



FERGUS GOODBODY LECTURE 2012

As part of the World IPF week, an educational program for Doctors entitled "New Horizons: Idiopathic Pulmonary Fibrosis" took place in the Royal College of Physicians of Ireland. The proceedings were opened by Dr Diarmuid O'Shea, Vice President of Education and Professional Development, Royal College of Physicians of Ireland and Dr Vera Keatings (Consultant Respiratory Physician, Letterkenny General Hospital, Donegal) chaired the meeting. Professor Jim Egan (Mater Hospital, Dublin) gave a presentation entitled "Transplant for Lung Disease" and Dr Anthony O'Regan (University College Hospital, Galway) spoke about Sarcoidosis.

Speakers at the Royal College of Physicians of Ireland (from left) Professor Jim Egan, Dr. Anthony O'Regan, Professor Ron du Bois, Dr. Vera Keatings and Professor Michael Keane.

ILFA INFORMATION DAY

Speaking at the ILFA Information Day in April Professor Jim Egan said that there had been considerable progress in the ten years since ILFA was founded in optimising and enhancing the treatment for people with lung fibrosis. He said that, as a culmination of research in which Irish patients participated, a new drug, Pirfenidone, had been approved in Europe and more and more new therapies were coming down the tracks as on-going studies were being conducted into other compounds.

He said the Mater transplant programme has been firmly established and a recent report in the British Medical Journal showed that the outcomes in Ireland were comparable, if not better, than in the UK and internationally.

Also speaking at the Information Day Ms. Karen Redmond, transplant surgeon in the Mater, said that Dublin was now one of the biggest centres in Europe offering transplant surgery for patients with IPF.

She said that the issue at the moment was that there were not enough organs for transplantation. She described how the use of Ex-Vivo Lung Perfusion (EVLP) could improve the number of lungs available for transplantation by reconditioning lungs that heretofore might not have been used. This new technique was developed in Toronto where Ms. Redmond trained and she is heading up a multi-centre trial to evaluate the outcomes of this technique.

Professor Michael Keane (St. Vincent's University Hospital, Dublin) discussed "Research Initiatives in IPF" and Professor Ron du Bois (Asmarley Professor of Respiratory Medicine, from the Royal Brompton Hospital & National Heart & Lung Institute Imperial College of Science, Technology & Medicine, in London) delivered the 2012 Fergus Goodbody Memorial Lecture. His presentation was entitled "Interstitial Lung Disease: A State of the Art Review".

Professor du Bois said he was honoured to be invited to give the Fergus Goodbody Memorial Lecture on the tenth anniversary of ILFA. He recounted how Fergus was a sportsman, a solicitor, a man actively involved in his community, a man of great courage and a champion in his fight against IPF. In his lecture, Professor du Bois reviewed the 2011 Consensus Guidelines that were agreed by an international panel of leading respiratory physicians for the diagnosis and the management of IPF. The evidence for various drug treatments was discussed and it was noted that not all patients respond in the same way, and some treatments are better suited to different subsets of patients. Life improving interventions such as oxygen therapy, pulmonary rehabilitation, counselling and the role of support groups and clinical nurse specialists were highlighted.

Prof. du Bois described the promising advances in research into IPF, in particular the number of clinical trials that have taken place in the last 10 years, and how future treatments are currently being investigated and developed. It is envisaged that in the future combination therapies will be the way forward. Prof. du Bois stressed to the audience the importance of early referral for transplant assessment, how an international collaborative approach is needed to progress research into IPF and how world-wide clinical trials are so important in the search for treatments to halt disease progression.

There was a lively discussion at the end of his lecture with questions from the audience. The ILFA would like to extend our sincere thanks to the Royal College of Physicians in Ireland, all the speakers, and in particular to Prof. du Bois for their participation in the excellent and informative educational symposium on Lung Fibrosis.

NEXT ILFA INFORMATION DAY

The next ILFA Information Day will take place on **SATURDAY, 10th NOVEMBER 2012** in the **Carlton Hotel, Dublin Road, GALWAY**. Registration will commence at 10am and lunch at 12.30pm. Speakers will include **Dr. Anthony O'Regan, Respiratory Physician, and Professor Jim Egan, Respiratory and Transplant Physician.**

INTER-CHURCH SERVICE TO CELEBRATE 10 YEARS OF ILFA

Fr. Brian McKay, Prior, Church of Our Lady of Mount Carmel, Whitefriar Street, Dublin.

