Pulmonary Hypertension Association - Ireland
Charity No. CHY 15486

# PHAnews

Spring 2014
Volume 1 No. 3

Welcome to our Newsletter.

## Contents

*Prof Sean Gaine addressing the 2013 annual meeting for patients & families held in the Grand Hotel Malahide.*

# 2013 was a very important year for Pulmonary Hypertension ... 2014 will be even more important

*Prof Sean Gaine, Consultant Respiratory Physician, Mater Misericordiae University Hospital (MMUH)*

The year started with the World Symposium on Pulmonary Arterial Hypertension in Nice, France in February 2013. At the World Symposium the classification of the different types of Pulmonary Hypertension was updated and a new treatment algorithm was proposed. Also new targets were suggested for scientific research to develop treatments for the future. The final report from the meeting was published in December and will be the roadmap for the next 5 years. Furthermore 2013 saw two new drugs approved for treatment. While these drugs are not yet available they are going through the approval process and should be in use in 2014.

There were important developments in Pulmonary Hypertension in Ireland during 2013. The initial draft of a 10 year review of activities in the Unit was published and is now undergoing review. It was also a year where we held our patient meeting in Malahide and also a national meeting for physicians and nurses throughout Ireland in Dublin in November. However, as important as 2013 has been in Pulmonary Hypertension, 2014 stands to perhaps be the most important in over a decade. Not only will we hopefully see the availability of two new drugs for Pulmonary Hypertension, Macitentan and Riociguat, the results of a number of studies on the treatment of Pulmonary Hypertension are expected to become available and published this year. One of the studies is looking at a new oral prostacyclin and is expected to be completed with the results available later in the year. Two other studies were looking specifically at how best to treat the patients with Pulmonary Hypertension, whether with one oral agent in the first instance with a second added or whether patients should have all the tablets given upfront. While this might seem a straightforward enough question it has taken many years to complete a research study to decide on which is the safest and most effective way. All of these we expect to be available in 2014.

Finally a big focus for fundraising in 2014 is to help our cardiology department in the Mater Hospital with the opening of a third catheterisation laboratory. Careful assessment of pulmonary artery pressures during catheterisation is a requirement for diagnosis of this disease but also is an important test to carry out from time to time to determine how treatment is progressing. The arrival of a third new laboratory in the Mater Hospital would greatly enhance our ability to diagnose and manage patients with Pulmonary Hypertension and therefore we are very supportive of the fundraising campaign along with the Mater Foundation to make this a reality.

# Medical Update News *continued* (Recent press release issued by Mater Hospital)

## Lung Transplantation Repatriated to the National Centre For Cardiothoracic Surgery at the Mater

The National Centre for Cardiothoracic Surgery at the Mater Hospital announced that all adult lung transplantation has been repatriated back to Ireland from Newcastle in the United Kingdom. The contract to perform some lung transplants in Newcastle for Irish patients ceased on Sunday January 26th, 2014. While the vast majority of lung transplants have been performed by specialists at the Mater Hospital since the first lung transplant in 2005, some of the more complex cases have been referred to Newcastle.

Repatriating lung transplantation to Ireland is now possible as the Mater Programme has demonstrated its ability to provide care for even the most critically ill and complex patients requiring lung transplants.

A further benefit to the repatriation of transplant services from the UK back to Ireland is the delivery of significant cost savings to the HSE, as patients and their families will no longer need to be transported and cared for outside of the State.

Last year was a record year for lung transplantation at the unit with a total of 32 lung transplants, with excellent survival rates and outcomes comparable to national and international standards. The increase in lung transplants is multi-factorial and would not be possible without the generosity of donors and their families, at an incredibly stressful time. In addition, with the advent of the HSE National Organ Donation and Transplantation Office there is an enhanced cohesive approach to organ donation and utilization.

**Mr. Jim McCarthy, Director at the National Centre for Cardiothoracic Surgery, Mater Misericordiae University Hospital)**, who performed the first lung transplant with Mr Freddie Wood in 2005 commented:
*"We will, in the next year, be celebrating ten years of performing lung transplants in Ireland. We have a very skilled and extremely busy surgical team undertaking complex cases."*

*"The number of thoracic procedures has increased by approximately 300% over the past 2 to 3 years. We have established a long and valuable relationship with Newcastle and we will continue to consult with them on a case by case basis, as we do with other transplantation facilities around the world. I would like to take this opportunity to express our gratitdue to our Newcastle collegues and, most importantly, to the donors and their families who have given the greatest gift in the most difficult of circumstances,"*

**Mr. Lars Nölke Cardiothoracic, Surgeon at the Mater Hospital, added:**
*"Since the first single lung transplant in Ireland was performed in May in 2005 the range and complexity of transplant surgeries has increased year on year, while maintaining the excellent survival results as published in the British Medical Journal (BMJ) in 2012. (BMJ Open 2012, Mar 28; 2(2))*

# Research Update *Dr Caroline O Connell,* Pulmonary Vascular Research Fellow, MMUH

*Many thanks to the patients who participated in the GRIPHON clinical drugs trial study. This study has finished recruiting 1150 patients from different centres around the world and the results should be available in mid 2014.*

The study is evaluating the efficacy and tolerability of a new oral agent called selexipag, which acts on the prostacyclin receptor. A previous study in a much smaller group of patients has already shown improvements in six minute walk and haemodynamic results. If the results of this present study are positive, we hope the drug may become a new addition to the therapeutic armamentarium available to us.

