

AUTUMN 2018

# emphasis

The magazine for supporters of PHA UK [www.phauk.org](http://www.phauk.org)

**WE NEED TO  
TALK ABOUT  
PULMONARY  
HYPERTENSION**

**PH  
AWARENESS  
WEEK  
2018**

***PH Awareness  
Week 2018***

**22nd - 28th  
October**

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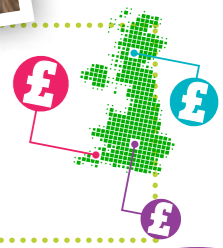
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**We need to talk about organ donation.**

**With this issue of Emphasis: FREE PH Awareness Week 'SELFIE CARDS'.**  
See page 13 for details

This magazine is printed on paper from sustainably managed sources



# Support people living with PH from just **£1 a week!**

We rely on regular donations to help us continue our work to support people affected by PH. By playing the **PHA UK Lottery**, you can contribute a little money on a regular basis – *and you might even win!*

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# Welcome

Welcome to the autumn 2018 issue of Emphasis. We're busy gearing up for our third annual **PH Awareness Week**, and this edition tells you all you need to know about getting involved. It's so important that we talk about pulmonary hypertension, and this year's campaign is all about having conversations – with family, friends, colleagues and the media.

Sometimes it can be as simple as sitting down with a hot drink together, which is why we're promoting 'Tea & Talk' events for PH Week 2018. Find out more about them, and other ways to help put PH under the spotlight, on page 11. This issue is also full of features to help you live a better life with PH. Read about the difference a cockapoo named Murray made to PHA UK member Sally on page 16, and find out how yoga can help both your mind and body on page 21. You'll find financial advice for carers on page 35 and we're pleased to bring you a special interview with Papworth volunteer Steve Stickler on page 36. Not all heroes wear capes, and it's important we celebrate those selfless people who give their time to help others. Talking of special people, we've been blown away over the last few months

by all the fundraising efforts of our wonderful PH community and for that we want to say a huge, huge thank you. Finally, do take a look at our update about access to Selexipag on page 24. English patients are getting left out in the cold and we're determined to get fair access to drug therapy for everyone. We hope you all join us to encourage conversations about pulmonary hypertension during our special week at the end of October.

*Iain Armstrong*

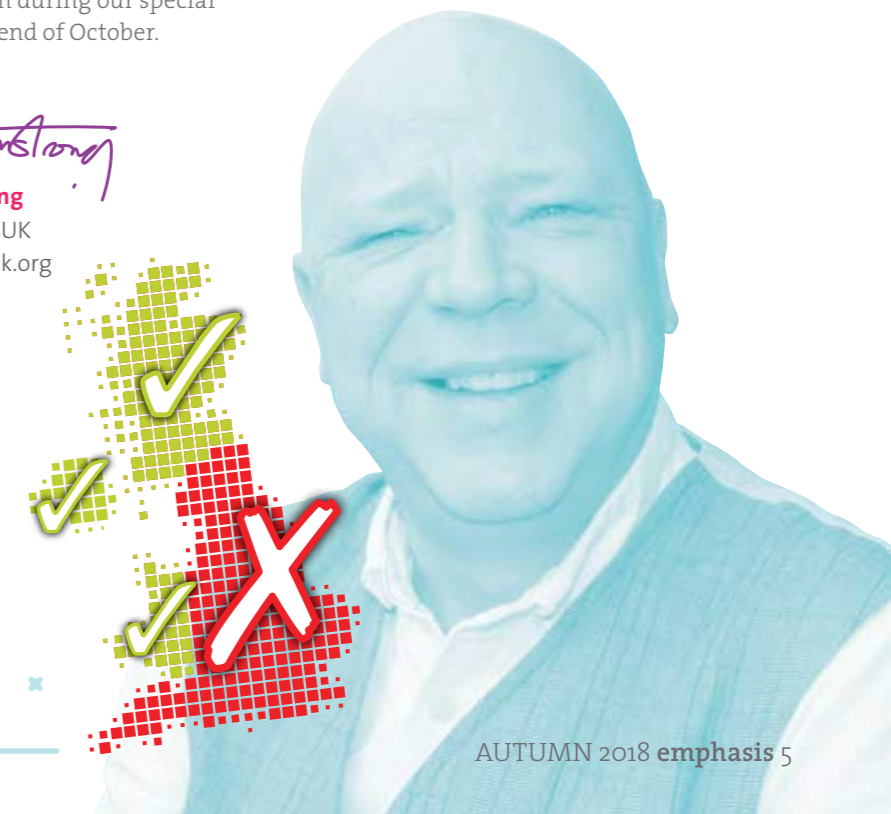
**Iain Armstrong**  
Chair of PHA UK  
[editor@phauk.org](mailto:editor@phauk.org)



**PH**  
AWARENESS  
WEEK  
**2018**

**22-28 October**

*“It's so important that we talk about pulmonary hypertension”*



# Emphasis *exchange*

If you have any news and views to share via the Emphasis exchange please e-mail [editor@phauk.org](mailto:editor@phauk.org) and don't forget to keep in touch via Facebook and Twitter too.

## Dear Emphasis

I've been very busy organising fundraising events for PHA UK and have raised £754.53. The reason I chose this charity is because in February 2017 my sister Vicki was taken into hospital. Whilst she was in hospital they diagnosed her with a hole in her heart and pulmonary hypertension and all of us are dealing with every day as it comes. The hospital put her in contact with the PHA UK, who have done brilliant work improving treatments and life quality for those affected by PH, and the Emphasis magazines they have been sending her help her know she isn't alone. My sister has been absolutely amazing with dealing with what she's been diagnosed with and is a huge inspiration to me! I have done lots of fundraising, including an afternoon tea and cake event in June which included a raffle, tombola, 'guess how many lollies are in the jar' game and a sweetie cone sale. During the event I also did a sponsored 30-minute hula hoop which was a success. The event went incredibly well with around 40 people from around the village of Ingoldsby showing their support. I have been an adult leader for the 1st Ingoldsby Rainbow Unit for five years and later in June we did an evening of hula hooping with PHA UK as the chosen charity. The fundraising event was a success!

**Stacie Eldred**



## Remembering Kirsty

Naomi Dean celebrated what would have been the 35th birthday of her sister Kirsty with an afternoon tea in her memory. The event, organised by the family, raised over £1000 for the PHA UK and went down so well that guests suggested it becomes a yearly occurrence.

In a special blog post that Naomi wrote to mark her sister's birthday, she said: "Throughout the ten years Kirsty lived with this disease she lived life to the full. She laughed often, she went travelling, got married, fell in love with baking and so much more. Every day she was in pain but she didn't complain much; Kirsty was one positive lady and I admire her deeply."



## WE'RE UP FOR ANOTHER AWARD!

We're really pleased that the report into the findings of our Living with PH survey has been shortlisted in the 'best publication' category at the 2018 Chartered Institute of Public Relations (CIPR) Pride Awards. The winner will be announced in November. Thank you to everyone who shared their voices to help the report have such an impact.

**PRIDE AWARDS 2018**  
#PRideAwards



## Social Media Round-up

Top tweets and popular posts from PHA UK's Facebook and Twitter pages



### Catherine Makin

Nothing better than sitting in the warm evening sunshine with the summer edition of Emphasis.



### @JuliaPHNurse

Great QI work here at Freeman Hospital to reduce our wait time for new patients referred to PH service. We were only seeing 19% of patients within 30 days, now 88% with some hard work from team.



### @wginsing

Finally able to write a prescription for Selexipag – frustrating that at present this can only be for patients in Wales and post TRACE study. Meanwhile patients in England are still fighting for NHSE approval.



### Kelly Stanley

My lovely brother Mark is doing a 50k in 12hrs Peak District Challenge to raise money for Pulmonary Hypertension Association UK! Please read his story and support him if you can. X



### @StefanieNimoy

Pets are good for the soul of PHighters!



In August, PHA UK member **Tess Jewson** was the guest curator of the @NHS Twitter account, giving her the opportunity to raise awareness of PH amongst a huge online audience. **Thanks for doing such a great job Tess!**

## Emphasis exchange

Me and my dad



With my husband Rich



With my little brother



Dear Emphasis,

My husband Rich and I held a joint 40th birthday and tenth wedding anniversary party this summer. Given that I have lived with PH since 2007, and was so ill with such a poor prognosis when initially diagnosed, I wasn't expected to make these significant milestones. However, thanks to my wonderful medical team and a vast array of drugs - and in fairness my own determination to live my life to the full - we made it; and so decided to recognise these very special occasions with a celebratory night with our dear family and friends.

We had a truly wonderful night, dancing and chatting into the very small hours, and came away with many wonderful memories to add to those we have already collected over the years. That said, I certainly felt it in the days after and was incredibly fatigued and achy from all the celebrations. We decided not to ask for any gifts or presents, but rather to kindly seek donations in support of the PHA UK. My wonderful husband Rich gave a very moving speech about the illness - to raise further awareness and explain some of the many ways in which PH continues to impact and limit my daily life. I am delighted to say that we raised a wonderful £800 in total.

With very best wishes,

Andrea Bown (nee Murphy) x

## Fifty years and fundraising

Maureen and Archie Clephane marked their golden wedding anniversary with a dinner party for 34 family members and close friends in Lincolnshire, and instead of gifts, they asked guests to donate to the PHA UK instead. Congratulations to you both and thank you for thinking of us on your special day!

## Conference is back!



**SAVE THE DATE: The PHA UK Conference returns to Heythrop Park Hotel in Oxfordshire on 4th - 6th May (Bank Holiday Weekend) 2019.**

This celebratory event will include interactive educational sessions, special keynote speakers, expert talks, and the chance to meet and share experiences with other PHA UK members.

This is a great opportunity to join us as we begin our 20th anniversary celebrations, which will conclude with a weekend for children under the care of Great Ormond Street Children's Hospital in 2020. Activities for children will be limited, but we hope to see as many members there as possible. We're not accepting expressions of interest at the moment, but we wanted to give you as much notice as possible - so please pop the date in your diary and keep an eye on our social media channels.

