

ILFA Newsletter



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

Issue: Winter 2018

Volume 16 Issue 3

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Irish Lung Fibrosis Association
www.ilfa.ie

Launch of the Irish Thoracic Society's Position Statement on IPF and IPF Registry

The Irish Thoracic Society (ITS) Position Statement on the Management of Idiopathic Pulmonary Fibrosis (IPF) and the National IPF Registry were launched on 31st August at the Royal College of Physicians in Ireland. The IPF Position Statement and Registry aim to increase knowledge of IPF and improve the care of patients in Ireland.

The Position Statement was developed by members of the ITS Interstitial Lung Disease Group including Nicola Cassidy (ILFA Director) and Matt Cullen (patient). The Position Statement gives guidance to healthcare professionals on the optimal diagnostic and care pathways for IPF patients and empowers patients to look for the best care. It is also aimed at policy and decision makers and describes the appropriate staffing and resources needed for IPF Specialist Centres to provide the best standards of care. Ideally, all patients with suspected lung fibrosis should be diagnosed and treated within 16 weeks.

Catherine Byrne, TD, Minister of State at the Department of Health with responsibility for Health Promotion and the National Drugs Strategy, attended the event and launched the National Patient Registry for IPF. The registry aims to capture data on the number of people living with IPF and newly diagnosed cases in Ireland.

Professor Anthony O'Regan, Consultant Respiratory Physician at University Hospital Galway and Chair of the group said "The world of treating lung fibrosis has changed dramatically over the past decade thanks to new treatments and an increase in the rate of successful lung transplants. These developments have brought real hope to patients, making early diagnosis and rapid referral to treatment more crucial than ever. A National Clinical Programme on lung fibrosis is needed to ensure the complex and multi-faceted needs of patients are met."

David Crosby, lung transplant recipient, spoke at the launch of the ITS Position Statement and said "As someone who has travelled the road from a devastating diagnosis through to a life-saving double lung transplant, I know what it means to have the opportunity to have a second chance at life. I have experienced first-hand the benefits of being under the care of a team of people with specialist expertise. I had a nurse specialist who was my main point of contact and guiding light, as well as access to a physiotherapist, nutritionist and counsellor who helped me to manage my condition physically and mentally. Of course, that's not to mention my consultant and the transplant team who gave me a new lease of life. But I was one of the lucky ones. Everyone with a diagnosis of IPF must have access to these supports, regardless of where they live."

Professor Ross Morgan, President of the Irish Thoracic



Professor Ross Morgan, Catherine Byrne, TD, Minister of State and Professor Anthony O'Regan.

Society said "The commitment of medical and healthcare professionals to optimising the care of patients with lung fibrosis is illustrated by the involvement of a wide range of disciplines in this work – including physicians, surgeons, pathologists, radiologists, nurses and physiotherapists. Patients had a particularly important role to play and were represented by the Irish Lung Fibrosis Association. This has been a truly multi-disciplinary process and one that fully reflects the complexity of the disease and the needs of patients. The Irish Thoracic Society has been very proud to facilitate this work."

Eddie Cassidy, ILFA Chairman, said "ILFA would like to thank the members of the ITS Interstitial Lung Disease Group for all their hard work, commitment and enthusiasm in producing the ITS Position Statement. Thanks also to everyone involved with developing and delivering the National IPF Registry. These valuable and ambitious projects will improve patient care, our understanding of IPF and help influence policy."

ILFA 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.



ITS Position Statement and IPF Registry Launch



Eddie Cassidy (ILFA Chairman), Catherine Byrne T.D. Minister for State and Professor Anthony O'Regan (Galway University Hospital).



David Crosby with Catherine Byrne T.D. Minister for State.



Edna Powell, Catherine Byrne T.D. Minister for State, Evelyn Cooper, Matt Cullen, Marion Ryan and Eddie Cassidy (ILFA Chairman).



Members of the ITS Interstitial Lung Disease Group who developed the ITS Position Statement on the Management of IPF. Clockwise from back; Dr Killian Hurley, Matt Cullen, Nicola Cassidy, Tara Hannon, Suzanne McCormack, Dr Emmet McGrath, Lindsay Brown, Professor Anthony O'Regan, Catherine Byrne T.D. Minister for State, Dr Michael Henry and Bettina Korn.



ILFA committee members: Gemma O'Dowd, Marie Sheridan (Treasurer), Eddie Cassidy (Chairman), Lindsay Brown and Nicola Cassidy.



David Crosby.



Members of the ITS Registry Group. Clockwise from back; Carita Bramhill, Nicola Cassidy, Colin Edwards, Brigid Mulholland, Suzanne McCormack, Lindsay Brown, Professor Anthony O'Regan, Catherine Byrne T.D. Minister for State and Dr Michael Henry.



David Crosby, Kenneth Powell and Edna Powell.

Awards and Honours

Irish Healthcare Awards

The Irish Lung Fibrosis Association received a Commendation Award for our special edition magazine, 'ILFA 15', at the 2018 Irish Healthcare Awards on Wednesday 17th October 2018.

The awards ceremony is known as 'The Oscars' of the healthcare world and the Clayton Hotel, Burlington Road in Dublin was packed with over 400 people attending. The ceremony was hosted by Dr Pixie McKenna and it was wonderful to hear about the inspirational work being carried out around the country to improve patient care. Edna Powell (lung transplant recipient), Michael Geoghegan (lung transplant recipient), and Gemma O'Dowd and Nicola Cassidy represented ILFA at the special black-tie event.

The 'ILFA 15' magazine was produced in 2017 and co-edited by Nicola Cassidy (ILFA Director) and Ken Powell who kindly volunteered his time, knowledge and expertise to deliver a superb publication. The magazine celebrates ILFA's 15th year anniversary and is extra special because it features articles written by patients, carers, fundraisers, healthcare professionals and supporters and describes their personal perspectives on their involvement with ILFA and the advances in IPF care over the last 15 years.



