

ILFA Newsletter



Patrons: Brian O'Driscoll, Charlie Bird, Senator Feargal Quinn, Andrea Corr.

Issue: Autumn 2015. Volume 12 Issue 2



IPF World Week 2015 Winning Photo!

Congratulations to Joan Doyle and Matt Cullen, the stars of the image that won the "Breath of Life" 2015 IPF World Week photograph competition. The photo was taken in Merrion Square, Dublin, and the fun had on the day shines through. Joan and Matt's photo will be used by international publicity campaigns across Europe to raise awareness of IPF. World IPF Week will take place from 5th to 11th October 2015.

ILFA Service of Prayer and Reflection 2015



The 2015 ecumenical ILFA Service of Prayer and Reflection will take place at 3pm on Saturday 17th October in Christ Church, Taney, Dundrum, Dublin 14. The service will be led by Reverend

Canon Charles Mullen, Deans Vicar, St Patrick's Cathedral. Refreshments will be served afterwards in the church hall. All are welcome.

During the service, a candle lighting ceremony will be held to remember lung fibrosis patients who have passed away. If you would like your loved one remembered, please contact us by email at info@ilfa.ie or by telephone on 086 871 5264, by 14th September.

National Patient Charter for IPF

ILFA has developed a National Patient Charter for Idiopathic Pulmonary Fibrosis (IPF) with input from patients, carers and healthcare professionals. We hope that the charter will support newly diagnosed patients by informing them and their families about the standard of care, medical treatments and services that they should have access to. A booklet explaining the charter and its background

will be sent to everyone on the ILFA mailing list in the coming weeks.

We will officially launch the National Patient Charter for IPF at an education session for TDs and Senators in Leinster House at 10am on Tuesday 6th October. The launch will take place during World IPF Week and is a valuable opportunity to raise awareness of IPF and inform our national representatives of the physical, practical

and emotional issues faced by IPF patients and their families. There are 3 invitations enclosed with this newsletter that you can give to your local TDs to encourage them to attend the event. More invitations can be printed from our website.

It will be crucial to have IPF patients present on the day to share your needs and experiences with the politicians. ILFA would like to invite you to come along and join us on the 6th October. Please contact Denise by telephone on 086 871 5264 or by email on info@ilfa.ie to register.

ILFA Patient Information Day, Athlone, 9th May 2015

Terence Moran, ILFA Chairman, welcomed everyone to the meeting and got proceedings underway with the announcement of ILFA's new leaflet Oxygen and Idiopathic Pulmonary Fibrosis.

Professor Jim Egan, Respiratory consultant from the Mater Misericordiae University Hospital acknowledged the great advances in the treatment of Idiopathic Pulmonary Fibrosis (IPF) in the last decade. He paid tribute to the pharmaceutical companies who have invested in the research and development of new drugs to treat IPF. Recent developments included the positive results for clinical trials for Nintedanib and Perfenidone, where both drugs slowed down disease progression, by different methods. There are a small number of other drugs that are currently being investigated as potential treatments for IPF and some of these drugs may proceed to clinical trials over the next 5-10 years.

Lung transplantation is the only effective treatment for IPF and this year the Mater Hospital celebrates its 10th year of lung transplantation. The national lung transplant programme has had remarkable successes since it started in May 2005 and it is currently the third largest lung transplant programme in Europe. A patient's age is not an automatic reason

for exclusion from having a lung transplant in Ireland. Your overall general health and IPF status are more important than one's numerical age but sometimes other medical problems can determine your suitability for a lung transplant operation.

The present government made a commitment to introduce a 'soft-opt out' model for organ donation in Ireland. This means that in circumstances where a person is not expected to recover, their family will be approached and asked to consider organ donation. If an individual has previously opted-out (decided against organ donation), their family will not be approached. Please ask your political representatives to ensure that initiatives to improve organ donation rates in Ireland remain a government priority.

