Pulmonary Hypertension Association - Ireland

PHéileacán

Newsletter from the Pulmonary Hypertension Association - Ireland: Vol 1: Issue 1 January 2018

THE IRISH NAVY SHOW SUPPORT FOR PHA – IRELAND

Read inside about the fundraising events organised on our behalf……

Contents:

Message from the Editor

Regina Prenderville, Project Manager, Pulmonary Hypertension Association

New name for our Newsletter:

Welcome to the first edition of our newly named Newsletter **PHéileacán**. During conversations at our support group meetings we decided we should re-name the Newsletter from 'PH News' to something more synonymous to PH. Other countries have a name for their newsletter – the UK booklet is called Emphasis and the newsletter of PHA Europe is Mariposa. The meaning of the Irish word Féileacán is butterfly - the butterfly symbol is often used to depict the heart and lungs – the wings being the lungs and the body being the heart. We thought it was appropriate to name our booklet PHéileacán and thank you to Sally Anne Breen for suggesting the name. Let's hope this will be the first of many informative issues. Please remember this is ***your*** Newsletter and we will always welcome submissions from you. You may like to send us something about how you are coping with PH or hobbies you have undertaken or books you have read…………………..the list is endless.

Support from Irish Navy:

We are extremely proud of the picture on the front cover of this issue. To show support of the Pulmonary Hypertension Association, the students in the 40th Potential NCO Class (non Commissioned Officers) organised a fundraiser (cake sale, raffle & Row-a-Thon) for the Pulmonary Hypertension Association. On **Saturday, 22nd July 2017**, the Row-a-Thon was held on Patrick Street in Cork and this was an extraordinary and wonderful event. The class rowed the equivalent distance that they travel from Tripoli to Palermo (314 Nautical miles or 581 Km) when they are on their rescue missions on the Mediterranean.

As an example of their interest in PH – the NCOs asked if a lecture on Pulmonary Hypertension could be organised prior to the Row-a-Thon. We are most grateful to Dr Sinead Harney from Cork University Hospital who travelled to the Base in Haulbowline to give a presentation on PH. Members of the Class were subsequently interviewed on TV3 (Ireland AM) and they spoke about their activities on the Mediterranean and also about their support of PH awareness. We were delighted with the coverage we received. We were particularly pleased the Lord Mayor of Cork – Cllr Tony Fitzgerald joined us and tested his fitness by rowing '*a few nautical miles'!!* The atmosphere on Patrick Street on that Summer's day was electric and the generosity of people will never cease to amaze me. There's an average footfall of 30,000 on Patrick St every Saturday and many, many people stopped to talk, to learn more about PH.

Local businesses also played their part by supplying food and sustenance to the NCO Class. Every person in an Irish Navy Uniform was given free food by McDonalds (which is located on Patrick Street). We also acknowledge the Cobh based businesses – SuperValu, Londis & Murphy's who provided drinks, chocolates, fruit, confectionary etc. For me it was a delight and a privilege to have met such wonderful and generous people. Members of the NCO class were some of the finest young people I have ever met and if this is the calibre of personnel who guard our shores – I feel very confident for the safety of our country.

On 10th August 2017, I was honoured to be invited as a guest to the Passing Out Ceremony for the NCO Class and to accept a cheque for €8,204 for the Pulmonary Hypertension Association.

European Award: Every PH Association in Europe is encouraged to organise an annual fundraising / awareness event. An award is presented for the most innovative event. In 2017, 38 Associations from across Europe entered the competition. We were elated that the **Irish Row-a-thon** was chosen as the winner and the PH Association – Ireland was awarded a cheque for €3,000. We must acknowledge Christine Coakley, who introduced us to members of the Irish Navy – without her, this memorable event would not have happened.

Support Group Meetings:

Our support group meetings are continuing to grow from strength to strength. In 2017 we held meetings in Dublin Cork and Limerick.

Annual Patient & Family Meeting 2017:

We were very pleased with the attendance and feed-back from our AGM which was held in the Crowne Plaza Hotel Blanchardstown on 22nd April 2017. Minister Finian McGrath TD., Minister of State at the Dept of Social Protection with Special responsibility for Disability gave a very good presentation on Lobbying your TD. He suggested we organise a committee to meet with him. On 19th October 2017 two members of the Association and I met with the Minister. We outlined difficulties our patients experience. The Minister will discuss our concerns with the Minister for Social Affairs and the Minister for Health and promised he will revert back to us.