Edna Powell, Nicola Cassidy, Michael Geoghegan and Gemma O'Dowd.

'ILFA 15' was short-listed in the Patient Organisation Project of the Year category which recognises improvements in patient care, innovation and collaboration. We were thrilled to receive a commendation award in this prestigious and competitive category. The award is a great testament to all those who have

helped and supported ILFA since our foundation in 2002.

'ILFA 15' is available to read on the ILFA website (www.ilfa.ie) and a limited number of copies are available by contacting ILFA on 086 871 5264 or by emailing info@ilfa.ie

Record breaker

Congratulations to Vera Dwyer who was awarded a gold medallion by Robert McCutcheon, Chairperson of the Irish Heart and Lung Transplant Association, to mark her 30th anniversary of receiving a lung transplant. Vera, who is aged 77 and from Sligo, is the world's longest surviving single lung transplant recipient and has a special place in the Guinness Book of World Records.

Vera was diagnosed with Idiopathic Pulmonary Fibrosis (IPF) in the 1980s and received a single lung transplant at Harefield Hospital in the UK in 1988. At the time, lung transplantation was not available in Ireland and she had to travel to the UK for the life-saving procedure. She has been in the care of the National Heart and Lung Transplant team at The Mater Hospital since it opened in 2003. Vera also received a kidney transplant in 2009.

Vera said "It is an absolute honour to receive this award. Thirty years ago I was given just days to live and I am very lucky to still be here. I would like to thank all the doctors and nurses who have helped me, especially those at The National Heart and Lung Transplant Centre at The Mater Hospital who have been wonderful in my care since the centre opened in 2003. But most especially my two donors, without whom I would not be here."



Gordon Dunne (CEO, Mater Misericordiae University Hospital), Sarah Kiernan (Vera's granddaughter), Robert McCutcheon (Irish Heart and Lung Transplant Association), Vera Dwyer, Professor Jim Egan, Sara Winward and Della Beirne (Vera's daughter). [Photo courtesy of Irish Heart and Lung Transplant Association].

Special Recognition Honour

Congratulations to Val Kennedy on receiving a special honour from the Tullamore Golf Club in recognition of his work promoting organ donation and his participation at the European Heart and Lung Transplant Championships in 2018.



Val Kennedy (centre) is pictured with Tullamore Golf Club Lady Captain Stephanie McNiff and Men's Captain Brian Gunning. [Photo courtesy of the Irish Kidney Association].

Annual Service of Prayer and Reflection

“The 6th ILFA Annual Service of Prayer and Reflection took place this year on Saturday 6th October in the Methodist Church on Brighton Road in Rathgar, Dublin. Reverend Canon Brian McKay O.Carm, Prior at Terenure College, the special speaker, emphasised the support that is generated when people come together in common cause and spoke about the need for courage in times of challenge. He closed his very meaningful and insightful address by praying that we would all be blessed with additional resources of courage in the days ahead. Canon Brian was joined, as in previous years, by Rev. Canon Charles Mullen, Dean’s Vicar from St Patrick’s Cathedral and by Rev. Vanessa Wyse Jackson, the minister in Rathgar Methodist Church and the service was followed by refreshments in the church hall. This annual service continues to be a poignant and extremely helpful part of the ILFA calendar.”

Report by Rev. Vanessa Wyse Jackson

The ILFA service is a very special event in the annual calendar and it would not be possible without the kindness and willingness of many people coming together and contributing their talents and time. The ILFA committee would like to extend special thanks to Rev. Vanessa Wyse Jackson, Anne Hagen, and the congregation at Rathgar Methodist Church for the warm welcome extended to all those who attended ILFA’s Service of Prayer and Reflection. We are indebted to the celebrants of the ecumenical service; Rev. Vanessa Wyse Jackson, Rev. Canon Brian McKay, O.Carm., and Rev. Canon Charles Mullen, for their enthusiasm and commitment in supporting this special annual event.

Rev. Canon Charles Mullen chose the theme of ‘Courage’ for this year’s service and the readings and prayers were carefully chosen to reflect this and provide comfort and encouragement to those present. Rev. Brian McKay also spoke on this theme in his uplifting and inspiring address. Sincere thanks to our wonderful musicians; Harry Carpendale (harpist) and Stephen Ferguson (organist), for the beautiful music that complemented and enhanced the service. We are very grateful to the readers, candle lighters and volunteers for their participation. After the service, we adjourned to the community hall for some delicious treats and refreshments, kindly served by Heather Rutledge, and Moss and Val Burns. Thank you to everyone who contributed cakes - Pam Martin deserves a special mention for her creative and delicious ‘ILFA’ apple pie!

We received lovely feedback on the service and are grateful to everyone who contacted us with messages of support. Some of your comments are included below;

- *“Another wonderful service. We always look forward to it.”*
- *“Well done on the organisation and preparations for what was a moving and meaningful service.”*
- *“That was such a lovely occasion. Well done because it really is such a treasured part of the ILFA calendar and always very moving.”*
- *“I just want to thank all at ILFA for once again making the prayer service happen in memory of our loved ones.”*
- *“Thank you so much. It has always been a great pleasure to be involved in the ILFA service, such an uplifting and positive experience.”*



Lynn Fox, Laura Grehan and Patricia Jones.



Canon Brian McKay, Rev. Vanessa Wyse Jackson and Canon Charles Mullen.



Barney and Brid Meaney.



Matthew and Dolores Williams and Joan and John Doyle.



Canon Charles McKay and Harry Carpendale.



Anne Casey and John and Alice Donnelly.

Advocacy, Education and Outreach Activities

The Human Tissue Bill

In September, ILFA wrote to Simon Harris T.D. (Minister for Health), Catherine Byrne T.D. (Minister for State with responsibility for Health Promotion), Finian McGrath T.D. (Minister for State with responsibility for Disability) and to Michael Conroy (Principal Officer, Cancer, Blood and Organs Policy Division, Department of Health) to request an urgent update on the status of the Human Tissue Bill which will legislate for the introduction of a soft opt-out consent system for organ donation for Ireland.

