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phan mail

magazine

Health Consumer Council
Gathering of Kindness Conference & Awards

WORLD PULMONARY HYPERTENSION DAY
5TH MAY GLOBAL CELEBRATIONS

Ask the Expert
Over the counter medications

The PH Bloggers "Dating with PH"

GoodHealth "When you feel anxious"

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

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WELCOME

Come inside our Autumn edition of PHan Mail Magazine, for our Australian PH Community and Beyond

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FIRST WORDS FROM THE EDITOR & CEO

Hello PHamily!

Welcome to another edition of PHan Mail magazine!

Our World PH Day 5th May 2018 celebrations were a big success. The Lions Club of Whitford hosted our "Superhero Quiz Night", where we were joined by the *Heart Lung Transplant Foundation & the Organ Donation & Transplant Foundation WA.* It was an exciting and fun night for the crowd that attended. We were very excited to go LIVE during our event with the first GLOBAL podcast hosted by *phaware.global* and join in with over 80 other organisations during the days celebrations.

The *Lung Foundation Australia* held it's first Live Webinar about Pulmonary Arterial Hypertension, which coincided with World PH Day. It was an interesting hour with questions answered live during the event. LFA will be hosting a further two **LIVE** webinars this year, one in August, and the other in time for PH Awareness Month in November. For more details, contact them directly. They Webinar will be posted on the LFA website and ours in the coming weeks. We also attended the Perth WA education day where we were asked to be a guest speaker. It was very exciting to share the first presentation in our new project "The LifeStyle Series", proudly supported by *Actelion Pharmaceuticals*. I spoke for 45 minutes about living with PH and how to manage life with a long term progressive chronic lung disease, and included the audience in questions and answers throughout. It was an excellent day with two other amazing guest speakers, *Louise Hesketh, senior dietician at Fiona Stanley Hospital*, speaking about lung conditions and nutrition and *Dr Sarah Pickstock, palliative care physician with Silver Chain* who gave an overview of palliative care and discussed some of the myths about palliative care.The *Rare Diseases Manager for the Lung Foundation Australia, Sharon Givioli*, did a wonderful job of making everyone feel welcome and engaged throughout the day. The dates for all states seminars in Australia are on our website www.phna.info/events/ and www.lungfoundationaustralia.com.au/events-and-training/

Our Team has been very busy in this first part of 2018 attending further education and training sessions, collaborating with other organisations, growing our Network, and working on the development of our "Lifestyle Series". All good things take time and this three year project will begin unfolding from our next edition, so look out for more soon! Enjoy this edition and please join up to our social media; check out our website, which is updated weekly and drop us a letter if you have anything to share, we love hearing from you.

BE KIND TO ONE ANOTHER

Melissa Dumitru x

'THE NETWORK'

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Visit us online at www.phna.info

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Contribute to our PHNA National Registry on our website under Membership

Plus! Subscribe to our FREE magazine "PHan Mail" hardcopy or electronic

mini-bites from the network

The Lung Foundation Australia Lung Health Education Seminar Perth WA

We were thrilled to be asked to step in and speak at the *Lung Foundation Education Seminar* in Perth WA on the 11th May. It gave us an opportunity to introduce our disease, pulmonary hypertension, to a new forum of people, and discuss some of the finer points of living with a long term chronic condition. We were able to launch the new "LifeStyle Series" first presentation and road test it on the audience. It certainly appeared to be well received and I enjoyed the interaction with the people attending, most who have a form of lung disease, along with their carers, family and allied health professionals. It was a successful day for the LFA with two other great guest speakers touching on subjects that were equally interesting and relevant to the audience. PHNA are very happy with the work the LFA has been doing in the last year in particular as they work torwards supporting our community in a larger and more collaborative way. Now available on our Facebook page and Website. Editor & CEO Melissa Dumitru

Lung Foundation Australia
when you can't breathe... nothing else matters®
1800 654 301
Information and patient support

The Digital Patient Experience Stories Project by ConnectGroups Association

ConnectGroups
helping support groups & individuals

In May this year we were asked to participate along with many others in the upcoming release of the new project, "Digital Patient Experience Stories". ConnectGroups Association wanted to share the many experiences and outcomes of people in our communities that attend, volunteer, or facilitate support groups. Both myself PHNA CEO, and our lovely member Maree Bouwer set out for a few hours to join the ladies at CG HQ who were filming and interviewing for the project. It was really cathartic for Maree to be able to share her experience and the benefits of being supported by the group and how its helped her in her journey as someone living with a chronic long term condition like pulmonary hypertension. As Founder of our community support group and organisation, I also had the opportunity to share how we had identified the need to form a support group for people with PH, to help improve our isolation, need for resources and information and to interact with others who understood your situation as they were going through it too. Once the project is complete we will share with you how to access it and watch it for yourself.

I see red, I See Red, I SEE RED!

When it comes to breakfast, lunch and dinner we say the brighter, the better. Meals made from red fruits and vegetables don't just taste good, they're also good for you, with antioxidants like anthocyanins, lycopene, and flavanols to keep your body healthy. Source/find more recipes at *eatbrighter.com.au & go to www.livelighter.com.au* for more information.