We subsequently met the Cork TD - Mr Kevin O Keeffe who invited us to meet with members of the Oireachtas and we graciously accepted this invitation. On 13th February 2018 we visited Leinster House. A short Powerpoint presentation about PH was made by Prof Sean Gaine. Mr Martin Breen (Sally Anne's husband) gave a very comprehensive insight into what it's like to witness the day to day relentless burdens of PH. Dr Brian McCullagh conducted an interview with Karen Doherty asking her relevant questions about her PH – *how she was diagnosed, current treatment, problems associated with medication etc*. The interview gave a very concise explanation of PH to those present and many questions were asked by interested politicians. We took the opportunity of stating that

- **PH should be recognised as a long term illness.**
- **That there must be more leniency in the awarding of discretionary medical cards to PH patients**
- **Exception must be made for those using oxygen, as the cost of charging the concentrators is unacceptably high.**
- **We emphasised that being sick in Ireland is very costly and hope concessions will be made soon**

Mr Billy Kelleher TD who is the Fianna Fail Spokesperson for Health was very interested in PH and has accepted an invitation to come to the Mater with Kevin O Keeffe to see the patient facilities and to learn more about PH. *(see photos of our Oireachtas visit on page 22)*

THE IRISH NAVY & THE PULMONARY HYPERTENSION ASSOCIATION OF IRELAND

A PHENOMENAL PAIRING WITH AMAZING RESULTS

Cake sale held in the Naval Base in Haulbowline – 19th July 2017

Saturday 22nd July 2017 – Rowathon starts on Patrick Street at 10 am

Lord Mayor of Cork – Tony Fitzgerald gives support to the NCO Class

Niamh Crowley, Leading Seaman offers a drink of water to the Lord Mayor at he starts to tire…. Difficult trying to keep up with the fitness of these guys !

Regina Prenderville & Christine Coakley accept cheque for €8,204

WHATS NEW IN THE PH UNIT

Prof Sean Gaine, Consultant Respiratory Physician, Pulmonary Hypertension Unit

There have been many new developments at the National Pulmonary Hypertension Unit at the Mater since the last newsletter. Perhaps the most significant is our successful recruitment campaign for an extra PH specialist nurse. We are delighted to welcome Raquel Valle who recently joined the team. Raquel had been working in the Intensive Care Unit in St. James Hospital but also worked in the Brompton Hospital in London in the past. With this extra support and expertise, we are hoping to have an extra clinic each week and to develop clinics outside the Mater. We are focusing on Cork in the first instance, but ultimately hope to have clinics in Limerick and Galway. These reach-out clinics will also help in increasing the awareness about PH around the country. It is planned that people will travel to Dublin at least for their initial assessments but after initiation of treatment and education about PH, patients could be managed on a shared care arrangement closer to home.

There has also been progress in the availability of new therapies. Many of you will have heard us talk about a new oral prostacyclin that is available in some countries in Europe. Selexipag or Uptravi has been shown to be beneficial in pulmonary hypertension, including in patients who are already on other treatments. There is an application before the HSE to support the funding of this drug in Ireland. We are hoping for a positive result in May of this year.

In February 2018 there was a very important meeting of pulmonary hypertension specialists from around the world. The 6th World Symposium held in Nice, France looked at new developments in science and came up with many proposals that will change the way we approach treatment. Hopefully we can review some of these developments at our Annual Meeting in April.

When it comes to the Pulmonary Hypertension Association, Regina, and many of you, have been working together to arrange regular meetings and there have been some remarkable fundraising and disease awareness efforts. Many of you will know and will read further in this newsletter about the great success from Cork. Christine Coakley got the support of the young recruits in the Irish Navy to spread the word about PH. Indeed, the European PH Association awarded it the best fundraising and disease awareness effort in 2017. We had a delegation from Ireland to receive the award in Spain during the summer. This was a remarkable achievement and a very proud moment for all involved.

Last summer I took part in an interesting fundraising effort with Team Phenomenal Hope in Germany along with Galway Consultant Dr Michael McWeeney. The German team was led by a wonderful couple, Katrin and Axel, whose daughter has pulmonary hypertension. We completed a 24-hour relay cycle around the famous Nuremburg ring race track. Indeed, Katrin has kindly agreed to come and speak at our April meeting about living with a child with PH and the efforts of she and her husband in raising support and awareness for PH in Germany.

It would be great to continue to collaborate with our European neighbours in fundraising and disease awareness campaigns. Ultimately, it would be hoped that we could develop a fellowship program to allow young doctors from Ireland travel to the US and Europe to learn new techniques and research approaches in PH to be brought back home here in due course.

Finally, a big thank you to all of you for all your efforts with the Pulmonary Hypertension Association and particularly to Regina for getting you all together and steadily increasing the awareness about PH in Ireland.

Raising awareness about PH: Racing for PH

Dr Michael McWeeney, Consultant Respiratory Physician, Galway Clinic, Co Galway.