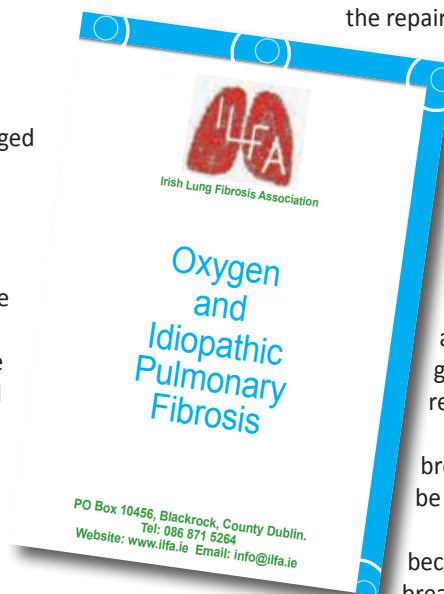
Professor Anthony O'Regan from University College Hospital Galway gave an overview of Idiopathic Pulmonary Fibrosis (IPF). 'Fibrosis' is the medical word used to describe scar formation. Our bodies all have the potential for healing when we are injured, for example if we get a scratch or cut to our skin, a scar forms over the injury. Our lungs are constantly bombarded with particles, dust, bacteria, viruses and these may cause injury to the lung. With IPF, the repair process in the lungs goes out of control and excessive scar tissue formation occurs.

IPF is more common in men and the average age for diagnosis is 66 years old.

There may be a genetic link but the way that genes cause IPF is not entirely clear. At present, there is no useful screening tool to test individuals and testing is not recommended. This is because the genes that are thought to be involved are present in a substantial proportion of the general population, but the incidence of IPF is relatively small.

Patients usually develop shortness of breath and dry cough and crackle sounds can be heard through a doctor's stethoscope.

As IPF progresses, the lungs stiffen and become more difficult to expand when you breathe in. The aim of treatment for IPF is to stabilise patients so that the disease advances at a slower rate. In 2014, clinical trials in IPF patients showed that two medications, Pirfenidone and Nintedanib, slowed down the rate of IPF progression. Professor O'Regan discussed how some





Terence Moran, Donna Langan, Matt Cullen and Maria Love.



Professor Jim Egan, Dermot King and Professor Anthony O'Regan launched the new ILFA leaflet entitled "Oxygen and idiopathic pulmonary fibrosis".

medications can help patients manage the effects of their IPF and other co-existing illnesses, however with all medications there can be side effects. Doctors must look at the benefits and drawbacks for all medications before prescribing them. Palliative care is very useful for helping to improve symptoms and quality of life for patients who are experiencing severe symptoms.

Professor O'Regan also described the development of a new disease registry by the Irish Thoracic Society to collect information on the number of patients diagnosed with IPF in Ireland. Six hospitals around the country will collect patient data for example

the patient's age, diagnosis, and if they are prescribed IPF medication, oxygen and pulmonary rehabilitation. The information will be collected in accordance with Data Protection Rules and will be confidential. It is hoped that the registry will be launched later in 2015.

Donna Langan, respiratory nurse specialist from University College Hospital Galway, described her role and the Interstitial Lung Disease Clinic that runs every month at her hospital. It is a multidisciplinary clinic where patients are seen by the doctor,

nurse, physiotherapist and lung function technician during their appointment and have regular blood tests, a 6-Minute Walk test, and CT scans carried out. This approach saves the patient time, as they do not have to make appointments to access all of these services individually. Donna described the different types of oxygen equipment available and how medical oxygen can impact on the whole family, as everyone needs to adapt to having the equipment in the home. Respiratory nurse specialists can give advice on holidays and travelling with oxygen but it is very important to start planning with your nurse well in advance. Donna encouraged patients to take part in pulmonary rehabilitation classes and to use the ILFA 2000 Steps a Day exercise programme to build up their daily exercise and push themselves to new limits, reminding everyone that "What you do today is what matters most!"

Maria Love, social worker at the Mater Misericordiae University Hospital, talked about anxiety and how it is our body's

Patient Support Groups

CORK

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

Contact Anne at 087 985 4587

KERRY

The Kerry Support Group meets at 3pm 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 3pm on the first Wednesday of every month in the lobby of the Tullamore Court Hotel.

Contact Tom at 086 150 0970

DUBLIN

The Dublin Support Group meets at 11am 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

If you would like information about setting up a Patient Support Group in your area, please contact ILFA on 086 871 5264.

natural response to coping with a difficult situation. Anxiety can affect;

(1) our thoughts - causing us to worry (2) our feelings - causing us to be on edge and nervous (3) our behaviour - causing us to become irritable and unable to relax and (4) our body - causing us to be tired, tense and feel that our hearts are racing. When anxiety becomes excessive, prolonged and unpleasant, we need to look for help, otherwise it will result in a vicious circle of negative responses that will lead to further anxiety.

