

SUMMER 2016

emphasis

The magazine for supporters of PHA UK www.phauk.org

When others can't see your pain

A closer look at PH as an 'invisible illness'

Dr Google will see you now...

Should we pay attention to medical information on the internet?

Travelling with pulmonary hypertension

An essential holiday planning checklist for people with PH

Pets as therapy

How pets can make you feel better

Atishoo!

Expert advice on summer allergies for PH patients

Supporting partners

Emma Offord considers the emotional impact of PH on partners

The Interview

Specialist PH nurse Wendy Gin Sing talks about her career



Free support & advice...



If you would like copies of any of our publications please contact the PHA UK office on 01709 761450 or email us at office@phassociation.uk.com



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Influence. Hope. Integrity.

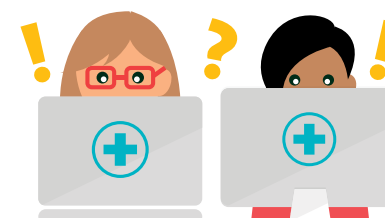
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Save the date
for our first ever
**PH Awareness
Week...**

PH
AWARENESS
WEEK
2016



Let's talk about PH...

Free downloadable resources: a letter to send to your GP or practice nurse; a press release for your local media; and a letter to send to your MP. A new leaflet all about PH to help you tell others about the condition. National media and social media campaign planned.

Watch out for more details on www.phauk.org and in the next issue of Emphasis.



Contact us at www.facebook.com/PULHAUK
On Twitter @PHA_UK
Call us on 01709 761450
Email us at office@phauk.org



Welcome

Welcome to the summer edition of Emphasis. As always, this issue focuses on a range of subjects important to people with pulmonary hypertension, their families and loved ones.



This edition includes a feature about the difficulties associated with having a serious illness that no-one can see. We know that having a so-called 'invisible illness' can be one of the greatest causes of frustration for people with PH – and can lead to all sorts of difficulties. Whilst, other times, people appreciate their condition not being obvious to strangers. What do you think about this? Let us know via editor@phauk.org or share your views with others on our Facebook page. We also have articles about the pros and cons of having so much medical information available on the internet, the impact of PH on the partners of patients, and the therapeutic power of our pets. Turn to the back of the magazine for a bumper summer feature on

travelling with PH. It contains lots of advice and information to help you plan your holidays. With more of your news, fundraising stories, advice from PH professionals and updates on research, we hope you'll find plenty of interest. The other good news is that back copies of Emphasis are now available via our new-look website at www.phauk.org so you can catch up on articles in previous magazines whenever you like.

Iain Armstrong

Iain Armstrong
Chair of PHA UK
editor@phauk.org

With more of your news, fundraising stories, advice from PH professionals and updates on research, we hope you'll find plenty of interest.



Emphasis *exchange*

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If you have any news and views to share via the Emphasis exchange please e-mail editor@phassociation.uk.com and don't forget to keep in touch via Facebook and Twitter too.

PUB CRAWL FOR PH

Paul Tyack and Kayleigh Snell are working their way around all the Red Lion pubs in the country to raise money for PHA UK.

The couple, who live in Oxon, are raising in money in support of Paul's five-year-old niece Emily, who has PH.

There are over 600 pubs called The Red Lion and they plan to visit all of them at least once. They hope to reach number 300 by September this year, 12 months after they started the challenge.

Kayleigh said: "The Red Lion is the most popular pub name in the country and that gave us the idea to visit every one of them as a bit of a personal challenge. We are now using our quest to raise money for PHA UK and to help spread the word about the illness."

Kayleigh and Paul have set up a Facebook page for people to keep up-to-date with their challenge. You can follow their journey here: www.facebook.com/KayleighPaulRedLionQuest
They are fundraising online here: www.justgiving.com/KayleighPaulRedLionQuest



Emily answers our Green Leaf Grew questions on page 34

The Rough Guide to Accessible Britain

Book review by Luke Marino

This easy to read guidebook is packed with practical details about accessible and enjoyable UK visitor attractions.

It features reviews of a wide range of attractions across different regions including the National Space Centre, in Leicester, Paignton Zoo and The Deep in Hull.

Each entry includes useful visual symbols which highlight facilities available, for example disabled toilets, accessible car parking, powered scooters and hearing loops.

The book contains more than 175 accessible attractions in all, all of which include contact details, entry fees and opening times. It is the perfect tool when planning a family day out.

The book is available to buy online at Amazon for £5, with alternative formats available.

Published by www.roughguides.com, April 2010, ISBN: 9781848366589



Short stories for PHA UK

Long-time writer Barbara Shrubsole is publishing a collection of some of her short stories as a gift for family and friends, and to provide charity support for PHA UK.

Barbara, who lives in Bath, has chosen the charity in support of her friends Sharon Pile, pictured, who was diagnosed with PH in 2011, and her mother Valerie Pile.

'Literary Allsorts' will be launched at Manvers Street Baptist Church in Bath on 3rd September and proceeds from the sales will go to PHA UK.

Barbara, who has self-published several poetry books, said: "This will hopefully not only raise money but also raise awareness of this somewhat lesser known challenging condition."

To find out more about Literary Allsorts or to attend Barbara's book launch, please email her at ba.s@btinternet.com



Social Media Round-up

Here are some top tweets and popular posts from PHA UK Facebook and Twitter

.....
@EuropePHA #PatientSurvey Excellent initiative. We look forward to reading your resulting articles on living with Pulmonary Hypertension.

Zoe Armstrong Well done everyone involved in the new PHA website, it looks really great & its very user friendly. The new shortened web address is easier to remember too.



Carol Childs All the doctors and nurses at Sheffield and Cambridge vascular disease units do great work, they go above and beyond their duties.

@DaniSaveker Day 116 of my random acts of kindness – donated to Pulmonary Hypertension @PHA_UK



Patricia Lavinia Riding Utmost respect to Papworth. Utterly amazing. Will never forget and will always be grateful for what they did for my brother. Thanks also to Sheffield for all you have done for him.

Tom French 5 hours 31 mins in the London Marathon and £1,200+ raised for PHA UK



Pulmonary Hypertension Association UK We are here at the first UK and Ireland PH forum and our chairman Iain and Sue (trustee & patient) are addressing the delegates about the experiences of living with PH.

.....
Join in the conversation online! Tweet us @PHA_UK and like our Facebook page at www.facebook.com/PULHAUK

PH patient launches petition to boost organ donation

A PHA UK member who had a double lung transplant four years ago has launched a petition calling for all UK residents to be automatically placed on the organ donor register.

Natalie Kerr, 34, lives in Adlington, Lancashire and received her life saving double lung transplant four years ago in 2012. She has now created a petition that calls on the government to change the law so that everyone is automatically placed on the register, with the option to remove themselves if they wish. Currently, people have to opt in.

Natalie, who has two children – Brandon, 13 and Isabelle, eight – said: “I am passionate about organ donation as it saved my life. My donor was a 52-year-old lady and she is my hero as she has given me extra time with my children. Sadly, however, I see that many people aren't as lucky as me and don't get this second chance, purely because not enough people are joining the organ donor register. This pushed me to start this petition as I want to use what happened to

me to make a difference.”

At the time of going to print, Natalie's petition already has over 2,500 signatures. The petition is open until 28th October and if it reaches 10,000 signatures, the government will respond. If it reaches 100,000 signatures it will be considered for debate in Parliament.

Natalie added: “When I was placed on the active transplant list I faced a real possibility that I would die if a match wasn't found and I began making plans to say goodbye to my children, which was heart-breaking. Doctors told me one in three people die whilst waiting for a transplant, simply due to the shortage of organs being available. I'm determined to help change this by spreading the word and getting those 10,000 signatures.”

You can sign Natalie's petition by following the link on the PHA UK website.



FRESH LOOK FOR PHA UK WEBSITE

PHA UK has re-launched its website to create a brighter, more welcoming and informative online resource.

It is now easier to access on all devices including smart phones, tablets and PCs and connects better to our social media platforms such as Facebook and Twitter.

It also includes a new 'Browse Aloud' function which means you can click on an icon in the top right-hand corner and the website text will be read aloud to you. This tool can also instantly translate the text into different languages.

Chair of PHA UK Iain Armstrong said: “Our new website has been designed to be as accessible and easy to use as possible. We've highlighted on our home page all the ways to get involved, support, fundraise and find out more about PH and the charity.

“We've also added digital versions of Emphasis magazine to the site – so that people can look at back copies and read them online at any time. And we've made our shared news section more prominent and dynamic too.

“The website can be reviewed and added to on an ongoing basis so if you have any feedback or suggestions for resources you would like to see on there, please get in touch.”

**Visit the PHA UK website at www.phauk.org
Contact office@phauk.org
or on 01709761450 with any feedback or ideas.**



BEST FEET FORWARD IN LONDON MARATHON

Runners from across the country put their best feet forward for PHA UK in the 2016 Virgin London Marathon in April, raising almost £13,000.

There have been 36 marathons to date, and this year saw runner number one million cross the finish line. A big thanks to everyone who took part and who helped raise money for PHA UK.

If you would like to find out more about running for PHA UK in other marathon events, please email applications@pha.org or call the office on 01709 761450.



PHA UK supports welfare benefits campaign

PHA UK is backing a campaign to encourage more people in financial hardship access the welfare support available to them.

The Benefits Awareness Campaign has been launched by Turn2us following their recent research which shows almost half of low income households are not claiming the welfare benefits and tax credits they could be entitled to.

The research has also shown that a quarter of people with disabilities feel recent welfare benefit changes have made it too difficult to apply.

Simon Hopkins, Chief Executive of Turn2us said: *"Shockingly around £15bn in welfare support still goes unclaimed every year, and as our findings show, people often feel that benefits simply aren't for them. Through our campaign, we want to show that financial hardship can happen for many different reasons and could affect anyone at any time in their lives."*

"Welfare benefits exist to provide a vital source of support for people in need, including those who are in-work, and as our research highlights, these can make a positive difference in paying for basic life essentials."

Through the campaign, Turn2us is urging anyone in need to use its free and confidential Benefits Calculator at Turn2us.org.uk to see what they could be entitled to and how to make a claim. The website also features information on benefits and other help for a range of different circumstances.

PHA UK is a partner of Turn2us, which a national charity dedicated to helping people in financial hardship – our members can access their free specialist services and advice via the PHA UK website link.

For more information about the campaign, please visit Turn2us.org.uk/BenefitsAware.

NATALIE'S BIG LEAP FOR GRANDMA

Natalie Ashe from Southport took part in her first ever skydive in memory of her grandma, raising £1,500. Here, she shares her experience of taking on the challenge.

"My Nan, Jennifer Ashe, died in January 2016 following a long battle with PHA. I noticed that when talking about her condition, few people had actually heard of it. I felt compelled to do something to raise awareness and at the same, raise funds to support the charity that does so much amazing work. One of my friends suggested a sponsored skydive. To say I wasn't overwhelmingly keen about the idea initially is an understatement but in early April as I sat with my legs dangling out of a plane at 15,000 feet above Lancashire, I realised that there was no way back. I felt a combination of excitement combined with total unadulterated fear and panic! Fortunately, I wasn't alone as strapped to my back was Chris,

a veteran skydiver. I discovered over the next 60 seconds as I fell to earth at 125mph how a tandem skydive is an easy and enjoyable way to experience the thrills of skydiving without having to learn how. The exhilarating freefall combined with the peace and tranquillity of the parachute ride makes Tandem skydiving a unique experience.

