ILFA Newsletter

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

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Irish Lung Fibrosis Association
www.ilfa.ie

Patient Information Day

The next ILFA Patient Information Day will be held on Saturday 9th May in the Sheraton Hotel, Athlone, Co Westmeath. The meeting will be addressed by Prof. Anthony O'Regan, Consultant Physician, Galway University Hopsital, and other healthcare professionals. Registration will begin at 10am. The meeting will conclude at approximately 1pm and will be followed by light refreshments. All are welcome to attend. Please contact Denise by email info@ilfa.ie or telephone 086 871 5264 if you would like more details. We look forward to seeing you there.

Raising Awareness of IPF

We are delighted that an educational article on Idiopathic Pulmonary Fibrosis written by Nicola Cassidy (ILFA) and Professor Jim Egan (Mater University Hospital Dublin) has recently featured in 2 leading Irish medical magazines.

In November 2014, the article appeared in "Hospital Doctor" and in March 2015 it featured in "Forum", a magazine for General Practitioners from the Irish College of General Practitioners. We hope that the article will help raise awareness of IPF among medical professionals. If your GP would like to know more about IPF, please refer them to the March 2015 edition of Forum.

Women's Mini Marathon 2015

The annual Women's Mini Marathon in Dublin is our biggest fundraising event of the year.

The 2015 VHI Women's Mini Marathon will take place in Dublin on Monday 1st June at 2pm. 2014 saw a wonderful turnout for ILFA's mini marathon team and we hope that the 2015 event will have just as many ILFA t-shirts and smiling faces!

If you are planning to take part in the mini marathon, whether walking, jogging or running the 10km course (or maybe a bit of each!), please join our fundraising team.

We need your help to raise much needed funds and raise awareness of lung fibrosis. Registrations are accepted online at www.vhiwomensminimarathon.ie.

The closing date for entries is 17th April, 2015 or when the maximum number of entries is reached. As usual, we will have an ILFA team photo before the race begins and we will meet up for refreshments afterwards. All those supporting ILFA are welcome to join us.

Keep an eye on the ILFA website for more information nearer to the time. If you would like details or a fundraising pack, please get in touch with Denise at info@ilfa.ie or call 086 871 5264.

National Charter for IPF

ILFA is developing an Irish Patient Charter for IPF. This document will help us to raise awareness and campaign on behalf of IPF patients and their families to ensure they receive a quick and proper diagnosis, and timely access to appropriate treatment and support. We would like patients to get involved in the review process to ensure that the charter meets your needs and priorities. If you would like to be part of the process, please contact Denise on 086 871 5264 or info@ilfa.ie.

Lessons from AIR (Advances in Idiopathic Pulmonary Fibrosis Research)

Prof Jim Egan, Nicola Cassidy and Sarah Masefield

The fourth annual AIR meeting fully dedicated to Idiopathic Pulmonary Fibrosis took place in Copenhagen, Denmark on 14th and 15th November 2014. Approximately 300 IPF doctors and specialist respiratory nurses from all over the world attended the conference to learn more about recent advances in IPF research.

The conference focussed on the best practical approaches to improve patient care. The topics covered included;

- Disease classification and treatment implications
- The problems and challenges with interpreting high resolution CT scans in diagnosing IPF
- The management of IPF and other co-existing illnesses
- The need for updated treatment guidelines for doctors
- Patient-centred issues including care pathways from diagnosis, future care and end of life, patient counselling and support, and patient perspectives on IPF.

Professor Jim Egan from the Mater Misericoridiae University Hospital and Nicola Cassidy from ILFA were invited to attend and speak at the conference by Dr Elisabeth Bendstrup and Professor Athol Wells, Chairs of the AIR organising committee.

Here are some of the key lessons;