## Education day helps medical staff learn more about PH

July saw us hold the latest in our series of 'Managing the Breathless Patient' education days at our resource centre in Sheffield. Designed to help frontline medical staff learn more about PH, speakers included clinical nurse specialists, a specialist physiotherapist, consultant pharmacist and a senior respiratory physiologist. All those who attended went away with an information pack full of resources.

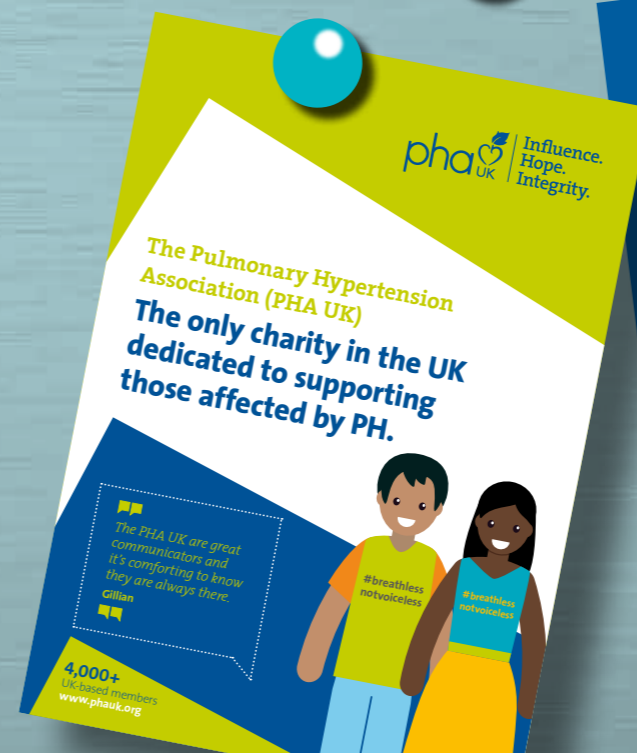
For details on future education days, email [office@phauk.org](mailto:office@phauk.org)



## New publication shines light on your charity

A new publication to help people learn more about the PHA UK is now available to order for free. The eight-page booklet contains information about our aims and objectives, areas of work and the support available to members. Shaun Clayton, director of membership services, said: "We have a lot of really useful resources but felt we were missing a comprehensive guide to the charity and what we stand for. The publication is already proving popular and we hope to share it with even more people."

Order your copy for free at [www.phauk.org](http://www.phauk.org)





PH Awareness Week is returning for 2018 and we need your help to make our third annual campaign the biggest and best yet. This year we've got a strong focus on encouraging conversations about PH, helping more people understand what it's like to live with the condition. We'll also be putting a special weekend spotlight

on organ donation, highlighting the importance of talking about your wishes with your family. And there will be a few surprises to look out for too! Below are just some of the ways you can get involved with PH Awareness Week 2018. You'll find more ideas and plenty of resources online at [www.phauk.org](http://www.phauk.org)

## Host a 'Tea & Talk' event

*We all love a cuppa and a chat, so this is the perfect excuse to get family, friends or colleagues together to understand more about pulmonary hypertension. Why not introduce some sweet treats and incorporate a bake sale too?*

Our free event pack includes everything you need to make the most of your Tea & Talk event – including quiz sheets to help people learn more about PH.

Download your **FREE EVENT PACK** from [www.phauk.org](http://www.phauk.org), including:

- Posters to advertise your event
- Cut-out bunting
- Information sheets about pulmonary hypertension, the PHA UK and organ donation
- Quiz sheets



**NEW FOR 2018!**

*If you don't have a printer, or would prefer a free pack sending through the post, email [office@phauk.org](mailto:office@phauk.org) or call 01709 761450. We'll even throw in a free tea bag!*



## Get social



**We need to talk about pulmonary hypertension.**



*Social media allows us to reach a huge audience, so much of this year's PH Awareness Week will focus around activity on Facebook and Twitter.*

Download your own PH Awareness Week profile and cover images for Facebook and Twitter from [www.phauk.org](http://www.phauk.org), and join the conversation using the hashtags **#LetsTalkPH** and **#PHWeek18**

Follow **@PHA\_UK** on Twitter and

**@PULHAUK** on Facebook to

share our posts during the week (we've got lots of exciting content planned!).

Don't forget to tag us in on your own posts too.



## Talk about organ donation

*This year, the final two days of PH Awareness Week will focus on encouraging conversations about organ donation.*

For some people with PH, their only option is a transplant. More people need to sign the organ donor register - and just as importantly, they need to let their families know their wishes too. Can you help us spread the word? You'll find a free organ donation information sheet online at [www.phauk.org](http://www.phauk.org)

*You can also download our 'Fast facts about PH' poster to display on noticeboards or in windows, help us promote our Medical Education Programme to your GP, or write a blog post about your life with PH. Visit [www.phauk.org](http://www.phauk.org) for more information.*

## Get snapping

*With this issue of Emphasis, we sent you four 'SELFIE CARDS' to help you get your message across in a photo.*

Either take a selfie, or ask someone to snap it for you, and get sharing on your social channels using **#LetsTalkPH** and **#PHWeek18**. We'll print the best in the winter issue of Emphasis!

If you didn't receive the selfie cards, or need some more, you can download them for free at [www.phauk.org](http://www.phauk.org)

**To help us make an impact, save your snaps until PH Week 22-28 October!**

## Share your PH story with the media

*Tell your local newspaper, magazine, or TV or radio station about your PH story – they will be really pleased to hear from you!*

You'll find hints and tips and a template press release online at [www.phauk.org](http://www.phauk.org). You can also contact our media team on 01226 766900 or [mary@capitalbmedia.co.uk](mailto:mary@capitalbmedia.co.uk) if you would like any advice.

**Want to talk to us about PH Awareness Week? Call 01709 761450 or email [office@phauk.org](mailto:office@phauk.org). Don't forget to let us know what you're planning!**



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Ronnie and his wife Kath

# The importance of passing on information

PHA UK member *Ronnie Spinks* has learned from experience that when multiple people are involved in your medical care, updates are not always passed between professionals. Here, he calls on other patients to help themselves by sharing information.

*"I do believe that, where possible, patients should participate in helping make life better for others, which is why I'm offering this advice."*

During clinic appointments, any concerns that affect your way of life can usually be addressed with the doctors and PH team who are in charge of your care, and this also includes anyone who is a family member or who cares for you.

*"Without any current up-to-date new information your PH team cannot be expected to give their best advice when dealing with your enquiries."*

However, patients can help their PH team with updates on any changes to their condition. Also, details of admissions into hospital should be fed back to the PH team where you are a patient, especially when there have been changes to medications or problems.

You may be surprised to learn that

not all details about a patient's hospital visits are automatically fed back to other hospitals, or directly to different doctors - other than to your GP.

Without any current up-to-date new information your PH team cannot be expected to give their best advice when dealing with your enquiries. It also saves doctors time having to readjust their records during assessments at clinics.

From bitter experience, I've learned that it's in a patient's own interest to either pass on their new information to their PH unit themselves, or ensure some other permitted person involved with their illness does it for them.

Patients are given contact details and phone numbers of their PH unit team, usually at clinics, so it's always wise to carry these useful details and up-to-date medication details with you. In the event of you becoming ill, it gives anyone treating you the best chance of providing correct PH treatment should that be the cause of you becoming poorly.

Sadly, I know from experience that not every hospital or A&E department has much knowledge about PH as an illness. I've had doctors researching PH on their mobile phones, and others telling me I've got COPD - plus insisting I have various respiratory



conditions during emergency admissions!

I understand this all may sound 'basic', but if we all work together on keeping each other up-to-date, then more knowledge will be given to those dedicated to their PH patient's wellbeing.

The more feedback relating to PH the better results for everyone, as what you may experience during your illness could help doctors find a treatment for others in the future. **Never think it's not worth mentioning any symptoms you believe are to do with your PH illness to the team looking after you, or to any doctors who may treat you for whatever reason.**

If you want to share any advice or experiences with other people with PH, please email [editor@phauk.org](mailto:editor@phauk.org)



# My life with Murray...



The decision to get a puppy a few months after being diagnosed with PH didn't just make Sally McHugh happy – it completely turned her world around. She told Mary Ferguson how a small cockapoo named after her favourite tennis player has made such a difference to her life.



**“**The period leading up to getting Murray was difficult. I first saw a consultant about my symptoms back in 2016 and ironically was told that it was 'very unlikely' to be a problem with my heart. A year later pulmonary hypertension was confirmed, and it sent both my husband Bernie and I into a tailspin.

I spent most of the first part of 2018 feeling very sorry for myself. I was really quite depressed, and felt like my future and the retirement I had been planning for had been taken away. I sat and watched box sets all day, and I was overwhelmed by feelings of how unfair everything was.

A low spot for me was in early February. Bernie and I had tickets for an Elbow concert and we had to park a long way from the venue. It was a horrid rainy night and I really struggled walking from the car park. I sobbed all the way through the concert as it made me realise just how ill I actually was.

Everything changed when my daughter's friend rang me to say her dog had given birth on Christmas Day. I'd met a cockapoo, a cross between a cocker spaniel and a poodle, before and thought they were fantastic, and being hypoallergenic they don't shed fur, which is great for someone with my condition. The timing was ideal and I persuaded Bernie that it would be a good idea.

**“** He has enhanced everything in so many ways

I truly believe in good things coming together at once. I'd started my medication in the December of 2017 and was finally starting to feel better, and

now Bernie had said yes to a dog.

This tiny thing came into our house and took over our lives. He has enhanced everything in so many ways.

I immediately had to stop feeling sorry for myself because I had this little dog that relied on me. I had to get up, get him out in the garden, and his needs came first. It was like a switch went on. It coincided with my medication being changed, and both things just came together.

