



ILFA Newsletter



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Denise Cassidy Memorial Prize for Excellence in Patient Care

The Denise Cassidy Memorial Award recognises and celebrates an act of kindness shown by a healthcare worker to a lung fibrosis patient. Earlier this year, ILFA members were invited to submit nominations and describe how their healthcare hero had helped them or a loved one. Eight individuals and two clinical teams were nominated and the ILFA committee was delighted to learn about the great kindness shown to lung fibrosis patients and their families in recent times.



The winner of the 2021 Denise Cassidy Memorial Award is Mary Ward, pictured, Clinical Nurse Specialist at St Michael's Hospital in Dublin. Mary was nominated by Paula Jacob whose mother, Marie, passed away from lung fibrosis in 2019. In nominating Mary, Paula told us that her mother had received exceptional care over 8-years while attending St Michael's Hospital. Mary treated Marie with kindness and compassion, really listened to her and always reassured her. Marie's family were

so appreciative that Marie's wellbeing was prioritised, and they often recall Mary's wonderful kindness to Marie. Once they knew about the Denise Cassidy Memorial award, they immediately thought Mary would be the perfect recipient!

Paula said that although her mother has passed away, the family will never forget Mary's many acts of kindness. Mary was presented with her award by Eddie Cassidy (ILFA Chairman) and Nicola Cassidy. **Also nominated were:**

- ◆ Catherine McGeoghegan, Clinical Nurse Specialist at Beaumont Hospital
- ◆ Sarah Winward, Advanced Nurse Practitioner at the Mater Misericordiae University Hospital
- ◆ Dianne Moran, Clinical Nurse Specialist at the Mater Misericordiae University Hospital
- ◆ Dr Nicola Ronan, Mater Misericordiae University Hospital
- ◆ Rita Cullen, Clinical Nurse Specialist at Cavan General Hospital
- ◆ Bernie Walsh, Clinical Nurse Specialist at Cavan General Hospital
- ◆ Folasade Olaosebikan, Registered Nurse at the Mater Misericordiae University Hospital
- ◆ Dr Micheal Henry and Respiratory Team at Cork University Hospital
- ◆ Roseanne Kenny, Orla Harnan, Angela Lawlor and the ICU Nursing Team at Connolly Hospital

Congratulations to Mary Ward and all the nominees for their exceptional kindness. All the nominees will receive a framed Certificate for Excellence in Patient Care in the coming weeks. The bespoke certificates were specially designed by Sandra Stuhli, of Stuhli Design and we are grateful to Sandra for her creativity and generosity to ILFA.

A warm welcome to Anne



Anne Griffin joined ILFA in September 2021 as our Support Administrator. Here is an introduction to Anne in her own words. "My name is Anne Griffin. I live in East Cork, and I'm married with two children. I joined ILFA very recently

as a Support Administrator. From my research of ILFA, I understand that the most essential resource for ILFA is its people and the support offered. I come from an IT administrator support background and look forward to bringing my skills and expertise to ILFA. I've had the pleasure of meeting some of you at the online exercise

classes that are delivered by Zoom. I look forward to helping you and hopefully meeting you all in person someday."

Patient Information Day

The next Patient Information Day will take place online on Saturday 12th March from 11am until 1pm. The meeting will take place using the Zoom online platform. If you would like help using Zoom, please contact us in advance and we can provide you with support. Our speakers will be confirmed nearer to the time and announced on the website (www.ilfa.ie), and Facebook and Twitter pages. Please register with ILFA in advance to attend this meeting by calling **086 871 5264** or emailing info@ilfa.ie

ILFA Information Day

September 2021

Nicola Cassidy (ILFA Director) welcomed everyone to the virtual ILFA Patient information Day. This event received support of the HSE National Lottery Grant Funding for 2021 and this was ILFA's first time to receive National Lottery Funding which was much appreciated.

The first speaker was **Professor Killian Hurley**, Associate Professor at RCSI and a consultant in Respiratory Medicine at Beaumont Hospital, and his presentation was entitled "Better Care for Patients - Scheduled Care Pathways for Interstitial Lung Disease (ILD)".

Prof Hurley started by explaining Pulmonary Fibrosis, which refers to scarring of the lungs. The scar tissue usually affects the very small parts of the lungs where air is exchanged. Scar tissue causes stiffening of the lungs which makes it difficult to breathe. Sometimes the cause for the scarring can be identified for example it may be from side effects of certain medications, radiation, exposure to different types of moulds or birds, or an auto-immune disease such as rheumatoid arthritis, or scleroderma. In most cases, there is no cause found and the term used is Idiopathic Pulmonary Fibrosis (IPF). People who are diagnosed with IPF typically have shortness of breath for up to 12 months before they present, a dry cough, weight loss, sometimes clubbing (rounding) of their fingertips, and characteristic "Velcro crackles" can be heard when listening to the lungs with a stethoscope.

IPF is more common in men and the average age at diagnosis is 60's and older. IPF is rare in those under 50 years. Around 400 people (8 per 100,000 people) are diagnosed each year. The prevalence (number of patients that have IPF) is about 1,000 patients in Ireland. Survival after diagnosis is wide ranging and people typically follow one of three patterns (1) an accelerated pattern with fast disease progression (2) a stepwise pattern where they have exacerbations or flare-ups of their IPF, and it gets worse each time (3) slow progression. It's difficult to give a prognosis at the time of diagnosis, as often the doctor does not know the patient or how their disease is behaving, and monitoring is needed.

Ideally, a diagnosis of IPF is reached by consensus at a multi-disciplinary meeting with a respiratory physician, clinical nurse specialist, radiologist, thoracic surgeon, and pathologist. The patient is at the centre of this meeting and each case is presented with the x-rays, investigations, and biopsy if available. When a consensus is reached on the diagnosis, a plan is made to communicate that diagnosis and management plan to the patient. Importantly, there is no cure for IPF, yet. Some patients may be prescribed medications such as antacids to treat acid reflux which can contribute to the disease. There are currently 2 anti-fibrotic medications; Pirfenidone and Nintedanib, that can slow the progression but

cannot reverse the lung damage already present. There can be side effects with these medications that can be managed. The anti-fibrotics may not improve your symptoms but are associated with a survival benefit.

It is important to be well informed about other non-medication treatments and ILFA has a range of leaflets and resources that are available free of charge. Other treatments include oxygen, pulmonary rehabilitation and exercise, and input from dieticians, social workers, palliative care experts who can help with symptom control and end of life care, and lung transplant assessment for patients who meet the criteria.

The second part of Prof Hurley's presentation focussed on discussions about a Care Pathway. Across the health sector, the term Care Pathway is often used interchangeably with clinical pathway, care programme, and integrated care pathway. These all refer to a process of systematically planning and evaluating that is focused on patient care and based on national and international guidelines. Essentially, it's a framework of care that is usually guided by principles and should be delivered locally to patients.

We know that there are benefits from attending an ILD Specialist Centre including reduced mortality in patients who are referred earlier and a worse prognosis for those who are referred later. Patients are more likely to get an appropriate referral and more likely to have their symptoms managed better if they attend a specialist centre.

ILFA has done a huge amount of work going back over 10 years to progress care for IPF patients. The National Patients Charter for IPF informs patients of the 6 key care areas that they are entitled to

- ♦ early diagnosis
- ♦ clear information about IPF
- ♦ access to medications of oxygen
- ♦ access to pulmonary rehabilitation
- ♦ early referral to national lung transplant center
- ♦ access to psychological and palliative care support services

In 2018, the Irish Thoracic Society (ITS) and ILFA prepared a report for the Department of Health which outlined what was needed in terms of Care Pathways; (1) A national registry to record patients diagnosed with IPF. It is important to appoint a national co-ordinator and data manager to track incidence, prevalence of the disease and the outcomes (2) Outline the

structure of care pathways and multidisciplinary meetings across the country (3) Improve diagnosis and treatment.