The skydive was unquestionably one of the most exciting moments in my life – the build-up, the jump and the aftermath. That said, it was never lost on me why I did it – and I was so pleased that I could raise money for a cause as amazing as PHA. Friends were immensely generous and the final amount was £1500.

I'm grateful to all those who helped me. My family and friends who donated, the 'Black Nights' skydiving team who organise charity jumps and PHA for doing so much good for so many, with so little."



When others can't see *your pain*

As well as being a little-known disease, PH also tends not to have any obvious visible symptoms, meaning many patients face the frustration of having to live with an 'invisible illness' which people can't see so don't always take seriously. But can having a hidden condition sometimes be a good thing too? *Mary Ferguson* considers both sides, overleaf...



Just because pain can't be seen, it doesn't mean it's not hurting. And for some, having to justify their illness to those who can't see any obvious symptoms can be embarrassing and frustrating.

As well as PH, there are many other chronic and acute conditions that often fall under the umbrella term of 'invisible illnesses'. Those with MS, mental illnesses, fibromyalgia and some types of cancer - amongst others - can all struggle with similar judgements and assumptions.

Clinician Professor Janelle York has spent years researching chronic respiratory conditions, including pulmonary hypertension. She told Emphasis: "My research has shown that people living with PH describe it as 'living with an invisible illness'.

"Patients have described how people

- family, friends and strangers - often comment on how well they look but they are in fact feeling very poorly, or putting all their energy into today, but it will take many days to recover. This has often led to feelings of frustration at trying to explain their condition."

Maritess Dunn, of Tiptree in Essex, was diagnosed with PH in 2008 and says although she sometimes enjoys being able to hide her illness from the world, she often faces difficulties because her symptoms can't be seen.

The 25-year-old, known as Tess to her friends, said: "People tend to judge me because I don't look ill and it drives

me mad. If I'm in a bad mood, I can get really irritated."

She said she often faces difficulties when parking her car in a disabled bay, with people being quick to judge on appearance.

"I drive a red mini with tinted windows, and when I park in a disabled space I'm often tackled about it because I don't look like a 'typical' disabled driver. People will make comments like 'that space is for disabled people you know', so I have to point out that I am. Sometimes I try and explain my illness but people are often so confrontational that I end up just walking away."



Maritess Dunn

One experience with a parking attendant soon after being diagnosed shook Tess at a time when she felt particularly vulnerable.

"The attendant didn't believe I was entitled to a disability badge and even when I showed him my photographic proof he declared the photo didn't look like me and gave me a ticket. I was 19, recently diagnosed, and told him I was upset with how he was treating me as having the illness was bad enough. His response was to say my 'sob story' sounded 'well-rehearsed' and I was devastated by it."

Tess also sometimes faces difficulties when she is in restaurants and asks to use the disabled toilet, as the staff tend to assume she is well. She has even been told 'you're young, you can walk upstairs to the main toilets'.

She carries a badge that identifies her as a person with a heart condition and she does sometimes show it to people, but mostly tries to avoid difficult situations by planning and communicating ahead.

“People tend to judge me because I don't look ill and it drives me mad.”

For example, when she goes on holiday, Tess emails the hotel and airline ahead to request disability access, and always warns them that she doesn't look ill, so that she is not tackled upon arrival. This, she says, can save confrontation and embarrassment.

But despite the frustrations that come with having an invisible illness, Tess admits that it can also be very positive.

"It's really important to me that I'm able to go out and get on with



Sarah Marshall

my life and not 'looking' ill can help me do that. I can get dressed up, go out clubbing, and not stand out as someone with a disability. I don't want to be known as 'Tess with the heart condition' and not looking ill helps. I want to be known as Tess who is studying for a masters, pursuing her love of music, getting married and getting on with her life."

When PH patient Sarah Marshall from Banbury was told earlier this year that she needed to take oxygen, one of her worries was that her illness would become more visible to people.

She said: "Even though I use a mobility scooter, before I had the oxygen I liked the fact that I could sit in a restaurant or pub and not look ill. People look at me sometimes on the scooter because I don't look like someone who should use one, so those times of not looking ill were important."

"I was worried that by wearing the oxygen people would stare at me, and yes, people do look but when they stare I just smile at them and carry on. I have nothing to be ashamed of. Sometimes little children will see it and ask what is wrong with me and I will just tell them my heart and lungs don't work properly."

"However, although it's nice not to 'look ill' sometimes, it can also be a positive thing when it's obvious something is wrong with you. People opening doors, giving up their seat or letting you use the toilet before them - without you having to ask - can be helpful, especially when you're having a bad day."

In America, an 'Invisible Illness

“Those times of not looking ill were important.”

Awareness Week' aims to put diseases like PH under a public spotlight, and although there is currently nothing similar in the UK, there are individuals who battle to raise awareness.

Sam Cleasby lives in Sheffield and suffers from ulcerative colitis, which like PH, also presents no obvious visible symptoms. In February 2015 she wrote an open letter on her blog to the woman who tutted at her for using a disabled toilet, which went viral, being seen by over two million people. As a result, Sam launched a campaign called More Than Meets the Eye to raise awareness of invisible illnesses and disabilities.

In an article for The Metro newspaper, she wrote: "Raising awareness of invisible disabilities is so important. Those who are judging think they are defending the rights of the 'genuinely' disabled but in reality they are just making life a lot more difficult for people already fighting a battle with their health." ●

What do you think?

Is having an 'invisible illness' positive or negative, and what have your experiences been?
Contact us at editor@phauk.org

At PHA UK, we have car stickers that can be used to tell people you have a medical condition that is not obvious. If you would like a sticker, please contact us.

TURN2US
FIGHTING UK POVERTY

STRUGGLING WITH MONEY?

► Find out if you could access welfare benefits, charitable grants and other support that you might be missing out on.

TURN2US.ORG.UK



PHA UK members can also use the Turn2us Benefits Calculator and Grants Search tool via **www.phauk.org**

Turn2us is a trading name for Elizabeth Finn Care. Elizabeth Finn Care is a charity registered in England and Wales No: 207812; and in Scotland No: SC040987.

Why life is **for living**

When Kathryn Graham from Hertfordshire was diagnosed with pulmonary arterial hypertension she began a blog to help herself make sense of the illness.



Her newly-discovered passion for writing then led to the publication of her own book, *Life is for the Living*, which she penned to raise awareness of PH and help others facing similar circumstances. Here, Kathryn talks about how becoming an author has given her a new direction in life.

"I read with interest an article in a previous issue of *Emphasis* about the therapeutic benefits of writing. It struck a chord with me, as after being diagnosed with pulmonary arterial hypertension in 2010 I started a blog, where I wrote regularly about my PH journey. I wanted to keep a diary because so many things were happening health-wise and it also helped me to write down my thoughts and feelings.

I was referred for a heart and double lung transplant in 2011 and around this time found that other PH patients were reading my blog and that it was beginning to help others.

Through my blog I started campaigning to raise awareness of PH as it frustrated me that people didn't understand the illness properly. I desperately wanted people to know about it.

My campaign gathered momentum as I faced a long wait for my transplant due to needing three organs - with a chronic shortage of organ donors.

Writing my blog led me to speak in the House of Commons about living with PH and waiting for a transplant, and my local newspapers and radio stations followed my story and gave me many opportunities to speak about these issues. I was also featured on the

national ITV news, talking about PH and waiting for a transplant.

My blog had become a hugely positive thing for me living in such difficult circumstances and I found writing a real therapy during this time.

Eventually, I received my heart and double lung transplant in 2013. Once again writing helped me through the difficult recovery period. Receiving my transplant fuelled more media attention and more chances to speak up about PH and organ donation. And post-transplant, I wrote a few articles that were accepted for publication by national magazines.

Undertaking this gave me a sense of satisfaction, especially to see them published. I even started a writing course so I could write about other topics, however, I couldn't stop thinking about writing a book.

Although I'd always wanted to write a book I found myself writing one about something I'd never anticipated: a book about the shock of being diagnosed and living with a rare disease that no-one understood; a story of a long wait for a heart and double lung transplant and a story of hope and miracles.

I began writing the book in 2014 and 18 months later I self-published my story '*Life is for the Living*'. It was a very therapeutic process, and also a steep learning curve to experience the whole sequence of writing, redrafting, editing and self-publishing a book.

I hope it helps others facing similar circumstances and that it helps to raise awareness of both PH and organ

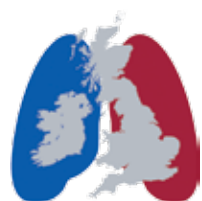
donation. So far quite a few PH patients have read my book and have given good feedback on how much of it resonates with them and what they face every day. **One PH patient even purchased eight copies to give out to family and friends so they would understand what she lives and copes with every day, and someone else purchased a set of ten books for their book club, which had all the members discussing PH and organ donation.**

My writing isn't done yet - I still continue my blog, as there is so much to do to raise awareness of PH and organ donation. I write a garden blog too and I'm planning more magazine articles to write on PH and organ donation. The book bug has struck again too - I've already started my next one, this time something for dog lovers.

From being forced to give up my work as a primary teacher because of my health, which was a big heartbreak at the time, I can honestly say I have a new direction in life. When people ask me what I do, I now say, 'I'm a writer and author.' Writing for therapy has opened up a whole new career for me." ●

Profits from *Life is for the Living* are being split between the four charities which have supported Kathryn - PHA UK, Papworth PH Matters Support Group, Papworth Transplant Support Group and Papworth Hospital Charity. The book is available on Amazon priced at £8.99 (Kindle edition £3.99)

Read more about Kathryn and her writing via her website: **www.kaggraham.wix.com/kathryngrahamauthor**



THE NATIONAL COHORT STUDY OF IDIOPATHIC AND HERITABLE PAH

We are looking for Patients with Idiopathic Pulmonary Arterial Hypertension aged at least 16yrs

The aim of this study is to set up a UK and Ireland cohort of patients with idiopathic and heritable pulmonary arterial hypertension (PAH) for research into the causes and potential treatments of this condition.

What will happen to me if I take part?

- You will be reviewed at your routine clinic appointment at your PAH centre
- Research bloods and urine will be collected
- We will record the results of the various tests or procedures that you have undergone as part of your routine clinical care
- A research nurse will complete an epidemiology questionnaire with you
- No extra hospital visits will be required

For further information and to register your
interest visit www.ipahcohort.com/

Funded by: National Institute of Health Research, Medical Research Council and the British Heart Foundation.

Jointly sponsored by Cambridge University Hospitals NHS Foundation Trust and the University of Cambridge.

UPDATE

Our current
recruitment
total is

460

The number of
samples so far in
our biorepository is

20,000

*A big thank you to
everyone participating
in the study!*

Call for more IPAH patients to take part in study

More patients with IPAH are needed to participate in important research into the causes and potential treatment of this condition.