A month after getting Murray I had an appointment at my specialist centre and I was like a different woman. I couldn't wait to tell everyone how much better I felt.

He makes sure I get out and exercise, whatever the weather, and it energises me. It feels like a pleasure rather than a chore. I do two walks a day now round where we live in Sutton Coldfield, and I feel lucky to have so many lovely routes to choose from.

The joy and healing power of the outdoors has really affected my mind, and I never would have realised that without Murray. He's optimistic, buoyant, and everyone's his friend. And that's the other thing – he's helped me meet so many people as there are always other dog walkers to stop and chat to. Bernie works, so without Murray I'd be on my own all day.

I'm so much more sociable since getting Murray. I ring friends to see if they want to come walking with us, and it's helped me get to know the neighbours more. He's brought a lot of joy to people on our cul-de-sac too! Getting him has been so expansive and opened up my world.

We now plan our holidays around Murray, and we've been to beaches in Northumberland and Wales, where we've done lots of walking. I'm not saying I'm

fixed – I couldn't climb a mountain – but as long as I'm sensible about where we go, it's great. We can walk for miles, and I never would have believed that last winter.

**“** Getting Murray has opened up my world

We're now making plans for when Bernie retires, and our latest dream is to get a big motorhome to drive round Europe, obviously with Murray. We used to think we would fly around the world, but my illness has changed that. I don't mind now though.

I feel much more grateful for the small things in life. I walked Murray up the hill near our house recently and witnessed one of the most amazing sunsets I've ever seen – it was like the sky was on fire. And I wouldn't have experienced that without Murray.

I refer to last winter as 'the dark days'. Now I feel like I'm in lighter days. I've really come out of the darkness and I'm sitting in the light again. I'm full of optimism, thanks to my specialist centre of course, but also thanks to Murray. I'm in a much better place. **”**



# Are you struggling with stress or anxiety?

AnxietyUK



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

- Dedicated helpline service 0344 332 9010
- Email support via [phauk@anxiety.org.uk](mailto:phauk@anxiety.org.uk)
- 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 **0344 332 9010**, email us at [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk), or visit [www.anxietyuk.org.uk](http://www.anxietyuk.org.uk)



## New look for vital information resource

Our flagship publication for people new to pulmonary hypertension has had a makeover to bring it up-to-date and make it easier to use.

**U**nderstanding pulmonary hypertension', the ring-bound book given to all new PHA UK members and patients across the country, is being re-launched this year with updated content and a fresh new look. As well as a name change to **'PH & You'**, the publication will be accompanied by a separate printed resource, **'Medication & PH'**, which provides information on treating and managing the condition. 'PH & You' contains chapters on how pulmonary hypertension affects the body, testing and diagnosis, clinic visits, the PHA UK and specialist centres. Both publications have gone through a rigorous review process to ensure they meet The Information Standard, a certification scheme for health and social care information established by the Department of Health. Iain Armstrong, Chair of the PHA UK, said: *"Relaunching this resource has been a major project for the team over the summer. It's vital that patients receive clear and accurate information at all stages of their PH journey, but it's particularly important at the point of diagnosis. We're confident these new publications will help both patients and their loved ones during what is often a worrying and confusing time."*

The books will be published later this year and will be available to order for **FREE** from [www.phauk.org](http://www.phauk.org). Keep an eye on our social media channels for news of when they become available.

Alternatively, you can pre-order your copies by emailing [office@phauk.org](mailto:office@phauk.org) or calling **01709 761450**.





# Play your part in the **fight against PH**

Clinical trials have transformed medical treatment for people with pulmonary hypertension – and more patients are needed to take part in research.

In the UK, before a new drug can be given to patients, it must be shown to be safe and effective in clinical trials, and must be approved by the Medicines and Healthcare Products Regulatory Agency (MHRA).

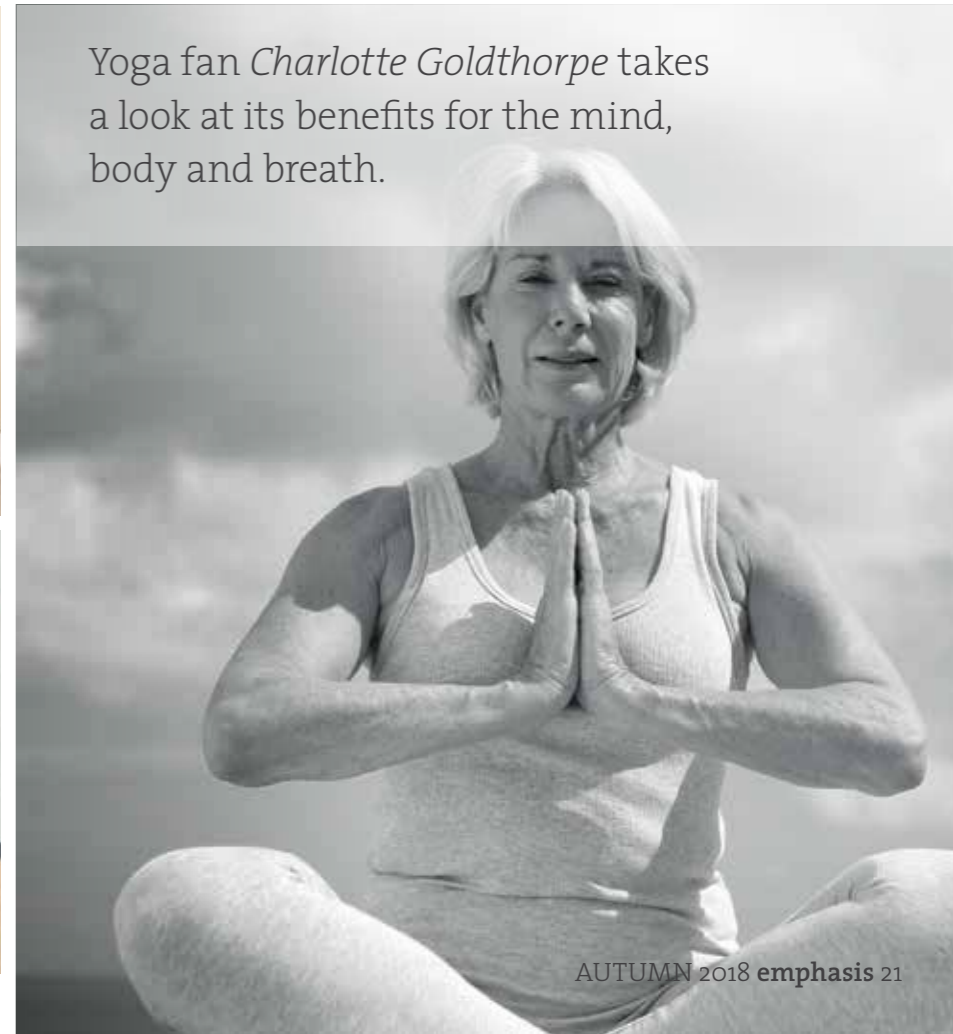
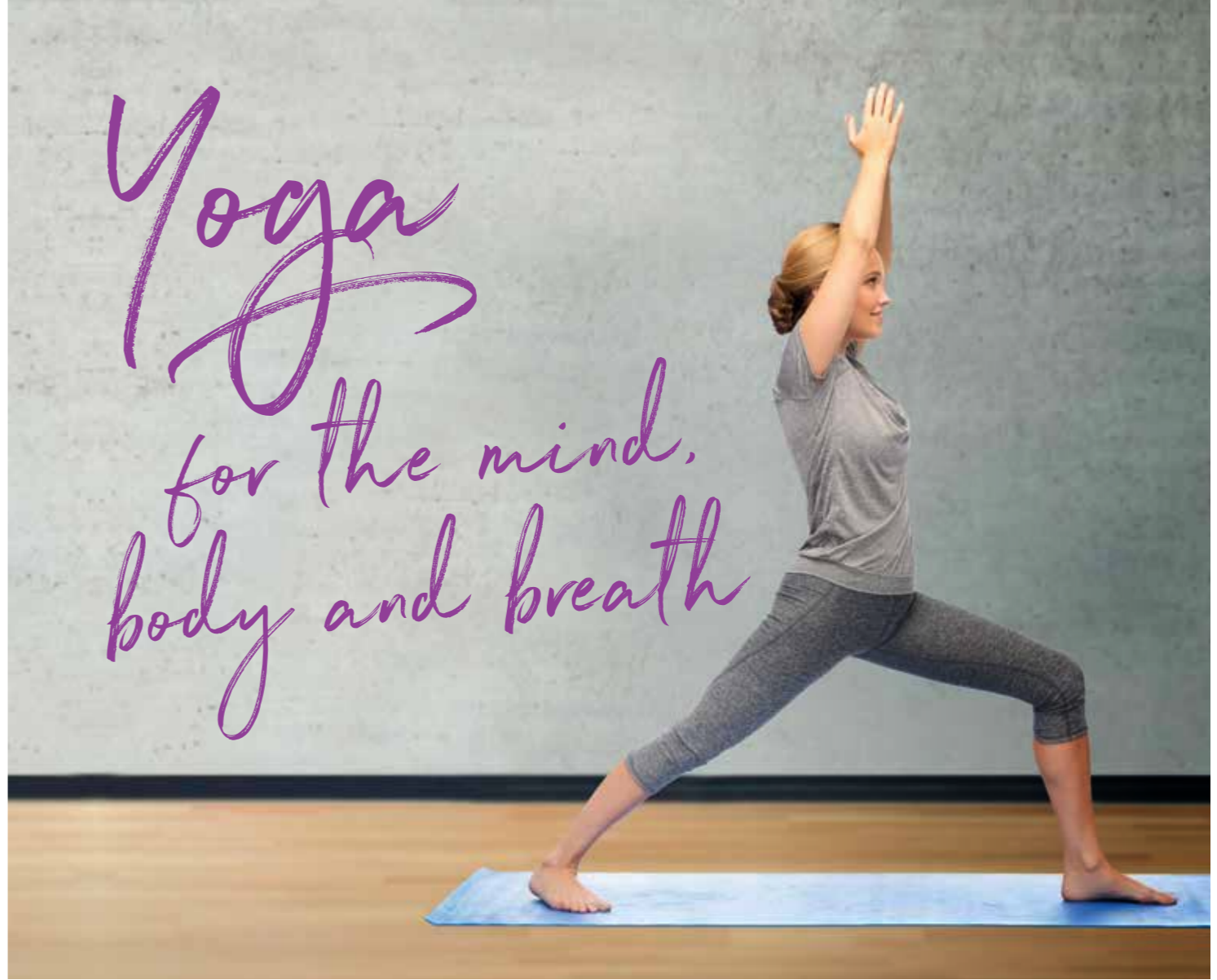
Before there were therapies available to treat PH, people diagnosed with the condition had an average life expectancy of about three years. Now, thanks to the approval of various new drugs, this life expectancy is much improved.

