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phan mail magazine

Spring is in the air!

A NEW CLINICAL ROLE FOR NURSES

An article from PH Nurse Ambassador Tara Hannon

My Health Record
It's Here!

The Spoon Theory
A must read for all people living with chronic conditions

Latest PAH Fact sheet

Lung Foundation Australia
when you can't breathe... nothing else matters®

"The PH Puzzle"
Putting the Pieces Together Towards Earlier Diagnosis

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come inside

Welcome to the Spring *PHan Mail Magazine, for our Australian PH Community and Beyond*

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Welcome & Hello!

Welcome to another edition of PHan Mail magazine!

I heard an amazing quote recently that I wanted to share with you.

"The most authentic thing about us is our capacity to create, to overcome, to endure, to transform, to love, and to be greater than our suffering". Ben Okri

These words really resonated with me, because they are words I know a lot of us live by.

The human spirit is an amazing thing, and our ability to adapt to our circumstances and rise above them is one of the things I find I have most in common with others who share this illness.

In effect you have to reinvent yourself to a degree, when you are diagnosed with pulmonary hypertension. The news of the diagnosis can be so devastating, that it drowns out everything else, but our PH community is a very healing place to belong to and I am constantly inspired by others, particularly when I may be at my lowest, and I am very grateful for this.

Our circumstances are such that many of us often find it hard to leave the house, so our team has been trying to devise ways to help us feel less isolated. We have already introduced our new Instagram page to you, and our Pinterest Boards are going through the roof! Hours of distraction and enjoyment await you, so please check them out.

The "PH Bloggers" are a group of men and women who write specific stories reflecting on their own personal experiences as people living with pulmonary hypertension. They offer us some great tips, insight, commonalities, laughter, and tears. We already share many stories and articles with you from pulmonaryhypertensionnews.com and encourage you to subscribe to their online eNews.

PULMONARY HYPERTENSION NEWS

We encourage you to attend the many support groups that exist around Australia for both people living with pulmonary hypertension, and with other lung diseases. You can receive wonderful support from just being with others who understand you and the life you lead. Please contact us today, or the Lung Foundation Australia for more information.

Thank You & Farewell

PHNA wanted to say a sincere thank you and farewell to the Lung Foundation Australia's Rare Disease Manager PAH, Sharon Gavioli.

Sharon joined the foundation around a year and a half ago bringing years of experience with her from nursing and education roles, and so much more. She embraced the rare disease sector, and has worked hard in collaboration and co-design with key stakeholders, including patient organisations like PHNA. She has produced resources and education materials, hosted seminars, webinars, as well as produced patient, carer, and medical professionals stories online for our PH community, and to promote awareness of our disease.

We were so pleased to finally work with someone from LFA, and to have a shared vision for the future of our PH communities, which is now being promoted by the peak body for all lung disease in Australia.

I congratulate Sharon on all her achievements in this and other fields of rare disease in the respiratory areas, and wish her well in her new role, and future. She will be missed.

"ALWAYS BE KIND, FOR EVERYONE IS FIGHTING A BATTLE". PLATO

Melissa Dumitru & Team PHabulous x

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PATIENT OPINION
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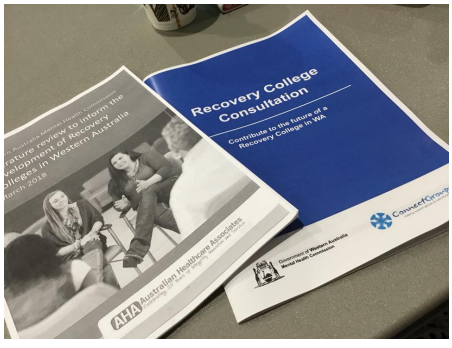
mini-bites from the network

ConnectGroups Support Groups Association (WA Peak body), conducted an interactive education seminar based around the principals of "Co-Design Facilitation", in regards to the models for support groups and organisations. Like so many organisations today, both here in Australia and globally in multiple industries, people are often making decisions for groups of people without any collaboration. From health to education, there is often no discussion or input, sought from the target groups. Think about that for a moment. The actual people who these decisions will affect, didn't get included in important decisions that more often than not are made by someone who has not shared their particular lived experience. No matter how empathetic these decision makers are, their lack of lived experience will make their programs incomplete. As you can imagine I found this approach exciting and intriguing.
As someone who is part of a large group of health consumers, and being someone personally that these decisions often affect, I certainly wanted to contribute. It was a very eye opening experience for many people, as they listened to the stories and roles that so many of us work from, and the amount of skills needed to meet them. One thing we identified is that the self help and support group sector is not given enough credit for the amazing amount of work it does in the community, nor the burden it lifts from the larger society. The majority of people who decide to start up or run a support group or organisation are often from highly qualified backgrounds who have developed an illness or an interest in this field, due to changing circumstances and views. They develop or identify a need within a specific group, their priorities change, and so does their life direction.
Many have gone on to study and learn more in order to be well informed and successful in the running of their groups. The group members can benefit in as many ways as possible from the community services sector and all it has to offer people living with illness, chronic conditions, and mental health problems. In WA particularly we are very fortunate to have the peak body ConnectGroups here on our doorstep, as they are so well connected and linked in to the communities that we work within. They provide an amazing service with a small dedicated and innovative team, and we all benefit from their hard work. It was very refreshing to actually be asked as people with "lived experience", what we thought was appropriate, or needed, instead of having it decided for us! The whole concept is exciting and a game changer for everyone. We will keep you posted on the "Best Practice" changes that are coming to the sector.
Editor Melissa Dumitru.



ConnectGroups Support Group Association (WA Peak Body), invited people with a lived experience, and carers of people with lived experiences, to attend a consultation that will contribute to and guide the development of a model for a Recovery College in Western Australia. (There are multiple colleges around the globe).
The WA Recovery College aims to bring together individuals from diverse backgrounds and communities in a safe and welcoming learning environment to share experiences, to support personal recovery, promote social and economical well being, and physical health. As participants we got to collaborate on the vision for exactly what a college model could look like and how it might operate within WA, as well a the benefits it could bring to the community. Both the PHNA CEO Melissa Dumitru and Coordinator of Education & Development Helen Blanchard, attended the second consultation hosted by ConnectGroups on behalf of the Mental Health Commission. We discussed the community based model from the consumer and lived experience at length, as the ConnectGroups Association CEO Antonella Segre, presented the comprehensive outline to the participants. It was quite liberating to be involved in such a visionary approach and we look forward to seeing the outcomes and sharing them with you.