Maria advised everyone to recognise if anxiety is becoming a problem by keeping a diary, consciously moving away from negative thoughts, breaking a problem down into small parts to cope with it one step at a time and knowing when to look for help. If anxiety is taking hold, we should reach out to family and friends for help, and to our GP and professional counsellors.

Other coping strategies include engaging with a hobby, reading self-help books, attending local support groups and learning about mindfulness. It is important to learn to live well and this can be achieved by setting small and realistic goals, noticing the positives around us and relaxing. We should acknowledge that we all have good days and bad days and if anxiety becomes a problem, professional help can help the bad days to pass.

Matt Cullen, IPF patient from Dublin, addressed the audience and shared his personal story. Matt described himself as a fit, healthy, non-smoker with many hobbies including gardening, painting, and badminton and being actively involved in the local Swords Tidy Towns competition.

He is still engaged in these activities but his involvement is curtailed somewhat because of IPF. Matt was diagnosed with IPF in 2010 and in 2013 he had a bad year with infections and complete loss of his voice for 3 months. Following his diagnosis, he contacted ILFA and started attending the Dublin Support Group. Matt described the benefits of learning more about his condition and getting to know other patients in a similar position to him. He described the camaraderie and laughter that take place at the support group meetings and how it helps those living with IPF. Matt uses the ILFA 2000 Steps a Day exercise programme and takes part in pulmonary rehabilitation classes.

Matt found that he was struggling to paint with oil paints as his breathing was being affected by the toxic paint fumes. Reluctantly, he stopped painting but a few months later discovered a new type of slow drying acrylic paint that allowed him to work in his usual style, slowly and patiently.

This was an exciting time for Matt as he rediscovered his passion for art and also developed a new style of painting which he believes was influenced by the science behind his diagnosis. Being able to paint again energised Matt and he described this as being a "tremendous transformation".

During his presentation, Matt showed a number of his fantastic paintings to the audience and described the significance of each piece in relation to his life and his personal journey through illness. In March 2015, Matt held his first solo art exhibition in Filmbase, Temple Bar, Dublin in aid of ILFA. The exhibition was called "Turning Full Circle" and it was a fitting title as it describes Matt's journey through life as an artist and patient.

Terence Moran finished the meeting by thanking the speakers for their presentations and the audience for coming along. Following the presentations, there was a chance for everyone to socialise and tea and sandwiches were served.

Read more on page 8.

The ILFA Patient Information Day was supported by Boehringer Ingelheim.

New international guidelines on the treatment of IPF

The American Thoracic Society, the European Respiratory Society, the Japanese Respiratory Society and the Latin American Thoracic Association have published new guidelines on the treatment of idiopathic pulmonary fibrosis (IPF). A panel of IPF experts from around the world analysed the available medical evidence to update the treatment guidelines of 2011. New guidelines were needed in

order to take into account the important results from clinical trials that have been conducted over the last 4 years.

The European Respiratory Society and the European Lung Foundation's paper of IPF incorporating patient perspectives (including valuable contributions from patients and carers attending the support groups in Ireland) is due to be published soon.

Supporting heart and lung transplantation



In December 2014, ILFA made a donation of €5,000 towards the purchase of an Ex Vivo Lung Perfusion (EVLP) machine, to support the incredible work carried out at the National Lung Transplant Unit at the Mater Misericordiae University Hospital.

EVLP technology helps to improve the condition of donor lungs and increases the number of organs available for transplantation. ILFA Chairman, Terence Moran, visited the Mater Hospital to meet staff members of the multidisciplinary transplant team, the finance department and the Irish Heart and Lung

Transplant Association (IHLTA).

Pictured are Robert McCutcheon (Finance Department, Mater Hospital), Suzanne Roy (Operations Manager), Professor Jim Egan (Clinical Director of the Heart and Lung Transplantation, Cardiovascular, Respiratory, Renal, Diabetes and Endocrine Directorate), Terence Moran (ILFA), Dr Margaret Hannan (Consultant Microbiologist), Mr Lars Nolke (Transplant surgeon), Ms Karen Redmond (Transplant surgeon) and Brendan Gilligan (IHLTA).

European Respiratory Society Congress 2015

The European Respiratory Society will hold its annual meeting in Amsterdam from 26th to 30th September. Matt Cullen from Dublin has been invited as a

patient representative to speak about his experience of exercising with a chronic lung condition. We wish Matt every success with his presentation. ILFA's

research results from our Patient and Carer Survey of 2014 will be presented by Nicola Cassidy during a session called 'IPF: Clinical aspects.'

