

## PATIENT SUPPORT GROUPS

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

**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. Contact Pauline 087 6851837

**KERRY** - The Kerry Support Group meets at 3.00pm on the last Saturday of the month in the Carlton Hotel, Tralee.

Contact Adrian at 087 2414004

**MIDLANDS** - The Midland Support Group meets at 2.30pm on the first Wednesday of every month in the lobby of the Tullamore Court Hotel. Contact Tom at 086 1500970.

## SERVICE OF PRAYER AND REFLECTION

The 2013 ILFA Service of Prayer and Reflection will take place on Saturday 28th September at 3pm in St. Ann's Church Dawson Street, Dublin 2 (off Grafton Street). This year the ceremony will be led by The Reverend Canon Charles Mullen, Deans Vicar, St. Patrick's Cathedral. He will be joined by Fr. Brian McKay, Prior of Our Lady of Mount Carmel, Whitefriar Street Church, The Reverend Vanessa Wyse Jackson, Rathgar Methodist Church and The Reverend Denis Campbell, Blackrock Presbyterian Church.

As part of the ILFA Service of Prayer and Reflection, we will remember those patients who are no longer with us with a simple candle lighting ceremony. If you would like your loved one remembered, please contact ILFA on 086 057 0310 or email [info@ilfa.ie](mailto:info@ilfa.ie) with their name by 31st July.



## SUPPORTING FROM THE SIDELINES

Nicola Cassidy and Caroline Grehan cheer on Andrew Grehan and Alex Savye who ran the Dublin City marathon for ILFA. Andrew ran in memory of his aunt, Denise Cassidy, and Alex took part to honour the memory of his father, Pierre, who died from IPF five years ago in France. Alex said that what ILFA does has no borders. "Their work reaches further than just Ireland and was an amazing source of information when Dad contracted the illness".



Irene Byrne, Senator Feargal Quinn and Michael Darragh Macauley at the launch of ILFA's 2000 Steps.

## THE 2000 STEPS A DAY CHALLENGE

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

We hope that you will enjoy this exercise challenge and it will motivate you to incorporate an extra 2000 steps into your daily routine. We want you to use the programme to help kick start, improve and maintain your level of fitness.

### The ILFA 2000 Steps a Day walking pack contains:

- The 2000 Steps a Day leaflet that explains the benefits of walking for Lung Fibrosis patients and gives tips and advice on how to get started and stay safe.
- An inspirational poem called "Promises to Yourself" by Christian D. Larson and a Contract for Success for you to sign and commit to the 2000 Steps a Day Challenge.
- A pedometer (step counter) to estimate the number of steps you take, the distance travelled (miles and kilometres) and the number of calories used when walking.
- A high visibility reflector vest to help keep you and your walking companion safe while out walking. The reflector vests have been kindly supplied to ILFA by the Road Safety Authority.
- An exercise diary to record your progress with the 2000 Steps a Day Challenge.
- An ILFA pen.
- A Donation card if you would like to make a donation to ILFA.

Please contact ILFA to request your 2000 Steps a Day walking pack by writing to ILFA, PO Box 10456, Blackrock Co. Dublin or via email to [info@ilfa.ie](mailto:info@ilfa.ie) or by calling 086 0570310

# ILFA NEWSLETTER



Irish Lung Fibrosis Association

Patrons: Brian O'Driscoll, Charlie Bird,  
Senator Feargal Quinn, Andrea Corr  
Issue: Spring/Summer 2013 Volume 10 Issue 1

## PIRFENIDONE

The ILFA committee was delighted and heartened by the members' response to the call for action in protest at the decision of the National Centre for Pharmacoeconomics (NCE) not to recommend Pirfenidone as a cost effective treatment for mild to moderate IPF.

We had hoped that the negotiations between the HSE Corporate Pharmaceutical Unit and the drug company InterMune on the pricing and reimbursement of Pirfenidone would have concluded by now but, despite some recent media reports suggesting that agreement has been reached, we still have not had any official report that this is the case.

Accordingly we would ask you to keep up the pressure on your local representatives and make your views known in whatever way you can so that IPF patients who need it can have this treatment. For the most up to date news on this keep an eye on ILFA's website at [www.ilfa.ie](http://www.ilfa.ie)

## FAREWELL TO LORNA

We would like to wish Lorna Murphy every success as she leaves ILFA to take up a new position this month. Lorna has worked with ILFA for the past four years offering help and support to IPF patients all over the country. Many thanks, Lorna. You will be missed.



Members of the Troy family who organised a Halloween fundraiser in Mackey's Public House in Thurles. The event was organised in memory of the late Daniel J. Troy by his wife and family and as well as being a great night out raised both awareness and €1,300 for ILFA.