donna hay

Spring is in the air here at the PHNA kitchen and we have found you a PHabulous recipe to cook. One of our favourite Australian cooks is the amazing Donna Hay, and this easy, healthy recipe is right up our alley. You can add in a side salad, and here is a delicious lunch or dinner ready to serve. Find more healthy and delicious recipes at www.donnahay.com

Ingredients

- 1kg sweet potatoes (kumara), peeled and cut into chips
- 1 tablespoon olive oil
- Sea salt and cracked black pepper
- 2 cups (140g) fresh breadcrumbs
- ½ cup flat-leaf parsley leaves, chopped
- 40g unsalted butter, melted
- 4 x 200g salmon fillets, skin removed
- Whole-egg mayonnaise, to serve

Method

1. Preheat oven to 200°C (400°F). Place the sweet potato on a baking tray, drizzle with oil and sprinkle with salt and pepper. Roast for 30–35 minutes or until golden.
2. While the sweet potato is cooking, place the breadcrumbs, parsley, butter, salt and pepper in a bowl and mix to combine.
3. Place the salmon on a baking tray lined with non-stick baking paper, top with the breadcrumb mixture and bake for 12–15 minutes or until golden and cooked to your liking.
4. Serve with the sweet potato chips and mayonnaise. Serves 4.

To spice it up: add finely grated lemon rind and dried chilli flakes to the breadcrumbs.

Bon Appétit

PULMONARY ARTERIAL HYPERTENSION

Pulmonary Arterial Hypertension (PAH) is a rare and progressive lung disease caused by narrowing or tightening of the arteries, which restricts blood flow to the lungs. It is a form of the overarching disease Pulmonary Hypertension (PH), which means high blood pressure in the lungs.

Although there is no current cure for PAH, early diagnosis is essential to ensure timely treatment that can improve symptoms and a person's quality of life.

PAH diagnosis is **delayed** on average

3.9 years

On average it takes

5 GP visits

before a specialist referral is given.

CAUSES

PAH can affect males and females of all ages and ethnic backgrounds. Causes can include:

Family history of PAH

Drug and toxin induced

Association with other systemic diseases such as

- connective tissue diseases (scleroderma, lupus, rheumatoid arthrisis)
- HIV infection
- Congenital heart disease
- Liver disease.

Idiopathic meaning the cause is unknown.

SYMPTOMS

Shortness of breath

Fatigue

A fast and/or irregular heartbeat

Dizziness

Light-headedness or fainting

Chest pain

Swelling in your legs or stomach

Lips and fingers turning purple or blue

DIAGNOSIS

The symptoms of PAH are nonspecific and can be mistaken for other diseases. It is important that the diagnosis of PAH is made by a physician who is an expert in this area. Diagnosis may require:

Chest X-ray

Blood tests

Lung function tests

Electrocardiogram (ECG) recording your heart's activity

Ultrasound of the heart

CT scans

Scan to compare blood and air circulation in the heart and lungs

SUPPORT

There are a range of treatment options, resources and support services available to help you live well with PAH. **Contact Lung Foundation Australia for more information.**

IF YOU EXPERIENCE ANY SYMPTOMS SPEAK TO YOUR DOCTOR.

FIND OUT MORE
lungfoundation.com.au
or phone 1800 654 301.

Lung Foundation Australia
when you can't breathe... nothing else matters

1. Strange G, Gallboy K, Aversen P, Williams T, Corrington M, Stewart S, et al. 2013;3(2):89-94.

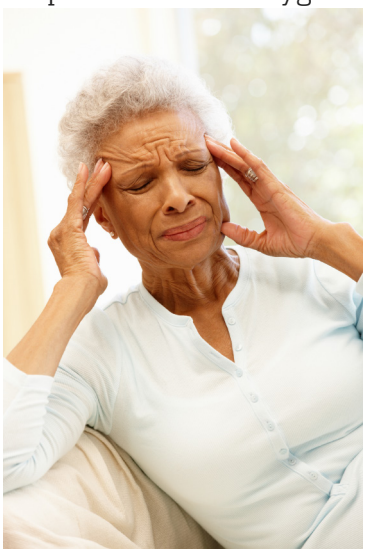
PULMONARY HYPERTENSION NEWS

In News. PAH News.PH News.
By Magdalena Kegel
April 27, 2016

PAH is rising in the elderly, and so are the challenges in diagnosing and treating their disease!

Elderly people at increased risk of pulmonary hypertension (PH) are increasingly also being diagnosed with pulmonary arterial hypertension (PAH). Diagnosis and management in this group can be quite challenging, and a report from Geneva University Hospitals suggested that all elderly patients with suspected PAH should be referred to an expert center for proper diagnosis and treatment of a disease that can have devastating consequences. The report, “Pulmonary hypertension in the elderly: a different disease?“, was published in the journal Breathe.

PAH, classified as group 1 hypertension by the World Health Organization (WHO) classification system, differs from other types of hypertension by being associated with remodeling of arterial capillaries in lung blood vessels. This particular disease mechanism differs in both underlying cause and treatment from other types of PH, such as group 2, caused by left heart disease, or group 3, caused by lung disease or exposure to low oxygen levels.



Currently, registry data show an increase in age at diagnosis, and an increased proportion of men diagnosed with PAH. Recent U.S. and Europe registry reports showed that the mean age at diagnosis is around 50 years, with some registries reporting mean diagnostic ages greater than 60 or 70.

Also, across registries 9 percent to 13.5 percent of PAH cases are older than 70 at diagnosis, with some registries reporting much higher figures. The proportion of women is also closer to half. This is a stark contrast to early registry reports published in the 1980s, showing a mean age at diagnosis of less than 40 years, and a disease affecting mostly women.

Since the patients present in the registries have been diagnosed at expert PH centers, where alternative scenarios are carefully excluded before a PAH diagnosis is set, the authors believe that the registry data indicate a real increase in PAH among the elderly, and hence, PAH in this group does not represent another kind of disease. But a risk of misclassification exists in the increasing elderly population diagnosed outside specialized centers, linked to the difficulty in setting an accurate diagnosis.

Many of the risk factors associated with group 2 PH are linked to an older age, obesity, atrial fibrillation, hypertension, coronary artery disease, and diabetes.

PAH, conversely, is associated with an entirely different set of risk factors — such as connective tissue disease, portal hypertension, and infections like HIV — and the identification of these factors might aid in diagnosis. PH and PAH are, however, not mutually exclusive in elderly people.

