



# PHéileacán

Newsletter from the Pulmonary Hypertension Association – Ireland

WINTER 2020

Vol 1 : Issue 3



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# Message from the Editor

**Regina Prenderville**

Project Manager, Pulmonary Hypertension Association



Welcome to the 3rd edition of **PHéileacán**.  
I hope you find the Newsletter interesting.

In 2019 the patient association was active throughout the year with meetings held in Dublin, Cork & Galway. These support group activities were proving to be very successful and we all miss our regular 'get together'. Our last meeting was held in February 2020 in the Crowne Plaza, Dublin.

During 2019 we had many exciting fundraising events and we are extremely grateful to all who participated & contributed – I refer to these activities on pages 6-9.

One positive aspect of the pandemic is that it has made us all embrace technology. On 16th October 2020, we held a scientific update meeting with presentations from experts in PH. We were delighted with the participation from patients and their families and hope we can continue to communicate in this manner. We are planning another meeting in the New Year and will forward details to you shortly.

We look forward to better days ahead when we can work together to continue raising awareness of PH. However, in the meantime, we do need to keep in touch. If you have not already done so, please forward your email address to [pha@mater.ie](mailto:pha@mater.ie)

May I take this opportunity of wishing you, your families & friends a very happy Christmas and a healthy & peaceful New Year.

A handwritten signature in blue ink that reads "Regina".



**Pulmonary Hypertension Association - Ireland**

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The Pulmonary Hypertension Association is affiliated to the Mater Foundation (CHY 9768)





# Progress with developments in Pulmonary Hypertension

## Diagnosis & Treatment during the pandemic

**Prof Sean Gaine**, Consultant Respiratory Physician



The year 2020 has been a very difficult one for all our patients, families and staff. Ever since the pandemic was announced in March the manner in which pulmonary hypertension is diagnosed and cared for at the Mater Hospital changed significantly. Delayed diagnosis has remained a real concern for us as the number of new patients being referred is significantly down on previous years which suggests there are people who have pulmonary hypertension who have not had the opportunity to attend their general practitioners or specialists to have the diagnosis confirmed. It is important that we continue with our disease awareness on social media and through professional channels to ensure that people with unexplained breathlessness are diagnosed early so that medical treatment can commence. For patients with pulmonary hypertension monitoring the disease has become more difficult.

In the initial phases of the pandemic we had to discontinue our face to face outpatient department visits, although this thankfully has now restarted, and we have had the opportunity to see people once again. Many people remain nervous of coming to the hospital and this is understandable. However, with all of the measures in place it is perhaps safer to be in the hospital than in many places out in the community! We have been working on a number of methods to improve our ability to monitor patients remotely.

We have a new mobile phone app called PHuman which has just been launched and available on the app store. The app allows patients to monitor their own symptoms and then forward them to the hospital so that we can review how things are going and perhaps expedite an earlier review.

It can be very difficult to cocoon and remain indoors and this has increased the isolation that many people have felt over the past 7 months. We have been really keen to get exercise programmes going and many of you will have met Ciara McCormack either online or in person. Ciara is working on a research project between DCU and the Mater Hospital to devise a safe remote exercise program using video links. We recommend a regular exercise programme to approach each day during lockdown to maintain aerobic fitness. Finally, it has been a difficult time for new drug development and clinical trials when patients were unable to attend the hospital for review. On a positive note however there are a number of new drug targets that have emerged over the past few months. We are currently in discussions about new therapies and I am hoping that in the next newsletter I will be in a better position to inform you about these. In the meantime I wish you all the very best for the rest of this year and look forward to a much more healthy and hopeful 2021.

# Introducing the PAHTool

**Dr Brian McCullagh**

Consultant Respiratory Physician



We in the Pulmonary Hypertension Unit at the Mater Misericordiae Hospital are always looking for ways to improve the patient care that we deliver. We do our best to keep abreast of novel therapies by being involved in international trials for new medications or embracing research of our own such as the PHASE trial (A bespoke home exercise trial) being run by our PhD student Ciara McCormack.

