ILFA Newsletter

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

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Irish Lung Fibrosis Association
www.ilfa.ie

ILFA patient and caregiver surveys

There are many physical, practical and emotional challenges facing people living with Lung Fibrosis. ILFA has developed 2 questionnaires to help us find out more about the experiences of our members. There is one survey for patients and another one for caregivers. They should take about 10-15 minutes of your time to complete.

We would like you to tell us about your experiences and how Idiopathic Pulmonary Fibrosis (IPF) impacts on your daily life. The feedback will be used to identify the needs of patients and caregivers and to develop new patient resources. A report will be prepared and will be available to read in a future ILFA newsletter and on the ILFA website and social media in the coming months.

Please fill in the survey that applies to you (patient or caregiver survey) and return it by post to ILFA, P.O. Box 10456, Blackrock, Co. Dublin by 10th May 2014. An online survey is also available on the ILFA website homepage, www.ilfa.ie

If you do not have IPF but have another respiratory condition, you are welcome to participate but please indicate your respiratory condition on the questionnaire. Thank you for sharing your experiences.

ILFA Patient Information Day, Belfast

ILFA will be holding our next Patient Information Day in Belfast on Saturday 5th April. We are looking forward to welcoming a range of expert speakers, including Joe Brolly, GAA star and organ donor champion; Professor Jim Egan, Consultant Respiratory and Transplant Physician; Dr Joe Kidney, Consultant Respiratory Physician; a Respiratory Physiotherapist; a Respiratory Nurse Specialist; and a family member of an organ donor. The Information Day will be held in the Wellington Park Hotel, Malone Road, Belfast, beginning at 10am and concluding with refreshments at 1pm.

We would be delighted to see both patients and family members at the event, which will be a great opportunity to meet the experts, and each other. **For more information, please ring or email Denise on 086 871 5264 or info@ilfa.ie.**

The gift of life

In 2013 there were 32 lung transplants carried out at the National Heart and Lung Transplant Unit at the Mater Misericordiae Hospital in Dublin. 12 lung transplants were in IPF patients. In addition, 11 heart transplants, 55 liver transplants, 147 kidney transplants and 10 pancreas transplants were performed.

This record number of transplants would not have been possible without the incredible generosity of the 86 donor families and the special expertise and talents of transplant coordinators, surgeons, doctors, nurses and the allied healthcare professionals who care for patients with such dedication, compassion and skill.

The government has committed €2.9million to organ transplant services in this year's health budget. ILFA welcomes this investment and looks forward to advances in transplant activity. Organ Donor cards are available from your local pharmacy or hospital, by texting the word "DONOR" to 50050 and can be ordered on-line from ***www.ika.ie***

Denise Dunne

Appointment: Denise Dunne

I am very pleased to announce that ILFA has recently retained the services of a Management/Development Officer. Her name is Denise Dunne and she comes to us with extensive experience in managing and leading various projects in the non-profit sector. Denise's role will cover a wide range of areas, including assisting members of the Managing Committee in the running of the Association from ordering paper clips to liaising with the various international groups representing Lung Fibrosis issues. She will also be fully involved in fund raising initiatives and raising the profile of ILFA generally.

I hope some of you will get to meet Denise at our Open Days or other events over the next while. She can also be contacted on the Association's email address, info@ilfa.ie, or by post, P.O.Box 10456, Blackrock, County Dublin, or by phone 086 871 5264.

Terence Moran, Chairman

Advancing in IPF Research

In November 2013 Professor Jim Egan (Mater Misericordiae University Hospital, Dublin) and Nicola Cassidy (ILFA) were invited to attend and speak at the Advancing in IPF Research (AIR) Conference in Nice, France. Over 340 respiratory doctors, nurses and scientists with an interest in Idiopathic Pulmonary Fibrosis (IPF) attended the conference to learn about current research and developments.