As difficult as a correct diagnosis might be in an older age group, the dangers of misdiagnosis are severe. PAH-specific treatments can be hazardous to patients with group 2 PH, and have not been studied in an elderly population. The most recent Phase 3 clinical trial of PAH treatment had a mean age far below 50, with less than 20 percent of patients age older than 65. One of the difficulties in establishing a correct diagnosis is that patients with both group 2 and group 3 might, in some cases, display an increase in pulmonary vascular resistance closely resembling PAH.

While the key investigation to precisely determine the specific contribution of post-capillary and pre-capillary mechanisms is right heart catheterization, the mixed disease states often make interpretations of hemodynamic measurements problematic, and as the authors put it: “Finding PAH among all PH is like looking for a needle in a haystack.” The research team concluded that it is necessary to refer all elderly patients with suspected PAH to an expert PH center, where a correct diagnosis, and treatment course, can best be set.

breathe PRACTICE-FOCUSED EDUCATION FOR RESPIRATORY PROFESSIONALS

CONCLUSION - Pulmonary hypertension in the elderly: a different disease?

The report quoted in the first paragraph of this article is quite lengthy. We have provided the conclusion, the full extract is available on request or on our website at www.phna.info Alternatively you can go directly to the source at www.https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4818237/ Breathe (Sheff). 2016 March

PH in the elderly is not different than in other age group. However, the distinction between disease and normal ageing and between PH and PAH may be more difficult. In fact, the many comorbidities that could lead to PH make its diagnostic classification much more difficult and the identification of patients with a true vascular disease even more challenging.

Elderly PAH patients suffer from severe pulmonary vascular disease with a poor survival rate and should be accurately diagnosed before introduction of PAH-specific drug therapy. In addition, age-related physiological changes should be considered if PH is suspected in the elderly because the normal process of ageing has the potential to lead to an over diagnosis of PH or an underestimation of PAH. Every patient with suspected PAH should be referred to an expert center to benefit from complete investigations and comprehensive haemodynamic evaluation. This is true for all patients but especially for the elderly. The modern available PAH-specific treatment may be differently tolerated in elderly patients. However, one should remember that PAH is a devastating disease that should be appropriately treated with ambitious goals.

A NEW CLINICAL ROLE FOR NURSES

Turn of the century advancements in pulmonary hypertension

AUTHOR Tara Hannon – MACN

PHNA

AMBASSADOR

Tara Hannon

Breathlessness or dyspnoea is a common symptom of a variety of conditions, such as asthma, pneumonia and emphysema. However, one of the most serious causes of breathlessness, which is difficult to diagnose, is the rare lung disease known as pulmonary hypertension (PHT). Blasi (2010) reminds us of the importance of remaining vigilant for less common causes of unexplained breathlessness, so diseases such as PHT are not missed.

PHT is a rare but serious multifactorial group of disorders with no real cure and can affect people from any race, gender or age at any time. Simply, PHT is raised blood pressure in the pulmonary circuit, clinically defined as a resting elevation of the mean pulmonary artery pressure (mPaP) greater than 25 mmHg as assessed by a right heart catheter (Simonneau et al., 2009).

In its early stages, the symptoms can be subtle and non-specific. Breathlessness and fatigue may only be problematic with exertion, such as when walking up steep inclines, climbing stairs or even the simple task of wheeling out the refuse bin. Often this is not enough of a discomfort to prompt a patient to seek medical attention. Patients may interpret this breathlessness and fatigue as "normal" (Blasi, 2012).

What is enough to prompt a patient to seek a medical assessment is an escalation of symptoms, often accompanied by other symptoms such as ankle oedema, dry cough, and syncopal and presyncopal episodes (Doughty and Mainwood, 2001).

With disease progression, pressure in pulmonary arteries slowly increases, ultimately leading to the development of right heart failure. Respiratory tests investigating causes of a patient's breathlessness often include spirometry, arterial blood gas and chest x-rays, which are often normal and will miss PHT.

Patients may be prescribed inhaled medications commonly referred to as "puffers" erroneously. It is not until patients have had an echocardiogram and conformational right heart catheter that a diagnosis of PHT is made. Unless suspected, this can often have significant delays in diagnosis. Data from one study reported inappropriate or delayed therapy can be up to two years after onset of first symptoms (Rich et al., 1987, cited Strange, 2014, p.117). Early diagnosis and treatment is vital in managing this disease known for its rapidly progressive nature if left untreated.

HISTORY OF PHT

Prior to the development of heart catherisation in the 1930s, there were only occasional observational accounts that describe PHT, as we know it to be today.

The first was in 1891 when Ernst von Romberg noticed at autopsy, abnormal structural changes in the pulmonary vessels (Anderson et al., 2016). The second was in 1901 when Abel Ayera coined the term cardiao negro (black heart) for a syndrome characterised with breathlessness, coughing, cyanosis and abnormalities in the pulmonary vessels. Thirdly, David Dresdale in the 1950s, with the application of heart catherisation, found increased pulmonary artery pressure in patients that had neither lung nor heart problems (Foshat and Boroumand, 2016). PHT was seeing us but we were only just starting to see it.

The catalyst that would finally catapult PHT onto the global arena was in 1965 when there was a surge in the number of diagnosed cases of PHT-pulmonary arterial hypertension (PAH) caused by the appetite suppressant, *Aminox*. This epidemic prompted the World Health Organisation (WHO) to hold its first PHT symposium in 1973, a year after *Aminox* was withdrawn (Anderson et al., 2016). The purpose of this meeting was to gather the experts with knowledge and experience related to PHT.

25 years after the first meeting, the 1998 PHT symposium proposed the PHT classification system referred to as the Evian Classification, named after the location of the symposium. The Evian Classification established individual categories of PHT, where within groups there was shared pathological and clinical characteristics and therapeutic options. PHT being a single disease, five groups of disorders were identified as causing PHT (Simonneau et al., 2004).

The PHT symposium continues every five years and the classification is reassessed each time. Refinements are made reflecting the knowledge that has accumulated. The current classification is the Nice Classification that was updated in 2013 and will be reassessed in 2018 (see the Nice Classification here: http://www.pah-info.com/Classification_of_PH).

PULMONARY ARTERIAL HYPERTENSION GROUP ONE

One of the most severe forms of PHT is Pulmonary Arterial Hypertension (PAH) Group One in the Nice Classification. PAH is a rare but devastating progressive disease that ultimately leads to right heart failure and death. The incidence of PAH is approximately 2.4 cases per million annually and it is more common in women that in men (Noel et al., 2017). Of the five classification of PHT, it is this group that has received the most research attention.