Currently, there are 8 specialist centres, however there is no joined up framework to connect these and other hospitals across the country. The pathway in the ITS document outlines what should happen at each hospital/clinic visit and the MDT discussion (for example who should be there, what should be discussed, the personal care plan devised, and the people that are involved in that care plan, including physios, occupational therapists (OTs), dieticians and other doctors/nurses and paramedical staff.

3 years on, ILFA tried to determine how we are faring in terms of care by holding a World Café on Pulmonary Services and a patient survey which 112 people completed. They found that:

- ◆ 58% of patients had access to a clinical nurse specialist
- ◆ 38% were referred to a pulmonary rehab programme
- ◆ 25% were referred to a dietitian and referral to other services was poor - OT 8%, palliative Care 6%, psychologist 6% and speech therapist 3%
- ◆ 45% had not been referred to any service.

There is no HSE funded care programme for ILD in Ireland that joins up the specialists with the support that patients need. We urgently need to establish a task force for lung health and include ILD in the Slainte Care Programme for scheduled care, create ILD networks across Ireland such as hospitals and care services in the community that are connected, develop ILD pathways around the principles of care, and improve access to personalised treatments, diagnosis and support. The HSE and Department of Health need to work with these groups to ensure that ILD Care Pathways are included in the Slainte Care Programme in future. We will continue to campaign for a care pathway for ILD

The next speaker was **Dr. Anne Marie Russell**, Senior Lecturer at the College of Medicine and Health at University of Exeter and Senior Clinical Fellow of the ILD Services at the Royal Devon and Exeter and Imperial College Healthcare NHS Foundation Trust. Dr Russell spoke about patient centred care.

Patients are the 'expert' in their care. The biopsychosocial model recognises that whilst a health condition is experienced as biological in origin, the impact is felt physically (pathology, symptoms, science, treatments, and investigations), psychologically (emotional well-being, stress, anxiety) and socially (impact on family/friends - burden, isolation, career, finances).

The key features of patient centeredness at an organisational level are:

- ◆ Fast access to reliable health advice
- ◆ Effective treatment
- ◆ Continuity of care
- ◆ Involvement in decisions and respect for preferences
- ◆ Clear, comprehensible information and support for self-care
- ◆ Involvement of and support family and carers
- ◆ Emotional support, empathy, and respect
- ◆ Attention to physical and environment needs

When it comes to Holistic Clinical Management, a multidisciplinary team is key to diagnosis, but there is also an interdisciplinary team which plays an important role in ensuring holistic care can be delivered. This team includes radiographers, clinical scientists, OTs, GP, dieticians, and other

clinicians, but also including secretarial support and the family. Patient advocacy has never been more important and patient advocacy organisations such as ILFA are fundamental to ensuring that we can maintain patient centred approaches.

When it comes to communication, 5 elements ensure full involvement of the patient, and that communication is two-way (1) Connecting and building rapport (2) Safety netting is a checkpoint for both sides to ensure that any uncertainty is addressed, particularly in the context of ILD - thinking about the unpredictable nature of exacerbations, or the potential side-effect of medication (3) Housekeeping concerns the day-to-day taking care of ourselves and our wellbeing (4) Clinicians should summarise by ensuring that you have understood the patients' expectations of the consultation (5) Ensure that the patient is happy with and understands the management plan. Following the consultation, the patient should feel informed and sufficiently confident of the management plan relating to their care which will include shared decision making (a collaborative process that involves a person and their healthcare professional working together to reach a joint decision about care).

Regarding digital and virtual consultations, it's important for clinicians to recognise that a lot of people are not comfortable with digital communication, therefore there is a need to personalise this connection even more and create empathy so that people can relax and talk. For patients it is important to make clinicians aware if you, live alone, or if you've got someone else on the call, as that might shape the discussion, volunteer how you are feeling psychologically. If you're using devices to monitor your condition remotely, it's important to understand what the parameters are, what the thresholds for change are and when you need to notify your team. Oxygen assessment is difficult to do over the phone, so it is essential to tell your team about any change in breathlessness, cough, fatigue, and fever. Ask about assessment for oxygen if you think that your requirements have increased.

The 'Patient-Centred Outcomes Research in ILD' statement from the American Thoracic Society identified that patient-centred outcome essential components are:

- ◆ health-related quality of life
- ◆ psychological and emotional well-being
- ◆ symptom experience
- ◆ functional status
- ◆ oxygen needs
- ◆ hospitalisation and survival
- ◆ acquisition of knowledge

Breathlessness is a symptom that is common to most ILDs and has both psychological and physical components. The psychological impact relates to being aware of the sensation of being breathless leading to anxiety, feeling of panic, thoughts about dying, anger, low mood. The physical impact can cause reduced activity, social isolation, reliance on help, cardio and muscular deconditioning, increased work of breathing.

The essential components of patient centeredness include providing a clinical environment for communication and a physical environment that makes one feel better, integrated care from an interdisciplinary team, being cognisant of the family impact and supporting people to have access to patient organisations, seeing the patient as a person, and sharing decision making and responsibility so that we can build a truly therapeutic alliance.

Dr Kate Devenney, Clinical specialist physiotherapist at the Respiratory Assessment Unit at St. James' Hospital and the University of Limerick, was the next speaker. In 2021, Dr Devenney collaborated with ILFA and a group of students from the University of Limerick to deliver an online programme for pulmonary fibrosis patients. Dr Devenney's presentation was entitled "Exercising with Chronic Lung Disease - start moving and keep moving."

Exercise and physical activity are two terms used in relation to exercise training. Both are beneficial but differ in what they are trying to achieve:

- ♦ Exercise is a planned structured intentional repetitive movement, and the overall aim is to either improve or maintain an aspect of physical fitness such as muscular endurance or muscular strength or cardiovascular fitness.
- ♦ Physical activity is any movement that is carried out by the muscles that requires energy. Studies that have shown very significant health benefits in people who have higher fitness levels, exercise regularly, and are physically active.

Those who exercise regularly will feel less breathless, maintain a healthy weight, have improved muscle strength and endurance, quality of sleep, wellbeing, mood, balance (to reduce the risk of falls) and bone mineral density. When it comes to breathlessness and inactivity, after diagnosis some patients must slow down activities such as walking, curtail some activities due to breathlessness, and experienced difficulties going up the stairs. When you slow down or stop these activities altogether, you inevitably lose fitness. By being less active your muscles become weaker (weak muscles use more oxygen and are less efficient), you feel more breathless, become fearful of doing activities that make you breathless and this can cause you to avoid activities. This is called 'the cycle of breathlessness and inactivity'. Regular exercise or a more formal programme of exercise and education, known as pulmonary rehabilitation, are needed to break the cycle of breathlessness.

Although exercise training will NOT improve your lung fibrosis, it does improve your cardiovascular conditioning and your muscles' ability to use oxygen. Research has shown that exercise improves exercise capacity, decreases shortness of breath, and improves quality of life in lung fibrosis patients. Pulmonary rehabilitation is a universal standard of care and the "Irish Thoracic Society Position Statement on the Management of IPF" includes pulmonary rehab as part of the patient care pathway.

The American College of Sports Medicine recommends the following as a weekly prescription of exercise:

- ♦ **Aerobic exercise:** Any exercise where you get your heart rate and breathing up. Over a week, you should achieve 150 minutes moderate intensity exercise - 30 minutes, 5 days a week
- ♦ **Resistance or strengthening training** requires the muscles to work and hold against an applied external force which can be by using a machine, a weight in your hand, a resistance band. This type of exercise makes your muscles more efficient at using oxygen.
- ♦ Flexibility, stretching and balance exercises to help reduce the risk of falls.