In addition, Nicola Cassidy (ILFA Director), Philip Watt (CEO of Cystic Fibrosis Ireland) and Robert McCutcheon (Chair of the Irish Heart and Lung Transplant Association) represented the Irish Donor Network and met with Professor Jim Egan of Organ Donation and Transplantation Ireland in August, and with Michael Conroy from the Department of Health and his colleagues in September. Robust discussions relating to the Human Tissue Bill were had. We look forward to news on the drafting of the General Scheme for the Human Tissue Bill for presentation to the government.

Education for General Practitioners

Idiopathic Pulmonary Fibrosis (IPF) is a rare disease that can be difficult to diagnose. Many General Practitioners (GPs) will only treat only a very small number of patients with this condition (typically less than 5 patients) in their career lifetime. In 2017, ILFA funded an educational video for GPs to raise awareness of IPF. The video describes the signs and symptoms of IPF, the tests and procedures needed to help reach a diagnosis, and the treatments for managing the condition. The video was hosted on the GP website; www.gpbuddy.ie for one year and the most recent viewing figures reveal that it is performing well. ILFA is grateful to Dr Emmet McGrath, respiratory consultant at St Vincent's University Hospital, Dublin for filming the video tutorial. The video can also be found on the ILFA website.

Outreach activities



Dr Killian Hopkins, Nicola Cassidy, Dr Ryan Birt, Sarah Nolan, Matt Cullen, Dr Ian Counihan and Dr Tidi Hassan.

Sarah Nolan, respiratory physiotherapist at Our Lady of Lourdes Hospital in Drogheda, kindly invited ILFA representatives to attend the respiratory team's multi-disciplinary meeting on

Tuesday 30th October. Nicola Cassidy (ILFA Director) and Matt Cullen (IPF patient and Dublin Support Group leader) travelled to Drogheda. Nicola gave an overview of ILFA's work to promote awareness of pulmonary fibrosis and support patients and families, and Matt shared his personal perspectives on the importance of exercise and living well with the condition.

National Ploughing Championship



Left: Kevin Pigott, Val Kennedy and Jim Kelly.

Above: Kevin Pigott, Val Kennedy and Frances Kelly.

The National Ploughing Championship took place at Screggan, Tullamore, Co Offaly in September. President Michael D Higgins officially opened the 87th National Ploughing Championships, an event that he previously described as "the most beloved rendezvous in Ireland's rural calendar".

The National Ploughing Championship is the largest outdoor event in Europe with thousands of visitors and 1,700 exhibitors including the Irish Lung Fibrosis Association. This was ILFA's second year to host an exhibition stand at the event and it was a great opportunity to highlight ILFA's work to support patients and families living with Idiopathic Pulmonary Fibrosis.

Preparations for the event started in March 2018 but despite our best laid plans, several members of the ILFA committee could not attend due to unforeseen circumstances. We had to issue a call for volunteers to help us via our Facebook page and were delighted and humbled to hear from so many willing people. We are indebted to Val Kennedy who kindly took charge of the event for ILFA and organised and led the team of wonderful volunteers; Kevin Pigott, Trish Conroy, Frances and Jim Kelly, Trish and Eddie Power, Barney and Brid Meaney, and Paddy and Kitty Keenaghan.

Unfortunately, Storm Ali arrived on the Tuesday evening and literally blew the roof off the building where ILFA was exhibiting. Val, Trish, Frances and Jim bravely rescued the ILFA stand in very challenging conditions. They fab four worked late into the night to save our equipment and returned the next day to set up and carry on once more. We cannot thank our volunteers enough for their generosity, enthusiasm, time and efforts to help ILFA and meet and greet the visitors to the ILFA stand. "Go raibh mile maith agaibh!!!"

Educational Bursaries for Healthcare Professionals

The Interstitial Lung Disease Inter-Disciplinary Network (ILD-INN) held its annual conference in Birmingham on 7-8th October 2018. There was a strong Irish presence and ILFA was proud to award educational bursaries to respiratory nurses and physiotherapists from around the country to support their participation. The recipients of the ILFA bursaries were; **Patricia Davis** (Community Healthcare Organisation Area 6), **Lisa Glynn** (Tallaght University Hospital), **Carol Doherty** (Letterkenny University Hospital), **Breige Leonard** (South West Acute Hospital, Enniskillen), **Deirdre O'Flaherty** (Beaumont Hospital), **Elaine Cribbin** (Tallaght University Hospital), **Irene Byrne** (Mater University Hospital), **Carita Bramhill** (St Vincent's University Hospital) and **Grainne Coffey** (University Hospital Kerry).

We were delighted to receive messages of appreciation from the bursary winners. Here are the edited highlights!

"Excellent conference. It was great to get the opportunity to meet up with like-minded and dedicated professionals with such patient focus. Thanks to ILFA for the support and opportunity to attend." **Irene Byrne**

"I really enjoyed the ILD-INN conference. From the perspective of working in the Primary Care setting, it provided me with fantastic opportunities to gain further insights into interstitial lung disease (ILD). The agenda was packed, intensive, interactive and worthwhile. It was great to see that improvements have been made in gaining an earlier diagnosis as discussed by Dr Sophie Fletcher. But we still have a long way to go when it comes to educating general practitioners and physicians to recognise the early signs of IPF. A retrospective review by her research team found that patient outcomes are significantly better if reviewed by a multidisciplinary team specialising in ILD within the first 6 months of presenting with symptoms. Many thanks to ILFA for giving me the opportunity to attend." **Patricia Davis**

"I would like to thank ILFA for the opportunity to attend the ILD INN conference. It was a great experience. I have gained a wealth of knowledge and I plan to incorporate elements into my practice. I enjoyed meeting other healthcare professionals with an interest in IPF which has motivated me to become a better advocate in providing care and support to patients and family living with IPF." **Carol Doherty**

