



ILFA GOES INTERNATIONAL

This year ILFA was invited to attend several international respiratory conferences. In September, ILFA had a stall at the World Village area at the European Respiratory Society (ERS) Congress in Barcelona. 21,000 delegates attended the congress making this the biggest lung health conference in the world.

The ILFA delegation, consisting of Nicola and Eddie Cassidy and Paddy and Pauline O'Mahony, attended a meeting with the IPF medical experts and members of the European Lung Foundation (ELF). In preparation for the meeting, the Patient Support Groups from Dublin, Kerry and the Midlands held discussions about patient and carer perspectives on IPF and a report was compiled by ILFA. Professor Athol Wells (Chairman of the IPF medical experts) called the ILFA report "A powerful piece of work" which was a great endorsement of the discussions and work carried out by Irish patient support groups. There was an interactive discussion about what patients want and expect from doctors, the importance of early assessment for lung transplantation, planning for the future and palliative care, and the importance of communication and empathy. ILFA also highlighted the need for written materials as well as online material, as not all patients have access to the Internet.

Claire Tunissen and Charles Lock attended the IPF Patient Advocacy Workshops in Dubrovnik (June 2013) and in Nice (November 2013). There was a round table discussion with other IPF patient organisations from the EU and Canada about developing a European Patient Charter for IPF. ILFA would like to



develop a Patient Charter for Ireland in 2014 and we will contact you at a later stage for your input, so please keep an eye on the ILFA website and ILFA Facebook page.

Professor Egan (Mater Misericordiae University Hospital) and Nicola Cassidy were invited to speak at the 'Advancing in IPF Research' Conference in November 2013. They delivered a joint presentation with Dr. Marlies Wijsenbeek and Lida Naber from Longfibrose Patientenvereniging, the Dutch Patient Association, and the title of their talk was "Patient Associations and Healthcare Professionals. How we can work together better". The audience consisted of 340 respiratory doctors, nurses and medical researchers from all over Europe who treat IPF patients. It was a great opportunity for ILFA to highlight our work and to tell doctors what patients need in order to understand the complexities of IPF. We also learned a lot from the experiences of our colleagues in the Dutch Patient Association.



Mary O'Connor-Bird

Thank you, Mary

I am sorry to have to report that, after many years' service, Mary O'Connor-Bird has decided to resign as Secretary of ILFA. In this position, Mary has been a great help and support to me, to the Committee and to the Association generally. Always reliable and efficient, Mary ensured that our correspondence was kept up to date, our meetings ran smoothly and she initiated and developed many ideas and policies. In addition to this work as secretary, Mary represented ILFA at various meetings of organisations involved in the areas of organ donation and transplantation, and was also instrumental in our two meetings with Ministers for Health.

The news is not all bad, however. Mary has indicated that she will remain a close supporter of our Association into the future and we look forward to many more years of Mary's support and wise counsel.

Terence Moran, Chairman.

Soft 'opt out' Organ Donation

ILFA welcomes the recommendation for the introduction of a soft 'Opt Out' Organ Donation System.

The Oireachtas all party Health Committee has recommended that the Government introduce a soft 'opt out' system for organ donation. The report from the Oireachtas Health Committee, published on October 1st, proposes to change the system of organ donation in Ireland to a soft 'opt out' approach, in line with the majority of European countries.

The proposed change means a person can be presumed to be in favour of donating their organs for transplantation in cases of unforeseen death, unless they have opted out. The next of kin will always be consulted prior to removing any organ(s) and if the family objects to the organ donation, the donation will not proceed. The change to a soft 'opt out' system is expected to lead to an increase in the number of potential organ donors and a rise in the number of patients who will receive a transplant.

ILFA would like to thank the TDs and Senators who participated in the all party consultation on the soft 'opt out' system and supported this positive change for organ donation in Ireland.

Tips and quotes

Every week ILFA adds a new "Tip of the Week" and a new "Inspirational Quote of the Week" to our website www.ilfa.ie and facebook page www.facebook.com/ILFAIreland. Take a look, "follow" us on our facebook page and "like" the tips and quotes.



