

Legislation for a new opt-out organ donation consent system

In July 2017, the Minister for Health, Simon Harris T.D. announced that the Government has approved the advancement of the long awaited Human Tissue Bill. This important legislation will pave the way for the introduction of an opt-out system of consent for organ donation.

Minister Harris said "An opt-out system of consent for organ donation and accompanying publicity campaign will raise awareness among individuals and encourage discussion among families of their intentions in relation to organ donation. In this way individuals can increase the chances that their organs might be utilised after their death, and can ensure that those left behind will have the satisfaction of knowing that their wishes were carried through."

ILFA has long campaigned for the introduction of a soft opt-out organ donation system and our patron Feargal Quinn first raised this issue in the Seanad in 2008. Writing for the ILFA special edition magazine, Feargal said "I am now delighted to see that Minister Simon Harris has taken my Bill on board and announced that he is



Professor Jim Egan and Minister for Health Simon Harris T.D. at the opening of the new Organ Donation and Transplant Ireland (ODTI) offices when the Minister announced plans for an opt-out donation system (Photo Courtesy of ODTI).

determined to implement this opt-out system in Ireland by next year. This will hugely increase Ireland's rate of organ donation."

Message from the Chairman

2017 marks the 15th anniversary of the Irish Lung Fibrosis Association and we are very proud to reach this significant milestone. Since 2002, ILFA has endeavoured to help patients and families affected by lung fibrosis by providing information and practical resources, and promoting education and research into Idiopathic Pulmonary Fibrosis (IPF).

To celebrate ILFA's 15th anniversary, we are producing a special edition magazine in the autumn. The magazine will feature articles from patients, family members, fundraisers, and healthcare professionals, and celebrates the advances in IPF care since 2002.

This year ILFA will engage in more outreach activities than ever before to help raise awareness of IPF. The autumn Patient Information Day and the ILFA Service of Prayer and Reflection will take place in October and we look forward to welcoming you to these events.

ILFA is delighted that the Minister for Health, Simon Harris T.D., plans to bring forward legislation on the introduction of an opt-out organ donation system. ILFA will issue a 'Call to Action' in the coming weeks to ask for your help to reach out to your local representatives for their support for this life-saving legislation.

Yours, Terence Moran, ILFA Chairman

Autumn Patient Information Day

The next ILFA Patient Information Day will take place on Saturday 21st October at the Crowne Plaza Hotel, Santry, Dublin. The meeting will start at 10am and finish at approximately 1pm and light refreshments will be served. Our speakers will include Prof. Anthony O'Regan, consultant respiratory physician, Anne-Marie Russell, researcher and respiratory nurse specialist, Irene Byrne, physiotherapist and Ciaran Heatley respiratory physiologist.

Patient Information Days are a great way to learn about pulmonary fibrosis, how to manage your health and wellbeing, and also meet others living with the condition. There is no charge to attend this event and all are welcome. **For more information and to register, please call Gemma on 086 871 5264 or email info@ilfa.ie.**

ILFA Service of Prayer and Reflection

The ILFA Service of Prayer and Reflection will take place on Saturday 14th October at Our Lady of Mount Carmel Church Whitefriar Street, Aungier Street, Dublin 2 at 4pm.

The ecumenical service will be celebrated by the Reverend Fr Brian McKay (Prior of Our Lady of Mount Carmel, Whitefriar Street Church), the Reverend Vanessa Wyse Jackson (Minister at Rathgar Methodist Church), and the Reverend Canon Charles Mullen (Dean's Vicar at St Patrick's Cathedral).

A special candle lighting ceremony will take place to remember lung fibrosis patients who have passed away.

If you would like your loved one remembered at the ceremony, please contact ILFA by calling 086 871 5264 or emailing info@ilfa.ie by the 18th September 2017.

Patient Information Day, April 2017

The first ILFA Patient Information Day of 2017 took place in Sligo at the Clayton Hotel on the 22nd April. This was our first time to hold an information day in the North West of Ireland and we advertised in 10 local newspapers and liaised with the local hospitals in the surrounding counties to let everyone know of the event. Terence Moran, ILFA Chairman, welcomed everyone to the meeting and got proceedings underway.

Dr Emmet McGrath, Respiratory Consultant at St Vincent's University Hospital in Dublin, gave an overview of Idiopathic Pulmonary Fibrosis (IPF). The word 'idiopathic' means 'unknown' and despite years of research, the exact cause of IPF remains unknown. What is known is that some trigger causes a cascade of events at a cellular level and the lung tissue becomes progressively more stiff due to scarring.

IPF is more commonly diagnosed in men and usually in people aged in their mid-to-late sixties. Unfortunately the diagnosis is often delayed as people think their symptoms are related to the normal aging process, however it is not normal to be short of breath or have a chronic cough. The symptoms of IPF include shortness of breath, a dry cough that is difficult to control, fatigue (extreme tiredness), finger clubbing (the fingertips and nail beds become enlarged and rounded) and generally feeling unwell. When a doctor listens to the lungs with a stethoscope, distinctive crackle sounds can be heard. This sound is often called 'velcro crackles' as it resembles the noise of velcro strips being pulled apart. However, not all patients have the classical signs and symptoms of the disease and the presence of other conditions (for example, heart disease or other co-existing respiratory diseases) can make the diagnosis of lung fibrosis more challenging.

