On 6th October, during Idiopathic Pulmonary Fibrosis (IPF) World Week 2015, ILFA launched the National Patient Charter for IPF. The launch took place at an information session hosted by ILFA’s Patron Senator Feargal Quinn and Professor Jim Egan from the Mater Misericordiae University Hospital. Patients and family members from all over the country joined politicians including Senators Jillian Van Turnhout and Sean Barrett; and Deputies Jerry Buttimer, Finian McGrath, Joan Collins, Billy Kelleher, Eric Byrne and Derek Keating to learn more about IPF, a chronic and life changing respiratory disease that affects approximately 800 people in Ireland.

ILFA developed the National Patient Charter to provide patients and carers with information on how to access the best treatment and support for IPF. The charter reflects the experiences and needs of patients and carers who took part in focus group discussions in 2013.

ILFA was fortunate to receive valuable input from IPF patients, carers, and health care professionals and we are extremely grateful for everyone’s help with this project.

The charter identifies six key areas needed to ensure patients get the best care:

1. Early and accurate diagnosis with multi-disciplinary team input
2. Clear and concise information about IPF in plain language
3. Access to appropriate medication and oxygen therapy
4. Early referral to pulmonary rehabilitation and exercise programmes
5. Early referral to the National Lung Transplant Unit for lung transplant assessment, with minimal emphasis on age
6. Access to social, practical, and emotional support

We hope you will find the charter useful and informative.

New IPF information leaflet

On 6th October, ILFA also launched our updated leaflet entitled “What is Pulmonary Fibrosis?” This leaflet gives information about the causes, symptoms, and treatments for IPF. If you would like a copy, please get in touch with us.

Christmas Cards

ILFA’s beautifully designed Christmas cards are now available. The cards are printed in Ireland and all proceeds will go directly to ILFA. One pack of 10 cards costs €6, and two packs cost €10. If you would like to order cards, please contact ILFA on 086 871 5264 or info@ilfa.ie.
ILFA Exercise DVD for Lung Fibrosis Patients

Early in 2015, Nicola Cassidy (ILFA), Irene Byrne and Petra Grehan (physiotherapists with the Heart and Lung Transplant Unit at the Mater Misericordiae University Hospital) met to discuss plans to produce an exercise DVD for lung fibrosis patients, something we have wanted to do for a few years. The aim was to produce a useful and enjoyable home-exercise resource for patients who could not attend pulmonary rehabilitation classes.

Under the guidance of our film-makers, Fergal and Ray, we wrote and edited scripts, rehearsed, and scouted for suitable filming locations. The exercise DVD features advice and words of encouragement from healthcare professionals including Professor Jim Egan, Irene Byrne and Petra Grehan, ILFA’s patrons - Senator Fergal Quinn and GAA football star Michael Darragh Macauley, and three enthusiastic patients - Joan Doyle, Dermot King and Matt Cullen. Filming took place one Saturday in August in the Mater Hospital gymnasium and great fun was had by all on the day.

ILFA is very grateful to Irene and Petra for their enthusiasm and dedication, and to their colleagues in the Mater Hospital; Dervilla Danagher and Anne Horgan (physiotherapy department), Catherine Holland (risk management) and Hospital CEO, Professor Mary Day, for their help delivering this ambitious project.

ILFA is delighted with the DVD and hopes it will help patients to exercise safely while managing their breathlessness. The Exercise DVD for Lung Fibrosis Patients was launched at the ILFA Patient Information Day in November.

The DVD can be ordered by contacting ILFA (Tel 086 871 5264 or email info@ilfa.ie). The ILFA Exercise DVD is available free of charge. A small donation would be welcomed if possible.

IPF World Week

IPF World Week was celebrated around the world in early October 2015. In Ireland, ILFA launched the National Patient Charter for IPF at a special gathering in Dublin. The event was well attended by patients, carers, public representatives, and healthcare staff, and a lively questions and answers session took place, chaired by Professor Jim Egan and Senator Fergal Quinn. Matt Cullen (IPF patient) also spoke at the event and shared his perspectives on living with IPF.