Warm Pumpkin, Beef, & Spinach Salad

Ingredients

- 1 kg Japanese, Kent, or butternut pumpkin, peeled and cut into 1 1/2cm dice
- 2 cloves garlic, unpeeled
- olive or canola oil spray
- 1 Tbls ground cumin
- 200 g baby spinach or mixed leaves
- 420 g can no-added-salt chickpeas, drained
- 1/2 bunch fresh coriander, chopped
- 500 g lean beef, fat trimmed
- 200 g low-fat natural or Greek yoghurt
- juice of 1/4 lemon
- 1/2 tsp ground cumin, extra
- 1/2 tsp honey

Method

1. Preheat oven to 180°C (160°C fan forced).
2. Place pumpkin cubes in a single layer on an oven tray lined with baking paper. Add garlic. Lightly spray with oil, sprinkle with ½ tablespoon cumin and roast in the oven for 25-30 minutes or until tender, turning halfway through cooking.
3. In a large bowl combine spinach, chickpeas and coriander.
4. Lightly spray a large non-stick frypan with oil and place on medium to high heat. Sprinkle remaining cumin onto both sides of steak. Grill for 3 minutes each side or until cooked to your liking. Remove from heat, cover and set aside to rest for 3 minutes before slicing thinly.
5. To make dressing, squeeze cooked garlic out of its skin and mash in a small bowl. Add in yoghurt, lemon juice, extra cumin and honey; mix to combine.
6. To serve, divide salad ingredients among serving plates then top with pumpkin and beef. Pour dressing over salad just before serving or serve in individual dishes on the side.

Eat brighter Live Lighter

Variations

- ✓ Add 300g blanched green beans or asparagus.
- ✓ Include other salad ingredients such as cherry tomatoes or sliced cucumber, radish or red onion.
- ✓ Replace chickpeas with drained no-added-salt cannellini beans, butter beans or four bean mixes.

Healthy tip! Try mustard instead of mayonnaise to add extra flavour to your salads and sandwiches

Reducing breathlessness with hand-held fans

Why use a hand-held fan?

Many people find using a fan can help control breathlessness, and research has shown that a cool draft of air from a hand-held fan can be effective. Hand-held fans are a great option because they are cheap and easily portable. A free-standing fan, a desktop fan or the breeze through an open door or window may also help. Some people find that a cool washer or a mist of water on the face has the same effect.

How to use a fan?

Follow the three steps below and you should start to feel a benefit in a few minutes:

- Hold the fan about 15 centimetres from your face so you can feel it on your top lip.
- Slowly move the fan side to side so that the breeze covers the bottom half of your face.
- Remember to use your controlled breathing and try and relax your shoulders. To find out more about controlled breathing techniques talk to your health professional.

When to use a fan?

You can use your fan as often and for as long as you like. Keep it handy when at home and also take it with you when you go out. You may find it helpful to use your fan if you stop for a rest after doing an activity that makes you breathless, such as walking, climbing stairs or for sudden breathlessness when you are still.

Why do fans help?

It is unclear exactly why a fan can decrease breathlessness. It is likely that the fan's breeze stimulates the nerves in the face which decreases the feeling of breathlessness. The fan is also a good distraction. It can help decrease anxiety and give you a feeling of control.

Lung Foundation Australia offers a range of services and resources to support people living with a lung disease.

Visit our website for more information:
lungfoundation.com.au

Content adapted with permission from Mary Roberts, Clinical Nurse Consultant, Breathlessness Clinic, Westmead Hospital.

FIND OUT MORE
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Foundation
Australia
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HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

Editors Note: PHNA has been following the work of the Health Consumer Council for several years now, since they introduced their initiative "The Patient Experience". As the CEO of our organisation I was naturally curious to see where this concept may take them. Several years on and this idea has continued to grow and include key stakeholders in our patient, medical, and allied health communities. Along with many other organisations the support of the "patient" or person living with the disease, is being raised more commonly than not. Often when you are diagnosed with a chronic long term or progressive disease, such as pulmonary hypertension, you feel like you have had all your power taken away through the disease and somehow with it, your voice. Any initiative that attempts to give back the patients voice in their care is something to be supported. We look forward to growing our relationship with the HCC and will continue to keep you apprised of their valuable work. **Note**: The following information was taken directly from the HCC website and shared here with you.