Some innovations are behind the scenes and may not be apparent to our PH community, one such innovation that we hope to introduce to the service in the coming weeks is a new software system called PAHTool. This has been two years in the making with much consultation with our European partners, local administrative and IT services and with support from Actelion Pharmaceuticals.

This is a computer software interface that will allow us to have information at the click of a button. The hope is that we won't end up spending all our time flicking forward and back through charts to find pertinent information, something that I'm sure you have seen us do countless times! It will allow us to have a more refined registry, audit and benchmark our practise to ensure we continue to meet the best standards and perhaps even help us in our decision making.

The final phase of instillation of this software is in place and we should be up and running soon. We have to thank our IT service at the Mater for all their hard work in getting this over the line, particularly in such difficult times when everyone is expected to do more with less and less resources.



## Managing Breathlessness during Physical Activity

**Ciara McCormack**, PhD Researcher,  
Clinical Exercise Physiology, DCU

Keeping physically active and avoiding too much sedentary behaviour (too much sitting) is important for our overall health and well-being. It can help improve our ability to carry out tasks of daily living (walking to the shops, playing with grand kids etc), help prevent against other chronic diseases, improve our sleep and help manage our weight as well as improving our mood and mental well-being. However, for many Pulmonary Hypertension patient's breathlessness may cause you to reduce your activity. The section below outlines 3 simple breathing techniques you can use to help manage your breathlessness and to make activities of daily living easier and physical activity.

### What do I do if I get Breathless?

Getting breathless when exercising can make you feel a little anxious. If you panic, it can make you feel even more breathless. The key is to stay calm and learn ways to manage your breathlessness.

There are several breathing techniques that you can use when you exercise to help you control your breathing. Here are some examples:

1. **Blow-as-you-go** helps make tasks and activities easier. Use it while you're doing something that makes you breathless. You can use it with pursed-lips breathing.

**How do I do it?** Breathe in before you make the effort. Then breathe out while you're making the effort. For example, when standing up, breathe in

before you step or stand up, and then blow out as you stand up. Try pursing your lips as you blow out.

2. **Paced breathing** is useful when you are active, e.g walking or climbing stairs. You pace your steps to your breathing. You can use it at the same time as pursed-lips breathing and blow-as-you-go.

**How do I do it?** Count to yourself as you walk or move. For example, breathe in for one step and then take either one or two steps as you breathe out. Take more steps as you breathe in or as you breathe out, if that feels better for you. Try different combinations to find what works best for you - for example, one step in, two steps out.

3. **Pursed-lips breathing** can be used at any time to help you control your breathing. This helps to empty all the air out of your lungs.

**How do I do it?**



1. *Inhale slowly through your nose*



2. *Exhale slowly with lips pursed (as you would to blow out a candle)*

Practice these techniques at home first and then start using them during physical activity or while carrying out activities of daily living, it may feel a little strange at first but once you practice for some time you will get the hang of it.





# Fundraising for Pulmonary Hypertension

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

## Static cycle by staff from Mountjoy Prison – a truly memorable occasion

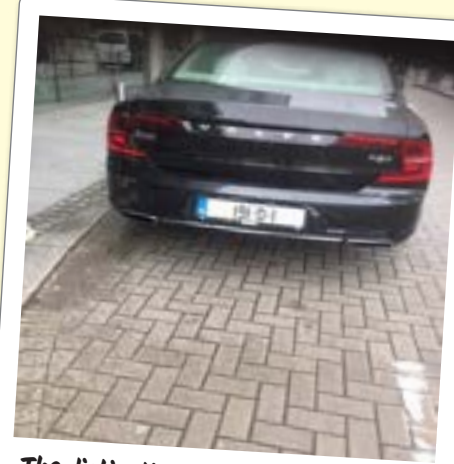
On Monday 9th September 2019, at 9.00 am, a large white van pulled up outside the Whitty Building of the Mater University Hospital. Two members of staff from Mountjoy Prison exited the van and started to unload exercise bikes, a

Bar B Que unit and lots of balloons. The fun and enthusiasm started there. Through communication with Eddie Mullins, the Governor of the Prison, the staff agreed to organise a fundraising / awareness event for Pulmonary Hypertension.