ILFA also launched a short information video to accompany the charter. The video features six healthcare professionals describing the main points of the charter. We would like to extend our sincere thanks to; Professor Anthony O’Regan and Tara Cahill from University Hospital Galway, Dr Emmet McGrath and Lindsay Brown from St. Vincent’s University Hospital, Dublin, and Dr Osin O’Connell and Maria Love from the Mater Misericordiae University Hospital, Dublin for their participation. The video can be viewed on ILFA’s website www.ilfa.ie.

Nurses and healthcare staff in Cork University Hospital, Ennis General Hospital, St Vincent’s University Hospital, Dublin, the Mater University Hospital, Dublin, and Limerick University Hospital held information stands to raise awareness of IPF.

Liam Galvin, ILFA Committee member, attended the European meeting of the IPF Patient Organisations in Brussels in September and met with MEPs to get their support for the European IPF Patient Charter.

In November, the European Respiratory Journal, a specialist publication for healthcare professionals, published a research article entitled “European IPF Patient Charter: unmet needs and a call to action for healthcare policymakers”. This article describes the development of the European IPF Patient Charter and how it will be used to raise awareness and inform healthcare policymakers who are driving improvements in IPF care across the European Union.

You can find a link to the article on www.ipfworld.org.
The 2015 Service of Prayer and Reflection

On the afternoon of Saturday, October the 17th, a sizeable and enthusiastic group of ILFA members and supporters gathered in the beautiful parish church of Christ Church, Taney, Dundrum, Dublin, for what has become an important part of the ILFA annual calendar. The service of thanksgiving and remembrance was presided over by the Revd Cathy Hallissey (curate-assistant in Taney), the Revd Vanessa Wyse-Jackson (Rathgar Methodist Church), the Revd Brian McKay (Whitefriar Street Church) and the Revd Canon Charles Mullen (St Patrick’s Cathedral) who devised and arranged the service.

This is now the fourth year that the annual service has taken place and it consists of readings, reflections, hymns, music and the very moving candle lighting ceremony which commemorates all the association’s beloved dead. The service is characterised by inspiring reflections which are intended to instil hope, courage and tranquillity among the participants. It is also an opportunity to pray for God’s blessing upon the work and support of a very important organisation in the lives of so many.

It is always very clear at this service that the work of ILFA since its inception in 2002 has become a source of strength and support for so many people and the hour of reflection is intended to spur us all on to work even harder for the good of those whose lives are touched by lung fibrosis, whether patient, lung transplant recipient, family member or friend.

This year, in the address, the energy, enthusiasm, humanity and joyfulfulness of this association were praised by the speaker (Fr Brian McKay, O.Carm) who encouraged all present to be thankful for what has been achieved by the association thus far and be inspired to find new ways of assisting those who need support into the future.

The reading out of the names of the deceased is always very moving and the accompanying act of candle lighting is a reminder of life that can never be extinguished. As the speaker expressed it: ‘for our departed, life is changed, not ended’. The service concluded with some beautiful harp music from Harry Carpendale after which there was time for tea and conversation. People who had not met each other for some time were able to catch up and old friendships were renewed. The sun shone brightly on Saturday 17th October, Taney parish church looked at its best and a very agreeable afternoon was had by all. A big thanks to the organising committee. As I write two days after the event, we have only three hundred and sixty-three days to our fifth annual service. May we all keep well and see one another then!

Fr Brian McKay, O.Carm.

The Reverend Vanessa Wyse-Jackson wrote “It was once again a most meaningful and helpful act of worship and greatly appreciated by those who had made the special effort to be there, some travelling long distances to remember their loved ones and to share their memories.”

The Reverend Cathy Hallissey wrote “It was a pleasure to have everyone gather in Taney. The service was beautifully organised and very moving.”

The ILFA committee would like to express our sincere gratitude to Canon Charles Mullen for his quiet, unassuming and industrious work behind the scenes in putting together the service; to all the celebrants - The Reverend Cathy Hallissey, The Reverend Vanessa Wyse Jackson, The Reverend Fr Brian McKay O.Carm., and The Reverend Canon Charles Mullen; to all the participants; the talented musicians - Martina Smyth, organ scholar from St. Patrick’s Cathedral and Harry Carpendale - harpist, Audrey Erangey who sang beautifully and to Heather Rutledge and her team of kind helpers who served the refreshments.