The doctors in the pulmonary hypertension unit in the Mater hospital have collaborated with researchers in the Conway Institute in UCD and have been working on a protein called CXCL12. This protein is closely involved in the pathogenesis of pulmonary hypertension, and much work has been done to assess the use of measuring this protein in the blood and to help doctors assess disease severity and prognosis. The results of this work were recently presented at the pulmonary hypertension physician's research forum in London.

The pulmonary hypertension database has shown encouraging survival figures, which compare very well with internationally published data and few complications of treatment for the patients with connective tissue disease associated with pulmonary arterial hypertension. With more and more treatments emerging and better knowledge of this debilitating disease, we should continue to see improvements over the coming years.

# The Clinical Nurse Specialist (CNS) Clinic

- *Caitriona Minnock* CNS for PH MMUH

The CNS clinic was set up in 2010 to provide clinical expertise to clients and families in all aspects of PH. As you will know the role of the CNS is varied and divided between inpatient and outpatient care. It was with this in mind that we decided to set up a service that could be specifically tailored to meet the needs of individual patients. The number of patients attending this service has increased exponentially and the response from the clinic has been very positive.

The diagnosis of PH is a major event for all patients. The knowledge that they may now have a rare disease, also referred to as an orphan disease affecting a small percentage of the population can be isolating. The CNS clinic provides an opportunity for patients to explore the many life changing issues that they may encounter as part of this new diagnosis. This environment allows the building of the trust and credibility that are essential for a therapeutic relationship to develop.

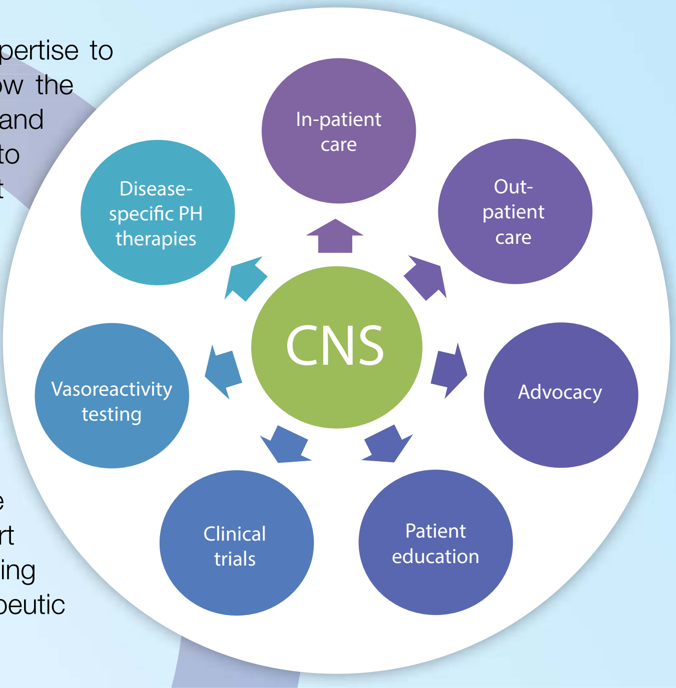


Figure 1. The varied role of the CNS

Most rare diseases are genetic and may not become apparent until later in a person's life and therefore many changes may need to be made in order to have the type of lifestyle that allows patients to regain the confidence to deal with their disease and tackle the challenges that may lie ahead. It is the intention in the CNS clinic to allow patients to have a forum so they may have a guided individual approach to treatment and enable their families to have the opportunity to be involved in the process.

On a practical level the CNS clinic allows patients to have therapy adjustments and assessment of the effect of these changes outside of the hospital environment. The commencement of advanced therapies can have a large impact on patient lives. Therefore the focus has changed in recent years towards the investigation of this impact. It is with this in mind that we will be asking you to complete quality of life questionnaires over the next few years at your clinic visits and indeed you may have already performed this activity for us. This information is very useful in allowing us to develop treatment plans that target the less obvious impact of the disease e.g. allowing patients to work, exercise and function more effectively.

**Table 2. Different areas addressed in the CNS clinic**

- Evaluation of response to targeted pulmonary hypertension therapies
- Assessment and management of right heart failure
- Patient and family education sessions for PH management
- Provision of social and psychological support (Galie et al, EurHeart J 2009)
- Support and optimisation of complex protacyclin therapies

Patients may often access the CNS clinic for a variety of different reasons not mentioned and we are usually happy to accommodate. It is however important to remember that your GP is your primary care giver and it is vital that you are availing of this service too. The CNS clinic does not replace the valuable role that the GP has in your care. It is intended that care is shared, with all parties involved communicating when necessary. We are always open to suggestions as to ways that the service may be improved so please summit any suggestions to us (no need to sign them!). We look forward to seeing you at your next visit.