A static cycle commenced at 9.30am and continued until 4.30 pm. During the cycle we had a bucket collection. The prison staff were amazing and collected €3,075 on the day. The cyclists were joined by the medical & nursing staff of the PH Unit. The catering department from Mountjoy set up a BBQ unit on the street and cooked burgers from 12 noon till 2pm. Burgers were sold for €3 and we had a steady stream of customers who were attracted by the waft of charcoal down the street. We must acknowledge our colleagues in the Hospital who were most generous in supporting the event.

At 12.30 pm a black Hybrid Volvo bearing the Registration 191 D 1 arrived and Mr Paul McAuliffe, the Lord Mayor of Dublin alighted. We were so very grateful to the Lord Mayor for taking the time to support us and his good spirits and willingness to participate in the cycle delighted the crowd of onlookers. Another attraction on the day was the attendance of



**The distinctive Number Plate 191-D-1 of the Lord Mayors Car**





the 'Dublin Superstars' – Philly McMahon and Rory O Carroll. Despite the concern of their forthcoming replay match against Kerry on 14th September, the boys were happy to wear the PH T-shirt and joined in the cycle – though their training was interrupted many times by 'fans' wishing to have photos taken with them. There was great banter along the street.

The staff of the prison raised a total of €9203.07 for PH. Part of this was collected on the day, part was from a raffle containing fantastic prizes including

- ▶ Baracuda Road Bike with 14 gears
- ▶ Voucher for Nevin Maguire's Restaurant
- ▶ Voucher for Roly's Bistro
- ▶ One for all voucher

The rest was made up of generous sponsorship and many donations received by the Governor and his staff. We will forever be grateful for the financial support but we will also say to Eddie Mullins and his friends & colleagues and of course to Paul McAuliffe, Lord Mayor of Dublin... Thanks for the memories – it was an amazing, unforgettable day!



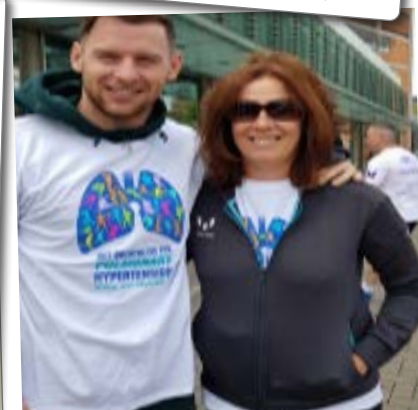
Lord Mayor of Dublin, Mr Paul McAuliffe is welcomed by Mr Alan Sharpe, CEO, Mater University Hospital & Dr Brian McCullagh



Prof Sean Gaine, Mr Eddie Mullins (Governor Mountjoy prison), Lord Mayor of Dublin & Dr Brian McCullagh



Dublin Senior Football stars, Philly McMahon & Rory O Carroll give their support on the day



Philly McMahon & Caitriona Minnock Clinical Nurse Specialist



Members of the Dublin Senior Football team lend their support for Pulmonary Hypertension



Dr Brian McCullagh & Prof Sean Gaine get into action



Baz Ashmawy was happy to exert himself in support of PH



Deirdre Clerkin & Denise Lennon take a break from work in the Centre for Lung Health



Dr Brian McCullagh & Philly McMahon



# Hair chop for PH

Sophie O Reilly is an amazing girl. Since Primary School – both she and Sarah Kate Breen (Sally Ann's daughter) have been friends. Sophie had beautiful long hair – she could do anything with it – French plats, pony tails etc. Having been friends with Sarah Kate & Sal over the years she has become very aware of Pulmonary Hypertension and is always willing to help to raise awareness of PH. Last Summer Sophie decided she would have her beautiful hair cut. She decided to organise

a sponsored 'hair chop' and the proceeds were shared between Rapunzel's Childrens' Cancer and the Pulmonary Hypertension Association.