Knowledge of the exact trigger for PAH is still unknown but Matura (2011) suggests that there is the existence of a common pathway whereby structural and remodelling changes occur in the pulmonary vasculature.

These changes are thought to be a result of sustained increase in pulmonary pressures and pulmonary vascular resistance (PVR) from a combination of in situ thrombosis, pulmonary vasoconstriction and the remodelling of the vascular wall (Matura, 2011, p.269.)

PAH SPECIFIC THERAPY

The main treatment goal for PAH is to slow the progression of the disease (Doyle-Cox et al., 2016).

Current PAH therapies have been developed to target the three main pathways involved in the pathogenesis of PAH. These pathways and the therapies available include:

- Endothelin receptor antagonists: *Ambrisentan, Bosentan, and Macitentan*
- Prostacyclin: *Epoprostenol, Iloprost*
- Phosphodiesterase type 5 inhibitor: *Sildenafil and Tadalafil*

The number of medications available continues to grow at a rapid pace. The first medication was approved in Australia in 2004 and since that time, a further seven have been approved, with the recent approval of *Riociguat*, a novel therapeutic class of therapy.

Prior to the development of PAH-specific targeted therapies the average life expectancy was less than three years. The life expectancy today is around seven years (Gin-Sing, 2010).

The future looks positive because with greater research focus and interest, more medications are being developed. Combination therapy, involving one medication from each of the three pathways, is proving to be more effective in achieving treatment goals than single use therapy (Strange et al., 2013).

In Australia, patients can only receive one medication funded by the Pharmaceutical Benefit Scheme (PBS) at this current time. The PBS mandates the prescribing of PAH therapies to designated specialist centres only and there are strict patient criteria and conditions of eligibility. Only patients diagnosed with Group One PAH are eligible to receive therapy. Currently there are 60 specialised designated centres throughout Australia.

THE PHT NURSE

We have seen the development of other types of specialist nursing roles in the care of patients with breast cancer, diabetes and asthma but only recently the PHT nurse. The majority of PHT nurses are attached to specialist teams at designated PHT centres in both public and private locations. Most of PHT care provided at these centres is outpatient based.

Essential to the role is an advanced nursing knowledge of PHT and the skill to make complex decisions, crucial in supporting, teaching and caring for both patients and their families.

Time is spent with patients and families helping them to understand the PHT disease process, recognising signs and symptoms of worsening, self-monitoring and discussing the various treatment options.

PAH-specific therapy requires patients to have ongoing monitoring mainly though outpatient appointments with telephone support. The more complex PAH therapies, like inhaled or intravenous therapies, require substantial time teaching patients and carers about how to self-deliver these medications using aerosol or intravenous delivery.

PHT nurses educate other nursing colleagues who are usually unfamiliar with this rare disease and its complex therapy. Patients with PAH from time to time will require hospital admission for acute care and for many nurses this may be their first time caring for a patient with PHT. This can be quite a daunting and challenging experience. The PHT nurse is a point of reference and a vital link for frontline nurses working in partnership with collaborative patient care.

With the complexity of this disease coupled with the changing regulatory PBS requirements, the PHT nurse is proving to be invaluable and essential in the delivery of high quality nursing care. This new role will continue to expand and develop keeping abreast with medical advances in PHT.

CONCLUSION

PHT is a rare, complex and multifactorial disorder, which has a devastating impact on a person's quality of life. PHT has witnessed major advances since the turn of the century and now commands global attention, and significant interest and awareness continues too.

Continually being challenged by a prognosis that remains poor, the future still looks promising, and further treatments and drug pathways are on the horizon.

The PHT nurse has a key role in supporting and caring for patients with PHT and their families, and this role will continue to expand and be recognised as new nursing specialist role.

Unexplained breathlessness must always be investigated and the possible diagnosis of the rare lung disease of PHT must always be considered.

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AUTHOR

TARA HANNON MACN

The Spoon Theory

by Christine Miserandino

My best friend and I were in the diner, talking. As usual it was very late and we were eating French fries with gravy. Like normal girls our age, we spent a lot of time in the diner while in college, and most of the time we spent talking about boys, music or trivial things, that seemed very important at the time. We never got serious about anything in particular and spent most of our time laughing.

As I went to take some of my medicine with a snack as I usually did, she watched me with an awkward kind of stare. Instead of continuing the conversation. She then asked me out of the blue what if felt like to have Lupus and be sick. I was shocked, not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. She had seen me cry in pain, what else was there to know?

I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I was a little surprised as being my roommate in college and friend for years; I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what if felt like, not physically, but what it felt like to be me, to be sick.

As I tried to gain my composure, I glanced around the table for help or guidance, or at least stall for time to think. I was trying to find the right words. How do I answer a question I never was able to answer for myself? How do I explain every details of every day being effected, and give the emotions a sick person goes through with clarity. I could have given up, cracked a joke like I usually do, and changed the subject, but I remember thinking if I don't try to explain this, how could I ever expect her to understand. If I can't explain this to my best friend, how could I explain my world to anyone else? I had to at least try.

At that moment, the spoon theory was born. I quickly grabbed every spoon on the table; hell I grabbed spoons off of the other tables. I looked at her in the eyes and said "here you go, you have Lupus". She looked at me slightly confused, as anyone would when they are being handed a bouquet of spoons. The cold metal spoons clanked in my hands, as I grouped them together and shoved them into her hands. I explained that the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to. The healthy have the luxury of a life without choices, a gift most people take for granted.

Most people start the day with unlimited amounts of possibilities, and energy to do whatever they desire, especially young people. For the most part, they do not need to worry about the effects of their actions. So for my explanation, I used spoons to convey this point. I wanted something for her to actually hold, for me to then take away, since most people who get sick feel a "loss of a life" they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case Lupus, being in control.

She grabbed the spoons with excitement. She didn't understand what I was doing, but she is always up for a good time, so I guess she thought I was cracking a joke of some kind like I usually do when talking about touchy topics. Little did she know how serious I would become.

I asked her to count her spoons. she asked why, and I explained that when you are healthy you expect to have a never-ending supply of "spoons". But when you have to now plan your day, you need to know exactly how many "spoons" you are starting with. It doesn't guarantee that you might lose some along the way, but at least it helps to know where you are starting. She counted out 12 spoons. She laughed and said she wanted more. I said no, and I knew right away that this little game would work, when she looked disappointed, and we hadn't even started yet. I've wanted more "spoons" for years and haven't found a way yet to get more, why should she? I also told her to always be conscious of how many she had, and not to drop them because she can never forget she has Lupus.