Marlies Wijsenbeek, Nicola Cassidy and Lida Nader

Key learning points included:

- IPF emerged as a medical entity in the second half of the 20th century and was a direct consequence of smoking. Free cigarettes were given to soldiers fighting in the First World War.
- IPF is common in patients who have previously smoked although some IPF patients have never smoked. If patients are smoking at the time of their diagnosis, they must stop.
- An increase in life expectancy over the last decades has resulted in an increased incidence of IPF diagnosis.
- IPF is more common in males.
- The median age (midpoint) for diagnosis is 70 years old.
- IPF can be very difficult to diagnose especially for doctors with no expertise in IPF. Misdiagnosis is common and in one study approximately 40% of patients were seen by more than 3 doctors before they were diagnosed with IPF.
- A diagnosis of early stage IPF is not always be possible. Patients often do not seek medical advice early on during the course of their condition because they consider the onset of a cough and shortness of breath to be age-related.
- Early diagnosis is usually associated with longer survival because patients can be managed better and there are more treatment options available.
- Newly diagnosed patients should be referred early to a centre with expertise in treating IPF.
- Early referral for lung transplantation assessment is needed.
- Some patients will need a surgical biopsy to help diagnose definite IPF. Not all patients are suitable for this surgical procedure because of their age or underlying illness.
- IPF can sound like “Velcro crackles” (the sound made when Velcro is torn apart) when the lungs are listened to through a stethoscope. The Velcro crackles may be heard even before patients have symptoms of IPF.
- Honeycombing is a distinctive pattern of fibrosis that can be seen on a high resolution CT scan of the lungs. Honeycombing can be difficult for medical experts to identify. It is usually a sign of advanced disease.
- The risk of family members having IPF is increased if individuals have the MUC5B gene. The search for genetic markers for IPF is on-going but large studies are needed in order to confirm research results. In future, it is hoped that a combination of genetic and clinical or biological markers will help screen patients for IPF and help predict survival.
- A patient’s prognosis is continually changing and will depend on how they respond to treatment. Monitoring of disease progression is important especially for patients who can be considered for lung transplantation.
- Disease progression is defined as any 10% change in lung function over a 6-12month period (NICE Guidelines from the United Kingdom).
- Emphysema is common in patients with IPF (due to a history of smoking), can complicate the picture seen on a CT scan and may lead to difficulties in diagnosing IPF definitively.
- Lung cancer is rare in patients with IPF.
- Acid reflux is common in IPF patients and causes inflammation in the lungs resulting in a vicious cycle of damage and wound repair with further lung fibrosis. Between 33-50% of IPF patients with acid reflux do not have symptoms. Reflux is thought to play a role in acute exacerbations (worsening) of IPF.
- Sleep apnoea is common in IPF patients and is not associated with being overweight. There are no treatment recommendations for sleep apnoea.
- IPF patients are more likely to have heart conditions including atrial fibrillation, angina and stroke.
- Pulmonary hypertension (raised blood pressure in the lungs) is present in approximately 8-15% of IPF patients at the time of their diagnosis. It is usually mild to moderate and can occur later on in the course of IPF.
- Healthcare professionals should engage with Patient Associations and learn from the patient and caregiver perspectives of living with IPF.

The current treatment guidelines for managing IPF are under revision by a panel of IPF experts. The panel hope to address the problems that doctors are experiencing using the existing guidelines to help diagnose and treat IPF in patients. Some recent research studies have had poor results and therefore some treatments are not recommended for IPF.

2014 will be an exciting year as some clinical trial results are due to be announced.

EU IPF Patient Charter

ILFA attended a conference held in Brussels on March 8, 2014 with a view to formulating an EU IPF Patient Charter. The charter will be launched during IPF World Week which will take place from September 28th to October 5th, 2014.

Areas covered during this conference were the Vision and the Mission of such a Charter and identifying the barriers and solutions for IPF Patients and their Caregivers in areas, such as Information, Diagnosis, Treatment, Access, Research, Engagement and Horizontal Issues.

Further work and collaboration between EU-wide patient organisations will be facilitated and ILFA will take part in further discussions and conferences.