On 4th September Sophie presented a cheque for €1,832.50 to the Pulmonary Hypertension - this was accepted by Sally Ann. We are so very grateful for this very generous donation and for the great idea and initiative shown by Sophie & Sarah Kate.



**SallyAnn Breen accepts cheque for €1,832.50 from Sophie  
- thank you to Sophie & Sarah Kate Breen for organising  
this amazingly generous achievement.**



# Climbing Kilimanjaro for PH

In November 2018 I received a call from Peter O Keeffe in Blarney, Co Cork. Peter told me he was thinking of climbing Kilimanjaro in memory of his wife Marian. He told me he was giving himself a few months to train. I was delighted to hear Peter was thinking of the PH Association as he took on this arduous endeavour. I immediately thought this man must be very fit, so I asked him what other training he did. He replied 'Nothing' – so I thought perhaps mountain climbing or even hill walking was his sport – but he informed me he had never in his life done anything like this. So Peter was taking on a real challenge !!

Over the months, we spoke regularly about his training and he certainly impressed me as being a very determined and strong willed man.

During the time of his training, Peter was fundraising for PH (it is important to note that Peter covered all of his own expenses and all money raised was given to the PH Association)

The month of July arrived and Peter called me to say he was 'off' and over the next few days I said a silent prayer that he would come home safely. I needn't have worried – Peter was enthused on his return and he spoke very highly of his guide Ramson who was an enormous help to him. He asked me to include Ramson's information just in case somebody else may be interested in a future climb. Ramson Swai is the owner and lead guide of Lava Peaks Adventures. His contact information can be found on his website

**[www.lavapeaks.com](http://www.lavapeaks.com)**

**email address [enquiry@lavapeaks.com](mailto:enquiry@lavapeaks.com)**

**or by trip advisor.**



- ▲ Peter O Keeffe with brother in law, Derry O Meara (Marian's brother) with cheque for €2,200 which was raised for the PH Association. We are extremely grateful to Peter and all of the patrons in 'Derry's Bar' in Bruff, Co Limerick who so kindly supported this venture.





# Holidays and Pulmonary Hypertension

**Denise Lennon**, Clinical Nurse Specialist

Even though travel abroad is currently not an option for many of us due to restrictions in place because of Covid 19, holidays are still a very important part of everyday life for all of us, whether abroad, or as a “staycation” – which seems to have been the buzz word of 2020! Having Pulmonary Hypertension means a little more planning and organising is required when arranging a holiday. Each patient will have individual needs depending on their illness and their medications; however, there are some general pointers to take into consideration before arranging a holiday, be it in Ireland or abroad.

## General guidelines

Ask your Pulmonary Hypertension Consultant for their advice regarding the idea of holidaying abroad in the first place. Bear in mind that some holidays may include a lot of travelling and may, in fact increase the burden of stress in some instances. Once decided upon, holiday planning should begin well in advance of the date of travel. It is important to ensure that you are up to date with all vaccinations including flu, pneumococcus and any specific vaccinations relating to the destination chosen. Make sure to take out travel insurance. Bring written information regarding Pulmonary Hypertension and your medications (including dose and frequency), the contact details of the Pulmonary Hypertension Unit and of your GP and Pharmacy with you, in case of any medical

issues that may occur. While travelling, carry out active leg exercises and have a short walk every two hours, especially if flying, in order to prevent risk of leg cramps and clotting.

## Destination

Choosing a suitable destination may be dependent on such factors as whether air, sea, road or rail travel is necessary. Areas of high altitude and hilly terrain are not advised. People using home oxygen may find certain destinations out of bounds due to prescribed oxygen requirements for air travel or the availability of oxygen at the chosen destination, however, with good organisation and planning, many people using supplementary oxygen can, and do, regularly travel abroad.