Exercise will look different for everyone and will depend on the severity of your symptoms and your disease, for some people aerobic exercise might be going out for a brisk walk,

for others that might mean going out for a slow-paced walk, for some patients, aerobic exercise might have to be performed in a seated position in a chair.

It is important to plan your days and fit exercise into your routine but remember not to expend all your energy in one day. With exercise, you need to make sure you are getting the right intensity of exercise. The Borg scale runs from 1 to 10 (0 indicates no breathlessness at all, 10 indicates maximum breathlessness). Aim to keep your level of breathlessness around 3 to 4 for moderate intensity exercise. If you feel your level going beyond moderate, you need to stop, slow down and pull back the level of effort.

When it comes to exercise training, start low and build slow both in the frequency, amount of time, intensity, and type of exercise. Begin with something that is manageable and achievable for you, and slowly build up over time to get those 150 minutes per week, not forgetting the resistance training two days per week. If you have any concerns about exercise or have been completely sedentary, you should consult your doctor before starting any exercise programme.

To exercise safely, avoid strenuous exercise if you are feeling unwell, have an exacerbation of symptoms, always use oxygen while exercising if it has been prescribed for you. The oxygen is to help you to do more so use it appropriately while exercising, pace yourself and allow yourself to recover between exercises. Stop exercising if you experience chest pain, dizziness/fainting or severe breathlessness.

Everyone will have a different preference for how to exercise; whether it's putting on a podcast, going for a walk, doing an online class, going to the gym by yourself – try different things and find out what's best for you. Goal setting will help you to improve your adherence and likeliness to continue with exercise. Be clear in what you want to achieve, set a realistic goal, break it down into smaller steps and write it down or tell someone for accountability!

Monica Devine, Occupational Therapy Manager at Clontarf Hospital in Dublin, delivered a presentation entitled "What do Occupational Therapists do?"

Data from a recent ILFA survey revealed that for a lot of patients with lung fibrosis, there is little access to Occupational Therapy (OT). 45% of IPF patients are not referred to any HSE support healthcare services and only 8% of patients were referred to Occupational Therapy.

There are a lot of specialist treatments that OTs can offer patients with lung fibrosis and the OT role can differ depending on where the OT is based whether in the hospital or in the community. OTs should help you to do things that are important and meaningful to you, such as help with bathing, dressing, eating, leisure, and sleep and this is achieved through education, useful aids and modification of your environment i.e. changing your home environment to make it easier and safer for you.

With hospital OT, the focus is on getting you home from hospital as soon as possible and as independent as possible, helping you with daily tasks such as washing, dressing, and cooking. You will be provided with techniques to make these tasks easier, so you waste less energy doing these essential tasks, energy conservation and stress management.

The Community OT or Primary Care OT will assess you in your home, recommend how you can change your home to make it easier for you to use it, give you equipment to make daily tasks easier, so you waste less energy, and help you with OT reports for grant applications for housing adaptations.

It is important that you are not afraid to ask to be seen by an OT. The referral routes, particularly within hospitals are not established yet, so services may only become available by asking! If you want to see an OT,

- ♦ you can ask at the hospital - whilst the service may not be established, it is becoming more common for patients with lung fibrosis to be seen by OTs
- ♦ You can ask your GP or public health nurse to refer you to a Community OT
- ♦ You can access an OT privately (See the list on the Irish Association of Occupational Therapists website – www.aoti.ie)
- ♦ See an OT privately if you need a grant report done quickly and most of the cost of that will be refunded by your county council.

Monica discussed some of the most important areas of your home that may require adaptation. Considering access to the home – are there steps? do you need a ramp, grab rails, are there holes in the driveway, adequate lighting. In the kitchen you should keep items you use regularly on the countertop to avoid unnecessary effort, use a trolley to carry items, clean spills immediately to avoid falls, consider meals on wheels if cooking is becoming difficult. In the bedroom ensure you have essential items within reach: light, glasses, alarm, and phone. Take your time getting out of bed, ensure the bed is a suitable height, be careful of loose sheets. In the bathroom use a non-slip mat in the bath/shower, consider a shower chair, leave the bathroom door unlocked, never use a towel rail to support your weight, install grab rails beside the toilet and consider a comfort high seat for the toilet. In relation to the stairs, you should always use the banister or rail, take one step at a time, consider a second rail or a stair-lift and don't carry anything on the stairs that requires two hands.

The OT can help you with grant schemes available for home adaptations, which can be expensive.

The Housing Grants Scheme (HAGs) are for private homeowners only with a maximum grant of €30,000. The grant is to help cover the cost of required adaptations to render an accommodation more suitable for the needs of the patient. Typical works include stair-lifts, access ramps, level access showers, and downstairs toilet. The County Council will provide documentation required for applications and discuss all the terms and conditions.

The Mobility Aids Grants Scheme is available to private homeowners only to a maximum grant €6,000. The grant helps cover the cost of basic works for mobility problems such as stair-lifts, access ramps. Please note that a report from an OT is required for stair-lifts.

The Housing Aid for Older People covers electrical re-wiring and roofing repairs etc. No OT report is necessary as the reason for work being required is due to the condition of the property and not ill health.

Disabled Persons Grants Scheme for Tenants - You should contact your Council for more information. It is important to know that for Housing Grants schemes, an application for any housing grant will NOT be entertained where works have commenced. Reports for works to be done should come from a Community OT or private OT but not from a hospital OT. The process can take a long time so plan. You can contact your local council for application forms and information.

Professor John Baugh, Associate Professor in Medical Science at UCD School of Medicine and Research Group

Leader in UCD Conway Institute of Biomolecular and Biomedical Research gave a presentation entitled "Role of the Diet and Microbiome in Respiratory Disease." Professor Baugh is involved in research on inflammatory cells including monocytes, macrophages (cells in the blood that respond to injury and normally co-ordinate a wound healing response) and fibroblasts (cells within the tissue in the lung that build the architecture of the lung and the scaffolding that all the important cells live on).

We all know that fruit and vegetables are good for us but why? We know that the fibre in fruit and veg help support the gut and the bacteria that live within the gut called the microbiota. There are links between the diet, the gut microbiota and gut health, and other organs including the lungs.

A Western diet is typically low fibre and high fat, and this coupled with sedentary lifestyles has contributed to cardiovascular diseases. The greatest number of bacteria is in the gut, and they produce energy for the cells in the gut. Because the modern diet is low in fibre, this causes an imbalance. We know that patients with diseases show a change in their gut bacteria, and we are trying to see if there is a link between the cause and the disease or whether it is just a coincidence. There is a lot of emphasis on emerging links between diet and lung disease - is the microbiome the crucial link? The Western diet has only evolved in the last four generations. One concern is that over the generations, we are losing the beneficial bacteria and they are becoming extinct. We need to protect these bugs to ensure a healthy gut.

There are two main types of dietary fibre (1) Insoluble fibre - the one we are most aware of. This keeps us "regular" and includes whole grains, roughage, brown bread, bran flakes (2) Soluble fibre is found in the same places - in wholegrains, fruit and veg, but it's soluble so it dissolves in liquid. Our digestive system cannot break it down so we cannot use it. Essentially it is a fibre, but it is soluble. It includes pectin in fruit, glucans in oats, inulin in wheat. All vegetables, wholegrains, and fruits (especially those with soluble fibres) form the fuel that these bacteria can breakdown to produce energy for themselves and in doing so, they produce Short Chain Fatty Acids which then get into the blood and circulate.

Prebiotics are the fuels that the bacteria breakdown, probiotics are the bacteria themselves (note there are some benefits to taking these orally) and postbiotics – science is working now to bypass the diet and bypass the bugs and give people the beneficial molecules. There is interest in the pharmacology of these molecules.