Participants in the Women's Mini-Marathon in Dublin on 3rd June 2013

## NEWS ON TREATMENT OF IPF

Recently the Irish Thoracic Society (ITS) issued a position statement on the treatment of IPF to ensure that physicians and patients are appropriately guided on the most up to date information to manage this condition.

In the statement the Society says that significant new information has emerged since 2008 which will alter the therapeutic management of Irish patients diagnosed with IPF.

Firstly, there was the approval, in February 2011, by the European Medicines Agency of the anti-fibrotic drug, Pirfenidone, as the first licensed treatment for patients with mild to moderate IPF.

The ITS Interstitial Lung Disease group recommends that patients being considered for this therapy should be managed and treated in designated centres with the support of a multidisciplinary team. Other forms of Interstitial Lung Disease that are not IPF, or advanced IPF, or patients with significant co-morbidities should not be considered for treatment with Pirfenidone

Secondly, the publication indicating that the triple therapy comprising N-Acetylcysteine, azathioprine and prednisolone used in the PANTHER trial was discontinued due to excessive deaths, hospitalisations and adverse events compared to placebo.

While the ITS paper says it is difficult to know the true extent of triple therapy use in the Irish IPF population it does recommend that new patients with definite IPF should not be initiated on a regimen containing prednisolone plus azathioprine. It also recommends that in patients with definite IPF receiving triple therapy the azathioprine therapy in particular should be withdrawn if there is evidence of disease progression, i.e. a decline in lung function.

For the full statement from the ITS see the ILFA website [www.ilfa.ie](http://www.ilfa.ie)



## THE OIREACHTAS HEALTH COMMITTEE DISCUSSES ORGAN DONATION

In April the Oireachtas Health Committee, chaired by Deputy Jerry Buttimer T.D., held a series of consultation meetings on organ donation and invited speakers to make submissions. The Committee will now prepare a report for the Minister for Health based on these submissions.

The Committee was told that the rate of organ donation in Ireland is approximately 20 donors per million of population but this rate lags behind countries like Spain, Portugal and Croatia who are achieving donor rates of up to 30 donors per million population. To meet the growing demand for organs, a change in the system for organ donation from an opt-in to an opt-out system, is being proposed.

In his submission on behalf of the Irish Donor Network, of which ILFA is a member, Philip Watt emphasised that a package of essential measures would need to accompany the change in the donation system. This should include the appointment of a network of donor coordinators; the establishment of an on-line donor registry and greater support for public awareness campaigns for organ donation.

He said that family consent is at the heart of organ donation and this position will not change if an opt-out system is introduced to Ireland. Next of kin consent must always be given before organ donation can occur.

In its submission, The National Organ Donation and Transplantation Office, led by Professor Jim Egan, supported the move to an opt-out system in line with the Spanish model, the gold standard for organ donation, following the introduction of key donation staff in ITU hospital departments and increased resources. Such a system could potentially allow for an additional two to six organ donors per million population, he said.

## ILFA Patient Information Day

At the ILFA Patient Information Day on 23rd March 2013 Dr Kate O'Reilly, who recently joined the Mater Misericordiae University Hospital as a Respiratory Consultant, gave an overview of Lung Fibrosis and stressed how the clinical course for each patient is different. Dr O'Reilly discussed some of the medical treatments that may be prescribed for IPF patients including Pirfenidone, antibiotics, anti-reflux medications, steroids and cough suppressants and she also touched briefly on oxygen and the need for exercise to keep fit and healthy. Dr O'Reilly encouraged patients to think of themselves as mountaineers and stressed the importance of oxygen as a tool to enable people to do more. The majority of mountaineers need supplemental oxygen in order to reach the summit!

### TRANSPLANTS

Professor Jim Egan told the meeting that in 2012 there were 14 lung transplants carried out at the Mater Hospital and 50% of transplants were for IPF patients. He said that, ideally, 20 lung transplants should be carried out yearly and the longer term goal is to achieve 30 lung transplants per year.

### DIET

Yvonne Duggan (dietician) stressed the importance of maintaining a healthy body weight and gave some tips for weight loss include planning your meals in advance, keeping a food diary to record all meals and snacks to identify your eating habits, and making smart food choices (choosing a plain biscuit rather than a chocolate covered biscuit). Individuals who have a sedentary lifestyle should only consume 2000 calories (male) and 1800 calories (female) daily.

John Carroll from Tullamore gave an inspiring account of his struggle with weight loss after being diagnosed with IPF. After trying all sorts of unsuccessful diets, John joined Weight Watchers with a family member, cut back on the portion sizes of his meals and started taking short walks (5 minutes out and 5 minutes back). John steadily built up the duration of his exercise and now walks for 2 hours twice a week with shorter walks on other days and he does pulmonary exercises when the weather is bad. Little by little John successfully lost 2 stone in weight.

