

Friends of Ciara Martin who participated in last year's WMM for ILFA.



Ciara said, "2010 was my first ever mini-marathon. Despite the rain a fantastic day was had by all of the girls. There was a great party atmosphere in Dublin city centre and the streets were filled with people clapping and cheering in encouragement for all of the women running the race. It was a pleasure to raise money for ILFA and I have been touched by all the support from friends, family, ILFA and strangers. The day was a great success and I can't wait until 6th June."

WOMENS MINI-MARATHON 2011

Calling all ladies...

The Flora Dublin Women's Mini-Marathon will take place on Monday 6th June at 3pm. ILFA would like to invite you to join our Mini-Marathon team. Every year we have a loyal group of ladies who take part and we really appreciate their dedication and enthusiasm. We are always delighted to welcome new ladies to our team so if your family members, friends, or colleagues would like to take part and raise funds for ILFA we would love to hear from them. We can guarantee a fun day for everybody, come rain or shine!

You can register for the Flora Women's Mini-Marathon 2011 by applying online at www.florawomensminimarathon.ie or using the official Entry Form which will appear in the Evening Herald every Wednesday and Saturday. Please remember to register early to avoid disappointment. The closing date for entries is April 27th 2011 or when the maximum number of entries has been received.

You can contact ILFA by emailing us at info@ilfa.ie or calling 086 0570310 and we can provide you with T-shirts or vests (sizes S,M,L,XL), sponsorship cards, and balloons.

And why not create your own personal fundraising page online? ILFA is registered with www.mycharity.ie. You can email the link to your sponsorship page to your contacts at home and abroad and the money pledged will go directly to ILFA.

Watch the News and Events section at www.ilfa.ie for more details of our meeting-up point on 6th June.

Good luck and don't delay ... register today!

GOOD LUCK to Brian Mc Carthy who is climbing Kilimanjaro to raise funds for ILFA. Brian's mother passed away just over three years ago of lung disease. Since he was doing the climb as a personal challenge Brian thought it would be a good idea to set up some fundraising to support research into lung diseases. If you would like to contribute to Brian's fundraising effort you can do so by clicking on mycharity.ie and going to the Irish Lung Fibrosis Association site.



Swimmers getting ready to take the plunge. Among them are Brian Lawless's sons, Stephen, Darren and Ronan and his daughter, Edel.

BALBRIGGAN SWIM

Christmas Day has long been the day for the charity swim in Balbriggan. Started in 1972 the number of swimmers and spectators has grown year on year to the large numbers that take part today. The swim, now run by O'Dwyers GAA Club, has fund-raised a lot over the years for local and other deserving causes. This year, among other causes, the swim was held for ILFA in memory of Brian Lawless who was a member of the club.

Despite the freezing weather conditions over 80 swimmers and a huge number of spectators took to the front beach to soak up the atmosphere and enjoy the festivities at noon. Among the swimmers were Brian's sons, Stephen, Darren and Ronan, and his daughter Edel started the swim. The weather leading up to Christmas 2010 was arctic but even the ice-lined waters couldn't stop the hardy men and women taking the annual dip for charity.

Cheered on by family and supporters lining the seafront, the swimmers raced into the water. As the tide was high they didn't have far to go. Some took just a few strokes and others stayed in a for a long dip before leaving the freezing water to be wrapped in the warm towels held for them by their proud families, and enjoying a well-earned hot whisky. After braving the cold to continue celebrations and a few final words with friends everyone returned to the warmth of their homes.

Well done and a big thank you to everyone for their generosity and support.

ILFA NEWSLETTER



Irish Lung Fibrosis Association

Patrons: Brian O'Driscoll, Charlie Bird

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APPROVAL OF PIRFENIDONE IN EU

In December InterMune announced that the Committee for Medicinal Products for Human Use (CHMP), the scientific body of the European Medicines Agency (EMA), had recommended the granting of a marketing authorisation for Pirfenidone for the treatment of mild to moderate pulmonary fibrosis.

This recommendation has now been forwarded to the European Commission for ratification. Ratification will result in approval for marketing Pirfenidone in all the twenty seven member states of the EU, including Ireland.

Preclinical and in-vitro evidence has shown that Pirfenidone has both anti-fibrotic and anti-inflammatory effects.