As everyone is different, and each person is in a different environment, large population studies are needed to understand the impact of diet on disease. Studies in the US (100,000 patients) and Sweden (45,000 patients) showed a significantly lower risk of COPD in patients who have a high fibre diet. Other studies highlighted that healthy adults with a high fibre diet, had improved lung function and this is independent of other variables. There is no evidence yet from patients with pulmonary fibrosis that diet has an impact on modifying the microbiome, but we do know there is an association between diet and lung function. In animal models, we know that if you feed animals the post-biotic, inflammation is reduced and therefore there are reduced viral problems. Experiments in animals show a benefit from a high fibre but it's very difficult to translate these findings to humans. Nonetheless, there is compelling evidence that manipulating either the diet, the actual bacteria, or the metabolites, can help improve respiratory disease.

Dr Baugh explained that diet can most definitely affect the inflammatory phase of the injury and his laboratory is researching fibroblast responses with financial support from ILFA. Although, the data is preliminary it appears that Short Chain Fatty Acids produced in the gut can modify the behaviour of fibroblasts and reduce their ability to make scars. Getting the balance right might lead to reduced inflammation and potentially help prevent or reduce the fibrotic responses. When it comes to our microbiota, we need to look after our diets by increasing the fibre to produce healthy molecules.

Sean O'Se who is based in Kerry delivered a short presentation entitled "An IPF patient perspective". Sean moved to Ireland after retiring as a Business Analyst in the IT industry. He was a fit person and enjoyed badminton, ballroom dancing and walking every day. 18 months after moving to Dingle he noticed that he was breathless when walking uphill and assumed it was age-related. His GP prescribed medication for reflux and his breathlessness was investigated further.

X-rays showed fibrotic changes in both lungs and Sean was referred to Cork University Hospital. After more tests, Sean was diagnosed with IPF and started on antifibrotic medicine. Sean joined ILFA and said, "I got a nice welcome from Gemma and was invited on an online exercise class run by University Hospital Limerick under physiotherapist Gordon Cagney".

Sean has taken part in the class for over a year and half and finds it very beneficial. Sean spoke about other

opportunities from ILFA that he enjoyed such as the World Café, attending the EU IPFF conference, patient information days, 'Let's talk' sessions, Sing Strong course, and a 12-week respiratory course by Limerick University physiotherapy students.

Sean said "Apart from being incredibly supported by ILFA, and fellow IPF patients, I've gained some really good knowledge about the disease process, especially with sessions like this one today. I've had access to the latest IPF research, respiratory self-care, learning and understanding about palliative care, and awareness of stresses caused to carers. And for me, I have a rewarding feeling that I am not alone in this disease and there are other people that I can talk with." He ended by saying "I want to thank everyone associated with ILFA. ILFA has made a very big difference to my life. Because there is no cure for IPF, I know that at least I am getting support in other areas and it helps me, not just physically, but also mentally. Of course, I have the ever-helpful Gemma – tremendous – always there every week. And I would also like to give a mention to Gordon Cagney and Petra Grehan for the excellent exercise classes".

A video of the Patient Information Day is available to watch via the ILFA website and You Tube channel. Sincere thanks to Paula Jennings for volunteering her skills and transcribing the text of the event for ILFA to edit.

Terence Moran Memorial Award

The Irish Thoracic Society Interstitial Lung Disease Education Day took place in September 2021. The event was held as a virtual ILD Multi-Disciplinary Team and Clinical Update with case presentations from trainees in respiratory medicine and contributions from leading clinicians. ILFA was humbled that the inaugural Terence Moran Memorial Award, named in honour of our esteemed founder and leader for 15 years, was awarded to the best-case presentation. The finalists for the Terence Moran Memorial Award were:

- Dr Padraic Ridge, Galway University Hospital
- Dr Eamon Mullen, Connolly Hospital
- Dr Peter Leahy, St Vincent's University Hospital
- Dr Sean Garvey, Beaumont Hospital
- Dr Liam Chawke, Mater Misericordiae University Hospital

Professor Jim Egan, Mater Misericordiae University Hospital spoke eloquently about Terence Moran with a warm and fitting tribute. Both men had worked together to set up ILFA in 2002, along with Nicola Goodbody and Marie Sheridan. The charity flourished under Terence's leadership, and the ILFA committee was shocked and saddened when Terence passed away suddenly in 2018. Nicola Cassidy, ILFA Director, also paid tribute to Terence and described how much this special award means to Terence's family, the ILFA committee and the wider ILFA community. Professor Killian Hurley announced that the winner of the Terence Moran Memorial Award was Dr Liam Chawke, Specialist Register at the Mater Misericordiae University Hospital. Warmest congratulations to Dr Chawke on his success. Dr Chawke will receive an engraved Dublin Crystal Award and an educational bursary as part of his prize.

ILFA's World Café is shortlisted for an Irish Healthcare Award

The Irish Healthcare Awards are Ireland's most prestigious medical awards. This was the 20th year of the awards that recognise and celebrate the impressive and diverse projects in innovation and excellence across the Irish healthcare sector. The Irish Lung Fibrosis Association was delighted to receive news that our multi-stakeholder "World Café on Pulmonary Fibrosis during Covid-19 and Beyond" was shortlisted for the Patient Organisation Project of the Year 2021. We were nominated alongside two other great charities; Asthma Ireland and Croi (who were the overall winners) in this hotly contested category. The black-tie awards night took place on Monday 15th November in Dublin. Nicola Cassidy (ILFA Director) and Gemma O'Dowd (ILFA Administrator) attended the dinner along with representatives from Roche Products Ireland, who supported the World Café, with additional support from The Community Foundation of Ireland / RTE Does Comic Relief Adapt and Respond Fund. Everyone had a lovely night out and enjoyed the awards ceremony that was presented by Dr Nina Byrnes.

Dr Tony Holohan, Chief Medical Officer of Ireland, received the Outstanding Contribution to Irish Medicine Award and delivered a virtual address to the attendees, thanking everyone for their good wishes. Dr Holohan thoroughly deserved the award and kindly dedicated it to the healthcare staff of Ireland who have worked so caringly under enormous and relentless pressure during the Covid-19 pandemic.

It was great to learn about amazing healthcare initiatives that are improving patients' lives across the country. ILFA was thrilled to be nominated and although we didn't win, we were delighted that our patient-centred work was recognised and helped create awareness of the healthcare challenges facing lung fibrosis patients. Sincere thanks to everyone who sent us good luck messages.



Nicola Cassidy and Gemma O'Dowd.

Advocacy

ILFA Joins HRCI

The Irish Lung Fibrosis Association (ILFA) was accepted as a member of Health Research Charities Ireland (HRCI) in September 2021 after a successful application. HRCI is the national umbrella organisation of charities active in medical and health research, together representing over 1 million Irish patients. 40 members span many areas of health, including rare diseases and many forms of chronic illness and disability. Through support and advocacy, HRCI represents their joint interests, working with them and the wider health research community to improve health and prevent illness through research.

Irish Donor Network Activities

The Irish Donor Network (IDN) is a group of patient organisations who advocate for organ donation and transplantation in Ireland. The patient groups include Cystic Fibrosis Ireland; COPD Support Ireland; Cystinosis Ireland; Children's Liver Group, the Irish Lung Fibrosis Association; the Irish Thoracic Society; the Irish Heart and Lung Transplant Association; and Alpha-1 Foundation Ireland. On 30th September, the IDN issued a press release to express deep concern at significant decline in transplantation and organ donation rates and call for a range of measures from the government. The press release highlighted some important data in relation to organ donation and transplantation.