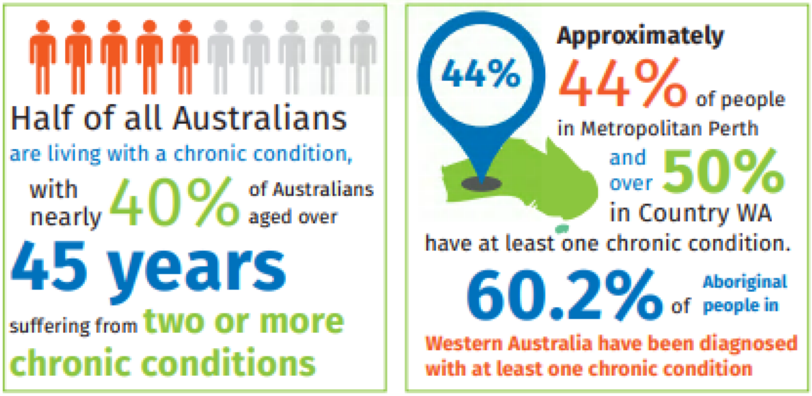
For six months of 2017, HCC has worked with the WA Primary Health Alliance and Curtin University on a project to explore consumers' experience of chronic disease, and what kind of care they are seeking from the GP and community based services.

People living with chronic health conditions and a range of community-based health service providers came together at a forum on Friday 1st December 2017, to hear the outcomes of a focus group study conducted by Curtin University and Health Consumers' Council in 2017.

The aim of the study was to better understand the current system of GP management of long term conditions, from the perspective of consumers. This information will be used as part of an overhaul of the primary care system being conducted by the WA Primary Health Alliance (WAPHA) in conjunction with GPs.

Forty-six consumers were involved in the focus groups which met in Wanneroo, Midland, Armadale, Rockingham, Bunbury and Albany. They represented a range of ages, backgrounds, and health conditions but had many key points in common:-

Chronic conditions are the leading cause of premature death in Australia.



Naïve Inquiry Study

- Consumers want a long term relationship with a GP who is a good listener and will work with them in partnership.
- Bulk billing and reduced up-front costs to care helps consumers to get the care they need.
- Chronic condition care plans are not well promoted and don't deliver enough care – especially to people who have more than one condition.
- There is a role for specialist "care coordinators" to acquire and support better taylor different services to meet patient needs.
- People with chronic health conditions should be treated differently within the GP system to people who only require occasional GP contact.

The full report from the focus group study is available from the WAPHA website http://www.wapha.org.au/community/engagement/
Kate Bullow, Project Co-ordinator. HEALTH CONSUMERS' COUNCIL (WA)

Health Consumers' Council (WA) Inc (HCC) is an independent voice, advocating for patients in Western Australia. It offers a unique perspective on health policy and service delivery matters. HCC receives funding from State agencies and comments publicly on all issues affecting health.

GATHERING OF KINDNESS CONFERENCE & AWARDS

"Patient Experience Week" is a global event to celebrate the people who impact on the patient experience every day. It is held in the last week of April each year with this being our third year we are mixing things up a little, and instead of holding all the events in April, we will be holding events in April and November. We want to ensure that "Patient Experience" is not just a day, but a movement!

The uniting theme this year is kindness. On Friday 27th April we hosted a "Gathering of Kindness", followed by the announcement of our "Consumer Excellence Awards". Then on Tuesday 13th November 2018, "World Kindness Day", we will hold a special event with a focus on achieving equity in the patient journey for people from new and emerging communities, and those for whom English is not a first (or second, or third) language.

Our 2018 "Patient Experience" logo references fabric. Fabrics come in all kinds of textures and colours, thicknesses and patterns. Some are traditional, others are contemporary. Some are as delicate as gauze while others are hard wearing and durable. Weaving is an integral part of fabric and we see our society as being woven together through our engagement with each other. Each engagement provides an opportunity to weave our fabric more strongly and more beautifully, and to create a society where the warp and the weft of kindness continue to hold us all together.

Beyond the Stethoscope

HCC partnered with *"Child and Adolescent Health Service"* and the "*WA Primary Health Alliance"* to host a Patient Experience Week breakfast. This event brought together clinicians, health professionals, consumers, carers, and community to hear from *Lucy Mayes, the author of Beyond the Stethoscope.*

Gathering of Kindness

HCC and Child and Adolescent Health Service celebrated Patient Experience Week with a mini-Gathering of Kindness. *Dr Catherine Crock from the Hush Foundation*, and co-founder of the "Gathering of Kindness" attended via video-conference. Lucy Mayes, Patient Opinion's Michael Greco, and World Kindness Day's Michael Lloyd Wright convened through a provoking panel discussion on what could we do to create a kinder health system.

HCC finished their day with the announcement of their "Health Consumer Excellence Awards" finalists and winners.

PHNA were in attendance to be part of this wonderful event and see that our nomination for CEO Antonella Segre and her amazing team at ConnectGroups Association made them finalists in two of the categories.

They were WINNERS of the Health Consumers Award and we couldn't be happier for them.

Congratulations on this much deserved award and for all the hard work you do for the support and self help community!

We look forward to sharing more with you about the Patient Experience later this year. Team PHabulous

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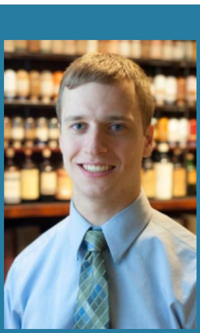
REMEMBER WHAT IT FELT LIKE TO BE EXCLUDED SO THAT YOU CAN HELP BUILD A COMMUNITY WHERE EVERYONE IS INCLUDED.