ILFA Service of Prayer and Reflection

The ILFA Service of Prayer and Reflection took place in St. Ann's Church, Dawson Street, Dublin on 28th September during IPF World Week. Our service was led by the Reverend Canon Charles Mullen and he was joined by his fellow clergy: The Reverend Vanessa Wyse Jackson, The Reverend Denis Campbell, Father Brian McKay O.Carm., and The Reverend David Gillespie. Patients, relatives, friends and healthcare staff gathered together as a community to join in prayer, song, music and reflection.

Eileen Bresnan, who travelled from Aberdeen to take part in the service, treated us to some wonderful flute music and Fr Brian McKay gave an inspiring and uplifting sermon based on a prayer by St. Theresa. We prayed for the sick, those in need, and for those who care for and minister to lung fibrosis patients. The candle lighting ceremony was touching as we remembered our loved ones who had passed away.

Afterwards there was an opportunity to socialise over a cuppa. ILFA would like to thank all those who gave so generously of their time to help with this wonderful service.

BOOK REVIEW

Robert Davidson is a Canadian gentleman, who worked as a Tax Consultant in Markham, Ontario and as a senior level soccer referee. He was diagnosed with Idiopathic Pulmonary Fibrosis in October 2007 and he decided to live as normal a life as possible, borrowing from Winston Churchill the mantra "Never Surrender".

In his book "Breathing should never be hard work", Robert describes with great candour, and sometimes "laugh out loud" humour, the worst symptoms and challenges of living with this disease.

Robert received a double lung transplant in January 2010 and is ever grateful to his donor, the selfless hero, who signed a donor card.

The book can be obtained through www.amazon.com.



ILFA Patient Information Day, Cork

The ILFA Patient Information Day recently held in Glounthane, Cork was well attended by patients and carers. Ms. Kathleen Lynch, Minister for State, Department of Health and Department of Justice, Equality & Defence with responsibility for Disability, Older People, Equality & Mental Health was our opening Guest Speaker. The Minister highlighted the fact that an Open Day such as this presented an opportunity for patients and their families to get valuable information from healthcare professionals and allowed people to meet, share experiences and exchange information. It is important for patients to realise that they are not alone as having a rare disease and feeling alone can be as bad as the disease itself.

Dr Mike Henry, Respiratory Consultant from Cork University Hospital, stressed that exercise and pulmonary rehabilitation are as important as any drug that is prescribed for patients. He outlined the 8-week long pulmonary rehabilitation programmes that take place in some of the Cork hospitals and the benefits for IPF patients. Dr. Henry outlined the usefulness of Pirfenidone for patients with mild to moderate IPF, but warned that the drug was not suitable for everyone and that strict guidelines should be followed prior to prescribing it to patients. He further discussed other medications for patients with IPF.

Next the meeting heard from Ms. Kate Murphy, Dietician from the Mercy University Hospital in Cork, who advised the audience to base meals around starchy foods (such as potatoes, pasta and rice), eat more wholemeal and wholegrain food varieties, make sure to have 5 portions of fruit and vegetables daily and to eat more fibre. Patients who are overweight should aim to achieve a slow and steady weight loss by making gradual and permanent changes to their lifestyle. The audience was encouraged to use fat and oils sparingly, to trim the fat off meat before cooking, to grill food instead of frying it, keep sweets, biscuits and cakes out of reach and to only have occasional takeaway foods as a special treat. Kate warned the audience of the hidden calories that are associated with alcoholic drinks. Finally she advised that patients on steroid medication should make sure that they are getting enough calcium and vitamin D to ensure good bone health. Dairy products, oily fish, eggs, fortified milk and cereals are good sources of calcium and vitamin D.