It is important for a doctor to take a detailed history from the patient to gather as much information as possible about potential risk factors. You will be asked about your age, if you ever smoked, your medication, family history of lung illnesses, your occupation, hobbies and previous exposure to chemicals and environmental pollution. A high resolution CT scan that provides detailed images of the lungs will be used to investigate the lung architecture in order to help reach a diagnosis. Radiologists (doctors who specialise in



Michael Cox, Lynn Fox and Evelyn Cooper at the ILFA Information Day in Sligo in April 2017.

reading x-rays and scans) look for changes called 'honeycombing' - these structural changes look similar to the inside of a 'Crunchie' bar. It is important to get an early and accurate diagnosis (ideally in a specialist centre) in order to be started on appropriate treatment. There are two drug treatment options; Pirfenidone and Nintedanib, that can slow down the disease progression; however they do not cure the disease or reverse the damage that has already occurred. The two medicines work in different ways. Some patients will experience side effects when taking the medicine and their treatment may have to be stopped for a short time or changed, depending on how serious the adverse effects are.

Dr McGrath spoke about the importance of regular exercise, having regular check-ups, bone scans and vaccines. He stressed the importance of stopping smoking and keeping your medical team informed of any weight loss, decrease in appetite or medication side effects.

Tara Hannon, physiotherapist at University College Hospital Galway, started by asking a question - "Why do we exercise?". The audience responded with several answers including "to keep fit ... for good physical and mental health ... to feel good ... to maintain muscle mass ... to help quality of life." All of the replies were correct and relevant. The importance of physical activity for lung fibrosis patients cannot be stressed enough. Tara explained that everyone's exercise baseline level is different so you should not compare yourself to others. It is important to know your own exercise baseline level and to work to keep it as high as possible. Regular exercise will help improve your exercise capacity. The better your fitness level is, the better your endurance.

It is important to find an activity that suits you for example, walking, using an exercise bicycle or a set of exercise pedals. You do not need fancy gym equipment to exercise - you can use the first step of the stairs to step up and down and work your leg muscles. It's always worth asking a relative or friend if they have an exercise bike that they no longer use - there are lots of these around the country!

Tara gave some tips for introducing exercise into your daily routine;

- ▶ Start exercising slowly and progress by gradually increasing the time you exercise. Begin your walking programme by going out, walk for 5 minutes and then return home. See how you feel and next time try to increase the length of time you exercise.
- ▶ Pay attention to how you feel when exercising. It's normal to



Speakers at the Information Day: Back row - Terence Moran (ILFA Chairman), Dr Emmet McGrath. Front row - Noreen O'Carroll, Lynn Fox, Tara Hannon, Vivienne Vize and Zita Lawlor.

experience shortness of breath when taking part in physical activity so don't let a fear of breathlessness stop you from exercising. For exercise to be effective, you should expect to be moderately out of breath.

- ▶ Don't make excuses! You should prioritise exercise - it is just as important as your medication.

Tara explained that patients with IPF often have thin arms and legs as a result of loss of muscle mass, which in turn impacts on your breathing, and ability to mobilise and maintain independence. Muscle loss can develop due to inactivity, poor diet, ageing, and steroid use. Therefore it is important to introduce resistance exercises to build and strengthen your muscles. For example, using dumb-bell weights (or a tin of peas or a 500ml bottle of water) use slow movements and do bicep curls. Start off with a small number of movements and gradually increase the number of repetitions you do. The movements must be slow in order to be effective.

ILFA can provide you with useful exercise resources including the 2000 Steps a Day walking pack and the ILFA Exercise DVD to help your exercise routine.

Call 086 871 5264 or email info@ilfa.ie

Lynn Fox, respiratory nurse specialist at the Mater Misericordiae University Hospital, spoke about some of the challenges faced by patients and the treatments and solutions that may help.

Breathlessness can be a major problem for patients and can lead to low blood oxygen levels which in turn result in fatigue, low energy levels, and poor concentration and decision making. Supplemental oxygen can help reduce shortness of breath and will also improve your quality of life and ability to do your activities of daily living such as bathing, dressing and exercising. You should tell your healthcare team if your breathlessness is getting worse as your oxygen prescription may need to be reviewed.

It's a good idea to plan your activities in advance to ensure your energy levels are the best they can be. Don't be afraid to ask your family and friends for help when necessary. Rest and sleep are very important to maintain energy levels and a short power nap for 20 minutes may help to revive you. Ensure you eat well and drink plenty of water to keep hydrated.

Anxiety and depression are common in IPF patients but may be

under-diagnosed and under-treated. It is a good idea to monitor your mood level and to speak to your healthcare team if you are concerned. Depression and anxiety can influence your mood, worsen your physical symptoms and lead to social withdrawal, but help is available. Lynn spoke about the benefits of attending a local support group and also how professional counselling can help improve your quality of life.

Palliative care is a medical specialty that can help improve your quality of life and symptoms. Palliative care is often wrongly associated with caring only for cancer patients at the 'end of life'. In fact, palliative care can be useful at any time for IPF patients and can help improve your symptoms, well being and quality of life as IPF progresses.

Lynn also discussed the medicines, Pirfenidone and Nintedanib, which can help slow down the rate of progression of IPF. Both medications have side effects and it is important to work with your healthcare team if you experience side effects so these can be managed effectively. Lynn finished by announcing the launch of ILFA's newest information leaflet entitled "Managing breathlessness - Advice for lung fibrosis patients". We hope you will find the leaflet useful.

Zita Lawlor, transplant co-ordinator at the National Lung Transplant Centre at the Mater Misericordiae University Hospital in Dublin gave an update on lung transplantation. Zita and her colleague Vivienne Vize, who also attended the event, are two out of a team of four transplant co-ordinators based at the Mater Hospital and who provide 24-hour cover.