ASK THE EXPERT



Nathan Verlinden received his Pharm.D from Drake University in Des Moines, Iowa, in 2013. He then completed a post-graduate year 1 (PGY-1) pharmacy practice residency at the University of Toledo Medical Center in Toledo, Ohio, followed by a PGY-2 specialty residency in cardiology at UPMC Presbyterian Shadyside Hospital in Pittsburgh. He currently practices as a cardiology clinical pharmacy specialist at Allegheny General Hospital in Pittsburgh where he regularly sees patients with cardiovascular disease, heart failure and pulmonary hypertension.
(This article originally appeared in Pathlight magazine PHA USA).

Seasonal allergies occur after exposure to allergens such as pollen, hay fever and ragweed. Common symptoms of seasonal allergies include runny or stuffy nose, itchy eyes, sneezing and coughing. Some people may experience seasonal allergies at certain times of the year — such as the spring or summer — while others may have symptoms year-round. In the United States, it is estimated that approximately 50 million people have allergies, so it should come as no surprise that many patients with PH may be affected. (Editor's Note: 4.1 million Australians (19.6% of the population) have at least one allergic disease; Google).

Nasal decongestants aren’t absorbed by the body as much as oral decongestants are, so therefore, they may have less of an effect on increasing blood pressure and worsening PH. On a case-by-case basis, nasal decongestants may be considered for short term use after discussion with your PH team. If nasal decongestants are used, they should be limited to no more than three days to avoid worsening nasal congestion. Nasal saline sprays or irrigation can be tried instead of decongestants for patients who have nasal stuffiness.

Decongestants are available over-the-counter (OTC), so take extra caution in avoiding these medications as many combination products may have these decongestants hidden within the product. It is always important to read the back label on any OTC medication to check what medications are contained in the product. If you have any questions or concerns about active ingredients within an OTC product, ask a pharmacist for help. As always, it is important to discuss any treatment options with your PH team before starting any new medications.

For patients with PH, it is also important to consider that several PH medications may mimic seasonal allergy symptoms. Commonly, endothelin receptor antagonists (ERAs) including Bosentan (Tracleer®), Ambrisentan (Letairis®) and Macitentan (Opsumit®) can cause nasal stuffiness. Other PH medications may also contribute to nasal stuffiness by causing vasodilation (widening of the blood vessels).

However, these medications generally do not cause other allergy symptoms such as itchy eyes. If you recently started one of these medications and noticed these symptoms, you should discuss these side effects with your PH team. Additionally, seasonal allergies generally do not cause worsening shortness of breath. Contact your PH care team immediately if you experience worsening breathing symptoms or dizziness.

Generally, the management of seasonal allergies consists of avoiding allergens that are known to trigger symptoms and taking medications for those who can’t control their symptoms with allergen avoidance alone. For patients with PH and seasonal allergies, it is important to be aware of what medications are considered safe and which medications to avoid.

Table 1. Safe medications for seasonal allergies in PH patients, lists several medication classes and specific medications that are considered safe to take for seasonal allergies for patients with PH. These medications include oral and nasal antihistamines, nasal corticosteroids, nasal anticholinergics, nasal cromolyn, nasal saline spray/irrigation and montelukast (Singulair®). Oral antihistamines or nasal corticosteroids are considered first-line therapies for most patients with seasonal allergies. However, many patients may require a combination of medications.

Newer generation oral antihistamines, such as loratadine (Claritin®) and cetirizine (Zyrtec®), are recommended over older generation antihistamines, such as diphenhydramine (Benadryl®), due to fewer side effects, such as drowsiness. Proper technique for using nasal inhalers is important to prevent side effects and enhance effectiveness of these medications (see table 1). Other side effects and tips for use with the various medications considered safe for patients with PH are shown in table 1.

Medications that usually should be avoided for patients with PH and seasonal allergies are shown in table 2. Decongestants, including pseudoephedrine (Sudafed®), phenylephrine (Sudafed PE®) and oxymetazoline (Afrin®), should typically be avoided because they cause vasoconstriction (narrowing of the blood vessels) and may worsen PH.

Verinden, N (2013). Ask the expert. Retrieved on June, 1, 2018, from Pathlight Magazine, PHAssociation.org USA.