The National Cohort Study of Idiopathic and Heritable Pulmonary Arterial Hypertension (PAH) is looking for more volunteer participants. More than 460 people diagnosed with IPAH have already signed up to the five year study.

They have consented to have the results of their routine tests and procedures added to a national database; plus give blood and urine samples and answer epidemiology questionnaires.

Research study co-ordinator Carmen Treacy said: "Volunteers play a vital part in contributing to this research study and we already have over 20,000 samples in our biorepository. We'd like to thank everyone who has participated so far and ask others to consider getting involved."

The National Cohort study is funded by the British Heart Foundation, Medical Research Council and the National Institute of Health Research. PHA UK also supports the study and follows its progress with interest.

Around 1,000 people are diagnosed with IPAH in the UK. The study would like to involve as many of those patients as possible. It started in February 2014 and will run for at least five years – hopefully longer with further funding.

Carmen added: "The key objective of our study is to investigate the genetic causes of PAH; to learn more about the mechanisms of the disease and the effects of potential new treatments."

This study involves patients over the age of 16 years with idiopathic and heritable PAH in the UK. The study is also inviting relatives of patients to take part.

Taking part in the study does not involve any extra hospital visits of any kind. All clinical data is gathered as part of patient's routine appointments at their local PAH centre.

.....
**For further information please visit
www.ipahcohort.com or talk to your
clinical team at your next PH Centre
appointment.**
.....

[ACCESS ALL AREAS]



Callum Hogg

.....
“Removing barriers to access is about being communicative and honest.”
.....

As the summer festival season gets underway, calls for better access for people with disabilities and health issues are getting louder. *Mary Ferguson* finds out more.

.....
Soul legend Stevie Wonder has added his voice to the growing campaign for live concerts and music festivals to remove barriers to accessibility for people with disabilities or health conditions.

The international singer, who has been blind since birth, used the Grammy Awards earlier this year to call for better access for disabled people. In a speech the singer said: “We need to make every single thing accessible to every single person with a disability.”

And in many ways the music industry has been making moves to address this issue. But there is still more to be done.

Many PH patients are used to having to plan carefully before attending events, but one of the main problems can be a lack of information available online – which can make this difficult.

Earlier this year, an investigation carried out by disabled music fans on behalf of the campaign group Attitude is Everything (AiE), found that the majority of the 386 venue and festival websites investigated failed to provide adequate information on access for people with disabilities.

The study found a third of the websites contained no access information at all

and less than 20 per cent contained information rated as ‘good’.

The research by AiE also collected first-hand experiences of disabled festival and concert goers and found that some had been ordered out of disabled toilets for taking too long; had their medical equipment such as oxygen packs searched; or been questioned about their need to sit in a supported area because they didn’t have an obvious disability.

Some festivals, however, are getting it right. In 2014, Glastonbury became the first festival to be awarded ‘gold’ status for its accessibility and has since campaigned for other festivals to step up their efforts.

Last year it introduced a dedicated area, which offered somewhere to charge up

electric wheelchairs, as well as alternative therapies and information and support.

Writing in the foreword of the AiE report, Glastonbury organiser Emily Eavis said: “It is vital that all festival goers can easily access clear information about how to buy tickets, what facilities are available onsite and how they can arrange for the necessary support in order to be able to attend.”

Reading, V Festival and Bestival all have separate, accessible campsites for wheelchair users and V Festival also offers secure refrigerators to store medication.

Callum Hogg is director at accessibility experts All In, a consultancy which works with festival organisers to ensure their events can be easily accessed by people with extra needs. He has worked with

Underneath the Stars, a folk festival organised on farmland in Yorkshire this summer, as well as The Lost Carnival, A Day At The Lake, and Just So Festival.

Callum said: “Festivals can be intense experiences, and disabled people can find all of the exclusion, assumptions and prejudice that they might face every day concentrated in these events.

“As someone working in festival access, I know that assumptions about disability and requirements can often create barriers to access but festival organisers are becoming increasingly aware that they have to accommodate all of their potential customers. That inclusion benefits everyone.”

Callum’s advice to people with health considerations and disabilities today

is to do their research – and pursue organisers for information about accessibility and facilities.

“The key to a good experience is doing research. This is why online information, that is comprehensive and useful, is so important. Removing barriers to access is about being communicative and honest.

“If that online information isn’t there or doesn’t cover what you need, look for a contact name and number and get in touch. I feel that today, the majority of organisers are aware of how diverse their audience is, but provision is always going to be best when it is audience led.”

.....
**Are you a live music lover?
What is your experience? Let us know. Email editor@phauk.org**

The impact of PH on relationships



.....
Clinical psychologist *Emma Offord* talks to *Steph Pollard* about the emotional effects of PH on partners.

No two relationships are the same and the way two people work out how they live their lives together varies widely.

External influences affect their partnership too. Some couples go through many challenging experiences in their life cycle – working through a range of family, work, health or other personal issues. Others have a much smoother ride, with far fewer bumps in the road.

Plus, whether you are near the beginning of your journey with lots of hopes and dreams ahead of you; or you have been together years and have perhaps raised a family, achieved some of your goals and have careers behind you – every aspect of your situation affects how you may respond together to a new challenge such as a diagnosis of pulmonary hypertension.

Dr Emma Offord, a clinical psychologist who has worked extensively with PH patients and their partners at Papworth Hospital in Cambridge, says: **“No two couples face a diagnosis of PH the same way and the level of disruption it causes to their lives is different for each one.** “If a couple are at the early stage of their relationship, they may have a great many more things to work through in terms of negotiating the

loss or adjustment of shared hopes and expectations for the future.

“Partners who have been together years can face the huge adjustment of having established roles and preferred identities challenged as they are required to review what responsibilities they take on in light of the change in circumstances.”

Emma also says that the adjustment to living with pulmonary hypertension may present very different demands on each couple’s relationship. For example, if this is their first experience of dealing with a chronic health condition there will be a lot of information to take in and lifestyle changes to adapt to. Those who have had other health issues may be more practiced and resourceful in managing PH but may face other pressures of ongoing and multiple health concerns - and the impact of these on their health, well-being, social and financial circumstances.

“These are all generalisations of course,” says Emma, “As we all know every relationship is unique. One thing is for sure though - it is important not to underestimate the emotional impact on the relationship and both partners.”

Partners, like the patient themselves, may feel shocked, confused, even angered or scared by the news. And it’s

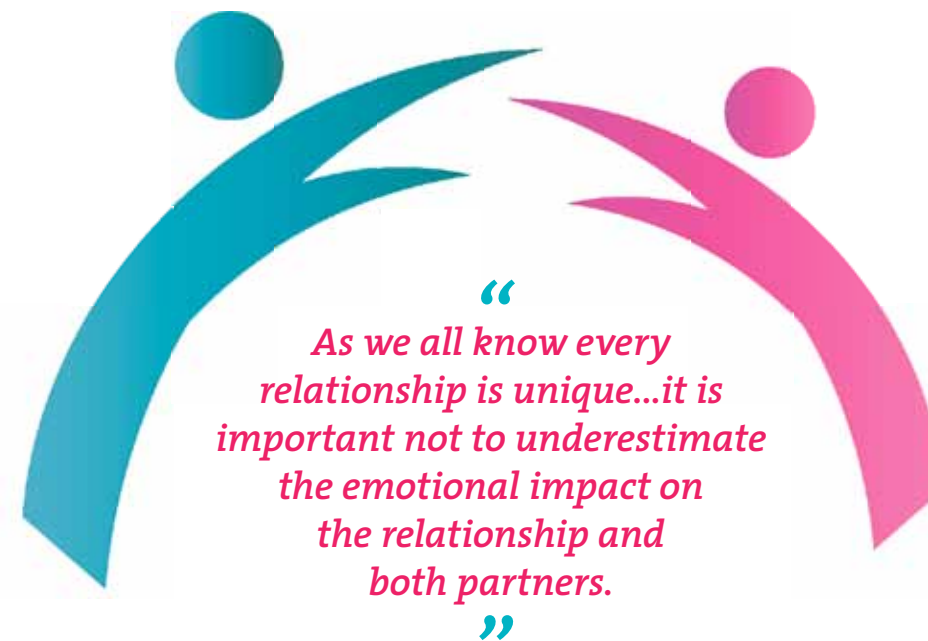
important for partners to acknowledge their emotions – the person with PH is obviously the focus of everyone’s attention; and is the person the partner loves and cares about – but they must accept they are allowed emotions too.

“It’s important for partners to look after themselves, and be supported to do so. Nurturing their own emotional well-being is important – not only for their own sakes - but how else are they going to be in a good position to support their partner with PH?”

Every relationship is different but Emma says partners shouldn’t think they are the only one who has ever felt in a certain way or had a very human – and imperfect – response to an emotional challenge.

“Sometimes partners with the best intentions can over-compensate and overwhelm the person with PH with their support and care,” says Emma. “They don’t mean to be insensitive, take over or encroach on their partner’s personal space and independence but a desire to ‘fix it’ and play the role of carer can be too much.

“Also there can be complex feelings spurred by trying to make sense of the situation. Feelings of helplessness, even rejection as partners feel ‘outside’ this big new thing in their shared lives can lead to difficult emotional challenges.



“
As we all know every relationship is unique...it is important not to underestimate the emotional impact on the relationship and both partners.
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“And the popular ideal of a family all ‘pulling together’ and facing whatever is thrown at them can also put pressure on partners who may feel ashamed to admit they are basically feeling fed up or out of their depth. This can lead to destructive feelings of failure, guilt and real anxiety.”

Emma stresses that it’s very important to remember that all relationships between two people are not easy and sweet-natured all the time. Couples facing very ordinary day-to-day challenges can easily fall out over trivial things like the shopping or where to put things in the kitchen cupboards. There’s no reason why having a serious illness should suddenly make your relationship perfect and either of you ‘wonder woman’ or ‘superman’.

“As always communication is key,” says Emma. **“It is easier said than done but its best to be open and talk directly to each other about what support you’d like, rather than get annoyed and grumble about what your partner’s not doing. For example, asking them to carry**

a heavy bag rather than hoping they’ll notice you are struggling with it.”

It’s also a good idea to maintain aspects of ‘normal life’ you’d both like to keep. You may need to make adjustments, but try to work out how you can carry on doing what you enjoyed before, within your new ‘norm’. Try not to throw out or diminish important aspects of your lifestyle in the face of this new challenge. Try to work out how you can positively review and pursue your shared and separate interests.

Emma also urges people not to hesitate to draw on the support networks of close family and friends; to be proactive and ask for help to share out some of the new and changing responsibilities. Don’t just keep it locked within the relationship.

With respect to intimacy, a serious condition like PH can both physically alter the body – with things like bloatedness, skin tone and texture, fitness and even IV therapy – and it can also affect a person’s feelings about themselves, their own body image and

self-esteem. Partners can feel worried, protective and desperately unsure of new boundaries; or thrown by new perceptions of themselves as carer rather than partner.

“It really is best to not let these feelings go underground,” says Emma. “Difficult though it may be for many couples to talk about them, unspoken questions and buried feelings can damage and distress a relationship. Relationships need nourishing and they thrive on understanding and honesty. If couples need help in this, and any other areas, it’s also vital to remember that asking for help is a sign of strength and a positive action rather than any sort of failure.”