- The medical understanding of IPF has improved significantly in the last 15 years largely due to the increased number of drugs being researched and developed. Clinical trials have put IPF firmly in the spotlight, generating new interest in the condition and greatly enhancing our knowledge of the disease.
- In 2001, IPF was first recognised as a distinct medical condition. Up to this point IPF was included within a family of more than 300 different types of Interstitial Lung Diseases.
- Although the exact cause of IPF is unknown, IPF develops after a trigger causes a cascade of events at a cellular level, resulting in uncontrolled fibrosis (scarring) in the lung. Basic science and genetic research is ongoing to investigate the underlying triggers and pathways that cause susceptible individuals to develop IPF.
- In 2011, guidelines on the management of IPF were developed jointly by experts from the European Respiratory Society and the American Thoracic Society to give doctors direction on the best way to diagnose and treat IPF. These guidelines are currently being updated and revised to reflect advances in knowledge, treatment options and monitoring of IPF.
- IPF is a highly complex disease and can be difficult to diagnose in a proportion of patients, particularly if they do not have the classical changes to their lungs, as seen on CT scans. The treatment options can be limited or delayed for patients without a definite diagnosis of IPF.
- The combined expertise from a multidisciplinary team of specialists consisting of medical doctors, surgeons, radiologists and pathologists at IPF specialist centres helps to improve the diagnosis of IPF, especially where some uncertainty exists.

- The use of surgical lung biopsies to help diagnose IPF should be carefully considered. Biopsies are not suitable for all patients due to their age, disease severity, reluctance to undergo a surgical procedure and the risk of complications. Approximately 15% of patients in Europe have a biopsy prior to diagnosis.
- Clinical trial results from 2014, delivered exciting news for the IPF community. Two drugs; Nintedanib and Pirfenidone slowed down the rate of disease progression in patients with mild to moderate disease. The results from the two drugs cannot be compared directly as the drugs work by different mechanisms that are not clearly understood, the characteristics of the patient population included in the clinical trials differed, and the research end-points focussed on different outcomes, for example lung function test results, development of acute exacerbations (an unexplained rapid worsening of fibrosis) and quality of life.
- IPF behaves differently in every patient and clinical trials do not take this variability into account. The clinical trial designs were very strict and only included patients with mild to moderate IPF. Future research should include patients with more advanced disease and monitor their responses to medication.
- The goals of IPF management are to slow disease progression, improve survival, prevent acute exacerbations and improve symptoms.
- The sooner a patient is diagnosed, the sooner treatment can begin. Early diagnosis can be difficult as most patients wait up to 18 months after symptoms start before seeking medical advice.
- IPF is currently described as "mild, moderate and severe" but these descriptions can cause confusion. A simpler classification scale describing IPF as "very limited, limited and advanced" has been proposed. This system will give doctors a better measure of the patient's IPF status at a discrete time point.
- Often patients have other illnesses in combination with IPF. Heart disease (including pulmonary hypertension), gastrointestinal reflux (heartburn), depression, diabetes, and lung cancer are common.
- IPF can place an emotional burden on patients and families and in some cases can lead to poor health, anxiety and depression. Healthcare professionals should develop a Care Plan with each patient and their families with advice on how to manage symptoms and guidance on how to access emotional and practical support.
- Nicola Cassidy (ILFA) and Sarah Masefield from the European Lung Foundation (ELF) gave a joint presentation entitled "IPF: Through the eyes of the patient - a summary of patient concerns". This presentation described a project organised by the European Lung Foundation and the European Respiratory Society with input from IPF patient groups across Europe.

Nicola Cassidy (ILFA), Prof David Hansell (UK), Prof Athol Wells (UK), Prof Katerina Antoniou (Crete), Prof Luca Richeldi (UK), Sarah Masefield (ELF), Prof Jurgen Behr (Germany), Prof Vincent Cottin (France) and Prof Venerino Poletti (Italy) of the ERS Taskforce on IPF.

The European Respiratory Society IPF Taskforce update

In 2013, the European Lung Foundation (ELF) invited IPF patient groups in Europe to participate in an exciting and progressive project with the European Respiratory Society. A group of IPF medical experts wanted to incorporate the patients' perspective on a number of topics relating to their experiences of living with IPF.

ILFA and IPF patient groups from Italy, Belgium, the Netherlands and the United Kingdom held focus groups with patients and caregivers to discuss topics including the diagnosis and misdiagnosis of IPF, definitions of mild, moderate and severe IPF, quality of life, and research. The ELF collated the reports from the 5 countries and identified common concerns among the patient groups. Currently, Sarah Masefield (ELF), Nicola Cassidy and the medical experts on the IPF Task Force are incorporating the patient views into a key document with physician and patient priorities that will influence future patient care. Watch this space!!!

Irish Healthcare Awards

The ILFA 2000 Steps a Day Exercise Challenge for Lung Fibrosis Patients won the 2014 Irish Healthcare Award for the Best Patient Organisation Project of the Year.

