at the Savoy Hotel in Limerick for a special lunch to mark IPF World Week and celebrate ILFA's 15-year anniversary. We had a delicious 3 course meal and a special birthday cake to celebrate! A great day was had by everyone who attended.

ILFA's Activities

Thank you to everyone who supported IPF World Week in Ireland to raise awareness of Idiopathic Pulmonary Fibrosis.

Here are some of the activities and events that took place in Ireland;

- ILFA launched a special edition magazine entitled ' ILFA 15' to celebrate our 15-year anniversary.
- a delegation from ILFA Ireland met with Simon Harris T.D., Minister for Health to discuss the introduction of an opt-out organ donation system.
- ILFA exhibited at the National Ploughing Championships in Co Offaly - the largest outdoor event in Europe.
- patient stories featured in the various newspapers including, The Echo, The Fingal Independent, The Swords Independent and online on www.independent.ie
- Noreen Carroll organised an information stand at Limerick University Hospital with the support of Advanced Nurse Practitioner, Paula Ryan, and her hospital colleagues.
- Eddie Cassidy (ILFA Chairman) and Peter Gallagher were interviewed in studio by Debbie McMahon on Near FM's Lifeline radio programme.
- ILFA raised awareness using the EU-IPF Federation's educational materials via our Facebook and Twitter pages.
- the HSE communications team were a great support and regularly tweeted information about IPF.
- members from 5 support groups gathered in Limerick for a celebratory lunch.
- ILFA hosted an information stand at the Irish Gerontological Society annual meeting in Wexford.

Thank you everyone for your support and raising awareness!



David Crosby, Clive Smyth, Bernard Meaney and Brid Meaney at the Support Group Lunch in Limerick.



Dr. Brian Casserly, Paula Ryan, Noreen O'Carroll, Maria Culhane and Olivia Quinn at Limerick University Hospital.



Peter Gallagher and Eddie Cassidy.

Fundraising Round Up

Cork Mini-Marathon



Congratulations to Aileen Swords who took part in the Cork Mini-Marathon on 24th September and fundraised for ILFA in memory of her father, Nicky Ring. Aileen was in touch and said "ILFA is a fantastic charity. Keep up the good work". Thank you for your great support Aileen!

Croagh Patrick Climb



Nicola Cassidy at the summit of Croagh Patrick.

Nicola Cassidy, ILFA Director, climbed Croagh Patrick in Westport, Co Mayo in August to fundraise for ILFA. It was a tough but pleasant climb helped by beautiful sunshine, light winds and great views of Clew Bay. At the top it was much cooler and windier!

Feile Lois Poil



Members of Feile Lois Poil on the fundraising walk.



John O'Sullivan presenting a cheque to Eddie Cassidy (ILFA Chairman).

Thanks to John O'Sullivan, his family, friends and neighbours, and Feile Lois Poil for fundraising on behalf of ILFA. The whole community came together and took part in a walk along the beautiful Kerry coast line in August.

John recently received a lung transplant and wanted to fundraise for ILFA as a token of his appreciation for the support he received through ILFA and the Kerry Support Group following his diagnosis with IPF.

Coffee morning

Thank you to the partners and staff at Hayes Solicitors in Dublin for holding a fundraising coffee morning for ILFA in September in memory of their esteemed colleague, Terence Moran (former ILFA Chairman). Marie McGowan from ILFA attended the coffee-morning.

A Heart for Art



Matt Cullen with Eddie Cassidy (ILFA Chairman).

Talented artist Matt Cullen sold two pieces of art that featured in previous exhibitions of his work in Dublin, and kindly donated the proceeds to ILFA.

Matt is one of the leaders of the Dublin IPF Support Group and a patient ambassador with the European Lung Foundation.

Wedding Favours



Congratulations and sincere thanks to the newly-wed couples who made kind donations to ILFA to support our work. We wish them all every happiness for the future.

Paul and Claire Evans are good friends of the O'Sullivan family in Lispole, Co Kerry, and they made a kind donation to ILFA to show their support for John O'Sullivan who is a lung transplant recipient.



Edel and Shane Kavanagh made a kind donation to ILFA in memory of Edel's beloved father, Dan, in lieu of wedding favours.



Annmarie and Gary Healy made a kind donation to ILFA in memory of Gary's father, Martin, in lieu of wedding favours.

The Pat Casey Memorial Cycle 2017



Cyclists at the start of the Pat Casey Memorial Cycle.

On Saturday 2nd September 2017, over 40 cyclists and support crew set out on the 122km round trip starting from the Cork City Ford Centre on Forge Hill, through Innishannon, Bandon, Clonakilty, Timoleague, Kinsale and finally returning to the Ford Centre again.

The weather was with us for most of the day - only turning nasty for the final leg of the journey.

Undeterred by this, the participants finished the route soaked

and exhausted, in an overall time of 6 hours and 12 minutes.

Amazingly, the leader of the pack finished one hour before the main group reached home!

The cyclists arrived back to a waiting barbeque and an amazing spread that was much appreciated by everyone.

On Friday 8th September, another fundraising event was held, and collectors took up posts at various locations around Cork city and

county, to help spread awareness and collect much needed funds.

A big 'Thank you' to all who were involved in both events.

We would also like to thank the ILFA for their continued support and partnership with this event. We are looking forward to the 2018 event already!

**A report by the event organisers
- Anne Casey, Daniel Casey
and Brian Aherne.**



Andrew Grehan.

Quadruple Challenge

Andrew Grehan took on an impressive quadruple challenge in August to fundraise for ILFA in memory of his aunt, Denise Cassidy. Andrew who has already completed 8 Dublin City Marathons for ILFA, set his sights on 'easier' challenges this year and took part in (1) the Celtic Warrior Half-iron Man Triathlon on 6th August, (2) Sprint triathlon on 7th August, (3) the Caroline Kearney Memorial Olympic Triathlon on 13th August and (4) the Pat Colgan Four Peaks Cycling Challenge on 26th August.