### Information about available resources and support

- Although some patients with PAH will be eligible for funded medical care, many will not. The CNS fulfils the role of advocate ensuring patient's individual specific needs are understood by the appropriate authority or body considering funding applications.
- The CNS can also act as an advocate liaising with pharmacists to ensure that the appropriate prescription is received and processed. They also ensure that any regular tests required by the Irish Medical Board (for example, liver function monitoring) is conducted.

*Patient education*

- Significant advances in PAH management have been made in the past decade and rapid progress is still being made. Appropriate training of CNS is a crucial component of the role to ensure that best practice is maintained. The CNS regularly attend International congresses and consult with European and American colleagues to ensure that management care in Ireland is in line with that in other countries.
- This learning is formally passed on to nurses working on the PH wards via structured sessions and mentorship to ensure a consistent management approach across the facility.

*Clinical trials*

- Clinical trials are an important part of clinical practice in a centre of excellence for PAH. As a research site, the NPHU is always actively involved in studying new therapies. The CNS is the study coordinator for all clinical trials in the NPHU.

*Disease specific PH therapies*

- It is the CNS role to ensure that patients receiving PH therapies have the correct supportive education in order to ensure effective drug delivery. This activity focuses primarily on the management of side effects in particular pain control and the use of pathways and scales.

# Pulmonary Hypertension Clinic visits

As many of you know from past experience it is very important to attend your PH clinic appointment. Most of you receive your return appointment before you leave the clinic, in addition you will receive a phone call a week before your appointment which serves as a gentle reminder.

As with many other clinics there is always someone else ready to take your appointment should you not be able to attend. Therefore it is always appreciated if you are unable to attend or running late, you give us as much notice as possible. This can be done by phoning the PH Unit on 01-8034420 and leaving a brief message, we will get back to you with a new appointment in due course.

### What to bring to your appointment

*There are few things we ask patient to bring to clinic appointments;*

1. An up-to-date list of your medications and doses.
2. Comfortable footwear as you may be asked to complete a 6-Minute-Walk-Test (6MWT).
3. We encourage you to bring along a family member or friend.
4. It is really useful to bring a list of any symptoms or problems that may have arisen since your last visit, or indeed any specific questions that you may have.
5. If you require portable oxygen, please ensure you bring along an adequate supply.

### Who you will meet at your visit

*During your visit you will meet a number of specialists that will provide the best possible care, including;*

- Consultant
- PH Clinical Nurse Specialist
- Secretary
- Senior Doctors
- Doctors in training

# Clinical Trials - *Diane Moran CNS for PH, MMUH*

A clinical trial is a controlled assessment of a new drug or medical procedure/device. To be approved for use in patients, new drugs must demonstrate their effectiveness in clinical trials aimed at treating a certain condition, therefore, people with that condition need to be included in the clinical trial. Here at the National Pulmonary Hypertension Unit (NPHU), clinical trials are sponsored by pharmaceutical companies and run by the medical, nursing and administration staff of NPHU, and involve patients with Pulmonary Hypertension who have consented to take part in the trial.

## Pulmonary Hypertension and Clinical Trials

Without clinical trials, new treatments would not be approved or developed for Pulmonary Hypertension (PH), indeed there would be little advancement in the treatment of PH. The very first oral treatment for PH was approved in 2002. Currently in Ireland there are four approved oral therapies and two new oral therapies scheduled for approval in 2014. Drug therapies resulting from clinical trials have transformed the medical treatment of people with PH, improving their quality of life and survival.

## Types of clinical trials

There are various trial types which drug companies may use to develop drugs to treat PH. In general, trials involving people with PH are 'placebo controlled studies'. In this type of study/ trial participants are given the drug being tested or a placebo 'dummy' drug in addition to a conventional therapy. The patient does not know if they are receiving the drug being studied or the placebo, ensuring that any change is definitely due to the treatment.

## Regulation of clinical trials

Under legislation set down by the government to protect patient safety, clinical trials are regulated by a number of governmental and healthcare bodies. This ensures that patients participating in a clinical trial are provided with the best possible standard of care. In Ireland, clinical trials must first be approved by the Irish Medicines Board, a governmental body that set down regulations regarding clinical trials and conduct inspections.

Clinical trials are regulated by a number of governmental and healthcare bodies. This ensures that there is no known risk to people entering the trials. Importantly clinical trials cannot be approved if it is thought that people will get a worse therapy than they would normally receive. This ensures that, even if you are among those people who do not get the new drug being tested, you will still be getting the best standard of care.

At a local level, hospitals involved in clinical trials also have an ethics committee which approve the trial before it can be started. These committees ensure that there is no known risk to people and that there is a medical need for the clinical trial.

## Why participate in a clinical trial for PH?

There are two main reasons for participating in a clinical trial in PH. The first is that you may be able to get a new treatment for PH before it is approved. This said, you need to balance this expectation with the chance that, in some studies, you may be assigned to take placebo instead. There is also the possibility that the drug being tested is not effective, so even if you do receive the drug (and not placebo), it may not improve your PH.

