



Wicklow 200K Cycle



In June 2007 a team of dedicated and enthusiast cyclists led by Professor Jim Egan undertook a huge cycling challenge across the Wicklow Mountains. Professor Egan, pictured here with some of the other cyclists, completed the 200K course in 11 hours. The event raised a fantastic sum in excess of €19,000 for ILFA. Well done everyone!



Nicola Goodbody wrapped up well after her swim at the ILFA Annual Swim in Sandycove last year. Nicky's father, Tom Figgis, came along to support her.

BRENDAN MERRY It is with great regret that we heard of the death on 3 November of Brendan Merry who, with his family, had been a great supporter of ILFA. We extend our heartfelt sympathy and condolences to his wife, Evelyn, his family and friends. May he rest in peace.

ILFA meets the Minister for Health and Children

On Tuesday 3 November a deputation from ILFA consisting of Terence Moran (Chairman), Mary O'Connor (Secretary), Marie Sheridan (Treasurer) and Eddie Cassidy, met with Ms Mary Harney, T.D., Minister for Health and Children, to discuss the issue of organ donation. The Minister was accompanied by her political advisor, a representative of the HSE and two officials from her Department.

One of the most hopeful developments in the treatment of IPF has been in the area of transplantation. The survival rate for patients who are fortunate enough to be offered a lung transplant is 90% to 95%, and the outcome, in terms of quality of life, can be dramatic.

However, it is an unfortunate reality that many IPF patients on the transplant list will die before a suitable donor lung becomes available as they tend to be diagnosed when the condition is already well advanced, and can deteriorate very rapidly.

There is, therefore, an obvious and immediate need for an increase in donor rates.

ILFA told the Minister that while we believe that a move from an "Opt-in" to an "Opt-out" system, as proposed by Senator Fergal Quinn recently, may be one step towards improving the chances of patients suffering from IPF getting a lung transplant, we also believe that other, equally important, steps need to be taken.

As well as fostering well-informed debate to raise public awareness and appreciation of the plight of people on a transplant waiting list, ILFA also believes that there is a need for a greater awareness by members of the medical profession. ILFA stressed to the Minister that to achieve a successful transplant of heart and lungs or lungs alone, speed is of the essence. It is generally accepted that there is approximately six hours from brain stem death within which lungs can be used successfully.

ILFA feels there is also a need for structures to be put in place to maximise the utilisation of donated lungs and told the Minister that we would like to see a Transplant Authority established to oversee and regulate this whole area.

The Minister was most receptive to our views and has agreed to involve ILFA in the consultative process she plans to initiate shortly on this matter.

PATIENT INFORMATION DAY

Our third annual Open Day took place in St Vincent's Hospital on the 12th of April 2008.

TERENCE MORAN, ILFA chairman, welcomed everyone and gave a brief history of the organisation and its objectives.

STRESS AND STRESS MANAGEMENT.

Bill Foley, Social Worker attached to the Mater Hospital, addressed the topic of stress. He suggested ways of managing stress and pointed out that a small effort can make a real difference. He emphasised the importance of being realistic and recognising one's limits. He advised patients to take one thing at a time, especially when they're feeling overwhelmed. Exercise, hobbies, talking and therapies such as meditation can be of great benefit.

THE IMPORTANCE OF EXERCISE AND OXYGEN

Irene Byrne, Senior Physiotherapist, Mater Hospital, focused on exercise, oxygen usage and energy conservation. She suggested that the reasons people with IPF do not exercise is because of breathlessness and fear they will do more harm than good. However there is a need to exercise. Irene noted that lack of oxygen is detrimental to all parts of our body and it is important to use it when necessary and not just when one is breathless. She advised patients to talk to their doctors about how much they need, and to always use it during exercise.

PROFESSOR JIM EGAN

Professor Egan said that when he began his career in the early nineties the textbook treatment for IPF patients was the use of steroids. However, it was not long before he realised that steroid treatment had significant limitations and side effects. A number of drugs are being investigated at the moment and a whole host of biological agents to target specific cell activity are in the process of being examined. Progress is being made and Ireland is an active participant in these treatment studies.