"Thank you ILFA for allowing me to attend this meeting. It was a great experience and a fantastic learning opportunity. Each talk was very interesting and applicable to my practice. The one I believed was most striking was music therapy for ILD patients. It was fascinating how music therapy changed the lives of patients living with IPF. This is something that we currently don't practice at our hospital however, it certainly gives food for thought when the benefits are so significant in improving the quality of life for patients." **Lisa Glynn**

"The ILD-INN conference was fantastic! Very enlightening, excellent content and great to see what other health care professionals are doing in terms of practice for ILD patients. I really appreciated the opportunity and bursary. I'm hoping to present what I learnt at our next respiratory nurses meeting in the hospital. Thanks again." **Deirdre O'Flaherty**

"The culture of the conference was one of learning and shar-



The Irish delegates attending the ILD-INN conference including the recipients of the ILFA educational bursaries.
ing. It helped me personally to pause and reflect and consolidate my past experiences and examine my present practices. It has motivated and inspired me to move forward and share what I have learned with my own team and respiratory colleagues for the benefit of our patients. Thank you so much to ILFA for all the work you do and for awarding me this bursary." **Breige Leonard**

"From the latest in clinical trials to politics, from managing cough in IPF to the latest in pharmacology and diet, immunosuppression clinics and telephone clinics were all discussed. Sara Winward from Ireland spoke about the work of the transplant team at the Mater Hospital in Dublin and provided impressive statistics about their cohort of transplant recipients. She was inundated with questions afterwards and I felt proud to be Irish! The highlight for me was the contemporary thinking in ways to manage cough and breathlessness using singing techniques!! Overall it was an excellent programme that certainly updated my knowledge. I would like to thank ILFA and everyone who supports and fundraises for ILFA for making it possible for me to attend the conference." **Grainne Coffey**

"A notable highlight was a presentation on the latest in clinical trials by Dr Sophie Fletcher. It was both heart-warming and inspiring to see clinical trials at the forefront of such a prestigious event. I have worked in the area of clinical trials for ten plus years and know first-hand the impact it has on patients' lives and the importance in patient care planning. Sara Winward from the Mater Hospital gave a detailed discussion on lung transplantation in ILD. It was massively beneficial to hear about the great work her and her colleagues are doing in the area of lung transplant in Ireland. I was honoured to have been chosen to attend the conference and it has certainly added to my learning in IPF."

Carita Bramhill

"I would like to thank ILFA for the bursary to attend the ILD-INN Conference. It was extremely informative, with practical and theory-based sessions from a variety of disciplines across the UK and Ireland. Topics presented covered the care pathway of various ILDs from initial presentation, diagnosis, pharmacological and conservative management of patients and end of life care. I particularly enjoyed the session on 'Rhythm and song for breath management' that focussed on integrating breath management strategies with patient focused activities positively impacting quality of life. Attending the conference was a great learning and networking opportunity and I would recommend for others to avail of this excellent bursary and attend in the future."

Elaine Cribben



**Back row: Bettina Korn, Gemma O'Dowd and Deirdre Shanagher.
Front row: Dr Anne-Marie Doyle, Irene Byrne, Maria Love, Lynn Fox, Anne-Marie Russell, Nicola Cassidy and Amy Boulstridge.**

Update on ILFA's World Café event on Palliative Care and Planning for the future

On 9th June 2018, ILFA held a World Café event on Palliative Care and Planning for the Future. The event was led by Anne-Marie Russell (Nurse Consultant at the Royal Brompton and Imperial College Healthcare Trust, London). 55 patients, carers, healthcare professionals and industry representatives took part and we are very grateful to them for sharing their thoughts and experiences with us.

The topics discussed were;

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

The World Café event provided a great opportunity for ILFA to work with experts in the field and our stakeholders to establish their priorities, experiences and challenges for the future. Participants were asked to complete an evaluation form after the event. We are delighted to report that the feedback was hugely positive, encouraging and useful.

The leaders of the World Café met in August to discuss the event and the data generated from the discussions and plan the next steps. Here's what has happened so far and what's in the pipeline.

- ◆ Two sets of spouses and a mother and son were interviewed by Anne-Marie Russell in August to explore their thoughts on the World Café event and their personal perspectives on IPF. Emerging themes from the interviews will be analysed.
- ◆ A report on the findings of the World Café event will be circulated to the leaders and participants for their input and feedback and will subsequently be made available on the ILFA website.
- ◆ ILFA presented a poster about the World Café and its evaluation by participants to the Irish Thoracic Society's annual scientific meeting in November 2018. The poster is published on pages 8 and 9 of the newsletter.
- ◆ An abstract entitled 'A World Café Approach to Palliative Care and Planning for the Future in Fibrotic Lung Disease' has been submitted to the 2019 American Thoracic Society meeting.
- ◆ ILFA will hold a special Patient Information Day on Saturday 6th April 2019 at the Hilton Airport Hotel, Malahide Road, Dublin at 10am. This event will provide specialist information on topics relating to Palliative Care and Planning for the Future for IPF to patients and family members. More information will be available on the ILFA website nearer to the date.

Evaluation of a World Café Forum on Palliative Care and Planning for the Future

¹Nicola Cassidy, ¹Gemma O'Dowd, ¹Marie McGowan, ²Tony Shone, ³Anne-Marie Russell.
¹Irish Lung Fibrosis Association, ²Invisio Ltd, ³Imperial College, London.



Introduction

The Irish Lung Fibrosis Association (ILFA) was set up in 2002 to support patients and families affected by Idiopathic Pulmonary Fibrosis (IPF).

IPF is the most common interstitial lung disease and is characterised by progressive scarring of the lungs, impaired gas exchange, breathlessness, low oxygen levels, fatigue and muscle weakness.⁽¹⁾

The main goals of therapy are to limit symptom burden, preserve independence and maintain a good quality of life for patients and caregivers.