Here are some of the comments received by ILFA;

• “I thought the service was beautifully organised and very moving.”
• “The service was magnificent.”
• “Thanks for a hugely enjoyable service. It was very uplifting and touching”.
• “It was a lovely ILFA ‘family’ occasion. It means a lot to people.”
• “Thank you for organising it.”
• “Thanks to all involved in organising such a beautiful service.”
The European Respiratory Society Congress took place in Amsterdam from 26-29th September. Over 22,000 healthcare professionals, researchers, scientists and patient organisations attended, making this one of the biggest lung health conferences in the world. Nicola Cassidy from ILFA attended the congress along with Matt Cullen, IPF patient from Dublin.

Nicola Cassidy presented the results from the ILFA Patient and Carer surveys that were carried out in 2014, at a poster discussion session entitled "IPF: Clinical aspects". The poster discussion generated a lot of interest and the Chairmen Professor Venerino Poletti (Italy) and Professor Michael Kreuter (Germany) asked many questions about the interesting results of the ILFA survey. Many people took photos of the poster and requested copies of our work. The poster presented by ILFA can be seen on the pages 6 and 7. Twenty other research projects were discussed in this busy session that was packed to capacity. Some of the other work presented included the development of a quality of life survey for IPF patients, the use of lung cyrobiospies (an alternative method to a surgical lung biopsy that involves a minimally invasive technique and freezing the lung biopsy tissue), the benefits of exercise, and the frequency of different diseases that co-exist with IPF. After each of the posters was discussed, the chairmen led a lively and fast moving questions and answers session. It was great to have such an enthusiastic audience present.

Matt Cullen was invited to speak at the congress by the European Lung Foundation to give a patient's perspective. Matt's presentation was called "Why taking the active option is essential for lung health". Matt described his life and exercise regime before he was diagnosed with IPF, how he subsequently had to reduce his physical activities due to breathlessness, and how he re-started exercising in order to keep fit and well while adjusting to life with a chronic lung condition. Matt told the audience how he returned to his favourite hobbies including gardening, badminton, art, and taking part in local Tidy Towns activities while adapting his physical efforts to suit his new limitations. Since being diagnosed with IPF, Matt has also started pulmonary rehabilitation classes that have been very beneficial to him. He remains very active but carries on his new limitations. Since being diagnosed with IPF, Matt urgently started pulmonary rehabilitation classes that have been very beneficial to him. He remains very active but carries on his new limitations. However, it is impossible to predict which patients will respond well to medication and the extent of their response. All medicines can have side effects and these need to be managed properly and explained to patients. Doctors were

to himself, a credit to ILFA and a credit to Ireland" and this sums up Matt's contribution perfectly!

Matt said "To take part in the ERS Congress was a wonderful experience for me. I genuinely feel that the support afforded to me by everyone was excellent and as an IPF patient it was great to be able to convey the patient's perspective to such a wide audience."

During the congress there were a number of sessions dedicated to IPF where the current understanding of the disease was reviewed and the latest research developments described. Two evening sessions dedicated to IPF were packed to capacity as the world’s IPF experts spoke about "Strategies to improve outcomes in IPF" and "IPF - where real world meets science".

Here are some of the key discussions that took place.

Early diagnosis: Professor Athol Wells (United Kingdom) described how the prevalence (the number of people living with IPF) is increasing. This could be because people are living longer or because IPF is being diagnosed better and earlier. Early diagnosis is vital, however it can be difficult for doctors to reach a definite diagnosis.

IPF Screening: Professor Wells also discussed the possibility of screening the general population to detect IPF (similar to national cancer screening programmes) but this is unlikely to be cost effective and of little benefit because the number of people diagnosed with IPF is likely to be very small. A much more effective way to detect and diagnose patients would be through careful monitoring of pulmonary function tests and CT screening, particularly in older adults and those who currently smoke or smoked previously. While CT screening is helpful to diagnose IPF, it is not always possible to make a definite diagnosis using this technology. A small number of cases will require a lung biopsy to look at the lung tissue under a microscope and identify the IPF pattern. Lung biopsies are not carried out on every patient because there are risks associated with this procedure, especially in older adults.