Sean Gaine, Katrin Hetebruegge (Germany), Mike McWeeney and Tommy Vansteenkiste (Belgium)

Racing the 24 hour Rad am Ring with 'Team Phenomenal Hope' in the Summer of 2017: where do you even start to describe this? The eerie silence of racing alone through the night on a track steeped in history. The tearful realisation that you are doing this to raise awareness for people with PH whose courage and bravery surpasses your own. The emotional rollercoaster of doing your absolute best for your team mates. The high of finishing such an epic event. This race had it all. Six months later and I'm not even sure I have the words to describe this experience fully.

Team Phenomenal Hope is an American PH charitable organisation dedicated to raising awareness and fundraising for PH. It was established by a young PH doctor now working in Denver and has affiliate Teams in Mexico and Germany. The central moto of Team Phenomenal Hope is 'Let me be your Lungs'. People link up with a PH patient and take part in marathons and events to increase awareness about PH and to fundraise for a cure. Last summer six teams of four joined forces to complete a 24-hour relay race around the famous Nürburgring in Germany. The hospitality and friendship extended to us by Axel and Katrin from Team Phenomenal Hope Germany was extraordinary. They worked tirelessly for weeks in advance in an incredible team organisational effort even before a pedal was turned.

My team included Tommy, Sean and Sarah. The nervous energy on the morning of the start was nauseating. If you could just get on your bike and go it will be fine, right? This was going to be tough! Windy as hell, 90 to 100 km per hour descents, hills so steep I very nearly had to get off and walk. The plan was to do the first lap at around 85% and try to build slowly from there but the waves of adrenaline coupled with the speed of the white knuckled descents just sucked me in. I was holding on for dear life. You can't ease up. A momentary lapse of concentration and you lose your racing line. I run wide, over the kerbs onto the grass at 75 kph. I lose my glasses and water bottle. Your life flashes by in an instant that was very close. I'm so tired. Only one lap to go, ok, concentrate. You can't die out here, can you?

The isolation of racing in darkness alone. Sleep deprivation. Fatigue. I'm just gonna give up and go home. Buck up you quitter, your team needs you. You are racing for people with PH who would do anything to be able to do what you are doing now but can't. I knew Tommy was the next rider up waiting to get that timing chip from me. His sister who has PH is here from Belgium in her wheelchair with oxygen. She is there to cheer him and all the team on. How does Tommy look so fresh - he just drove half way across Europe to do this for his sister. I wonder how Sarah can do this with jet lag having just flown in from Australia to take part.

The sun rises. Its scarily quiet, just the whirr of chains and the unmistakable sound of carbon wheels spinning fast. You are coming up the straight, there is the chequered flag. It's over. You seek out your team mates and hug them like family.

It took days to recover from the emotional rollercoaster that was Rad am Ring 2017. I'm not certain that it didn't change me somehow forever. Being someone's lungs who can't do it does something to your brain, your processing that makes you a better person. I went there to do the event with enthusiasm, I left feeling a part of a community that I never knew existed before. I was only a very small part of the team and yes, I was insignificant. But they couldn't have done it without me. The team couldn't have done it without everyone. Each little link was critical. I will never forget that event, Team Phenomenal Hope and my 3 teammates who did it with me.

NURSE LED CLINIC

Caitriona Minnock, Clinical Nurse Specialist, PH Unit

The nurse-led clinic has been running now for about 8 years. The function of the clinic is primarily to plan and initiate care and treatment modalities within agreed protocols to achieve patient centred outcomes. Follow-up focuses on evaluating these measures and allowing patients and their families to participate in decisions about their health.

At present we initiate approximately one patient per week on a new PH therapy. This is completed following a comprehensive health assessment in the clinic with the CNS. The side effect profile of any new medicine is discussed and possible barriers to adherence identified. A follow – up plan is then established. At this point many patients often ask “why do I need to come back” or “when will I feel better”?

Initial dual oral combination therapy is a recommended treatment strategy for PAH in the current ESC/ERS guidelines for PH (2016). This has been the strategy at the National Pulmonary Hypertension Unit for some time. Historically however, initiation has been staggered for a variety of reasons including tolerability/side effects, lack of evidence and financial constraints. The emergence over the last few years of clinical trial data to support and give credence to this treatment strategy has changed the approach. It is now possible to initiate a PH therapy and quickly follow this up with a second therapy depending on what PH group the patient is in.

The Ambition study (2016) positively demonstrated the benefits of such an approach. Patients were given PH medicines in a staggered fashion over a period of eight weeks and subsequently had improved outcomes. The Optima study (2017) is hot off the press having been recently presented at the ERS and the ATS annual conference. This study supports the rationale that introducing two different PH therapies early has positive effects for patients. This study used a more up front regime with patients reaching dual therapy status within a week of initiation. Obviously, this approach is not suitable for all PH patients but where possible, in the clinic we will be seeking to achieve this goal. It does require patients after their initial diagnosis, to attend more frequently and have certain parameters including blood work, 6MWT and other functional activities measured. Hopefully, the ultimate outcome of this activity will reduce your need to see us too often and assist in “ironing out “any issues along the way. We look forward as always, to seeing you in the clinic.