The first lung transplant in Ireland took place in 2005 and since then 194 lung transplants have been completed (up to April 2017). Zita explained the referral pathway whereby a respiratory specialist will write to the team at the Mater Hospital recommending a patient for assessment. Early referral is important and those who may be suitable candidates will have to undergo a series of thorough tests and investigations to ensure they have no other serious health conditions (apart from their lung disease) which could impact on their suitability for a transplant. The results of blood tests, lung function tests, x-rays, scans, general examinations, and the social support available to the patient are all taken into consideration by the multi-disciplinary transplant team. Lung

transplantation is a major surgical procedure and the risks and benefits for each patient need to be carefully managed. In 2012, 40 patients were assessed for lung transplant and this figure jumped to 104 cases in 2016. In 2016, 56% of lung transplants were in IPF patients.

If you are considered to be a suitable candidate for a lung transplant, you will be added to the active transplant list. You will receive a weekly call from the transplant coordinator who will check in with you regarding your health and any concerns you may have. The transplant coordinators will also call you and arrange transport to the hospital if an offer of a potential lung donation is received. If the surgery goes ahead, the patient and their family members are asked not to disclose the date of their lung transplant online and on social media to protect the identity of the organ donor and their family. Following a lung transplant, the patient will need ongoing after-care and support, and frequent hospital visits.

The final speaker was **Noreen O'Carroll** from Limerick. Noreen was diagnosed with IPF in 2016 and she described how she managed to take control back after her initial shock and upset. Noreen spoke about her positive experience of seeking counselling to come to terms with her diagnosis. Six free counselling sessions are available from the HSE and you should ask your GP or healthcare team for a referral. Noreen advised the audience to be informed about IPF and she recommended the ILFA website, www.ilfa.ie, as a reliable and balanced source of educational and practical information. Noreen also spoke about the benefits of seeking support and speaking to others affected by lung fibrosis. Noreen set up the Mid-West Support Group in 2016. Noreen described how she took part in a mini-marathon for ILFA with her family and friends, and also shared her hopes for the future including her plans to travel to Indonesia to visit her daughter and build a poly-tunnel! Everyone appreciated Noreen's positive insights and she received a rapturous round of applause after a very powerful and inspirational presentation.

After the talks from the invited speakers, there was a lively questions and answers session with the good audience participation. Some of the discussions that took place concerned diagnosis, the 6-Minute Walk test, lung transplantation and screening for familial lung fibrosis.

Terence Moran concluded the meeting by thanking the audience, speakers, the oxygen companies Air Liquide Ireland and BOC Healthcare Ireland for hosting information stands, and Roche Products Ireland for supporting the meeting. Refreshments



Pictured are Stephanie Cahill and Rory O'Connor (Air Liquide Healthcare) and Joyce O'Hara (BOC Healthcare) who had information stands at the event.

were served after the meeting and the attendees had a chance to socialise.

The presentations from Tara Hannon, Lynn Fox and Noreen O'Carroll are available to watch on www.ilfa.ie and YouTube. We are very grateful to Tara, Lynn and Noreen for permission to video and share their presentations online.

What you thought ...

ILFA asked the attendees to fill out a short questionnaire to evaluate the Patient Information Day and give valuable feedback.

- ▶ 70.6% said the event was excellent while 29.4% said it was very good.
- ▶ 70.6% felt the programme definitely met their information needs and 17.7% said their information needs were probably met.
- ▶ All the speakers scored very highly in the evaluation.
- ▶ 70.6% indicated that they would definitely attend another ILFA Information Day and 29.5% said they would probably attend again.
- ▶ 88.3% said they would definitely recommend the ILFA Patient Information Day to another patient.

Additional comments received included;

"Thank you. Excellent speakers, very informative."

"Noreen was absolutely brilliant."

Approval of Nintedanib for the treatment of IPF

The ILFA committee was delighted to receive news that the anti-fibrotic medicine, Nintedanib (also called Ovef) was approved for reimbursement by the HSE for patients diagnosed with Idiopathic Pulmonary Fibrosis, from 1st June 2017.

Nintedanib is recommended for IPF patients whose forced vital capacity (the amount of air which can be forcibly exhaled from the lungs after taking the deepest breath possible) is between 50% and 80%. Nintedanib helps to slow down the progression of IPF, as it reduces lung function decline and improves quality of life for patients.

Professor Jim Egan, Respiratory Consultant from the Mater Misericordiae University Hospital said "This news is a very welcome development that will improve the treatment options for patients with this difficult condition".

Adding to this, Nicola Cassidy, ILFA Director, said "ILFA is

delighted that Nintedanib will be available to IPF patients. ILFA would like to thank the National Centre for Pharmacoeconomics, the HSE and Boehringer Ingelheim for working together to ensure this vital medicine can now be prescribed for patients diagnosed with IPF. This news will be warmly welcomed by the IPF community and healthcare staff working in respiratory medicine, and will give hope to patients and families living with IPF."

This welcome news means that IPF patients in Ireland now have two anti-fibrotic medicines that can be prescribed to slow down disease progression, Pirfenidone and Nintedanib. These medicines work in different ways and have a number of side effects. Your doctor will explain the pros and cons of each medicine with you when deciding on the best treatment option to suit your lifestyle and health concerns.

Outreach and Awareness Activities

Organ Donor Awareness Week 2017



Professor Jim Egan (Director of ODTI), Vivienne Traynor (ambassador of Organ Donor Awareness Week), Paddy O'Mahony and David Crosby (photo courtesy of IKA).



Pictured are Paddy O'Mahony (lung transplant recipient), Professor David Healy (cardiothoracic transplant surgeon at the Mater Misericordiae University Hospital, Dublin) and David Crosby (lung transplant recipient).

Gemma O'Dowd and Nicola Cassidy from ILFA attended the launch of Organ Donor Awareness Week, hosted by the Irish Kidney Association (IKA), on Tuesday 28th March. The launch took place at the Mansion House in Dublin and there was a great attendance of people from all over Ireland.