The photograph shows all the Delegates who participated in the Conference from Germany, Austria, Spain, France, Belgium, the Netherlands, the UK and Ireland.

Photo and Video Competition

As part of IPF World Week, taking place from September 28th to October 5th, a Photo and Video Competition involving the theme of “Bubbles” will be launched on the website www.ipfworld.org. The winning photograph(s) and video will feature on the posters to be used to promote IPF World Week and the website.

Keep an eye out for further information about the competition on www.ilfa.ie and our Facebook page, where we will post information as to how to get involved!

New home for the National Heart and Lung Transplant Unit

On February 24th the National Heart and Lung Transplant Ward at the Mater University Hospital, Dublin, relocated to new, state of the art, purpose built premises in the Whitty Wing of the Mater Hospital. The out-patients Department has moved to the 7th floor of the Whitty Building.

ILFA would like to wish the staff and patients all the very best as they settle into their new, modern and spacious home.

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.

Oxygen, Energy, Life

Oxygen is needed to sustain life

When we breathe in air, oxygen crosses from the tiny air sacs in the lungs into the blood supply which is then pumped around the body by the heart. Oxygen is involved in energy production at a cellular level in every tissue in the body.

Without oxygen it would be impossible to survive! With IPF, fibrosis (scarring) causes the lung tissue to harden preventing adequate transfer of oxygen into the bloodstream. This results in low oxygen saturations (oxygen levels) in the blood and causes breathlessness, dizziness, low energy, fatigue, concentration difficulties and confusion. Low oxygen levels impact negatively on your overall health and your ability to stay active and carry on with day to day activities.

Oxygen therapy

Your doctor may prescribe supplemental oxygen (oxygen therapy) to correct low oxygen levels in your blood. Supplemental oxygen will help you to breathe more easily, function better and feel better. Oxygen can be delivered by nasal prongs (soft plastic tubing that is placed in your nose) or by a facemask worn over the nose and mouth. Some patients may need to use oxygen at all times , while others may only need to use oxygen for a number of hours as their doctor prescribes i.e. when they are active.

Your oxygen requirements may change with time and you should tell your doctor, nurse or physiotherapist if you notice increasing breathlessness. It is important to use your oxygen correctly as prescribed by your doctor. Your oxygen prescription is just as important as your prescribed medications. Don't try to survive on a lower amount of oxygen, follow your doctor's orders. If you are prescribed supplemental oxygen you should request a Medical Alert Card from ILFA (see below).

Fears and embarrassment

Some patients are afraid that they will become "addicted" to oxygen. While oxygen is not an addictive substance, it is necessary to sustain life and to maintain normal body functions. Therefore, we're all addicted to oxygen! Think of the elite mountain climbers who need supplemental oxygen to help them reach the summit. They take oxygen as they push their bodies to the limits of endurance - the same could be said for IPF patients.

Some people feel self-conscious and embarrassed about using oxygen but it is important to realise just how necessary and vital your oxygen therapy is. If people stare, just smile, shrug your shoulders, point to your oxygen or wave at them ... they'll soon be embarrassed! Don't hide away, stay indoors or avoid social events because of your oxygen. Life is for living.

Physical activity and oxygen requirements

You may find that you are more breathless when you are doing everyday activities that require more energy, for example showering, getting dressed, using a hairdryer, doing light housework or gardening, climbing stairs, walking or exercising.

Sometimes simple tasks such as brushing your teeth or eating a meal can put pressure on your breathing. If you experience breathlessness, you should increase your oxygen flow for a short time until your breathing stabilises and you have completed your task. Once your breathing is under control again, reduce your oxygen flow to normal.

Remember to practice the **STALL breathing technique.**

S = Stop what you are doing
T = Turn up your oxygen
A = Assume a position of comfort
L = Let your imagination take you to a safe place
L = Let your breathing return to normal.

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.

Exercise, Exercise, Exercise!