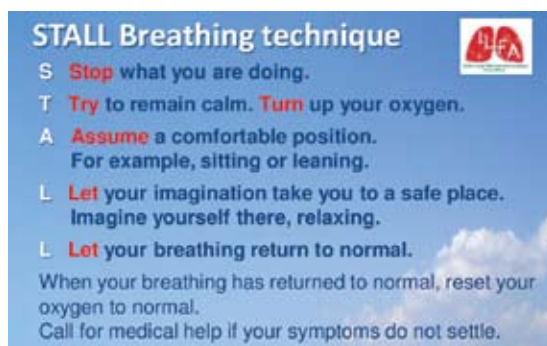
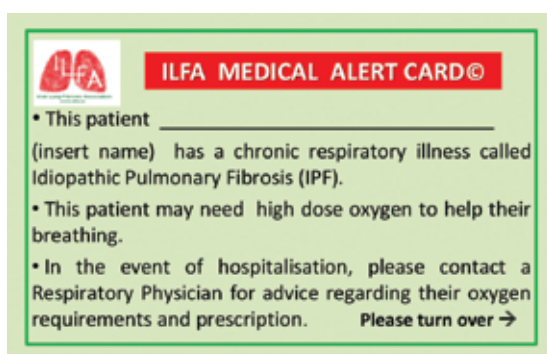
Irene Byrne, Senior Physiotherapist at the Heart & Lung Transplant Ward, Mater Hospital gave an inspiring talk on coping with breathlessness, the benefits of exercise and the proper use of oxygen. Irene encouraged all patients to speak with their oxygen company about the latest equipment and mobility aids for carrying oxygen. IPF patients should use their oxygen wisely to minimise their breathlessness during periods of exertion. It is very important to turn up your oxygen when doing activities that leave you breathless, for example showering and getting dressed in the morning, moving around, and eating. Daily exercise is vitally important for IPF patients and it should be considered as important as any medication. Exercise is beneficial for maintaining bone health, making patients stronger, ensuring good muscle strength, lifting mood and helping with weight management.



STALL CARD and MEDICAL ALERT CARD launched

Ms. Kathleen Lynch and Irene Byrne launched the ILFA STALL Breathing Technique card. The ILFA STALL card is designed to be carried in a wallet, purse or pocket and it has simple instructions on how to control your breathing if you experience breathlessness.

The ILFA STALL breathing technique card can be ordered from ILFA by emailing info@ilfa.ie or calling 086 057 0310



THANK YOU

ILFA would like to thank all of our fundraisers for their great efforts to raise money and awareness of IPF through various activities, including:-

- Sponsored cycle from Cork to Limerick and back organised by Pat and Anne Casey and Brian Aherne in April 2013.
- Barbara O'Connell and John Sheridan took part in the Spar Great Ireland Run in the Phoenix Park, Dublin in May 2013.
- Carolyn Tierney, Helen Malone, Carmel Malone and Sara Byrne walked 115km from Sarria to the Cathedral at Santiago de Compostela in May 2013.
- Niamh Ryan took part in the Sean Kelly Tour of Waterford (100km cycle) in August 2013.
- All the ladies who took part in the Cork Mini Marathon in September 2013 and wore our ILFA t-shirts with pride.
- Priscilla Quinn did a sky dive with the Irish Parachute Club in Co. Offaly in October 2013.
- All Your Life Fitness Club, Donoghue's Bar and members of the Troy family in Co. Tipperary organised the Inaugural Highland Games in October 2013.
- Halloween Fancy Dress Party organised by the Troy Family in Co. Tipperary in October 2013.
- Andrew Grehan, Sadie McDevitt, Brian Killoran, Anthony Corrigan, Colm Donoghue and Eddie Hogan took part in the Dublin City Marathon.
- Lorraine Ryan organised a Table Quiz in Limerick and ran the Great Limerick run with friends.
- Michael Mahon took part in a 100km cycle in Co. Wexford.
- The Ramor Theatre company in Co. Cavan raised funds with their very own 'Calendar Girls' 2014 calendar with some very imaginative poses!
- Caroline Corley and her husband Stephen O'Donnell and Amy Haskins and her husband David Aughney made



New Year's Day Swim

Looking for a great start to the New Year?