Vivienne Traynor of RTE News is the IKA Ambassador for Organ Donor Awareness Week and she introduced the guest speakers who shared their inspiring stories of receiving heart, lung, liver and kidney transplants, and the difference organ donation has made to their lives and the lives of their families and friends.

David Crosby, a lung fibrosis patient from Kingscourt, Co Cavan who received a double lung transplant in 2016, shared his remarkable story. David thanked the staff of the Mater Misericordiae University Hospital for the great care he received, his family for their support, and his donor and their family who so generously gave permission for organ donation to take place, giving David the gift of new life. To honour his donor and support lung transplantation research, David and a group of family and friends and Professor David Healy will take part in the New York City Marathon in November.

The Minister for Health, Simon Harris T.D., also spoke at the event and gave a firm commitment to develop legislation to provide for an opt-out system of consent for organ donation. Professor Jim Egan from Organ Donation and Transplantation Ireland praised the skilled staff working in the transplant units at Beaumont Hospital, St Vincent's University Hospital, and the Mater Misericordiae University Hospital. He also thanked the families that make brave decisions to allow organ donation to take place. Their kindness and generosity bestows the precious gift of life to those in desperate need of life saving operations.

ILFA encourages everyone to discuss their wishes for organ donation with their families and next of kin.

The Active Retirement Show

The Active Retirement Trade and Tourism Show took place on Tuesday 23 May 2017 at the RDS in Dublin and ILFA was represented at the event by Lindsay Brown and Gemma O'Dowd. 140 companies and health organisations exhibited at the event, including ILFA, Cystic Fibrosis Ireland, Concern Worldwide, Osteoporosis Ireland, The Rutland Centre and the Alzheimer Society of Ireland.

Gemma and Lindsay met attendees from all over the country and distributed information leaflets and ILFA newsletters to those who visited the ILFA exhibition stand. It was a great opportunity to help raise awareness of idiopathic pulmonary fibrosis (IPF) and ILFA's work.

Lindsay, a respiratory nurse specialist at St Vincent's University Hospital, spoke during a panel discussion on health issues and explained what IPF is and how ILFA supports patients and families affected by the condition. Lindsay did a great job and many people approached the ILFA stand afterwards to learn more.

Anail Conference

ILFA hosted an information stand at the annual Anail respiratory nurses conference in Athlone on 10th March. It was a busy day and many delegates dropped by to request our free information leaflets and exercise resources for patients with lung fibrosis.



Gemma O'Dowd from ILFA with Patricia Davis, Clinical Nurse Specialist - Respiratory Integrated Care.

An update from patientMpower



As some of you may know, with your help we at patientMpower have developed an electronic

health diary (an “app”) which can be used by people with lung fibrosis to help them keep track of their symptoms and lung health.

The patientMpower app works on any smartphone or tablet device (like an iPad). The idea is that you use your mobile phone to keep a diary of various symptoms and other factors related to your lung health. For example, you can keep track of the number of steps walked each day or your level of breathlessness. If you have a connected spirometer, the breathing test information will also be recorded and the app can be used as a reminder to take your medicines each day. When attending clinic appointments, it may be useful to have this type of information to hand so you can tell the doctor or nurse about issues that may have been troubling you.

Since we last wrote, a group of ILFA volunteers have tested the app with home spirometry in a user experience survey and given us useful feedback on their experience of the app. patientMpower want to thank these volunteers for their help in guiding us on how we can improve the app and its use with measurement devices (like home spirometers). We are now analysing this information and will use this to improve the design of the app. This analysis will be completed by the end of the summer and we will share this information with you and may also publish a summary at medical conferences and present it at the ILFA patient information day on October 21st.

We are also working with other patient groups (for example, the PF Warriors in Texas) and asking them for feedback to get a variety of views on how we can improve the app and associated measurement devices (like spirometers).

If you would like to learn more about the patientMpower electronic health journal for lung fibrosis, our research work and future developments, please feel free to contact patientMpower at 01 903 8558, e-mail info@patientmpower.com, follow us on facebook www.facebook.com/patientmpower, or visit www.patientmpower.com/ipf

Once again, thanks to the early ILFA pioneers who tested the patientMpower app and gave us feedback.

Report by Colin Edwards, patientMpower

International Experience Exchange of Patient Organisations

The International Experience Exchange of Patient Organisations conference took place in Madrid in March 2017. Liam Galvin, ILFA Director and Secretary of the European IPF Federation (EU-IPFF) attended the event along with 350 attendees from 300 patient organisations across 56 countries. The speakers highlighted their work, experiences, advocacy skills, and shared best practice.

Liam gave two presentations on behalf of ILFA and the EU-IPFF and used examples of patient and ILFA experiences in Ireland in his presentations and during the panel debates afterwards. IPF groups from Australia, Bulgaria, Colombia, Croatia, Georgia, Israel, Peru, Poland and Switzerland were very interested in the work of ILFA and the EU-IPFF. It is expected that one outcome from this meeting will be the expansion of the EU-IPFF with new countries joining to campaign for IPF patients’ rights.

ILFA’s lobbying and advocacy activities

- 1) On 17th May 2017, ILFA delegates, Gemma O’Dowd, Liam Galvin and Nicola Cassidy met with Finian McGrath, T.D., Minister of State, with special responsibility for Disabilities. ILFA was pleased to have the opportunity to discuss;
 - ◆ the financial and practical challenges experienced by patients dependent on oxygen
 - ◆ our concerns about unopened beds, staffing levels and resource issues at the National Heart and Lung Transplant Unit at the Mater Hospital, Dublin
 - ◆ and the need to advance the introduction of a soft-opt out organ donation system to increase the number of life saving transplants that can take place.
- 2) Gemma O’Dowd and Nicola Cassidy met Simon Harris, T.D., Minister for Health informally at the opening of the Organ Donation and Transplantation Office. ILFA subsequently wrote to the Minister for Health to request a meeting to discuss the introduction of soft opt-out legislation to increase the number of potential organ donors in Ireland.
- 3) ILFA has written to all the elected TDs to seek their support for the introduction of a soft opt-out organ donation system.



