

# ILFA Newsletter



Irish Lung Fibrosis Association  
www.ilfa.ie

**Patrons:** Michael Darragh Macauley, Charlie Bird, Andrea Corr.

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## Covid-19: A message from the ILFA committee



The ILFA committee would like to take this opportunity to thank all our members and friends for your continued support in these challenging times. We are especially grateful to Gemma O'Dowd, ILFA's administrative assistant, who has supported and reassured patients and family members who have contacted ILFA with their questions and concerns. We thank our newsletter designer Niamh Hogan and our printer Ben Brady and his colleagues for helping us reach out to you via this newsletter.

ILFA is in regular contact with the Department of Health via the Covid-19 stakeholder group and will keep you updated with news via our website and social media channels. Please continue to follow the advice and requirements of the Health Service Executive (HSE) and public health experts in relation to handwashing, social distancing and self-isolation, and use only trusted websites and news outlets for your news updates.

At this time of uncertainty, it is important that we look after each other, act responsibly, be kind and stay strong. Our support group networks have closed for the moment but please call Gemma if you are a patient who would like to speak to another patient by phone and we'll see if we can help you with valuable peer support. Remember that it's okay not to be okay and talking to others might help. If you live alone or are self-isolating and need help collecting your groceries,

prescriptions, running errands etc., please contact ILFA and we will see if we can match you with a 'community hero' to have your items delivered to the safety of your home.

Given the enormity of what lies ahead in the coming days and weeks, we think especially of ILFA's network of respiratory healthcare professionals who work in hospitals, hospices, and community settings around the country; the doctors, surgeons, nurses, physiotherapists, allied healthcare professionals and care assistants who will be called to work in the most difficult and challenging of circumstances. You have always been there for us and loyally supported ILFA's work, and now we send our thoughts, prayers and gratitude to you - our heroes. We wish you and your families good health and wellbeing.

ILFA would also like to send sincere and heartfelt thanks to all frontline HSE staff who are working diligently and compassionately to ensure our safety and care for those who are ill. We thank our government leaders and politicians for being decisive and making difficult decisions to protect us, we thank the policy makers for their expertise and guidance, and we thank those working in key service industries who work so hard to meet our daily needs.

Although most of us are in isolation, everyone matters, and as a community we stand united and remain collectively strong together. We look forward to brighter, happier, safer days.

## Irish Healthcare Award Commendation for ILFA

Everyone at the Irish Lung Fibrosis Association was over the moon when two of our recent patient-centred projects were short-listed for Irish Healthcare Awards in 2019. Our first project entitled '**Namaste- ILFA's Yoga DVD for Lung Fibrosis**' was shortlisted in the hotly contested **Best Patient Lifestyle Project** category along with 9 other outstanding patient organisation projects. Our second project '**ILFA's World Café on Palliative Care and Planning for the Future with Lung Fibrosis**' was shortlisted in the highly competitive **Best Patient Organisation Project of the Year** category with 4 other contenders.

The awards night took place in November 2019. Nicola Cassidy (ILFA Director) and Gemma O'Dowd (ILFA Administrator) were joined by Dr Anne-Marie Russell who expertly helped develop and facilitate the World Café on Palliative Care and Planning for the Future, and Pamela Martin, Evelyn Cooper and Matt Cullen who starred in the Yoga DVD along with ILFA Patron and Dublin GAA Star, Michael Darragh Macauley. ILFA was thrilled when the World Café on



**Above:** Nicola Cassidy, Anne-Marie Russell, Gemma O'Dowd, Matt Cullen, Evelyn Cooper and Pamela Martin. **Left:** Gemma O'Dowd, Nicola Cassidy and Anne-Marie Russell.

Palliative Care and Planning for the Future was awarded a commendation. This collaborative project involved patients, carers, healthcare professionals, industry representatives and leaders in patient care.

# Coronavirus COVID-19



Coronavirus  
**COVID-19**  
Public Health  
Advice

**If you have fever and/or cough you should stay at home regardless of your travel or contact history.**

**If you have returned from an area that is subject to travel restrictions due to COVID-19 you should restrict your movement for 14 days. Check the list of affected areas on [www.dfa.ie](http://www.dfa.ie)**

## All People Are Advised To:

- > **Reduce** social interactions
- > **Keep a distance** of 2m between you and other people
- > **Do not** shake hands or make close contact where possible

If you have symptoms visit [hse.ie](http://hse.ie) OR phone HSE Live **1850 24 1850**

## Symptoms

- > Fever (High Temperature)
- > A Cough
- > Shortness of Breath
- > Breathing Difficulties

## How to Prevent



**Stop**  
shaking hands or hugging when saying hello or greeting other people



**Distance**  
yourself at least 2 metres (6 feet) away from other people, especially those who might be unwell



**Wash**  
your hands well and often to avoid contamination



**Cover**  
your mouth and nose with a tissue or sleeve when coughing or sneezing and discard used tissue



**Avoid**  
touching eyes, nose, or mouth with unwashed hands



**Clean**  
and disinfect frequently touched objects and surfaces

## For Daily Updates Visit

[www.gov.ie/health-covid-19](http://www.gov.ie/health-covid-19)  
[www.hse.ie](http://www.hse.ie)

Ireland is operating a delay strategy in line with WHO and ECDC advice



Rialtas na hÉireann  
Government of Ireland

# Coronavirus Disease (COVID-19)

## Advice for patients from the Irish Lung Fibrosis Association



***Please note that some of this information may change as our understanding of Covid-19 increases.***

***For the most up to date information please see [www.hse.ie](http://www.hse.ie)***

Covid-19 (Coronavirus) is a new virus that was first identified in December 2019 in Wuhan, China. The family of coronaviruses include viruses that cause 'colds' but also some viruses that cause very serious diseases with a high mortality rate like SARS and MERS. As this is a novel (new) virus people do not have any immunity so large numbers of patients are becoming infected in a short period of time. Over the last few weeks, the spread of the virus has become a worldwide concern as the number of people who have developed an acute respiratory viral infection and have tested positive for the Covid-19 virus is increasing in many countries including Ireland.

While there is a lot of good, factual, evidence-based information emerging about the new virus, there is also a lot of misinformation in circulation that can lead to heightened anxiety and worry. It is important to use trusted sources of information to inform yourself about the current news and developments relating to Covid-19. Some useful and reliable websites are included below. Here, we hope to provide you with useful information and practical advice to help you stay safe.

### How does the virus spread?

The virus is spread from person to person. Covid-19 spreads directly via tiny respiratory droplets when someone infected with the virus coughs or sneezes close to you, or indirectly if you touch your face after coming in contact with contaminated surfaces, such as handrails and door handles.

The Covid-19 virus enters the body when it comes in contact with your mucous membranes through your mouth, nose, or eyes. This is why it is so important to wash your hands frequently and keep a distance away from

people - this is called social distancing. People who have been exposed to the virus may be contagious before they themselves have any symptoms. This is one reason the virus is spreading so much.

Countries including Taiwan, Singapore and China that have employed strict hygiene measures and social distancing, isolated symptomatic cases and curtailed the movement of people have successfully reduced the number of cases. Unfortunately throughout Europe (including Ireland), US and Iran the number of cases continues to increase.

## Who is at risk of catching COVID19?

Covid-19 is contagious and can affect anyone, and this has significant implications for the individuals infected with the virus and their close contacts, and also for public health and healthcare systems. The majority of people who have tested positive for the virus so far have developed mild symptoms and have recovered relatively quickly in an average of two weeks. People with pre-existing health problems and older people are not at any greater risk of getting the disease but they certainly are at significantly higher risk of developing severe disease and needing to be hospitalized. Patients have become critically ill with pneumonia, respiratory failure and have died after contracting Covid-19.