Irene Byrne, Senior Physiotherapist from the Mater Misericordiae University Hospital and Nicola Cassidy from ILFA, who jointly developed the exercise challenge, accepted the award at a dinner held in the Shelbourne Hotel, Dublin on 6th November.

Everyone at ILFA is delighted and honoured that our home-based exercise programme specifically designed for lung fibrosis patients has been recognised with such a prestigious award. We are especially grateful to the 15 patients who helped to pilot the exercise programme to assess its suitability and effectiveness. This special award is dedicated to the memory of Charles Lock, Pat Casey, John Glackin, Denis Donaghy, Vincent Foley and Frank Tierney, who were instrumental in the development of the ILFA project and always enthusiastic and positive about the benefits of exercise for IPF patients.

Exercise is essential for lung fibrosis patients. The 2000 Steps a Day Challenge exercise goal is determined by the patient's baseline step count. This means that the exercise programme can be used by those with limited and advanced disease. Exercise is recorded over the course of the day and can be carried out indoors or outdoors. IPF patients said the programme was practical and motivational, and helped promote a positive attitude to exercise and increase physical activity.

If you would like to order an ILFA 2000 Steps a Day walking pack, please contact ILFA by phone, 086 871 5264 or email info@ilfa.ie.

Pat Campion of sponsors Lundbeck presenting the award for Patient Organisation Project of the Year to Nicola Cassidy and Irene Byrne.

Photo features Colin Edwards (Boehringer Ingelheim), Irene Byrne, Fergal Bowers (RTE News Health Correspondent) and Nicola Cassidy.

Organ Donation

In 2014, a total of 251 organ transplantations were carried out in Ireland thanks to the generosity of organ donors and their families who gave the gift of life to others. A record 31 lung transplant and 18 heart transplant operations were carried out at the Mater Misericordiae University Hospital. The number of kidney and liver transplants was lower than in previous years due to a reduced availability of organs. In 2014, there were only 63 deceased organ donors, compared to 86 donors in 2013.

One organ donor can potentially save the lives of 7 people. Please have the conversation about organ donation with your family. To request an organ donor card please free-text the word "DONOR" to 50050.

In 2015, the Mater Misericordiae University Hospital will celebrate the 30th anniversary of heart transplantation and the 10th anniversary of lung transplantation in Ireland. We congratulate all the transplant team and healthcare staff on reaching these remarkable milestones.

A fundraising tribute by Jane Marie O'Connell

In January 2009, my father took his first sick day off work that I ever remember him taking. Pat Malone was a real family man and loved his wife Chris, son Derek and 4 daughters Linda, Sharon, Gillian, myself and his grandchildren very much. He worked for CIE and drove the Bus Eireann bus from Kilkee to Limerick for many years. He was always a jolly, healthy man. He loved music and singing and was a member of the Kilkee church choir. He instilled his love of rugby in me and we spent many a day cheering on Young Munsters RFC and Munster in Limerick.

It started with a flu, then pneumonia and then to our horror IPF. Like many others, we had never heard of IPF. I always wanted to do something to raise money for ILFA as without them, my family would not have known so much about daddy's condition.

Daddy fought like a trooper, taking his oxygen, learning how it all worked and still went out and about. Unfortunately, his condition worsened and he then needed to be in a wheelchair. Mammy was his 'Florence Nightingale' and looked after him so well from the first day he was diagnosed to his last. We still took him out to mass and even for the odd half pint of Guinness. On Monday 30th August 2010, I had my car packed and was driving back to start my first teaching job in London. He was very proud of me. But unfortunately that was the day daddy lost his battle with IPF. Even in the ambulance that day he was apologising for 'ruining my plans'. He was always thinking of everyone else and hated if he felt he was a burden. On 30th August 2010 I lost my hero, my father and my best friend. We miss him more and more every day.

On the 3rd January 2015, I did a skydive in memory of my father Pat Malone in Sydney's North coast. I could hear him saying 'what kind of a mad idiot are you jumping out of a plane but good girl for doing it for ILFA' the day I booked it. It was originally booked for Byron Bay Australia for the 28th December but got cancelled twice due to bad weather (I think dad was testing me to see if I actually would do it). It was a fantastic experience and I felt very close to daddy the whole way. The encouragement and support I received was overwhelming and I want to thank all who donated to ILFA.

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.

Fundraising Round-up

Through the winter months, our committed fundraisers continued to give their time and energy to raise vital funds and awareness for ILFA. If you have an event or idea for an event, please get in touch with us, we are always happy to support you in whatever way we can.