- Organ transplant rate decreased by 32% in 2020 compared with 2019 with deceased organ donation rate down by 27%
- Ireland was placed 18th out of EU 28 countries for transplants in 2020 (down from 14th place in 2019)
- Ireland was placed 17th out of EU 28 countries for deceased organ donation in 2020

The IDN called on the Government to revive organ donation and transplantation in Ireland by developing a plan to bring Ireland into the Top 10 EU countries for transplantation and organ donation; increasing investment in facilities and staffing; and enacting the Human Tissue Bill to introduce soft opt-out organ donation. In Ireland, data from Organ Donation Transplant Ireland revealed that:

- Lung transplants down 58.2% in 2020 compared with 2019
- Heart transplants down 42% in 2020 compared with 2019
- Liver transplants down 44.9% in 2020 compared with 2019
- Kidney transplants, from both living and deceased donors, are down 21.3% compared with 2019

The IDN has repeatedly called for the urgent enactment of the Human Tissue Bill and soft opt-out organ donation to make more organs available for transplantation, as per the commitments of the current and previous Programmes for Government. There is a need to accelerate the full return of all transplant facilities used for COVID-19 (and those impacted by COVID-19) for their original transplant purpose and to significantly increase investment in organ donation and transplantation, including an immediate organ donation and transplant 'revitalisation fund.'

Philip Watt, Chairperson, Irish Donor Network and CEO Cystic Fibrosis Ireland said "The Irish Donor Network is aware

that one of the key reasons for the decline in transplants in Ireland between 2019 and 2020 is that transplant resources, including clinical staff, were diverted to treat COVID-19 patients, or because transplants and assessments were paused due to facilities being adjacent to COVID-19 wards. This is likely to explain, for example, why the heart and lung transplant programme in the Mater Hospital was most disrupted by COVID-19 compared with all transplant programmes. "It's also likely that the number of transplant assessments decreased significantly during this period, so the lengthening waiting lists for approved transplants will not give the full picture of all those who need a life-saving transplant."

World Physiotherapy Day

World Physiotherapy Day took place on 8th September and ILFA extended our best wishes on social media to all physiotherapists especially those helping lung fibrosis patients reach their full potential. Special thanks to Gordon Cagney, Niamh Julian, Petra Grehan, Roisin Cahalan and Kate Devenney for their help in delivering online classes in association with ILFA in 2021.

Healthcare Education

ILFA recently awarded educational bursaries to 8 clinicians from various hospitals to study Cognitive Behavioural Therapy (CBT). The award recipients are:

- Gordon Cagney, Respiratory Physiotherapist, University Hospital Limerick
- Carmel McNerney, Advanced Nurse Practitioner Respiratory, Ennis Hospital
- Liga Kokina, Respiratory Clinical Nurse Specialist Respiratory University Hospital Limerick
- Olivia Quinn, Clinical Nurse Specialist, Nenagh General Hospital
- Jean Ryan, Clinical Nurse Specialist, Mater Misericordiae University Hospital
- Noelle Ryan, Clinical Nurse Specialist, University Hospital Limerick
- Grainne Coffey, High Dependency Unit, Tralee University Hospital
- Grainne Murphy, Senior Respiratory Physiotherapist, Mater Misericordiae University Hospital

Anail Conference 2021

The Anail Respiratory Nursing Conference took place virtually on 17th September. Nicola Cassidy, ILFA Director, gave an update on ILFA's recent news and events and began by thanking all the healthcare professionals for their incredible efforts during the pandemic. ILFA is grateful to Anail for the opportunity to raise awareness about our work.

ILFA'S Virtual Candle Lighting Ceremony



In October we usually celebrate the ILFA Ecumenical Service of Prayer and Reflection and gather as a community. Even though some of the public health restrictions had eased, we decided that the ILFA Service would not take place to ensure everyone's health and safety.

For the second year running, ILFA invited people to light a candle at home at 6pm on Saturday 23rd October in support of patients and their families, and to remember loved ones with lung fibrosis who have died.

We were delighted that so many of the ILFA community near and far responded to this event from the comfort and safety of their homes. We even had people join us from as far away as Norway and the USA and candles were lit in support of lung fibrosis patients and in memory of those who are no longer with us. Many people posted appreciative comments and shared photos on the ILFA Facebook page. A selection of photos is included here. The candle lighting event proved to be a unifying, and comforting activity for many people. Thank you all for coming together virtually as a strong and supportive community.



Greetings from Canon Charles Mullen

"The lifting of Covid-19 restrictions has been welcomed by most, though many of us remain cautious. The restrictions forced difficult adjustments on us, yet amongst the problems there are 'lock-down' things I find comforting. The phone, messages, e-mails, cards, and letters, along with Zoom, Teams and so on have kept us in touch so that we feel less isolated but still safe. Added to these is prayer – our conversation with God through which we offer our requests, our concerns about the wellbeing of others, and our thanks for God's mercies. We come to know that we're surrounded and supported by the prayers of others, by the faithful departed, by the saints and angels, the whole company of heaven.

A wonderful example of this is the remote candle lighting ceremony to support us in prayer and to remember the dear faithful departed who died in the hope of the Resurrection.

We're greatly blessed by our fellow members of ILFA. We give thanks for all ILFA does to keep us together as a community that hasn't been diminished by restrictions, but which continues to flourish every time we remember one another and keep in touch with one another and pray for one another."

The Reverend Canon Charles Mullen
Dean's Vicar,
St Patrick's Cathedral, Dublin

Research

Irish Thoracic Society Meeting

The annual meeting of the Irish Thoracic Society took place virtually on 19th November. ILFA presented three electronic posters at the event that were based on recent research activities.

1. The Irish Lung Fibrosis Association's Multi-Stakeholder World Café on Pulmonary Fibrosis Services in Ireland During Covid-19 and Beyond:

This work described the methodology and results of ILFA's virtual World Café forum to identify key stakeholders' experiences of healthcare services during COVID-19 and priorities for future care. Seventy-two people participated and discussed (1) Diagnostics, (2) Healthcare Supports, (3) Psychological Support, (4) Integrated Care. Most patients experienced significant delays in diagnosis; paucity of access to dietetic advice, palliative care, social support, and psychological services for patients and caregivers, and lack of integrated care across hospital and community-based services. Post COVID-19, a blend of face-to-face and virtual care while considering patient preference could improve future healthcare access. The findings of the World Café indicate that a National Clinical Programme for pulmonary fibrosis is required to improve diagnosis and ensure equity of access for healthcare supports.

2. Lung fibrosis patients identify deficiencies in vital healthcare support services: ILFA conducted an online survey from 19 July-2 August 2021 to determine the healthcare support needs and experiences of lung fibrosis patients. 99 lung fibrosis and 13 post-transplant patients responded. The results showed that essential support services are lacking for lung fibrosis patients.

- 42% of patients did not have a clinical nurse specialist
- 62% had never been referred to a physiotherapist-led pulmonary rehabilitation programme
- Only 25% were referred to a dietitian and other services; social worker (9%), occupational therapist (8%), palliative care (6%), clinical psychologist (6%) and speech therapist (3%)
- 45% of patients had not been referred to any service

For all services, most referrals happened more than 12-months after diagnosis, but patients felt they would have benefitted from referral to the following specialties at the time of diagnosis; physiotherapist-led pulmonary rehabilitation programme (65%), dietitian (51%), clinical psychologist (45%).

3. Survey of pulmonary fibrosis patients who participated in online group exercise classes to facilitate physical activity during Covid-19 pandemic:

ILFA was delighted to collaborate with the respiratory team at University Hospital Limerick on the survey of ILFA's online exercise classes. The physiotherapist-led weekly exercise classes commenced in May 2020. 53 participants completed an online survey in May 2021 to assess the impact of the virtual classes and attitudes towards physical activity.