If the drug in a phase 3 clinical trial is shown to be effective, you may be offered the chance to take that drug after the trial has finished. This takes place even though the drug has not yet been approved, and is part of what's called a compassionate use programme. In these circumstances, people are offered the active drug even if they were taking placebo during the clinical trial. There are also certain circumstances where you can be given a drug before it is approved as part of a compassionate use programme, even if you haven't been involved in the clinical trial.

The second reason to participate in a clinical trial is to help more forward treatment for PH. Clinical trials are essential for new drugs and medical advances to be approved for use. Unlike some conditions, e.g. heart disease or diabetes, there are relatively few people with PH. Because of this, it can be difficult for drug companies to get enough people in a clinical trial. Only through people with PH consenting to take part in clinical trials can medical advances be made in treating PH.

## Importance of clinical trials for the future of PH treatment

Over the past 20 years, the treatment of PH has experienced huge growth and improvement. These improvements have been the result of clinical trials to test new drugs. These included hundreds of people with PH, who consented to take part in these clinical trials. We are now in the position where PH specialists can slow the progression of the disease and treat the symptoms. However, there is still a long way to go.

We still have a lot to learn about the causes of PH and much research is on-going in this area. It is hoped that future treatments can build on this research and treat the causes of PH. There are also improvements that can be made in the way the drugs are administered. Drugs that are currently administered intravenously or subcutaneously (injected under the skin) may one day be available in tablet form. In addition medications that need to need to be taken numerous times a day may one day be able to be taken once a day.

Current Trials at the National Pulmonary Hypertension Unit include:

- Griphon
- Freedom

# Acupuncture - *Gerry Rothwell* Lic. TCM

www.gerryrothwellacupuncture.ie
Mobile: 086 2545990

*I have been practising Acupuncture for 16 years, and since 2011, I have been treating paitents with PH at the Centre for Lung Health, 56 Eccles St. Some of the most common questions I am asked include: what is acupuncture? How does it work?*

### What is Acupuncture?

Acupuncture is a complex medical system that is used to diagnose and treat illness, prevent disease and improve well-being. It originated in China more than 3000 years ago and has been embraced throughout the world.

It involves the insertion of extremely fine, pre-sterilised needles at predetermined points on the body's surface to restore health on a physical, psychological and emotional level. Acupuncturists use methods of diagnosis and treatment programmes that take into consideration that we are not just a collection of bodily parts but an individual whole of mind, body and spirit, and use acupuncture to treat any imbalance or disharmony in our health.

Acupuncture can be used alone or combined with other forms of Traditional Chinese Medicine, including moxibustion, cupping, food therapy or Chinese herbal medicine.

### How does Acupuncture work?

In Traditional Chinese Medicine the human body is seen as an energy system. The Chinese call this energy Qi (pronounced 'chee'). The Qi flows along specific pathways known as Jing Luo or meridians in the body. In health the Qi moves around the body with ease, in order to nourish and stimulate all aspects of the person. If, for some reason, the Qi does not flow in the right direction, or there is not enough, or the Qi is blocked, generally the person will become ill.

The severity and the location of the illness will depend on where and how the flow of Qi has been affected. Acupuncture seeks to balance the flow of Qi in order to restore health.

Some of the most common conditions that I treat in the Centre for Lung Health are acute and chronic pain, inflammation, fatigue, insomnia, panic attacks, COPD, Cystic Fibrosis and side-effects from some prescribed medications.

The World Health Organisation recognises Acupuncture and Traditional Chinese Medicine as a viable means of treatment for a wide range of conditions.

# Get breathless for pulmonary hypertension campaign

- *Regina Prenderville*
*Project Manager,* Pulmonary Hypertension Association

***To coincide with World PH Day on 5 May 2013, the Irish Ladies Rugby Team (winners of the Triple Crown and Grand Slam) launched our Get Breathless for PH Campaign***

Members of the Irish Ladies Rugby at their training grounds in Donnybrook
Jenny Murphy, Fiona Coughlan, Prof Sean Gaine & Shannon Houston

## World PH Day - raising awareness

The 2nd World PH Day was held on 5 May 2013. This day was celebrated globally by 40 PH associations in five continents.

PHA Europe campaign for the day revolved around the theme of sports. People were encouraged to take part in sporting activities to 'Get Breathless for PH'. This was a powerful way of highlighting the restrictions on physical activity faced by many PH patients and provided an effective way of raising awareness of Pulmonary Hypertension while bringing challenges faced by patients the forefront.

Ireland received funding from PHA Europe to organise the campaign - posters, T Shirts etc. A letter was sent to all our patients informing them of the campaign and we requested support from families and friends. Nothing could have prepared us for the amazing response we received. So many of you organised families, friends & neighbours to come out and support Pulmonary Hypertension in the Mater Hospital.

Activities ranged from tea parties, card games to half marathons, Ladies Mini Marathon, Hell and Back Challenge, a mini-triathlon and Currach race on the Aran Islands and a Seine Boat Race on Valentia Island. Large donations were also received from Credit Unions, Social Clubs etc. We are so grateful to all of you who have supported the campaign.