Christmas Cards

Thank you to all who supported our Christmas card campaign in 2014. Our Christmas cards help raise awareness about lung fibrosis and all proceeds raised go towards supporting ILFA's work.

Shamrock Vintage Tractor Club

Huge thanks to the Shamrock Vintage Tractor Club in New Ross, Wexford for organising a fundraising event for ILFA in December.

Seamus Murphy and his team of tractor enthusiasts raised funds and awareness about ILFA in the Wexford area and are pictured presenting a cheque to Joan Devereux and her husband Paul on behalf of ILFA. Thank you to everyone involved.

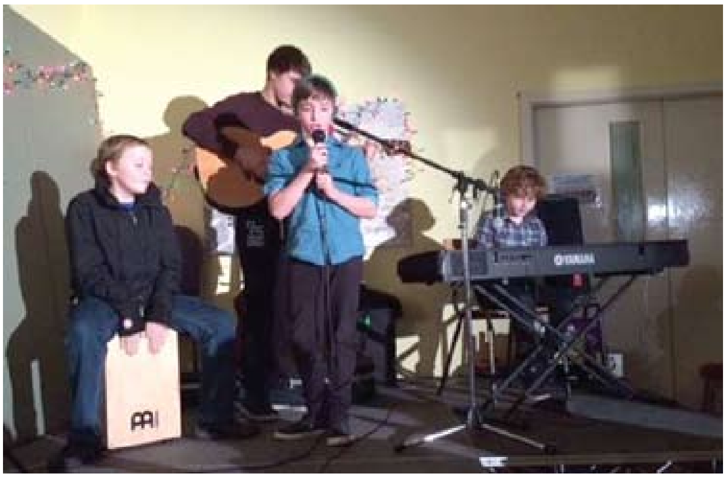
Christmas Swim

The ILFA Christmas Swim took place on St Stephen's Day 2014. Bob Hughes, Gabriel Cooney, Colin and Honora Ireland and Nicky Figgis braved the Irish Sea at Dun Laoghaire and enjoyed warming refreshments afterwards at Fitzgerald's pub. This dedicated group of ILFA supporters has taken to the seas every year since 2002 to raise awareness and funds for ILFA, and the ongoing support is hugely appreciated.

Hell and Back

The Doran family and friends, 31 people altogether, went to Hell and Back in January, taking on the infamous 10km course at Kilruddery House, Co Wicklow. The cold and wet conditions were no match for this dedicated group who took on the icy waters, mud, sludge, electric shocks and a tyre squeeze as part of their extreme effort! The group came together in memory of Peter Doran Snr. The funds raised were well earned by this dedicated group, and ILFA is sincerely grateful for all the effort made.

The Doran Family continued their support with a family party, at which they requested donations to ILFA in lieu of gifts. We are very grateful for this very kind support.

