



NEW PATRON FOR ILFA

ILFA is delighted to announce that Andrea Corr has agreed to become a patron of ILFA.

Andrea, a musician, songwriter and actor, was the lead singer in The Corrs, with her sisters, Caroline and Sharon and her brother, Jim, before embarking on her solo career in 2007.

Andrea's latest album, Lifelines, in which she sings covers of songs that were important to her when she was younger, was released in May 2011. In 2005 she was awarded an honorary MBE for her contribution to music and to charity.

Andrea has a particular interest in IPF. Her mother, Jean, had the condition, but, unfortunately, died in 1999 while awaiting a lung transplant.

The Corrs tribute album, Home, released in 2005, is dedicated to her memory.

Andrea said "I am delighted to be a patron of ILFA which is obviously a charity very close to my heart."

SPECIALIST LUNG SURGEON TAKES UP POSITION IN MATER

Ms Karen Redmond has recently been appointed as a Consultant in Thoracic Surgery and Lung Transplantation at the Mater Hospital in Dublin.

Ms Redmond completed her medical degree and postgraduate doctorate from University College, Dublin and Cork. Following a Young Investigators Award from the European Association for Cardio-thoracic Surgery, she went on to win the prestigious Society Medal from the Society for Cardiothoracic Surgery in Great Britain and Ireland for her work on the "Role of Human Stem Cells in Tumour Angiogenesis". After completing specialist training in cardio-thoracic surgery from the Royal College of Surgeons Ireland in June 2007, Ms Redmond was awarded a United States Surgical Minimally Invasive Surgery Scholarship and trained in her subspecialty field of thoracic surgery and lung transplantation at Toronto General Hospital, Canada.

In September 2008 she was appointed as a Consultant in Thoracic Surgery and Lung Transplantation at the Royal Brompton and Harefield NHS Foundation Trust, London, with a lecturer position at Imperial College. In March 2009, she successfully established a clinical programme and was the lead for Ex-Vivo Lung Perfusion within the transplant directorate. Ms Redmond is a co-lead principal investigator of a recently awarded NIHR-HTA grant for a UK EVLP trial involving all 5 adult lung transplant centres.

PATIENT INFORMATION DAY

The next ILFA Patient Information day will take place in the **CROWNE PLAZA HOTEL, SANTRY, SWORDS ROAD, DUBLIN, on SATURDAY, 28th April, 2012, from 10.00am to 12.30pm.**

Speakers will include Professor Jim Egan, respiratory consultant and transplant physician; Karen Redmond, cardiothoracic and transplant surgeon; Amanda Casey, social worker and Irene Byrne, physiotherapist.

The meeting will conclude with the usual Question and Answer session. Light refreshments will be provided after the meeting.
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Pat Casey and Joyce O'Hara at the Patient Information day in Limerick

OUR 10TH ANNIVERSARY

ILFA will be ten years in existence this year.

In 2002 the wife and friends of Fergus Goodbody, who died as a result of IPF, got together and decided to form an organisation that would

- Support and provide funding for research into lung fibrosis and associated diseases,
- Further research, training and education in lung fibrosis and related subjects,
- Inform and provide a network for patients, their families and others in relation to lung fibrosis,
- Educate the general public in all matters related to lung fibrosis and associated diseases.

CEREMONY OF HEALING, THANKSGIVING AND COMMEMORATION

As part of our celebration of our 10th anniversary ILFA is holding an interfaith ceremony of Healing, Thanksgiving and Commemoration on Saturday, 12th May, in WHITEFRIAR STREET CHURCH, Aungier Street, Dublin, from 4-5pm. The ceremony will be followed by a tea and coffee reception in the Church Hall. All are welcome to attend: patients, family members, friends, fundraisers, healthcare professionals and all those associated with lung fibrosis. For the Remembrance part of the ceremony, we will have a candle lighting ceremony and the names of lung fibrosis patients who have passed away will be read out from the altar. If you would like your loved one's name included on the Remembrance List, please contact ILFA. **RSVP before 30 April at info@ilfa.ie or by post at ILFA PO Box 10456, Blackrock, Co. Dublin, or call 086 0570310.**

THANK YOU

ILFA wishes to thank the **GOVERNORS OF MERCER'S HOSPITAL FOUNDATION**, who made a donation of €5,000 to ILFA, to fund our series of new information leaflets. The latest leaflet on **Nutrition and Weight Management for Pulmonary Fibrosis** is now available. For copies contact ILFA at info@ilfa.ie or phone Lorna at 086 8715264. **ILFA would also like to thank** - ANGELA COLLINS who organised a concert in Ballydehob, Co. Cork in December and raised €1,000 for ILFA. Angela also organised a car boot sale which raised €300.