Managing IPF: Professor Cottin (France) described the importance of doctors managing patient's IPF, helping to alleviate patient's symptoms, and educating patients about their condition in order to optimise patient care. The anti-fibrosis drugs Perfinidone and Nintedanib have positive effects for some patients and can delay disease progression and prolong life. However, it is impossible to predict which patients will respond well to medication and the extent of their response.

All medicines can have side effects and these need to be managed properly and explained to patients. Doctors were
encouraged to speak with their patients regarding different treatment options available and take the patient’s personal wishes into account. The capabilities of medication needs to explained realistically so the patient has an accurate expectation of what the treatment can do for them.

Professor Alberra (Italy) described how new drug treatments can potentially give patients the opportunity to live better and longer, and enjoy a better quality of life. The aim of medication is to preserve lung function for as long as possible. Early diagnosis will allow patients to start treatment sooner, be prescribed suitable medicine earlier, and have better outcomes.

Clinical trial results Vs ‘real life’ experience: During drug development, researchers have to follow strict guidelines for carrying out clinical trials. Patients who take part in clinical trials must meet all the criteria, for example, patients must be a certain age, have a definite IPF diagnosis, have defined lung function test results, and attend IPF centres for their treatment. The results from clinical trials are stronger and more uniform when patients with similar disease characteristics are chosen and studied for a set time (typically clinical trials last for one year). However, this process is not representative of ‘real life’; IPF patients are all different, their diagnosis can be uncertain, most patients have other co-existing diseases and IPF disease progresses at different rates for each person. ‘Real life’ situations where large numbers of patients taking prescribed medicines are followed long term for a number of years can give a more realistic picture of the drug’s effects.

Patient Registries collect information about every aspect of a patient’s health status, including information about their diagnosis, test results, lung function and treatments, and can give a window into the ‘real world’ of IPF. More and more countries are setting up patient registries to establish the characteristics and behaviour of IPF in a national and international context.

Co-existing conditions: Many IPF patients have other conditions as well as their lung disease, making treatment and disease management more challenging. The older the patient, the more likely they are to have other chronic illnesses. Results from the German IPF Registry have shown acid reflux (indigestion or gastro-oesophageal reflux disease - GERD), Sarcoidosis, and depression are common co-existing conditions for patients. There needs to be more investment into psychological support services so that IPF patients can access help and support when needed. If depression is treated appropriately, this will lead to a better quality of life.

Overall, the ERS Congress was a very exciting and fast moving affair with excellent educational presentations from doctors, healthcare workers, scientists and researchers from all over the world. Next year the congress will take place in London.

Patient Support Groups

CORK: The Cork Support Group meets at 11am on the last Thursday of every month at The Elm Tree, Glounthane.

Contact Anne at 087 985 4587

KERRY: The Kerry Support Group meets at 3pm on the last Saturday of every month in the Carlton Hotel, Tralee.

Contact Adrian at 087 241 4004

MIDLANDS: The Midlands Support Group meets at 2.30pm on the first Wednesday of every month in the lobby of the Tullamore Court Hotel.

Contact Tom at 086 150 0970

DUBLIN: The Dublin Support Group meets at 11am on the first Tuesday of the month in the Carmelite Community Centre, Whitefriar Street Church, Aungier Street, Dublin 2.

Contact Paddy at 087 412 8612

If you would like information about setting up a Patient Support Group in your area, please contact ILFA on 086 871 5264.
Introduction

Idiopathic Pulmonary Fibrosis (IPF) is a chronic, progressive, debilitating interstitial lung disease that causes irreversible scarring of the lungs, low blood oxygen concentrations, breathlessness, fatigue and muscle weakness.1

The Irish Lung Fibrosis Association (ILFA) was set up in 2002 to support patients and families affected by IPF in Ireland.

Aim

To identify the physical, emotional and financial burdens of IPF for patients and carers in Ireland and prioritise their information needs.

Methods

A structured questionnaire on the physical, emotional and financial impacts of IPF was developed using a standard five-point Lickert-type scale. Surveys were posted to ILFA members and were available online for a period of 8 weeks.

Respondents were asked to give anonymous personal information, to answer questions based on their experience using the categories of “always, often, sometimes, rarely or never”, and to prioritise their information needs.