Emma often involves partners in talking through emotional issues with individuals with PH. And mediation organisations like Relate are there to support couples facing any sort of difficulties – they are often misconceived as only being there for those who feel close to a breakdown.

In conclusion, partners of people with PH should be kind and compassionate to themselves as well as their partner. And they mustn’t be alarmed or ashamed by the strength of their own reactions which are common and perfectly normal. Partners should forgive themselves for any negative thoughts and feelings and try to see them as reactions to the situation and not their loved one. Most importantly, couples need to talk and seek help and support for each other and/or their relationship if they feel they need it.

Through PHA UK’s relationship with Anxiety UK, PH patients can access informed support from this specialist counselling and support charity. Contact 00844 3329010.

A free guide to relationships and intimacy for people with pulmonary hypertension and their partners called ‘It matters to me’ is available from the PHA UK office on 01709 76145. ●

Clinical psychologist Dr Emma Offord has supported more than 150 people with PH whilst attached to the PH team at Papworth Hospital. She is currently on secondment to Addenbrookes Hospital.

Dr Google will see you now...

Horror stories, scare stories and complete works of fiction – the internet is littered with medical advice which can, at best, be incomplete and inaccurate; and at worst, confusing and dangerous. On the other hand, the internet is an open and freely accessible source of health information for us all. So should we pay any attention to Dr Google? *Steph Pollard* investigates.



Latest research published by the Oxford Internet Survey suggests that nearly two thirds of us use the internet to research health information. Sometimes we're looking for healthy lifestyle advice; other times we're researching a specific illness and its treatment options; and, increasingly, we're checking out our own symptoms online ... for a spot of self-diagnosis.

Doctors and medical professionals are well aware of this growing trend as increasing numbers of patients come to them with a short-list of serious conditions they've found online which they feel match their symptoms – or maybe they don't!

Another recent Australian study by the Queensland University of Technology called 'Dr Google doesn't know best – search engine self-diagnosis and 'cyberchondria' concludes that 'online consultations' can provide misleading results that can do more harm than good. They lead people to dig deeper and deeper until they've reached more and more serious possibilities and concerns about their health.

The key is to remember that the internet is an unregulated space in which anyone can publish a website, set themselves up as an expert, offer advice or write long, detailed comments on a forum. A great deal of the information which pops up when we google a condition is very general, tends to focus on the most extreme prognosis possible and may well state and repeat false, misleading or dangerous information. A lot can be sensationalist. No wonder 'cyberchondria' has become a modern phenomenon.

But, on the other hand, the internet can really be an easily-accessible and instant source of sound, clearly-endorsed information, advice and shared experience. It can provide answers to questions and guidance – day or night – and crucially, point people in need to key services, support groups, organisations or care providers.

In his definitive book 'Medical Information on the Internet', first published more than ten years ago, Robert Kiley stressed the growing need to acknowledge the potential positive impact of the internet as a source of knowledge, as well as guard against the pitfalls and risks.

also mean that patients become much more informed participants in the healthcare process. He concludes in his book: "Although the internet can in no way replace the health professional, used effectively I believe it can enhance the doctor –patient relationship."

There is no sense in doctors and patients denying the existence of the internet. And, it has become increasingly common to "google" everything including questions about the weather, our shopping, the latest news, train times, restaurants – and health conditions. We've all just got to realise that an important part of

.....
The key is to remember that the internet is an unregulated space in which anyone can publish a website, set themselves up as an expert, offer advice or write long, detailed comments on a forum.
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He urged doctors to accept that the web is now part of our lives, suggesting that health professionals have a part to play in helping patients to use it well. He writes: "Directing patients to appropriate sources of information, highlighting the possible dangers of medical misinformation and quackery and introducing the notion that all information should be critically appraised are new responsibilities which the internet imposes on health professionals."

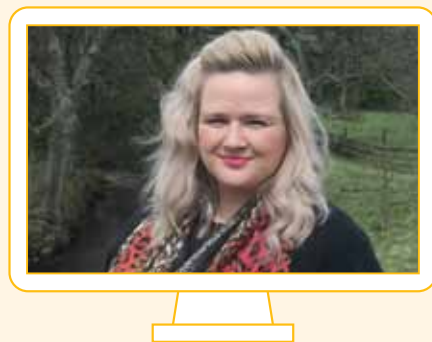
Kiley was optimistic, though, that access to the wealth of information about research, drugs, treatment options, long-term prognosis and health policies on the internet would

being 'internet savvy' – is being savvy about checking our sources, and not believing everything we read just because it is published online.

Most importantly for every PH patient, it is essential that if you do find something online which concerns you – always talk to your doctor or your PH team who know you as well as the condition. There is absolutely no substitute for that personal knowledge.

**READ MICHELLE'S
PERSONAL VIEW...**

Me & Dr Google



COMMITTED internet user *Michelle Tyma* explores the web and sees the good, the bad and the ugly about health information online.

There are many excellent websites providing a really interesting insight into lots of health issues relevant to me and my family. Of course, the NHS was my first thought when googling health and you can access lots of comprehensive information in plain English on www.nhs.uk. There's an A-Z of symptoms, conditions, medicines and treatments and pulmonary hypertension is listed on there, with a link through the PHA UK website.

Through the NHS website I found the NHS Symptom Checker www.nhs.uk/symptom-checker. And I also had a look at Boots' own online doctor website too www.webmd.boots.com. As this website is endorsed by Boots, I was assuming it's not a bad website – trusted brand and all that. So I tried both the NHS and the Boots symptom checkers and personally, I found the NHS one is thorough, encourages you to see your doctor, and explains why the questions being asked are being asked. The Boots Web MD symptom checker also lists many illnesses and gives you information about them – this one got me panicking though when I saw three

types of cancer listed in the very long list of possible ailments my symptoms might be caused by! I'd say the NHS Symptom Checker is far superior, doesn't panic you, gives good advice and explanations.

It's funny how much internet users are actually encouraged to self-diagnose with the number of symptom checkers you come across online. Another 'online doctor' website I found seemed very dodgy. It claimed you were speaking directly to a doctor. You just type in your issue and send your question - then you have to pay a 'deposit' to get an answer sent back to

.....
“It's funny how much internet users are actually encouraged to self-diagnose...”
.....

you. I'd definitely avoid sites like that. It had a UK website address – but I think it was USA based.

In my opinion, it's best to be careful of the many international health information websites that come up on Google because, whilst some may be absolutely fine, it's not as easy to be

sure of their credentials and standards.

I also found it was a good idea to check the date of any information and articles I read, as much of the information on the web is outdated and you can find yourself reading some very old information if you're not careful.

And another thing to be wary of is that Google Images will include photographs which show all levels of severity for any health condition. This can be tough to look at!

If you are trying to seek support and advice from other people with the same condition as you, you'll be able to do that through a host of online forums. Just remember that you'll be reading other people's opinions and their perspectives or understandings of their condition, not necessarily facts. You can literally google any question, and find a conversation or debate about it online. But unfortunately there can be lots of scaremongering and contradiction, especially on entirely open forums like Yahoo Answers. If you want to interact on forums, it seems far better to me to try and find official charity-backed forums, where members can discuss issues and share experiences within a safe, moderated community, such as PHA UK's Facebook group where there are ground rules about respect and so on. ●

Creature comforts

Research shows that pets not only provide great company, but can have significant health benefits too. In this special feature, overleaf, PH patients tell us how their animal friends make a difference in their lives. And *Mary Ferguson* considers the evidence for pet therapy.



Pets can make a big difference to our lives, in many different ways.

As well as alleviating mental health symptoms like depression, stress and anxiety, research suggests that being around animals can also reduce blood pressure and help improve our feelings of well-being.

A study by Cambridge University titled 'Beneficial effects of pet ownership on some aspects of human health and behaviour', found that owning a pet can lead to improvements in general health in as little as one month, with owners found to suffer fewer ailments, such as headaches, colds and hay-fever.

Plus, the study said playing with a pet also helps alleviate depression by elevating levels of serotonin and dopamine. Many of us find that the gentle exercise provided by walking a dog or riding a horse, for example, can be helpful both physically and mentally.

In 2013, the American Heart Association (AHA) released a scientific statement saying that owning a pet may help lower blood pressure, obesity and cholesterol, as well as reducing the risk of heart disease. They also claim that keeping animals can have a positive effect on the body's reactions to stress.

And according to information issued by the Pet Health Council in 2007, looking after an animal brings structure and routine to your day, which can promote feelings of purpose and fulfilment, 'satisfying the human need to nurture'.

Some care homes have recently started introducing chickens to their grounds to boost the wellbeing of

elderly residents and Pets As Therapy (PAT) dogs often visit hospitals, care homes or hospices to provide comfort to patients. A category for 'PAT dog of the year' is even now included at Crufts.

The Pet Health Council also claim that animals can help alleviate loneliness not only by being loyal companions, but by helping you meet new people.

A report published in The Journal of Social Psychology titled 'The role of pet dogs in casual conversations of elderly adults' found that people walking a dog have far more positive encounters with others than those out walking alone, with the pet often providing a topic of conversation.

Although the decision to take on a pet is not one to be taken lightly, it does seem that a lot of evidence points to the fact that animals can be good for our health and lots of fun besides. Here, two PH patients tell us how their dogs make a difference to their lives.

In 2013, the American Heart Association (AHA) released a scientific statement saying that owning a pet may help lower blood pressure, obesity and cholesterol, as well as reducing the risk of heart disease.



Ann Sharp from Devon is the proud owner of 11-year-old Golden Retriever Henry and says she doesn't know what she'd do without him.

"Henry really came into his own when I was diagnosed with PH six years ago. He picked up on my distress from the word go and has increased in sensitivity year by year. He knows, by some amazing instinct, when I am more unwell than usual and will stay by my side providing comfort and love as only such a dog can."

I do not know what I would do without him. How can a dog be so understanding of the human condition? I don't know how, but he is. All this is made more wonderful by the fact that Henry himself is a very poorly dog and has been so from a very young age. He suffers from, amongst other things, Inflammatory Bowel Disease and is on almost as much medication as I am!

The photograph shows Henry in his 'glory days'. Nowadays, medication has reduced his beautiful silky golden locks to a mass of bear-like wooliness, but he is still my special boy."



Gill Luck from Worthing rescued her boxer dog Ollie from the RSPCA three years ago. She helps reduce her stress and anxiety, as well as providing companionship.

"I'm retired due to ill health and living with Chronic Thromboembolic Pulmonary Hypertension and other chronic conditions and without my dog I know that I would be susceptible to depression."

Ollie gives me a reason to get up every morning. She listens to me and can tell if I'm upset. She can even alert others if I have a seizure. Stroking her very quickly reduces stress and anxiety. I am so lucky to have her as my companion."

My husband has to walk her but the three of us often go out with my mobility scooter which is also good for my emotional and physical wellbeing."

We rescued her from the RSPCA when she was two and our children had left home- empty nest syndrome! She's now five and we say that in fact, it was her that rescued us."





When money is tight... what financial support could you be eligible for?