## Medications

Ensure all prescriptions are up-to-date, and that there is an adequate supply of medications brought for the time spent away from home. Keep all medications close at hand while travelling and ensure they are correctly and safely stored, as advised by the PH team, while away from home. A letter may be required by the airline to facilitate bringing medications on board, your doctor can give this letter to you.





## Oxygen

People using oxygen who wish to travel by air, will require an oxygen assessment by their GP or clinic. A prescription for the oxygen and a letter confirming “Fitness to Fly” will be issued. Oxygen cylinders may not be brought on board the airline; however, the airline may be in a position to supply in-flight oxygen in some cases. This needs to be arranged at time of booking.

If choosing to go on a ferry/ cruise, once notice is given, many companies will permit passengers to bring their own oxygen delivery device on board with them. If travelling by rail or road with a portable concentrator, ensure a back-up battery is brought along.

The oxygen company, once issued with an up-to-date prescription may be in a position to allocate an oxygen concentrator to your holiday accommodation prior to your arrival, there is a fee involved, and they will require notice well in advance of travel.

The general guidelines relating to oxygen and holidays include:

- ▶ No smoking/vaping within the vicinity of the oxygen delivery device.
- ▶ Ensure the oxygen delivery device is stowed safely while travelling and stored safely at the destination.
- ▶ Keep all oxygen delivery devices at least 5 meters away from any heat source.
- ▶ Never use oil or grease to lubricate oxygen valves/taps.
- ▶ Avoid the use of Vaseline or any oil-based creams or lotions on your skin while using oxygen.
- ▶ Bring the contact details of the oxygen supply company with you, in case of any issues while away.

## Warm temperatures

Whether you choose to travel abroad or not, in times of high temperatures it is important to remain cool in order to avoid any heat-related illnesses. This may be achieved by:

- ▶ **Hydration** – Keep well-hydrated in hot weather, being mindful of any fluid restrictions advised by the PH team. Avoid excesses of alcohol and caffeine.
- ▶ **Clothing** - light, loose-fitting is best advised and a wide brimmed hat will afford plenty of shade
- ▶ **Air-conditioning** should always be availed of, where possible.
- ▶ **Sunblock** – Use regularly and re-apply after swimming. Stay out of the sun between the hours of twelve midday and three pm.

The most important point about holidaying is to have an enjoyable time and to come home feeling relaxed and refreshed!

# Learning to live with COVID

**Mary P Burns** B.Sc., Psychotherapy & Counselling



We are now living in the new normal and the Covid 19 has impacted on all our lives, in so many ways. We have all learned so much in the past few months and each individual has had to mould their lives to fit in with Covid 19. When interviewed recently a 16 year old boy describes Covid 19 as war. Unlike traditional war where people left home to fight the war, we now have to stay at home to fight the war of Covid19.

The spread of Covid 19 is a new and challenging event. Some people might find it more worrying than others. Keeping a realistic perspective of the situation based on facts is important. If you are feeling anxious and afraid due to Covid19, there is nothing wrong with you. This is a normal reaction to an abnormal situation. It is natural to feel scared when you do not feel in control and life, as you know it, has changed dramatically. Many of you have had difficult times in the past and gotten through them, you will get through this too. It is not what happens to us that matters but how we deal with it. Here are some mental health wellness tips that may be helpful, in managing any anxieties you may have.

- ▶ Stick to a routine. Go to sleep and wake up at a reasonable time, write a schedule that is varied and includes time for work as well as self-care.
- ▶ Dress for the social life you want, not the social life you have. Get showered and dressed in comfortable clothes. Take the time to have a bath. Put on some bright colours. It is amazing how our dress can impact our mood.