VOLUNTEERS REQUIRED FOR IMPORTANT RESEARCH

Project title: Evaluating the role of the bone morphogenetic protein pathway and inflammation in the development of pulmonary hypertension.

Investigators:

1. Dr Brian McCullagh MD, Consultant Respiratory & General Physician, Mater Misericordiae University Hospital Centre for Lung Health, 56 Eccles St, Dublin 7.
2. Dr. Christine Costello (PhD), UCD Conway Institute, UCD Conway Institute of Biomolecular & Biomedical Research, University College Dublin, Belfield, Dublin 4.

What is this research about?
Recent research in the Conway Institute UCD has implicated certain proteins in the development of pulmonary hypertension in susceptible patients. More specifically, proteins that antagonise the bone morphogenetic protein pathway and inflammatory pathways, such as CXCR7 mediated signalling, may be particularly important in the aetiology of pulmonary hypertensive diseases. In this study we hope to expand our knowledge of the role these protein pathways play in pulmonary hypertension by measuring signalling proteins involved in these pathways in peripheral blood samples from normal controls and different categories of pulmonary hypertensive patients.

Why have you been invited to take part?
You have been invited to take in this observational study as a healthy control volunteer who has no history of pulmonary hypertensive disease. Your data will be used to compare levels of biomarkers of interest in your peripheral blood and the peripheral blood of hypertensive patients. This may indicate their utility as diagnostic and prognostic biomarkers, and potential new therapeutic targets.

What will happen if you decide to take part in this research study?
If you decide to take part in this study, you will be asked to submit to routine venesection (peripheral blood sampling). This will be obtained in the usual way using a cuff and monovette apparatus. A total of 3 tubes will be drawn:

1. Serum - 1 x 4.9ml tube
2. Plasma (Li-Heparin) - 1 x 4.9ml tube
3. Plasma (EDTA) - 1 x 7.5ml tube

You will also be asked your date of birth, smoking history, if you have any recent history of upper respiratory tract infections and if you are currently taking steroids or prostacyclin agonists. This information will be recorded and anonymised (coded).

How will your privacy be protected?
Your identity will remain confidential. A study number will identify you. Your name will not be published or disclosed to anyone.

What are the benefits of taking part in this research study?
Your participation in this study will help us elucidate if biomarkers of interest are significantly altered in pulmonary hypertensive patients.

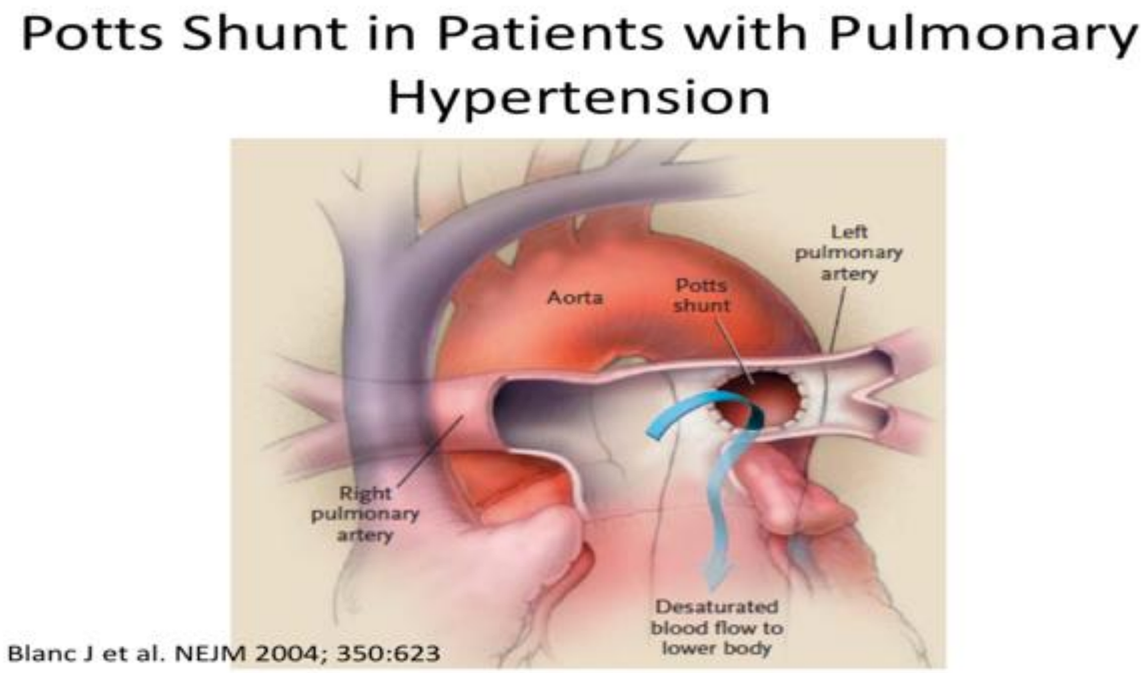
What are the risks of taking part in this research study?
The risk to you is minimal but may include bruising or mild pain associated with peripheral blood sampling.