Delegates attending the EU-IPFF meeting in Brussels.

EU-IPFF annual meeting

The European IPF Federation (EU-IPFF) held its 2nd annual meeting in Brussels on 1st July. Nicola Cassidy and Gemma O’Dowd represented ILFA along with Liam Galvin who is also Secretary of the EU-IPFF. Representatives from 14 countries attended the meeting; Spain, Italy, Poland, Great Britain, Bulgaria, Croatia, Greece, Belgium, Germany, Austria, France, Canada, Brazil and Ireland. The meeting was a great success and delegates shared ideas for IPF World Week which will take place from 16th-24th September 2017. The theme for the 2017 campaign is ‘Listen for the sounds of IPF’ and hopes to raise awareness of the signs and symptoms of IPF to encourage early diagnosis and referral to an IPF expert centre.

ODTI Annual Report 2016

On 8th May, Gemma O'Dowd and Nicola Cassidy represented ILFA at the grand opening of the Organ Donation and Transplantation Ireland (ODTI) office at St George's Church, Temple Street in Dublin city centre. Professor Jim Egan, Director of ODTI, welcomed all those in attendance and paid tribute to his colleagues in ODTI for embracing change as they moved from their office in Parnell Street to their new, historic and iconic headquarters.

The beautiful St George's Church on Temple Street was designed by Francis Johnston, who also designed Dublin's General Post Office, and is the location where the famous Duke of Wellington married in 1806. The new location for the ODTI office is ideally situated to serve the three national transplant centres at Beaumont Hospital, the Mater Misericordiae University Hospital and St Vincent's University Hospital in Dublin.

The Minister for Health, Simon Harris T.D., officially opened the new ODTI office and launched the 2016 ODTI Annual Report. In 2016, 77 organ donors saved the lives of 230 people by giving them the precious gift of life. 35 lung transplants, 15 heart transplants, 58 liver transplants and 122 kidney transplants took place, as well as 50 living donor kidney transplants. Minister Harris paid tribute to the organ donors and their families, healthcare staff, ODTI staff and the patient organisations committed to promoting organ donation and transplantation. Minister Harris once again stated his commitment to bring organ donation legislation to the government and to hold a public consultation on soft opt-out organ donation.

Gemma O'Dowd and Nicola Cassidy met the Minister and congratulated him on his commitment to bring legislation on transplantation before the government.

Transplantation Facts

- Approximately 700 people are currently awaiting life-saving organ transplants in Ireland.
- Ireland's deceased organ donation rate is approximately 22 per million population.
- Statistically, you are more likely to need a life-saving organ transplant than to die in circumstances that would allow you to be considered a potential organ donor.
- Over one third of families refuse to give consent to the donation of their loved one's organs when faced with this choice. A common reason for refusing to give consent is that the potential donor's family were not aware of their loved one's wishes.
- The current system (opt-in) is not doing enough to match the high degree of public support for organ donation with actual donations of organs.
- The National Lung Transplant Programme at the Mater Hospital celebrated 10 years of lung transplantation in 2015. This programme has had remarkable successes since it started in May 2005 and it is currently the third largest lung transplant programme in Europe.
- A patient's age is not an automatic reason for exclusion from having a lung transplant in Ireland. A person's overall general health and respiratory status are more important than their numerical age but sometimes other medical problems can determine their suitability for a lung transplant operation.



Minister for Health Simon Harris with Professor Jim Egan, Director of ODTI



(Left to Right): Lynn Martin, Fiadhna McMonagle, Orla Nolan (National Organ Donor Coordinators), Minister Simon Harris, Nessa Lynch Chief Operating Officer, Caroline Lynch National Organ Donor Coordinator, Prof Jim Egan Director ODTI, Kathleen Tyrrell Senior Administrator. (photos courtesy of ODTI)

Context and Terminology

- **Opt-out:** The person is presumed to have consented to donate his or her organs after death, unless he or she has specified otherwise.
- **Opt-in:** The person can decide in advance to consent to donate his or her organs or to nominate someone to make the decision on his/her behalf after death. Where the deceased has not made a decision, his or her family may do so if asked.
- **'Hard' and 'Soft' Presumed Consent:** The terms 'hard' and 'soft' indicates how much weight is placed on the views of Next of Kin (NOK) when a person is being considered as a potential organ donor in circumstances where they are unlikely to survive. 'Hard' means that there is no consideration of NOK agreement to organ donation and organ donation will proceed irrespective of the NOK views. There are very few countries that operate a 'hard' opt out approach. 'Soft' means that significant consideration of NOK views is taken into account and organ donation will only proceed if the NOK consents.

The Irish Donor Network (a group of patient organisations campaigning for organ donation consisting of Alpha-1 Ireland, Cystic Fibrosis Ireland, Cystinosis Ireland, the Irish Heart & Lung Transplant Association, Pulmonary Hypertension Association of Ireland and ILFA) believe Ireland could improve on our present performance on organ donation, and the change to soft opt-out, as part of a package of measures, could make a real difference.

VHI Women's Mini-Marathon 2017

On Monday 5th June 2017, over 33,000 ladies took to the streets of Dublin for the city's 35th Women's Mini-Marathon. Mini-marathon day is always great fun and there is a real sense of camaraderie, excitement and anticipation in the air as the ladies gather before the start of the race. And race day 2017 was no exception! Dublin's city centre was filled with ladies from every part of the country all chatting excitedly about the weather forecast, their reasons for taking part, their expectations and even their race strategy.