- ▶ Get out at least once a day, for at least thirty minutes. If you are concerned of contact, try first thing in the morning, or later in the evening, and try less travelled streets or routes. If you are high risk or living with those who are high risk, open the windows.
- ▶ Find some time to move each day, again daily for at least thirty minutes. If you don't feel comfortable going outside, there are many YouTube videos that offer free movement classes.
- ▶ Reach out to others, at least once daily for thirty minutes. Try to do FaceTime, Skype, phone calls, texting - connect with other people to seek and provide support.
- ▶ Being hydrated and eating well may seem obvious, but stress and eating often don't mix well, and we find ourselves over-indulging, forgetting to eat, and avoiding food. Drink plenty of water, eat some good and nutritious foods, and challenge yourself to learn how to cook new recipes.
- ▶ Develop a self-care toolkit. This can look different for everyone. A lot of successful self-care strategies involve a sensory component (seven senses: touch, taste, sight, hearing, smell, vestibular (movement) and proprioceptive (comforting pressure). An idea for each: a soft blanket or stuffed animal, a hot chocolate, photos of vacations, comforting music, lavender or eucalyptus oil, a small swing or rocking chair, a weighted blanket. A journal, an inspirational book, or a mandala colouring book.





- ▶ Give everyone the benefit of the doubt, and a wide berth. A lot of cooped up time can bring out the worst in everyone. Each person will have moments when they will not be at their best. It is important to move with grace through blow-ups, to not show up to every argument you are invited to, and to not hold grudges and continue disagreements. Everyone is doing the best they can to make it through this.
- ▶ Everyone finds their own retreat space. Space is at a premium, particularly with city living. It is important that people think through their own separate space for work and for relaxation. It is good to know that even when we are on top of each other, we have our own special place to go to be alone.
- ▶ Focus on safety and attachment. We are going to be living for a bit with the unprecedented demand for meeting all work deadlines, home-schooling children, running a sterile household, and making a whole lot of entertainment in confinement.
- ▶ Lower expectations and practice radical self-acceptance.

We are doing too many things at this moment, under fear and stress. This does not make a formula for excellence. Instead, give yourself what we in the Psychological Field call “radical self-acceptance”: accepting everything about yourself, your current situation, and your life without question, blame, or pushback. You cannot fail at this - there is no roadmap, no precedent for this, and we are all truly doing the best we can in an impossible situation.

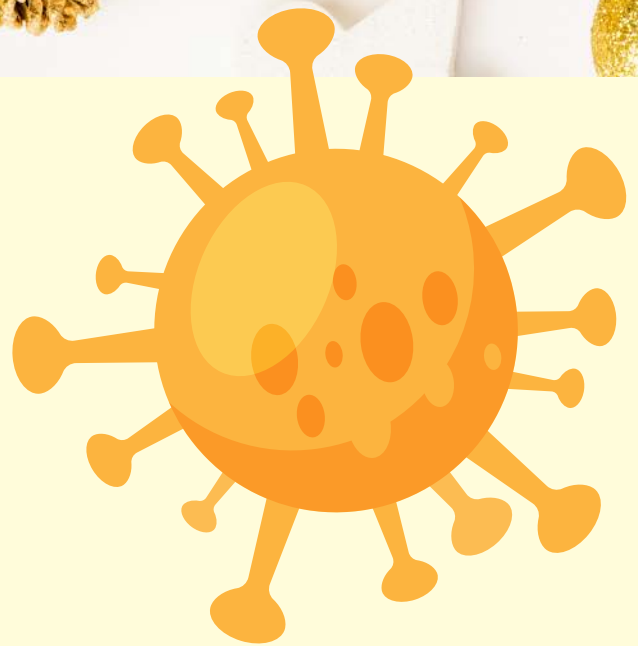
- ▶ **Limit social media and COVID conversation,** especially around children. One can find tons of information on Covid 19 to consume, and it changes minute to minute. The information is often sensationalised, negatively skewed, and alarmist.

Find a few trusted sources that you can check in with consistently, limit it to a few times a day, and set a time limit for yourself on how much you consume (again 30 minutes tops, 2-3 times daily).