Contact details for further information: If you have any further questions or queries regarding you participation in this study, please contact Dr. Christine Costello at christine.costello@ucd.ie or (01) 7166724.

THE POWER OF BLOGGING

Many of us had the pleasure of meeting Julia Nolan, her sister Aimee and Mum June at our meeting in Limerick and at the Christmas lunch held in December. We are very grateful to Julia for sharing her story with us. This photo was taken in Crumlin Hospital of Julia with James Kavanagh and William Murray (James partner). The blog (below) was written by James Kavanagh who has over 80K followers on Instagram. Julia is a huge fan of James and William and was absolutely shocked and delighted when they came to visit her. As you will see the blog received almost 22,000 Likes !!

"Today we met the v v v v gorge @julia_grace7 💘 Her lovely sister Aimée messaged me to send her a video from me and William, but we decided to actually call into her in Crumlin Children’s Hospital and say hello - and I’m so glad I did (she’s v inspirational ✨). Julia suffers from pulmonary hypertension, a rare incurable disease. She’s currently recovering from a procedure that she had last week called a ‘Transcatheter Potts Shunt’ which should make everything a bit better. She’s also become a bit of a pioneer, because it was the first time this operation has been performed in Ireland or the UK (a doc came over from France especially to do it). Lead the way, bish! Aimee and her Dad both said she’s fighting fit because she’s so positive (and she glows). On the way up to Crumlin from her home in Cork for the surgery, she blared Disney songs (same babes) and sang to her heart’s content with not a care in the world. Aimee also said she ousted the family away from the hospital the night before so she could relax with her tea & toast and watch Netflix (I also hear you gal). The morning of the surgery, she went down happy and told the nurses she won't be in long. When she woke up from surgery she was smiling and rolling her eyes at her family saying they are too dramatic and to calm down. In the words of her sister, she’s a fantastic 16 year old with the best, positive attitude. It was so lovely to meet you Julia, slay your life, & can’t wait to see you again!"



Potts Shunt in Patients with Pulmonary Hypertension

Blanc J et al. NEJM 2004; 350:623

NOTHING GREAT IS EASY - A SWIMMER'S PH STORY

On the 26th September 2017, former PH sufferer, Patrick Corkery attempted to fulfil a lifelong dream and swim the English Channel, from Dover to Cap Gris Nez, in France. Known to swimmers the world over simply as, 'The Channel', it is the pinnacle for all Open Water swimmers to test themselves against. Completing the swim was no fait accompli, as Patrick knew only too well…..

Swimming since I was 4, and lifesaving from age 10, I've competed in Open Water races and Masters galas, for over 20 years. The highlight of my open water career was winning the Dun Laoghaire Harbour Race, in 2011.

With a dream of swimming the English Channel, I undertook longer and longer marathon swims, including 16m Lake Zurich in 2013 and the 28m Manhattan Island Marathon Swim in 2014. Following these successes I made an attempt on the North Channel from Northern Ireland to Scotland. Unfortunately, this swim was stopped by my crew just a mile from Scotland after 11 hours, due to breathing difficulties caused by multiple jellyfish stings. Subsequently it was discovered that these had caused massive pulmonary embolisms or blood clots on both lungs, which led to pulmonary hypertension.

Luckily, I was suitable for an operation to clear these blockages and Prof. Gaine referred me to Papworth Hospital in Cambridge where I underwent open lung surgery in January 2016. This pulmonary endarterectomy surgery cleared 2/3rd of the right and 1/3rd of my left lung of clots. Given the nature of the surgery, the road to recovery was long and slow and the thought of swimming, with all the strain that would place on the chest was daunting.

After 3 months I was back in the pool and later introduced some medical rehab gym classes for strength. After 10 months, I felt strong enough and, with support from my wife Alice, I re-booked my deferred English Channel swim for September 2017, just 20 months post-surgery……