Table 1. Safe medications for seasonal allergies in PH patients

MEDICATION CLASS	COMMON MEDICATIONS	MECHANISM	SIDE EFFECTS	TIPS FOR USE
Oral Antihistamines	• Loratadine (Claritin®) • Fexofenadine (Allegra®) • Cetirizine (Zyrtec®)	Blocks histamine receptors	Dry mouth, drowsiness	• Diphenhydramine (Benadryl®) generally not recommended due to higher rate of side effects • Higher doses are more likely to cause drowsiness • Avoid combination products with decongestants (e.g., Allegra-D®, Claritin-D®)
Nasal Corticosteroids	• Fluticasone (Flonase®) • Mometasone (Nasonex®) • Triamcinolone (Nasacort®)	Reduces inflammation	Nose bleeds, bitter aftertaste, nasal dryness, throat irritation, headache	• Blow nose to clear nostrils before use Prime inhaler before first use or after long periods of nonuse • Aim nozzle away from middle of the nose to avoid nose bleeding • Stand upright with head tilted slightly forward during administration
Nasal Antihistamines	• Azelastine (Astelin®, Astapro®) • Olopatadine (Patanase®)	Blocks histamine receptors	Nose bleeds, bitter aftertaste, nasal dryness, headache	
Nasal Anticholinergics	• Ipratropium (Atrovent®)	Blocks acetylcholine receptors	Nose bleeds, headache, nasal dryness	
Nasal Cromolyns	• Cromolyn (NasaCrom®)	Prevents histamine release	Nose bleeds, sneezing	• Takes several weeks to see full treatment effect
Nasal saline spray/ irrigation	• Saline nasal spray (Ayr®, Ocean®) • Saline nasal irrigation (Neti pot)	Moisturizes nasal passages, breaks up mucus	Nose bleeds, nasal discomfort	• Can use prior to other nasal sprays to improve drug absorption • Alternative to decongestants for nasal stuffiness
Leukotriene receptor antagonist	• Montelukast (Singulair®)	Blocks leukotriene receptors	Generally well-tolerated, upset stomach, headache possible	• May be useful for patients with both asthma and seasonal allergies

PH = pulmonary hypertension

Table 2. Medications to avoid for seasonal allergies in PH patients

MEDICATION CLASS	COMMON MEDICATIONS	REASON TO AVOID	TIPS ON USE AND AVOIDING
Decongestants	**Oral** Pseudoephedrine (Sudafed®) Phenylephrine (Sudafed PE®) **Nasal** Phenylephrine (Neo-synephrine®) Oxymetazoline (Afrin®)	• Medications work by causing vasoconstriction of blood vessels • Can increase blood pressure and worsen PH	• Always read back label for any OTC medication • Oral decongestants may be found in combination products (e.g. Allegra-D®, Claritin-D®, Tylenol® Cold and Sinus) • Ask a pharmacist about active ingredients within OTC medications • Consider nasal saline spray/irrigation instead of decongestants • Less absorption by body with nasal decongestants; may consider use after discussion with PH team (limit use to three days or less)

PH = pulmonary hypertension, OTC = over-the-counter

goodhealth...

As part of our PHNA mental health and well being initiatives we have begun to share various articles, exercises and quotes on our Facebook and Pinterest pages. This particular post below got a hit rating of over 1200 views to our page, so we decided to share it with you in the magazine.

We will be introducing our Coordinator Education & Development Helen Blanchard to you in our next edition. Helen will be introducing the new LifeStyle Series, our three year initiaitve for which we will be collaborating and co-designing with our PH community, medical professionals and allied health professionals. (Graphics taken from Pinterest).

2018 World PH Day - 5th May Celebrations

SUPERHEROES QUIZ NIGHT AND PHAWARE.GLOBAL LIVE PODCAST

Review Study Supports Tracleer as Effective Treatment in Pulmonary Arterial Hypertension

Feb 2018 - Article Jose Margues Lopes, PHD

Appeared in CTEPH NEWS.NEWS.PAH NEWS

Treatment with Tracleer (bosentan) is effective in patients with pulmonary arterial hypertension (PAH), a new review study and analysis of data from clinical trials shows.

The research, (Bosentan Therapy for Pulmonary Arterial Hypertension and Chronic Thromboembolic Pulmonary Hypertension: A Systemic Review and Meta-Analysis," was published in The Clinical Respiratory Journal (Xinwang Chen et al., 2018).

Exaggerated production of endothelin-1, a potent vasoconstrictor (narrowing of blood vessels), plays an important role in the development of PAH. As it blocks endothelin receptors, Tracleer (marketed by Actelion) is able to provide a vasodilator (widening of blood vessels) effect.

A prior meta-analysis — (a type of statistical study that combines the results of various studies) — showed that Tracleer is able to improve exercise capacity and hemodynamics (the dynamics of blood flow) in PAH patients.

However, two of the studies used in the analysis were not conducted in PAH patients, but rather in patients with chronic thromboembolic pulmonary hypertension (CTEPH) and chronic obstructive pulmonary disease-related pulmonary hypertension (COPD-PH), which may have introduced bias.

Although research showed that treatment with Tracleer can also improve cardiopulmonary hemodynamics in CTEPH patients, the potential improvement in CTEPH symptoms with this medication remained unknown.

That led the research team to conduct a systematic review of the literature and a meta-analysis to determine the efficacy and safety of oral treatment with Tracleer for both PAH and CTEPH patients.

The study analyzed 10 clinical trials (eight in PAH and two in CTEPH) with random assignment of participants to Tracleer or placebo treatment groups. Overall, the trials included 1,185 patients (1,003 with PAH and 182 with CTEPH).