***Without clinical trials, and the patients who agreed to be involved in them, these drugs would not be available.***

All of the specialist PH centres in the UK are involved in research, so you may be asked if you would like to take part in a clinical trial. If you can, please think about getting involved and playing your part in the fight against PH.

Interested in taking part in clinical research?  
*Let your specialist centre know!*

.....  
***“I intend to continue to take part in any research, study or trial in the hope that one day we can all be cured of this disease.”***  
.....  
Carole Ayrton  
PHA UK member  
.....



Yoga fan *Charlotte Goldthorpe* takes a look at its benefits for the mind, body and breath.



Always speak to your specialist centre before embarking on a new exercise routine.

It's easy to see why yoga might be perceived as a fad. Its popularity has surged in recent years, with everyone from athletes to celebrities catching the yoga bug, not to mention the Instagram stars uploading their daily yoga routines for inspiration.

There's a growing yoga industry that's developed around this popularity and it's much more than clever marketing. Two of the top three reasons why people practice yoga are for stress relief and its impact on their general health.

**I know what you're thinking - yoga is just for flexible 20-somethings who drink smoothies and eat quinoa, right? Wrong.** There are many common myths surrounding yoga, such as the need to be fit, or super flexible. Others believe it's not for men or it's too expensive. But having practiced yoga for two years myself, I have never come across any barriers to my practice - and yoga is certainly for both men and women.

Yoga is a group of physical, mental, and spiritual practices or disciplines which originated in ancient India.

Many different kinds of yoga exist, so it can be hard to know which particular style is right for you. Most are based on the same basic yoga poses called 'asanas', however, the experience of one style can be very different from another.

**If you're new to yoga, hatha and restorative practices are recommended for beginners.** Other more energetic styles include vinyasa and ashtanga.

Whichever style you choose, you are likely to see improvements in many areas of your health, both physically and mentally. Some of the benefits

include increased muscle tone and strength, better sleep, increased energy levels and taking control of anxiety and depression.

So, let's look at some of the beginner styles which could help improve your PH symptoms.

**Hatha yoga is a general category that includes most yoga styles.** It is an old system that includes the practice of asanas (yoga postures) and pranayama (breathing exercises), which help bring peace to the mind and body, preparing the body for deeper spiritual practices such as meditation.

Today, the term hatha is used in such a broad way that it is difficult to know what a particular hatha class will be like. In most cases, however, it will be relatively gentle, slow and great for beginners who prefer a more relaxed style where you hold poses longer.

One of the main benefits of practicing hatha yoga stems from one of the pillars of the hatha style: breathing. Controlling breath can help improve oxygenation of the body and alleviate stress in some forms. Other elements of hatha yoga also help with relaxing the body and fighting the stresses of the modern world.

**Restorative yoga is a gentle, relaxing, passive style that allows you to relax and release the body into a gentle stretch that is held for as long as ten minutes.** This style makes use of a wide range of props, including bolsters, blocks, straps and blankets. The intention is to provide support within each pose, making it easier to completely let go. It's good if you're looking for deep relaxation, and just generally, a long lie down!

## All the gear but no idea?

### COMMON QUESTIONS ABOUT YOGA

#### Do I need any equipment?

Most yoga studios provide mats, but you're advised to take your own. As well as being more hygienic, this also encourages you to practise at home in-between sessions. A good yoga mat can be bought online from around £10 to £20.

#### How much do classes cost?

Yoga classes generally cost between £6 and £10 per session, or a block of sessions can be bought at a discounted rate.

#### How many people attend per session?

This can vary greatly depending on the size of the studio, so this could be anywhere between six and ten in a community hall or small yoga studio, to 20 in a gym.

#### How long do yoga classes last?

Classes tend to be 60 to 90 minutes long. Some studios also offer full or half day workshops to deepen your practice.

#### Where do I find out about a class near me?

Search online for yoga classes near you or head to your community hall or leisure centre to find out their programme of activities.

#### What should I wear to a yoga class?

For women, comfy leggings and a loosely-fitted t-shirt and for men shorts or tracksuit bottoms and a t-shirt. Remember socks and a cardigan or hoodie for relaxation at the end.

# A BEGINNER'S GUIDE TO YOGA

Jacqui Payton is the joint owner of Cocoon, a yoga and wellbeing studio in Holmfirth, West Yorkshire. She trained at the Devon School of Yoga and describes her style as an 'eclectic blend of hatha yoga and mindful movement, with a strong emphasis on the use of breath'. She is also a restorative yoga trainer and a member of the Independent Yoga Network. Here, she gives her tips for practicing yoga.

**"If you're just starting out, remember to 'start where you are'. Work with your own body and don't try to push against it - particularly not comparing yourself to anyone else. Yoga is not a competitive sport.**

*During your class, develop an awareness of what your body is telling you and then listen to it and follow its wisdom. Your body will know what it likes and dislikes. Everybody is different and your body may want different things on different days. Yoga is about deepening your connection to your body and mind.*

*Use the breath at all times - it will let you know if you are going too far or too fast. If it becomes strained or ragged, draw back and slow down. Aim for deepening the breath. In our stressful daily lives our breathing tends to be shallow. To help us relax and draw ourselves into the great effects of the parasympathetic nervous system, allow the breath to deepen and lengthen.*

**Anyone can do yoga. I have students who sit in a chair for the whole session, but they still get maximum benefit from moving the joints through the full range of movements, using the muscles and stretching out.**

*The mental and emotional benefits of yoga cannot be overstated. With the help of the breathing exercises and*

*the mindful moving, the mind is taken away from the stresses of everyday life and into the realm of pure moment-by-moment awareness. You let the past and the future go and come into the present moment.*

*It's always good to find a teacher you like and can relate to - we're all different and I try not to take it personally if someone doesn't stick with me. Then you'll feel more comfortable about talking things through with them, expressing any difficulties or issues and setting goals with their support.*

*Try to set up a short home practice so that you can continue your yoga between lessons. Have your mat or chair set up all the time if you have space at home, as a visual reminder to do it. Maybe play some relaxing music and always start with being still and silent while you tune into your body and breath. Maybe try to remember a short sequence of postures or movements so that you don't have to think too much - it becomes automatic. If it's manageable you'll do it and stick with it.*

**Remember that yoga isn't all about the body. Meditating can be even more beneficial for some people, just learning some breathing practices (and there are plenty of them to help in lots of different ways), or relaxing can all be equally, and for some people, even more important.**

*Try the gentler, and in some ways more powerful, practices such as restorative yoga to help with relaxing the mind as well as the physical body. Deep relaxation is something we tend to forget our body needs as much, and sometimes more than, physical movement."*

Jacqui Payton



Carol Keen, a clinical specialist physiotherapist in pulmonary hypertension at the Royal Hallamshire Hospital, said: "Breathlessness is the most common symptom of PH and patients often fear that taking part in any kind of exercise will worsen their symptoms. However, there are particular forms of gentle exercise and breathing techniques that can help improve breathlessness. Just as

*you would train the muscles in your legs to walk or run, it is important to train the muscles in your diaphragm to be able to control your breathing. Yoga is an exercise that focuses on breathing control and strengthening the muscles. Practicing yogic breathing at home or attending a yoga class could help manage symptoms of breathlessness."*

Carol Keen



Check out page 10 for a review of the 'Yoga Studio' app.

# The ultimate postcode lottery

By Iain Armstrong, Chair, PHA UK

A new drug to treat PH has been made available in every UK country except England – highlighting a fragmented and opaque commissioning process that leaves some patients out in the cold. And frankly, we're fed up of not being listened to.

In July, NHS England announced that it would not be making Selexipag, a new drug developed to treat pulmonary hypertension, available to patients with an English postcode. Those living in Scotland, Wales and Northern Ireland can now be prescribed the treatment – making a mockery of the concept of a 'United Kingdom'.

Your voices played a key role in overturning the initial rejection of Selexipag in Scotland in May, and in securing access to the drug in Wales in June. The results of the Living with PH survey, which gave the PH community a voice, provided important evidence in both cases.

The decision to make the drug available in Northern Ireland was announced in August – making the English decision rub even more.

The rejection of Selexipag in England is exceptionally unjust and grossly unfair, and we're really angry. I was invited to be part of the decision-making process in Scotland and Wales, who were fully engaged with the patient voice and ultimately delivered the right decisions. NHS England have

been anything but. We've had to fight to even get around the table in order to make the patient voice heard.

NHS England will review the drug again in November, but they are not accepting any further evidence.

We gave them the opportunity to talk directly to English PH patients via the pages of this magazine, to explain why Selexipag was turned down. They declined, telling us they had nothing more to add to the press release they issued at the time – so they didn't even have the decency to try. Their press release contains just one line about Selexipag and in this context, it's actually quite meaningless.