Coffee taken with dear friends starts conversations and sometimes the direction of the conversation is slightly unexpected! Such was my experience on January the 6th last when I, Nicola and Eddie Cassidy met for a chat and a cuppa. By the end of the conversation, the church was booked, the date set and the editorial committee appointed for the service on May the 12th. Initially, the group consisted of myself, Eddie, Nicola, John Donnelly and my very good friend, Canon Charles Mullen of St. Patrick's Cathedral, Dublin. Our task was to draw up an order of service to worthily celebrate the 10th anniversary of ILFA. We planned on having two or three meetings, but as time went by, it became clear that we had a great deal of work to complete so the meetings multiplied and the editorial board expanded.



We added Dawn Ellis and Nicola Figgis to our ranks and it was full steam ahead!! Our fear was that we would be short of material for the readings and reflections, but our fears were totally unfounded. Thanks to some wonderful cooperation from many members of ILFA the material poured in and we spent several meetings making our own short-list of what we would need. We were blessed by the generosity of the Culwick Choral Society who got behind us with gusto and it is generally acknowledged that the music on that memorable afternoon was superb. Also, the ecumenical nature of the service made it so very special. No one denomination dominated - all were equal and all were cherished. By the beginning of May, we were convinced that all was going to be well, and thanks to the organizational skills of Nicola Cassidy, nothing seemed to have been forgotten. The rest, as they say, is history! The day was sunny, people were in good spirits, Whitefriar Street church looked well, the choir, clergy and readers were in good voice, the organ stirred us to the core and the reception was so pleasant. Even the part of the service which recalled the passing of so many people in 10 years had its own sense of tranquility, peace and hope. By 6 o'clock on that lovely day, the editorial committee was well pleased with how the day had proceeded. The sermon was given that afternoon by Canon Mullen. It was the first time that a non-Roman Catholic preached in Whitefriar Street church and what a tremendous day to make history!! This article is being written after the new clerical appointments for summer 2012 have been published and as the new Prior, I have been invited to preach in St. Patrick's Cathedral. I believe that this also is a first. What ILFA has done for me!! It was a wonderful experience and well worth all the effort that went into ensuring that the day was a success. Be assured ILFA is always welcome in this church!



Canon Charles Mullen, the Reverend Denis Campbell, the Reverend Vanessa Wyse Jackson and Fr. Brian McKay at the Interfaith Ceremony in Whitefriar Street Church.

Charles Mullen, Canon of Saint Patrick's Cathedral, Dublin

It was a privilege to be invited to give the address at the ILFA celebration service on 12th May. It seems that history was made on the day. According to our host, Fr. Brian McKay, O Carm., I was the first non-Catholic to have preached in the Whitefriar Street Church. This news put me under considerable pressure to deliver the goods! There was a wonderful atmosphere of prayer and reflection, and smiles of joy, during the ceremony. The candle-lighting ceremony was simple and dignified, the readings and prayers were well chosen and well delivered, the music was skilfully performed, and I was very moved to be sharing these things with clergy from the Catholic, Presbyterian and Methodist traditions. As I said in my address, we can look forward to the next ten years, and the ten after that, and so on, with thanksgiving for all those who serve us with such dedication to the work of ILFA.

Vanessa Wyse Jackson, Minister of Rathgar Methodist Church.

I was delighted to be able to take part in the inter-church service organised by ILFA on 12th May and to meet so many warm and positive people. ILFA's tremendous work seems to bring such hope and support to so many.

A DVD featuring highlights of the inter-faith service is available to order. It is free of charge but a donation to cover production and postage costs would be gratefully received. To order your DVD please email info@ilfa.ie or call 086 0570310.

If your loved one's name was included in the Remembrance List that was read out during the ceremony and you have not received the candle lit in their memory, please contact ILFA at info@ilfa.ie or call 086 0570310 and we will post it to you.



Karen Redmond (Mater Hospital), Philip Watt (Irish Donor Network) and Lorna Murphy (ILFA) at the launch of Organ Donation Week in the Mansion House.