The top three answers for the physical, emotional and financial burdens are presented here, based on the frequency of the “often/always” responses.

Results

Symptom burden for patients

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Never/rarely</th>
<th>Sometimes</th>
<th>Often/always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disturbed sleep</td>
<td>24%</td>
<td>21%</td>
<td>55%</td>
</tr>
<tr>
<td>Tiredness</td>
<td>41%</td>
<td>56%</td>
<td></td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>29%</td>
<td>68%</td>
<td></td>
</tr>
</tbody>
</table>

Symptom burden for carers

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Never/rarely</th>
<th>Sometimes</th>
<th>Often/always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disturbed sleep</td>
<td>26%</td>
<td>21%</td>
<td>53%</td>
</tr>
<tr>
<td>Stress</td>
<td>27%</td>
<td>70%</td>
<td></td>
</tr>
<tr>
<td>Tiredness</td>
<td>25%</td>
<td>63%</td>
<td></td>
</tr>
</tbody>
</table>

Emotional burden on patients

<table>
<thead>
<tr>
<th>Emotional concern</th>
<th>Never/rarely</th>
<th>Sometimes</th>
<th>Often/always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt</td>
<td>31%</td>
<td>32%</td>
<td>37%</td>
</tr>
<tr>
<td>Infection fear</td>
<td>34%</td>
<td>26%</td>
<td>40%</td>
</tr>
<tr>
<td>Family concern</td>
<td>17%</td>
<td>23%</td>
<td>60%</td>
</tr>
</tbody>
</table>

Emotional burden on carers

<table>
<thead>
<tr>
<th>Emotional concern</th>
<th>Never/rarely</th>
<th>Sometimes</th>
<th>Often/always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt</td>
<td>30%</td>
<td>29%</td>
<td>41%</td>
</tr>
<tr>
<td>Inadequate</td>
<td>33%</td>
<td>23%</td>
<td>44%</td>
</tr>
<tr>
<td>Worry</td>
<td>30%</td>
<td>58%</td>
<td></td>
</tr>
</tbody>
</table>

Figures 1-4: The physical and emotional impact of IPF on patients and carers.

Key: 
- Never / rarely
- Sometimes
- Often / always
Results
38 IPF patients and 34 carers completed the questionnaire. Demographic data are presented in Table 1. The median time from diagnosis for patients was 4.5 years.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients (n=38)</th>
<th>Carers (n=34)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>24 (63%)</td>
<td>5 (15%)</td>
</tr>
<tr>
<td>Female</td>
<td>14 (37%)</td>
<td>20 (59%)</td>
</tr>
<tr>
<td>Gender not specified</td>
<td>0</td>
<td>9 (26%)</td>
</tr>
<tr>
<td>Median age</td>
<td>65 years</td>
<td>63 years</td>
</tr>
<tr>
<td>Age range</td>
<td>47-82 years</td>
<td>28-75 years</td>
</tr>
<tr>
<td>In employment</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Had to retire/stop working</td>
<td>17 (45%)</td>
<td>14 (41%)</td>
</tr>
</tbody>
</table>

Table 1: Patient and carer demographics.

63% (n=24) of patients were oxygen dependent and 6 patients lived alone. The majority of carers were spouses (n=24, 71%) or daughters (n=8, 24%). Two carers did not specify their relationship to the patient.

The physical and emotional impacts of IPF on patients and carers are presented in Figures 1-4. The principle financial concerns for patients were worry about the economic effect on family (45%), daily living costs (37%) and heating costs (35%). Carers reported worry about the economic effect on family (50%), electricity (46%) and heating costs (38%) as their main financial concerns.

Information priorities are presented in Table 2.

Discussion
IPF affected the daily lives of patients and carers and impacted on their physical and emotional well being, social activities and finances. The responses from patients and carers were broadly similar and consistent with the findings of previous studies.\(^2\,^3\)

Healthcare professionals should ensure that patient care pathways include comprehensive monitoring to address all aspects of patients’ wellbeing in order to improve their quality of life. The survey also highlighted the educational needs of patients and carers for healthcare professionals and patient organisations.

Conclusion
The perspectives from patients and carers provided valuable insights on the burden of IPF for families in Ireland. These findings will inform advocacy work to help raise awareness among healthcare professionals.