I asked her to list off the tasks of her day, including the most simple. As she rattled off daily chores, or just fun things to do; I explained how each one would cost her a spoon. I practically jumped down her throat. I said "No! You don't just get up. You have to crack open your eyes, and then realise you are late. You didn't sleep well the night before. You have to crawl out of bed, and then you have to make yourself something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today and tomorrow too." I quickly took away a spoon and she realised she hasn't even gotten dressed yet. Showering cost her spoon, just for washing her hair and shaving her legs. Reaching high and low that early in the morning could actually cost more than one spoon, but I figured I would give her a break; I didn't want to scare her right away.

Getting dressed was worth another spoon. I stopped her and broke down every task to show her how every little detail needs to be thought about. You cannot simply just throw clothes on when you are sick. I explained that I have to see what clothes I can physically put on, if my hands hurt that day buttons are out of the question. If I have bruises that day, I need to wear long sleeves, and if I have a fever I need a sweater to stay warm and so on. If my hair if falling out I need to spend more time to look presentable, and then you need to factor in another 5 minutes for feeling badly that it took you 2 hours to do all this.

The Spoon Theory

by Christine Miserandino

But You Don't Look Sick?
The stories behind the smiles

I think she was starting to understand when she theoretically didn't even get to work, and she was left with 6 spoons. I then explained to her that she needed to choose the rest of her day wisely, since when your "spoons" are gone, they are gone.

Sometimes you can borrow against tomorrow's "spoons", but just think how hard tomorrow will be with less "spoons". I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So you do want to run low on "spoons", because you never know when you truly will need them. I didn't want to depress her, but I needed to be realistic, and unfortunately being prepared for the worst is part of a real day for me.

We went through the rest of the day, and she slowly learned that skipping lunch would cost her a spoon, as well as standing on a train, or even typing at her computer to long. She was forced to make choices and think about things differently. Hypothetically, she had to choose not to run errands, so that she could eat dinner that night.

When we got to the end of her pretend day, she said she was hungry. I summarized that she had to eat dinner but she only had one spoon left. If she cooked, she wouldn't have enough energy to clean the pots. If she went out for dinner, she might be too tired to drive home safely.

Then I also explained that I didn't even bother to add into this game, that she was nauseous,cooking was probably out of the question anyway. So she decided to make soup, it was easy. I then said it is only 7pm, you have the rest of the night but maybe end up with one spoon, so you can do something fun, or clean your apartment, or do chores, but you can't do it all.

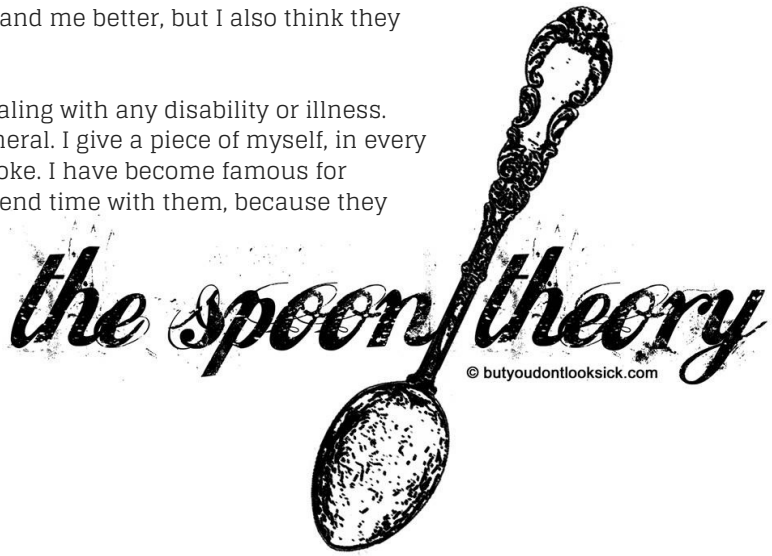
I rarely see her emotional, so when I saw her upset I knew maybe I was getting through to her. I didn't want my friend to be upset, but at the same time I was happy to think finally maybe someone understood me a little bit. She had tears in her eyes and asked quietly "Christine, how do you do it" Do you really do this everyday?". I explained that some days were worse than others; some days I have more spoons than most. But I can never make it go away and I can't forget about it, I always have to think about it. I handed her a spoon I had been holding in reserve. I said simply, "I have learned to live life with an extra spoon in my pocket, in reserve. You need to always be prepared".

It's hard, the hardest thing I ever had to learn is to slow down, and not do everthing. I fight this to this day. I hate feeling left out, having to choose to stay home, or to not get things done that I want to. I wanted her to feel that frustration. I wanted her to understand, that everything everyone else does comes so easy, but for me it is one hundred little jobs in one. I need to think about the weather, my temperature that day, and the whole day's plans before I can attack any one given thing. When other people can simply do things, I have to attack it and make a plan like I am strategising a way. It is in that lifestyle, the difference between being sick and healthy. It is the beautiful ability to not think and just do. I miss that freedom. I miss never having to count "spoons".

Afterwards we were emotional and talked about his for a little while longer, I sensed she was sad. Maybe she finally understood. Maybe she realised that she never could truly and honestly say she understands. But at least now she might not complain so much when I can't go out for dinner some nights, or when I never seem to make it to her house and she always has to drive to mine. I gave her a hug when we walked out of the diner. I had the one spoon in my hand and I said "don't worry, I see this as a blessing. I have been forced to think about everything I do. Do you know how many spoons people waste everyday? I don't have room for wasted time, or wasted "spoons" and I chose to spend this time with you."

Ever since this night, I have used the spoon theory to explain my life to many people. In fact, my family and friends refer to spoons all the time. It has been a code word for what I can and cannot do. Once people understand the spoon theory they seem to understand me better, but I also think they live their life a little differently too.

I think it isn't just good for understanding Lupus, but anyone dealing with any disability or illness. Hopefully, they don't take so much for granted or their life in general. I give a piece of myself, in every sense of the word when I do anything. It has become an inside joke. I have become famous for saying to people jokingly that they should feel special when I spend time with them, because they have one of my "spoons".



Christine Miserandino, ButYouDon'tLookSick.com
for more information & to order posters

goodhealth

LifeStyle Series

The Spoon Theory was created as a way for people with chronic illness and disease, to explain their experience to others. SPOONS = ENERGY!