Those at particular risk of developing severe disease include older adults, people with underlying medical conditions like pulmonary (lung) fibrosis and cigarette smokers. However young patients without any health conditions have died as a result of this infection. Healthcare workers are also at increased risk of developing a severe infection. However, the majority of patients do recovery completely.

## What are the symptoms?

The symptoms of Covid-19 viral infection most commonly include;

- a cough
- fever - high temperature
- fatigue (tiredness)
- headache
- runny nose
- sore throat
- shortness of breath or breathing difficulties can develop and may indicate more severe disease

It is important to remember that if you have these symptoms, it does not mean that you automatically have Covid-19. Influenza (flu) and the common cold are also present in Ireland and it is likely that some people with these symptoms will have a cold or flu rather than Covid-19. There are laboratory tests available to identify the influenza and



Covid-19 viruses using nose and throat swabs from people with symptoms.

## What should I do if I have symptoms?

If you develop a fever, cough and difficulty breathing or symptoms listed above, you should seek medical advice and telephone your General Practitioner (GP) or hospital emergency department. The HSE have a helpful website and a telephone helpline. 1850-24-1850. Different areas have different public health service numbers to offer guidance. Please do not attend your GP surgery, pharmacy or hospital for outpatient appointments if you have symptoms. First telephone to get advice and be directed to the safest type of assessment. Also please let your doctor know if you have had contact with someone who has tested positive for the virus, someone who has symptoms, or someone who has recently travelled abroad to a high-risk area.

Let your GP know what your symptoms are and tell them

**COVID-19 Information**

Coronavirus COVID-19 Public Health Advice

- Wash**  
your hands well and often to avoid contamination
- Cover**  
your mouth and nose with a tissue or sleeve when coughing or sneezing and discard used tissue
- Stop**  
shaking hands or hugging when saying hello or greeting other people
- Distance**  
yourself at least 2 metres (6 feet) away from other people, especially those who might be unwell
- Avoid**  
touching eyes, nose, or mouth with unwashed hands
- Clean**  
and disinfect frequently touched objects and surfaces

Rialtas na hÉireann Government of Ireland HSE

that you have lung fibrosis; they will advise you on the next steps to take. You should avoid contact with other people to help prevent the spread of disease.

## What should I do to stay safe?

It is important for everyone to follow the safety advice from public health experts to protect themselves and their close contacts to prevent the spread of viral infections. If you have a serious health condition such as lung fibrosis, it is especially important that you and your family members take precautions to avoid getting the infection because your symptoms could be more severe. As the virus starts to circulate more in the community the chance of picking up the virus from a person who has been exposed but doesn't know it will increase. For this reason, everyone should limit contact with other people (including people they know) as much as possible. Always ensure you and everyone around you is maintaining good hand washing and following the other precautions.

### Public health experts advise people to;

- Wash your hands thoroughly with soap and warm running water for at least 20 seconds or use hand sanitiser gel regularly to help kill viruses that may be on your hands. It is a good idea to soap your hands and nails thoroughly before scrubbing them under the tap. Soap kills the virus.
- Cover your mouth and nose with a clean disposable tissue when you cough or sneeze. If you do not have a tissue cough or sneeze into your bent elbow. Put used tissues into a closed bin immediately and wash your hands.
- Don't touch your eyes, nose or mouth if your hands are not clean
- Avoid contact with people who are unwell
- Stay at home and seek medical advice if you feel unwell
- Avoid public places and large crowds if possible
- Avoid unnecessary travel to areas where Covid-19 is reported
- Stay informed on the latest developments about Covid-19 using the websites below

Follow the advice given by the HSE and your healthcare professional. Good hand hygiene is vitally important to prevent

the virus spreading. You should wash your hands;

- after coughing or sneezing
- before, during and after preparing food
- before eating
- after using the toilet
- when caring for the sick
- when hands are dirty
- after handling animals or animal waste

ILFA's medical experts issue additional advice to vulnerable patients with lung fibrosis (\* This reflects specific medical opinion and may not correspond with HSE or Public Health Advice)

- Avoid gatherings of people including cinemas, theatres, restaurants and gyms/clubs
- Avoid contact with people who are sick
- Keep at least 2 meters away from other people even if they are not unwell
- Avoid all non-essential travel
- Avoid (as much as practical) public transportation
- When you do need to use public transportation or be in a public space, ensure that you stay at least a meter or more from other people
- If you can work from home take that option

**In short, we recommend that you limit contact with all other people including family and friends as much as is possible. Following these precautions will help you to stay safer and will also help the community by helping to limit the transmission of this serious disease.**

## Trusted websites for up to date factual information about Covid-19

- Health Service Executive (HSE) [www.hse.ie](http://www.hse.ie)
- Health Protection Surveillance Centre [www.hpsc.ie](http://www.hpsc.ie)
- Department of Health [www.gov.ie](http://www.gov.ie)

*Article by Dr Kate O'Reilly  
(Mater Misericordiae University Hospital)  
and Nicola Cassidy (ILFA). 20th March 2020*

# The European IPF & Related Disorders Federation Patient Summit

ILFA awarded educational bursaries to 8 healthcare professionals in Ireland to attend the first European IPF and Related Disorders Federation Patient Summit in Warsaw that was due take place in April. Unfortunately, the conference had to be postponed with the Covid-19 outbreak in Europe. The organisers are hopeful that the summit will take place at a later date that is still to be decided. We will keep you updated with news on this.

The recipients of the educational bursary were; Nora McNamara, respiratory nurse specialist at South Tipperary General Hospital, Oragh O'Shea, Lecturer at Royal College of Physicians of Ireland, Dr Evelyn Lynn, Specialist Respiratory Registrar at St Vincent's University Hospital, Niamh O'Malley, physiotherapist,



Galway University Hospital, Fatijon Alickolli, respiratory nurse specialist at Bon Secours Hospital Cork, Bridget Murray, Course Director Diploma in Respiratory Nursing at Royal College of Surgeons in Ireland, Avril Hallahan, Senior Physiotherapist at Cork University Hospital, Dr Cian O'Leary, Pharmaceutics Lecturer, Royal College of Surgeons in Ireland.

# Practical health advice during the Covid 19 Pandemic

No one can deny that this is one of the most challenging times our health service and our society has ever faced. As a person using oxygen the added pressure for you must be very difficult. In writing this I hope to provide you with some useful information that will allay some of your main concerns.

## Supply - Is there a possibility the country might run out of oxygen?

We are privileged in Ireland to have very dedicated oxygen suppliers, who have a genuine interest in the care and comfort of all persons requiring oxygen. There is also a dedicated oxygen processing plant based in the Republic of Ireland that is generating a huge amount of extra oxygen at the moment to not only keep your supplies but also hospital supplies topped up. Our procurement teams are working hard, round the clock, to ensure we have a good supply of additional oxygen equipment such as concentrators. Never before have these teams worked so hard to ensure you are well maintained. They will continue to do so throughout this crisis even at risk to themselves. So if you see their teams on the road give them a thumbs up!

## Safety – All the usual rules apply!

Now would be a great time to do your own home oxygen safety check. Your suppliers are extremely busy so may have less time to remind you about all the safety precautions surrounding oxygen. Have a look at some of the leaflets your supplier and ILFA have



provided to you, they hold lots of valuable information. This is your opportunity to inform yourself on what you should be checking at home, for example:

- Do I have a working smoke alarm and a fire extinguisher?
  - Is there anyone smoking in the home? This needs to stop immediately as it puts you, your family and your neighbours at risk
  - I'm washing my hands more frequently so remember to ensure the alcohol gel has completely dried before touching oxygen equipment. Hand care is important but remember NOT to use any petroleum based creams or lotions. Check the ingredients!
  - Can I possibly raise up some of my oxygen tubing from the floor? This will help reduce your chance of tripping.
- These are trying times but please rest assured your oxygen suppliers, procurement teams, hospital and community teams are working hard to look after you. If you are feeling unwell or have a more detailed question about your oxygen, contact your usual clinics. We are expecting your calls and want you to keep in touch.