It is crucial to exercise every day when you are on oxygen. Fear of breathlessness can lead to avoidance of physical activity which impacts negatively on your fitness levels and causes you to become de-conditioned. This will lead to a worsening of your breathlessness and reduces your ability to cope with daily activities and so you might be inclined to do less and less and so continues the vicious circle of breathlessness and inactivity.

The good news is that this cycle of inactivity can be broken. Exercise, especially walking, is essential for IPF patients to maintain well - being, bone health, mobility and confidence. The ILFA 2000 Steps a Day Challenge is an ideal exercise programme for IPF patients. (See end for more details).

Breathlessness is to be expected when exercising; this is true for everyone even Olympian athletes! When exercising, you should aim to be moderately breathless and you can turn up your oxygen to help your body cope with the increased oxygen demands.

Equipment

There is a vast range of equipment and mobility aids available for carrying oxygen. Your oxygen company can give you information about the best equipment for your needs as well as the latest technology and gadgets to help make your life easier.

Oxygen is available in many forms and some devices have wheels and long-life batteries and can be plugged into the electricity supply when out and about. The oxygen supply companies are a great source of information and advice and their staff can discuss any concerns with you. The oxygen supply companies in Ireland are:

Baywater Healthcare (Tel: 1850 240 202)
BOC Gases (Tel: 1890 220 202)

You are entitled to 6 cylinders of oxygen per month (for medical card holders). If you need more than 6 cylinders to enable you to carry on with your normal routine, ask your doctor to increase your oxygen prescription. Once your oxygen prescription specifies the number of cylinders required the extra cylinders will be supplied by the HSE.

Home oxygen machines (concentrators) run off the normal electricity supply in your home. It is important to register with your electricity supplier to let them know that you are dependent on medical oxygen and are a **"Priority Support Customer"**. In the event of loss of electricity, the ESB Network will prioritise your local area for electrical power restoration. When there are planned electrical interruptions, the ESB Network will contact priority support customers to inform them in advance of the date and likely duration of the disruption of the electricity supply.

To register as a Priority Support Customer contact:

(1) ESB/Electric Ireland Tel: 1850 372 757
(2) Airtricity Tel: 1850 812 220
(3) Bord Gáis Tel: 1850 632 632

Lifestyle

Being on oxygen should not curtail your life-style, instead it should give you more opportunities to get out and join in activities that you enjoy as you will have more energy. It is possible to travel abroad with oxygen but you will need to plan in advance to ensure a smooth trip and an enjoyable holiday. You should discuss your travel plans with your doctor to make sure that you are well enough to travel and also to arrange an oxygen prescription for the purposes of travelling. You must also inform your oxygen company, travel agent, insurance company, airline and the hotel of your oxygen needs. When flying, it is a good idea to book a seat near the toilets. Altitude can affect your oxygen levels and it will require a lot of effort to move about the plane if you need to use the bathroom. Remember to turn up your oxygen if you need to. When travelling by bus, coach, train or ferry, check if there are electrical sockets for you to plug in your oxygen equipment.

Tips for oxygen

- Order replacement oxygen cylinders before your stocks run low or at least 3 days before a new cylinder is needed. Remember to have sufficient oxygen supplies over a bank holiday weekend. Ensure that your back up cylinder is full and working properly. If you have any problems with your oxygen supply, contact your oxygen supply company immediately.
- Do not use your oxygen near a naked flame or other sources of heat.
- Make sure that your home has a working fire alarm and check that the batteries are working regularly.
- Oxygen equipment may be heavy. Never try to lift your oxygen equipment if you have problems with your mobility or strength.