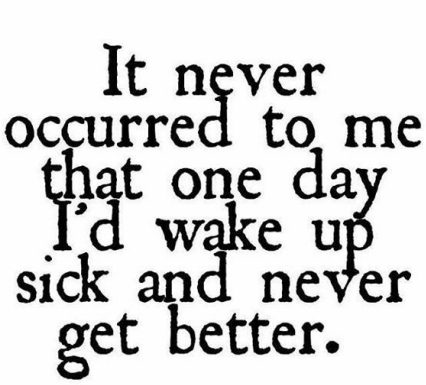
Spoon Theory is used widely among people with chronic conditions all around the world today, as a way of explaining what it feels like to actually live with their individual diseases it reflects the decisions we must make, about the smallest things, constantly throughout each and every day. Whether you live with a disease such as Pulmonary Hypertension, Lupus, Fibro Myalgia, Arthritis or Cancer, we all experience massive changes to our bodies, minds, and everyday lives.

Nobody plans to get sick, let alone with a long term or progressive chronic illness. There is no handbook that you can purchase that tells you how to suddenly go from a "normal" everyday healthy person, to someone who basically has to become a "professional patient", in order to navigate their daily life.

We look to others including our medical and health professionals for help, but no one person or area has all the answers. Experience is what helps you decide how to "spend your spoons", so to speak. You can plan your week out, write out lists of chores you would like to complete, organise a fabulous outing with friends or family, only to have the entire week fall apart when you suddenly find yourself so unwell over one or two days that the bad days add up into multiple digits sending your well intentioned "to do list" out the window!

Essentially your life becomes a series of choices. Every day, every week, every month, year after year. Choices that sound pretty straight forward, like getting up and getting ready to go out somewhere, anywhere, work or play. The difference with people who live with chronic disease is that we have a whole set of different symptoms and side effects due to our disease and the impact it has on our bodies, not to mention the medications and how those can impact on you. Anything from feeling like you are going to combust from heat stroke, faint from low blood pressure, bleed out from vasodilation, vomit from the nausea, smile through the jaw pain and headache to name a few.... you get the picture, don't you? So lets find out a little more about the Spoon Theory. PHan Mail Editor

The Spoon Theory was born as a way to explain to others what it is like to live with chronic illness and the constant negotiations we must make every day. Our currency is our energy and functional abilities, and these are represented as spoons. The idea is that healthy people have an infinite amount of spoons they can pull from, but those of us with chronic illness, such as Pulmonary Hypertension, have a finite amount each day. We must weigh up whether it is worth it to go out with a friend or instead be able to make dinner and take a shower...or do we go for that walk or finish that project we need to get done?



Some may say these negotiations are what all people need to consider, but the difference is that with chronic illness it's not jut about time, it's about realising that you will be paying for overdoing it the next day in pain, sickness or needing to sleep all day. You can borrow spoons but you can't expect them to be replenished the next day.

This causes an underlying anxiety when making plans with healthy people that don't quite understand. You are doing calculations in your head of what time you need to get out of bed, can you stay out that extra hour and still be functional the next day.

The Spoon Theory allows us to talk in a code that doesn't necessarily make us have to explain the whole situation each time; we can just ever so gently say to our friends and family, "I'm out of spoons, time to head home..." I also think this theory works for people who are in the role of carer as well.

The Spoon Theory of Energy - How will you spend your spoonful's of energy today?

WHAT IS THE MOST IMPORTANT THING IN YOUR EVERY DAY LIFE - PACE YOURSELF!

Here are some helpful suggestions we have come up with to help you with your spoons.

Taking a shower or washing your hair, brushing your teeth: Sounds simple enough? Depends on how you slept, if you slept. Can you shower the night before? Pop into the local hairdressers and see if they can negotiate a reasonable rate to wash your hair for you? Sit down while you brush your teeth. Pay attention to your environment, do you have everything you need within easy reach?

Doing the food shopping: Shopping has never been easier before than it is today, providing you are online! The majority of shopping centres have electronic scooters you can use. Most major supermarkets have online shopping available with delivery at a very reasonable rate, they bring it into your kitchen, and will even assist you to put it away if you have a disability. You can order online and then "click and collect", which means they get it ready for you and you collect it. They will put it in your car for you too, you just need to ask. I personally enjoy the outing, and walk up and down the isles as a way to exercise and even socialise. You'd be surprised how many people chat to you over products. NEVER go out shopping if you are in great pain, or really fatigued. Take your carer or a friend and ask for help. Keep a list so you don't forget all the items you need.

Go to a medical appointment or test: Be prepared, have your list of questions ready for the doctors and nurses. Take your PH Patient Pack with you as it has all the tools you need such as your medications list and a pad and pen. I would highly recommend you take your carer and or a friend or family member you can trust who will be a second pair of ears. Your carer is allowed to accompany you into your reviews with the doctor, it is their legal right. They are also a good source of support for you as the patient if you are having a particularly bad day, or receive unexpected news about your test results. Ask the clinic to organise your tests on the same day as your clinic review, within the same time frame, so that you do not have to spend the whole day at the hospital waiting around, getting exhausted. Have healthy snacks and water available, and wear appropriate clothing and shoes. Take along a magazine or your iPad for entertainment and take advantage of the wheelchair assistance and have the porters escort you to the various areas around the hospital campus if you are feeling really tired or unwell.

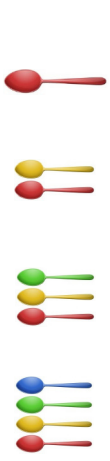
Go to the pharmacy to get your medication: This will depend on whether you need to go to the hospital pharmacy or your local community pharmacy. If you currently use medications produced through Actelion Pharmaceuticals, they have a home delivery service at no charge. You can organise to fax or email the script to the hospital pharmacy in advance so you can avoid the long waiting times that usually accompany a visit to this service. Most community pharmacies will also deliver to you free of charge and to most areas, you just organise this over the phone. They can also put your daily pills into a webster pack, which you dispense from daily to help keep track of your medications in case you forget to take them.

Cook breakfast, lunch & dinner: I personally don't eat breakfast or lunch so the most food prep I do throughout the day is making espresso and figuring out when the best time to start dinner prep is, usually while I am still not completely out of energy! I actually cannot imagine preparing three meals a day for myself and my husband, let alone for a family as well. I think this area is particularly challenging as people living with pulmonary hypertension must try to follow a low sodium diet and often restricted fluids. I struggle with producing a well balanced diet, usually because I have resorted to a pre-packaged product or a sandwich! I think the key is preparation and make a list of meals you would enjoy, then have some nutritious snacks you can nibble on throughout the day (mine are gluten free) such as chickpeas. Measure your daily fluid allowance into a jug so you know how much you are drinking (including hot beverages). I have snap lock containers that I use to store all the salads and veggies and often I will even chop them up in advance before storing them to make it easier to cook on the day. Make sure your fridge and pantry are well organised with a variety of options for those days when you just cannot face cooking a big meal. Cook up bulk meals in advance and freeze them, such as soups, curries, casseroles (slow cooker is great here and economical). If you are making a roast dinner, buy a slightly larger cut of meat so that you have leftovers you can then make into sandwiches for lunch the next day. You can chop up fruit or even buy it prepared for you (its a little costly though). I have found its all about making things really accessible and easy so you are motivated enough to eat properly and regularly and less inclined to order in or grab take-away. Get your family and friends together for a big cook up and swap recipes every month or so, give everyone a different job to do and ingredients to bring and make a day of it.