This year, over 70 ladies fundraised for ILFA, making this one of our largest women's mini-marathon groups ever, with ladies taking part to support loved ones and friends living with lung fibrosis, and to remember those who have passed away. As usual before the race, we met at the Mespil Hotel for a group photo. Approximately 40 ladies and their supporters came along to join Team ILFA for our group photo shoot. The ladies were welcomed by ILFA committee members, Eddie Cassidy, Nicola Cassidy, Nicky Goodbody and Gemma O'Dowd.

This year the Borris in Ossary Walking Club chose ILFA as their charity for 2017 and we were thrilled to have their support. The ladies travelled together to Dublin by bus and made their way to the Mespil Hotel en masse. They arrived in a whirlwind of excitement and never stopped laughing from the time they arrived. Their laughter, enthusiasm and sense of fun was infectious and uplifting. The ladies of the group included Charlie Origan (doing her first marathon in memory of her grandmother Margaret Maloney), Laura Mulhall, Brid Sinnott, Fiona Phelan, Roisin Kelly (in memory of her mother Rose Fahy), Karen Power, Triona Meade, Claire Meade, Avril Bergin, Geraldine Hough, Kay Dowling, Grace Fitzpatrick, Geraldine Corby, Sharon Delaney, Elaine Gleeson, Mary Doheny, Siobhan Doheny and Denise Origan (in memory of her mother Margaret Maloney).

This year there were lots of familiar faces who once again signed up to support ILFA. Good friends, Rosemary Wilson, Rita O'Regan and Margaret Ivers have supported ILFA numerous times and are dedicated mini-marathoners. Rita said that the mini-marathon "was a highlight of the year" for the trio. Ann Kennedy and her daughters Deirdre and Marianne took part once again in support of Michael Kennedy. Sinead Carroll, Coleen Berry and Laura McEvoy travelled from Tullamore in support of family members. Friends, Susie Harrison and Nicky Goodbody took part once again for ILFA in memory of their loved ones; Patricia Harrison, Fergus Goodbody and Tom Figgis.

It was wonderful to welcome back Edna Powell for her second mini-marathon for ILFA after her lung transplant in 2015. Edna was accompanied by her good friends Sue Kenny and Liz Bourke and afterwards told us that she "really enjoyed the day".

Other participants included Hazel Leonard, Jacqueline Moynagh, Laura Hempenstall and Kim Hanneffy. Marie Hackett and her daughter Sorcha were cheered on by their husband and father Anthony Hackett. The Healy family was represented by Lynn Healy,



Clockwise from top: Marie Hackett with her daughter Sorcha and husband Anthony; Leona Wogan; and Team ILFA 2017.

Ciara Healy, Helen Forster, Frances Healy, and Geraldine Forster who took part in memory of Martin Healy. The Mahon family took part in memory of Christy Mahon and was represented by Fiona Lawless, Carol Mahon, Clare Mahon, Rita O'Connell, Denise Mahon and Jennifer Dunne. Carol was in touch to say "We are all so proud of ourselves and feel even better knowing we might have raised even the slightest bit of awareness for ILFA!"

Siobhan Flynn took part in her first mini-marathon with her friend Janice Brazil in memory of Siobhan's father, Michael Dempsey. Leona Wogan from Kentstown, Co Meath took part in memory of her father in Law, Desmond McEneaney and contacted us to say "What a great day!"

It was a family affair for Annette Grehan and her sister Martina Osborne who took part with their daughters Caroline Grehan and Kathleen Osborne, and niece Nicola Cassidy. The group who took part in memory of their sister, aunt, and mother, Denise Cassidy who had run the women's mini-marathon countless times before being diagnosed with IPF and also took part in her wheelchair in 2006 to raise funds for ILFA. Annette took part in the first Women's



Clockwise (from top left): Family members ; Nicola Cassidy, Caroline and Annette Grehan and Martina and Kathleen Osborne; The Borris in Ossary ladies walking group; Sue Kenny, Edna Powell and Liz Bourke; Siobhan Fynn and Janice Brazil; The Mahon Family; The Healy Family; Sinead Carroll, Coleen Berry and Laura McEvoy; and Deirdre, Ann and Marianne Kennedy.

mini-marathon 35 years ago and recalled that she ran wearing her tennis shoes, badminton skirt and gym knickers as there was no Lycra then! It was Caroline's first mini-marathon and afterwards she said "It was great fun - the first of many to come!"

After some photos with our photographer David Kennedy, we headed to Fitzwilliam Square and waited for the claxon to sound the start of the race. There was a real party atmosphere while we counted down the minutes and sang along to iconic music tunes that were played by DJs - "Sisters are doing it for themselves" was a real favourite with the crowd. At 2pm we were off! This year the course route was reversed and it was a nice and pleasant change. While everyone thought it might be easier, there were still some sneaky inclines to challenge us!

The bands along the route were in great spirits and entertained and encouraged everyone with their energetic tunes. Another classic springs to mind - "Show me the way to Amarillo" certainly gave some a very welcome energy boost. Ladies were running along, singing, and punching the air to the sound of the music. The volunteers and spectators along the route also deserve special

praise for their support and words of encouragement ... "One more lap to go!" was shouted quite a few times and was always met with a laugh and a groan.

The weather was great to start with, with a nice cool temperature and a gentle breeze. Unfortunately when the rain started, it didn't stop! Thankfully the downpour didn't dampen our spirits. It was great to see the finish line so close after reaching the top of the sneaky hill at Leeson Street. At that point many women sprinted the final 200 metres to reach the end, which no doubt helped many to achieve a personal best time.