What is Palliative Care?

The World Health Organisation (WHO) describes palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”⁽²⁾

Results

Six groups of mixed participants discussed:

- (1) Practical planning
- (2) Palliative care and symptom management
- (3) End-of-life considerations
- (4) Psychological support needs
- (5) Acute exacerbation management and lung transplantation
- (6) Legal matters

10 patients, 10 carers, 6 healthcare professionals, 3 industry representatives and 3 others completed a formal evaluation of the World Café event.

Respondents strongly agreed/agreed that:

- they enjoyed the event (100%)
- they were well informed of the forum's objectives (96.67%)
- discussions were helpful (100%)
- it was a good way to learn about palliative care (96.97%)
- they are more likely to plan for future care (96.97%)

4 people agreed/strongly agreed that they were upset by the discussions but 100% felt there was a good level of emotional



ILFA supports this approach whereby palliative care is not the hallmark of end of life but rather offered at earlier stages, sometimes at the time of diagnosis of a life-limiting illness such as IPF.

Guidelines to support a consistent and timely approach to the initiation and delivery of palliative care in IPF are needed.

Aims

To identify stakeholders' priorities for palliative care, advanced care planning and end-of-life issues with pulmonary fibrosis.

Methods



ILFA developed a World Café forum in collaboration with healthcare professionals and an industry leader to discuss important and sensitive topics.

Patients, carers, healthcare professionals and industry representatives were invited to participate. The World Café was delivered by 3 facilitators, and 6 leaders facilitated rotating group discussions which were recorded by 6 note takers.

Given the sensitive nature of the topics, individual support and counselling were made available to participants who were upset by the discussions. Participants were asked to evaluate the event using a questionnaire.

References

1. Raghu G, Collard HR, Egan JJ *et al.* An official ATS/ERS/JRS/ALAT statement: idiopathic pulmonary fibrosis: evidence-based guidelines for diagnosis and management. *Am J Respir Crit Care Med* 2011;183(6):788-824.
2. World Health Organisation. www.who.int/cancer/palliative/definition/en/ [accessed June 2018]

support provided.



Analysis of free text responses indicated that the event was;

- informative (65.38%)
- helpful (19.23%)
- open (15.48%)

One participant said "A very powerful day, run very professionally and organised extremely well. Well done to all concerned and I am personally appreciative of all that is done on our behalf."

Participants at the World Café

Discussion

Working in small groups valuable information was generated in a short period of time. Patients, caregivers, healthcare professionals and other key stakeholders engaged in open conversations identifying core aspects of palliative care and planning for the future that will influence ILFA's future work.

Conclusion

The 'World Café' forum provided an innovative, dynamic and opportune approach to engage with key stakeholders and discuss sensitive topics in a positive and meaningful way.



Fundraising Round Up

Rathdowney Easy Riders



The Rathdowney Easy Riders cycling group with the Cork Pulmonary Fibrosis Support Group.

The Rathdowney Easy Riders group chose ILFA as their 2018 Charity of the Year and we are so grateful to them for this honour. The group have been cycling and fundraising for 16 years and organised many fundraising events over the summer. The main event was the epic 220km cycle to Cork that departed from Rathdowney, Co Laois on Saturday 4th August. The team made great progress and rested in Cork overnight. The following morning an enthusiastic group of supporters from the Cork Pulmonary Fibrosis Support Group met the team to cheer them on their way for the last leg of the cycle. We would like to extend our warmest thanks and heartfelt appreciation to the cyclists, organisers and support team for their great efforts on our behalf.

Berlin Marathon



David Crosby with his medals from the New York Marathon and Berlin Marathon.

Congratulations to David Crosby, inspirational double lung transplant recipient, who completed the Berlin Marathon on 16th September 2018. David was accompanied by his wife Katie, David McNally, Professor David Healy and a group of special friends. David has now completed 2 marathons in 10 months - New York in November 2017 and Berlin in September 2018. David has inspired us with his enthusiasm, courage, determination and commitment to honour his donor and raise awareness of IPF and organ donation. What a Champion!!!



David Crosby with Professor Jim Egan, respiratory consultant at the Mater Misericordiae University Hospital.



Participants in the Tullamore Angling Club competition.

Tullamore and District Angling Club

The Tullamore and District Angling Club Juniors raised the fantastic sum of €451.11 on behalf of ILFA at a coarse angling competition on Sunday 26 August 2018 in Tullamore.

18 junior anglers took part and all caught fish. Afterwards a prizegiving ceremony was held at the local Foresters Hall and we were informed that they had a hoot blowing up the balloons and bursting them!

By all accounts it was a good day and the story featured in the Tullamore Tribune. Well done and thank you to all the organisers and the juniors for their great support!

Swords Table Quiz

Dymphna and Donal Cassidy organised a very successful and enjoyable Table Quiz at St Colmcille's GAA Club, Swords, Co Dublin in aid ILFA on Saturday 20th October. A great night was had by all and the venue was full. The total raised so far is €1,300. The table quiz was well supported with kind donations from local businesses in Swords. Thanks to the organisers, local businesses and participants for your great support!



Matt Cullen, Dymphna Cassidy and Eddie Cassidy.



Pat Casey Memorial Cycle

Saturday 29th September: This year's Pat Casey Memorial Cycle took place on Saturday 29th September. 32 cyclists set off from the Cork City Ford Centre on Forge Hill starting the 122km round trip in memory of Pat.

This year we were blessed with good weather for the entire day which contributed to the amazing performance of all who took part, finishing the route a whole two hours quicker than last year.

We would like to express our deep gratitude to ILFA for their continued support, all the staff of the Cork City



Ford Centre for once again hosting the send-off and return festivities and to all who took part in the cycle. A special thanks to the support crews in the First Aid car, the equipment van and the

food van, to the members of the Cork Pulmonary Fibrosis Support Group for their continued support and providing tasty snacks for the returning cyclists, and to everyone for contributing to a successful event again this year.