Results showed that, in PAH patients, Tracleer improved the six-minute walk distance (an exercise test measuring the distance an individual can walk over six minutes), reduced mean pulmonary arterial pressure by 5.7 mmHg (millimeters of mercury — the units used to measure blood pressure), and increased cardiac index (which assesses cardiac output per body surface area).

Tracleer also reduced vascular resistance in the lungs (which improves blood flow), and limited clinical and functional worsening.

In CTEPH patients, Tracleer also improved cardiac index and decreased pulmonary vascular resistance, though at a lower level than in PAH patients. This reduced efficacy in CTEPH patients may be due to the different nature of the diseases, the scientists hypothesized, including the lack of increased production of entothelin-1 in CTEPH.

The lack of improvement in exercise capacity and hemodynamics in CTEPH patients contrasts with previous analyses, the authors observed. This may be explained by methodological differences, as those prior studies compared the effects of Tracleer with the patients' values at baseline, rather than with placebo treatment.

In both PAH and CTEPH patients, no differences were observed between Tracleer and placebo regarding mortality and adverse events. However, Tracleer increased the risk of abnormal liver function in both patient groups.

Overall, "[Tracleer] is effective in treating PAH, whereas it only improves certain hemodynamic parameters of CTEPH," the researchers wrote.

Among the study's limitations, longer follow-up periods are required to evaluate if the improvements seen with Tracleer are sustained over a longer term, the team observed. In addition, the small sample size and low number of clinical trials analyzed draw caution in the interpretation of the CTEPH results.

Dating with a chronic illness

In Columns, Life After PH - A Column By Kathleen Sheffer. May 2018

PULMONARYHYPERTENSIONNEWS.COM

My health has always served as an extra filter for my relationships, romantic or otherwise. One man asked me to be his girlfriend on a Friday night and then broke up with me on Sunday, citing his desire for biological children as the sticking point. At 19, starting a family was far from my mind, but I had opened up to him about my inability to bear children while sharing more about my disease.

Other PH patients had told me similar stories of rejection due to life expectancy, childbearing, and health maintenance issues. One patient shared that his teenaged girlfriend broke up with him because she thought it would be too difficult to be more than friends when he died. Some people just couldn't handle the disease, and I figured it was better to know that earlier rather than later. Soon after my heart-lung transplant, I asked my nurse practitioner how long I had to wait before kissing someone on the lips.

She dodged the question, but when pressed, told me, "We can talk about that in six months." I had been expecting a standardized answer in line with the amount of time I had to wait to raise my arms above my head or drive a car. Six months?! And even then just a discussion? In my pained and drugged state, I felt hopeless. If I went on a date, would I have to disclose that we couldn't talk about kissing for another six months? I resolved to be a cat lady.

As with most aspects of normal life that I believed were permanently over after my transplant, I was wrong. On average, transplant centers advise waiting six weeks for intimacy with a partner, and encourage kissing much earlier than that, as long as they're healthy (and ideally brush their teeth)!

Anyway, I didn't listen to the nurse and started dating when I went back to living on my own a few months after surgery. I was listing my hobbies — making art, cooking, playing board games — when my date interjected. He never really got into playing games, he said, because he always preferred to play outside. My love for board games and jigsaw puzzles developed over the many days I spent sick at home. Of course, I would have preferred to play outside, too.

It occurred to me then that many of my preferences are the product of a disease I no longer have. My life with pulmonary hypertension (PH) was fairly sedentary, but now I'm up early to exercise nearly every morning. Dating after transplant helped crystallize the reality that my priorities have changed, and that I'm still developing the way I want to live my life.

I've always been very open about my condition, for reasons I describe in an earlier post. My online dating profile featured pictures of me in the hospital.

I expect people to ask me about my condition because it constitutes a big part of my life — I spend hours writing about it every week! My ideal partner acknowledges my health challenges and makes space for me to talk about them when I want to, without letting them define me or our relationship.

Some guys can't hang with my dark transplant humor, so when a guy takes a photo of my dissected sick heart in stride, simplifies "heart-lung transplant" to "switcheroo," and starts quoting my blog posts (mostly to tease me about being a "fall risk"), I know he's special.

So many couples vow to have and to hold in sickness and in health without ever knowing sickness. Circumstances change over time and test the relationship.

As a woman with chronic illness, I envy those who never worry that their partner might leave them because they want biological children, or because they don't ever want to be a caretaker, or maybe because they're just not that into chests covered in scars.

But healthy women should envy me because I get to begin a relationship knowing my partner will remind me to take time-sensitive medications, buy me pasteurized cheeses, and tell me I look good in a hospital gown.

Are Two Drugs Better Than One for PAH?

by Phyllis Hanlon, Contributing Writer Article by the Pulmonary Hypertension Association USA

Research in managing WHO Group 1 PH (PAH, pulmonary arterial hypertension) has resulted in new drugs and strategies that have extended and are improving life for patients. Lately, some doctors have started prescribing more than one drug for patients. Researchers from Brazil and France teamed up to examine how doctors are thinking about multiple-drug therapy for patients with PAH. Their editorial comments were published in the European Respiratory Journal.