Welsh patients are treated at specialist centres in England and it beggars belief that someone could be denied a treatment that the person sitting next to them can access – purely because of the postcode on their address. The whole process stinks and we're calling for an urgent review to give the PH community the same equality and access to treatment as other disease areas like cancer. It's imperative that the next review

of Selexipag in November provides the right outcome for England.

We are currently working on a strategy to ensure we have the biggest impact possible so we ask that for now, you don't do anything. When the time comes, we'll unite and show commissioners exactly how loud the PH community can shout for what's fair.

Keep-up-to date with developments on Selexipag via our Facebook page (@PULHAUK) and Twitter account (@PHA\_UK)

Carl Harries, clinical nurse specialist in the PH service at Royal Brompton Hospital, said: *"Fundamentally, the decision on Selexipag is wrong. It has brought about a huge amount of disappointment for patients and clinicians alike. This is no longer a postcode lottery, it is a national lottery - where some people who come from a different part of the United Kingdom can get this drug, but those in England can't. And that is unjust, given the nature of this therapy within a rare disease area and what it can do to help people have a better quality of life."*



IN THE



# LIVING WITH AN INVISIBLE ILLNESS

PHA UK member *Yasmin Swift's* story made national headlines in July after an anonymous driver accused her of not being disabled. Charlotte Goldthorpe spoke to her about her experience.

Yasmin, aged 19 from Ashford in Kent, was diagnosed with idiopathic pulmonary arterial hypertension just nine months ago, which severely restricts her quality of life. Like many people living with PH, she struggles to do the simplest of tasks without becoming out of breath or exhausted.

But even though Yasmin had come to terms with her PH diagnosis, she wasn't prepared for what was to come. One summer's evening she headed out for tea with a friend and parked in a disabled space on the high street. Despite clearly displaying her blue badge, an anonymous person left a cruel note on the windscreen of her car accusing her of not being disabled – which left her shocked and saddened.

The incident spurred Yasmin on to raise awareness of invisible illnesses and change people's attitudes, so she took to her Facebook page to call out whoever left the message.

She was overwhelmed with the response she received and was inundated with requests from journalists who contacted her via Facebook. Her story featured in her local

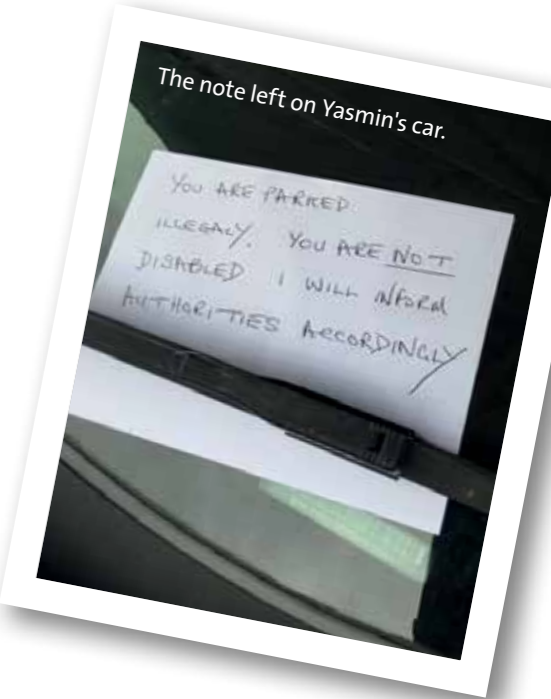
paper, The Kentish Express, and even made national headlines in The Daily Mail, The Independent, The Mirror and The Sun. Yasmin also appeared on BBC 5 Live to help raise awareness of PH.

She said: *"When I first got my blue badge I was a bit sceptical. I expected people to say things and that I'd get funny looks because I don't look disabled, but I never expected someone would go as far as leaving a note."*

*"What made it worse was that it was anonymous. I've always felt that if anyone ever asked me then I would be happy to explain my situation but they didn't even leave a number."*

*"My advice to other PH members who might find themselves in a similar situation would be to remember your worth, hold your head up high, be proud of who you are and use your blue badge with pride. We already have a big enough battle on a daily basis, so don't waste your energy and thoughts on ignorance. Learn to practice and replace one negative thought with at least three positive thoughts."*

*"Speaking up about life with an invisible illness through social media really helped to channel my*



*frustrations. At first, I was really unsure about whether to talk about what had happened to me and I did receive some negative comments, but the majority were really supportive and I hope it's gone some way to help raise awareness of PH." ●*

# CELEBRATING RICHARD'S LIFE

*Sue White completed a personal swimming challenge to mark what would have been her son Richard's 25th birthday. Deborah Wain tells the story of the mother and son's close bond.*

**R**ichard White, from Redcar, in the North East, sadly passed away in 2014, aged 22, after battling pulmonary hypertension for most of his life.

There are many occasions when his mum Sue thinks about him, but one moment has particular significance. It was two years following Richard's death when she was about to step on to a rollercoaster at the Wizarding World of Harry Potter theme park in Orlando, Florida. Richard was a huge Harry Potter fan and he and Sue loved to watch films in the J.K. Rowling series together. Because of his illness Richard wasn't able to fulfil his dream of visiting the theme park, so Sue strongly felt the significance of her trip. She was determined to overcome her trepidation of the thrill-seekers' ride in her son's honour. She said: "There were a lot of times when our family visited theme parks and Richard and I would sit out the rides, him because he couldn't go on and me because I didn't like them. "Richard would have loved to have gone to the Harry Potter park. He said when it opened that it was something he was going to do one day. The Harry Potter films were among films we enjoyed watching together, along with the Lord of the Rings series.

“I had never heard of PH of course and I felt so awful that I'd always been chivvying Richard along, thinking he was being lazy.”

*“When I got the chance to go, I decided I wanted to try the rollercoaster and ride it for Richard. As I walked up the steps, I really didn't want to go on but I felt I had to do it for him. I did it and then went on other scarier rides!”*

Richard first showed signs of having PH while at nursery school but, like many parents in their position, Sue and Richard's dad, Paul, were told his breathlessness was due to minor conditions. Richard twice collapsed at school during PE lessons but doctors insisted he was suffering from a virus. As he got older, Richard was unable to join in normal activities with his older brother and sister, Joe and Emma. However, it wasn't until he was nine, following a spell in hospital in Middlesbrough, that he was referred to the specialist PH centre at Newcastle's Freeman Hospital, where a right heart catheterisation procedure confirmed the condition.

*“I had never heard of PH of course and I felt so awful that I'd always been chivvying Richard along, thinking he was being lazy,”* recalled Sue.

Sue remembers having everything that was known about the condition at the time carefully explained to her by the 'fantastic' team of specialists. She learned that had Richard been diagnosed just two years earlier, his life expectancy would have been two years unless he underwent a heart and lung transplant. But, as it was, new drugs were becoming available.

The youngster was initially put on nebulised Iloprost. This was eventually replaced by Bosentan tablets when these became available for children. While in his teens, Richard had a Hickman line fitted at London's Great Ormond Street Hospital through which he was again given Iloprost. He was also put on Sildenafil.

Although Richard could not join in physical activities at school, he enjoyed spending time with his friends. Sue describes her son as "very astute and bright". Richard developed a passion for digital technology and spent hours filming and editing video-logs, or vlogs. One of the vlogs he produced was about how he coped living with PH and it was viewed by internet users all over the world. "Richard couldn't control his health and a lot of the things

*going on around him, so he completely focussed on doing what he enjoyed and did it wholeheartedly and to the best of his ability,”* said Sue. At the age of 21, as his condition deteriorated, Richard was assessed for a double lung transplant but "it was not to be for him," said Sue. In November 2013, Richard became very ill. Staff at the Freeman Hospital worked with the family to plan Richard's end-of-life care in line with his wishes, which were to remain at home during his final months. Richard and the family were supported by Macmillan Nurses. He sadly died in February, 2014. Richard is desperately missed by Sue along with Joe, now 31, and Emma, 30, and Paul. Sue said: "He's left a massive gap in our lives. He was just amazing. I still talk to him. I'm a great believer that the spirit does not disappear totally." Together Sue and Richard raised funds for the Freeman and also for PHA UK. The family had benefitted from a family weekend and Richard also went on a trip to a Center Parcs resort with other young people from which he returned 'very positive'.

Sue now lives with her second husband Bill Waister with whom she runs a shop business. She has continued to fundraise since Richard's death and most recently set herself the challenge of swimming 100 lengths at her local pool. Sue embarked on the marathon swim to mark what would have been Richard's 25th birthday. Although she's not a strong swimmer, Sue diligently trained two or three times a week in the six months leading up to her big swim and she was thrilled to complete it within two hours. Again, it was the thought that she was doing the challenge in memory of Richard that spurred her on. She said: "A lot of my friends are sporty but I've never been a fitness person and I really didn't think I'd be able to swim so far, but the regular swims built up my stamina and I began to really enjoy it too." As well as raising money, Sue sees collecting donations as a way of promoting awareness of PH and its impact, as well as sharing her memories of Richard. "A lot of people I talk to now didn't know Richard, but we talk about him and we talk about PH. That's really important to me," she added.

If you would like to share your family's PH story, please email [editor@phauk.org](mailto:editor@phauk.org)

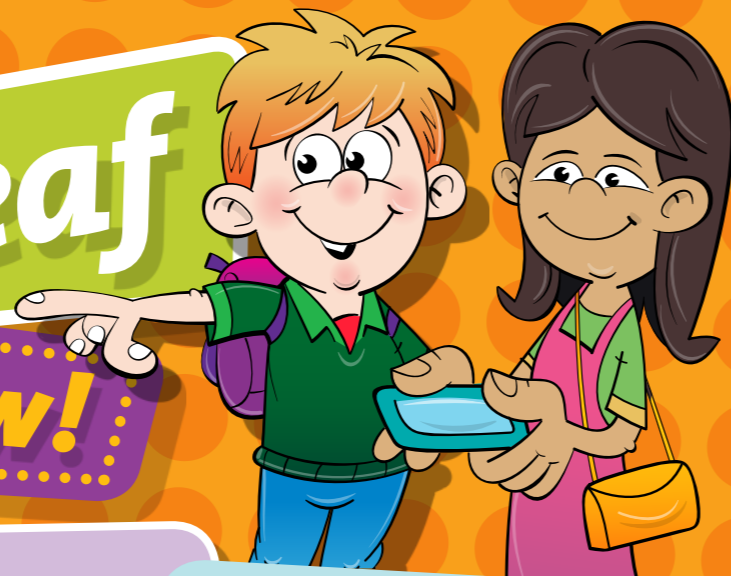


“He's left a massive gap in our lives. He was just amazing. I still talk to him. I'm a great believer that the spirit does not disappear totally.”