- ▶ Keep news and alarming conversations out of earshot from children - they see and hear everything and can become very frightened by what they hear.
- ▶ Notice the good in the world, the helpers. There is a lot of scary, negative, and overwhelming information to take in regarding this pandemic. There are also a ton of stories of people sacrificing, donating, and supporting one another in miraculous ways. It is important to counterbalance the heavy information with hopeful information.
- ▶ Help others. Find ways, big and small, to give back to others. Support what you can offer to grocery shop, check-in with elderly neighbours, write psychological wellness tips for others - helping others gives us a sense of achievement when things seem out of control.
- ▶ Find something you can control and control the heck out of it. In moments of big uncertainty and overwhelm, control your little corner of the world. Organise your bookshelf or wardrobe, or office, put together that furniture, and group your toys. It helps to anchor and ground us when the bigger things are chaotic.
- ▶ Find a long-term project to dive into. Now is the time to learn how to play the keyboard, put together a huge jigsaw puzzle, paint a picture, read the Harry Potter series, binge watch an 8-season show, crochet a blanket, solve a Rubik's cube, or do that thing that you haven't had time to do. Find something that will keep you busy, distracted, and engaged to take breaks from what is going on in the outside world.



- ▶ Engage in repetitive movements and left-right movements. Research has shown that repetitive movement (knitting, colouring, painting, clay sculpting, jump roping etc.) especially left-right movement (running, drumming, skating, hopping) can be effective at self-soothing and maintaining self-regulation in moments of distress.
- ▶ Find an expressive art and go for it. Our emotional brain is very receptive to the creative arts, and it is a direct portal for the release of feeling. Find something that is creative (sculpting, drawing, dancing, music, singing, playing) and give it your all.
- ▶ Find lightness and humour in each day. There is a lot to be worried about, and with good reason. Counterbalance this heaviness with something funny.
- ▶ Take it moment by moment. We have no road map for this. We don't know what this will look like in 1 day, 1 week, or 1 month from now. Find what feels possible for you and set a timestamp for how far ahead in the future you will let yourself worry. Take each challenge one at a time and move through stress in bite-size pieces.
- ▶ Remind yourself daily that this is temporary. It seems that it will never end. It is terrifying to think of the road stretching ahead of us. Please take time to remind yourself that although this is very scary and difficult and will go on for an undetermined amount of time, it is a season of life and **it will pass**. We will return to feeling free, safe, busy, and connected in the days ahead.



- ▶ Find the lesson. This whole crisis can seem sad, senseless, and at times, avoidable. What can each of us learn here, in big and small ways, from this crisis? What needs to change in ourselves, our homes, our communities, our nation, and our world?

Many of you are worried facing into the winter but remember after every winter there is a spring which is the birth of a new year.

If you find you are struggling and finding Covid 19 overwhelming, please reach out for help. If you are having difficulties and want to talk about it, please email me @ [burnspmary@gmail.com](mailto:burnspmary@gmail.com) or phone 085 763 1102 and we can arrange a call, a video session or a one to one session. Although many of you are physically distant, we can always connect virtually.





# A day in the life of a Medical Secretary

**Deirdre Clerkin**, Secretary,  
Pulmonary Hypertension Unit

As many of you may know I have been with the Pulmonary Hypertension Unit now for many years, now going into my 15th year. I started way back in 2005 as a temporary/agency person and here I am.

Monday to Friday my day starts very early with the alarm beeping away at 5.30a.m. I would love to say that I jump straight out of the bed but I would be lying... especially in the dark winter mornings it can be very hard to move myself. Once I am up I am ok and set about getting ready to leave the house, which I have off to a fine art and I am out the door by 5.55a.m. I then have to drive about 15 minutes to the bus stop (the pleasure of living in the countryside) and stand in line and hope the bus comes soon and has enough seats left to take me on. The journey, depending on traffic, can take anywhere between 30 mins to 50 mins to reach my destination. Most mornings I am usually at my desk by 7.30a.m.