STALL Breathing Technique© for Lung Fibrosis patients



- Breathlessness can cause fear and anxiety.
- If you experience an episode of worsening breathlessness, try the **STALL** method to regain your breathing, composure and confidence.
- Show this card to your carer so that they can support you. It is important that your carer does not panic when you experience breathlessness.

Irish Lung Fibrosis Association

www.ilfa.ie

STALL Breathing Technique©



- S Stop** what you are doing.
- T Try** to remain calm. **Turn** up your oxygen.
- A Assume** a comfortable position.
For example, sitting or leaning.
- L Let** your imagination take you to a safe place.
Imagine yourself there, relaxing.
- L Let** your breathing return to normal.

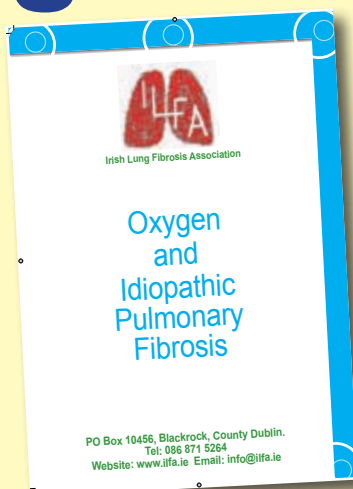
When your breathing has returned to normal, reset your oxygen to normal.
Call for medical help if your symptoms do not settle.

Oxygen and IPF

In May 2014, ILFA launched a new leaflet entitled "Oxygen and Idiopathic Pulmonary Fibrosis". This leaflet gives patients and carers an overview of how oxygen can improve breathlessness and quality of life. There is practical advice for ordering oxygen, travelling with oxygen, exercising, and what to do when there is an electrical power cut. We hope you will find the leaflet useful.

To order a copy of the leaflet or any of our patient resources, please call ILFA on **086 871 5264** or email info@ilfa.ie

The ILFA Patient Information Pack



contains a series of leaflets for patients and carers. These include;

- "The treatment of idiopathic pulmonary fibrosis"
- "Getting the most out of your hospital visit"
- "Tips for Caregivers"
- "What is Pulmonary Fibrosis?"
- "Weight Management and Nutrition for Pulmonary Fibrosis"
- "Get Moving with ILFA! ILFA 2000 Steps A Day Challenge"
- "STALL" breathing technique card and "Medical Alert" card.

Coming soon!



ILFA is producing a home exercise DVD for lung fibrosis patients in collaboration with the physiotherapy department at the Mater Misericordiae University Hospital. We will keep you posted with news about this exciting project!

ILFA is also revising our "What is Pulmonary Fibrosis?" leaflet and it will be available in the coming months.



World Physiotherapy Day

World physiotherapy day will take place on 8th September 2015. ILFA would like to acknowledge the excellent work carried out by physiotherapists and pay tribute to their enthusiasm, care and commitment to improving patient's lives through exercise and physical activity.

We are especially grateful to respiratory physiotherapists who care for patients with IPF and other lung conditions. We hope physiotherapists everywhere enjoy their special day.

Oxygen Companies in Ireland

Two companies supply medical oxygen to patients in Ireland. They are;

BOC Healthcare Tel: 1890 220 202

and

Air Liquide Healthcare Ireland Tel: 1850 240 202.
(formerly Baywater Healthcare)

If you have any queries about medical oxygen, please contact your oxygen company directly.

The Denise Cassidy Memorial Prize

ILFA is excited to announce a new award that recognises and celebrates an act of kindness shown by a hospital healthcare worker to a lung fibrosis patient. Patients and carers are invited to nominate a person who showed you or your loved one special kindness.

Please fill out the nomination form and tell us why your healthcare hero deserves to be honoured. You can nominate a doctor, nurse, physiotherapist, social worker, counsellor, dietician, pharmacist, healthcare assistant, member of the chaplaincy team, clerical worker, catering or cleaning staff etc., in fact anyone who works in a hospital. Everyone who is nominated for the award will receive a certificate of excellence for patient kindness and the winner will receive a special award.