*Article by Patricia Davis, Clinical Nurse Specialist - Respiratory Integrated Care (RIC), Community Healthcare East (CHEast), Dublin South/Wicklow.*

## Virtual Hospital Clinics

Since the Covid-19 outbreak all clinic appointments have been cancelled. Your Interstitial Lung Disease (ILD) team acknowledges that this creates concerns for some people awaiting results of investigations or multi-disciplinary team discussions. Similarly, we are acutely aware that some people are awaiting decisions to start anti-fibrotic therapy, if it is deemed appropriate. For those on anti-fibrotic treatment, there is the need to know that blood tests are within normal limits and also to receive repeat prescriptions.

In an effort to address some of these concerns, many hospitals are operating virtual clinics or phone clinics when manpower allows this. The ILD team will review your medical record and may telephone you at home to assess your current health status and discuss a plan of care for you. A letter will be sent to your GP updating them of the Virtual Clinic outcome.

Please keep in touch with your ILD Nurse by phone or e-mail should you have any issues that need addressed but bear in mind that many hospital staff may be redeployed and may not be able to respond to you in a timely manner.

**Lindsay Brown, Respiratory Advanced Nurse Practitioner, St Vincent's University Hospital**

## Medication Supplies

ILFA Ireland has received communications from Roche Products (Ireland) Ltd and Boehringer Ingelheim Ltd., the manufacturers of anti-fibrotic medications used in the treatment of Idiopathic Pulmonary Fibrosis, stating that they do not anticipate any issues with the supply chain for medication. In accordance with HSE guidelines, they must stock at least 12 weeks or more of forecasted requirements in Ireland. Both companies will continue to actively assess and monitor the situation to ensure continued market supply of the medicines.

# Looking after your wellbeing in times of uncertainty

**Gaye Cunnane**, Director of Health and Wellbeing, RCPI.

Professor of Rheumatology, St James's Hospital and Trinity College Dublin.

The world as we know it has shifted in a very short period of time. The expressions 'surreal', 'scary', 'unbelievable,' now regularly crop up in conversation. There is no chance encounter (at a distance) that does not involve the terms covid19 or coronavirus, new words in our vocabulary that were unknown or unfamiliar just a few weeks ago.

The situation has infiltrated itself into our everyday lives. Things we have always taken for granted – eating out, visiting family, spending time with friends, even hugging, are no longer recommended while this threat is amongst us. Many people have lost their jobs or have been forced to discover new ways of working, while those at the frontline have had to face the problem head on, using their skills to look after the sick or keep the medical centres and essential services running.

The advice from the World Health Organisation and other authorities has been clear and cohesive, with social distancing and rigorous hygiene measures amongst the best strategies to avoid contracting the virus. This is a time, like no other, to prioritize to your health and wellbeing, so that you can give yourself the best chance of getting through this difficult period and be in a position to look out for others too.

Good nutrition is the cornerstone of optimal health. With restaurants closed, there is an opportunity to be creative about cooking and storing food, exploring different recipes, and involving all those at home with meal preparation. For frontline workers, having proper breaks with healthy snacks, as opposed to coffee and chocolate, will mean lasting energy during long days.

Sleep is essential for immune function and should never be considered a luxury. Do what you can to optimize your sleep, while remembering that rest or relaxation periods also help to restore energy levels. If you struggle with sleep, there are some helpful online resources that are worth exploring.

Our bodies were built to move, and exercise should be a daily routine where feasible. There are many benefits from being outdoors, but if physical activity is difficult, try to identify other options, such as chair-yoga which helps to build strength and resilience.

One of our greatest current challenges is in the management of our mental and emotional health. Although it is tempting to check constantly for updates on Covid19, this



behavior can hugely increase anxiety, while over-frequent use of social media results in a plethora of information, not all of which is accurate. I would recommend confining your sources of information to reliable news outlets, and think twice before forwarding on any stories, no matter how well-intentioned – you may be harming someone else's wellbeing in the process.

If your routine has been altered, try to establish another one. Be mindful of work/life boundaries if you are working from home. Communication is key if you are living with others whose lives have also been disrupted. Set goals, which give you both hope and purpose. It can be helpful to spend 5 minutes each morning setting an intention for the day and a further 5 minutes in the evening reflecting on any positives the day has brought. Sometimes, it is the small things that give us the greatest pleasure.

It is quite normal to feel anxious during these challenging times. If these feelings are overwhelming, make sure that you tell someone who can acknowledge them and give you perspective. Learn some helpful breathing techniques to calm the normal physiological responses associated with anxiety, such as fuzzy thinking, sweating, fast heart rate, etc.

Although we need to stay physically apart at present, it is important that we keep in close touch with family, friends, neighbours and colleagues. Have a shared cup of tea or coffee on FaceTime, check in with telephone conversations or email, send a friendly text, or consider a virtual party via the internet. Thinking of others helps us put our own troubles into context. We are a global community fighting a common cause.

If you have symptoms of physical or mental distress, it is always okay to look for help. Phone your GP or check the HSE and WHO websites, which have detailed and updated information on all aspects of Covid19. The world has been through such crises before and will get through this one too. In the meantime, following expert advice, looking after yourself, and keeping in touch with those around you will help limit the spread of disease, reduce the impact on the health service and foster a renewed sense of common humanity in unpredictable times.



Dr Anne-Marie Russell, Prof Jim Egan, Katie and David Crosby.



Dr Martina Vašáková and David Crosby.

# Advancing in ILD Research Educational Meeting (AIR)

The 9th AIR meeting took place in Malmo, Sweden on 18th and 19th of November and brought together over 300 respiratory healthcare professionals from across Europe. This conference is dedicated to Interstitial Lung Disease (ILD) and idiopathic pulmonary fibrosis (IPF) and focuses on recent developments and outcomes, current research interests and advances in our understanding of the condition. The meeting brings together some of the world's leading experts in the field to share their knowledge and insights. The 2019 meeting was chaired by Professor Athol Wells from the United Kingdom and Professor Magnus Sköld from Sweden.

The Irish delegates invited to attend the meeting included Dr Michael Henry and Ber Bowen from Cork University Hospital, Dr Cormac McCarthy from St Vincent's University Hospital and Nicola Cassidy from ILFA. Also, in attendance were Professor Jim Egan from the Mater Misericordiae University Hospital who chaired a session on lung transplantation for IPF, and David Crosby (ILFA Ambassador) and his wife Katie who shared their experiences of IPF in two interactive workshops. The meeting got off to a great start with a session entitled "What's new in ILD? A year in review" that was chaired by Professor Wim Wuyts from Belgium. Some of the topics covered the mechanisms of lung fibrosis, biomarker developments: predicting the future in patients with ILD, and recent advances in connective tissue related ILD with perspectives from a rheumatologist.

**Session 2** was entitled "Diagnosis, differential diagnosis and the multi-disciplinary team" and topics included diagnostic guidelines, interstitial lung abnormalities and their significance in the development of ILD, radiological changes on high-resolution CT scans, and a lively discussion on the need for diagnostic certainty in deciding when to start anti-fibrotic medications. The session was followed by a series of interactive workshops where challenging real-life anonymised cases were presented by a multi-disciplinary team of healthcare professionals who work together. The audience was invited to participate and share their opinions on the diagnosis and treatment pathways.

**Day 2** got off to a great start with a keynote speech from Professor Riise entitled "Lung transplant in IPF: lessons learned from Sweden" that was followed by a lively questions

**Interstitial Lung Disease (ILD):** There are more than 200 different types of lung (pulmonary) fibrosis diseases. Doctors call these 'Interstitial Lung Diseases' because the tissue damage happens in the interstitial space which is the area around the tiny air sacs in the lungs.