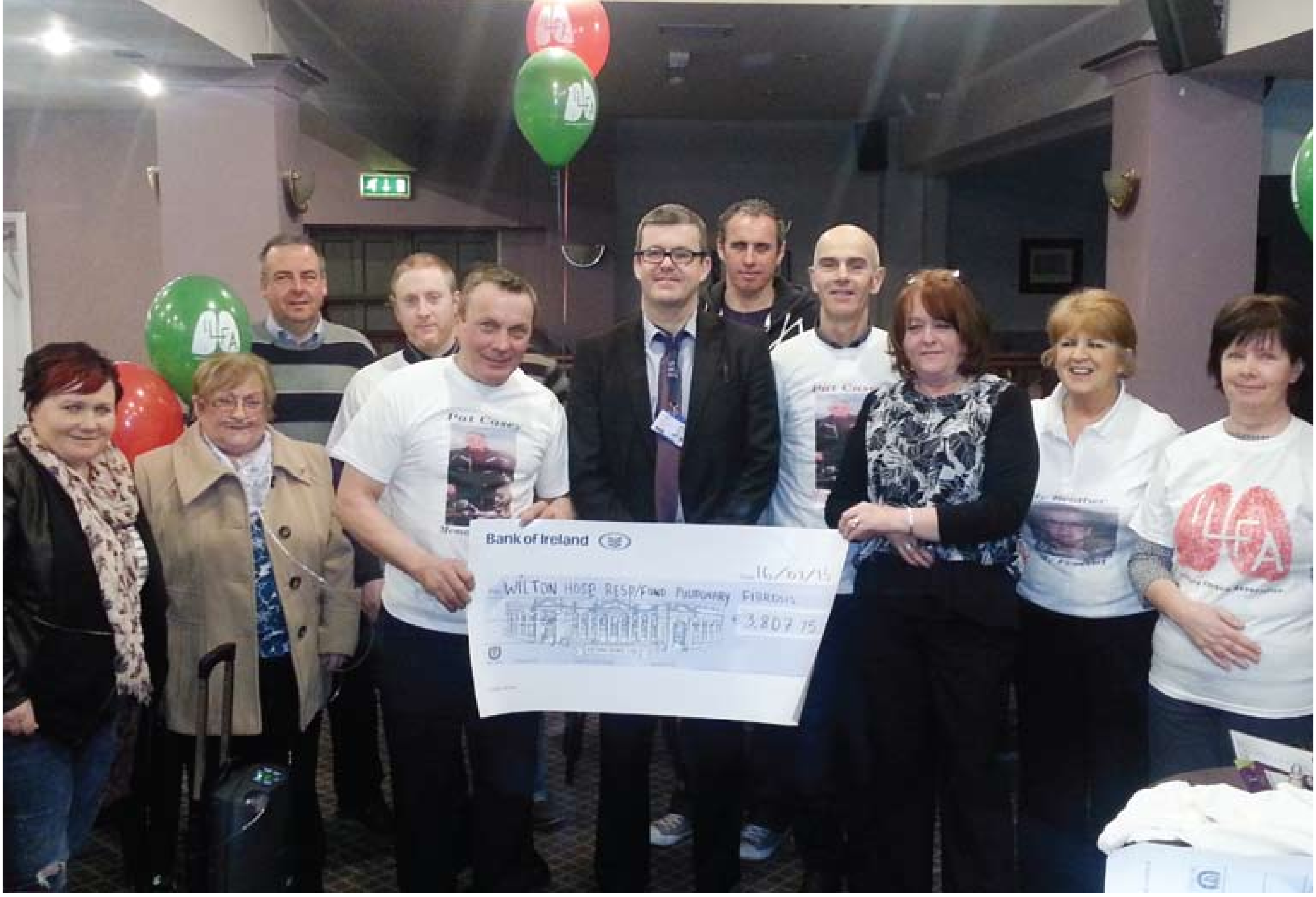


Ballydehob Concert in aid of ILFA

Congratulations to Angela Collins and her wonderful team of helpers for organising another successful Christmas/New Year concert in Ballydehob, Cork in aid of ILFA. The concert took place on 30th December and was a great success.

There were stellar performances from The Red Foxes; Gabriel O'Mahony, Lorcan Harris and Sean Parson (average age 9 years old) and Mongoose who have taken part in the concert for the last 4 years. A great night was had by all and valuable funds were raised for ILFA.

Sincere thanks to Angela for her dedication and commitment to fundraising for ILFA, to her enthusiastic team of capable helpers, the talented musicians, singers and performers, and the patrons who supported the event.



Lisa Gamble, Betty Gamble, Anthony Ford, Graham Desmond, Brian Aherne, Dr Michael Henry, Ray Leahy, Martin Casey, Anne Casey, Linda Wallace and Mary O'Donovan.

Pat Casey Memorial Cycle

Congratulations to all the cyclists and fundraising team who took part in the Pat Casey Memorial Cycle between Cork and Limerick in 2014. The event was organised by Anne Casey and her son Daniel, Brian Aherne and friends and family of the late Pat Casey. The proceeds of the cycle were divided between Cork University Hospital and ILFA. Members of the organising committee are pictured presenting a cheque to Dr Michael Henry, Respiratory Physician at Cork University Hospital. Congratulations and sincere thanks to all those involved with the fundraising event.

Special Dedications

We extend our sincere appreciation to the families of patients who kindly requested donations to ILFA in lieu of flowers at the funerals of their loved one. We are most grateful for this consideration and generosity.

Thanks also to the couples who made donations to ILFA on the occasion of their marriage and wedding anniversary celebrations.

Moustache Madness

Thanks to Eamonn Mernagh and the patrons of Mernagh's Lounge, Oylegate, Wexford for organising a Movember Moustache fundraiser in aid of ILFA.

A novel fundraising idea!