References
ILFA’s fundraisers continued to turn out in force during the autumn months to raise essential funds for ILFA and support our work. We are continually amazed by the dedication, efforts and bravery of our supporters with the challenges they undertake. If you would like to take on a challenge or organise event for ILFA, please get in touch.

1. Tullamore Ladies Golf Club

Special thanks to the Tullamore Ladies Golf Club for holding a raffle in aid of ILFA. They raised the fantastic sum of €650. The ladies in photo 1 are (from left to right) Joan Keegan - Social Secretary, Kathleen Moylan - hamper winner, Mary Guiney - ILFA representative, and Helen Egan - Lady Captain Tullamore Golf Club. Warmest thanks to everyone who supported the raffle.

2. Margaret Maloney Memorial Darts Tournament

The Margaret Maloney Memorial Darts Tournament took place on Saturday 26th September in Breretons Bar, Ballybrit, Roscrea, Co. Tipperary with all proceeds going to ILFA. The inaugural 2014 tournament was a very successful and enjoyable fundraiser and this year’s event was even better! The tournament involved a mixed doubles competition and a thrower and a non-thrower were paired on the day. Tasty food and music ensured that everyone had a great time. Thanks to the Maloney Family, all the organisers and to Joe and Mary Murray of Breretons Bar for their support.

3. Dublin City Marathon

Well done to our marathon heroes, Andrew Grehan, Stephen Lawless and Niall Coughlan who took part in the Dublin Marathon on Monday 26th October. The dedication of all of our athletes is amazing, and those who take on the incredible distance of 26 miles and 395 yards to raise funds for ILFA are a huge inspiration to us all.

4. International runners

We are delighted that our international friends continue to support ILFA. Brother and sister, Alex and Soraya Sayve took part in a French 10km race in the autumn in memory of their father Pierre. Alex has also completed the Dublin City Marathon for ILFA in the past – a dedicated supporter. Merci beaucoup.

5. Sky dive

Congratulations to Laura Shannon who was willing to jump out of an airplane to support ILFA and help raise awareness of lung fibrosis! Laura undertook this remarkable challenge in memory of her Grand-dad who sadly passed away earlier this year.

6. Tipperary Mini-Marathon

On 27th September, dedicated women took to the Clonmel streets for the Tipperary 10km mini marathon. Among the 800 women who enjoyed the day were the O’Neill sisters and friends. Congratulations and thank you to Sharon, Robyn, Keira, Brigid and Cathryn who completed the mini marathon to raise funds for ILFA in memory of Kathleen O’Neill.

7. Tullamore Table Quiz

Lisa Kennedy, whose Dad, Val, is an IPF patient, organised a very successful table quiz in the Brewery Tap, Tullamore in September. Speaking about the quiz Lisa said, “during this time ILFA have been a great support and he’d like to send some well needed funds their way.” A great night was had by all and ILFA greatly appreciates the support.

8. Cork Mini Marathon and the Pat Casey Memorial Cycle

Congratulations to Anne Casey, Daniel Casey, Mary Donovan and Sarah Aherne for taking part in the Cork mini-marathon for ILFA in memory of Pat Casey from Cork. The Casey family, Brian Aherne and friends also organised the Pat Casey Memorial Cycle, a round trip cycle from Cork to Limerick and back again which took place on 19th and 20th September. The funds raised from the cycle were shared between Cork University Hospital and ILFA. Huge thanks to all who took part.

9. Galway Bay Half-Marathon

Huge congratulations to Pat Rooney from Galway on completing the Galway Bay half-marathon on Saturday 3rd October. Pat’s marathon success is all the more special and a truly phenomenal achievement, as he has IPF. Speaking about the challenge, Pat said, “It was a perfect day for the run, cloudy with very little wind and I finished it in 2 hours and 4 minutes – a personal best! One of my goals in doing this was to offer some good news about IPF.” Pat was delighted with his time and we salute his incredible determination and remarkable achievement. Pat is an inspiration to us all!
Members of the Grehan family who cheered on Andrew in his 7th Dublin marathon for ILFA.
Make every breath count

A report by Tom Erangey

Tom Erangey and his wife Audrey (Aud) from Cork have produced a beautiful CD of well-known songs, with all proceeds going to ILFA. In the text below, Tom describes how the CD came about and how he and Aud hope to raise awareness of IPF. The CD can be purchased from ILFA for €10 and would make a lovely gift!