Rogério Souza, M.D., Ph.D., from the Heart Institute at the University of Sao Paulo Medical School, offered some background on the latest in PAH drug therapy. He explained that the current drugs target one of three pathways: the nitric oxide (NO) pathway, the endothelin pathway, and the prostacyclin pathway. He noted that for many years, unless a patient was very sick, doctors initially used one drug (monotherapy). If a patient's disease continued to get worse, or if the patient and his or her physician did not feel the patient was "responding" to the chosen drug, doctors then frequently added a second drug onto the first – combination therapy. Recent clinical trials began to look closer at combination therapies.

For instance, the AMBITION trial examined the use of both Ambristentan and Tadalafil in patients with PAH and found that together they worked better than either drug alone. Summarizing all existing evidence, the European Society of Cardiology (ESC)/European Respiratory Society (ERS) issued guidelines recommending the use of combination therapy, particularly in the early stages of disease.

The editorial added that although existing evidence provides robust support for the use of combination therapy, the RESPITE study took a different approach; instead of combination therapy, this study looked at the effect of switching from PDE5 inhibitors (e.g., Sildenafil or Tadalafil) to a soluble guanylate cyclase (sGC) stimulator (Riociguat) if a patient was not responding adequately to the PDE5 inhibitor.

In the RESPITE study patients were given Riociguat after they had been taking Sildenafil and Tadalafil without any noticeable improvement. All three drugs target the nitric oxide pathway, but in a different manner. The results showed that 84 percent of the patient participants completed the 24-week trial. Patients showed improvements in six-minute walk distance, in NT-proBNP, (a blood test to look for signs of heart failure;) and functional class improvement. Of great importance is the fact that nearly half of the patients in the RESPITE study lowered their risk profile as defined by the ESC/ERS guidelines.

While RESPITE demonstrated good results and raised some important questions, the study did have limitations, according to the authors. They noted that because the study was open-label in design (the researchers knew what drug was being used and there was no placebo involved), it’s difficult to draw any real conclusions. Also, 16 percent of participants failed to complete the entire study; adverse events (“side effects”) might have impacted the final results.

Dr. Souza and co-authors noted that the idea of switching drugs is common in other medical situations, such as treating systemic high blood pressure. But he said that using this approach in PAH faces some different challenges. They asserted that when you look at all the different drugs for PAH in a particular class there is not one that has been proven to be better than the others. Additionally, no study has created a profile of patients with PAH who respond more favorably to one drug over another. Finally, patients with PAH continue to have a relatively high death rate, limiting attempts to test potential switches.

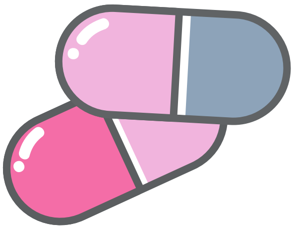
Despite these challenges, several studies on transitioning patients from one drug to another have taken place, to better understand when this would be appropriate and in whom.

While studies have yielded promising results, more questions exist and more clinical trials are needed to answer them. The REPLACE study (Riociguat rEplacing PDE5i therapy evaLuated Against Continued PDE5i thErapy) is currently enrolling participants and is attempting to answer more of these questions.

Each PH patient is different. It is essential that you talk to your own doctor about what treatment options are best for you.

Editorial comments published in the European Respiratory Journal look at combination and switching therapies.
The AMBITION trial looked at the use of both ambrisentan and Tadalafil in patients with PAH and found that together they worked better than either drug alone.
The findings on combination therapies prompted the European Society of Cardiology (ESC)/European Respiratory Society (ERS) to issue guidelines recommending the use of combination therapy, particularly in the early stages of disease.
In addition to looking at research on add-on therapies, the editorial looked at a study in which the drug was switched to another.
In this approach that is used in treatment for other conditions, a the patient may be switched to a different drug altogether before trying to add second drugs.
More research is needed. The editorial authors note a trial that is currently enrolling patients.

PHNA Editors Note:
We have a comprehensive list of PH Treatment Centres on our website www.phna.info Information/Treatment Centres.
For medical professionals you can go to www.phna.info Information/Medical Professionals.
For support groups go to www.phna.info Support/Support Groups Nationwide coordinated through the Lung Foundation Australia.
In WA, PHNA Community Support Group & the Lung Leaders Network of Western Australia through the Institute for Respiratory Health.



Wearing Oxygen Has Taught Me the Lessons I Needed to Learn

In Columns, Recharged & Rewired - A Column By Brittany Foster. April 2018
PULMONARYHYPERTENSIONNEWS.COM

Just when we think we figured things out, the universe throws us a curveball. So, we have to improvise. We find happiness in unexpected places. We find ourselves back to the things that matter the most. The universe is funny that way. Sometimes it just has a way of making sure we wind up exactly where we belong.” –Meredith Grey, “Grey’s Anatomy”

Two years ago, right before April vacation week, I was admitted to the hospital. After years of suffering with shortness of breath, dizziness, and fatigue, I finally got answers. When doctors found that my oxygen levels were repeatedly dropping to the 80s with minimal exertion, my life changed. Nobody provided instructions for how life should be lived with diagnoses of chronic hypoxia and exercise-induced pulmonary hypertension. I just got the diagnoses and a prescription to use supplemental oxygen for all activity. Two years ago, I had a different mindset. It took a major life event to put parts of my life into perspective and understand what is truly important.