# Green Leaf

## Crew!



### GREEN LEAF CREW Q&A BEX BENNETT

Bex Bennett is 12 years old and lives in Barry, South Wales with her mum, dad, brother Sam, dog Alfie and two fish. Here Bex, who was diagnosed with PH in 2016, shares some of her favourite things.

**Q.** What's your favourite subject at school?

**A.** Art.

**Q.** Where would you most like to go on holiday?

**A.** I'd love to see Hawaii.

**Q.** If you could be anyone in the world for a day, who would it be and why?

**A.** I would be Zendaya (American actress) as she is good friends with Tom Holland.

**Q.** Do you have a favourite film or TV programme?

**A.** My favourite film is Infinity War and my favourite TV programme is Friends.

**Q.** What would be your dream job when you're older?

**A.** I'd love to be a photographer.

**Q.** What do you like to do at weekends?

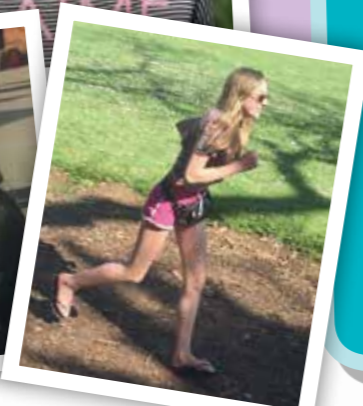
**A.** I like to meet up and go out with friends.

**Q.** If you could take a selfie with any celebrity who would it be?

**A.** Tom Holland.

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

**A.** I'd like to be able to read minds.



### SUMMER 'SAND WALK' FOR HANNAH AND FRIENDS

Congratulations to 12-year-old Hannah Welch and seven of her friends who completed a sponsored six-mile sand walk along Bournemouth beach to raise money for the PHA UK. Hannah, who was diagnosed with PH in 2011, was joined on the walk by Mia Crawley, Chloe Baraclough-Pierce, Chloe Green, Thea Martin, Imogen Durham, Rebecca Stranack and Eloise Motton. The girls raised a total of £1207.

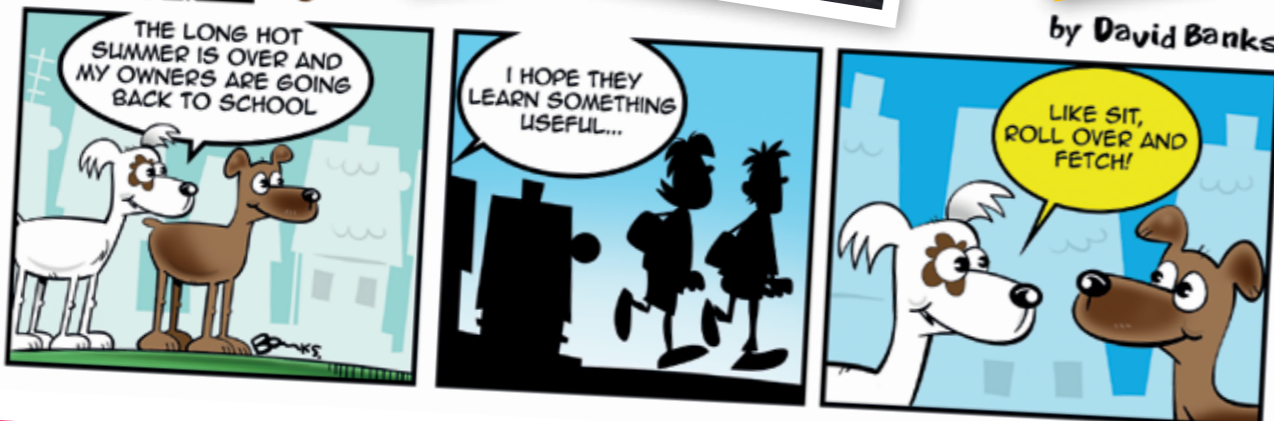


### The GREEN LEAF CREW

BY DAVID BANKS



### Patch



# 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**.



**£315  
RAISED**

## Taking on Tough Mudder

PHA UK director of membership Shaun Clayton, his fiancée Becky and friend Zoe all completed a Tough Mudder event at Broughton Hall in North Yorkshire. Shaun said: "It was one of the hardest things I've ever done. It was physically and mentally draining, but that's nothing compared to what some of our members go through every day. We were delighted when people were coming and asking us about the organisation and looking it up on their phones."

## Pacing pavements for Priya

Ajay Anand organised a sponsored 10k walk around Leicester to raise money for the PHA UK in memory of his sister Priya Mistry, who passed away in December 2017. Ajay said "We are pleased that family and friends have helped to raise over £3,000 for PHA UK, in memory of our Priya who we miss dearly. Hopefully this money will be well used towards much needed research."

**£3,000  
RAISED**



## Running the Downs for Will

Tom Payne, Holly Baker and Seb Tyler from Hampshire ran the South Downs trail half-marathon in memory of their friend Will Acres, who passed away earlier this year. Tom said: "I saw there was a local half marathon happening and decided it would be a great fundraising opportunity for the PHA UK. To raise over £1,000 was incredible - we hope that this has carried on Will's legacy whilst raising awareness of PH."

**£1,027  
RAISED**



## Skydive in memory of mum

Lizzy Elgie from Boroughbridge in North Yorkshire completed a tandem skydive to raise money in memory of her mum Clare, who passed away in 2011. Lizzy said: "It was a surreal feeling - it was only my third time ever in an aeroplane and I didn't know what to expect as I hadn't done a skydive before. The amount of support I have had is incredible and I am overwhelmed by the generosity of people in my community for a charity that is close to the hearts of me and my family."

**£3,637  
RAISED**



## BBQ for Yasmin

Nicole Swift from Kent held a barbecue fundraiser to raise money in support of her sister Yasmin who has PH. Nicole donated 50 per cent of the money raised to the PHA UK, with the other half going towards Yasmin's future medical costs. Nicole said:

"The day went better than I could have ever imagined. We were expecting around 100 people to attend but had nearly 150 in total. My sister also was overwhelmed and incredibly grateful for the support she received - the money raised has made her recovery a lot easier and will continue to help in the future."

**£1,570  
RAISED**



If you have any ideas for raising money for PHA UK visit [www.phauk.org](http://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



# What really happens when you give blood?

The NHS Blood and Transplant unit is in urgent need of more blood donors. *Chris Coates* explains why you should encourage friends and family to give blood, and what effect their donation could have on the lives of those in need.

**I**n the UK, over 8,000 blood donations are needed every day to treat patients in need.

200,000 new donors are also needed each year to replace those who can no longer give blood. Of course, if you have PH you cannot give blood, but it's important to encourage friends and family to donate.

The NHS Blood and Transplant unit (NHSBT) is in desperate need of more donors, and most people aged 17-65 can give blood. Men can book an appointment every 12 weeks, and women every 16 weeks. **There are thousands of blood donor centres in the UK – you don't have to go to a hospital to do it. Schools, hotels, village halls and pubs are just some of the venues which host blood donation sessions.**

Your donation could be used to treat patients with medical conditions such as anaemia, cancer blood disorders, or those having surgery. Transfusions can also be given to terminally ill people to improve their quality of life.

In order to give blood, you first have to register online, and then you can book an appointment. There are a limited number of walk-in slots available and some centres don't offer any at all, so it's better to book in advance.

If you are suffering from a fever such as a cold or chesty

cough, it is better to wait until you fully recover before you give blood. If you have had an infection, you are advised to wait at least 14 days after recovery before donating.

On the day of your appointment, it's important to eat regularly to keep your blood sugar levels high, and to drink plenty of water beforehand because this allows your body to replace the blood you donate more quickly.

Before your blood is taken, you'll be taken for a private health screening to confirm your identity and check that you're eligible to have your blood taken. This is done by taking a small amount of blood from your finger to test haemoglobin levels.

After your screening, your blood can then be taken. A vein will be selected in your arm and it will take five to ten minutes for a full donation. Donors are advised to do muscle tension exercises during donation to maintain blood pressure.

When your blood has been taken, you'll be invited to relax for 15 minutes and have at least two drinks before leaving the centre. For the rest of the day try to avoid doing strenuous exercise or heavy lifting until your body has replaced the blood you've donated. ●

**John Smith, who works with the PHA UK to design Emphasis magazine, recently gave blood for the 70th time. He said:**

*"I first started giving blood in the 1990s when I was living in London, and it's become habitual since then," he said.*

*"I think the publicity around giving blood has increased the amount of people who do it now. It's nice to see such a variety of ages as well – I often see young people giving blood for the first time as well as the older generation.*

*"My local centre is less than a mile away and the whole process takes no more than 45 minutes. NHSBT have also started sending me texts when my blood has been used, which is a nice touch as you know then that you've made a difference to someone's life.*

*"I'd urge people who are able to give blood to register online and start donating. It's an easy process and so rewarding to think that you might have helped save a life just by giving away a pint of your blood."*



To find out more about giving blood and to locate your nearest donor centre, visit [www.myblood.co.uk](http://www.myblood.co.uk)

## Research shows early physiotherapy intervention is integral to managing PH

A study into physiotherapy delivered to patients with PH in the UK has found that early intervention with physiotherapy practice is integral to managing the condition. Here we take a closer look at the findings.