PROFESSOR FREDDIE WOOD

Professor Freddie Wood, Director of the Lung Transplant Programme in Ireland, gave an overview of lung transplantation in Ireland. He said that in patients with IPF the lung becomes hardened like a dried out sponge and the lungs can't move. Once the process of fibrosis starts the progression is fairly inexorable. However, with dry lung failure a single lung transplant can have a very satisfactory outcome. He said that of the 17 transplants carried out since the inception of the Lung Transplant Programme in 2005 all patients were discharged. The length of survival after a single lung transplant can range anywhere from 4 to 16 years. The length of survival depends on whether rejection occurs or not.

DIRECTORY OF SERVICES

At the Information Day ILFA's Directory of Services was officially launched by our new patron, CHARLIE BIRD. He said that the provision of information was hugely important and to have it put together in an accessible way would be of great benefit to everyone faced with a diagnosis of IPF.

NICOLA CASSIDY presented the Directory which was dedicated to the memory of her mother, Denise, "a very brave and wonderful person". Copies of the Directory can be downloaded from the ILFA website at www.ilfa.ie



In the swim at Sandycove last year were Gab



Professor Jim Egan, Eddie Cassidy, Nicola Cassidy and ILFA patron, Charlie Bird, at the Launch of the ILFA Directory of Services.



Gabriel Cooney, Chloe Meehan and Rosanna Cooney

DUBLIN CITY MARATHON

Congratulations to Andrew Grehan, Eavan Murray, Angela Collins, Niall Kerley, Stephen Cassidy and Peter Edwards, who successfully completed the 29th Dublin City Marathon on 27 October. These brave athletes undertook 26.2 miles to raise money for ILFA. We appreciate the huge effort they made.



After the Marathon Andrew said, "This is my third year running the marathon. I've always run for ILFA and will continue to do so to try to create more awareness for lung fibrosis and to help continue to support the good work being done by all involved. Knowing I can make some sort of difference to someone else's life is very uplifting and motivational and makes finishing a marathon all the more worthwhile."

ANNUAL SWIM



Wendy Cox, Sally Keane, Tom Figgis and Shirley Piggins at the St. Stephen's Day Swim

FUNDRAISING

The Erne Vintage Car Rally

This year's annual rally of vintage and classic cars was dedicated to the memory of the late Raymond McCartney, founder Chairman and much loved Honorary President of the Erne Vintage Car Club. Friends came from all over Ireland to remember Raymond who died from IPF, and to have a wonderful, happy weekend. We thank everyone who turned up and helped raise over £4,000 sterling for ILFA.



Caroline McCartney with Judith Wilson, Miss Northern Ireland 2008, at the Erne Vintage Car Rally in Enniskillen.

Womens Mini Marathon 2008

This year the WMM was held on 2 June 2008. It was a beautiful sunny day with a slight cooling breeze. As usual, there was an excellent turn-out by ILFA participants, both old friends and newcomers too numerous to mention individually. They deserve special thanks for putting in the enormous effort, both to take part and to raise funds, many walking or running because they are connected to someone with the disease.

Some of us gathered for the group photo beforehand at Leeson Park, where a carnival atmosphere prevailed, thanks to the red and green balloons provided by Joanne Coyle and Marie Sheridan. As we joined the main crowd, we were the only charity to have them and so we could be easily spotted. Well done to Nicola Cassidy for having the idea!

Later we regrouped at the Dome Cafe in the St Stephen's Green Centre, where we relaxed over tea and scones. Special thanks to Pembroke McDonnell and Delphine Kelly for their generosity in providing funds for prizes, which were awarded later. This year a fantastic sum in excess of €25,000 was raised for ILFA.

Helen Durney yet again organised a team of women from Kildare to run for ILFA in the WMM. "Every year I approach family and friends and ask them to join our fundraising team. I also advertise in the parish newsletter and ask for participants. Thank you to all those who support us by taking part."