The award is named in honour of Denise Cassidy who was diagnosed with IPF at the age of 56. Denise was a non smoker and lived a happy, busy, healthy, sporty, active life. She loved badminton, running, walking, gardening, socialising and chatting! Her symptoms developed suddenly over a few weeks, and came completely out of the blue. Denise started to experience increasing breathlessness and a debilitating cough. After many difficult months, Denise was eventually diagnosed with IPF.

Denise was admitted to the Mater Hospital in Dublin on three occasions and was placed on the lung transplant list. While in hospital, Denise met many friendly, caring, and dedicated staff and other lung fibrosis patients who helped and supported her enormously. She experienced many acts of kindness while in hospital and two particular occasions stand out in her family's minds. One time a kind nurse, Michelle O'Grady, showed special kindness when she spent 10 minutes with Denise giving her a hand massage and painting her nails, whilst also having a good chat about life. This simple act meant so much to Denise and helped her to relax and take her mind off her breathing difficulties, at least for a short while. Another special nurse, Fiona Lee, was a pillar of strength and kindness to Denise when she had a sudden and frightening deterioration in her health, one Saturday



morning. Fiona stayed with Denise and reassured her that help was on the way and that she would be ok, and thankfully she was, due to Fiona's quick and kind response.

Denise was always positive and cheerful and her enthusiasm and ability to say "YES!" to everything, inspired everyone who knew her. Sadly Denise passed away in 2006. Her husband Eddie and daughter Nicola joined the ILFA committee the following year, and other family members, including her sons, mother, siblings, brothers in law, sisters in law, nieces and nephews have continuously fundraised for ILFA ever since. Denise's family are honoured and humbled to have this special award dedicated to her memory.

Let's get behind our lung fibrosis healthcare heroes and celebrate their great work!

Full details can be found on the enclosed entry form, which you can complete and return by post to PO Box 10456, Blackrock, Co Dublin.

You will also find the entry form on our website, www.ilfa.ie, and on our Facebook page.

The closing date for entries is 20th September.

Fundraising Round Up

It has been a busy summer for ILFA's fundraisers! Many of our supporters have given their time and energy to raise essential funds and awareness for ILFA. If you have an idea for a fundraiser, please get in touch and we will support you in any way we can. Your support means the world to us and helps us to continue with our work for lung fibrosis patients. Go raibh mile maith agaibh!

VHI Women's Mini Marathon 2015

Congratulations and a big thank you to all the ILFA mini-marathon ladies who braved the elements and did us proud on Monday, 1st June.

We are very grateful to everyone who took part, to the supporters who turned out to cheer on the ladies and to all those who donated with generous sponsorship. *(Photos 3,4,5,8&11)*

Rainbow Run

Congratulations to the Caffrey Family who took part in the Rainbow Run in Dublin on 21st June in aid of ILFA. Gillian Hilliard was in touch and said "I am happy to say that we completed the Rainbow Run in aid of ILFA. It was a great pleasure to raise money for such a great charity that does so much to help a special lady in our family, Dolores Williams." *(Photo 6)*

Murder Mystery in Thurles

A "Murder Mystery Dinner" in aid of ILFA was organised by Liam Galvin in Thurles, Tipperary on 22nd May. A great night was had by all with fun and laughter, a meal and "school disco". Thanks to all who attended and supported the evening, and particular thanks to Carol Walshe and her daughter, Karen, for donating artwork for the raffle.

Natural Power Cycle

Congratulations to David Dunne, Marc Lamphiere, Tom Drennan, Diarmuid Doyle, Sean Manley and Robert Pollock who cycled from Dublin via Newry and Belfast to Scotland, to fundraise for ILFA.

The Natural Power team arrived safely at The Greenhouse in Dumfries and Galloway to a warm reception and a cool refreshing beverage! *(Photos 1&2)*

Luxembourg marathon champions

Congratulations to the team of runners who took part in the Luxembourg marathon to raise funds for ILFA. A 14 strong team took part in the event and they are pictured here enjoying the post race celebrations with their supporters.

The team included Keith Nolan, Andy Nolan, Denise Cunningham, Emma Farrell, Paul McLaren, Dee McLaren, Orla McCarthy, Tom O'Dea, Shane Mullally, Maree Mullally, Tracey McDermott, Keith Darlington, Gen Kyne and Françoise Tilly. *(Photo 7)*

Another Great Limerick Run!

report by Lorraine Ryan

"It was a great day. The weather was not in our favour and it was more like a 'Great Limerick Swim' in parts but it was still a truly enjoyable experience. It was great to get our t shirts and get the ILFA name known! I had great support from my friends and family pictured from left to right are Hazel D'Arcy, Caroline Fahy, myself, Ann Conway and Dawn Conway.