Living with an illness or disability can not only affect you emotionally and physically, but also financially, especially if it means you're unable to work.

It can often be difficult to find out what financial support is available and how to access it.

That's why PHA UK is working with Turn2us, a national charity that helps people in financial hardship in the UK. Turn2us provides a number of free services to help people find support. Here the charity tells us how you can use these services if you're living with pulmonary hypertension (PH) and struggling to make ends meet.

Welfare benefits

There are several welfare benefits to help people living with an illness or disability. You can use the free Turn2us Benefits Calculator, which you can access via the PHA UK website, to check which welfare benefits and other support you might be entitled to, the amounts you should receive and how to make a claim.

Statutory Sick Pay

Statutory Sick Pay (SSP) is money paid to you by your employer if you are sick and unable to work. Most employees get SSP, including part-time

workers, agency workers and those on fixed-term contracts.

You must earn an average of at least £112 per week before tax to qualify. If you do not earn enough, or are self-employed, then you can claim Employment and Support Allowance instead.

SSP is £88.45 per week and is paid in the same way as your wages. You may get more sick pay on top of this depending on your contract of employment.

You can receive SSP for up to 28 weeks of sickness. After that, if you are still unable to work, you can claim Employment and Support Allowance.

If you are off sick and you are not sure whether you can get Statutory Sick Pay, you should consult an experienced adviser. You can use the 'Find an Adviser' tool at Turn2us.org.uk to locate one in your area

Employment and Support Allowance

If you are unable to work because of sickness or disability but do not get Statutory Sick Pay, you may be able to claim Employment and Support Allowance (ESA).

There are two types of ESA. You

can get contributory ESA if you have paid enough national insurance contributions within a certain time. If your income and savings are low enough you may be entitled to income-related ESA.

You may be able to get both types of ESA depending on your circumstances. Both usually require assessments to prove you have limited capacity for work. The amount you might receive depends on which type of ESA you are receiving and other factors including age and whether you live with a partner.



Personal Independence Payment

Personal Independence Payment (PIP) is for people aged 16-64 who have care needs and/or mobility needs. This applies to people living in England, Scotland and Wales – if you live in Northern Ireland, you will claim Disability Living Allowance (DLA) instead.

PIP has two parts – a daily living component looking at your ability to carry out daily activities, and a mobility component looking at your ability to get around independently when you are not at home. Each component has two rates of payment, a standard rate and an enhanced rate.

To see whether you will qualify, you will be assessed by a healthcare professional on daily living and mobility activities, and points are awarded based on how difficult you find each activity. These points determine how much you might receive.

You will need to meet the disability conditions for PIP for a period of three months before making a claim, and be expected to continue to meet them for a further nine months after making the claim. An exception to this if you are terminally ill or transferring on to PIP from DLA.

Most awards of PIP will be for fixed periods, after which you will have to re-apply, in case your needs have increased or decreased over time.

Disability Living Allowance (children)

If you have a child aged under 16 who has extra care needs or mobility needs as a result of a disability, you may be entitled to Disability Living Allowance to help with the extra costs of looking after the child.

DLA (children) is paid at different

rates for mobility and care needs the amount you are paid depends on the level of help the child needs.

To qualify, the child will must meet eligibility conditions and may need to have an assessment to work out what help they need, and they must have had difficulties for three months which are expected to last for at least six months. An exception to this is if the child is terminally ill.

Attendance Allowance

If you are aged 65 and over and have care needs, you may be eligible for Attendance Allowance.

To qualify, you must not be living in a council care home or a hospital. You must usually have had care needs for at least six months before you can receive it, unless you are terminally ill.

Attendance Allowance is paid at two rates depending on how often you need care. The lower rate is £55.10 per week if you need frequent care throughout the day or night, and the higher rate is £82.30 per week if you need frequent care throughout the day and night or if you are terminally ill. It can be paid for a minimum of six months or longer if your care needs continue.

Attendance Allowance does not include a mobility component. However, if you are already getting a DLA or PIP mobility component when you become 65, you can carry on getting it.

Charity grants

If you're struggling financially, you may also be eligible for help from a grant-giving charity.

The free Turn2us Grants Search, available on the PHA UK website,

features over 3,000 charitable funds that give grants and other support to individuals with a number of different needs and circumstances. The Grants Search also includes details of each fund's eligibility criteria and how to apply.

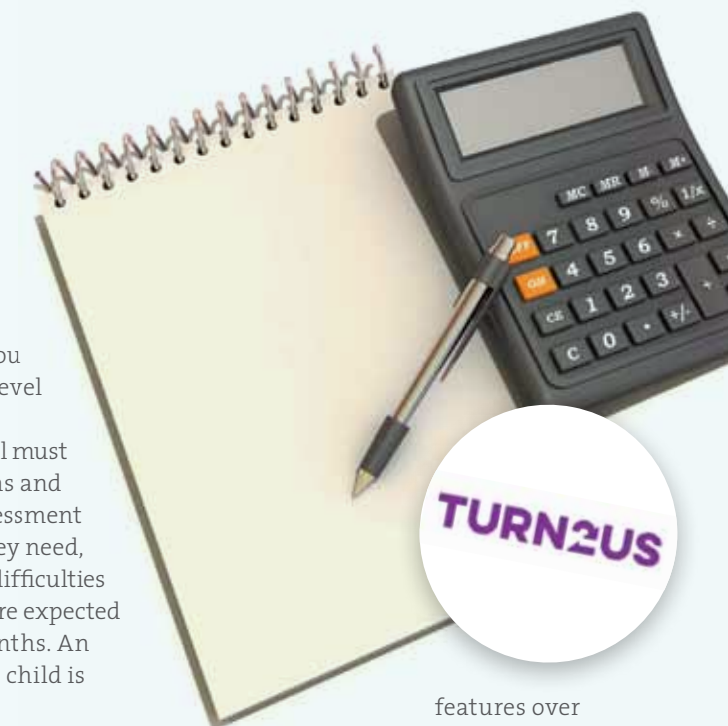
In most cases the funds have been set up to assist people in financial hardship that have something in common, including specific illnesses and disabilities. Many funds also help the partners or children of the people their grants support. Grants may be able to help with bills and other living expenses, or for one-off items including disability equipment.

Other help and information

There are other forms of support that may be available for people living with an illness or disability, for example help with travel and health costs.



The Turn2us website features a section on this help and benefits and grants for people affected by illness and disability, which you can find at www.turn2us.org.uk/your-situation. The website also includes the latest information on upcoming changes to benefits and tax credits.

The free **Turn2us Benefits Calculator** and **Grants Search** are available to use at www.phauk.org



Fundraising **roundup**

Catching up on some of your fantastic fundraising antics from all corners of the UK.

To see more of the fundraising that's taking place for PHA UK, or to publicise your event, join us on Facebook & Twitter  

Two-wheeled challenge for Oli

Keen cyclist Oli Barker from Leeds took on the hills of the Lake District to raise over £1200 for PHA UK. He completed the Fred Whitton Annual Sportive in May, cycling 110 miles and 12,000 feet in hot sunshine. Oli said: "I am supporting PHA UK in memory of the mother of my half-brother and sister, who died a number of years ago as a result of PH. They have done various things since then to raise money and awareness. I've never done an event on this scale before, so decided to take the opportunity to raise money for a great cause."



**£1,316
RAISED**

Punching for PH

Becky Burton from Mold in North Wales took to the ring to take part in a 'pink collar' boxing match to raise £482 for PHA UK, as her youngest sister Emily was diagnosed with pulmonary aortic hypertension last year. She said: "I had never heard of PH before, as I'm sure lots of people haven't. I felt helpless as I couldn't fix Emily as I did when she was little, so thought raising money was the only way I could help. I had never boxed before, but fancied a new challenge as I've already done various running challenges."



**£482
RAISED**

Money from music

Howard Betts from Telford organised a spring concert at his village hall to raise money for PHA UK. The concert featured a jazz band, flautist, guitar player and vocalist and the University of Nottingham a' Capella society, Radio Octave. The event raised over £1,300. Howard and his wife Hilary organised the concert in support of their niece Sarah Marshall, who has PH. Sarah said: "It was a great evening. We got to enjoy some amazing performances - we particularly loved the singers - whilst raising awareness and funds for the PHA UK."



**£1,341
RAISED**

Darts and dominoes

A darts and dominoes competition held at a pub in Northumberland raised £50 for PHA UK. The Pheasant Inn at Kielder Water holds the competition every year, usually alternating the charities that benefit. Landlord Robin Kershaw and his team have chosen to donate to PHA UK for the last few years in support of regular customer Sheena Robinson, who was diagnosed with pulmonary arterial hypertension in 2002. Sheena said: "I think it's great that they raise money for PHA UK - and the competitions are a really good way of raising awareness of the illness too."



**£50
RAISED**

Remembering with love

When newlyweds Marcus and Amanda Dysch of North London got engaged, they requested donations instead of presents, in memory of close friend Victoria Lynn who died of PH in 2003. Friends and family donated £1,452 and the couple were married in March. Marcus said: "PHA UK is a charity that has always been very important to me. Victoria died shortly before her 21st birthday and had always been incredibly brave during her life and did a lot of work for the charity to raise awareness and help others. It is lovely that our celebration has meant others with PH will benefit."



**£1,452
RAISED**

If you have any ideas for raising money for PHA UK visit www.phauk.org. Fundraising mini-packs are also available. And, don't forget to share news of your achievements via our Facebook page or tweet about them tagging @PHA_UK

Don't hide away *this summer*

Senior pharmacist *Neil Hamilton* urges PH patients with hay fever to seek advice on remedies and enjoy the outdoors.



This Spring, we enjoyed all four seasons in one month during April. We had high winds, rain, bright sunshine and even some snow and hail. Now we're in June and for most people, the onset of summer is great news, with long evenings and a chance to get out and enjoy the garden or the countryside.

Any hayfever sufferers won't share my enjoyment of all things hot, sunny and outdoors though. With rising pollen counts come the chance of sneezing, itchy eyes and maybe even hives or prickly heat. These may sound trivial, but in reality are troublesome and on top of other conditions such as PH can cause anything from mild to severe and intense irritation.

Your local pharmacy will be a very good source of advice and remedies to make the summer more bearable for hay-fever sufferers. I would advise that you ask them for help if you are affected. There are a whole range of products on offer, from herbal remedies (widely trusted but will often be untested alongside regular medicines) to tablets, nasal sprays and eye drops.

These medicines fall into three main categories but all work to dampen the body's response to allergic stimulation. Firstly anti-histamines, which block the action of histamine in the body. Histamine is a substance produced and stored in the body. It is released when the body comes into contact with

as chlorphenamine (Piriton®) are highly effective but come with a chance of causing drowsiness. This won't affect everyone but would be a problem for drivers and those needing to work and would be exaggerated further with alcohol. If you are not affected or bothered by the drowsiness, chlorphenamine remains the best choice, particularly for skin reactions. Newer anti-histamines such as loratidine and cetirizine were developed to get around the drowsiness issue. They also offer the advantage of lasting 24 hours with once daily dosing as opposed to up to four times daily chlorphenamine. Other anti-histamines are also available, but would need a prescription as opposed to being readily sold at your pharmacy, usually pretty cheaply. Interactions are rare, and none of these interfere with any specific PH treatments, but when buying any medicines, always check with the pharmacist if it may interact with other things you already take. Anti-histamine creams are often chosen for holiday first aid and may relieve itching caused by bites and stings, but generally tablets are a better option.