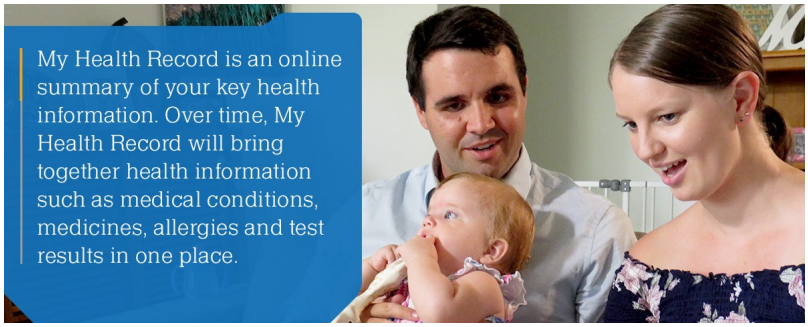
Do the dishes, the laundry, sweep or vacuum: My best friend in the kitchen is the "dish-washing machine"! I try to keep mine empty ready for the dishes of the day and run a load before going to bed, then empty it in the morning so its ready for you to start again. Its really satisfying to see your kitchen sink all clear and clean, most of the time... not to say I don't have piles at times but overall try to clean as you go its so much easier on you. I often do the laundry in smaller loads every day or two which helps to keep the amount of work more manageable. At times there are two laundry baskets overflowing with clean dry clothing and towels that are still waiting on being folded and hung or put away. I think by keeping the loads smaller it makes the task more achievable in my experience. When sweeping or vacuuming any action that requires you to move both legs and arms simultaneously can potentially be problematic due to increased pressure on the heart and lowering your oxygen levels. Always wear your oxygen when you clean especially sweeping and vacuuming. If you are eligible for home care assistance with cleaning then I would definitely organise this through the local area coordinator (currently HACC). Try not to do too many chores on the one day, rather spread them out over the week. Take breaks in-between so you don't become overtired. Get the children involved and introduce a rewards system to motivate them, and ask for help.

Getting the children ready for school, helping with kids homework, getting to kids after school activities: Now I don't have children, but as a child I remember mum encouraging us to lay out our school clothes the night before, in a row. In the morning she would make it a competition to see who got dressed the fastest. We earned gold stars and got little treats as rewards. Get your children involved in their nutrition and making their lunches the night before. Have snacks portioned out and pre-packed in the pantry and fridge. Start their homework from the minute you collect them in the car by reviewing their day, get them to read out what is required so you are ready to hit the ground running when you get home. Work out a car pool schedule with other parents to assist with driving to after school activities. Open and calm communication with your children and partner is essential. They need to be aware of your limitations, expectations need to be managed, goals can be set, rewards are a great motivator.

Keeping Track of Your Spoons!



Get out of bed
Get Dressed
Take pills
Watch TV
Bathe
Style hair
Social Media
Read or Study
Prepare meals
Make plans & socialise
Light housework
Drive somewhere
Go to work/school
Do grocery shopping
Medical Appointment
Exercise/Self-Care



Australian Government
Australian Digital Health Agency

My Health Record

5.9 Million+ people, have a "My Health Record"

10.0K+ "Health Professionals" are connected

6.7 Million+ "Clinical Documents Uploaded"

My Health Record

Keep track of your important health information all in one place.

This year, you will get a My Health Record unless you tell us you don't want one.
If you don't want a My Health Record, let us know by 15 October 2018.

Log on to their site at www.myhealthrecord.gov.au Need help? Contact our Help line ☎ 1800 723 471

My Health Record is an online summary of your key health information.

When you have a My Health Record, your health information can be viewed securely online, from anywhere, at any time – even if you move or travel interstate. You can access your health information from any computer or device that's connected to the internet. Whether you're visiting a GP for a check-up, or in an emergency room following an accident and are unable to talk, healthcare providers involved in your care can access important health information, such as:

allergies
medicines you are taking
medical conditions you have been diagnosed with
pathology test results like blood tests.

This can help you get the right treatment. You don't need to be sick to benefit from having a My Health Record. It's a convenient way to record and track your health information over time.

You control your record

You can choose to share your health information with the healthcare providers involved in your care. If you wish, you can manage your My Health Record by adding your own information and choosing your privacy and security settings. For example, you can:

add personal notes about your allergies and allergic reactions, an advance care plan or custodian details
set access controls to restrict who can and can't see your health information
review your own health information, and seethe information your healthcare providers can see
set up SMS or email notifications so you know when a healthcare provider first accesses your record.

Next time you see your doctor, ask them to add your health information to your My Health Record. By allowing your doctors to upload, view and share documents in your My Health Record, they will have a more detailed picture with which to make decisions, diagnose and provide treatment to you. You can also ask that some information not be uploaded to your record.

A My Health Record for every Australian in 2018

This year, you will get a My Health Record unless you tell us you don't want one. As more people use the My Health Record system, Australia's national health system becomes better connected. The result is safer, faster and more efficient care for you and your family.

If you don't have a My Health Record, and don't want one created for you, you can opt out between 16 July and 15 October 2018. Find out how you can opt out.

When will I get a My Health Record?

The new records will be available from 13 November 2018. If you want a My Health Record before then you can register now. (Speak to your doctor if you have questions or go directly to My Health Records for more information).

PULMONARY HYPERTENSION NEWS

RECHARGED AND REWIRED

by Brittany Foster

In Columns July 6, 2018

My social life, based solely on my pictures online, may seem somewhat average for a 20-something-year-old. On my social accounts, you can find pictures of my friends and me; photos from the beach or of fancy drinks, and selfies from long car rides. What people don't see is the oxygen cannula I took off before taking the picture, the many times I have to rest just to be able to go to the beach, and the two sips I took of a drink that I probably shouldn't be drinking.