Ladies mini marathon participants: Ann Barnes,
Marian English, Catherine Byrne & Rita McQuillan

## Ladies Mini Marathon

The annual Ladies Dublin Mini Marathon is always a great spectacle and charities from all over the country are generously supported. This race has been held in Dublin for the past 30 years and since then over €130m has been raised for charitable organisations.

This year the event attracted over 40,000 ladies onto the streets to run for their various charities. We are most grateful to the ladies who organised groups of friends to run for Pulmonary Hypertension. It was great to pick out our 'Get Breathless for PH' T shirts among the throngs and the ladies wore them with pride as they crossed the finishing line in the sweltering heat in June.

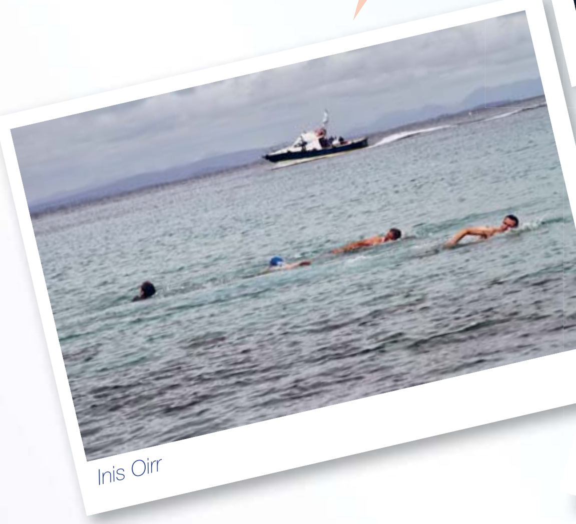
Mother & Daughter support from Val McDonnell,
Sarah Flood, Adrienne Flood and Elaine McDonnell

# Support from the Islands


Inis Oirr

## *Triathlon ar an Tra*

The smallest island of the Aran Islands (Inis Oirr) held a Mini Triathlon. The island is 3 sq kilometers, so not really sure how many times the island was circled. The event was organised by Sinead Crowe, Muinteoir ar an Oilean (teacher on island) and as you can see we have some really memorable pictures of the event. The Island of Inis Oirr received international recognition recently when it scooped two major awards at the LivCom 2013 ceremony held in Ziamen in China.


Inis Oirr


Inis Oirr

A delegation from Inis Oirr travelled to China to attend the ceremony. There were 60 finalists in the competition representing 30 countries. The island community were awarded the Special overall award in the Healthy Lifestyle category but also won the overall award in the category for Places with a population up to 20,000. I understand pictures of the Triathlon ar an Oilean were used as part of the submission from Inis Oirr.

The LivCom awards was launched internationally in 1997 and is endorsed by the United Nations Environment Porgramme. It is a major international competition which recognises best practice regarding the management of local environment. Further information from www.livcom.com


Inis Oirr

## *Seine boat race on Valentia Island*

On Sunday 14 July, the men of Valentia Island were out in force to support us when they participated in a Seine Boat race held during the Templenoe Regatta. The race involves rowing for 30 minutes and while the weather was good, the waters off the south Kerry coast were cold and choppy. We are delighted to say that ‘our team’ captained by Leo Houlihan achieved 1st prize in the regatta. This is the 3 year in a row that Leo’s team has won this coveted prize on Valentia. We are very grateful to all of the islanders on Inis Oirr and Valentia for helping in our awareness campaign.


Valentia Island

Valentia Island

Charlie & Bridie Fineran present cheque to Prof Sean Gaine and Regina Prenderville

## Card game in Roscommon

Charlie & Bridie Fineran from Roscommon organised a card game and a local walk for the Get Breathless Campaign. The community really got behind the events and we are so very grateful to all for their enormous commitment. The Finerans travelled to Dublin to present their cheque for €2430 to Prof Gaine

There were many other innovative events organised and it's great to know we have such good support. Patients and friends of patients collected money for various events and we were amazed by such enormous generosity and enthusiasm.

## Half Marathon in Dublin

We were with Gerry Martin every step of the way (as supporters only) when he ran a half marathon in the Phoenix Park. Well done Gerry – you sported the T shirt very well and raised €1600 for your efforts.

Community walk in Roscommon

Aidan Hayes, Caroline O Connell, Joanna Cornwall & Michael Hayes

## Caughoo Challenge

Joanna Cornwall, Aidan Hayes, Michael Hayes and Caroline O'Connell took on the Caughoo challenge on 17th of August, raising money for the Pulmonary Hypertension Association. This was a 10km run from Sutton which brought runners to the top of the hill of Howth with beautiful views on Dublin bay. Dr Caroline O Connell (second from left) is a Pulmonary Hypertension Research Fellow in the Centre for Lung Health in the Mater Misericordiae University Hospital

- See more at: http://www.pulmonaryhypertension.ie/caughoo-challenge/#sthash.AaAqHqCr.dpuf

# A BREATHTAKING ACHIEVEMENT...

**We are extremely grateful to Susan Sheehan and her family for their very generous donation. Susan organised an afternoon tea in her home and we asked her to write the following article, which gives a very good insight into all of the work and enthusiasm involved in the organisation of the event**

# Afternoon tea in Co Cork - Susan Sheehan

*As the last people left on that Sunday evening, we were delighted that the event had been such a huge success and a great time had been had by both young and old. Little did we realise that we had raised €3,851 for the PH Unit, thanks to the wonderful generosity of our family, neighbours and friends.*

After seeing the posters for World PH Day 2013 and Regina's quest for fundraisers, we decided to try and support and came up with the idea of having an Afternoon Tea Party. Wondering first about hosting a coffee morning but with me not being the most organised person in the mornings, we decided something in the afternoon would work much better, so with the wonderful help from friends and family we planned to hold it on World PH Day, Sunday 5th May.