Since my dad was diagnosed in 2007, my friends have been so supportive in their fundraising efforts. Dawn hasn't missed a single fundraising event for ILFA; she is always so enthusiastic and willing to do anything to help. She even roped in her mother Ann this year. Ann did great training and finished in a great time. I really appreciate all the great support from my friends for all the fundraising events we organise. There were a few more who fundraised for ILFA by doing the Great Limerick Run; they are Lennon Clarke, Julie Treacy, Ruth Kelly and Martina Treacy. Thanks to all. Better get training for next year!!!"

Thanks also to the fabulous O'Malley sisters and their brother John who also took part in the Great Limerick Run for ILFA in memory of their dad, John O'Malley, known affectionately as "Hairy Jaws". They were cheered on their way by their mother, Eileen. Well done to Geraldine Mulcahy, Teresa O'Malley, Noelle O'Malley, Majella O'Neill, Catherine Meehan and John O'Malley. *(Photo 9)*

Limerick Table Quiz

Lorraine Ryan is one of our most dedicated fundraisers! She also organised a table quiz in Limerick on June 12th in aid of ILFA. Thanks to Lorraine and her great team for all their hard work on our behalf!

Turning Full Circle

On 24th March, Matt Cullen, artist and IPF patient, held his first solo art exhibition entitled "Turning Full Circle". The exhibition in Filmbase, Temple Bar, Dublin, was opened by Minister James Reilly and was a lovely evening for all who attended. Matt very kindly donated 20% of the sales of his beautiful work to ILFA. Sincere thanks to Matt, his family, friends and colleagues, Minister James Reilly and everyone who supported the exhibition. *(Photo 10)*





Lilliput legends

Well done to Andrew and Laura Grehan on their great performances on Saturday 18th July in the Lilliput Adventure Race. The brother and sister team took part to raise funds for ILFA in memory of their aunt, Denise Cassidy.

They were supported on the day by their family; Tom, Annette, Caroline, Stephanie, Lily and Nicola. Andrew and Laura showed nerves of steel before the race got underway despite the daunting presence of ultra fit participants stretching and warming up.

The Grehan groupies were a bit apprehensive as Andrew and Laura got into their kayak after only one previous kayak lesson. Team ILFA started out cautiously, gathered momentum, positioned themselves strategically and overtook 7 other kayaks on the first bend of Lake Ennel. They soon found their rhythm and powered home the 2km course. Next they jumped out of their kayak, splashed through the water and sprinted to their bikes for the 20km cycle.

Andrew headed off first as Laura had a slight problem with socks and runners but soon she was chasing him at high speed! What happened next is a mystery. Officially the participants had to climb Croghan Hill, cycle back 20km to the adventure centre and run cross county for 400m to the finish line. Some of the super athletes had finished and the Grehan supporters were prepared for quite a wait but were stunned when Laura rounded the corner to start the last leg of the race.

As Laura sprinted the last few metres to the finish line, she even overtook another male athlete. Her supporters were screaming and jumping up and down with excitement.

En masse, we all gathered to cheer on Andrew but where was he? We were starting to worry ... but then he rounded the corner and shouted "Where's Laura?"

"There she is", we chorused.

"What happened to you?" shouted Andrew, worried in case his little sister was injured.

"I'm finished" beamed Laura.

With that Andrew broke the national record for the 400 metres as he raced to the finish line to figure out how, when and why Laura got home first.

Let's just say that these questions may never be answered. Did Andrew end up doing the longer run up Croghan Hill? Was Laura at an advantage given her posh racing bike compared to Andrew's mountain bike? Was there super fuel in those protein bars? There was talk of comparing split times for each section of the race, a demand for a stewards' enquiry and a call for a re-match next year! This tale and the various conspiracy theories will be discussed at family gatherings for years to come.

Later that evening, the official race results revealed that Laura Grehan was 3rd lady home and 21st overall in the "45km Bad Ass" category. Andrew couldn't be more proud of his little sister. ILFA is very grateful to Andrew and Laura for all their hard work.

Upcoming Fundraising Events

The Margaret Maloney Memorial Darts Tournament

The Margaret Maloney Memorial Darts Tournament will take place on Saturday 26th September in Brereton's Bar, Ballybrit, Roscrea, Co. Tipperary. All proceeds will go to ILFA.