**Idiopathic Pulmonary Fibrosis (IPF):** Idiopathic pulmonary fibrosis is the most common type of interstitial lung disease. The word 'idiopathic' means that the cause of the pulmonary fibrosis is unknown. IPF can be difficult to diagnose and medical experts will need to look at your medical history, symptoms, test results, x-rays and CT scans to reach a diagnosis. IPF is only diagnosed when all other known causes of lung fibrosis have been ruled out.

and answers session, chaired by Professor Jim Egan. In the next sessions, the conference delegates were assigned to two workshops that focussed on;

- Healthcare professional involvement in patient advocacy
- Multi-disciplinary team challenges
- Pulmonary Hypertension in IPF
- Treatment persistence
- Palliative and supportive care
- Caregiver burden

David Crosby facilitated the roundtable discussion on Palliative Care with Dr Martina Vašáková from the Czech Republic, and Katie Crosby facilitated the discussion on Caregiver Burden with Dr Anne-Marie Russell from the United Kingdom. David and Katie did a fantastic job sharing their lived experiences of receiving a diagnosis of IPF, coming to terms with the diagnosis, and undergoing a lung transplant.

The final sessions focussed on the outcomes of recent clinical trials with antifibrotic medications for patients with other types of pulmonary fibrosis, acute exacerbations and home monitoring technologies that can be useful for patients.

The AIR Malmo Conference was highly educational and afforded great learning opportunities. Sincere thanks to the organisers for inviting such strong participation from Ireland at this prestigious meeting.



# Emerging Clinician Scientist Award for Dr Killian Hurley

Congratulations to Dr Killian Hurley, Consultant Physician in Respiratory Medicine at Beaumont Hospital and Senior Clinical Lecturer at Royal College of Surgeons in Ireland, University of Medicine and Health Sciences, who was awarded research funding from the Health Research Board (HRB). Dr Hurley was one of five doctors awarded an 'Emerging Clinician Scientists' awards and €1 million research funding in February 2020.

The HRB €5 million investment aims to advance research careers of five emerging medical leaders and improve health outcomes for the patients in their specialty areas. Using the HRB funding, the five successful 'emerging clinician scientists' must take responsibility for advancing knowledge in their expert areas and ensuring they translate their findings into clinical practice. They will establish themselves as fully independent investigators, become mentors and develop a team-based and collaborative approach to their research programmes.

Dr Hurley and his team will conduct research into familial pulmonary fibrosis in Ireland in order to understand the condition better and find new treatments. Dr Hurley said "We want to improve the quality and safety of care for patients with pulmonary fibrosis in Ireland by conducting genetic testing and counselling for those with a strong family history of fibrosis. We also aim to find new treatments for patients with familial pulmonary fibrosis. Our vision is that patients and families with familial pulmonary fibrosis will have the ability to attend a special clinic to better understand their disease and receive specific treatments and advice based on our research,"

**ILFA would like to extend our warmest congratulations to Dr Hurley on his great achievement. We also want to express our appreciation to the HRB for their vision and major investment in this important and valuable research that will directly benefit patients with pulmonary fibrosis.**



**Dr Killian Hurley**

Dr Hurley will keep ILFA members informed of the project going forward.

**Familial Pulmonary Fibrosis:** Sometimes pulmonary fibrosis develops in different family members, suggesting a possible genetic link. If more than one member of your family has pulmonary fibrosis, it is called 'familial IPF'. However, the same gene defect is not always present in family members with pulmonary fibrosis. This suggests that multiple genetic and environmental factors are involved in the development of the condition. At the moment there is no routine test available but research is ongoing.

## Tang Soo Do National Championships

Huge congratulations to the talented Kevin McSkeane - leader of the Monaghan-Cavan Pulmonary Fibrosis Support Group and medal winner at the Tang Soo Do National Championships.

"In October 2019, I competed at the Irish National Championships held in Monaghan with clubs from all over Ireland in attendance. It was a great experience. Having been diagnosed with pulmonary fibrosis in 2013, you might think I'm mad, but my children started Tang Soo Do in 2015 and after three years of sitting outside in the cold, I decided I'll give this a go. In I went and explained my condition, and I was told



to do what you can, as good as you can. So now I'm a purple belt in Tang Soo Do. This photo shows me on the right with my children Korey, Hannagh, and Reece; nieces Alecia and Grace, nephew Daire and of course my big brother Barry - with a total of 10 national medals between us. I won the gold medal for 'Forms' and was over the moon at that point but then to get a silver medal for 'Fighting' was just unbelievable. I can't forget to mention my wife Tracey who was on the side-line cheering us on and praying I wouldn't pass out. Tang soo".

Pictured are the McSkeane family.

*A report by Kevin McSkeane*

# Education

## Update Respiratory Medicine Journal

A series of educational articles on Idiopathic Pulmonary Fibrosis (IPF) were published in the **Update Respiratory Medicine Journal** (Volume 5, Issue 10, 2019) of the Irish Medical Independent in November 2019. The journal is aimed at General Practitioners, specialist nurses, and respiratory physicians at both training and consultant level.

- **Dr Anne Marie Russell (Imperial College London) and Nicola Cassidy (ILFA Director)** co-authored an article entitled *"Palliation of symptoms; World Café conversations and end-of-life strategies in IPF."*
- **Dr Killian Hurley, consultant respiratory physician at Beaumont Hospital,** wrote an article entitled *"Making change*

*happen: Building a team to care for patients with pulmonary fibrosis"* and described the establishment of a new Interstitial Lung Disease Service at Beaumont Hospital.

- **Professor Anthony O'Regan, Respiratory Consultant at Galway University Hospital** contributed an update article entitled *"Update on Interstitial Lung Disease in Ireland"* and provided an update on the status of the Irish Thoracic Society's National Pulmonary Fibrosis Registry.
- **Dr Colin Rutherford and Dr Michelle Murray, transplant physician at the Mater University Hospital,** co-authored an article entitled *"Lung transplantation for idiopathic pulmonary fibrosis"*.

## IPF Study Day

Gemma O'Dowd, Nicola Cassidy and Lynn Fox from ILFA attended the 6th annual Idiopathic Pulmonary Fibrosis (IPF) Study Day organised by Roche Products Ireland on 7th February 2019 in Dublin. Dr Michael Henry, respiratory consultant at Cork University Hospital and Dr Cormac McCarthy, respiratory consultant at St Vincent's University Hospital, co-chaired the medical education event dedicated to healthcare professionals. Almost 100 respiratory nurse specialists, physiotherapists and respiratory doctors attended the study day.

The programme was packed and there were excellent presentations from many leading respiratory clinicians. Nicola Cassidy gave a presentation entitled "ILFA - Patient Organisation Update" which highlighted recent developments in IPF patient care, and ILFA's upcoming events and plans. Peter Gallagher from Dublin also spoke at the event and shared his personal experiences of being diagnosed with IPF, living with the condition and receiving a single lung transplant in 2019. Peter spoke from the heart and described the challenges he faced, the highs and lows, and the value of friendships made through attending ILFA's Dublin support group. Paula Ryan, respiratory advanced care practitioner and Niamh Julian, respiratory physiotherapist at Limerick University Hospital gave a presentation entitled "Living your best life with IPF". Dr Feargal Twomey, Palliative care consultant at University Hospital Limerick discussed "Life is for living – palliative care and the IPF patient". Dr Cormac McCarthy gave a



**Back row: Triona Rice (Roche Products Ireland), Peter Gallagher, Dr Cormac McCarthy (St Vincent's University Hospital), Dr Feargal Twomey, Dr Michelle Murray (Mater University Hospital), Nicola Cassidy (ILFA), Gillian Hession (Roche Products Ireland).**

**Front row: Dr Francesco Bonella (Germany), Paula Ryan and Niamh Julian (Limerick University Hospital), Dr Michael Henry (Cork University Hospital).**

*Photo courtesy of Roche Products Ireland*

presentation on "Unclassified interstitial lung disease" and described the challenges in diagnosing the different lung conditions that are classified under the ILD umbrella. The international speaker Dr Francesco Bonella (Germany) discussed the genetics of IPF and Dr Michael Henry (Cork University Hospital) discussed the use of cryo-biopsy techniques to help with the diagnosis of ILD.