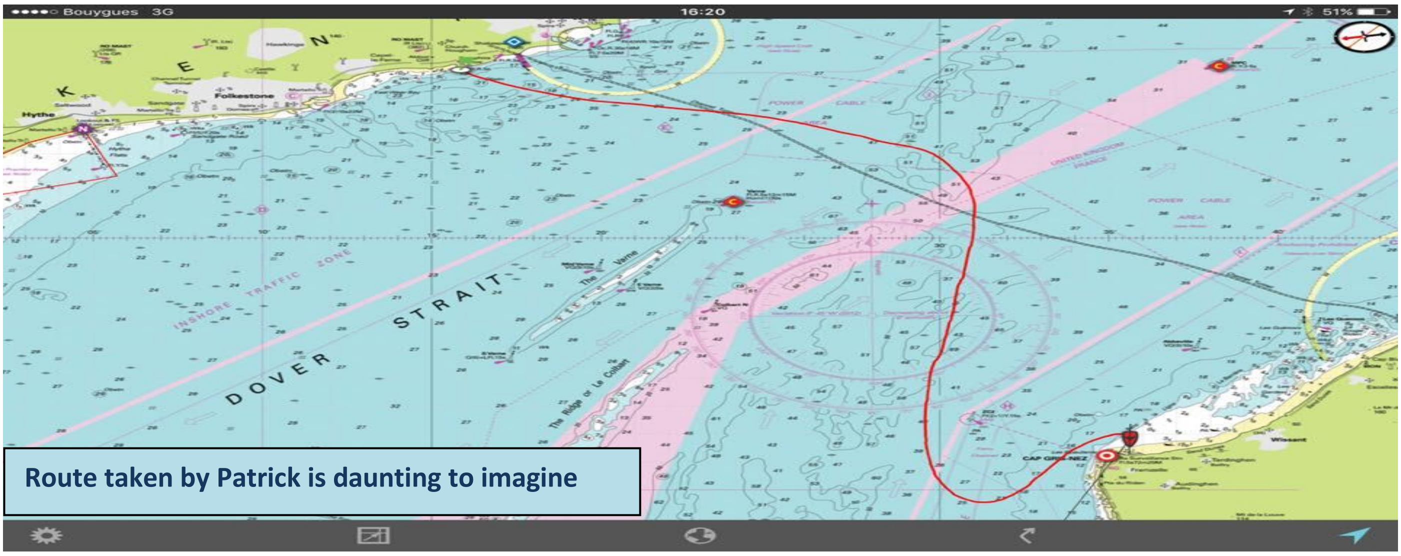
As the Chinese proverb says, 'even the longest journey begins with a single step'. Each metre, each length of the pool would bring me closer to the swim I'd dreamt of doing, ever since I was a kid.

Having passed all the medicals and been given the all clear by the doctors, I was ready.

Swimming under the auspices of the Channel Swimming & Piloting Federation (CS&PF) and guided by experienced pilot Eddie Spelling, I was assisted by my good friends and crew of Fergal Somerville and John Kenny. Just one hat, togs and goggles are allowed, they also forbid any contact with the boat or other assistance during the swim. The sea conditions, currents, water temperature, threat of hypothermia and sea-life are all things that must be dealt with.

With a straight line distance of 21 miles, due to the tides in the channel, the swim would likely take longer than all the others. Given all I had been through after the North Channel attempt, I knew there were no guarantees on a swim of this magnitude, but after a lifetime spent training for it, I was confident of my ability all the same.

Starting at night, at Samphire Hoe beach, the first 3 hours were in darkness. Like a string of pearls, the lights of 10 other boats, stretched out on the horizon with solo swimmers and relays who had started ahead of me. Swimming in darkness alongside the pilot boat is a surreal experience. The whole day brings different challenges. Dawn was followed by 3 more hours where I had difficulty keeping the half-hourly feeds down. Sickness has finished many a channel attempt. Having been through all I had, it was going to take more than this to deter me now. Maintaining my stroke rate through this rough patch, everything then calmed down for a few hours, before the wind picked up to Force 3-4 and a strong 4 knot tide was encountered towards the finish which endeavoured to sweep me away from the coastline. Guided by the pilot boat and urged on via crew updates from supporters I finished strongly, some 50,000 strokes later, to finally complete this iconic swim, in a time of 13hr 12m – Channel Swimmer!



Route taken by Patrick is daunting to imagine

On the day, there were swimmers from China, Australia, Uruguay, Namibia, Ireland and the UK, but only 2 out of 8 solo swimmers attempting the crossing were successful in making the swim, an Australian….and a former PH sufferer. As Channel swimming pioneer Captain Matthew Webb said, 'Nothing Great Is Easy'!

Patrick wishes to express his thanks to all the doctors, nurses and hospital staff who looked after him throughout his illness, operation and recovery.

Two very important and loyal friends were also members of Patrick's crew and accompanied him all the way - (PHA Ireland & Papworth Hospital Teddy Bears)

Siel Bleu Ireland is a non-profit organisation that aims to improve the quality of life of older adults and those living with chronic disease through fun and interactive, tailored exercise programmes. We are all aware of the importance of physical activity but its benefits for older adults and those living with chronic disease can often be underestimated. Siel Bleu Ireland believe in challenging mind sets to transform the lives of Ireland's older population in the long-term, insuring each person has the ability and confidence to live as full, independent and happy lives as possible.

Once adapted to the needs and goals of participants we have found physical activity can have a tremendous impact on not just physical wellbeing but social and psychological as well. Our trainers use their skills and knowledge base to create a fantastic atmosphere that encourages participants to join in.