“After seeing how popular the video of Aud singing in memory of my Dad at our wedding was, I asked her if she would be willing to record some songs on a CD, in an effort to raise money for ILFA. Aud is shy and modest but she really liked the thought of raising money for a charity that is so close to our hearts. My Dad, Jimmy, died from IPF on January 13th, 2011. My Dad’s best friend and brother, Martin, also lost his battle with IPF recently on August 7th, 2015.

We spent five days in the recording studio, three days recording and two producing and mastering the recordings. Aud did an amazing job in the recording booth. All together we recorded 14 songs and chose the best 9 for the CD. One track is the actual audio recording from the YouTube video of our wedding. On the CD cover we put a photo of a dandelion being blown and called the CD “Make every breath count”.

We are amazed at the wonderful response the CD has received. The support we are receiving is great. People are so generous and really like the CD which is fantastic. Local businesses and friends have taken CDs to sell. In 2014, I did two half-marathons to raise money for ILFA and create awareness. My efforts went well but this is much better. People are asking about ILFA and want to know about Pulmonary Fibrosis. There are a lot of well-known charities that do great work and most of these are linked to well-known diseases. Not a lot of people know much about IPF even though it isn’t too uncommon. My hope is that a lot more people will soon know about this condition.”

Tom has continued his support for ILFA by hosting an information stand on IPF and ILFA in some of Cork’s busiest shopping centres. Thank you very much for all your work on our behalf, Tom!

Wild Atlantic Marathon, Sligo

A report by Farnan Rushe

When I reached 40, and the first stages of midlife crisis set in, for some strange reason, the running bug hit me. Since then, I have been fortunate enough to have run races all around the world, so when my sister informed me in June of this year, during our summer trip back to Ireland, that there was a Half Marathon being held in Sligo, I just had to do it. And when my father came up with the fantastic idea to take advantage of this occasion to raise funds for the Irish Lung Fibrosis Association, a date was set.

Just a couple of points to set the scenario. I have been living in Spain for the last 25 years. And my father has been bravely battling a difficult pulmonary illness for the last few years. So the opportunity to return to Ireland for a weekend, and in the process, support the ILFA, who have been a magnificent support to both him, my mother, and all of us, was too good to miss.

On Thursday September 10th, my oldest daughter Sara and I flew from Madrid to Dublin. We picked up my parents, and drove down to Sligo the following day, being met later in the evening by my sister and brother-in-law. A couple of Skype calls from my 2 other brothers and my wife and youngest daughter during dinner in the hotel, made it feel like we were all together.

The next day, 12th September, was race day. I have run many marathons and half marathons, but from the outset, there was something special about this one. Before setting off, Dad and I had our picture taken together with Knocknarea in the background. For being the first staging of the race, the Wild Atlantic Run (www.wildatlanticrun.com), the organisation was fantastic. We left from Sligo Airport, and were immediately sent off into the dunes of Strandhill, over beaches, across narrow paths, through a forest and eventually out onto the main road.

Despite the fact that there were severe weather warnings for the weekend, the rain stayed away. But the wind made its presence known, putting the “Wild” into the Atlantic Run. We flew into Sligo town from Strandhill, but upon making the turn at the bridge and heading out to Rosses Point, we were running into a gale. However, when I passed our old house in Ballincar, a new lease of life came upon me.

I don’t think I could ever express eloquently enough in words the feeling of crossing the finishing line and falling into the arms of my daughter, sister, mother and, finally, my father. I had finished in 8th place, with a respectable time of just over 1 hour and 32 minutes, but, most importantly of all, we had raised over € 3,000 for the ILFA, and had a memorable family weekend back in our hometown.

Thanks to everyone who supported us in our quest, too many people to mention. And thank you to the ILFA for their terrific work.

Next year? A new challenge will have to be found...
Congratulations to Matt Cullen (IPF patient) from Dublin who won the 2015 “Volunteer of the Year” Award at the Volunteer Ireland Awards. Matt was nominated by Niamh Tracey from Swords Tidy Towns Committee and was chosen as the successful winner from 300 nominees.