The Annual ILFA Swim will take place on Wednesday 1st January at midday at Sandycove Pier, Dublin. As usual, we will be warming up immediately afterwards with soup and mulled wine at the Eagles House, Glashule. All are welcome, particularly brave swimmers and those who can raise sponsorship!

donations to ILFA in lieu of wedding favors on their special day.

- Church collections in Counties Cavan and Monaghan organised by the Smith family.
- Members of the McGowan family took part in the Mayo Mini Marathon.
- Special thanks to all the families who made donations to ILFA in lieu of flowers on the occasion of their loved one's funeral.

Women's Mini-Marathon 2013



The Dublin Women's Mini Marathon took place in Dublin on 3rd June in glorious sunshine. The customary group photos of our 40 ladies took place at the Mespil Hotel and it was good to greet annual participants as well as our new team members for this great race. The race got underway at 2pm following the traditional sing along to "Molly Malone"! Bands and supporters were dotted along the 10km course and the thought of "the best cup of tea of the year!" in The Duke Pub once the race had been completed, kept everyone going.

The ILFA Committee would like to extend sincere thanks to all of you who took part and helped raise valuable funds for our charity. Each person who wears the ILFA t-shirt is also helping to raise awareness of IPF and this act alone can have a tremendous impact.



1. Remembering Loved Ones

2. Niamh Ryan participated in the Sean Kelly Cycle

3. ILFA Delegation at the ERS Congress, Barcelona

4-5. Ladies Mini Marathon, Dublin

6. Ladies Mini Marathon Cork

7. Collection for ILFA at Cork University Hospital

8. Participants in the Cork to Limerick and back again Cycle

2000 Steps A Day Walking Challenge



Walking is an ideal exercise for Lung Fibrosis patients. The 2000 Steps a Day Challenge has been specifically designed for Lung Fibrosis patients. This challenge aims to help you achieve your best level of fitness and well being while taking into account your limitations and oxygen requirements. The 2000 Steps a Day Challenge was devised by Ms. Irene Byrne, Senior Physiotherapist with the Heart and Lung Transplant Unit at the Mater University Hospital Dublin and developed with the ILFA.

We want you to use the programme to help kick start, improve and maintain your level of fitness. Please contact ILFA to request your 2000 Steps a Day walking pack by writing to ILFA, PO Box 10456, Blackrock Co. Dublin; or requesting the walking pack via email info@ilfa.ie or by calling 086 0570310.

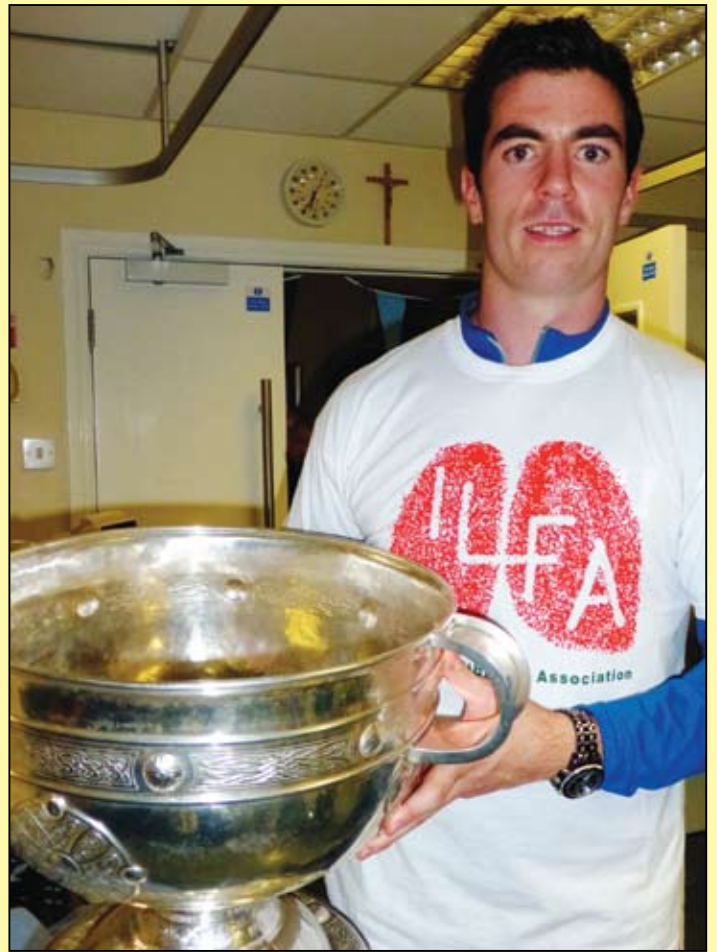
ILFA Educational videos to watch on www.youtube.com