THANK YOU

To **Brigid McArdle** from Co. Louth. Brigid's husband, Thomas, was diagnosed with Pulmonary Fibrosis in March 2000, but sadly died suddenly in October 2011 while on the transplant list. At his funeral Brigid asked for donations to ILFA and raised €270. Brigid said of Thomas, "His illness never stopped him from doing anything. He'd always find a roundabout way to do things. He was always in good form and never complained. He was an inspiration to us all."

To **Deirdre Linnane** and **Mark Moran** and the guests at their wedding who donated over €5,000 to ILFA.

To the **Taylor family** who asked for donations to ILFA in lieu of Christening presents and to **Tom Flynn** who asked for donations to ILFA in lieu of birthday presents!

Patient Support Groups

CORK

On Lung Fibrosis Day, Thursday 28 June, members of the Cork Support Group manned two stands in Cork University Hospital from 9am till 4pm and distributed ILFA literature and Organ Donor cards. Dave Mulcahy said; "There was a great response here with approaches from many people within the HSE to tell us of their appreciation of what we were doing. Thanks to Ber Bowen who pointed us in the proper direction. I suppose a measure of our success here is that we gave out about 300 Organ Donor cards."

The Cork Support Group holds regular meetings at 11.00am on the last Thursday of every month at the Elm Tree, Glounthane. Contact Dave at 087 2865297.

KERRY

The Kerry Support Group meets on the last Saturday of the month at 3.00pm in the Carlton Hotel, Tralee. Contact Michael Horan at 087 1336406.

LAOIS OFFALY

The Laois Offaly Support Group meets on the third Wednesday of every month at 2.30pm in the lobby of the Tullamore Court Hotel. Contact Tom at 086 1500970.

MY STORY

My name is Patrick O Mahony, better known to my friends and colleagues as Paddy. I am married to Pauline and we have recently moved to Marino in Dublin. I have been a member of Dublin Fire Brigade for nearly 35 years.

I started my career as a fireman, or should I say firefighter, and have progressed through the



Paddy and his wife, Pauline

ranks to the rank of District Officer. I have served in many different stations throughout Dublin City and County and am now stationed in Brigade headquarters in Tara Street. My role is the mobilisation Officer for D watch with responsibility for all day-to-day operational needs.

In April 2010 I was not feeling well and, like most men, a visit to the doctor would be a last resort, but my boss, Pauline, had other ideas so a visit to her doctor was quickly arranged. She examined me and quickly realized that I needed to be seen in the Emergency Department at Beaumont Hospital. This was my first introduction to blood tests, examinations, X-rays as I had never been sick before (lucky me).

I had a number of tests carried out to try to identify what the problem was. At first they suspected that it could be TB and I was put into an isolation ward overnight. The following morning I was informed that it was not TB but I had a condition called Idiopathic Pulmonary Fibrosis (IPF). I asked the question – What is IPF? So it was explained to me in no uncertain terms the seriousness of my illness, and there we will leave Beaumont Hospital other than to say I was lucky enough to meet a respiratory physician called Dr. Cedric. He very kindly made an appointment for me to see Professor Michael Keane in St Vincent's Private Hospital. I cannot say enough about the positive attitude of Professor Keane and I came out of his clinic feeling much more positive about things.

Professor Keane put me on medication and made an appointment for me to have a number of tests carried out. During this time we went on the internet and discovered Irish Lung Fibrosis Association (ILFA). It was great to know to we had a support group available to us and through ILFA we learned more about the condition.

We also came across an article in the ILFA information leaflet about a new drug called Pirfenidone. We discussed this new drug with Professor Keane at my next visit and when it became available in Ireland I was put on it.

In March this year Professor Keane made arrangements for me see Professor Jim Egan with a view to being assessed for a transplant, another man with a very positive attitude, and again I left his clinic feeling very positive. Over the next month I had all the necessary tests and met the rest of the transplant team. I cannot praise the team enough for their professionalism, dedication, support and humanity.

In May 2012 I was put on a transplant list. Already I have had one call but unfortunately it did not go ahead. Every Tuesday I get a call from the co-ordinators who are brilliant in their support and encouragement to me.