Matt has been a great friend to ILFA over the years and he is an active fundraiser and regular attendee at the Dublin Patient Support Group where everyone knows him by his beaming smile, positive outlook and enthusiasm to learn and participate in all that life has to offer. Matt could teach us all a thing or two about living well and making the best out of every opportunity. ILFA would like to offer our huge congratulations on this well-deserved recognition.

In January, Matt’s 2015 New Year resolution was to say “YES” to everything he could and what a year he has had! Here are some of Matt’s 2015 achievements.

• January and February - Matt was busy painting!
• March - Matt held his first solo art exhibition in Filmbase, Temple Bar, Dublin and donated 20% of proceeds to ILFA. Matt was interviewed on radio and his story appeared in the national media.
• May - Matt spoke at the ILFA Patient Information Day in Athlone in May and told the audience how he manages his pulmonary fibrosis through a combination of exercise, keeping active and volunteering with the Swords Tidy Towns Group.
• June - Matt’s wife Teresa and daughter Debbie, took part in the Women’s Mini Marathon for ILFA and Matt came out to cheer them on.
• July - Matt won first prize in the local Garden Competition.
• August - Matt volunteered his time to help with the Swords Tidy Town campaign and he also found time to volunteer to take part in the ILFA Exercise DVD for Lung Fibrosis Patients.
• September - Matt was invited to speak at the European Respiratory Society Congress by the European Lung Foundation. Matt’s presentation was called “Why taking the active option is essential for lung health”.
• October - Matt and his friend and fellow IPF support group member, Joan Doyle, were chosen as the faces of ‘IPF World Week’ across Europe.
• November - Matt was nominated for the Volunteer of the Year Award and the Charity Hero of the Year Award by his friend Niamh Tracey of Swords Tidy Town.
• December - Matt won the coveted Christine Buckley Volunteer of the Year Award and was presented with his award at a reception at Dublin City Hall. Matt’s success was featured on the RTE news. Congratulations to Matt, his wife Teresa and their family from everyone at ILFA.

The inaugural Denise Cassidy Memorial Prize was awarded to Katie Barry, an inspirational nurse from Cork University Hospital. Katie was nominated for her great compassion and kindness while caring for an IPF patient. Katie attended the autumn ILFA patient information day with her family to receive her prize.

Three commendations were also awarded to the runners up; Irene Byrne, Senior Physiotherapist at the Heart and Lung Transplant Unit in the Mater Hospital Dublin, the staff of the Heart and Lung Transplant Unit in the Mater Hospital, and Lorna Murphy, former ILFA respiratory nurse.

A full report on the nominations and prize will be featured in our spring newsletter.
Ways to donate to ILFA

If you would like to make a donation to ILFA, there are a number of ways you can support our work; you can make a once off donation, regular standing order donations, or an on-line donation through our My Charity webpage. Please get in touch by phone 086 871 5264 or by email info@ilfa.ie if you would like more details.

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

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

Quiz Time

Questions:
1. In which country was Boxing Day renamed Day of Goodwill in 1994?
2. Who served up figgy pudding in Charles Dickens’s ‘A Christmas Carol’?
3. Father Christmas is known as Pai Natal in which European country?
4. In literature, which fictional character said it is ‘always Winter, but never Christmas’?
5. Which of Santa’s reindeer shares its name with a mythical god of love?
6. How many Lords-a-leaping are there in ‘The 12 Days of Christmas’?
7. What Christmas item takes its name from the old French word estincelle, meaning spark?
8. In 1973 which record did Slade have a Christmas number one with?
9. Which word, often associated with Christmas, stems from the Greek word for circle dance?
10. In which country is St. Nick called Sinterklaas?

The ILFA committee wish all our members a happy and peaceful Christmas and a healthy and prosperous new year.

Christmas Swim

Are you willing to brave the seas at Christmas? The ILFA swimmers will take to the waters on St Stephen’s Day, 26th December at 12 noon at Sandycove Pier, Co Dublin. Afterwards, all will be welcome to join us at Fitzgerald’s Pub for warming refreshments.

If you would like to join the group, please get in touch with us on 086 871 5264.

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

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