SHIRLEY RYAN AND HER FRIENDS who took part in the Cork Mini-Marathon and raised €1,310 for ILFA
CAROLE WALSH, COLETTE MCGOWAN, LOUISE OSBORNE, DAWN ELLIS AND LORCAN CASSIDY for the specially designed ILFA Christmas cards, the sale of which raised over €1,000 for ILFA. We hope to provide you with more specially designed cards next Christmas – there will be more about this in our Autumn Newsletter.



Pam Martin and Dave Mulcahy representing ILFA at the launch of Love Your Lungs Campaign

LOVE YOUR LUNGS WEEK

The Irish Lung Health Alliance is a group of charities, including ILFA, who have joined forces to promote lung health.

Launching the Love Your Lungs Campaign on 13th February, **Dr. Edward McKone**, Consultant Respiratory Physician and president of the Irish Thoracic Society said; "Early diagnosis of lung disease, which can vastly improve outcomes and quality of life for patients, continues to be a challenge due to poor awareness levels. The fact is shortness of breath, cough and wheeze are not normal and, if present, should be checked out by your GP."

Also speaking at the launch, Olympic legend, Dr. Ronnie Delaney, said; "We know only too well how dependent athletes are on good lung function. What's probably less well known is the reverse – the role that sport and physical activity can play in preventing lung disease and in improving quality of life for people with lung conditions. It's therefore very fitting that the Irish Lung Health Alliance and the World Spirometry Day Campaign have chosen this Olympics year to launch their campaign."

The Love Your Lungs Campaign also aims to highlight the fact that lung disease affects people of all ages, all socio-economic backgrounds and many non-smokers as well as smokers.

The Campaign will culminate in a new Love Your Lungs Week that will run from 25th to 29th June 2012 and will incorporate **World Spirometry Day on Wednesday 27th June**, when the charities will be working with medical centres throughout the country to offer free lung function tests. For further information see www.lunghealth.ie

LUNG FIBROSIS AWARENESS DAY

ILFA will be organising the first Lung Fibrosis Awareness Day on Thursday, 28 June, as part of Love Your Lungs Week. If you would like to volunteer to help promote Lung Fibrosis Awareness Day by organising something in your area, or for more information, please contact Lorna at 086 8715264.

DAVE'S STORY

"Days are extended by new lungs" said Jessica, a nurse in the Mater Hospital after my lung transplant in 2011.

My name is Dave Mulcahy and I live in Whitechurch, Co. Cork. In 2008 I was diagnosed with Idiopathic Pulmonary Fibrosis (IPF), a progressive, terminal disease which entailed a scarring of the lungs and by mid-2009 the disease had progressed to the stage where drug treatment was unable to prevent on-going deterioration.

I learned that my best (and only) hope was to get a lung transplant. This is, of course, a major operation and there is a small chance of failure. If I wanted to have it then an appointment would be made with Professor J. Egan in the Mater in Dublin for assessment. After meeting Professor Egan I underwent a process of tests to ensure that I was medically and psychologically capable of having the operation. These tests took place in late 2009 and early 2010 during which period I met with two other patients from the Cork area, Shelley Fennelly and Pat Casey. The three of us went on to start the Cork Support Group which meets on the last Thursday of each month at 11.00am in the Elm Tree pub/restaurant in Glounthane.

Well, the result of the tests was positive and in February 2010 I was put on the transplant list, as was Pat Casey -Shelley was already on it. It was now a case of sit and wait.

After one false alarm I got a call from the Mater in early 2011 and thirty minutes later an ambulance pulled up at my door to whisk me off to the Mater. I said goodbye to my family – my wife, children and grandchildren and we were off. This time the operation went ahead and in the early hours of Tuesday I had a new lung. Two weeks later I was home to my family with a new life to look forward to.

Between then and now I have been improving and getting stronger to the extent that last November I was able to travel to Kansas in the USA to visit my daughter and her family and to be godfather to my youngest grandson. This ceremony took place on Thanksgiving Day which I thought was rather nice. Anyway it was great to be able to travel again.

I have now reached my 65th birthday and so am happily retired.

Pat is still waiting on a lung and Shelley, after a long illness, passed away last autumn.

Please note that this story would not be written if my Lung Donor had not made his organs available. To him and his family I give my profound thanks.