- 94% of patients were diagnosed with IPF, 6% were post-transplant patients

- 36% used oxygen all the time or most of the time
- 11% of the respondents were on a public waiting list for either face-to-face or virtual pulmonary rehabilitation.
- A rating of 'excellent' was awarded by 73% of respondents for help in overcoming anxiety about exercising online.
- 64% reported being more active and 68% reported being less fearful about doing exercise since starting the online classes.

Overall online exercise classes have provided substantial physical and emotional benefits to IPF patients.

ILFA Research Published in the BMJ Supportive & Palliative Care

ILFA's patient centred research entitled "**Fibrotic interstitial lung disease - palliative care needs: a World-Café qualitative study**" was published in the British Medical Journal Supportive & Palliative Care in October 2021. The paper describes the methodology and outcomes of the ILFA World Cafe on Palliative Care and Planning for the Future that took place in June 2018.

Sincere thanks to everyone involved in this project especially the patients, carers, healthcare professionals and industry professionals who participated in the World Cafe, and the facilitators, leaders, and note-takers. Special acknowledgment to our wonderful medical writer Amy Boulstridge, who provided enormous help and support progressing the paper. Thanks also to our amazing collaborators and friends - the healthcare professionals, patients and carers who contributed to the paper. You can read the article via the ILFA website, www.ilfa.ie

Celebrating our recent publication!



In November some of the authors of "Fibrotic interstitial lung disease - palliative care needs: a World-Café qualitative study" met online to celebrate the publication of ILFA's patient-centred research. Huge thanks to everyone involved in this valuable collaborative project. ILFA would like to dedicate this special paper to Liam Mullaney, Joan Doyle, Barney Meaney and Kathleen Evans who were involved in the project both in 2018 and more recently, but who have since passed away. Their contributions helped shape this important research and we are grateful to them for sharing their experiences and insights.

ILFA's Online Activities for Patients

Here are some of the online activities offered by ILFA. Please contact us if you would like to know more, get information on how to use Zoom to join the events, and to register in advance to take part. Email info@ilfa.ie or call **086 871 5264** to join the class. We look forward to seeing you!



physiotherapists delivering the classes.

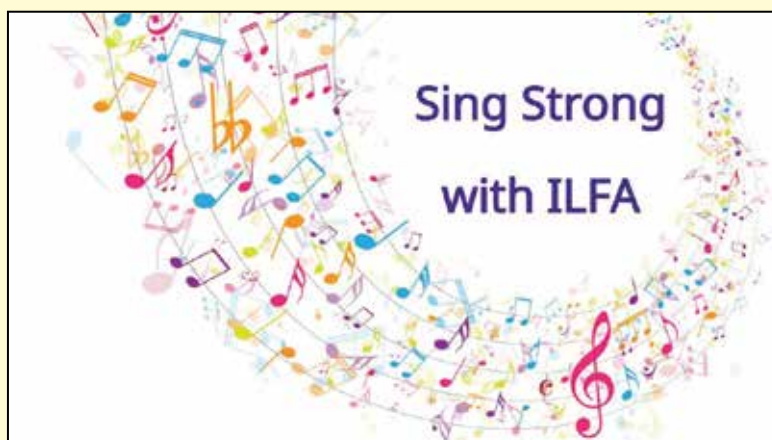
ILFA's online exercise classes for lung fibrosis patients usually take place on Monday and Thursday every week at 11am. Occasionally we need to change the time and date to suit the schedule of the respiratory

We are enormously grateful to Gordon Cagney, Respiratory physiotherapist at University Hospital Limerick and Petra Grehan, Respiratory Physiotherapist at the Mater University Hospital for their work and commitment to the exercise classes. We have received great feedback and appreciation from the participants.

Online Support Group Meetings take place every few weeks via Zoom. Participants can meet in small groups for a social chat and to exchange tips and experiences. People join from all over the country, and this helps greatly to reduce feelings of isolation and enables new friendships to be established.

Sing Strong classes take place weekly with Ciara Meade, Choir Mistress. The classes are great fun with many participants reporting improvements in breathing, wellbeing, and impact of their disease. If you would like to know more or to register for future classes. Please contact ILFA.

Keep an eye on the ILFA website (www.ilfa.ie) and our social media channels for upcoming events.



Sing Strong for Pulmonary Fibrosis

Sing Strong for Idiopathic Lung Fibrosis (ILF) is a singing and breathing retraining programme that was delivered to members of ILFA during the spring of 2021. Originally piloted in people with Chronic Obstructive Pulmonary Disease (COPD), the programme is led by Dr Roisin Cahalan, Senior Lecturer in Physiotherapy at the University of Limerick and vocal coach and choir leader Ms Ciara Meade. The 45-minute online weekly classes are comprised of gentle physical and vocal warm-ups, breathing re-training and of course, singing. The rationale for the intervention is that by developing good vocal techniques, key muscles of respiration are also strengthened, leading to improved breathlessness control, endurance and overall quality of life for participants. Not to mention, that it's great fun and very sociable, even in an online setting.

An evaluation of the ILFA Sing Strong programme involving data from 15 participants has shown promising results. The eight males and seven females had an average age of 67 years (range 49-78 years), and were mostly retired (80%), not seeking work (13%) and one person was in full time employment. Questionnaires were completed by participants before and after the Sing Strong intervention,

including the St Georges Respiratory questionnaire which is a detailed evaluation of the impact of disease on all facets of a person's life. There was a small but clinically non-significant improvement in the result of this questionnaire post intervention. A second ILD-specific questionnaire focussing on breathlessness and the impact of the disease showed a significant improvement in outcomes after the Sing Strong programme. Participants also separately reported small improvements in how they felt generally, and in the urgency of coughing post intervention.

Importantly, on a scale of 1 to 5 (5 being the best score), participants reported the average effectiveness of the Sing Strong programme in helping the management of their lung disease at 3.7/5 and programme enjoyment at 4.7/5. All but one of the 15 participants said that they would be happy to engage in another session of Sing Strong if it were available. On that note, we at Sing Strong are extremely happy to be collaborating with ILFA to roll out the next programme of Sing Strong classes, which is currently underway.

Report by Dr Roisin Cahalan, Senior Lecturer in Physiotherapy at the University of Limerick.



John Fitzgerald, Mary Madigan, Pat Madigan and Fiona Fitzgerald, winners of the team event with Sally Brennan.



Visiting team from Wexford Golf Club - Sally O'Neill, Osnat Manning, Martina Dempsey and Ann Conway with Sally Brennan.



Margaret Gallagher and Eileen Walsh relaxing on Carmel's seat.



Sally Brennan with Kathleen Walsh who won the 9-hole competition.

CLASSIC @ THE CASTLE

“On Saturday 11th September 2021, Waterford Castle Golf Club hosted a special fundraiser in memory of their esteemed former member, Carmel Flynn. Carmel was a founder member and trustee at Waterford Castle Golf Club and served selflessly for 25 years in a variety of roles. Sadly, Carmel passed away in May 2020, having been diagnosed with Pulmonary Fibrosis in 2019. The Classic @ The Castle golf event raised €21,000 in total and all proceeds went to the **Irish Lung Fibrosis Association and Waterford Hospice**, both very worthy charities who supported Carmel during her illness.

There was huge interest in the open four-person classic with any combination of ladies and gents allowed to play. Fifty teams took part on the day with the first team out at 8am. We also had more than 30 playing the 9-hole singles competition.

In conjunction with the golf classic, a Mega-Draw was organised which was greatly supported. The prizes for the golf classic and draw were exceptional and were all donated by very generous sponsors. Prizes included fourballs in some of Ireland's best golf courses, short breaks in some of Ireland's nicest hotels and the very best of Waterford Whiskey to mention but a few.