## Anail Respiratory Nursing Conference

Thank you to everyone who visited the ILFA exhibition stand at the 7th Annual Anail Respiratory Nursing Conference in Portlaoise on 28th February 2020. Gemma O'Dowd, ILFA's Administrative Assistant enjoyed meeting healthcare professionals from all over the country and discussing ILFA's work supporting patients and families living with Pulmonary Fibrosis.



# Fundamentals of Lean Six Sigma for Healthcare

## – White Belt Programme

On 8th January 2020, 13 healthcare professionals from across Ireland attended a 'Fundamentals of Lean Six Sigma for Healthcare – White Belt Programme' at the Centre for Nurse Education, at the Mater Hospital in Dublin. This educational activity was funded by ILFA as part of our commitment to supporting healthcare education. By all accounts it was a fantastic day and provided valuable training and tools to those who attended. ILFA hopes this valuable training will facilitate quality improvements at a local level and encourage future healthcare projects to support lung fibrosis patients.

**Mary Poland**, respiratory nurse specialist at Tallaght Hospital said "Thanks to ILFA for providing the opportunity to attend. The importance of Self-Care for those caring for others was highlighted and I found this both thought provoking and refreshing. We are there when a patient gets the devastating diagnosis of Lung Fibrosis. We can see how it effects, not just the patient, but the family. We try and care for all and can do this more effectively if we are familiar with caring for ourselves. Caring for our patients is not done in isolation, it's a team approach. This day gave us time to reflect on how and why we do the things we do! Our roles are very demanding. It was good to have time to think about ways of making changes ... small changes can sometimes have a great impact and may be cost neutral. They may improve the quality of services that we provide and ultimately improve the patient experience."

**Eilis Gleeson**, respiratory nurse specialist at Limerick University Hospital said "Many thanks for allowing me the opportunity for undertake this training. I really enjoyed the day. The presenter gave very beneficial examples of how the lean method was incorporated to make simple, beneficial quality improvements. We are looking at streamlining clinics and ensuring we are providing good quality service to our vulnerable patients."

**Carmel McInerney**, respiratory nurse specialist at Ennis Hospital said "I learned that you could evaluate and improve your service with very little resources. I thoroughly enjoyed the group exercise where we had to identify a problem and find the solution. The course has shown me ways to improve the existing services, for example how we can work closely across the sites to avoid duplication of tests/appointments for this group of patients and provide a more streamlined approach."

**Rosaleen Anglim**, physiotherapist at South Tipperary General Hospital said "The training day provided a valuable chance to have time out of your busy work-day to look at your own workplace practices. The information about projects already completed using lean principles was very useful in motivating you to consider trying to replicate those successes. Thanks so much to ILFA for the opportunity to attend this training session."

**Carol Doherty**, respiratory nurse specialist at Letterkenny Hospital said "I found the white belt lean programme extremely beneficial as it allowed me to reflect on my own practice. It highlighted how on a personal level I could be more productive in my working day. Focusing on time management, in practice a lot of time is spent going through patient's medical notes to get information for example, medication, investigations, oxygen prescription, date of referrals etc. The development of a Pulmonary Fibrosis Care Bundle would enable me to document all appropriate information onto one sheet that would be kept in the patient's medical notes and easily accessed by all health professionals. I would be very interested in pursuing further learning with the LEAN programme."

**Mary Nagle**, advanced nurse practitioner at the Bon Secours Hospital in Tralee said "Thank you ILFA so much for giving me the opportunity to attend the Lean White Belt programme. It was a very interesting day and made me think about different ways of doing things in the length of time you have available. I have already used one of the techniques that was demonstrated to us on the programme - the time and motion skill - that is, how much time do I have in the day? I feel this is a good way to plan out the day and gives a real idea of the time slots we should allocate for each patient interaction."

**Nora McNamara**, respiratory nurse specialist at South Tipperary General Hospital said "This was a most enjoyable course. It provided great vision and methods on how to achieve goals and deliver a quality service. It highlighted what can be achieved if we look at things in a different light. I am currently in the process of establishing a clinic for lung fibrosis patients and this has shown me that I can deliver an excellent service even if all the chains of the link are not available in my facility. I would highly recommend the course to other healthcare professionals, and I would very much like to go on and enhance my knowledge of the LEAN programme."



From left: Spo O'Keeffe Clonmel, Ann Togher Mullingar, Liz Ryan Kilkenny.

Gemma O'Dowd (centre) pictured with Deborah Casey and Grace O'Sullivan from Cork University Hospital.

Aisling Madden (Beaumont Hospital), Patricia Davis (Respiratory Integrated Care, Wicklow) and Patricia Long (St Vincent's University Hospital).

# Santa



The 11th Santa Dash took place on Sunday 1st December on Dollymount Strand in Dublin and ILFA was thrilled to be the charity partner of this fun festive family 5km and 10km run.

ILFA is enormously grateful to Sean McFadden and the Santa Dash organisers for the valuable opportunity to raise funds and awareness of lung fibrosis at this prestigious event. We are indebted to our team of wonderful, enthusiastic, generous and talented ILFA volunteers who answered the call when we appealed for help with running the event. The ILFA volunteers braved the very early morning start and the cold conditions to help the organisers on race day. The industrious ILFA team helped with running the registration desk, Santa suit collection area, the finish line, medal stations, serving tea, coffee and refreshments to all the finishers, and finally the clean-up operation.

As the volunteers gathered at 8am on Dollymount beach we were treated to an amazing sunrise before the runners, walkers and canine participants arrived. Although the morning started off with cold temperatures and rain, thankfully this cleared, and the sun shone for all the human Santas and dogs who took part. The real Mr Santa Claus himself made an appearance in front of the 'pretenders' and officially started the race after encouraging everyone to "be good". It was an incredible sight to see so many red suits and white beards taking off at speed and running from the North Pole to the South Pole and back again to the finish line. The atmosphere was certainly festive, and everyone was laughing and smiling as they embraced the Christmas spirit!

Some of the participants taking part for ILFA included the McSkeane family from Co Monaghan, Daniel Bourke, Sean Duggan, Scott Glenn, Aidan Boyle and Ronan Hennelly from SSA Recruitment Ireland, the Loughrey-Kennedy family from Galway and Dublin, the English family from Co Meath, aunt and niece duo Annette Grehan and Nicola Cassidy (ILFA Director), Gil Hilliard, Stephen Byrne and Rob Farquhar who took part in support of a family member, and members of the Slattery Family from Clare among others. We're very grateful to everyone for their great support and for fundraising for ILFA.

Our fantastic volunteers deserve special praise and our deep gratitude for their hard work, positive energy and endless enthusiasm. Huge thanks to Yvonne Lynch, Stephen Moody, Eamonn Delaney, Philo Mullaney, Rita Callaghan, Mary Ellen English, Deirdre O'Dwyer, Damien Osborne, Laura Grehan, Teresa Barnett, Patricia Swords, Louise Houghton, Eddie Cassidy (ILFA Chairman), Annette Grehan, Nicola Cassidy.