Attendees at a recent meeting of the Cork group

CYCLE FROM CORK TO GALWAY VIA LIMERICK

Pat and Anne Casey, from Cork, are organising a sponsored cycle in aid of ILFA to take place on **14/15th April, 2012**. The cycle, from Cork to Galway, will take place over two days; the first stage from Cork city to Limerick city will take place on Saturday, 14 April, and the second stage from Limerick to Galway on Sunday, 15 April. If you are interested in joining in and would like more information contact Pat or Anne at annecasey@live.ie

If you want to help and give the GIFT OF LIFE then get an Organ Donor Card and fill it in. You can get this from the Irish Kidney Association (IKA) www.ika.ie or from your local GP or Pharmacy.

ORGAN DONOR AWARENESS WEEK

Organ Donor Awareness Week will take place this year from 31 March to 7 April. The week will be launched, with the help of Joe Duffy, in the Mansion House on Monday 26 March.

CORK GROUP

The Cork group still meets at the Elm Tree in Glounthane on the last Thursday of each month and welcomes new members. If you want to join contact Dave at 087 865297 or at dave.mulcahy03@gmail.com or Pat and Anne Casey at annecasey@live.ie. Transport can be arranged if necessary.

KILIMANJARO CLIMB



At the beginning of December 2011 Saileog O'Keeffe, Mairead Diviney, Caroline Rawdon, Sinead O'Carroll and Angela Lyons embarked on the biggest challenge of their lives – to climb Kilimanjaro.

Saileog wrote; "We started out our seven day climb at the Machame gate. We wanted to raise awareness and money for the ILFA charity. The journey was thought provoking and emotional and it brought us to a place of inner peace that made us see the world in a whole new light. The experience was challenging, at times it tested the mind and body, but the whole experience was very rewarding. We had many laughs along our path, together with our guides. Reaching the summit was emotionally uplifting as we struggled climbing through the night.

The soul purpose of the climb was to highlight the need for more research into pulmonary fibrosis, and to give hope and support to sufferers and families with this medical condition."

The girls raised €14,500. ILFA says thank you and well done!



GARRYVOE SWIM

Aine and Colm Power took to the waves in Garryvoe in East Cork on Christmas morning to raise funds for ILFA. Aine said she was delighted with the support they got from ILFA which helped to make their swim "an enjoyable but cold experience." We are very grateful to Aine and Colm for their efforts on behalf of ILFA.

WOMEN'S MINI-MARATHON



Some of the ILFA women's mini-marathon team 2011. **This year ILFA celebrates its 10th year anniversary so let's make 2012 our biggest mini-marathon ever!**

The Flora Women's Mini-Marathon will take place in Dublin on Bank Holiday Monday, 4th June, at 3pm. The closing date for applications is Friday, 20th April, or before then if the maximum number of entries has been reached. So please register early to avoid disappointment. On-line entries can be made at www.florawomensminimarathon.ie. The ILFA team will meet up before the race for photos and after the race for refreshments. Consult the website www.ilfa.ie or call 086 0570310 for more details, nearer to race day.

CORK CITY MARATHON - The Cork City marathon, half marathon and team relay will take place on the same day. For further information about this or to register see www.corkcitymarathon.ie

Please contact ILFA by email info@ilfa.ie or call 086 0570310 if you would like to join our special 2012 mini-marathon team. We can provide you with T-shirts or vests and sponsorship cards.



At the ILFA AGM in October Colette McGowan, Marie McGowan and Ryan McGowan from Dromod Co. Leitrim, presented a cheque for €4,005 to Eddie Cassidy, ILFA Treasurer, and Terence Moran, ILFA Chairman. ILFA is very grateful for their support.

DIRECTIONS TO THE CROWNE PLAZA HOTEL FOR THE PATIENT INFO DAY

To get to the Crowne Plaza from Dublin city centre follow the signs for the Airport/M1. Once you join the dual carriageway at Whitehall proceed towards the airport. From this road take the second exit, signposted Santry/Coolock/Beaumont. At the top of the exit ramp take a left towards Santry. Continue to the T-junction and once there you will see a public park ahead. Take the right-hand turn and proceed past the National Running Stadium. At the next set of traffic lights take a left into Northwood Park and the Crowne Plaza is on your right-hand side.

To get to the Crowne Plaza via the M50 coming from the south or west, take the northbound route towards the airport. Proceed towards exit 4, signposted Ballymun/Naul. Follow signs for Ballymun. At the bottom of the exit ramp you will see a slip road to your left with the Northwood Park entrance directly ahead. The Crowne Plaza is located at the other end of the park on your right-hand side.

Bus routes from Dublin City Centre to Northwood, Santry, include 16A (from O'Connell St.), 27B (from Eden Quay), 33 and 41/41C (from Lower Abbey Street). For further information contact Lorna at 086 8715264.