I continue to work fulltime in Dublin Fire Brigade and enjoy the challenge as it helps to keep my head focused. I exercise and go to the gym twice a week in order to keep myself as fit as possible so I am in the best physical condition when the call comes.

I would like to take this opportunity to thank all my colleges in Dublin Fire Brigade for all their support. I would also like to thank my wife and family and a special thank you to all the people and their families who carry organ donor cards and make this wonderful gift available to people like me.



Paul Carpenter, Derek Murphy, Caroline Hayes, Louise Wilkinson and Celine Carpenter who ran the Cork City Half-Marathon and raised €1,723 for ILFA.

Muchas gracias y aprecio sincero a Rafa



ILFA would like to thank Rafa Benitez (former manager of Liverpool Football Club) for his generous donation of €5,000 to our charity. Rafa was in Dublin on 13 September and presented a cheque to Pamela Martin, Eddie Cassidy (ILFA Treasurer) and Stephen Cassidy. Rafa also mentioned the importance of supporting a small charity like ILFA in his presentation entitled "Champions League Dreams" at the Bord Gais Energy Theatre.

Thanks also to the many friends of Pamela Martin belonging to the irishkop.com Liverpool Supporters Club who have taken part in numerous events such as sky-dives, hiking challenges, charity nights and mini-marathons to fundraise for ILFA. On 12 August a group of Pamela's friends ran the Dublin Port Tunnel Run and have collected over €600 to date.

SONG FOR LIAM

Eamonn Wall, musician and song-writer, has produced a CD entitled "Song for Liam" in memory of Liam Clancy who suffered from Pulmonary Fibrosis. The CD contains two songs, *Song for Liam* and *Cry of the Burren*. The CD is available to purchase for €5 and all proceeds from the sale of the CD will go to ILFA. If you would like to order a CD please email info@ilfa.ie or call 086 0570310.

ST. STEPHEN'S DAY SWIM

The annual ILFA swim will take place at 12 noon on St. Stephen's Day, 26th December 2012, at Sandycove Pier. Please join us and take the plunge for ILFA. The group will adjourn to Eagles House, Sandycove, to warm up afterwards. Sponsorship Cards are available from Lorna at 086 8715264



Thank you to all those who organised and participated in the sponsored cycle from Cork to Galway in April and raised a whopping €13,680 for ILFA.

Limerick Table Quiz

Lorraine Ryan, Limerick

Five years ago my dad was diagnosed with Idiopathic Pulmonary Fibrosis and after this diagnosis we found the ILFA website. I spent a lot of time going through the website and reading all the useful information it had. I decided I wanted to do some fundraising for ILFA and I signed myself up for the Flora Women's Mini-Marathon. Five years on, I am still doing mini-marathons for ILFA but I've changed to the Great Limerick Run as this is more convenient as I live in Limerick.

This year while discussing the Great Limerick Run my friend, Dawn, suggested that we do a table quiz in aid of ILFA. Through the last few years of fundraising for ILFA my friends have been unbelievably supportive both for doing the mini-marathons with me and also sponsoring me. Hazel D'Arcy, Dawn Conway and Carrie Halvey have been a continuous support to me and have helped me with every event.

There was lots of planning involved for the table quiz but I knew I had plenty of helpers and together we raised an amazing €1,616.30 for ILFA and we also raised awareness about Pulmonary Fibrosis. I heard this saying before that says "alone we can do so little, together we can do a lot". I now really know that this is true. Thank you to my family and friends for their help and support.



Mike Daly, Chairman Tullamore Anglers (centre) presenting a donation for ILFA to Tom Flynn (left) and Anthony Marnell of the ILFA Laois Offaly Support Group.

Every year the Tullamore and District Angling Club host a coarse fishing competition on the Grand Canal between Present Junior members and Past Junior members. The members collect sponsorship for a charity. The winning captain chooses the charity and Pdraig Carroll, captain of the Past Juniors who won the competition, chose ILFA, a charity close to his heart. Pdraig's father has Pulmonary Fibrosis and his uncle, who died recently, was also affected by the condition. On behalf of ILFA Tom Flynn thanked the Club for their generosity and assured them that the funds would be put to good use.