Preparations for the next year's event will begin again very soon and we look forward to it!

**Report by Anne Casey,
Martin Casey and Brian Aherne -
the organisers of the
Pat Casey Memorial Cycle.**

'Paddy's Angels' Walking For ILFA

On Sunday, 16th September, with the sun shining down, a group of 19 ladies assembled in Cork City to participate in the Evening Echo Cork Ladies Mini Marathon in memory of Paddy O'Connor, a fantastic husband, father, brother and great friend to all of us.

Paddy passed away in April 2013, after a brave battle with lung fibrosis. It was an honour for each one of us to complete the mini marathon in his memory knowing that he was looking down on us and probably having a great laugh at our expense.

Paddy's eldest daughter Sharon is getting married to Fergal on 2nd November and mentioned that in lieu of wedding favours they would make a donation to the Irish Lung Fibrosis Association (ILFA). From this, the idea of participating in the Mini Marathon to boost their donation was born.

Not one of the 18 walkers needed to be asked twice to join us. Our group named "The Pawfilfas" (Paddy's Angels Walking For ILFA) included Liz, Sharon, Anne and Della O'Connor, Margaret Linehan, Rosarie O'Flynn, Suzanne Hynes, Deirdre Casey, Michelle and Shannon Hallihan, Shona Rochford, Nuala Crowley, Fiona and Gemma Denton, Tracy O'Callaghan, Joan O'Carroll, Laura Ring, Bridget Ann O'Donoghue and Eileen Carroll.

Our walkers raised €2,058 for ILFA and we give sincere thanks to all family, friends, neighbours, local businesses and work colleagues who sponsored us and a special thanks to Lylas Café, Buttevant who took a sponsorship card on our



behalf. Sharon and Fergal contributed a further €200 in lieu of wedding favours bringing the total donated to €2,258.

After the walk, the group assembled in McCarthy's Pub in Buttevant where we raised a glass to Paddy and pledged to take part in the Mini Marathon again next year in support of ILFA to whom we wish continued success in everything they do.

Report by Suzanne Hynes



Ciaran McCabe and Culann Ryan.



Eddie Cassidy (ILFA Chairman) and Ciaran McCabe.

Dublin Half Marathon

Huge thanks to Ciaran McCabe for fundraising for the Irish Lung Fibrosis Association in memory of his father, Bert McCabe. Ciaran took on an incredible challenge and ran while carrying 19 kilos of army kit!!! Ciaran, his brother Martin and girlfriend Lisa presented a cheque for €2,254 to Eddie Cassidy, ILFA Chairman at the ILFA Patient Information Day on 20th October.

Read more about Ciaran's remarkable achievement in his own words ...

"Ciaran McCabe, 25, from Multyfarnham Co. Westmeath ran the Dublin Half Marathon in full army kit (19kg) alongside fellow soldier Culann Ryan. I ran it in memory of my late father Bert McCabe who died of Pulmonary Fibrosis in 2013. I'd like to thank all those who kindly donated and helped me reach over my target of €2,000.

I hope these funds go towards the research of Pulmonary Fibrosis and to those people who suffer with this disease."



Ryan Family cheque presentation

Thanks to the amazing Ryan Family, pictured above, who raised €3,000 for ILFA by taking part in the VHI Women's Mini Marathon in June. Marion Ryan received a single lung transplant and decided to take on the 10k challenge in aid of ILFA with the support of family and friends.

Marion and her family are pictured with Eddie Cassidy (ILFA Chairman) and staff from the National Heart and Lung Transplant Unit at the Mater University Hospital.

Wedding Favours



Congratulations and sincere thanks to Caroline Grehan and Kevin O'Hanlon, left, who were recently married and made a kind donation to ILFA in lieu of wedding favours.

Here's what Caroline said: "On 29th of June we got married in the beautiful seaside setting of the Waterside House Hotel Donabate on one of the hottest days of the year. Instead of having wedding favours, we decided to make a donation to ILFA in memory of my late Aunty, Denise Cassidy, who lost her battle with IPF. I will always remember Aunty Denise as a woman who lived life to the full and always had a smile on her face. She would have been in her element at our wedding, probably at the centre of it all and up to mischief with my mam.

ILFA supplied us with beautiful place cards for the tables to let our guests know about our donation in lieu of wedding favours. We also asked (or perhaps guilted) our guests to donate some of the money won from the bets taken on the

length of the speeches - you'd be surprised how much money is in those glasses!!!"

We wish Caroline and Kevin every happiness for the future!



Congratulations and warm thanks to Sharon and Fergal O'Connor, left, who got married on Friday 2nd November and made a kind donation to ILFA in memory of Sharon's dad Paddy O'Connor.

We wish them every happiness for the future.

Sharon was in touch and said, "Just wanted to say thanks so much for our lovely cards in lieu of wedding favours - they were fab!"

Team O'Brien

Thank you to 'Team O'Brien' in Kerry for fundraising for ILFA and raising awareness to remember and support their loved ones with IPF.

Here's a report from the O'Brien Family.

"Sunday September 16th saw 'Team O'Brien' once again complete their 'Walk for JP' on both sides of the pond. JP was the second member of his family to be diagnosed with IPF. He sadly lost his short battle with the disease in 2017 in Boston, USA. While he is missed terribly every day, the

family are grateful that his sister Joan (an IPF warrior!!!) is doing very well following her lung transplant in 2015. Coincidentally, their brother-in-law Niall Horgan also was diagnosed with the disease.

Niall's legacy lives on through the Kerry IPF Support Group he helped set up some years ago. Being no strangers to the disease, the family both in Boston and Kerry have become dedicated to help

raise awareness and fundraise for crucial research. What began as a once off memorial walk has now become a special family tradition where a day of sharing memories is enjoyed while raising awareness of this insidious disease."