Remember: Oxygen is your friend and has been prescribed because you need it. Oxygen will help your breathlessness and transform your quality of life! **To order your ILFA 2000 Steps a Day walking pack, an ILFA STALL Breathing Technique Card or a Medical Alert Card please email info@ilfa.ie or call 086 871 5264**

THANK YOU

- ILFA would like to acknowledge the great generosity of families from all over Ireland who requested donations to ILFA in lieu of funeral flowers when their loved one passed away.
- Thanks to everybody who supported the 2013 ILFA Christmas card campaign. The additional donations to cover the postage and packaging were greatly appreciated and helped to keep our costs down.
- Thank you to Tomás Kennedy who recently celebrated his 40th birthday with family and friends. Tomás kindly asked for donations to ILFA instead of birthday gifts and an incredible €600 was raised. Thank you to Tomás and to everybody who gave so generously.

- Sincere thanks to Angela Collins and her fantastic team of helpers who organised a concert in Ballydehob on 30th December in aid of ILFA. This was Angela's 4th concert for ILFA and she deserves huge thanks for her hard work, commitment and enthusiasm. Anne Cronin emailed us to say "It was a wonderful night. The music was fantastic, the food on offer superb and the general all round craic and entertainment perfect to get people into New Year party mode. A big thank you to all who contributed making it a memorable night for everyone there."

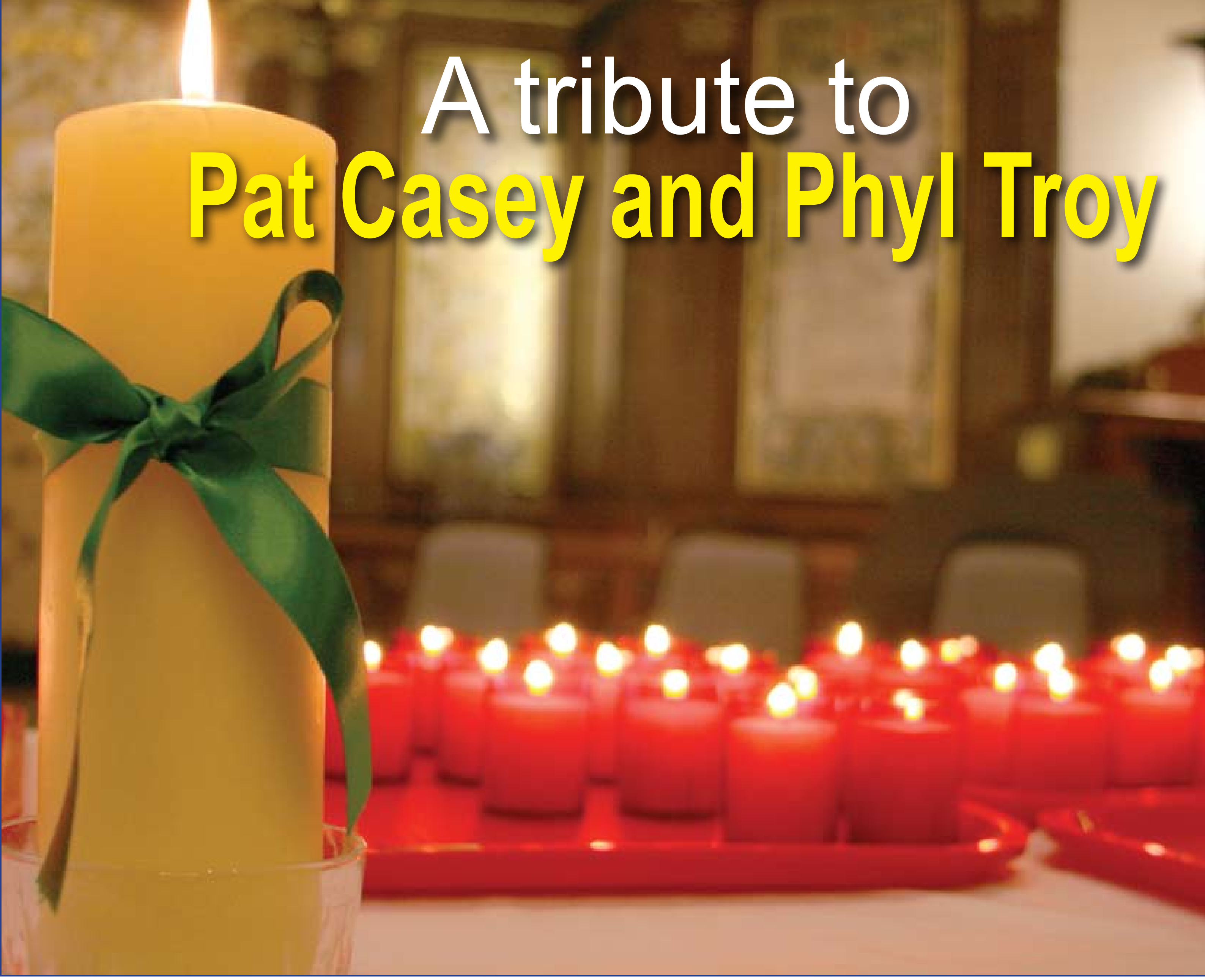
- Nicola Goodbody told us that "The ILFA swim was held on New Year's Day and went ahead, despite the poor weather conditions! Due to the high tide and strong winds, we swam in the protected Sandycove harbour area (the pier, off which we normally swim, was practically submerged). Bob Hughes, Niall Deegan, Colin and Honora Ireland, Katy Duff, Gabriel Cooney and I braved the water, which was remarkably mild, in comparison with other years. Afterwards we adjourned to the Eagle House, with our loyal supporters, and enjoyed mulled wine, soup and mince pies to warm us. Do think of joining us another time as, although swimming is a horrible thought at that time of the year, it is a great challenge, and it leaves you feeling healthy and glowing afterwards!"