Some of the presentations delivered at the ILFA Patient Information Day in Dublin in March 2013 are now available to view on YouTube by clicking on the links below. We hope you that you will find these videos useful.

If your loved one has lung fibrosis, please help them to view these videos if they are not familiar with using a computer. ILFA would like to extend sincere thanks to Jonathon Levy for his help with filming and editing these educational videos.

1. Irene Byrne, Senior Physiotherapist at the Heart and Lung

'SAM' visits the Heart and Lung Transplant Unit



Special thanks to Michael Darragh Macauley, ILFA Exercise Ambassador, and his Dublin team mates Ciaran Kilkenny, Ger Brennan, and Johnny Cooper for visiting the Heart & Lung Transplant Ward in the Mater Hospital in October. Michael Darragh made a special surprise visit with SAM and there was great excitement among the patients and staff. Míle Buíochas!

Transplant Ward at the Mater Hospital Dublin, discusses exercise, oxygen use and the ILFA 2000 Steps a Day exercise programme.

2. Yvonne Duggan, Senior Dietician at the Heart and Lung Transplant Ward at the Mater Hospital Dublin, discusses nutrition and the importance of maintaining a healthy weight for lung fibrosis patients.

3. John Carroll, Lung Fibrosis patient, gives an inspiring account of his successful weight loss and the importance of exercise.

To access the videos either click the links to the videos on the ILFA website www.ilfa.ie or type "ILFA Ireland" in the search box on the www.youtube.com home page.

Second chance

One day in early 2013, at 9pm I received a call from Vivienne who is the transplant co-ordinator for the transplant team. This was my third call, the first two were unsuccessful – so fingers crossed 3rd time lucky. At 9.30pm the ambulance arrived to take Pauline and myself to the Mater Hospital.

On our arrival at the Mater we were taken to St Cecilia's ward. Vivienne was there and told Pauline and me that an offer had been made and things looked good but as usual nothing was certain. The preparation began, blood pressure, weight, height, blood samples, x-ray and a shower and shave. A member of the transplant team came and discussed the operation with us and answered any questions we had, the long wait then began. At this stage my mind went to the family of the donor and what they must be going through, and still they thought of somebody like me and made a life saving gift. It makes you feel very humble.

As you can imagine the wait was torture. This is where Pauline comes into her own with support which is priceless and without which I would have found it very difficult to cope. She has been there for me all the time. At 4.30am Vivienne came into the room with the news that the transplant was going ahead. My emotions were all over the place with tears, fears and hope. Very quickly I was on my way to the operating theatre. Pauline came with me as far as she was allowed but this was a very difficult time for both of us. She kissed me and said 'See you in a while.' I felt vey alone.

I was taken into a small room where I met the transplant team, they reassured me that everything would be ok and left me in the hands of the anaesthetist and in a short time I was asleep. I woke a number of hours later and realised I had survived the operation. The first person I looked for was Pauline. I could not wait to see her. While I was lying there my mind wandered back to the people who made it all possible: the transplant team led by Professor Jim Egan and his co-ordinators and Mr David Healy, transplant surgeon and his team. I cannot forget my donor. How can I say thanks to someone I don't know but yet made this gift of life available to me?