Wearing oxygen has taught me to believe in the good of other people. Although I have had my negative encounters with people who question my disability, there are truly more good people in the world. Whether it’s people stopping to hold a door for me, commenting on my strength, or telling me they will keep me in their thoughts and prayers. Moments like these should outweigh the negative experiences.

I have learned that my voice is the most powerful tool I have and is the very thing that will help create change. Before diagnosis, I was intimidated and afraid to take control of my health. For 24 years, I relied heavily on my mom to remember appointments, surgeries, procedures, and past medical history. Wearing oxygen and having a rare condition has taught me the importance of speaking up for both myself and others. I continue to advocate for awareness of invisible illness because, at one point, my illness was invisible, too. No one is alone in their struggles, and it’s up to each person to make their voices heard.

Oxygen taught me that there is so much more to life than “looking good.” For many of my teenage years, I struggled with dieting and a desire to fit the “perfect” image. Being put on oxygen was frustrating, considering the numerous times I spent in the past disliking my reflection and trying to change parts of myself. Having my life change so drastically has taught me that true beauty is self-love. Anyone can be thinner, change looks and hair color, spend hundreds of dollars on makeup, and beat themselves up at the gym. But doing these things will never make anyone happy without self-acceptance. When people release fear of being who they are, they find there’s so much more to life than realized.

In two years, I’ve learned that those who love me at my best, aren’t always the ones who love me at my worst. I realized that I don’t have the time or energy for mediocre relationships. Life guarantees nothing. Life can change at any moment. Why waste it in halfway relationships? Why would I want to spend it wondering if the people I surround myself with truly care about me? I have learned that if someone doesn’t make me happy, they aren’t worth my time. I have learned that true love from those who love me at my best and worst is the only kind of love that matters. Anything else is pointless.

Regardless of how hard people try to keep the ideal picture of life in mind, it never works out that way. It’s important to have hope that there will be better days and to trust that the universe knows what it’s doing. Change is the scariest thing in the world, but sometimes it’s exactly what we need. Something like an oxygen prescription may seem like the worst thing to happen, but you can find the positive in life’s curveballs.

Every year we announce our new theme for 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!

This project is 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

Thank you to our support group gathering raffle participants April, we raised $51.00.

World PH Day 5th May Quiz Night proudly hosted by the Lions Club of Whitford. At our event we were joined by our Network partners, the Heart Lung Transplant Foundation WA, & the Organ Donation Transplant Foundation WA.

Lions Clubs International

WESTERN AUSTRALIA HEART & LUNG TRANSPLANT FOUNDATION

Organ Donation & Transplant Foundation of WA

PHNA are "Paying it Forward" by making a donation to the Lung Foundation Australia's Respiratory Nurse Initiative. Our not for profit NGO HCG is entirely funded by our community and 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

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 projects. Our small but valuable organisation would not survive without your generosity. In particular we thank the Arthritis & Osteoperosis Foundation WA, ConnectGroups Association, the Lung Foundation Australia, Carers Australia, Lions Club of Whitford, Dependable Laundry Solutions, Weigh n Pay & Colombian Café and Gifts.

TO OUR PATRON & AMBASSADORS

Patron Professor Eli Gabbay, Ambassadors, Clinical Nurse Specialist 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

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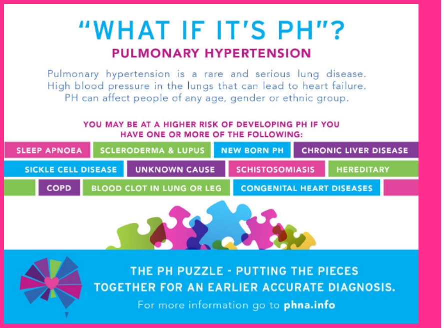

"WHAT IF IT'S PH"?

PULMONARY HYPERTENSION

Pulmonary hypertension is a rare and serious lung disease. High blood pressure in the lungs that can lead to heart failure. PH can affect people of any age, gender or ethnic group.

YOU MAY BE AT A HIGHER RISK OF DEVELOPING PH IF YOU HAVE ONE OR MORE OF THE FOLLOWING:

- SLEEP APNOEA
- SCLERODERMA & LUPUS
- NEW BORN PH
- CHRONIC LIVER DISEASE
- SICKLE CELL DISEASE
- UNKNOWN CAUSE
- SCHISTOSOMIASIS
- HEREDITARY
- COPD
- BLOOD CLOT IN LUNG OR LEG
- CONGENITAL HEART DISEASES

THE PH PUZZLE - PUTTING THE PIECES TOGETHER FOR AN EARLIER ACCURATE DIAGNOSIS.

For more information go to **phna.info**

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