Here she is receiving a cheque from Ladbrokes some of whose employees walked in the WMM with her.





**THIS YEAR'S SWIM WILL TAKE PLACE ON
ST. STEPHEN'S DAY AT 12.30pm
AT SANDYCOVE PIER, CO. DUBLIN.**

We are delighted that our Patron, CHARLIE BIRD, has agreed to take part in our Swim this year. If you would like to sponsor Charlie you can do so by going to Charlie's fundraising page at www.mycharity.ie/charity/ilfa and click on the list of fundraisers.

ILFA Committee Changes

During the year Nicky Goodbody, a founder member of ILFA, resigned as ILFA Secretary. Nicky has taken up a new job and felt she would not have as much time to give to her ILFA work which has been tremendous over the years since ILFA was founded. Members will be delighted to know, however, that Nicky will continue to serve on the ILFA committee and help us with her experience and wisdom. Mary O'Connor has agreed to take over the job of Secretary.



ILFA Committee members at the Patient Information Day, April 2008. Back row (from left) Professor Jim Egan, Marie Sheridan, Terence Moran and Bob Murray. Front row (from left) Joanne Coyle, Nicky Goodbody, Nicola Cassidy, Mary O'Connor and Eddie Cassidy

We welcomed two new additions to the Committee. Helen Durney has agreed to be ILFA's Kildare representative and Joanne Coyle, who many members will know from her previous role as Research Assistant in the Heart and Lung Unit in the Mater, has agreed to be our Cavan representative.

FRENCH CONNECTION

ILFA would like to thank the Sayve family from France for their contribution to ILFA's funds in memory of Pierre Sayve who died from IPF. Alex, Pierre's son, came to Dublin to support the ILFA runners in the Dublin City Marathon. Alex said he and his family wanted to thank ILFA for the information they were able to access on the website because they had no such resource in France when Pierre's illness was diagnosed.

ILFA St. STEPHEN'S DAY SWIM

The ILFA Swim on St Stephen's Day 2007 was blessed with perfect conditions for the winter season and the high tide matched our midday swimming time of 12:30pm.

We were thrilled to see so many people supporting the event. Many thanks to Aidan O'Sullivan, Kevin O'Sullivan, Nicklas Persson and Jean Orr, who took the plunge for the first time with us. Stalwart swimmers included Binky Walker, Shirley Piggins, Delphine Kelly, Gabriel Cooney, Yvonne Lee-Cooper, Diane Orr and Honóra Ní Chríogáin who appear to have no problem getting into the water. We were delighted to see Susan Hood, Colin Keane and Julie Keane back again with us. Major thanks to Chloe Meehan and Rosanna Cooney for coming along and swimming in much colder conditions than they are used to. Special thanks to Tabby Keane (responsible for the idea of the annual swim back in 2002) for bringing along Nuria O'Donovan, Emma Reardon and Aimee Powderly. Well done and major thanks to all of you.

Once again we are indebted to Colin Ireland for acting as life guard and to our loyal helpers Eric and Lesley Rankin, Giles Baily, Chris Meehan and Philip Meehan. Marie Sheridan, ILFA's Treasurer, a person of many talents, is responsible for taking all the extraordinary action packed photos. Last but not least thanks to the Eagles House for the wonderful wine and mince pies, which were kindly provided afterwards on the house, and for giving us the opportunity to raise our glasses to those who are no longer amongst us like John O'Sullivan, Leslie Knight and Fergus Goodbody.

***We look forward to seeing everyone back again at
Sandycove Pier on St. Stephen's Day, 2008, at 12.30pm.***

As usual all swimmers are invited for the traditional mulled wine and sandwiches courtesy of the Eagles House, Glasthule, afterwards.

COFFE MORNING IN CAVAN

Thank you to the Side Street Cafe, Cootehill, Cavan, for holding a coffee morning in aid of ILFA. A fantastic sum of money was raised!