To add to Andrew's fundraising total his family organised a collection at the Fox-Grehan Annual Golf Challenge. Thank you to Andrew and all his supporters.

'Team 'O'Brien' Walk for JP during IPF World Week



The Boston Team.



The Kerry Team.



Eddie Cassidy (ILFA Chairman), Professor Jim Egan, Joan Beirne and Sheila Purcell (JP's sisters) from Tralee.

On 10th September 2017, a memorial walk took place in honour of JP O'Brien (of Tralee, Co Kerry and Boston, USA) who sadly lost his battle with IPF on 13th April 2017. It was an international event as his family and friends in Boston and Kerry did a 5km coordinated walk, with both teams setting out at the same time. The scenes however couldn't have been more different!! While the Boston bunch enjoyed a sunny lakeside walk wearing t-shirts, the Kerry crew were nearly blown into Tralee Bay whilst braving the elements. They were especially grateful at the end of the walk with the surprise refreshments provided by JP's nephew!

Both walks were a huge success with over 60 walkers taking part. Not only did they raise much needed funds for the IPF charities; the American PFF and ILFA, they also raised awareness of the condition. This was especially important for the O'Brien family as it's the third time this insidious disease has affected them. Niall Horgan (JP's bother-in-law) also lost his battle with IPF in 2015 after a second lung transplant and Joan Beirne, JP's sister, is doing extremely well after a lung transplant in 2015. So, they know only too well the importance of research and the work of ILFA.

Both JP and Niall are missed terribly by their families and

friends, and those dearest to them want something positive to come from their loss. They plan to continue to raise awareness of IPF by carrying on the new tradition of a yearly September walk. The families wish to extend their sincere gratitude to all who walked and generously donated, and to those who helped spread the word. They hope to see you all again next year!!

Report by Grainne Coffey

Malin to Mizen Cycle



Jason Nichol and Ciaran Holland.

Jason Nichol and Ciaran Holland took on the mighty 642km Malin to Mizen Challenge in aid of ILFA in August. The cycle started at Ireland's most northerly point in Co Donegal and ended at Ireland's most southerly point in Co Cork.

Jason was in touch to say "Our four days was quite an adventure to say the least. We had to contend with storm force winds, torrential rain and a few punctures. The support we received along the route was incredible. We were delighted to get to Mizen Head in the end!"

Well done and huge thanks to Ciaran and Jason for their fantastic dedication and determination.

Giving in Remembrance

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

Dates For Your Diary

- The ILFA New Year Swim will take place on at the 1st January at 12.30pm at Sandycove in Dublin. All are welcome!
- The 2018 Fergus Goodbody Memorial Lecture on ILD will take place on 14th March 2018 at the Royal College of Physicians in Ireland. The guest speakers are Dr Toby Maher and Ms. Anne-Marie Russell from the Royal Brompton Hospital in London.

Patient Support Groups

Cork Support Group

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

Dublin Support Group

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

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at the Fels Point Hotel. **Please call Adrian on 087 241 4004 or John on 087 280 9801 for more details.**

Midland Support Group

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

Cavan Monaghan Support Group

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

Mid West Support Group

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

If you would like information about setting up a patient support group in your area, please contact ILFA on 086 871 5264

Condolences

The ILFA committee would like to extend our sincere condolences to the family and friends of the late Tom Flynn from Mountmellick. Tom was a lung transplant recipient, one of the leaders of the Midlands Support Group, and a fundraiser. Tom was a man with a big heart and he touched the lives of many with whom he came in contact. He was always willing to reach out to help patients and was a great source of support and encouragement to his support group friends and the wider ILFA community. Tom will be greatly missed. May he rest in peace.

Keep in touch with ILFA

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

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



Christmas message from the Chairman

This year will be remembered with sadness, joy and hope. Terence Moran, ILFA founder and Chairman (2002-2017), passed away suddenly in August and we were left shocked and saddened by his passing. A special edition magazine was produced to celebrate ILFA's 15-year anniversary and the advances in IPF care since 2002, and was launched during IPF World Week. The magazine is dedicated to the memory of Terence Moran and acknowledges his input in helping ILFA to achieve our milestones.



ILFA attended many national and international conferences in 2017 and welcomed the opportunities to present our research. In February, Professor Jurgen Behr from Munich delivered the Fergus Goodbody Lecture and in October four allied healthcare professionals attended the ILD-Inter-disciplinary network conference in Birmingham and were supported by ILFA educational bursaries.

We met with government Ministers Simon Harris and Finian McGrath during the year and requested their support with the introduction of a soft opt-out organ donation system and other pressing concerns.

We had exhibition stands at the National Ploughing Championships, the Active Retirement Trade and Tourism Show, the Irish Gerontological Society Meeting and the Irish Thoracic Society meeting to help raise awareness of IPF and ILFA's work on behalf of patients and families.

In September, our support group members gathered for lunch in Limerick to celebrate the value of peer support and the special friendships established in recent years. We held two Patient Information Days; one in Sligo and one in Dublin, with speakers of the highest calibre, and our annual Ecumenical Service of Prayer and Reflection was another special and great occasion.

The ILFA committee is grateful to everyone who helped raise awareness and supported our work in 2017 through volunteering, fundraising, donations and support. Special thanks to Gemma O'Dowd for her hard work for ILFA during the year.

On behalf of the ILFA committee I would like to wish you and your loved ones, "A very happy and healthy Christmas and New Year."

Eddie Cassidy and the ILFA Committee