Sincere thanks to the Santa Dash organisers for choosing ILFA as their charity partner in 2019. This was a wonderful honour and ILFA is grateful for the media coverage in the lead up to Santa Dash. The DJ at the event also deserves great praise for generously promoting ILFA every few minutes and encouraging everyone to visit ILFA's website to learn more and donate to a worthy cause.

Here's a selection of photos from the day.

# Dash 2019



Niamh, Sean and Caoimhe English from Trim, Co Meath were delighted to take part in their first Santa Dash. Caoimhe (11 years old) said afterwards "It feels great to be part of something like ILFA. A massive thank you to everyone who sponsored me especially my teachers and classmates who were very supportive ". Sean (13 years old) finished the 5k run in 5th place in a fantastic time - 20 minutes 40 seconds and said his experience was "great craic, and it was lovely to see all the people in their costumes and everyone of all capabilities participating".





# West Kerry Tractor Run 2019

In 2018 John Patrick O'Sullivan and Séamus Devane set the wheels in motion for the amazing inaugural West Kerry Tractor Run in Dingle, Co Kerry. Together with their family and friends they organised an incredible fundraising event that brought 147 tractor enthusiasts together to travel through beautiful West Kerry in glorious sunshine. The spectacular event raised a phenomenal €21,00 for two charities – ILFA and An Gáirdín Mhuire - a local day care centre in West Kerry. The ILFA committee was overjoyed to be bestowed with such a generous donation that made such a difference to our work. In 2019, ILFA was once again thrilled to be named as one of the charities to benefit from the West Kerry Tractor Run. To date ILFA has received the fantastic sum of €5,500 for which we are sincerely grateful. Here is a report from Neasa O'Sullivan and some photos of the day.

## West Kerry Tractor Run 2019

"Where do we start! Another overwhelming outcome to the tractor run weekend. The fun day out at the mart was everything we hoped for with craic, ceol, and an audience to showcase our amazing Irish history. Thank you to Brendan Ferris and his crew of helpers for making the threshing happen. Of course, I can't go without mentioning our skilful welly throwers as well! "Thank you" to Neilus, Bridie and Mharglann an Daingean for allowing us take over the mart and for all their help organising it.

The main event went (the Tractor Run) as well as the year previously. The atmosphere and positivity on the day was electric. A whole peninsula and beyond coming together to raise money for people in need is very special. The auction that followed in the Marina Inn fronted by the talented and hilarious Dónal Ó hAiniféin also went beyond expectation. We are absolutely blown away.

To name just a few who made the weekend possible thank you to John Patrick O Sullivan, Seamus Devane, Sharon Ní Shúilleabháin (who will be mad we mentioned her because she is very shy but brilliant!) and their amazing committee. Macra na Feirme Chorca Dhuibhne were also a fantastic addition to the tractor run family this year. Thank you to Dingle Chamber of Commerce, the Gardaí, Kerry County Council and the Department of Agriculture, Fisheries and Marine for allowing access to the pier.

The Kavanagh family and all staff at The Marina Inn Dingle - you have so much patience, thank you for all your hard work and generosity again this year.

To everyone who took part in any way big or small, to those who donated, the people who volunteered, the legends who drove their tractors, people who sent good wishes and helped spread awareness about our three important charities we cannot thank you enough.

Donations are still welcome and we will let you know what the final figure is when we do ! Go raibh míle maith agaibh!"

# Fundraising Round Up

## Hair Donation



Sarah Loughrey aged 9 years old, from Galway decided to fundraise for ILFA Ireland in memory of her grandad Michael Kennedy. Sarah cut her beautiful long blonde hair and kindly donated it to the Little Princess Trust that provides real-hair wigs to children with hair loss. Sarah raised the fantastic sum of €700 for ILFA in the process.

Sarah presented a cheque to Gemma O'Dowd and Nicola Cassidy from ILFA on 22nd November. We are very grateful to Sarah for her kindness in helping others and remembering her grandad Michael in such a special, beautiful and touching way.

"Thank you, Sarah from everyone at ILFA"

**Photo shows Sarah Loughrey with her Mum and Dad Marianne and Alan, and her brothers Tom and Michael presenting a cheque to Gemma O'Dowd and Nicola Cassidy from ILFA.**

## Rugby World Cup Pontoon

Peter McLoughlin from Bray, Co Wicklow held a Rugby World Cup Pontoon in aid of ILFA and raised the fantastic sum of €530. Thanks to Peter and his friends for their generous support. Peter is pictured with Eddie Cassidy, ILFA Chairman.



**Pater McLoughlin and Eddie Cassidy (ILFA Chairman).**

## Team SSA take on Santa Dash

Scott Glenn and his colleagues at SSA Recruitment Ireland took part in Santa Dash 2019 in aid of ILFA on 1st December. Here's report from Scott.

"Five of us from SSA Recruitment Ireland took part in Santa Dash 2019; Daniel Bourke, Sean Duggan, Scott Glenn, Aidan Boyle and Ronan Hennelly. We were keen to get behind a charity and we felt that taking part in an event would be the best way to do so. We researched different events and the charities that they were linked to, and ILFA stood out as a very good cause, albeit we didn't have links to the charity prior to this. The day was very enjoyable, it was great to be able to run as a group at an organised event fully dressed in the Santa outfits, it just added good fun to the run and got us in the Christmas spirit. It was really refreshing to see such a huge number of people out to support a great cause. The beach was red with Santas as far as you could see".



**The 5 SSA Santas raised the fantastic sum of €2,300 for ILFA and presented a cheque to Eddie Cassidy, ILFA Chairman, on 16th December.**

## Art Exhibition

Sincere thanks to Matt Cullen from Swords Co Dublin for fundraising for ILFA and raising the fantastic sum of €2,100 as a result of his 'Seeing the Light' Solo Art Exhibition.



**Eddie Cassidy (ILFA Chairman) and Matt Cullen.**

"It was wonderful to have the kindness and support of so many people in relation to my recent 'Seeing the Light' fundraising event for the Irish Lung Fibrosis Association in the Atrium, Fingal County Council, County Hall, Swords from 21st to 25th October 2019. €2,100 was raised for ILFA as a result (representing 50% of the proceeds from the show).

All 22 artworks were sold! There were three reasons for the fundraising event.

“First of all, it was to raise much needed funds for ILFA. Secondly, it was to raise awareness of idiopathic pulmonary fibrosis (IPF). Thirdly, it was to highlight another milestone for me - living with IPF.

“The artwork for the exhibition was influenced from my love of the Fingal area where I live, my love of science and gardening and some of the work was influenced by my medical condition. Art for me is a welcome distraction from thinking too much about my medical condition. It was the culmination of approximately three years’ work (it takes me a long time to do most of the artworks, as some are carried out dot by dot!) so it was a very special, worthwhile and personal event for me.

“Fortunately, the response to the fundraising event from family, relations and friends was beyond expectations. It was very helpful to have the Mayor of Fingal Eoghan O’ Brien launch the exhibition and to also have local playwright David Gilna who was a tremendous help to me in launching the exhibition.

“They both helped in their speeches to increase awareness of IPF, highlighting the importance of the fundraising event and to demonstrate their genuine empathy and kindness shown towards me.

“I am very grateful to ILFA and Fingal County Council for their help and support and to all that attended and supported my solo art exhibition. It was great to have the interest and coverage of the event by the news media in the Fingal area and by Phoenix FM.

It was an occasion that I will never forget, largely due to the kindness and generosity of all concerned which has continued well after the event. Many thanks to all concerned for making the event such a success.” Matt Cullen

## Christmas cards

Sincere thanks to everyone who supported the 2019 ILFA Christmas Card Campaign and helped raise awareness of lung fibrosis and the Irish Lung Fibrosis Association (ILFA). We hope you enjoyed the festive season!