Congratulations to Saileog O'Keefe from Kildare who took 'the pledge' and gave up alcohol for 6 months to raise funds for ILFA. Saileog previously climbed Kilimanjaro in aid of ILFA in 2011 and she has now proved that there is no challenge too great for her.

Thanks to all of Saileog's family and friends for rewarding her with generous sponsorship and words of encouragement along the way.

Upcoming Fundraising Opportunities

Upcoming races for 2015 include:

3rd May	Great Limerick Run www.greatlimerickrun.com
4th May	Belfast City Marathon www.belfastcitymarathon.com
1st June	Cork City Marathon and Half Marathon www.corkcitymarathon.ie
26th October	Dublin City Marathon www.dublinmarathon.ie

Quiz Time

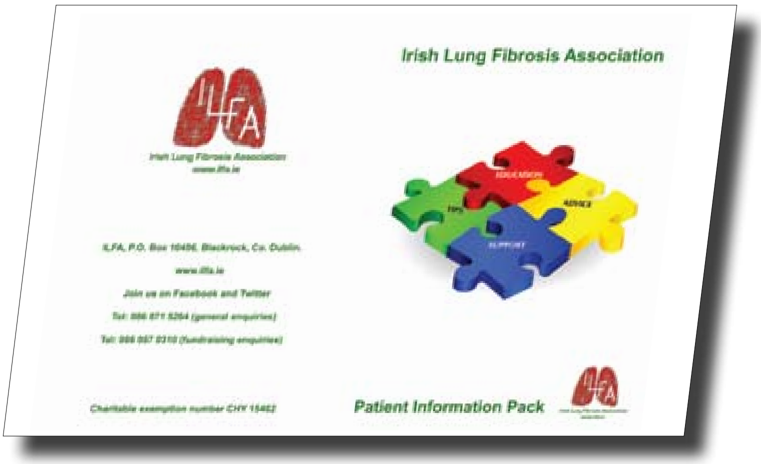
Questions:

1. **What are the small indentations on a golf ball called?**
2. **What are Alpha Centauri and Sirius?**
3. **Which instrument is James Galway famous for playing?**
4. **What are the traditional Easter colours?**
5. **Which actress starred in High Society?**
6. **What is Osterhase?**
7. **The first television set was sold in which year, 1928, 1938 or 1948?**
8. **Who is singer Eithne Ní Bhraonáin better known as?**
9. **For which royals were Fabergé eggs created?**
10. **How many members of Boyzone were there?**

Answers:

1. Dimples
2. Stars
3. Flute
4. Purple and yellow
5. Grace Kelly
6. The Easter Hare, who delivers eggs in Germany.
7. 1928
8. Enya
9. The Russian Tsars, Alexander III and Nicholas II
10. 5

Patient Information Pack


Irish Lung Fibrosis Association

Patient Information Pack

ILFA works to support lung fibrosis patients and their families. We provide information on lung fibrosis to help patients and carers understand and manage the condition in order to improve their quality of life and live as well as possible. The information leaflets available include:

- What is Pulmonary Fibrosis?
- The treatment of Idiopathic Pulmonary Fibrosis.
- Weight Management and Nutrition for Pulmonary Fibrosis.
- ILFA. Join Us Get Involved!
- Get moving with ILFA. The 2000 Steps a Day Challenge for Lung Fibrosis Patients.
- Advice for carers of people with Idiopathic Pulmonary Fibrosis.
- Getting the most out of your hospital appointments.

We also provide STALL cards, with instructions on how to manage shortness of breath and a medical alert card for those who use medical oxygen.

In the coming weeks, ILFA will launch a new patient information leaflet about oxygen and its use for IPF patients. The leaflet will include information on oxygen, how to register as a priority customer with the electrical companies, what to do in the event of a power cut and advice on exercising and travelling with oxygen. The leaflet will be available at our Patient Information Day on 9th May in Athlone. **If you would like an information pack, please get in touch – info@ilfa.ie or 086 871 5264.**

Serious illness/critical illness insurance policies

Recently ILFA has become aware of a small number of IPF patients who are having difficulties with their insurance companies honouring serious illness / critical illness policy claims. If you have one of these policies and your insurance company is refusing to recognise lung fibrosis as a serious/critical illness, please contact ILFA. Email info@ilfa.ie or call 086 871 5264

Find us on Twitter and Facebook – ILFA Ireland
Tel: 086 871 5264 (general enquiries)
Tel: 086 057 0310 (fundraising enquiries)