The good weather really added to the special occasion and there was a fantastic atmosphere around the clubhouse all day long. Carmel's brother Oliver came over in the afternoon and was delighted to meet so many of Carmel's friends. Without a doubt the Classic @ The Castle on September 11th in memory of Carmel was the highlight of the year for Waterford Castle Ladies' Club - a fitting tribute to Carmel who was such a dedicated club member and a wonderful friend to so many.

The Ladies Club at Waterford Castle Golf Club would like to thank everyone who sponsored prizes, tee boxes and greens. Also, many thanks to those who helped on the day and made it such an enjoyable occasion for members and visitors alike. A special thank you to Val Kennedy and the pro shop team who helped us in so many ways and contributed hugely to the success of the day. We would also like to thank Seamus Walsh, owner of Waterford Castle Hotel and Golf Resort, for his generosity in making the golf course available for this very special event.”

Report by Sally Brennan



Right: First team out at 7.50am representing the pro shop Frankie, Gavin, Val and Brian pictured with Sally and Karen. Left: Bridget and Sheelagh with Carmel's brother Oliver.

Cheque Presentation

Liam Galvin, ILFA Director, attended a cheque presentation on Saturday 6th November with Sheelagh Browne and Sally Brennan of the Classic @TheCastle in Waterford.

In September 2021, Waterford Castle Golf Club hosted a special fundraiser in memory of their esteemed former member, Carmel Flynn. The event raised a fantastic sum of money that was shared between ILFA and Waterford Hospice. ILFA was thrilled to receive €10,500 from the organisers and we are enormously grateful to Sally Brennan and the team at Waterford Castle Golf Club for their help and wonderful support.



Liam Galvin (ILFA Director) accepting a fundraising cheque from Sheelagh Browne and Sally Brennan.

VHI Women's Mini Marathon



Siobhan Fagan after completing her 10k challenge.

Siobhan Fagan, a nurse from Connolly Hospital in Dublin took part in the VHI Women's Mini Marathon in memory of her friend and colleague Christine Ormsby McCarthy. Siobhan kindly fundraised for ILFA and told us "It was an emotional but lovely day. Thank you for your help and support." Congratulations Siobhan and sincere thanks for your support.



Margaret McIver, Rosemary Wilson, and Rita O'Regan after their mini marathon.

Congratulations to three of our most loyal fundraisers; Margaret McIver, Rosemary Wilson, and Rita O'Regan who took part in the Women's Mini Marathon on Sunday 19th September in Dublin in aid of ILFA. Each year, we're always delighted to see these great friends taking on the 10k challenge in their ILFA t-shirts. Huge thanks from all of us!



Lisa McGowan.

Congratulations to Lisa McGowan in Roscommon who took part in the VHI Women's Mini Marathon 2021 to raise funds for the Irish Lung Fibrosis Association. Thanks to Lisa for her wonderful support in 2021 and in previous years.

Cork Mini Marathon



Congratulations to the ladies who participated in the Cork Echo Mini Marathon on Sunday 19th September. The team was led and inspired by Irene McGrath who received a lung transplant in 2020. Irene was joined by her family members; Valerie Daly, Anna-Marie Kavanagh, Gina O' Sullivan, Eleanor Kavanagh, Emma Daly, Sarah Sheehan and Deirdre Kavanagh. The ladies were cheered on by members of the Cork Pulmonary Fibrosis Support Group. Well done and sincere thanks from everyone at the Irish Lung Fibrosis Association.

Mary Gamble and Gladys Seymour also took part in the Cork mini marathon to raise funds for ILFA. We are very grateful to Mary and Gladys for their great support.

Media Coverage

Irene McGrath's remarkable story featured in the Cork Echo in September 2021 and helped raise valuable awareness about pulmonary fibrosis and the importance of organ donation and transplantation. Irene was diagnosed with scleroderma in her 30's and this auto-immune disease subsequently led to pulmonary fibrosis. In the article written by Maeve Lee, Irene explained that she required oxygen and was on the waiting list for a lung transplant for four years. Thankfully Irene received a

double lung transplant in 2020 and hasn't looked back since.

Irene expressed enormous gratitude to her donor and their family along with her "fantastic" husband, family, and friends and all those who sent her cards and best wishes. Irene decided to take on the challenge of the Cork Echo mini-marathon with family and friends and said "It's just a new lease on life. It's being able to do walk and jog hopefully, 6k on Sunday, but it's something I wanted to do to prove I can do it and to give something back to ILFA." She described the work of ILFA as "pure amazing". Irene was joined by her sisters Gina O'Sullivan, Valerie Daly and Annamarie Kavanagh, sister-in-law Deirdre Kavanagh, and nieces Emma Daly and Sarah Sheehan. Photos of Irene and her team are reprinted courtesy of the Irish Examiner. No doubt Irene will have inspired many, many people with her recovery and enthusiasm to take part in the Cork mini-marathon following her life-saving double lung transplant surgery.

Earlier in the summer Irene sent us in some photos following a trip to Skellig Michael with her family. Irene climbed the 600 steps, less than 1 year after her lung transplant, and met Keith Duffy (Boyzone fame) on the trip. She asked for his consent to share his photo in the ILFA newsletter, so we're delighted to oblige!

Fundraising Round Up

The ILFA committee would like to extend our sincere thanks to everyone who supported our work in 2021 through volunteering, fundraising, donations, and support. This year was especially challenging as many fundraising activities were cancelled or moved online resulting in a reduced income from fundraising activities compared to previous years.

We were blessed to have 3 major fundraising events in 2021 that significantly buoyed our finances.

Remembrance Walk for Christine McCarthy was organised by staff from the Theatre Department at Connolly Hospital in March 2021. This special fundraiser enabled Christine's friends and family to unite virtually to celebrate her life on her one-month anniversary. They raised an incredible €13,762.62 for ILFA.

Pedal the Perimeter of Ireland Cycling Challenge with the Dublin Minor Footballers and Management Team took place in April 2021 and helped raise great awareness of lung fibrosis. This great fundraiser raised over €10,600 for ILFA.

Classic @TheCastle was organised by Sally Brennan of the Waterford Castle Golf Club and took place in September 2021. ILFA was thrilled to receive €10,500 from the organisers and Waterford Hospice also benefitted from the proceeds of this event.

ILFA also received valuable **donations via Facebook Fundraising**, and we would like to thank everyone who held a birthday fundraiser and those who donated to ILFA over the year. We are humbled to have support from amazing individuals and groups who are committed to fundraising and raising awareness of lung fibrosis. Their hard work ensures ILFA can fulfil our aims of research, education and support for lung fibrosis and continue to help patients, families, and healthcare professionals. **Please contact ILFA if you have any fundraising ideas or would like to make a donation.**

Inspired Painting by Matt Cullen

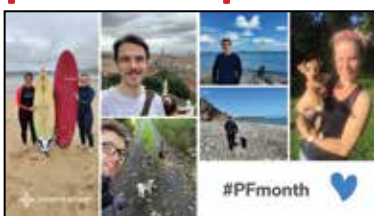


Matt Cullen is a talented artist living in Dublin and known to many people within the ILFA community. Matt recently made a kind donation of €200 to ILFA following the sale of one of his paintings entitled "For peat's sake it is the end of the line!" An image of Matt's impressive painting is included here

with kind permission from the new owner of the artwork.

We are very grateful to Matt for his generous donation that will help support our work.

IPF Awareness Month at patientMpower



Sincere thanks to the team at patientMpower for their kind donation to ILFA following their staff fundraising walks to mark Idiopathic Pulmonary Fibrosis Awareness Week

in Europe. Megan Kerr contacted ILFA with a short report and some photos of her patientMpower colleagues. "IPF awareness month took place globally in September 2021 and the patientMpower team showed their support by taking part in a virtual walk across all corners of the globe, sharing important facts about Pulmonary Fibrosis on their social channels throughout the month of September and donating to some amazing IPF support groups, which included the Irish Lung Fibrosis Association."