## Festive Donation

Thank you to everyone at Air Liquide Ireland for their very kind festive donation to ILFA and their support during the year. This was very much appreciated.

## VHI Women’s Mini Marathon 2020

Thank you to everyone who expressed an interest in taking part in the annual VHI Women’s Mini Marathon 2020. The original event scheduled to take place on Sunday 31st May 2020 has been cancelled due to the Covid-19 outbreak but there are plans to hold the event later in the year. We will keep you posted!

## Kris Kindle Donation

Ballyfermot College of Further Education, Dublin decided to make a kind donation to ILFA instead of holding their annual Christmas Secret Santa / Kris Kindle gift exchange. Jacqueline Maloney from the college contacted ILFA to inform us that staff

collected €500 in memory of Anthony Hackett, their much-loved colleague, who passed away in 2019. Sincere thanks to the College for this kind donation.

## Thank you from the ILFA Committee

The ILFA committee would like to extend our sincere thanks to everyone who helped raise awareness of pulmonary fibrosis and supported our work in 2019 through volunteering, fundraising, donations and support. ILFA does not receive government funding and therefore must rely on fundraising activities and donations.

We are fortunate and blessed to have support from amazing individuals and groups who are deeply committed to fundraising and raising awareness of lung fibrosis. This enables ILFA to invest in research, education and support activities to help patients and families, and the healthcare professionals who care for them.

2020 will be a challenging year for everyone including charities, as community and sporting events are cancelled, and this will impact on our ability to fundraise. Thankfully ILFA is fortunate to be able to continue our advocacy work. The committee members are all volunteers who give their time and expertise for free, and we have sufficient funds to continue our work. Donations are always welcome and if you are in a position to support ILFA financially, we would be most grateful for your support.

**Please contact ILFA if you would like to make a donation or set up a standing order to donate regular amounts yearly or monthly to charity.**

## In Remembrance

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

## Online Fundraising

ILFA is registered with the trusted online website **Everydayhero.ie** to receive online donations and help with online fundraising activities. Your family, friends and colleagues can donate any amount to ILFA in an easy, safe and secure manner. You can even make an anonymous donation if you prefer your donation to remain private. All donations are automatically transferred to the ILFA bank account and you will receive an acknowledgment via email. ILFA pays a small fee for this service but it is hugely beneficial as it helps generate valuable funds for our charity.

## Bank transfer

Please contact Gemma if you would like to make a donation to ILFA using a bank transfer. Gemma will provide you with all the details and assist you with any queries you may have.

## Facebook fundraising

ILFA is in the process of setting up a fundraising facility with Facebook whereby followers can choose to ask for donations to charity instead of birthday gifts. There will also be a facility to make a once-off secure donation.





**Philippe Hamel, Matt Regan, Colette Hamel, Mark Richardson and Maria Richardson.**



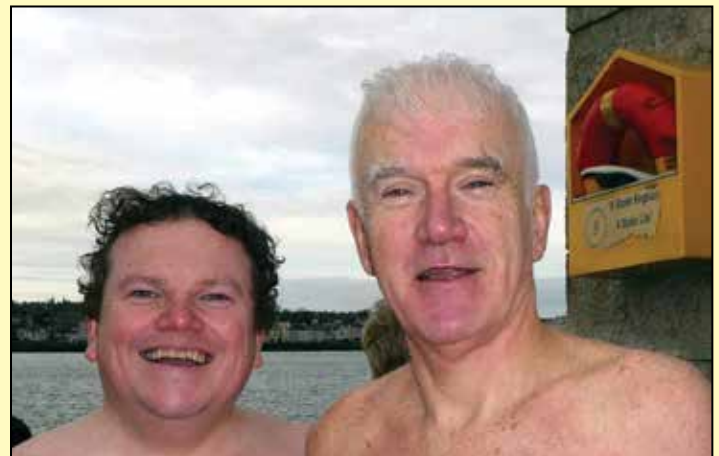
**Evelyn Cooper, Avril Paterson, Nicola Cassidy, Gerard McDonnell, and Eddie Cassidy.**



**Elizabeth Ivers, Colin Ireland, Nicky Goodbody and Mary Anne Williams.**



**Andrew Cooper, Evelyn Cooper and Eddie Cassidy.**



**Michael Maguire and Professor Jim Egan.**

## **ILFA Annual Swim**

Congratulations to all the brave swimmers who took the plunge into the Irish Sea at the ILFA Swim at Sandycove Pier in Dublin on 27th December. Although it was a lovely mild day with blue skies and warm temperatures, the valiant swimmers all said the sea water was particularly cold. We salute their bravery. Some of those taking part included Nicky Goodbody (ILFA co-founder), Professor Jim Egan from the Mater Hospital, Michael Maguire, Matt Regan, Mark Richardson, Elizabeth Ivers, Andrew Cooper and Colin Ireland (lifeguard). The loyal supporters cheering on from the water's edge included Evelyn Cooper, Giles Bailey, Avril Patterson, Gerard MacDonell, Maria Richardson, Mary Anne Williams, Philippe and Colette Hamel, Nicola Cassidy and Eddie Cassidy (ILFA Chairman). Well done and thank you everyone!

# Rare Diseases

## Synopsis of An Easyguide to Rare Diseases in Ireland and Consensus for Action

The Easyguide was launched on 24th February 2020 by the Rare Disease Taskforce.

### It highlights 5 key aims:

- Define what a rare disease is and its definition in health policy
- Provide insights into living with a rare disease
- Identify priorities that patient advocacy groups would urge the Irish Government to include in the Programme for Government, 2020 and beyond, including Sláinte care and the annual HSE Service Plans
- Provide an overview of policy and research developments at international and national policy levels
- Provide sources of information and support for rare diseases, including the National Rare Diseases Office (NRDO) and Rare Diseases Ireland (RDI).

Rare diseases are characterised by their relatively low prevalence (less than 1 in 2000 people in the EU) or less than 1 in 100,000 for ultra-rare diseases. Often having a rare disease results in delays with diagnosis, and challenges in finding a suitable care pathway for treatment and access to therapies. Finding a health professional with necessary expertise can also result in long journeys with emotional and financial challenges.

Rare diseases impact on both children and adults, although rare diseases are far more likely to be found in children and young people. 12% of rare diseases are exclusively adult onset. 81.9% of rare disease are ultra-rare. Orphanet Database (2020) found at least 3.5-5.9% of the World population have a Rare disease. Life expectancy for patients with a rare disease varies. Most have no cure and symptom-management can be hindered by lack of knowledge or failure to translate knowledge into new therapies. It is hoped genetic and research advances will offer hope in the future.

### Patient Advocacy Groups

The emergence of 3 networks that work together as part of the Rare Disease Taskforce; HRCI, IPPOSI and RDI with positive interaction from the Department of Health/HSE, resulted in a number of important developments including the implementation of some important aspects of the National Rare Disease Plan such as:

- The establishment of the National Rare Disease Office
- The roll out of the National Clinical Programme for Rare Diseases and the interaction with European Reference Networks (ERN)

- The shaping of Government policy on access to new and innovative medications
- Highlighting patient concerns and helping to shape policy responses 'when drugs go wrong'.

There is increasing recognition of the importance of Public and Patient Involvement in health policy and research in Ireland. For this to be meaningful, it requires a vibrant, informed, evidence based, independent and resourced patient advocacy sector.

### Patient Registries

The absence of a clear national strategy on patient registries for both common and rare diseases in Ireland is a significant weakness in the present health system in Ireland.

A Patient Registry is defined as an organised system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure and that serves predetermined scientific, clinical, or policy purpose(s).