After the race, Team ILFA gathered at The Duke Pub and were welcomed by Eddie Cassidy and Gemma O'Dowd from ILFA. We were well looked after by our hosts Dom and Geraldine who served the best tea and sandwiches in Dublin! It was great to catch up with everyone and share stories of our mini-marathon successes and our plans to return again next year.

Well done to all the ladies of Team ILFA. You should be very proud of yourselves - you are AMAZING !!!! Thank you for your support.

Fundraising Round Up

ILFA relies on donations and the fundraising activities of our supporters, and you have kept us going year after year since 2002. We are hugely grateful to everyone who fundraises for ILFA and we really appreciate your hard work, dedication, enthusiasm and goodwill for our charity.

Hell and Back Challenge



Thanks to Laura Carroll from Tullamore and her family and friends for taking on the infamous 'Hell and Back' Challenge in aid of ILFA. The team had a great day. Here are the before and after photos;

Before: Back row: Eoghan Ryan, Alan Ryan, Cathy Ryan, Julianna Paz, Laura Carroll, Jennifer Wheatley, Andrew Carroll, Jacinta Carroll.

Front row: Padraic Byrne, Ciarán Dickinson, Ian Carroll, Robert Wheatley, Rodrigo Paz.

After: Andrew Carroll, Ciarán Dickinson, Padraic Byrne, Laura Carroll, Jacinta Carroll, Julianna Paz, Rodrigo Paz and Ian Carroll. Thanks also to Stephen Donohoe, Paul O'Neil and Dan O'Neil who also took part.



Donation from the Nestor Family



Sincere thanks to Bridie Nestor and her family and friends in Co Clare for fundraising for ILFA in memory of her husband Cormac.

Bridie and her daughter Clare Gallagher met with Martin Troy of ILFA in April to present him with

the proceeds of their fundraising efforts. Thanks to everyone who donated so generously.

Darts Tournament in Borris in Ossary



The Borris in Ossary Women's Walking Group's chosen charity for 2017 is ILFA. Each year a charity is chosen that is personal to a group member. ILFA was chosen in memory of the late Margaret Maloney and Rose Fahy, mothers of Denise Origan and Roisin Kelly.

On Saturday 29th April, the Borris In Ossary Women's Walking Group held their first ever darts tournament. It was an open tournament meaning anyone could throw. We paired a non-

player with a player to even the odds. It was €10 to register. We had a huge turnout of 32 throwers who came to make our first darts tournament a great success. It was a great day full of great banter, craic and fun with some non-darts throwers throwing superb darts. Pictured are Owen Maloney and Kay Dowling.

Our sincere thanks to Kelly's Bar, Billy and Triona for sponsoring the Slieve Bloom marquees. Thank you, to Fiona in Sals Diner for sponsoring hot food, to the walkers for supplying the sambos, to Owen, Mark and Marcella Maloney for their help setting up and running the darts tournament and to all who turned up on the day. A massive thank you to all our sponsors of the dartboards and frames, adverts and raffle prizes, and to all who bought raffle tickets. Our heartfelt and sincere thanks to all. A super, super day raising funds for the Irish Lung Fibrosis Association.

Report by Denise Origan

Cake sale and car wash in Carlow



Huge thanks to the students of YOUTHREACH CARLOW for holding a cake sale and car wash in aid of ILFA on Thursday 1st June. The students did a fantastic job and raised €110 that was added to Martina Osborne's mini-marathon sponsorship card.

Martina is the Youthreach Co-ordinator and she was delighted to have the students support.

The Lord Mayor of Carlow, Fintan Phelan, dropped by to say hello, have a cuppa and learn more about the student's fundraising efforts. Well done and thank you to everyone involved!

The photo shows PJ Ryan, Ryan Preston, Martina Osborne, the Lord Mayor of Carlow, Fintan Phelan, and Mati Kutt. Other students who helped out were Aisling Mannion, Oisín Corcoran and Jamie Moran.

ILFA supporters do the Camino Trek



Ann and Fiona Kennedy

Congratulations to Ann Kennedy and her daughter Fiona who walked the Camino Way to Santiago del Compostela in Spain, in aid of ILFA. Sincere thanks to Ann and Fiona for taking on the challenge and wearing their ILFA t-shirts to help raise awareness. A few days after their return, Ann also took part in the VHI Women's Mini-marathon with her other daughters Marianne and Deirdre to fundraise for ILFA.

Here's a report from Fiona:

"Normally the 10k mini marathon in June is enough of a challenge for us but this year we decided to bring our ILFA support to Northern Spain where we did the last leg of the Camino

de Frances, 80km over 3 days walking. Despite the heat and some unforgiving hills we managed it with no problems. The route was amazing with plenty of beautiful cafes and restaurants along the way ensuring we never got too dehydrated! We met many other pilgrims along the way and finished Day 3 with the pilgrim mass in the impressive Cathedral of Santiago de Compostela.

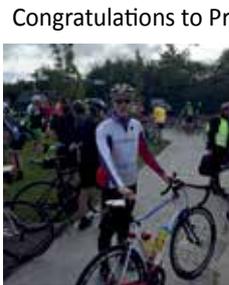
We arrived back into Dublin the day before the mini marathon and Ann finished off her week of walking in style by completing the 10k mini marathon with her other daughters, Marianne and Deirdre."

Cake Sale



Well done and thank you to Alanah Cantwell (10 years old) and her friends Lana Burke and Isobel Fitzgerald who held a cake sale to fundraise for ILFA and the Irish Cancer Society in memory of Alanah's grandfather, Frank Tierney. The friends raised €38 for each charity and we're very touched by their fantastic fundraising efforts. **The photo shows Lana, Alanah and Isobel.**

Wicklow 100 cycle



Congratulations to Professor Jim Egan from the Mater Misericordiae University Hospital who completed the Wicklow 100 km cycle on 11th June in aid of ILFA. Professor Egan sent a personal message of thanks to all those who sponsored him. "Thanks to everyone for their support and generous sponsorship for my Wicklow 100 cycle in aid of the Irish Lung Fibrosis Association."