We didn't advertise the tea party; it was just by word of mouth through the local community. I suppose one of the main reasons I didn't advertise was reluctance on my part of publicising the fact of what illness I have. Though since the tea party a few people have come back to me and asked about PH which is a good thing in that it raises awareness of PH. Also people realise that yes we are struggling everyday with this illness but we can still look well and 'healthy'. This for

Susan Sheehan, 2nd row (centre) with family & friends me can be one of the frustrating things of having PH is other people's belief that if you look fine then you must be fine.

So the planning began – with the help of my family and friends we started organising and getting the house presentable - though I'm not sure if anybody would have taken any notice if we had a few cobwebs here and there. We decided to host the tea party at home rather than at the local community centre as we felt it would be more personal. It was a great way to get those long outstanding jobs on the' to do list' done!

Table and chairs were borrowed from the local community centre. Cups, saucers and tea pots were borrowed from neighbours and friends and we managed to get our house looking like a tea room for the day. We were amazed by the amount of people offering to bake and help for the day.

Bouncy Castles were installed in the garden for the kiddies. A friend of ours, Martina, sells Aloe Vera products so she brought along her products on the day and gave all the profits to the PH association. A field for parking was kindly provided by a neighbour.

A bit of panic set in on Sunday morning – I started to wonder if anyone would turn up and if they did had we enough for everyone. But under the watchful eye of a wonderfully calm husband, an equally practical mum and fantastic family members, everything went according to plan. It turned out to be a wonderful afternoon. We had a packed house with over 150 people calling and it was great to catch up and chat with everybody.

Exhaustion set in on Sunday night but it was certainly all worth it when we opened the donation boxes and saw the amounts inside. Before the day we had already raised a few hundred euro and we had hoped we might make it to €1,000 but never imagined it would get to where it did.

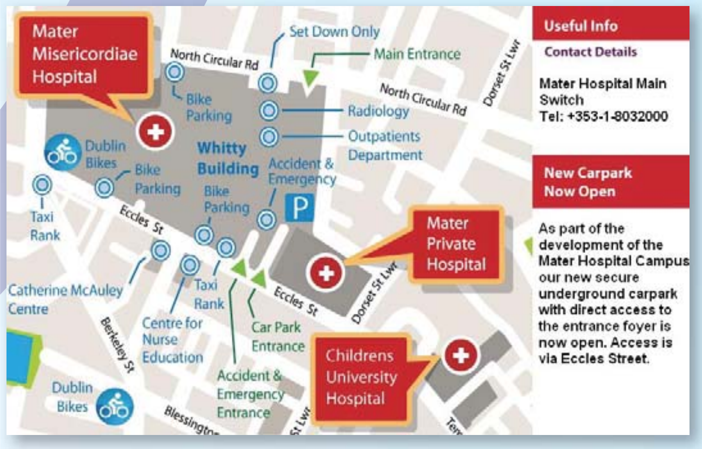
We would like to thank all that helped and supported to make this day a huge success. It was great to support the PH Unit at the Mater and it is only a small repayment for the fantastic help and support they have given to me and my family over the past four years.

Finally, to anyone out there thinking of arranging an event to support PH, I would recommend go and do it as it is hugely satisfying and rewarding and gave me a personal boost.

Susan xx

## CLINIC LOCATION

The Pulmonary Hypertension Clinic location can occasionally vary, it is important to read your appointment letter to prevent you from arriving at the wrong location. Currently our two locations are;



Mater Hospital Main Switch
Tel: +353-1-8032000

As part of the development of the Mater Hospital Campus our new secure underground carpark with direct access to the entrance foyer is now open. Access is via Eccles Street.

1. **Outpatient Clinic Department,**
   **Clinic 1, Level 1, Whitty Building,**
   **Mater Hospital, Dublin 7.**
   *We recommend entering the hospital via the North Circular Road entrance. Reception, bus stops, taxis and wheelchairs are all available at this entrance.*

2. **Centre for Lung Health,**
   **56 Eccles Street, Dublin 7.**
   *(across the road from the Eccles Street entrance to the hospital) An outdoor lift is available for those unable for the steps.*

Your visits are very important and you may have travelled a long distance to get here. Remember we are here to help and making the most of your appointment is an important part in the management of Pulmonary Hypertension. If you have any concerns or queries in relation to your appointment, please do not hesitate to get in contact with us.