They use their expertise to adapt a programme to suit the group's needs, e.g. whether for a dementia specific class or for those who would like to improve their confidence in their own ability to walk with our fall prevention programmes.

Currently, our team of sport scientists deliver programmes to over 3750 people per week in 21 counties in the Republic of Ireland. We are in the process of designing a programme for people with Pulmonary Hypertension and are delighted to roll out this programme in 2018.

With a continuous focus on prevention, Siel Bleu Ireland aims to add life to years and years to life!

Note: The PH Association has asked Siel Bleu to organise classes for our patients – we are awaiting confirmation of dates.

MORE FUNDRAISING EVENTS IN 2017

In memory of Addis Doyle who sadly passed away in 2017 – his friends and family organised a team to do Hell and Back. This was held in **Kilruddy House and Gardens in Wicklow in September 2017.**

Left to right: Lily Gregg, Chris Andrews, Aideen Murphy, Donna Gould, Anthony O Riordan, Andrew Gregg, Chloe Ashe, Yasmin Hollywood, Tracy Doyle and on the ground is Brian Murray with and Katie Rose Doyle

Support from Tracy Doyle's colleagues in the Mater Private Hospital. Well done ladies for completing the Ladies Mini Marathon in June 2017 and raising funds for Pulmonary Hypertension Association.

Left to right are Tracy's colleagues: Sandra, Aisling, Tracy, Michelle, Rosie, Maureen

SONIA O SULLIVAN SHOWS SUPPORT FOR PULMONARY HYPERTENSION ASSOCIATION-IRELAND

Susan Sheehan, Sonia O Sullivan & Christine Coakley

On Monday, 6th November two school friends had the pleasure of meeting again. They hadn't been in touch for almost 30 years. Both have had very different lives. One girl Sonia O Sullivan, became a world champion and an Olympian. Her achievements include: Four times Irish Olympian - **Barcelona 1992:** 4th place in 3000m, **Atlanta 1996:** 5000m finalist, **Sydney 2000:** Silver Medalist 5000m, **Athens 2004:** 5000m finalist. Current World record holder over 2000m, ***5:25.36***, Edinburgh 1994, three times World Champion, 1995, 5000m, 1998 World Cross Country long & short course, three times European Champion, 1994, 3000m, 1998 5000m & 10,000m, Twelve times All-Ireland Champion, currently holds ten Irish records in every distance from 1000m to half marathon, Dublin City Marathon Winner 2000.

The other girl, Christine Coakley remained in Co Cork where she lived and worked for many years. In Nov 2014 Christine was diagnosed with Pulmonary Arterial Hypertension. While PAH has created a change in Christine's life, it most certainly has not dampened her spirits nor enthusiasm and she has thrown herself into our PH awareness campaign. It was Christine who introduced us to the members of the Irish Navy who performed the **very successful Row-a-Thon** for PH in July 2017.

Not one to rest on her laurels, Christine decided that she would contact her class mate Sonia to ask if she would help with our PH awareness campaign. She sent an email and wasn't sure if Sonia would have the time to respond. Christine explained all about PH and our Get Breathless campaign. She also mentioned that November was awareness month for PH. Within hours, a response was received from Melbourne, Australia (where Sonia lives). She told Christine that by coincidence, she would be home for a few days in November and was delighted to be part of the awareness event. Sonia had read all about Pulmonary Hypertension and was very explicit when speaking about it.

The PH Association issued Press Releases to journalist and to local politicians. We were astounded with the response we received. We were given both National and local coverage. Three politicians attended the event in the Coral Leisure Centre in Cobh, Co Cork. They had never heard of Pulmonary Hypertension before and were very concerned about certain issues which patients endure. They would like to learn more about the condition and have vowed to help to make the lives of patients easier if they can. Consequently, the Pulmonary Hypertension Association has been invited to meet politicians in Government Buildings after Christmas. Prof Sean Gaine will make a presentation to 20 Members of our Government. Our Pulmonary Hypertension Clinical Nurse Specialists and some patients have also been invited to attend this very prestigious occasion. We will be very happy to update Mariposa News with outcomes of this meeting.

Lieutenant Commander Diarmuid O Donovan joins in the fun at the Coral Centre

Sonia was delighted to meet with Gearóid Sheehan who introduced her to his parents Susan & Brian (below)

PHA Ireland greatly appreciated the support received both from the Navy & local politicians.

L-R : Sonia O Sullivan, Cllr Padriag O Sullivan, Mr David Stanton TD, Minister for State for Equality & Lieutenant Commander, Lieutenant Commander Diarmuid O Donovan

EURORDIS BLACK PEARL AWARDS

The annual ceremony for the Black Pearl Awards took place in Brussels on 20th February 2018. Since 2012, EURORDIS-Rare Diseases Europe has organised this event to recognise the major achievements and outstanding commitment of patient advocates, patient organisations, policy makers, scientists, companies and media who strive to make a difference for the rare disease community. Nominations are submitted by the general public and shortlisted by an ad hoc committee. The winners are selected by the EURORDIS Board of Directors, based on the criteria for each category.