**B**ack in the Summer 2015 edition of Emphasis, you may remember that we invited readers to take part in a research programme into physiotherapy and the management of PH, funded by the Chartered Society of Physiotherapy.

The programme, which ran over an 18-month period from December 2015, aimed to identify what role physiotherapists play in the care of patients with PH, in specialist centres and in other settings too. The researchers were also interested in what worked well for different groups of patients, and if there were any gaps in services.

Three patients volunteered to take part in the study who all described themselves as 'active' and regularly exercised independently. One patient had been through a pulmonary rehabilitation programme several years previously, whereas the others had had no physiotherapy involvement. There were two female patients and one male patient aged between 44 and 66 years old. All the patients had stable PH and

had been diagnosed for eight to ten years previously.

Interviews were carried out with a physiotherapist at each of the specialist PH centres, and survey data was also gathered from 63 physiotherapists caring for patients with PH in specialist and non-specialist settings.

### THE FINDINGS

The study showed that physiotherapists would like to do more to achieve better health outcomes for acutely unwell patients at the specialist PH centres through early rehabilitation. This might involve getting patients standing, walking around the ward, and starting to look after themselves physically, as early as possible while they are in hospital.

Survey data found that physiotherapists and PH patients see the benefit and potential of increasing physical activity in and out of hospital, to help patients be able to do as much

as they can for themselves, and to become more independent. However, at the moment, physiotherapy only supports the most unwell inpatients and planning for hospital discharge. This means that current procedures differ from what research evidence and clinical guidelines recommend.

The research also found that physiotherapists will occasionally refer patients to existing community services, e.g. community pulmonary rehabilitation. However, specialist knowledge of this rare condition can be lacking in these local services which provides a barrier to accessing quality care.

The study concluded that physiotherapy should become routine in the management of PH - promoting physical activity, functional independence, and self-management. To achieve this, physiotherapists will need to work closely with local services to deliver quality care in line with patient needs throughout the lifespan of their disease. ●

Carol Keen is a clinical specialist physiotherapist in pulmonary hypertension at the Royal Hallamshire Hospital. She said:

*"This study highlights the importance of participating in research to generate outcomes which can change services. The information we gathered from patients in this research was vital in helping us put together a picture of what patients need. The data from this study was collected over two years ago now, and since then we are slowly seeing a greater emphasis on the importance of physiotherapy and physical activity in caring for patients with PH, but there is still a long way to go."*

**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.

## Benefits available to carers

# Benefits Advisor

With Shaun Clayton

*It's not just PH patients who are entitled to financial support from the Government - carers who give up their time to look after friends or relatives could also be eligible for benefits.*

If you're caring for someone with PH, you may be entitled to receive **Carers Allowance**, which is a benefit applicable to somebody who looks after an individual for at least 35 hours a week. This is defined as simply being available to support the person, which is very easy to prove if you live with them. Even if you don't live with the person, as long as you can explain how you spend those 35 hours, you shouldn't have an issue obtaining the benefit.

In order for the carer to be eligible, the person they're caring for must receive **Personal Independence Payments (PIP)** or **Disability Living Allowance (DLA)**.

### How much can I claim?

Everyone who receives Carers Allowance is entitled to **£64.60 per week** – it is not needs or income-based. As long as you're caring for the person and they're receiving PIP or DLA, you will continue to receive Carers Allowance, but you must notify the Government if your circumstances change, such as if the person you're caring for goes into hospital.

### Who is excluded from Carers Allowance?

You will not be eligible for Carers Allowance if you earn more than £120 per week, after tax. However, this excludes expenses including childcare or care for the person while you're at work. It also excludes 50 per cent of your pension contributions, so it's important to calculate your weekly expenses before you apply. You cannot claim Carers Allowance if you are in full-time education, study for more than 21 hours per week or are under 16. If you care for more than one person, you will still receive the same allowance per week.

### What other benefits might I be entitled to?

It's worth noting that for certain benefits that both the carer and the patient can apply for, the carer will often be entitled to more support than the individual being cared for. This means it's often better for the carer to apply for things like housing benefit (if of course they live with the person). However, I would recommend that both the carer and the person being cared for find out what they would be entitled to, in order to ensure the person who would get more support is the one who applies for it. You can do this by using the **Turn2Us benefits calculator** at **www.phauk.org**

### How do I claim?

To apply for Carers Allowance, visit the **www.gov.uk** website or call the advice line on **0800 7310297**.

### What if I'm unsuccessful?

If you feel you have been wrongly denied Carers Allowance, you should challenge the decision. If you are planning to appeal, make sure it is within one month of the initial decision to deny you support. **Remember that your eligibility may change, so even if your claim was turned down, you may be able to claim successfully in future.**



Shaun Clayton is Membership Services Director at PHA UK, and specialises in helping members navigate different aspects of the benefits system. If you would like a particular subject covered in a future issue of Emphasis, please email **editor@phauk.org**



# Not all heroes wear capes!

Eight years after his own pulmonary endarterectomy operation at Papworth, volunteer Steve Stickler has helped hundreds of other patients prepare for the surgery. He spoke to Mary Ferguson about his journey to diagnosis, the importance of giving back, and why supporting other candidates at the hospital means so much to him.

**W**hen he moved into a house less than half a mile from Royal Papworth Hospital, 70-year-old Steve had no idea that the facility would one day change his life.

On Armistice Day, 11th November 2009, surgeons carried out a pulmonary endarterectomy (PTE) to remove blood clots on his lungs – the culmination of a long and frustrating journey to be diagnosed with thromboembolic pulmonary hypertension.

*“In meeting with candidates, I have realised that my own experiences with symptoms and diagnosis were quite common”, he said. “In 2006 I was a pretty fit guy, going to the gym on a regular basis, but I was finding I was getting a bit out of breath. I went to my GP who checked my stats and told me I was fine. She said it could be the*

“I’m speaking from personal experience when I tell them they will be well looked after.”

*pressures of my job, or anxiety, causing my problems. I was given relaxation and breathing exercises to try and I was quite happy with that, thinking it must be in my head more than anything else.”*

After his symptoms worsened, Steve was given inhalers and angina sprays - before collapsing whilst climbing the stairs led to an emergency hospital admission.

*“I feel like this was my lucky break in a way, because the chest specialist who checked me over worked with Papworth too so her mindset with regards to my symptoms was totally different. I was sent for a scan, which showed blood clots all over my lungs, and I was referred to Papworth. I wasn’t too sure what it all meant, other than it was serious.”*

After a series of tests, it was here that Steve was finally given his diagnosis and prescribed oral medication whilst being kept under review. Eventually, he was put forward as a candidate for a PTE operation to clear the blood clots from his lungs.

to meet with future candidates to talk about his own journey.

*“My answer was ‘yes, absolutely”, he said. “It was a very small payback as far as I was concerned, as the team there had turned my life around. Although I still have what’s classed as ‘residual PH’ I’m doing all the things I want to do; I cycle, I garden, I play with my grandchildren - and all that was just not possible before the operation.”*

Steve has now met with hundreds of PTE candidates, making the short journey to the hospital two or three times a week over the last eight years. As well as face to face support, he also chats with them via email, and although the frequency and duration varies, meetings with the same person often take place numerous times.

*“I’ve spent time with all sorts of candidates, from age 18 to age 80. I make it clear that I’m not there on an advisory basis, but to tell them about my journey with PH, and draw them into discussions. It’s important for me to find out about*

Steve often meets people after their operations too and keeps in touch to see how they are getting on down the line.

*“It’s wonderful to see how lives have been turned around”, he said. “I’ve had guys contact me to say they are back out on the golf course, or back refereeing, and someone even contacted me to say he wanted to do what I do in terms of volunteering - he now covers me for holidays.*

*“I get a lot of emails from people telling me how encouraged they were to see me and hear about how ill I was, and how well I am now. I do keep the letters people send to me and some of them are really quite warming.”*

Although everyone put forward for a PTE operation will feel differently about their situation, there are two pieces of advice that Steve gives to everyone.

*“I always promote PHA UK membership, as my illness didn’t just affect me physically, it affected me psychologically too. It made me very low and I questioned at times whether everything was in my head. As well as support, membership connects you with others in similar situations, and as an organisation, they really helped me.*

*“The other piece of advice is to be careful of the internet. When I was initially given my diagnosis I went straight onto Google when I got home and read that, without a heart and lung transplant, my life expectancy would be two to three years. If I’d been aware of the PHA UK at the time I would have received far better advice.”*

Although Steve has already dedicated many hours to helping people put forward for PTE operations, he has no plans to sit back from it just yet.

*“What I do in terms of volunteering is small payback”, he repeated. “The team at Royal Papworth have turned my life around.” ●*

“It’s wonderful to see how lives have been turned around”

*“I remember being told that even though I couldn’t be cured, the team were confident they could get me from a WHO functional class three to one, giving me a far better quality of life. Without it, I would have two or three years left of a life that was probably going to be lived in a wheelchair. So, when I was offered the procedure, I made the decision to accept it that same day.”*

About a year after his operation, Steve was asked if he would be interested in returning to the hospital

their own journey to diagnosis. As you can imagine, in a lot of cases, the candidates can be quite traumatised - so if they have someone with them, it’s normally them asking the questions.

*“I never look to raise their expectations. I keep things realistic; it is a big operation, and there are risks, but in my opinion, this centre is the best in the world. They’ve now carried out something like 1800 or 1900 procedures. I tell people they will get incredible support and guidance, which is what I had.*

.....  
**theinterview**  
.....



.....  
Lead Nurse for the  
Pulmonary Vascular Disease Unit  
at Papworth Hospital NHS Trust

**NATALIE DOUGHTY**

=====  
*in conversation with*  
**Deborah Wain**

Natalie's experience with pulmonary hypertension goes back over three decades and includes caring for the first PH patients in the world to be given intravenous (IV) Prostacyclin. She has acted as a coordinator for industry trials and in-house clinical trials and projects, and she was also co-developer of CAMPHOR, the first disease-specific quality of life questionnaire used all over the world for assessing this important outcome for patients. She has won awards from the Health Enterprise East Innovation.