# TO HELL AND BACK Challenge

Eight volunteers took part in the To Hell & Back Challenge. This gruelling obstacle course was over a 12 km stretch in Belmont Estate, Co Wicklow at the foot of the Sugar Loaf Mountain. Apparently the scenery from the estate was magnificent, but the participants informed us they were not there to enjoy the views !

The brave contestants started the challenge by running through the Ditch of Doom to ensure they were covered from head to toe in mud, then they had to plunge themselves into a freezing cold pond to 'clean off the mud'. Next challenge was to wade up to their necks in a swamp which swallowed up many shoes and items of clothing! Then when they were feeling really miserable, they had to complete a 3km climb up the Sugar Loaf Mountain. To make the challenge a bit more exciting – participants were required to carry a cement block for part of the journey. Next challenge was to complete a barbed wire crawl through mud before finishing the course by scaling a 10 ft wall. In true military fashion, snipers were hired to shoot at competitors from behind with air rifles which made everyone 'Run for their Lives'. The Hell & Back Challenge is designed to push contestants to their limits – all in the name of fun and a good cause.

At the end of the day our beautiful white T shirts were practically unrecognisable. Our volunteers were delighted to complete the course, however, I wonder why they didn't offer to do it again next year ??

The Enthusiastic Eight: Conor McIntyre, Courtney Flynn, Ron Doyle, Stephen Fogerty, Elaine McDonnell, Ciara McDonnell, Niamh Prenderville & Kate Faughnan

## *To everybody who donated cash, cheques, postal orders etc. may we say a very big thank you to you all for your interest and support.*

The campaign raised almost €20,000 and we greatly appreciate the effort put into all of the events. We must stress however, that the 'Get Breathless for Pulmonary Hypertension' campaign was the brain child of PH Europe and events were held all over Europe throughout the year. It was intended that the campaign would be more of a public awareness campaign rather than a fundraiser.

Ireland was the only country who made it a fundraiser and we are delighted to report that PH Europe awarded a certificate to Ireland for organising the most cost effective and innovate event in Europe !

## Development of 3rd Cath lab in the Mater Hospital

On behalf of the PH Association, Prof Sean Gaine has made a donation of €15,000 to Prof Declan Sugrue toward the development of a 3rd Cathlab in the Mater Hospital. This new development will be a great asset to the hospital and to our PH patients

# Events held during 2013

## Patient & Family Day

The annual patient & family day was held on 27 April. We had an attendance of 94 and the presentations were very well received by all. While the hotel was very comfortable, the service was excellent and the food superb, many felt there was too much walking involved between the lecture and the dining areas. Having taken this into consideration we have booked an alternative venue for 2014.

Mr Iain Armstrong (PHA UK) & Dr Noel McCaffrey, speakers at patient & family day meeting

Patricia Shaw & Gerry Martin

Karen & Shay Doherty

## All Ireland Pulmonary Hypertension Meeting

This specialty meeting was held in September 2013. Consultant respiratory physicians, cardiologists & rheumatologists from Ireland and the UK presented findings at this meeting which was held in the Royal College of Physicians. The meeting was so well received that it has been decided the meeting will become an annual event. It will be held each alternate year in the Republic and we are very pleased to note that Northern Ireland will host the 2014 meeting.

*Dr John Wort, Imperial College London UK, Dr John Cannon, Papworth Hospital, UK, Prof Paul McLoughlin, University College Dublin, Prof Sean Gaine, Mater University Hospital, Dr Carol Wilson, Belfast Health & Social Care Trust, Dr Gerry Coghlan, Royal Free Hospital, London UK, Dr Dermot O Callaghan, Mater University Hospital*

# Forthcoming Events

**World PH Day 2014:** *World PH Day will be held on* ***Sunday 4 May 2014****. Since this is the Bank Holiday Week-end in Ireland, it may restrict us in organising events on the day. However we have plans.......... Guinness World Records have accepted our challenge to break the Longest Kissing Chain. The guidelines are as follows:*

- The line must stay connected and in place until the record is completed
- All participants must be lined up one after the other (the current record is 361 people)
- All participants must kiss each other on the cheek, give and receive two kisses each
- The attempt must take place at a single location and be in a restricted area

We hope to make our challenge as near to 4 May as possible. I have requested permission to have our challenge in Croke Park and am still awaiting a response. If we don't get this venue we will source another without delay. As an eye catching way to grab people's attention, we may use the idea used by PHA UK some years ago by giving everybody blue lipstick ? We are confident we can break the record of 351 participants, so now is the time to start gathering your family and friends to help us create the longest kissing chain in the world. As soon as I know the exact date and venue, I will contact you.

**Patient & Family meeting:** The 2014 Patient & family meeting is scheduled for **Saturday 10 May 2014.** This will be held in the Gibson Hotel at the Point Village. The venue is accessible by car or by rail. Nearer the time we will forward you the programme and exact directions.

## Support Groups - a message from your Association

*- Regina Prenderville, Project Manager*

We wish to encourage the development of support groups around the country. However to ensure the success of this, we need the support of those who have a connection or interest in Pulmonary Hypertension.

Through the Pulmonary Hypertension Association - Ireland, we can help and would be delighted to offer any organisational assistance that may be necessary to progress your ideas.