My day varies and each day is very different. Three out of the five days are clinic days, the remainder are what I like to call catch up days which entails preparing clinics, pulling charts, typing, dealing with correspondence, phone calls and messages. Then of course you can get the call to cover for colleagues who are on annual leave which happens on occasions. Never really a dull moment... busy but enjoyable.

My work day comes to an end at 4.00pm when I make the journey via the bus home. Some evenings (if I am feeling energetic) I will head to the gym for a few hours otherwise its relax and get ready for the next day ahead. It is safe to say that once Friday arrives I am very happy and ready for the weekend.

## Christmas Lunch

The annual Christmas lunch was held for patients & family members on 11th December 2019. We had an attendance of 27 and while we are very disappointed we cannot plan the Christmas Lunch for 2020 – we look forward to further celebrations in the future.

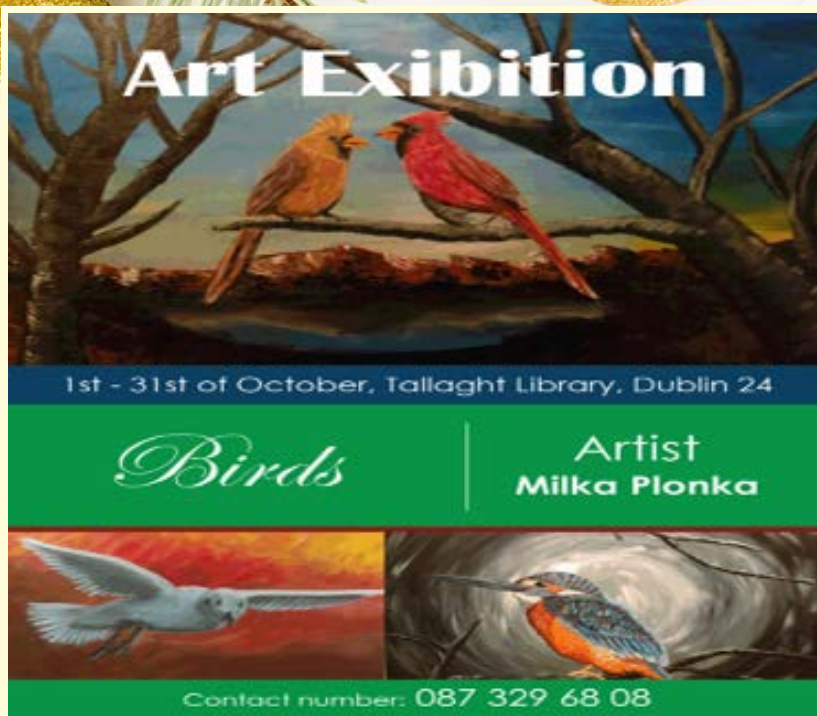


# Patient Story

My full name is Dobromila Wasiluk-Plonka but casually named Milka Plonka.

In 2013, after I had my second baby, I started to have PH symptoms. Initially I ignored it, thinking that it was tiredness lack of sleep, overweight etc. In 2015 I started to ask for medical examination. Asthma was a first diagnosis - for 2 years I was taking different medication and my condition was getting worse. In 2017, I was diagnosed with PH and was given the first medication which actually worked. Before I was diagnosed with PH, all I could do was sit at home thinking how sick I was feeling and I thought that I was slowly dying. I could not do simple task at home and could not properly care for my family. I was always a very positive person and also strong mentally. I was born with a hole in my heart and was operated on when I was 6 years old. The doctors did good job and until 2013 I had a good life and did not suffer and I appreciated the life I had.

I was hungry for some creative activity so I started to paint. I never thought I had a talent for painting but since I was able to work from home and it took my mind off my illness, I started to enjoy it.



I now attend professional art classes and have had art exhibitions in Tallaght Library. My advise to anybody who has been diagnosed with PH is – stay positive, get involved in something you enjoy – you are in charge of your own PH.



Milka displaying her artwork in Tallaght Library

**We are very grateful to Janssen for supporting the production of this Newsletter**