A MILESTONE

Roland du Bois, Professor of Respiratory Medicine at Imperial College, London, and co-chair of the Phase 3 clinical trials evaluating Pirfenidone for the treatment of IPF, said,

"IPF is among the most urgent of unmet medical needs in respiratory medicine, with no approved therapies in the EU and with survival rates as poor as many forms of cancer. The opinion of the CHMP represents a major milestone in the treatment of IPF and is extremely exciting news for the more than 100,000 Europeans who suffer from IPF, and for the physicians who care for them. What all patients have waited for so long – hope and new therapy for their disease – will soon be realised."

Asked how soon Pirfenidone would be available to IPF patients in Ireland, Professor Jim Egan of the Heart and Lung Unit, Mater Hospital, Dublin, who was also involved in the clinical trials evaluating Pirfenidone, said that "as the Mater University Hospital was an investigating centre I would be hopeful that the drug would be available for patients later this year."



Dr. Hal Collard and Professor Jim Egan at the Inaugural Fergus Goodbody Lecture held in the Mater University Hospital on 10 December.

Dr. Hal Collard, Director of the Interstitial Lung Disease Programme in the University of California's Division of Pulmonary and Critical Care Medicine, was the guest speaker at the Inaugural Fergus Goodbody Lecture. He said, "I am grateful to have the opportunity to participate in the ILFA's Fergus Goodbody Lectureship. Raising the profile of interstitial lung diseases is critically important to patients and their families, and the ILFA is playing a central role in this process."

Nicola Goodbody, wife of Fergus Goodbody who died from IPF in 2002, thanked everyone for a wonderful event. She said, "I have no doubt that Fergus would have been very touched that it was dedicated to his memory."



Phyllis, Lorraine, Carolyn and Glenn Lavery, who attended the ILFA Open Day in Belfast.

ILFA OPEN DAY

The next ILFA Open Day will take place on **SATURDAY 16th APRIL, 2011**, in the Education and Research Centre in St. Vincent's Hospital, Elm Park, Dublin. As usual the day will start with coffee/tea at 10.00am and finish at 12.30pm with a Question and Answer session. Light refreshments will be available after the meeting. Speakers at this Open Day will include Professor Jim Egan, Consultant Respiratory Physician, The Mater University Hospital; Shakila Devi Rerumal, Senior Respiratory Physiotherapist, St. Michael's Hospital, Dun Laoghaire and John Donnelly, transplant recipient. For further information contact Lorna at 086 8715264.

THANK YOU MARIE



MARIE SHERIDAN, whom many of you will know as the welcoming face of ILFA at registration on Open Days, is sadly leaving the committee due to work commitments. Without exaggeration, she could be described as a twenty-first century polymath, her professional skills ranging from accountancy to the field of art. A founder member of the committee, her unstinting contribution to ILFA, from November 2002 to March 2011, has been primarily as custodian of ILFA's finances, a mammoth task in itself, delivered with typical efficiency and exactitude. However, other duties which she took on were as ILFA's photographer (requiring her presence in all weathers at events such as the Women's Mini-Marathon and the Christmas swim), painting a Gauguinesque Nativity for our Christmas card and hosting committee meetings at her home in Monkstown, with the always loyal support of her husband Chris and her family, Philip and Chloe (a regular runner in the WMM and swimmer for ILFA). Marie's skills and experience will be sorely missed by the committee and ILFA at large. On a personal note, I would like to add that Marie's generosity with her time to ILFA stemmed from the loss of my own husband, Fergus, and to her, I will always remain deeply indebted.

Nicola Goodbody
March 2011

2010 – A BAD YEAR FOR ORGAN DONATIONS

According to the Annual Report of the Organ Procurement Service in Beaumont Hospital there has been a dramatic decline in organ transplantation in 2010.

The total number of transplants carried out in Ireland in 2010 was 174 compared with 261 in 2009. Of the transplants carried out in 2010, 121 were kidney transplants, 8 pancreas, 38 liver, 3 heart and 4 lungs.

Commenting on the figures Mr. Mark Murphy of the Irish Donor Network said, "2010 has seen the worst decline in organ donation on record. We had only 58 deceased organ donors in 2010, 35% less than 2009, when we had 90 deceased donors. We are going backwards fast."