If you would like to become involved in the setting up or joining a support group - please email me at pha@mater.ie

The following venues have been reserved to facilitate meetings - (7.00 - 8.30 pm). I will be there and hopefully those of you who live relatively near will come along to further discuss how we can support each other. A short lecture will be presented on both evenings.

**Wednesday 2 April:** Mullingar Park Hotel at 7pm (details will be confirmed shortly).

**Thursday 10 April:** Lecture entitled *'Social support for Patients & Families'* will be presented by Dr Mary Rose Day, College Lecturer, School of Nursing & Midwifery, University College Cork at 7 pm in the Vienna Woods Hotel, Glanmire, Co. Cork.

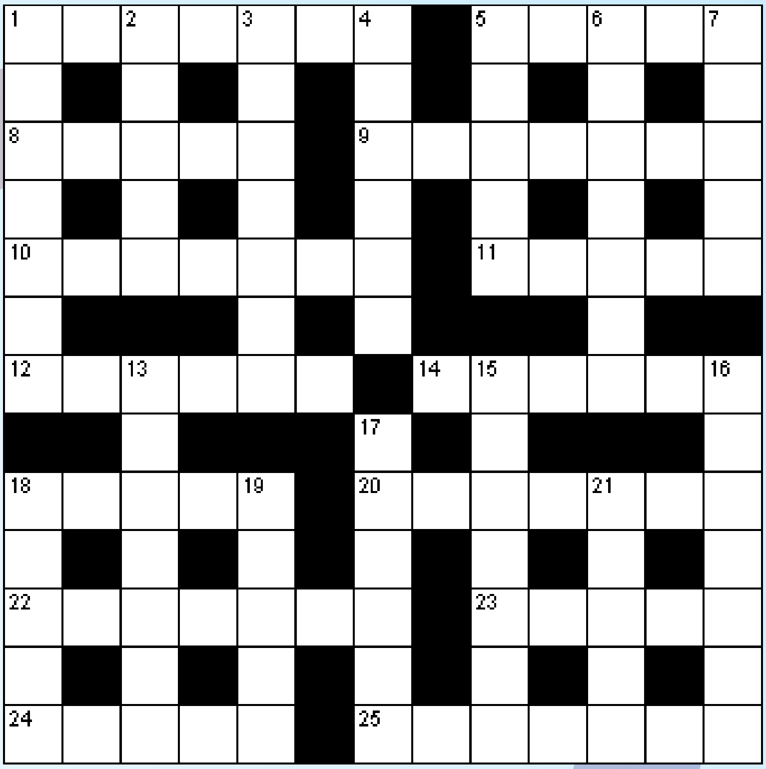
*To help with logistics, it would be very helpful if you can confirm if you and / or your family members will attend on the above evenings by calling 087 637 6563 or email pha@mater.ie*

Pulmonary Hypertension Association - Ireland

**Pulmonary Hypertension Association - Ireland**
Centre for Lung Health,
Mater Misericordiae University Hospital,
56, Eccles Street, Dublin 7.
**Tel:** 01 854 5172 or 087 637 6563
**Fax:** 01 854 5177 **email:** pha@mater.ie
**website:** www.pulmonaryhypertension.ie

DUBLIN ACADEMIC MEDICAL CENTRE

# CROSSWORD



**Across**
1. Large house (7)
5. Pieces of information (5)
8. Profits (5)
9. Gruesome (7)
10. Retaliated (7)
11. Form of transport (5)
12. Hostility (6)
14. Stick (6)
18. Permit (5)
20. SIncere (7)
22. Creatures (7)
23. Doctrine (5)
24. Ledge (5)
25. Sweet (7)

**Down**
1. Tycoon (7)
2. Dissonance (5)
3. Perceptiveness (7)
4. Wanderers (6)
5. Aspect (5)
6. Vegetable (7)
7. Austere (5)
13. Discomfort (7)
15. Mocks (7)
16. Pull out (7)
17. Stopped (6)
18. Accumulate (5)
19. Dock (5)
21. Bird of prey (5)

**Completed crossword puzzles should be returned before Friday 28 March to:**

**Regina Prenderville,**
**Pulmonary Hypertension Association - Ireland**
**Centre for Lung Health,**
**Mater Misericordiae University Hospital,**
**56, Eccles Street, Dublin 7.**

All correct applications will be placed in a draw for a prize of €20.

Pulmonary Hypertension Association - Ireland

# PHA Ireland **Membership Form**

Please complete this form and return it to Regina Prenderville, Pulmonary Hypertension Association, Mater University Hospital, 56 Eccles Street, Dublin 7.

**NAME**

**ADDRESS**

**TELEPHONE**

**MOBILE**

**EMAIL**

**MEMBERSHIP** **Patient** ☐ **Carer** ☐ **Other** ☐ (Please tick)

**I WISH TO TAKE PART IN:**

**The PH Association** **Yes** ☐ **No** ☐ (Please tick)

**The PH Support Group** **Yes** ☐ **No** ☐ (Please tick)

**SIGNED** **DATE**

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