Team O'Brien in Boston

Report by Grainne Coffey



Team O'Brien in Kerry

Upcoming lecture for healthcare professionals

The irony of lung fibrosis: A fibroblast to treat Idiopathic Pulmonary Fibrosis

Professor Luis Ortiz is a leading clinician scientist at University of Pittsburgh Medical Centre who focuses on mechanisms of lung injury that lead to the development of lung fibrosis. He has been a pioneer of the use of using a type of stem cell (the mesenchymal stem cell) as a potential cell therapy for lung diseases. His recent work explores how these cells function and the molecular and cellular mechanisms that appear to block damaging inflammatory processes.

Professor Bernard Mahon at University of Maynooth will host Professor Luis Ortiz at Maynooth University in March 2019. Prof Ortiz has kindly agreed to deliver a public presentation on his research. All are welcome to this free lecture. Please email info@ilfa.ie if you would like to attend.

Title: The irony of lung fibrosis: A fibroblast to treat Idiopathic Pulmonary Fibrosis

Date: Wednesday 13 March 2019

Venue: Corrigan Hall, Royal College of Physicians, Dublin.

Time: 19:00

Summary of presentation:

Idiopathic Pulmonary Fibrosis (IPF) is the most common form of the Interstitial Lung Diseases (ILD). Although recent clinical trials demonstrated the efficacy of pirfenidone, and nintedanib in slowing IPF progression, no specific therapy is available for this disease. Medical care of IPF is challenging as the new drugs are poorly tolerated, and their cost is expensive. The annual IPF-attributable medical cost to the US health care system is > \$2 billion.

Advances in stem cell research have spurred development of progenitor cell-based therapies. Mesenchymal stem cells (MSCs) are at the forefront of these efforts due to their superior safety profile. However, while MSCs have shown efficacy in treating inflammatory diseases, a scientific rationale supporting the use of MSCs in IPF is only now being realised.

The overall goal of this talk is to review the pre-clinical and clinical experience, and the data supporting the assembly of a multidisciplinary team of researchers from five U.S. academic centers with expertise in MSC biology, research, lung disease, epidemiology, Current Good Manufacturing Practice (cGMP) regulations and manufacturing, and human clinical trial design to establish a Progenitor Cell Translational Consortium to test the safety, tolerability, and potential benefit of non-HLA-matched allogeneic bone marrow derived mesenchymal stem cells (MSCs) in subjects afflicted by IPF.

To accomplish this goal, I will review experimental data demonstrating that MSC modify the gene expression and inflammatory activity of lung macrophages and epithelial cells in the distal lung and improving the pulmonary circulation and the coupling of the right ventricle in animals. I will validate the importance of these data on a large cohort of subjects afflicted by IPF who receive their medical care at the University of Pittsburgh.

Professor Luis Ortiz

Support Group News

New Support Group in Co Clare



On 7th November, Carmel McInerney (respiratory nurse specialist at Ennis Hospital) and members of the respiratory teams at Ennis Hospital and Limerick University Hospital held a valuable

information evening on Pulmonary Fibrosis for patients and family members. The aim of the meeting was to see if there was interest in setting up a local support group for patients in county Clare. Noreen O'Carroll and Noel Connelly from the Mid-West Support group attended the meeting to lend their support and share their experiences.

ILFA is pleased to announce the establishment of the Clare Pulmonary Fibrosis Support Group. Please contact Michael on 087 637 4068 if you are interested in attending the new support group in Ennis.

Midlands Support Group



Gemma O'Dowd and Nicola Cassidy visited the Midlands Pulmonary Fibrosis Support Group in November and received a very warm welcome from Val Kennedy, Andy Carroll, Tim Guiney, John

Carroll, Kevin Pigott and Paddy Keenaghan. The group meets on the first Wednesday of every month at 2.30pm at the Tullamore Court Hotel, Tullamore, Co. Offaly.

Dublin Support Group



Carita Bramhill, research coordinator at St Vincent's University Hospital visited the Dublin Support Group in November to discuss the Irish Thoracic Society's National Pulmonary Fibrosis Registry. The

group enjoyed learning about the registry and having the opportunity to ask questions. The registry aims to increase knowledge of pulmonary fibrosis and improve the diagnosis and care of patients in Ireland.

Cork Support Group



Tom O'Sullivan from Dublin visited the Cork Support Group on Thursday 27th September to share his personal perspectives on palliative care. Tom's talk was very well

received and sparked some conversations.

Chairman's Report

I would like to start by thanking our fundraisers, volunteers and supporters for their great work during the year. ILFA was founded in 2002 and is solely funded by fundraising activities and donations. We are enormously grateful to everyone who has supported the charity over the years.

2018 was another busy and eventful year for ILFA. We were delighted and honoured to be chosen as the charity of the year for three major fundraising campaigns during 2018; the Easy Riders Cycling Club in Rathdowney, Co Laois, Musgraves Cycling Club, Co Cork and the West Kerry Tractor Run in Dingle, Co Kerry. More details on these exciting events will follow in the 2019 Spring ILFA Newsletter.

Some of this year's notable highlights included;