RAREDISEASEDAY.ORG

Award is accepted by Oksana Kulish, PHA Ukraine & Hall Skaara, PHA Norway

Why is the event called the “EURORDIS Black Pearl Awards”?

The EURORDIS Black Pearl Awards are presented to individuals, organisations and companies who dedicate their lives to making a difference for the rare disease community.The formation of a natural black pearl is extremely rare. Black pearls are widely considered as the most valuable and beautiful kind of pearls in the world. Just like these pearls, the recipients of the EURORDIS Black Pearl Awards are unique and deserve our recognition for the work that they do. Despite important advances, the rare disease community continues to face enormous challenges. The work and achievements of the awardees are of paramount importance to improving lives and finding cures for people living with a rare disease.

The EURORDIS Black Pearl Awards takes place in February to celebrate Rare Disease Day; a EURORDIS initiative to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients’ lives. Over the past 10 years, Rare Disease Day has become an internationally recognised awareness-raising campaign, with events taking place in over 90 countries and regions, uniting millions of people living with a rare disease worldwide.

We are very proud to announce that the winner of the EURODIS – Patient Organisation Award for 2018 was the European PH Association!! We commend all our friends and members of the PH Family in 40 patient associations in 35 countries across Europe.

AWARENESS CAMPAIGN FOR 2018

WORLD PH DAY 2018

In this cold weather, it's difficult to imagine the summer months are just around the corner and we'll soon be sporting our Pulmonary Hypertension T-shirts. We'll make plans and as always, look forward to better days.

As we aware, World PH Day is recognised every year on 5th May. It's not always possible to have our events on the exact day but we try to do something as near to this date as possible. Here are some of the events which will take place in our name over the coming months . However, not every event needs to be as dramatic or energetic as the first one on our list !!!!

Paddy Brennock will climb Mount Everest

Paddy sets off on 2nd May, 2018. The trek to Everest Base camp (height 17,600 ft) will take around 19 days in total. He has decided to give the trip an extra purpose and try to raise some money and awareness for PHA Ireland. Sadly Paddy's Mum died in 2013 at the age of 57. He has paid for all costs himself, guides, flights, accommodation etc., so everything raised will go to the PH Association. We are extremely grateful to Paddy for this recognition. We have given him T shirts and promotional material. It would be wonderful if we could get some pics for our website.

Good luck Paddy, stay safe and thank you from everybody in the PH association.

Subsidised Social event for PH Patients

Anita Padgett from Co Clare has secured tickets for sailings on the Shannon Ferry. The owners of the Ferry will be delighted to welcome us and have suggested we wait until the Summer months – when the dolphins will be there to greet us. Anita has also enquired about a light lunch at the Vandeleur walled garden & visitor centre as well as a visit to the Foynes Flying Boat Museum of the Tarbert Jail House !! It sounds as if we'll have a very exciting day in Co Clare. I'll keep you informed of dates etc. We greatly appreciate all of the work Anita is doing for us.

Friday, 4th May 2018 – PH Awareness Day in the Mater Hospital

Together with the nurses in the PH Unit we will organise an awareness day. We have booked a space along the long corridor on the 1st floor of the Whitty Building. Patients who would like to be involved are most welcome to join us on the day.

Saturday 5th May 2018 – 5K run

Thanks to Kathy Rooney, Tallaght Athletic Club have allowed a PH Team to run in a 5K event. The PH Association will have an exhibition stand at the event with information and promotional material. All are welcome to join us. I will confirm location of our exhibition, times etc nearer the date.

IMPORTANT DATE FOR YOUR DIARY

Saturday, 28th April at 10.00 am – 2.00 pm. Patient & Family Meeting – Crowne Plaza Hotel, Blanchardstown. Programme will follow shortly

Visit to Leinster House by PHA Ireland on 13th February 2018

Mr Kevin O Keeffe TD(Our Host for the afternoon & Prof Sean Gaine)

Dr Brian McCullagh, Prof Sean Gaine & Mr Martin Breen

Ms Karen Doherty explains to Dr Brian McCullagh how PH affects her life.

Prof Sean Gaine, Mr Billy Kelleher TD & Dr Brian McCullagh

Annual Patient & Family Meeting
Saturday, 22 April 2017

Please feel free to contact your association at anytime:

Pulmonary Hypertension Association - Ireland
Centre for Lung Health
Mater Misericordiae University Hospital
56 Eccles Street, Dublin 7
Tel: 001 854 5172 or 00 353 87 637 6563 E: pha@mater.ie