West Kerry Tractor Run



The third West Kerry Tractor Run/Mórchuaird Tarracóra Chorca Dhuibhne was led in style by the irrepressible Seamus Devane in his 'popemobile', along the highways and byways of the peninsula on Sunday 28th November. As well as raising much needed funds for our chosen charities (West Kerry Community Hospital, Gairdín Mhuire & ILFA), it raised the hearts of many to see so much incredible community spirit on show.

The organisers would like to pay particular thanks to John Liston and his staff at Dingle Eco Farm, Joe Dwyer, the Garda Síochána, The Marina Inn, and Dingle Chamber of Commerce. The meitheal of stewards who directed traffic at every junction along the route, in the rain, to ensure the convoy passed through safely deserve a special mention. So many offered their time to help that we were running out of jobs for them!

The event would not happen without the farmers and

contractors who travelled from all over the locality to take part. Huge thanks to the one hundred individuals who showed up (especially the hardy souls on the vintage tractors) despite the fog and rain. Thanks also to all the photographers, videographers and journalists who have advertised and highlighted the event. A final heartfelt thank you to everyone who has donated to the tractor run. Covid has made the past year and a half very difficult for so many, but it does not seem to have affected the overwhelming generosity of the people of Kerry with close to €10,000 being raised so far. Donations are still welcome through the Go Fund Me page or directly into the tractor run credit union account. Míle míle buíochas.

Credit Union Details

IBAN: IE 12 CCHD 99220110 100 136

BIC: CCHD IE 21

Repot by Sharon O'Sullivan

Set yourself a challenge for 2022

If you're setting yourself a fitness challenge or a personal challenge for 2022 and would like to fundraise for ILFA, please get in touch. Perhaps you'll undertake a daily step challenge, start training for a race, marathon, triathlon or commit to 100 days of walking or even a 'dry January'. ILFA will gladly support you and help with fundraising logistics and raising awareness. Best of luck!

Giving in Remembrance

Thank you to families who requested donations to ILFA in lieu of flowers at the funerals of loved ones to honour their memory. We are always humbled by the capacity of people to think of ILFA at times of deep personal loss. Thank you for your kind support.

Giving in Celebration

Celebrate your special occasion by asking family and friends to donate instead of buying you gifts. Enjoy your birthday, wedding or special anniversary celebrations knowing you're supporting ILFA's work. Please contact ILFA if you would like information on how we can support you to support us.

Legacy Giving

A legacy gift or a charitable legacy is a donation left to a charity in an individual's will. If you are making your will or updating it, please consider leaving a legacy gift to ILFA after you have looked after your loved ones. All amounts would be greatly appreciated and will be used to help ILFA continue our work supporting lung fibrosis patients. As an added benefit, all legacy gifts are excluded from inheritance tax. If legacy giving is something you would like to do, please update your will to reflect your decision and ensure that your wishes are carried out in the future. Thank you.

Partnering with ILFA

There are many ways your company, business, society, sporting body, school, college, or club can be involved in supporting the work of ILFA. We would be delighted to work with organisations of all sizes seeking a charity partner through corporate social responsibility or simply giving back to society to help raise awareness and valuable funds. In return, we will support your campaign with ILFA branded merchandise and fundraising assistance, and will gratefully acknowledge your support online, in print and via social media to recognise your

commitment to charity. Please consider ILFA as a potential partner for the future and help make a difference. Contact ILFA on 086 871 5264 or email info@ilfa.ie for more information.



Making a Donation to ILFA

The Irish Lung Fibrosis Association is the national patient organisation for Lung Fibrosis patients, families and healthcare professionals working in Interstitial Lung Disease. ILFA was founded in 2002 and became a company limited by guarantee in 2003. ILFA is run by a group of dedicated volunteers whose lives have been touched by Lung Fibrosis. The committee is enormously grateful to everyone who fundraises and makes donations to help support our work. If you would like to help, there are several ways to make a secure donation to the Irish Lung Fibrosis Association (ILFA) and we hope you will find a method that is convenient for you. Please ensure you use the correct name for our charity to guarantee that ILFA receives your donation. The Irish Lung Fibrosis Association is **NOT** the same charity as the Irish Lung Foundation.

On-line donations for ILFA

Just Giving: You can donate easily and securely to ILFA directly using your debit or credit card via the online site www.justgiving.com and searching for 'ILFA'. A small percentage fee is applied when using this platform, but donors can choose to pay this to ensure ILFA benefits from 100% of the donation.

Facebook Fundraising: ILFA Ireland has been added to Facebook Fundraising making fundraising campaigns easy and secure for ILFA's Facebook friends and followers. 100% of donations go to ILFA. www.facebook.com/fund/ILFAIreland/

Paypal Giving Fund: ILFA Ireland has been added to Paypal Giving Fund. When you donate to PayPal Giving Fund through this page, 100% of your donation will go to ILFA <https://www.paypal.com/ie/fundraiser/charity/4043546>

Standing order: Why not consider making a regular contribution of your choice to ILFA using a standing order? A standing order form is available from ILFA or can be downloaded via the website www.ilfa.ie for your convenience. Once completed, the form can be returned to ILFA and forwarded to your bank for processing.

Bank transfer: You can transfer money directly to ILFA's Bank Account. Please contact ILFA by calling 086 871 5264 or by emailing info@ilfa.ie for our bank account details.

Patient Support Groups

The ILFA pulmonary fibrosis support groups monthly meetings remain cancelled for the foreseeable future in the interest of patient safety. We hope that the face to face support group meetings will be able to resume in the future and will update the website with this information. Stay safe everyone.

Cavan Monaghan Support Group

Please call Kevin on 085 243 6828 or 087 762 3485 for more details.

Clare Pulmonary Support Group

Please call Michael on 087 637 4068 for more details.

Cork Support Group

Please call Anne on 087 985 4587 for more details.

Dublin Support Group

Please call Matt on 086 244 8682 or Pam on 086 178 9055 for more details.

Kerry Support Group

Please call John on 087 280 9801 for more details.

Midland Support Group

Please call Val on 087 233 2653 for more details.

Mid West Support Group

Please call Noreen on 087 262 7976 for more details.

ILFA would like to thank the support group leaders for their commitment. For safety reasons, the groups will not meet in person during the Covid-19 outbreak but will use mobile phone technology to have virtual meetings and stay connected.

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

086 871 5264

Email Correspondence

If you are registered with ILFA and have an email address, we would be grateful if you would send it to ILFA (email info@ilfa.ie) so we can update our records. If you are happy to be contacted via your email address, ILFA can communicate with you more easily if we have upcoming events or important news to share. Rest assured your contact details are stored securely and not shared with other parties as required under GDPR.



Christmas Message

The ILFA committee would like to wish all our members a very happy and peaceful Christmas and a happy and healthy new year. We hope you will be able to spend time with your loved ones and enjoy the festivities. Thank you for your wonderful support over the year.

Dates For Your Diary

- **ILFA's Virtual Exercise Class** for lung fibrosis patients takes place every Monday and Thursday at 11am via Zoom. The classes are led by a respiratory physiotherapist.
- Small and virtual sporting and fundraising events are currently taking place in line with public health guidance. If you are planning on taking part in a virtual walk, run or jog or another event in 2022 for charity, please consider raising funds for ILFA.
- **ILFA's Patient Information Day** will take place online on Saturday 11th March 2022 online via Zoom. See page 1 and keep an eye on the website, www.ilfa.ie, for updates.

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.