If allergy symptoms are localised to the eyes or nose, there are other treatments, which may be best for you. Eye drops, such as sodium cromoglycate (e.g. *Opticrom*®), which



in when they are wearing lenses, but the pharmacist can advise on the best choice for them.

If your main trouble is congestion and incessant sneezing, then a nasal spray is likely to be the best option for you. The sprays for allergic symptoms are generally steroid nasal sprays such as beclomethasone (*Beconase*®) or fluticasone (*Flixonase*®). Steroids are an alternative way of dampening the body's response to allergy and inflammation. It is quite possible that your hayfever is triggered by a particular type of seed or pollen, specific to a certain time of year. Steroid nasal sprays take a few days to reach maximum benefit, so are more of a "preventer" than a "reliever" treatment. Hence, it is important to use these regularly throughout the period of the year when you are most affected.

Some patients using long-term oxygen experience ongoing nasal congestion. This is not really an allergy, but may be helped somewhat by the anti-inflammatory properties of a steroid nasal spray. This is something you can ask your centre about for more information.

To sum up, I'd say that allergies and especially hayfever can be a nuisance, but there are some fairly simple options readily available. Don't be afraid to ask for more advice or information about any of these medicines at your local pharmacy, GP surgery or specialist centre.

I hope we have a great summer of good weather after the mixed up springtime, so don't be kept indoors by the pollen count but instead get out and enjoy the great outdoors, wherever you are! ●

.....
“Hay fever can be a nuisance, but there are some fairly simple options readily available...”
.....

anything that the person is allergic to. It causes the redness and itchy sensations, along with making eyes itchy and watery, nasal congestion and sneezing and even wheeziness when lungs are affected.

Anti-histamines are usually tablets but creams are also available. Older anti-histamine tablets, such

can be bought over the counter, help to flush out the foreign body or pollen, which may be irritating. If used regularly they can help to prevent reactions from being so acute. More potent eye drops can be prescribed if these give inadequate relief. Contact lens wearers would have to avoid putting drops with preservatives



Green Leaf Crew!

GREEN LEAF CREW Q&A EMILY GRAVENSTEDE

Emily Gravenstede is five years old and lives in Burghclere, near Newbury, with her mum Lorna, dad Jeremy and big sister Rachel. Emily was diagnosed with IPAH at three-and-a-half years old, but that doesn't stop her enjoying her favourite summer things which she shares with us here.

Q. What is the best holiday you have been on?

A. St. Lucia.

Q. What is your favourite ice cream flavour?

A. Vanilla.

Q. If you could have any superpower, what would it be?

A. To be invisible.

Q. What's your favourite thing to do at school?

A. Everything, I love school!

Q. What do you like to do at home?

A. Dance, bake, play with my big sister and ride my bike.

Q. What's the best thing about school summer holidays?

A. Getting to jump in the paddling pool.



Emily with her big sister Rachel

Would you like to answer the Green Leaf Q&A? Contact us at editor@phauk.org



YUMMY RASPBERRY COCONUT ICE LOLLIES

Why not try making these easy (but very tasty!) lollies on a hot summer day?

INGREDIENTS:

150g raspberries
4 tbsp icing sugar
450g coconut flavoured Greek-style yogurt

METHOD:

1. Purée raspberries in a food processor along with icing sugar. Sieve to remove the seeds.
2. Spoon half the Greek-style coconut yogurt into a bowl and stir in 2 tbsp of purée so it is stained pink.
3. Spoon into lolly moulds, add the rest of the purée then the rest of the yogurt. Push in lolly sticks and freeze until solid.
4. Enjoy!

This recipe is taken from www.bbcgoodfood.com where you'll find lots more yummy ice lolly ideas!



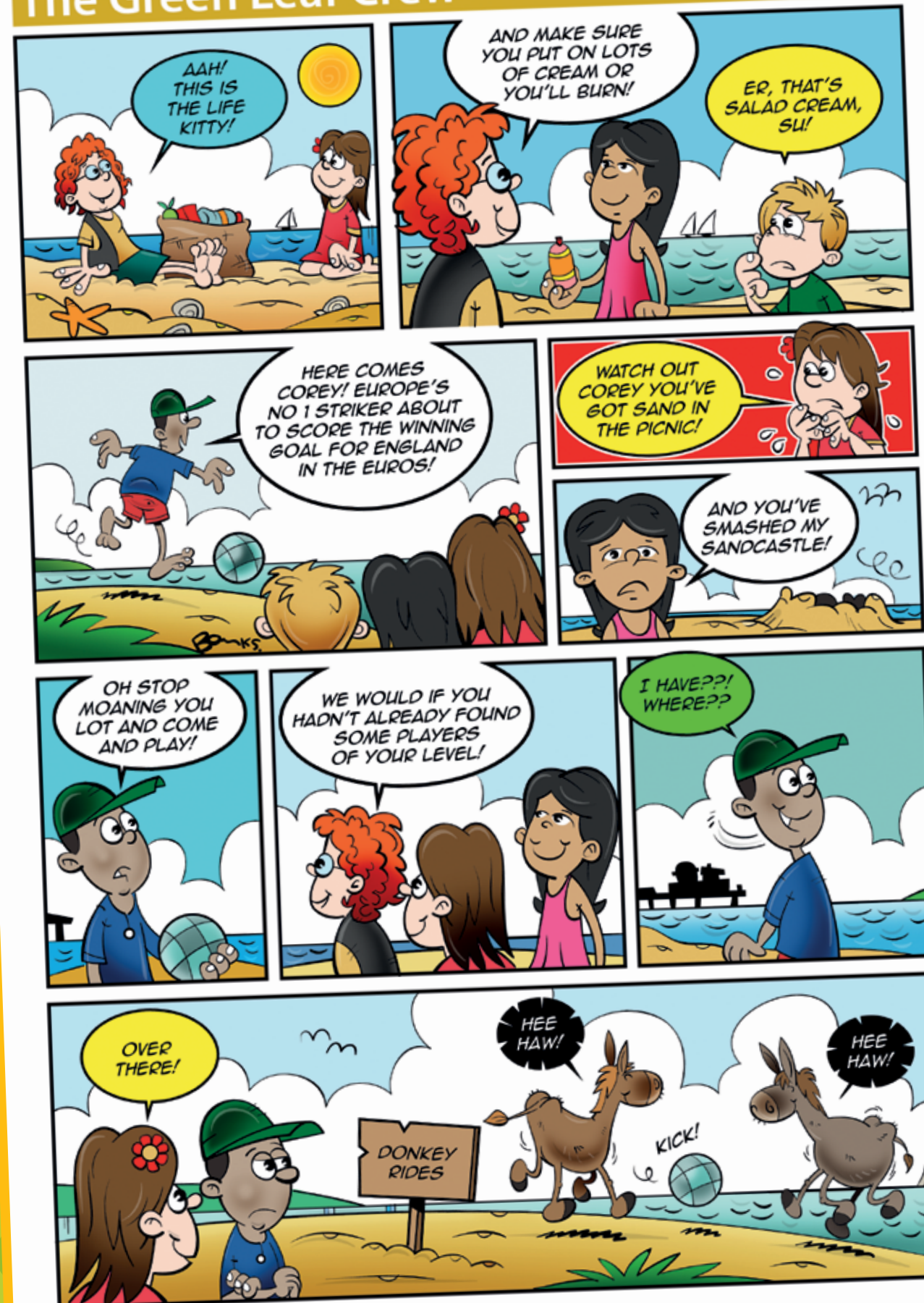
Patch

by David Banks



The Green Leaf Crew

by David Banks



Are you struggling with stress or anxiety?

Help is available to members of PHA UK if you or your family have concerns about your emotional wellbeing

- Dedicated helpline service 0844 332 9010
- Assessment and therapy provision for those who need emotional support
- Training and resources for PHA UK professionals and members

To find out more about how Anxiety UK can support the emotional aspect of having a diagnosis of PH contact us today on **0844 332 9010** or visit **www.anxietyuk.org.uk**



Life after surgery and why I'd do it all again

An operation called a *pulmonary endarterectomy* (PEA) can really improve the quality of life for people with a type of PH called Chronic Thromboembolic Pulmonary Hypertension (CTEPH). Many patients undergo this serious surgery without complications - whilst others can have a rockier ride.

Here, *Patricia Higgins* of Wallsend, Tyne and Wear, shares her experience of going in for surgery and waking up weeks later in intensive care. We'd like to thank Pat for sharing her frank and honest story.

She had a tough time but now leads a full and active life and has nothing but praise for the people who treated her. Read about her journey and why she says she 'would do it all again'.



looked after by the brilliant PAH team at Freeman Hospital, whom I see now every six months. **However, I live a full independent life and am always grateful for that.**

I drive my own manual car. I can walk short distances without any mobility aids. I can even do a six minute walk test now! I cook, clean, look after my husband, my dog and my cat. Obviously climbing, cleaning windows and floors get done by my eldest daughter!

I am also able to go on holiday abroad in the same way as anybody else and join in most activities.

I returned to Papworth in March 2016 to thank Mr David Jenkins and his wonderful staff, for without them I wouldn't still be a wife, a mother, a Grandma and a great Grandma. Without my fantastic family and friends and doctors and nurses my recuperation would have taken a lot longer. These people gave me the strength and courage to recover.

If you have the nerve to have this operation, you CAN recover and live a great life as I do now almost four years later. I would do it all again." ●

"On May 31st 2012 I went into Papworth Hospital for a pulmonary endarterectomy. My surgery was scheduled for the next morning. After kissing my husband I went into theatre.

This is how I remember things after that. I woke to find that my chest wasn't sore, which I was surprised about because I had been told it would be very painful the day after. Then I realised I had machines all around attached to me and they were beeping. I was in ICU.

My husband Davie came into see me and the first thing I asked about was my little dog. He said she was fine but my family wasn't! He said they had all took turns talking to me for ten weeks as I had been put into an induced coma.

During this time, of which I have no memory, I had had lots of problems, including infection, kidney failure and a bleed on the brain. Obviously I knew nothing of this and remember very little, luckily.

As I grew stronger - and more belligerent - I was transferred to the Freeman Hospital in Newcastle near my home. I recall little of that journey and things went blank again. I was transferred in ICU straight away when I got there.

But I made a good recovery and was then sent to Ward 29 to recuperate and to learn how to walk again. This is where I found my toes were black! It turns out the ECMO machine that was keeping me alive in Papworth couldn't quite oxygenate all my extremities so my toes were starved of oxygen. They had turned gangrenous and painful. There was nothing for it - they had to be amputated. Six days later this happened.

Once again I had to learn to walk, but I only stayed in hospital for a week. Not bad for a double amputee!