Last year the Maloney Family held a very successful and enjoyable fundraiser for ILFA and this year hope to surpass their 2014 fundraising total. Thanks to all the organisers and to Joe and Mary Murray of Brereton's Bar for their support with the darts tournament. This year the tournament will involve a mixed doubles competition with a thrower with non-thrower and the draw will be made on the day.

For more information please contact Owen on 087 241 4475



2015 Cork-Limerick-Cork cycle in memory of Pat Casey

Family and friends of the late Pat Casey are organising a special memorial cycle in Pat's honor to raise funds for ILFA and Cork University Hospital. Pat was a dedicated fundraiser for ILFA and he was a huge support and inspiration to others, especially those with IPF. To celebrate Pat's life and to help raise funds, an organised cycle from Cork via Tipperary to Limerick and back, will take place on 19th and 20th September.

The registration cost is €60 and covers an evening meal and an overnight stay with B&B in the Southern Court Hotel. For more information, please contact Anne Casey at 087 985 4587 or Brian Aherne on 086 088 1604 or email annecasey@live.ie.

ILFA is very grateful to Anne Casey, Daniel Casey, Brian Aherne and all their cycling enthusiast friends for organising this fundraising event.

Wild Atlantic Marathon, Sligo

Farnan Rushe will take part in the Wild Atlantic half-marathon from Strand Hill to Rosses Point in Sligo on 12th September. Farnan is travelling from Spain to run in his home town and raise funds for ILFA. We wish Farnan every success!



Skydive

Best of luck to Laura Shannon who will take to the skies for ILFA, doing a sky dive in Kilkenny on 5th September in memory of her Grandfather.

Tipperary Mini Marathon

Cathryn O'Neill and her sisters will be pounding the Clonmel

pavements on 27th September in the Tipperary Mini Marathon. Fingers crossed the weather will be better than it was in Dublin or Limerick earlier in the year!

Dublin City Marathon

The Dublin City Marathon will take place on Monday 26th October. Please let ILFA know if you would like to fundraise on our behalf.



Quiz Time

Questions:

- 1) Exposure to sunlight is one of the best ways for the human body to get which vitamin?
- 2) Derived from the Italian word for beach, what name is given to a public outdoor swimming pool and its surrounding facilities?
- 3) Which of Shakespeare's sonnets opens: "Shall I compare thee to a summer's day?"?
- 4) On what date is St Swithin's Day?
- 5) What is the main herb in a recipe for pesto?
- 6) Which organisation has the motto: "Nation shall speak peace unto nation"?
- 7) In which country did reggae music originate?
- 8) Which is the smallest ocean in the world?
- 9) Which element has the chemical symbol "He"?
- 10) How many bones do sharks have in their bodies?



- Answers:**
- 1) Vitamin D
 - 2) Lido
 - 3) Sonnet 18
 - 4) 15th July
 - 5) Basil
 - 6) The BBC
 - 7) Jamaica
 - 8) Arctic Ocean
 - 9) Helium
 - 10) None

Ways to donate to ILFA

If you or someone you know would like to make a donation to ILFA, there are a number of ways you can support our work through a once off or regular standing order donation, and through our My Charity (Everyday Hero) webpage. Please get in touch by phone 086 871 5264 or by email info@ilfa.ie if you would like more details.

Autumn Patient Information Day

The next ILFA Patient Information Day will take place on Saturday 7th November, 2015 in the Crowne Plaza Hotel, Santry, Dublin. The meeting will start at 10 am and finish at approximately 1pm when light refreshments will be served. Prof Jim Egan, consultant respiratory physician will address the meeting along with other healthcare professionals.

The patient information days are a great way to learn about IPF, how to manage your condition, and also meet others living with IPF. Registration is not required and all are welcome to attend.

For more information, contact Denise on 086 871 5264 or info@ilfa.ie.

Keep in Touch with ILFA

You can keep in touch with ILFA

by phone on 087 871 6254 (general enquiries)

or 086 057 0310 (fundraising enquiries)

by email info@ilfa.ie

on Facebook www.facebook.com/ILFAIreland

on Twitter @ilfaireland on web www.ilfa.ie

If you would like to be removed from our mailing list, please call or email us as above and we will remove your details.

Dates For Your Diary

Charter launch	6th October
ILFA Service of Prayer and Reflection	17th October
Patient Information Day	7th November