The next day I was moved from the Intensive Care Unit to the Heart and Lung unit where I was well looked after by the nursing staff who were just fantastic. Each day I was visited by Irene Byrne, the physiotherapist. Her job was to get me back on my feet as quickly as possible - which she did. My recovery



went so well I was allowed home after 9 days, it was good to be going home.

On arrival home my emotions once again were all over the place. Once again Pauline stepped in and did her thing: we had a cup of tea and everything was good. The next day I started my daily exercise routine which consisted of walking for twenty minutes and slowly building up to an hour. At this early stage I was wearing a mask. While out walking one day a man approached me and enquired was I going to rob a bank? I asked him would he like to come along and we could share the loot 50/50 – we both laughed. You have to keep your sense of humour. Very quickly I progressed to cycling and in no time I was doing a round trip of 18 miles. My new lung was doing its job and I felt great. I had a small set back when I got an infection in my stomach, but once we got that sorted out, things were back on track.

I returned to work - just 6 months after the operation – who would have believed it. The support I received from my colleagues in work was just incredible, a great bunch of people. I enjoy waking up every day and look forward to the future, I am now in a position to enjoy my grandchildren growing up.

I attend the outpatients department of the Heart and Lung Unit where I am looked after by Sarah and Ian, two of the best - thanks to them both. I would like to say a very special thanks to my wife and family who have been there for me, but I could not finish without a very special thank you to my donor. Without that person's generosity none of this could have happened I think of you every day and thank you for giving me a SECOND CHANCE.

God bless you, you are always in my prayers.

Paddy O'Mahony lung transplant recipient



Christmas Quiz

1. Which tree produces conkers?
2. What are the names of Santa's reindeer?
3. How many gifts would you receive if you received all the gifts in "12 Days of Christmas"?
4. What year did BandAid release the song "Do they know it's Christmas? In Ireland?"
5. Who was the author of "A Christmas Carol"?
6. What gifts did the Three Wise Men bring to the Baby Jesus?
7. How many doors of an Advent Calendar would you open before Christmas Day arrives?
8. Which Scandinavian country is home to Lapland?

1. The horse chestnut tree; 2. Dasher, Dancer, Francer, Vixen, Comet, Cupid, Donner, Blitzen and Rudolf; 3. 364 gifts (it adds up day by day!); 4. 1984; 5. Charles Dickens; 6. Frankincense, Gold and Myrrh; 7. Twenty-Four (24); 8. Lapland

ANSWERS

Patient Support Groups

CORK: The Cork Support Group meets at 11:00am on the last Thursday of every month at The Elm Tree, Glounthane.

Contact Dave at 087 286 5297

KERRY: The Kerry Support Group meets at 15:00pm on the last Saturday of every month in the Carlton Hotel, Tralee.

Contact Adrian at 087 241 4004

MIDLANDS: The Midlands Support Group meets at 15:00pm on the first Wednesday of every month in the lobby of the Tullamore Court Hotel.

Contact Tom at 086 150 0970

DUBLIN: The Dublin Patient Support Group meets at 11:00am on the first Tuesday of the month in the Carmelite Community Centre, Whitefriar Street Church, Aungier Street, Dublin 2.

Contact Paddy at 087 412 8612

Anyone wishing information about setting up a Patient Support Group in their area, please contact ILFA at 086 871 5264.



Christmas Cards for Sale

ILFA Christmas cards are now on sale. Each pack contains 8 cards (2 each of 4 designs). One pack costs €6 and 2 packs cost €10.

Please ask your family, friends and colleagues to support ILFA by buying some of our Christmas cards and help to raise awareness of Lung Fibrosis.

Call 086 057 0310 or email info@ilfa.ie to order your cards.



Find us on Twitter and Facebook – ILFA Ireland

Tel: 086 871 5264 (general enquiries)

Tel: 086 057 0310 (fundraising enquiries)