Mr. Murphy said,

"We do not know what has gone wrong. We don't believe it is the lack of public willingness to donate organs but we are suspicious that the families of potential donors in hospitals are not being approached, possibly because of staffing shortages and pressures in the country's Intensive Care Units."

He called on the HSE and the Minister for Health to "address all areas relating to organ donation, procurement and transplantation with a sense of urgency which currently seems to be lacking to ensure that our transplant programmes operate to their optimum potential and that lives are not needlessly lost."

PROGRAMME FOR GOVERNMENT 2011 TO 2016

It is in this context that ILFA welcomes the commitment in the Programme for Government to "legislate to change the organ donation system to an opt-out system for organ transplantation rather than an opt-in system so as to improve the availability of organs for patients in desperate need."

ILFA looks forward to seeing this legislation enacted quickly.

APPOINTMENT OF CLINICAL LEAD FOR TRANSPLANT OFFICE

ILFA welcomes the recent appointment of Professor Jim Egan as the Clinical Lead for the HSE's National Organ Donation and Transplant Office to provide national clinical leadership in the areas of organ donation, retrieval and transplantation.



Vincent & Catherine McAnerney, Armagh, at the Belfast Open Day

SEAN'S STORY

Submitted by his daughter, Margaret.

Sean McGlynn was diagnosed with IPF on the 7th July 2010 at the age of 63 years. A native of Tralee, Co. Kerry, and married to Bridget with two daughters and two granddaughters, Sean had worked as a carpenter all his life. On hearing that the only viable option for his condition was a lung transplant, he immediately said, "if that's what it has to be, that's what it has to be." His motto in life was, "you have to take a chance."

Sean's breathlessness seemed to worsen steadily from May 2010 and by the time he received his diagnosis of IPF, he was already on oxygen therapy. His mobility became severely restricted and the things he loved to do socially, like going out to play cards, became very difficult for him, even with oxygen therapy. Despite the difficulties he showed tremendous strength and courage. He had always had a huge sense of humour with a positive outlook and he managed to maintain this throughout his illness.

On the 5th August 2010, Sean was transferred from Cork University Hospital to the Mater Hospital in Dublin to be assessed for the possibility of a lung transplant. Here he spent the next week going through all the various rigorous tests necessary for assessment. This week at the Mater opened up a new world for him and gave him a great sense of hope. He was attended by the fantastic medical team of the Heart and Lung Unit and formed a great camaraderie with the other patients in the ward. He even met a patient who had received a lung transplant for IPF less than a year earlier and this to him was living proof that in the Mater "miracles" can happen.



Sean with his two daughters, Patricia and Margaret, and son-in-law, Joe, in Dingle, Co. Kerry, on Father's Day, June 20, 2010.

Before Sean could be accepted on the lung transplant list, he was put on a weight loss programme and was due to return to the Mater in November 2010. He left the Mater hospital on the 13th August 2010 totally motivated and focussed on reaching his target weight.

Over the next few weeks, Sean stuck rigidly to his diet and exercise bike, steadily losing weight each week – he now was a man with a mission. His 64th birthday on August 30th was even celebrated with 'sugar-free' jelly instead of the customary cream cake. Despite his efforts his illness was not letting up and he was again admitted to Tralee General Hospital on September 9th. Sadly his condition continued to worsen and he spent the next number of weeks in Intensive Care Units at Tralee, Limerick and Dublin. He passed away peacefully at the Mater Hospital on Tuesday morning, September 28th 2010.

Unfortunately, time was not on Sean's side and he never got a chance at his "miracle." Sean's family, who deeply and profoundly miss him every day, can't emphasise enough the need for awareness and early diagnosis of this deadly disease.

WOULD YOU LIKE TO BECOME MORE INVOLVED WITH ILFA?

Perhaps you could do a once-off fundraising event such as a coffee morning or maybe you would be interested in setting up a local branch in the area where you live. You can decide what level of involvement you would like to have.

If you are interested in getting more involved ILFA would like to hear from you. You can contact us by post at PO Box 10456, Blackrock, Co. Dublin; by email at: info@ilfa.ie or by phone at 086 8715264.