- ◆ The launch of the Irish Thoracic Society's Position Statement on Idiopathic Pulmonary Fibrosis and the National IPF Registry in August 2018. ILFA was proud to participate in these great initiatives that will lead to improved care for patients diagnosed with IPF.
- ◆ ILFA received a commendation at the Irish Healthcare Awards for 'ILFA 15' – our special edition magazine that was produced in 2017 to celebrate our 15th year anniversary.
- ◆ The Fergus Goodbody Memorial Lecture took place in March and we were delighted to collaborate with the Royal College of Physicians of Ireland. The speakers at the Respiratory Medicine Masterclass were Professor Toby Maher, Anne-Marie Russell, Professor Ed McKeon and Professor Anthony O'Regan.
- ◆ ILFA hosted two Patient Information Days and produced three newsletters in 2018.
- ◆ ILFA held a World Café event in June 2018 and brought together patients, carers, healthcare staff and industry representatives to learn about their experiences, preferences and perspectives on these important topics.
- ◆ The 6th annual Service of Prayer and Reflection took place at Rathgar Methodist Church in Dublin in October.
- ◆ ILFA volunteers hosted an exhibition stand at the National Ploughing Championship in Co Offaly in September and we are indebted to everyone who volunteered their time to help us.
- ◆ ILFA awarded 9 educational bursaries to healthcare professionals from all over Ireland to attend the ILD-INN Conference in Birmingham in October.
- ◆ ILFA continued its advocacy work campaigning for the introduction of an opt-out consent system for organ donation.
- ◆ Liam Galvin continued in his role as secretary of the EU-IPFF and represented ILFA at a European level. We are grateful to Liam for his advocacy work.
- ◆ Many fundraising events were held during the year and we are indebted to all the fundraisers, organisers and those who made donations.

Finally, I would like to extend my sincere thanks to Gemma O'Dowd and the ILFA committee members for their time, commitment, enthusiasm and hard work in 2018.

Eddie Cassidy,
Chairman of the Irish Lung Fibrosis Association

Treasurer's Report

ILFA has had another busy and eventful year. I took over as treasurer from Eddie Cassidy on March 1st, the start of the new financial year - many thanks to Eddie for doing such a great job and for all his help.

As one of the founders of ILFA and a former treasurer, it was great to see how ILFA has flourished in the years since I was last involved. It's been a pleasure working with Eddie, Nicola, Gemma and all the committee during the year. We're facing challenging times, along with all charities, but with the commitment of the committee and the amazing support of our fundraisers and supporters, ILFA will continue to work hard and thrive.

ILFA's accounts are prepared in accordance with accounting standards as set out by the professional body of which I am a fellow - the Institute of Chartered Accountants in Ireland. These standards have been set out to comply with the requirements of Companies legislation. During the year I attended several courses to keep up to date with accounting requirements in the Charities sector, which are constantly evolving. ILFA's accounts are audited each year and an audit report produced by our auditors, Whiteside Cullinan. This report states that proper books of account have been kept by the company, that we have prepared financial statements in accordance with the law, and that these financial statements give a true and fair view of the assets, liabilities and financial position at period end.

We cannot thank all our fantastic fundraisers and supporters enough. It is entirely due to you that we are able to continue our work on behalf of all those affected by IPF. We are constantly delighted by the new and innovative ways that our supporters come up with to raise funds, as well as being heartened by the continuing tried and true events every year, such as ILFA's supporters' participation in the Women's Mini Marathon, the Pat Casey Memorial Cycle and the Margaret Maloney Memorial Darts Tournament.

There are so many wonderful fundraisers to whom we owe thanks - too many to mention individually. I'll just give special congratulations to our supporters who received lung transplants and fundraised for ILFA - David Crosby, Val Kennedy, Edna Powell, John O'Sullivan and Marion Ryan. Thanks and sincere condolences are due to our supporters who thought of ILFA and donated in lieu of funeral flowers. We really appreciate you thinking of ILFA at a very sad time. And thanks too to those who shared their happy times with us and donated in lieu of wedding favours and birthday gifts.

Wishing all our supporters a Happy Christmas and every good wish for the New Year.

Marie Sheridan,
Hon. Treasurer, ILFA

Patient Support Groups

Cork Support Group

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

Dublin Support Group

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

Kerry Support Group

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

Midland Support Group

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

Cavan Monaghan Support Group

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

Mid West Support Group

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

Clare Pulmonary Support Group

Please contact Michael on 087 637 4068 if you are interested in attending a new support group in Ennis.

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

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

086 871 5264

Christmas message from ILFA



The ILFA committee would like to extend our warmest thanks to everyone who helped raise awareness of pulmonary fibrosis and supported our work in 2018 through volunteering, fundraising, donations and support. We are indebted to our amazing fundraisers for the commitment, enthusiasm and hard work they invest to help us support patients and families and healthcare professionals working in respiratory medicine. We would also like to extend our deep gratitude to Gemma O'Dowd for her hard work for ILFA during the year. We wish you and your loved ones, "A very happy and healthy Christmas and New Year."

Dates For Your Diary

Upcoming ILFA Events

- The **ILFA Christmas Swim** will take place on Thursday 27th December at 1pm sharp. Refreshments will be served at Fitzgerald's Pub afterwards at 1.30pm. Please contact ILFA on 086 871 5264 if you would like to take part and fundraise for ILFA. This year's swim is dedicated to the memory of Honóra Ní Chríogáin, co-founder of ILFA and organiser of the swim since 2002.
- The **2019 Great Limerick Run** will take place on Sunday May 5th 2019. Please see www.greatlimerickrun.ie for more details.
- The **2019 VHI Women's Mini-marathon** will take place on Sunday 2nd June 2019 at 2pm. Please see www.vhiwomensminimarathon for more details.
- The **2019 Cork City Marathon** will take place on Sunday 2nd June 2019. Please see www.corkcitymarathon.ie for more details.
- The **2019 KBC Dublin Marathon** will take place on Sunday 27th October 2019. Please see www.kbcdublinmarathon.ie for more details. Contact ILFA on 086 871 5264 or email info@ilf.ie for a fundraising pack if you would like to fundraise for ILFA.

Educational Activities

- **Patient Information Day on 'Palliative Care and Planning for the Future'** will take place on Saturday 6th April at 10am at the Hilton Airport Hotel, Malahide Road, Dublin.
- Professor Luis Ortiz from the University of Pittsburg Medical Centre, USA, will deliver a lecture entitled '**The irony of lung fibrosis: A fibroblast to treat Idiopathic Pulmonary Fibrosis**' at the Royal College of Physicians of Ireland on Wednesday 19th March 2019 at 7pm. All are welcome.

Please contact ILFA on 086 871 5264 or email info@ilfa.ie to register your interest in attending.

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.