Giving in remembrance

Sincere thanks to all the families who requested donations to ILFA in lieu of flowers at the funerals of their loved ones. We are very grateful for your support and kindness to ILFA at a time of great personal loss.

Mick O'Keeffe Memorial Golf Day

Saileog O'Keeffe from Celbridge organised a hugely successful charity golf day for ILFA in memory of her father, Mick O'Keeffe. The event took place on Saturday 25th March at Liffey Valley Golf Course in Dublin and was very well supported with golfers travelling from all over Ireland to take part and support Saileog's fundraising event. It was a glorious sunny and warm day and everyone who took part really enjoyed themselves. Huge thanks to Saileog and her family, the organisers, volunteers and supporters, and to all the participants who helped raise over €6000 for ILFA. Saileog is pictured with her uncle Con and her mother Cait.



Wedding favours

Huge thanks to the happy couples who make donations to ILFA in lieu of wedding favours for their wedding day celebrations. We are very grateful for your support and for helping raise awareness among your wedding guests. We wish you every happiness for the future.

Special thanks to Collette McGowan and Niamh Hogan who have created beautiful, personalised table cards to match the couple's wedding colours and theme. For more information, please contact ILFA on 086 871 5264 or email info@ilfa.ie.

Congratulations to Emma and James

Congratulation to Emma Lynch and James Seery who married in July in Doolin, Co Clare. James and Emma made a donation to ILFA in lieu of wedding favours in memory of Emma's dad, Donal Lynch. Emma was in touch to say "We had just the best day and the weather was phenomenal! The wedding favour cards from ILFA were lovely and worked really well with the theme of the table decoration. Thank you so much!"



Patient Support Groups

Cork Support Group

The group meets at 11am on the last Thursday of every month at The Elm Tree, Glounthane. **Please call Anne on 087 985 4587 for more details.**

Dublin Support Group

The group meets on the first Tuesday of every month at 11am at the Carmelite Community Centre at Whitefriar Street Church, Aungier Street, Dublin 2. **Please call Matt on 086 244 8682, Pam on 086 178 9055 or Paddy on 087 412 8612 for more details.**

Kerry Support Group

The group meets on the last Saturday of every month at 3pm in Tralee at the Rose Hotel. **Please call Adrian on 087 241 4004 for more details.**

Midland Support Group

The group meets on the first Wednesday of every month at 2.30pm at the Tullamore Court Hotel, Tullamore, Co. Offaly. **Please call Tom on 086 150 0970 or Anthony on 087 258 5699 for more details.**

Cavan Monaghan Support Group

Kevin McSkeane is hoping to set up a support group in Cavan - Monaghan. **Please call Kevin on 085 243 6828 for more information.**

Mid West Support Group

The group meets monthly at Matt The Threshers, Birdhill, Co Tipperary. **Please call Noreen on 087 262 6828 for more information.**

If you would like information about setting up a patient support group in your area, please contact ILFA on

086 871 5264

Dates For Your Diary

Upcoming ILFA events

- The Autumn Patient Information Day will take place on Saturday 21st October at the Crowne Plaza Hotel, Northwood, Santry, Dublin from 10am to 1pm.
- The ILFA Service of Prayer and Reflection will take place on Saturday 14th October at Our Lady of Mount Carmel Church, Whitefriar Street, Dublin 2 at 4pm.

Upcoming events for healthcare professionals

- IPF World Week will take place from 16 to 24th September 2017. Please contact ILFA if you would like to hold an information stand at your hospital.
- The Interstitial Lung Disease Inter-disciplinary Network (ILD-INN) conference will take place in Birmingham on 8-9th October 2017. For more information, please visit www.ild-inn.org.uk
- The Irish Hospice Foundation's Forum on End of Life Conference will take place on Tuesday October 10th at Dublin Castle. See www.hospicefoundation.ie for more information.

Upcoming fundraising events

- **The Pat Casey Memorial Cycle**, in Cork will take place on Saturday 2nd September. Please call Anne on 087 985 4587, Brian on 086 088 1064 or email annecasey@live.ie for more information.
- **The Margaret Maloney Memorial Darts Tournament**, will take place on Saturday 30th September at The Central in Roscrea and promises to be great fun. Please contact Owen Maloney on 087 241 4475 for more information.
- **The Dublin City Marathon** will take place on Sunday 29th October. Please contact ILFA if you would like a fundraising pack.

Lung Transplant Team wins 'Clinical Team of the Year'



Congratulations to the Lung Transplant Team at the Mater Misericordiae University Hospital in Dublin who were the worthy winners of the 'Clinical Team of the Year' at the Irish Healthcare Centre Awards on 10th March 2017. The team received their award from Marty Whelan at a gala dinner held at the Royal Marine Hotel, Dun Laoghaire, Co. Dublin.

Congratulations also to the Interstitial Lung Disease Service at the Mater Misericordiae University Hospital who were shortlisted for the Specialist Care Centre Award.

Pictured are Patricia Ging and Professor Jim Egan with the award, and members of the Lung Transplant team and the ILD Service team.

Keep in touch with ILFA

You can keep in touch with ILFA

by phone on 086 871 5264 (general enquiries)

or 086 057 0310 (fundraising enquiries)

by email - info@ilfa.ie

on the web - www.ilfa.ie

on Facebook - www.facebook.com/ILFAIreland

on Twitter - [@ilfaireland](https://twitter.com/ilfaireland)

Please contact ILFA if you would like your details to be added or removed from our mailing list.