- Liverpool football heroes Jamie Carragher and Didi Hamann held an enjoyable, informative and amusing night with great stories of their football careers in the Olympia Theatre on 27th February 2014. Pamela Martin (IPF patient) has been a loyal and dedicated Liverpool football club fan all her life and runs the Irish Kop club. Pam sold 100 tickets for the event and raised €500 for ILFA.

Good luck, Paddy!

Best of luck to Paddy O'Mahony, IPF lung transplant recipient, who will take part in the 15th European Heart and Lung Transplant Championships in Vilnius, Lithuania from 12-17th July 2014. Paddy's chosen sports are cycling, golf and table tennis. We wish Paddy every success and enjoyment with his training and participation at the Championships. We'll be cheering him on all the way!

- Sincere thanks to all our members who support ILFA by making a regular donation via a Standing Order. **If you would like to donate a regular weekly, monthly or yearly amount or to make a once off donation, please contact ILFA by emailing info@ilfa.ie or call 086 871 5264.**



A tribute to Pat Casey and Phyl Troy

The ILFA Committee was greatly saddened to learn about the passing of two of our most dedicated fundraisers who were themselves patients and friends. Pat Casey from Cork and Phyl Troy from Tipperary were both instrumental is setting up the IPF support groups in their native counties and they were a valuable source of support, wisdom and encouragement to others affected by IPF. They shared many excellent qualities; Pat and Phyl were positive, engaging, generous, and inspiring people who bore their illness with great courage and humility.

Pat, his wife Anne and friend Brian Aherne organised two cycling challenges (Cork to Galway and Cork-Limerick-Cork) for ILFA in 2012 and 2013 and raised thousands of euro for our charity. Pat also promoted organ donation on TV, radio and in newspaper articles. Phyl, her husband Liam and their extended family raised thousands of euro by holding Halloween Fancy Dress parties and organising the Highland Games in Thurles in 2013.

In 2013 Pat and Phyl helped front a successful campaign calling for the approval of Pirfenidone, the only drug available to slow the progression of Lung Fibrosis. Phyl and her family gathered 1014 individual signed letters from their local community and sent them to each of North Tipperary's TD's and also received motions of support from Thurles and Templemore town councils.

Always positive, always supportive and always good-natured, humorous and kind, Pat and Phyl will be missed but they will continue to inspire those of us who knew them.