Overall, I would say my PEA surgery was a partial success, as I still have to take Sildenafil and I continue to be

As with any surgical intervention or medical treatment, patients may face risks, potential extra challenges and vastly different recovery times. If you are considering PEA, and have any queries raised by about Pat's story, please talk to your PH team at your local PH centre and/or Papworth Hospital.

theinterview



PH Clinical Nurse Specialist **WENDY GIN-SING**

in conversation with
Deborah Wain

Wendy Gin-Sing has been caring for patients with pulmonary hypertension for 20 years and has been a specialist nurse with the PH service at Hammersmith Hospital, in London, since 2000. Together with lead clinician, Dr Simon Gibbs, she has overseen the development of the fast expanding service at the prestigious research and teaching hospital. With a previous background in coronary care and high dependency nursing, Wendy has developed a widely respected expertise in PH. She believes strongly in a holistic approach, aware that chronic conditions affect the lives of both the patient and their family around-the-clock. She has a Master's degree in cardiorespiratory nursing from Imperial College, London, and is currently undertaking a doctorate in healthcare at the capital's King's College.



Wendy is on the Medical Advisory Board for PHA UK, is a member of the Working Group for the Pulmonary Circulation and the Right Ventricle at the European Society of Cardiology and was part of the Curriculum Development Forum for the PH Medical Educational Programme, run by Edge Hill University. Wendy is deputy chair of the PH Professionals Forum, and has taken part in national and international conferences, steering committees and advisory boards. She is a mother of four.

Q. How did your career path lead you to working with PH patients?

A. It was a lucky coincidence. In 2000 I was looking for part-time work during the week as all my children were at school and this was just when Dr Simon Gibbs was realising that it would be good to have a nurse to help manage his PH patients. I had been caring for patients with PH on the coronary care unit at weekends for the past few years and already had some idea about the complex therapies and the holistic care needs of the patients and families. Little did I know that this would lead me to where I am today.

Q. Is there such a thing as a typical working day?

A. Every day is different and rarely goes to plan as there are always unexpected problems that pop up and take precedence. On Mondays there is a busy outpatient clinic at the Hammersmith, with a mixture of follow-up patients and new referrals and, as I can prescribe and undertake physical examinations, I see patients in the same setting as a doctor would. We also have day case patients every day, planned inpatients for investigation, and emergency admissions, so I spend quite a lot of time on ward rounds. I get to escape from London and attend the monthly outreach clinics in Bristol and Portsmouth with the PH consultants.

Q. How has the PH service at Hammersmith developed during your time there?

A. When I first started in the role in 2000 we had 35 patients

with PH, the numbers doubled in the first year and have increased every year since with us seeing over 1,200 patients last year. The staff numbers have also grown from just one part-time consultant and nurse to three full-time consultants and nurses, a team of administrative staff to support us and a dedicated research team.

Q. What gives Hammersmith PH Centre its unique identity?

A. Our hospital has several tertiary and quaternary specialist services and we therefore get to see many patients with complex problems and diagnoses. We are very fortunate to have good links with our colleagues in rheumatology, cardiology, respiratory medicine, renal, haematology, obstetrics and gynaecology. We run joint clinics with several of these specialities as well as regular genetics clinics with Professor Richard Trembath.

Q. What's your view of the extent to which treatment of PH has improved over the last 16 years?

A. There have been dramatic improvements – not only in the number of drug therapies that are now available but in the development of multidisciplinary teams to manage the diverse needs of patients. Initially PH therapy was used to keep patients stable while waiting for a transplant, over the last decade a combination of drugs was used to help reach treatment goals and now, in 2016, there is evidence to start a combination of therapies as early as possible to keep patients well for longer. PH has changed over the years from being >>>



theinterview

PH Clinical
Nurse Specialist
WENDY GIN-SING

“Although many of the symptoms of PH are common every patient has their own set of circumstances and need for support throughout their PH journey.”

rapidly progressive to what is now a chronic disease but much more work still needs to be done.

Q. As a champion of a holistic approach to care, how do you think that is best achieved?

A. By good communication and education delivered by a multidisciplinary team. Although many of the symptoms of PH are common every patient has their own set of circumstances and need for support throughout their PH journey. We encourage the involvement of local psychologists, heart failure teams and community nursing teams and recommend that all our patients, and carers, join PHA UK.

Q. You share your expertise with a lot of people. What is the single most important message you would like to get out to the world about PH?

A. Patients with suspected PH should be referred without delay to expert centres so that they can be diagnosed and treated early.

Q. Please tell us about a couple of dates in your diary that you're especially excited about.

A. In October I will be presenting the nurse's views about the international PH guidelines at the European Society of Cardiologists Annual G6 PH Course in Nice. The meeting has representatives from physicians, patients, nurses, industry, healthcare providers and regulatory bodies and it is a good opportunity for networking. We are organising another national study day for healthcare professionals in November. The one last year was very well attended and I have had lots of positive

feedback but, sadly after organising everything, I could not attend as I ended up having my gall bladder out instead. Iain Armstrong, chair of PHA UK, was a star and stepped in to chair the meeting well but it will be nice to actually make it this time.

Q. What is the most rewarding aspect of your job?

A. Hopefully making a difference and helping support patients with PH and their carers. I have personal experience both as a patient and as a close relative when it comes to chronic disease management. This has given me an insight as to how essential specialist teams can be in understanding and coping with the disease as well as the difference a friendly face can make when you are stressed and anxious. A simple 'thank you' can be very rewarding and makes up for all the extra hours at work and fights with NHS management..

Q. And finally, how do you relax when not working?

A. I keep busy. I am in the fifth year of a part-time doctorate in Healthcare and currently recruiting patients to my research which is investigating the factors that influence decision making when patients are offered intravenous prostanoid infusions. I also use my leave to attend international PH meetings and conferences, these are a great opportunity to network with other specialist nurses from around the world and are often inspiring and an ideal opportunity to share best practice. On a Sunday, I like nothing better than to cook a big roast dinner, or barbeque in the summer, for my family which includes my husband, four grown-up children, their partners and my niece, who lives with us. We have a big table and sit around it for hours eating, chatting and putting the world to rights. ●

Tell your story when claiming Disability Living Allowance for children

Benefits Advisor

With Shaun Clayton

Although Personal Independence Payments have replaced Disability Living Allowance for adults, children with PH are still able to receive DLA.

To be eligible, your child must be under 16 years old and need extra looking after, or have walking difficulties. To claim DLA, every child must be assessed as requiring more care and attention than other children of a similar age. You can claim DLA for a child as long as you look after them as if you're their 'parent' (so guardians, grandparents, foster parents and even older brothers are able to claim if they fit this role.)

“When you are applying, don't be afraid to tell your story. You need to give them as much information as you can to make it as difficult as possible for them to say no.”

Like PIP, there are two different components of the benefit; care and mobility. Both are assessed separately so you can receive either or both components.

The care component is split into a lowest rate (£21.55 a week), a middle rate (£54.45 a week) and the highest rate (£81.30). Mobility is split into a lower rate (£21.55) and higher rate (£56.75). So the maximum you are able to claim through DLA is £139.75 a week.

When you are applying, don't be afraid to tell your story. You need to give them as much information as you can about your child and their situation to make it as difficult as possible for them to say no.

Unlike PIP applications, which are now very prescriptive and have little room for additional information, your descriptive evidence can really count in a DLA application.

The DLA decision maker is not medically qualified. They may wish to contact the child's medical specialist responsible for their healthcare, or any schools or nurseries they attend. This benefit is not counted as income for other benefits and tax credits. The funds are designed to help the child and they will not impact any benefits your family may already be receiving. You can make your claim for PIP either by calling 0345 712 3456 or going online to www.gov.uk/disability-living-allowance-children/how-to-claim You will need to complete the application forms and post them back. Once you have submitted the claim, you should get a reply within two weeks to let you know it has been received, and a decision should then be made within three months. Payments will be backdated to the date the claim was made.

If your claim is turned down, or paid at a rate you don't agree with, you are able to appeal, but must do so within one month. For further advice on DLA or making a claim, visit www.gov.uk/disability-living-allowance-children/overview ●

Shaun will look at different aspects of the benefits system in future issues of Emphasis. If you would like a particular subject covered please e-mail editor@phauk.org

Sun, sea & sensible planning

Holiday season is here and however and wherever you take your break, it's important to be well prepared for travelling.

Location, location, location

If you or your child has PH, the first thing to consider when planning a holiday is the location. Whether you decide to stay in the UK or travel abroad, there are lots of things to check before choosing the best destination for you.

For example, how far a journey are you comfortable with, how are you going to get there and when would be the best time to make your journey? What temperature is ideal for you? It's nice to get a bit of sun but extreme heat can make people with PH feel tired and breathless. You may also want to consider your proximity to a hospital, in case you need emergency treatment.

You may also want to take a close look at your hotel or room – how easy is it to get to? Is there a lift? Most accessibility information for hotels can be found on their website but it's always good to give them a quick call to check too.

Many people find that booking through a travel agent can be useful, as you then have one point of contact for questions about any aspect of your holiday.

ABROAD?

HOME?

Breathe easy

Travelling by air with oxygen will require a fair amount of additional planning and unfortunately, due to tightening regulations and security, it has become more difficult to organise your own oxygen for flights.

Obtaining expert help is essential and fortunately, companies specialising in oxygen, like Pure O2, can help by supplying PH patients with portable concentrators for flights that don't provide oxygen themselves. Pure O2 can also supply oxygen to use whilst holidaying in the UK, or for travel abroad by other means.

They offer a rental service, delivering the unit a few days before departure to give you time to get to know it, and all hire fees are free of VAT. Also, should you wish to purchase equipment, Pure O2 offer this service as well. They also provide emergency backup services for all patients travelling abroad.

Adele Heath, one of the directors at Pure O2, said: "It's really important, if you are planning to fly, that you seek advice from a professionally company like ours to ensure you are prepared. We have good relationships with all the major airlines and with over 16 years of experience, there's not much we don't know about flying or travelling with oxygen."

As well as offering advice and organising rentals and sales, Pure O2 will liaise with the airline should any problem occur. They offer expert travel assistant on all matters, to help take the stress out of holidaying on oxygen.

They can be contacted on **0161 747 26 17** or via their website, **www.healthoxygen.com**

If you do decide to fly then ultimately, our advice at PHA UK is to check with the airline before booking a flight to avoid wasting money.



Choosing to cruise

Cruising has always been a popular option for people with pulmonary hypertension and has become even more attractive now as a result of increasing difficulties associated with organising oxygen for flights.

Again, if you rely on oxygen to manage your PH, it's important to plan ahead and make sure you have your supply covered for your holiday before you even set off.

Omega Advanced Aeromedical offers a wide range of support services to help people with oxygen requirements plan worry-free holidays, and the company's founder, Bill Quantrill, says they are seeing an increasing number of people with PH choose to cruise instead of fly.

He told Emphasis: *"Cruises are so well-prepared to support passengers with any health issues and it's the method of travel we now recommend for people who need to take an oxygen concentrator and a supply of oxygen cylinders along with them."*

Omega Advanced Aeromedical work in partnership with all the cruise liners and can deliver all the necessary equipment to people's cabins ready for arrival.

"The equipment is all compatible with on-board electricity supplies and because there are such strict rules about the storage of gas and liquid oxygen – due to it being so flammable – we also liaise directly with stewards to ensure oxygen cylinders are kept in a safe storage place until they are needed."