### FIRE SAFETY

Tom Daly, Fire Prevention Officer with the Dublin Fire Brigade spoke about the importance of fire safety in the home and the need to have an escape plan in place for all the family. He encouraged the audience to have working fire and carbon monoxide alarms in their homes and to check them regularly, to keep a phone in the bedroom in order to call the emergency services if needed, to close all doors when going to bed in order to prevent the spread of fire, and to always unplug the TV and any appliances that are on "stand-by".



*Congratulations to Noel Mangan who won the raffle held on March 23rd at the ILFA Patient Information Day. Noel is now the proud owner of a print by artist Carol Walsh. Carol has long been a supporter of ILFA and has previously designed a number of our Christmas cards. Carol donated the beautiful framed print to ILFA to raise funds. Thank you to everybody who supported the raffle and donated so generously to ILFA. Noel is pictured (centre) with Nicola Cassidy and John Donnelly.*

## May McCarthy

By Celine McCarthy-Beckett, Ontario, Canada.

My mother was a very petite woman, at 4ft 11ins and 7 stone in weight. Her forward thinking and optimistic attitude was always there whether at work, home or volunteering. May was married for 41 years to Matt, my father. They were inseparable. My brother Brian and I were very fortunate to have these wonderful, loving and caring individuals as our parents. Their love and support was endless. May worked as office manager at the Irish Family Planning Association for almost 30 years. The first symptoms of her illness started to appear in 2002 with a dry cough, it progressed months later into what her family GP said was pneumonia. She was referred to a respiratory consultant. Medication in the form of inhalers and steroids were prescribed. The next few months she underwent a series of tests which included x-rays, blood work, breathing tests and scans. She was told she might have "Farmers Lung". The cough never went away. More tests were carried out and in 2004, after a biopsy to shed more light on her symptoms, both lungs collapsed and only a third capacity in each lung was regained.

Shortly after the lungs collapsing May was diagnosed with Sarcoidosis and in 2006 was placed on a lung transplant waiting list under the excellent care of Prof. Jim Egan at the Mater Hospital, Dublin.

The transplant would have to take place in Newcastle-upon-Tyne as facilities were not yet available in Dublin. Thus began an education on this procedure for the whole family.

I was living in Canada and would come home to visit annually or my parents would visit us. At this point, however, May's visits to Canada (to see her three grandchildren), had to stop due to her illness progressing. May started using oxygen at night to assist sleep and the oxygen unit eventually had to be taken to work. She eventually ended up using it 24/7. She continued working but reduced her hours to part time, eventually making a difficult but necessary decision to retire in August of 2006. My father retired from his job a week later to look after her. My annual trip home turned into several visits at this point.

Early in 2007 my father requested a stair lift to be installed at home to assist May as her mobility became an issue. She was removed from the lung transplant waiting list later that same year when it was discovered that a valve in her heart was narrowing. Dr.Egan had always remained positive and given us all hope when he told my mother "as long as the ticker is healthy there should be nothing preventing the transplant". If the heart was compromised in any way she would have to come off the transplant list. She underwent an angioplasty early January 2008. It was successful and we thought she would have about three more months or longer.

May's perseverance, strength and never ending optimism for everyone around her gave us all strength. Her heart was too weak and her lungs too damaged. She passed away peacefully on Wednesday afternoon January 24th 2008 in the Mater Hospital with her family by her side.

Eleven short weeks later my father Matt, died suddenly at his home in Dublin. He missed May too much to be separated from her. I wish to take this opportunity to thank all the special people in my mother's life: her only sister Teresa, her friends, work colleagues, family, neighbours and the nurses at the Mater hospital and Prof. Jim Egan. Without their love and support it would have made my mother's Sarcoidosis even harder to live with. My mother's inner strength and willingness to fight to the end has given us all inspiration and beautiful memories of what a wonderful woman she was.

**Sarcoidosis is an inflammatory disease that can affect the lungs, skin, heart, brains and nervous system, eyes and other organs. It is thought to occur as a result of an abnormal immune response. An excess build-up of white blood cells leads to the formulation of granulomas on the affected organ. It is a difficult disease to diagnose and symptoms can be very similar to other diseases such as IPF.**

For more information see [www.isarc.ie](http://www.isarc.ie) or contact ISARC, the Irish Sarcoidosis Support Network at Ard Aoibhinn, Mount Bolus, Tullamore, Co. Offaly. Telephone 057 9354492 or email [info@isarc.ie](mailto:info@isarc.ie)