Honestly, my social life is nothing like it appears. Since my pulmonary hypertension diagnosis and oxygen therapy initiation, my social life has changed in ways that social media can't capture; in ways that even my closest friends don't understand.Having a lung disease has made social event participation physically exhausting and leaves me with crippling fatigue for days afterward.

It has caused me to cancel plans and makes it hard for me to be spontaneous. Managing illness and trying to maintain some sort of social life is extremely difficult.

Going out with friends almost always means having to pay for a fun time the next day. When I get an invite to do something, I ask myself, "Is this worth the price I will pay?" Staying out later than usual, using energy to participate in conversations, and being more physically active greatly impact how I feel the following day.

I am willing to make the sacrifice sometimes, but if I am already feeling more fatigued than usual, then I have to forfeit plans. Canceling plans is difficult for others to understand. I've had experiences where those who are closest to me do not fully understand the impact that pulmonary hypertension and another heart condition has on my body because I look "OK" from the outside.

I can see why people would get confused when I can go from feeling "OK" to unwell within a few hours. It's even hard for me to wrap my head around such a dramatic shift in how my body feels. I was never one to cancel on a friend last minute. I would set plans days in advance. Now, it's hard for me to make these types of plans. My health doesn't care about dinner dates.

It doesn't care that I had something planned for weeks. It gets in the way of my life, and that's something that I have learned to accept. Accepting it does not make it any less frustrating to call someone and say, "I'm sorry, I can't make it." I would love to go back to the days of being carefree. Now, going anywhere while dependent on oxygen and medications throughout the day takes careful planning.

Any social event requires enough oxygen tanks to get me through, and an estimated time of how long I will be at a certain place to plan for medications. Although my social media shows pictures of me looking like I have a typical social life for someone my age, that is not my reality.

With my diagnosis and need for oxygen, I am limited in what I choose to do and what type of social events I attend. Adjusting to a new social life is difficult and an ongoing process. Some days, it is easier to recognize and accept my limitations.

On other days, I still find myself pushing through trying to be like everyone else.

Has your social life changed since your diagnosis of pulmonary hypertension? How does the disease limit your social life? How do you cope with this and learn to accept limitations? Join the PH News forums to discuss this topic and add to the conversation.

inspire.enable.support

SIGN UP!

Have you joined our PHamily yet?

Pulmonary Hypertension Network Australia

Become a Member

Membership Benefits

Socialise, share stories, feel safe & welcome
Be included in collaboration & co-design of our community
Get a member discount card for select sponsor services
Get our quarterly "PHan Mail" Magazine
Read our monthly eNewsletter, "The Hype"
The LifeStyle Series - Support Group Network
Vibrant website updated weekly
Resources - Information - Education - Workshops
Special Events, Fundraisers, and Awareness Days
Social Media FaceBook, Pinterest, Instagram

Apply for membership at www.phna.info/membership
International members welcome

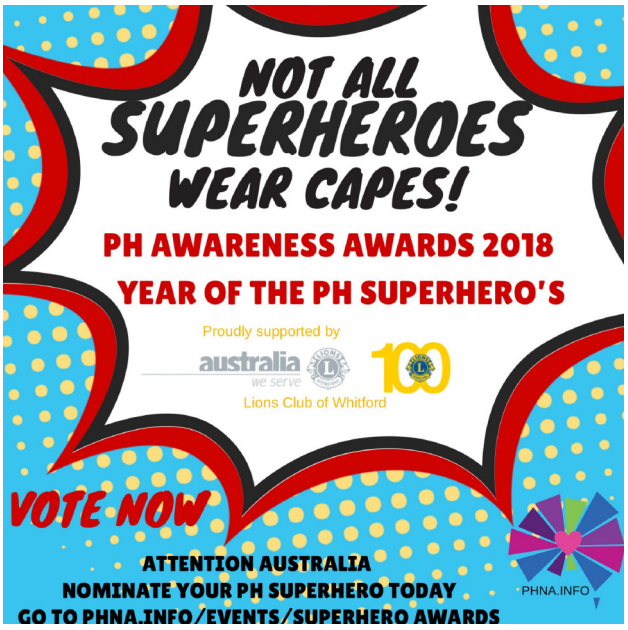
inclusive.collaborative.innovative

ANNOUNCEMENTS Notice Board

Every year we announce our new theme that goes from World PH Day 5th May, through to November, PH Awareness month. Our theme for 2018 is the Year of the PH Superhero's!

We have officially launched PHNA's first Awareness Awards for our Australian PH Community, and you can now begin to NOMINATE your PH Superhero from one of three categories, TODAY!

Awareness Awards are proudly supported by the Lions Club of Whitford, and our Junior Ambassador Tyler Wilding. You can find out more at www.phna.info and click on the Home page graphic that leads you to the voting page!



Understanding is rare, lung disease is not!

DONATIONS & FUNDRAISING

Thanks to our support group gathering raffle participants we raised $74.00 at our June gathering and $72.00 in August. Our not for profit (Non Government Organisation, Health Consumer Group), is entirely funded by our community, educational grants, donations and fundraising.

Pulmonary Hypertension Society of Australia and New Zealand

For Medical Professionals

ACKNOWLEDGEMENTS

PHNA strives to keep administration costs to a minimum, with the bulk of funds raised or donated going directly into patient projects, support and information. We are so grateful to everyone who supports us, and your ongoing commitment to see our Network grow and succeed. Our PH community spirit is alive and thriving, and we appreciate everything you do for us.

SPECIAL MENTION TO OUR SUPPORTERS

Thank you to our sponsors who have offered special membership discounts, provided us with a meeting place to gather for support, assisted us with fundraisers and awareness campaigns and other projects. Our small but valuable organisation would not survive without your generosity. In particular we thank the Arthritis & Osteoporosis Foundation WA, ConnectGroups Association, the Lung Foundation Australia, Carers Australia, Lions Club of Whitford, Dependable Laundry Solutions, Weigh n Pay and Colombian Café and Gifts.

TO OUR PATRON & AMBASSADORS

Patron Professor Eli Gabbay, Ambassadors, Clinical Nurse Consultant Tara Hannon, and GP Dr Chris Denz.

TO OUR EDUCATION & DEVELOPMENT TEAM

Clinical Nurse Specialist Jim Blanchard and Helen Blanchard, for their contributions to the PH community in Australia, and to Pulmonary Hypertension Network Australia.

Pulmonary Hypertension Network Australia

phna.info

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A lung disease that's Breathtaking

THE PLEDGE

"Working hand in hand with our community"
Thank you to our supporters, please read about this initiative on our website at www.phna.info/aboutus