#### Patient Registries can:

- ▶ Capture disease demographics, clinical outcomes and survival rates
- ▶ Support patient recruitment for clinical research
- ▶ Support the undertaking of research studies and clinical trials
- ▶ Support pharmacovigilance
- ▶ Allow patients access to their own data, through patient portals
- ▶ Allow patients to submit their own data e.g. quality of life data or patient reported outcomes.

The funding of a service to provide advice and practical tools for emerging patient registries would be an important priority. Some priorities are outlined in the report include"

- ▶ Full implementation of National Rare Disease plan (2018)
- ▶ Resources for Prevention, diagnosis and care
  - ▶ National Centres of Expertise and European Reference Networks for groupings of Rare diseases.
  - ▶ National Patient Registries
- ▶ National Clinical Programme for Rare Diseases Model of Care (2019) and Transitional Model of Care (2018)
- ▶ Improve access to and reimbursement times for new and innovative medications for rare diseases.
- ▶ Fund key clinical genetic services
- ▶ Sláinte care mainstreaming and targeting to ensure inclusivity of Rare diseases and at-risk minority groups.
- ▶ Improved health and social supports

**Report by Lindsay Brown, Respiratory Advanced Nurse Practitioner and ILFA Committee Member**

# Advocacy

## General Election 2020

The General Election took place in February 2020 and in the lead up to polling day ILFA issued a statement calling on politicians and public representatives to support:

- Fair and fast approval of Medical Cards: Idiopathic Pulmonary Fibrosis (IPF) is a devastating and progressive disease that places a huge financial burden on patients, caregivers and families as their medical care needs increase.
- Adequate oxygen supplies: Some patients face difficulties accessing their prescribed oxygen amounts based on where they live and local health budgets. Patients should not have to ration their oxygen supply and limit their participation in daily activities out of fear of running out of oxygen.
- Opt-out organ donation: The Human Tissue Bill needs to be enacted to introduce a system whereby everyone will be considered a potential organ donor unless they have registered their objection (opted-out). Opt-out legislation has the potential to increase the number of organ donors and life-saving transplant operations that can take place. Additional funding to support staffing, infrastructure and resources for the national transplant centres is crucial.
- Funding for the National IPF Registry and healthcare inclusivity for IPF patients: The National IPF Registry needs government investment and support to facilitate its work to understand the true incidence of IPF in Ireland and help plan for future healthcare needs. Slainte Care has focused on COPD and ILFA is calling for healthcare inclusivity for all chronic respiratory conditions and fair and equal access to Pulmonary Rehabilitation facilities and clinical psychologists for IPF patients.
- More health funding for resources to support patients accessing primary care, community care, palliative care services and acute hospitals.

The Irish Lung Fibrosis Association is registered with the Register of Lobbying, maintained by the Standards in Public Office Commission.

## A record year for lung transplants in Ireland

ILFA is a member of the Irish Donor Network (IDN) - a network that represents 8 patient groups who advocate for organ donation and transplants in Ireland including Cystic Fibrosis Ireland, Irish Heart and Lung Transplant Association, Alpha-1 Foundation Ireland,

Cystinosis Ireland, COPD Support Ireland, Pulmonary Hypertension Ireland and Liver Disease Ireland.

The Irish Donor Network welcomed the announcement on 30 December 2019 that 274 organ transplants were performed in Ireland in 2019 - the same as 2018. In particular, the IDN welcomed the fact that 2019 was the best year ever for lung transplants with 38 lung transplants undertaken compared with 28 in 2018 and beating the previous best year of 36 in 2017 and 2015. It was also a record year for liver transplants (66 in 2019 compared with the previous highest figure of 64 in 2009).

**Philip Watt, Chair of IDN and CEO of Cystic Fibrosis Ireland** stated: "The organ transplant figures for 2019 are in general positive with a record year in lung transplantation and liver transplantation and the same amount of organ transplants as 2018. However, there has also been a slight decline in kidney transplants – 153 in 2019 compared with 167 in 2018 which appears linked to a decline in transplants in the living donor programme. IDN warmly welcomes the re-commitment by Minister Harris and the HSE to bring in soft opt out organ donation consent in early 2020 and the promised €0.5m in additional funding, though more will be needed with the promised change in organ donor consent.

IDN takes this opportunity to thank all organ donors and their families for the fantastic gift of life and for the wonderful work of all clinical and nursing staff in our hospitals; to Professor Jim Egan and the ODTI and to those in patient groups, many of whom are volunteers."

## Covid-19 Health Communications Stakeholder Support

As part of the national response to Covid-19, the Department of Health, the Department of Rural and Community Development and the HSE set up a national stakeholder group to support patient organisations, community groups and other stakeholders representing some of the most vulnerable and elderly members of society.

ILFA is part of the stakeholder network and the authorities are keeping in regular email contact with all the stakeholders to provide us with the most up to date information, prevention materials and content for social media posts.

According to the **HSE Communications Team**, "Our collective efforts are critical, we need to do this together, as one community. We will be asking everyone to play their part, to help each other and we're here to help you."

# Keep Moving with ILFA's Exercise Resources

The HSE advises people that even though your routine may be affected by the coronavirus outbreak in different ways, it's best if you can keep some structure in your day during periods of self-isolation. You may still be able to do some of the things you enjoy and find relaxing. It is also important for people with lung fibrosis to keep up their exercise and keep moving to keep your muscles strong.

Why not use the ILFA Exercise DVD and ILFA Yoga DVD

to help keep you active and motivated from the safety of your own home?

The exercises that are featured in the videos are tailored to people with

lung fibrosis and take into account breathing.

The exercise resources are available to watch on the ILFA website and on YouTube. If you would like to order your free copy, please contact Gemma on 086 871 5264 or email [info@ilfa.ie](mailto:info@ilfa.ie)



## Patient Support Groups

### Cavan Monaghan Support Group

Please call Kevin on 085 243 6828 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 organising the monthly support group meetings. 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 keep connected during times of self-isolation.

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

**086 871 5264**

## Get Creative and Share Your Talents

ILFA would love for you to get creative during your time of self-isolation and show what resilience and wellbeing means. We know you're a talented community so why not send us your paintings, sketches, poems, and short stories and we'll share them online and, on our Facebook and Twitter pages to inspire others. You don't have to be an acclaimed 'artiste' to join in - perhaps this will be your first time to attempt some poetry, a work of art or even a challenging jigsaw! Let's focus on the positive and try to get through these uncertain times with a bit of creative genius and find the joy in small, simple, lovely things. We look forward to seeing your creations! Email [info@ilfa.ie](mailto:info@ilfa.ie)

## Dates For Your Diary

- **The ILFA Spring Patient Information Day** scheduled to take place on Saturday 4 April 2020 in Tullamore Co Offaly has been cancelled. The decision was made ahead of the government restrictions on mass gatherings, following the advice of two respiratory consultants to ensure patient safety given the early emergence of Covid-19 in Ireland.
- **The 2020 Dublin City Marathon** will take place on Sunday 25th October 2020. It is too early to say if this event will go ahead as planned, but if you were one of the lucky ones to secure a marathon place, please consider fundraising for ILFA Ireland. Contact ILFA on 086 871 5264 or email [info@ilf.ie](mailto:info@ilf.ie) for a fundraising pack if you would like to fundraise for ILFA.
- ILFA is hoping to organise a **skydive** fundraising event in the coming months. If you would like to join the ILFA team, please contact ILFA on 086 871 5264 to register your interest.
- **Fergus Goodbody Memorial Lecture** for healthcare professionals will take place on 23rd September at the Royal College of Physicians in Ireland. The invited speakers are Dr Maria Molina-Molina from Spain and Dr Nazia Chaudhuri from Manchester, United Kingdom.

## 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](mailto:info@ilfa.ie) on the web - [www.ilfa.ie](http://www.ilfa.ie) on Facebook - [www.facebook.com/ILFAIreland](http://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.