Bill's team will endeavour to meet and greet wherever possible, at ports in Southampton, Dover and Harwich, and will discuss all specialist needs.

Omega Advanced Aeromedical can also arrange for customised on-board scooters, chairs and hoists. They can be contacted on **01273 308 176** or at **info@omegaoxygen.com**

If you are travelling to America, their US office can be contacted on **info@aeromedic.com**



If you use mobility equipment and choose to cruise instead of fly, follow these top tips from *Alison Smith* of accessible cruising experts *Mobility At Sea*:

WATCH OUT FOR TENDER PORTS

This is where the ship will anchor off shore and use a small vessel to carry passengers to and from shore. As your safety is paramount, those with reduced mobility may not be permitted to board the tender if considered unsafe to do so. Please ensure you are aware of the cruise operator's tender policy before you book to avoid any disappointment.

GET TO KNOW YOUR EQUIPMENT

All mobility equipment may vary slightly. You should take the time to get to know yours, especially if it is a model you haven't used previously.

DON'T LEAVE EQUIPMENT OUTSIDE YOUR CABIN

If you use a mobility scooter, power chair or wheelchair, leaving it unattended outside your cabin means there is a high chance that housekeeping will remove it and store it (adhering to health and safety regulations). Finding exactly where it went can be time-consuming and frustrating.

CHARGING YOUR MOBILITY EQUIPMENT

In order for your equipment to work at its optimum condition, ensure you charge each item for as long as possible (minimum eight hours). It is easy to underestimate how often you use or travel in a single day – it can be miles and miles. Please also ensure that the charger is plugged into the correct socket otherwise charging time may be effected.

ACCESSIBLE CABINS AND MOBILITY SCOOTERS OR POWER CHAIRS

Regular cabins have restricted access into the stateroom due to narrow cabin doors and walkways. The strict fire and safety regulations mean that mobility equipment cannot be stored in corridors. It is paramount that an accessible cabin is booked if you require a mobility scooter or power chair – we can offer alternatives if an accessible cabin is not available including the Di Blasi R30 folding mobility scooter and Cruiser 12A foldable power chair. However, if you are contemplating this then please check permission with the cruise operator.

TRY NOT TO WORRY

If you're not completely confident with any embarking/disembarking procedures whilst using your equipment, the ship's crew will assist you. They are there to help!

Mobility At Sea provide rental of mobility equipment and everyday living aids to help people enjoy cruise holidays. They can be contacted on **0800 328 1699** or via their website, **www.mobilityatsea.co.uk**



Insurance

Travel insurance can be another headache for people with PH. It hardly seems fair, but just having a 'pre-existing condition' - as health issues like PH are called in insurance speak - can make it harder to find insurance cover, and much more expensive. In fact, most standard policies do not cover you if you already have a medical condition. In addition, because PH is such a rare condition, the few standard policies that do exist for people who already have medical conditions will still not cover PH. Because of this, if you have PH, you should be prepared for travel insurance to cost more. PHA UK recommend the following three insurance companies for PH patients travelling abroad:

Staysure - 0800 033 4902 www.staysure.co.uk
Able2travel - 0845 839 9345 www.able2travel.com
Freedom Travel - 0870 774 3760 www.freedominsure.co.uk

Jonathan Buttery, director of Able2travel, warns of the importance of checking the benefits of the policy meet your needs. He said: "Cheaper travel insurance policies are generally cheaper for a reason. Particularly check that the cancellation amount is adequate for the cost of your holiday and that you have enough medical cover. Costs for medical treatment in places like the USA can easily cost hundreds of thousands of pounds. Also check that any medication or aids are included in cover - some policies don't cover things like prescribed medication or walking aids if they are lost or damaged while you are on holiday."

Shaun Clayton, director of membership support at PHA UK, added: "Because PH is often diagnosed as a secondary condition, it seems there are only now a handful of companies who will insure. Insurance can be so dear, sometimes costing even more than the holiday itself, so we always recommend you check insurance costs before booking the holiday."

The British Insurance Brokers' Association (BIBA) can also provide you with a list of insurers who cover people with PH. For more details, visit www.biba.org.uk or phone the helpline on 0870 950 1790.

Medication and treatment

A key part of your pre-holiday checklist should include remembering to order enough medication to cover the time you are away.

PH patients who manage their condition with prostaglandins need to make sure they have plenty of the special equipment and kit required to administer the drug intravenously throughout their vacation too. If you are planning to fly, there are things you may need to consider such as obtaining a letter from your GP or specialist centre that confirms you need to take the equipment on the plane.

You may also need a 'fit-to-fly' letter to confirm that you are well enough to travel by air. It's best to ask your GP or PH specialist for these well in advance of travelling. If you are travelling with others, it can also be a good idea to distribute your supplies of medication into more than one hold bag, and to keep some with you in your hand luggage, in case hold bags go missing. PHA UK have produced a quick reference guide called Travelling with PH. This contains some tips for preparing for a holiday and translations of handy phrases relevant to PH and its treatment. This is contained in the members' pack that is given to all members, and additional copies can be requested by calling 01709 761450 or emailing office@phauk.org

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ME & MY JOB

Welcome to our regular column where PH professionals tell us more about themselves and their work.

NAME: Lisa Martin.

PLACE OF WORK: The Pulmonary Vascular Disease Unit at Royal Hallamshire Hospital in Sheffield.

JOB: Ward Sister.

HOW LONG HAVE YOU WORKED WITH PH PATIENTS?: I have worked with PH patients for the last 19 years in various roles - staff nurse, clinical nurse specialist in PH and ward sister for the last nine months.

BEST THING ABOUT YOUR JOB: You never know what direction your day is going to take or what new challenges you will face when you walk on the ward. I enjoy meeting new patients then getting to know them and trying to help them through their PH journey. This can be a struggle for many mentally, physically and emotionally - and for their families and carers. At times we have a good cry with them too. (Well, we are human!) We have many patients who visit the unit every three to four months and they enjoy being met by a familiar face. It can make them feel relaxed ready for their tests. It's also good for them to get to know other PH patients and develop a support network.

FIRST THING YOU DO WHEN YOU GET TO WORK: After getting changed into my uniform, I usually have a catch-up with my manager Paul Sephton about what is happening on the ward.

WHAT'S ON YOUR DESK: Sheffield United mug, lucky teddy, bag of pear drops... I share a desk with Paul and he is VERY tidy! Everything has a place so my mess usually ends up thrown in my draw out of view!

FAVOURITE SANDWICH: Warm chicken and stuffing in a crusty roll from Lyn's pantry across from the hospital. Yummy.

WHAT DO YOU LIKE TO DO OUTSIDE WORK?: I spend most of my time with my 12 year old daughter and husband and visiting family. I also have to do the usual mundane tasks such as cleaning, shopping and washing of course and in the evening I love to relax with a cold glass of vino and a spot of Masterchef. I also love to cook and try out new dishes on my family too. You never know one day I may be on Masterchef!

TELL US ABOUT ANY KEY DEVELOPMENTS YOU'VE SEEN FOR PH PATIENTS: During my nursing career I've seen many developments with PH treatment. New oral medications have come on the market which have improved the overall quality of life for patients, enabling some to continue to work, go to university and do physical activities. I've also seen some PH treatments sadly withdrawn from the market due to their increased cost which the NHS can't pay for which is regretful. The PHA UK has also done some outstanding work and without their support many patients and their families/ carers would feel very isolated. I've had the privilege of attending some of their conferences and the amount of work that goes into them to make them informative and enjoyable is amazing. Finally, it is a privilege to work with such an amazing team on the ward and within the PH community. My only dream before I retire is that a cure can be found.

TEA OR COFFEE?: I have never drunk a hot drink in my life! Odd I know! I'm a bit of a Diet Coke or cordial drinker.

If you work with people with PH and would like to answer our Q&A please e-mail editor@phauk.org



Join the PHA UK Lottery today!

It's easy to sign up and a great way to donate regularly to PHA UK. Help raise vital funds to improve the lives of people with PH and fund research into better understanding and treatment of the disease. **Play for as little as £1 a week!**

It's easy to sign up! Visit the PHA UK page at www.unitylottery.co.uk to register as a regular player. Or call the PHA UK office on 01709 761450 for a simple entry form to sign up.

Please note you must be over 16 to play.



In your Autumn issue of Emphasis...

The next issue of Emphasis is due out in September and we have planned features about:

- **PH Awareness Week 2016** – how to get involved in our campaign to raise awareness, November 19th until 27th.
- **Prescription charges** – who pays what and the campaign for change.
- **Transplant stories** – PH patients share their experience of having heart and lung transplants; and we take a closer look at the process.

Plus, lots more articles, interviews and news...

You can get involved in Emphasis too:

Emphasis Reviews - don't forget we'd like to hear from you if you'd like to share a review of a good book, app or film you think other Emphasis readers may be interested in.

Family Matters - if you're interested in telling your family's PH experience in our regular feature, drop us a line.

In the News - let us know if you raise awareness of PH through the media.

Take the biscuit! - and please get in touch if you'd like to answer the Green Leaf Crew Q&A.

To get involved and to offer feedback and ideas, contact editor@phauk.org

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*The only charity in the UK dedicated
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Are you living with PH? Do you have family or friends who are? Are you interested in knowing more about the treatments available? Would you like to get involved with fundraising or stay up to date with the latest PH news and events? If so, we are here to support people like you.

At PHA UK we are committed to helping improve the lives of people with PH, and supporting the PH community across the country through funding research, raising awareness, and helping our members in their day-to-day lives. Our website provides useful advice, access to publications, audio and video presentations, plus ways to get involved with the organisation.

Our quarterly Emphasis magazine keeps people informed and engaged with all things PH. In addition our friendly, knowledgeable office staff are just a phone call away with one to one advice. But most importantly it's our 3,000 members who form a unique network of support and inspiration to each other. We think of it as one big family and there's always room for new people.

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PHA UK Contact Details

Office hours: 9am to 3pm, Mon to Fri for general enquiries
Tel: 01709 761450
Web: www.phauk.org
Email: office@phauk.org
Address: PHA UK Resource Centre,
Unit 1, Newton Business Centre, Newton Chambers Road,
Thornccliffe Park, Chapeltown, Sheffield, S35 2PH

Anxiety UK

PHA UK works closely with our partners at Anxiety UK. To speak to someone about how you are feeling, call the dedicated PHA UK helpline on: 0844 332 9010

Turn2us

PHA UK has joined forces with Turn2us, a national charity that helps people in financial hardship in the UK. The charity aims to help people in need access support; and provides a range of information and resources on welfare benefits, charitable grants and other services via its website: www.turn2us.org.uk. Through our partnership with Turn2us, PHA UK members can also use the Turn2us Benefits Calculator and Grants Search on our website at www.phauk.org

Do we have your correct details?

Please email us on office@phauk.org if any of the following apply to you:

- Are the details incorrect on the mailing you've just received?
- Have you moved house recently?
- Has your contact number changed?

CHARITY CHRISTMAS CARDS
available from the PHA UK office
from July. Please look out for details
via our website on www.phauk.org
or phone 01709 761450

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