Fundraising News:

Upcoming Events

Every year there are more and more sporting events taking place around the country. Please ask your family, friends and colleagues to take on the challenge of taking part in a mini-marathon and fundraising for ILFA. We can supply you with a t-shirt, sponsorship cards, on-line donation facilities and plenty of encouragement as you start your training and compete on the big day. **Please contact ILFA by emailing info@ilfa.ie or call 086 057 0310 if you would like a fundraising pack.**

Women's Mini-Marathon

This year the Flora Women's Mini-marathon will take place on Monday, June 2nd in Dublin at 2pm. Please register early to avoid disappointment, as registration will close once the maximum number of participants is reached. **See the Evening Herald or www.florawomensminimarathon.ie for more information.**

Other mini-marathons taking place around the country include; The 2014 Cork City Marathon, half-marathon and team relay will also take place on 2nd June. **See www.corkcitymarathon.ie for more information.**

The Great Limerick Run featuring a marathon, half-marathon, mini-marathon and team relay will take place on 4th May. **See www.greatlimerickrun.com for more details.**

The Western People West of Ireland Women's Mini-Marathon takes place on 4th May. **See www.westofirelandwomensminimarathon.com for more details.**

Charity Cycle

A fundraising cycle to raise awareness of Lung Fibrosis and Organ Donation will take place on Sunday 25th May 2014. The cycling challenge is being organised by Paddy O'Mahony, District Fire Officer and lung transplant recipient, and supported by his colleagues in the Dublin Fire Brigade at Tara Street Station.

There are 2 cycle routes to choose from; (1) an 80 km Challenge Route north along the Dublin coast for the more experienced cyclists (2) a 40km Leisure Route for the less experienced cyclists. The starting and finishing point is the O'Brien Institute in Marino in Dublin, which is the Dublin Fire Brigade's Training grounds. The event will start at 10.30am.

It promises to be a fun day and all are welcome. Please note that the cycling challenge is for adults only. Participants are asked to either collect sponsorship for the event or to pay a €20 registration fee. **For more information please call Paddy on 087 412 8612. Alternatively contact ILFA by email, info@ilfa.ie, or call 086 057 0310.**

QUIZ TIME

Questions:

1. **The Titanic was built at which Irish Shipyard?**
2. **What does GAA stand for?**
3. **What was the title of Bram Stoker's first novel?**
4. **Which Irish poet was killed at the Battle of Ypres during the First World War?**
5. **What are the ingredients for Coddle?**
6. **What was the name of the first Irish Boy Band created by Louis Walsh?**
7. **Which Irish singer was born on the Falls Road in 1966?**
8. **Why is St. Patrick's Day celebrated on March 17th?**

Answers:

1. *Harland & Wolff, Belfast*
2. *Gaelic Athletic Association*
3. *"The Primrose Path".*
4. *Francis Ledwidge*
5. *Sausage, streaky rashers, potatoes, onions*
6. *Boyzone*
7. *Brian Kennedy*
8. *It is believed that St. Patrick died on March 17th, 491 AD.*

New Patient Information Leaflets

"Getting the most out of your hospital visit" gives advice about interacting with doctors, tips for taking a proactive approach to your health and questions that you might want to ask your doctor in order to understand your condition better.

"Advice for Caregivers" focuses on the issues facing family members and friends caring for a person with Lung Fibrosis. Carers play a vital role supporting and helping patients. It is important to support and encourage caregivers as they cope with the day-to-day demands of their role.

Other materials available from ILFA include: *"What is Pulmonary Fibrosis?"; "Weight Management and Nutrition for Pulmonary Fibrosis"; "Get Moving with ILFA! ILFA 2000 Steps A Day Challenge"; "ILFA Join Us! Get Involved!"; "STALL Breathing Technique Card" and "Medical Alert Card".*

Find us on Twitter and Facebook – ILFA Ireland

Tel: 086 871 5264 (general enquiries)

Tel: 086 057 0310 (fundraising enquiries)

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