Competition and the World Health Organization 3rd International Symposium on PAH. Natalie now leads the nursing team that delivers care to Papworth PH patients and among her other professional activities she acts as a peer reviewer for the International Journal of Nursing Practice and is a visiting lecturer for Anglia Ruskin University where she teaches on the Advanced Nursing Course. She is married to Chris and has two children, Bryony and Richard.

.....  
**Q. Did you always want to be a nurse?**

**A.** *I did. One of my earliest memories is of my brother's comic in which two children played doctor and nurse, using their toys as patients. I loved it. I thought about doing other things growing up, but always came back to being a nurse. I never really gave anything else serious consideration.*

.....  
**Q. Did PH find you or did you find PH?**

**A.** *Serendipity! When I first came to Royal Papworth Hospital we had just started using IV Prostacyclin for PH patients. We were the first place anywhere in the world to use it this way and I remember sitting with the other nurses trying to rig up a reasonably safe system that the patients could manage themselves, and then teaching them. It was all very cutting-edge. About 20 years ago I got involved with clinical trials at a time when the interest in new treatment pathways was exploding, and I was involved in the clinical trials for nebulised Iloprost, IV Sildenafil, Bosentan, Sitaxentan, Macitentan and sub-cutaneous – under the skin - Remodulin. It was an exciting time to be a PH research nurse.*

*After I'd completed my Masters degree, I was asked to take over the fledgling PH specialist nurse service at Papworth. I've been doing this for about 13 years now.*

.....  
**Q. What insight can you share about your experience working on clinical trials?**

**A.** *Clinical trials are a good way to give back. All the treatment*

*we have now are a result of clinical trials, and it is the determination and generosity of patients that makes new treatment possible. From a research nurse perspective, I remember it as being very exacting work. Every little thing is noted, analysed and documented, and no deviation from the protocol is acceptable.*

.....  
**Q. What impact do you think CAMPHOR has had?**

**A.** *The UK specialist nurses have been meeting regularly for sixteen years and one of the main focusses of meetings has been about how to put the patient's experience front and centre when decision makers (commissioners, managers, physicians) are negotiating management guidelines and policies. The CAMPHOR was an extremely well-researched and well-constructed outcome measure, and it was the first PH specific measure to be used regularly with UK patients. When the CAMPHOR was developed, we had, at last, an objective quality of life measure that was sensitive to treatment-related changes. It meant the measure achieved real importance in assessing treatment effects.*

.....  
**Q. Has the role of nurse in the care of PH patients changed much during your career?**

**A.** *Dramatically. Most PH specialist nurses now do their own out-patient or tele-clinics. In the early days, there were relatively few patients, but they tended to be sicker. Now in common with the other specialist centres, our patient throughput has increased six-fold in the last decade. Our patients... >>>*

theinterview

NATALIE DOUGHTY

“For many patients the diagnosis is an odd sort of relief. At last someone has taken them seriously, and there is a name and treatment for their condition.”

...now tend to be older with more co-morbidities, additional disorders or diseases, so we have to be expert at holistic care, and be familiar with a much wider range of therapies and interventions.

**Q. Please tell us a bit about your current role. Do you still get to work directly with patients?**

**A.** I lead the PH nurses service at Royal Papworth. There are my three wonderful specialist nurse colleagues Samantha Ali, Nicola Speed and Nisha Abraham and our administrator, Suzanne Turner. I regularly attend clinics and see patients on the ward.

**Q. What is the most rewarding aspect of caring for PH patients?**

**A.** For many patients the diagnosis is an odd sort of relief. At last someone has taken them seriously, and there is a name and treatment for their condition. Their increasing survival is also a source of great satisfaction. I love that I have patients under my care for a couple of decades now. We build a real relationship. I also like to see the patients at our local support group. Watching them interact with each other is satisfying, and so is seeing real hope dawning for patients who see others with the same condition leading useful, contented lives.

**Q. How important is teaching to you?**

**A.** I enjoy teaching. I act as a visiting lecturer at Anglia Ruskin University on their cardiothoracic course. I also - in common with all the specialist nurses - do regular teaching for other groups in and out of the hospital. My team also runs regular teaching sessions for housekeepers and care assistants and administrators and I get a real kick out of seeing their increased engagement after these sessions. I also give talks to various

groups in the community, usually Women's Institute and Rotary groups. One of the major delays to diagnosis is patients not going to their GP for a long time when the symptoms start. Raising awareness among the general public is as important as raising awareness for hospital doctors in secondary care.

**Q. How much talent is coming through in PH services?**

**A.** PH attracts good people. In my own institution we have many applicants for the research fellow roles. Specialist nurse vacancies are actively sought after. I think PH will be well-served by the next generation of specialists coming through now.

**Q. And finally, how do you relax when you're away from work?**

**A.** My family first and foremost. I was a single parent and my children were so patient and good about my absences at work as they were growing up. I think they understood that nursing wasn't something I could just down tools and walk away from at 5pm, even when it impacted after-school activities. I'll always be grateful that they made juggling my work-life balance as easy as possible given the circumstances. They are just two lovely people.

It's a bit of a busman's holiday, but I act as a Community First Responder, so I attend education and training for that at least once a month.

I enjoy pub quizzes. My local village pub runs a quiz in the winter and I enjoy the fellowship and teasing! I've lived in the same village for about 35 years so community is important to me. I love dancing, and I'm usually the last off the dance-floor. I also love reading, and I'm currently into 'Meditations' by Marcus Aurelius. Finally, my favourite time of all is spent walking around our village with my lovely husband, Chris. I am happy and I know it, so am doubly blessed! ●



## PHinding Your Hope International PH Conference in Florida

PH community members from around the world were invited to join the American Pulmonary Hypertension Association's 2018 International PH Conference in June.

The 13th biannual conference, titled 'PHinding Your Hope', took place from 29 June to 1 July at the Renaissance Orlando at SeaWorld. It brought together nearly 2,000 people with PH (both newly-diagnosed and long-term survivors) and their families, caregivers and PH-treating health care professionals and researchers.

The three-day event provided a safe space to help people living with PH, and their families and caregivers, feel more empowered. Medically-led sessions covered the latest advancements in research, treatment and care, and delegates had the opportunity to participate in future research that could lead to new discoveries.

PHA UK chair Iain Armstrong attended the conference with trustee Kay Yeowart and her husband David, and Dr. Helen Stockdale, an associate of the PHA UK.

Kay and David's son Lewis was diagnosed with PH in the 1990s and the family travelled to the USA to seek treatment for his condition.

Kay, who helped set up the PHA

UK in 2000, said: "Attending the US conference is always really interesting and provides the opportunity to network with others around the world and learn more about medical advances. I was able to exchange ideas with other associations and bring back new knowledge that will benefit patients and members in the UK."

"I was really impressed with the research hub where I was able to give blood to three different studies into PH. I thought it was a great way of obtaining blood from people in the PH community at such a well-attended event."

"During meal times we had the chance to talk to different medical professionals and listen to motivational talks. One I found particularly inspiring was by Elvis Medrano - a Washington, D.C Golden Glove Lightweight Champion boxer who was invited by the American PHA to be their celebrity champion. At 27 years old, he'd battled PH for six years and his speech really resonated with everyone in the audience, especially the men."

Dr. Helen Stockdale is currently working with the PHA UK to conduct research into pregnancy and PH.

She attended a practical session titled 'Childbearing Potential: The importance of Contraception and Pregnancy Prevention in PH'.

Helen said: "In the session, we heard that pregnancy is high risk and best to be avoided. What I found interesting was that in amongst this very clear message, there was an acknowledgement that things may change in the future. When discussing contraception, the advice was for young women to choose reversible contraception because who knows what the medical advice will be in ten years' time. Some other areas discussed were egg harvesting and the tricky question of when to start discussing contraception with your daughters who have PH."

"It highlighted how important it is to have open and informed discussion about contraception and childbearing. The experience will certainly be useful in my current project with PHA UK; the questions and issues raised at the conference will add to the stories and information I have already and help to shape the finished product."

"The most important legacy of the conference for me was hearing all the stories of those affected by PH - from those speaking at the front, to those making comments from the floor, to conversations over a coffee. The conference was titled 'PHinding Your Hope', and amongst these stories there was indeed hope to be found." ●

"You just have to carry on..."

PHA UK member *Maria Fernandes* wrote to *Emphasis* to share her story of trying to keep positive with PH. In this letter, she looks back on her journey.

## Dear Editor,

My name is Maria and I am 44 years old. I guess all this started when I was born with a heart defect. As I was growing up it did not affect me; I enjoyed school and college and got my first job in the caring profession at the age of 18. I visited my local hospital for check-ups on my heart every year.

Pulmonary hypertension did not come into my life until my early thirties, when I noticed I was getting short of breath. After a visit to my GP I was sent off to be reviewed by a lung specialist at my local hospital and after tests and a CT scan, the diagnosis was confirmed.

I learned to live with it and carried on with life and work. My symptoms at this point were very manageable and I started a job at my local hospital as a nursing auxiliary.

I attended medical appointments for check-ups on the condition of my lungs and had chest x-rays every year.

I carried on with life as normal but noticed very quickly I was getting worse. My shortness of breath got more complicated, followed by chest discomfort. My ankles started to swell and get uncomfortable, rising up my legs.

I was still working but struggling, and I said to myself, 'I have to do something, as I cannot carry on like this'. This was around May 2017.

I had an emotional discussion with both my cardiologist and lung specialist. They did not have the resources of more specialised care - but they knew of somewhere that did. This meant I had to travel far - but I did not care - I just wanted help.

My employers were also very supportive at this point and told me to do what I had to do to get well.

I got referred to Bristol Royal Infirmary Heart Institute by my local hospital, where I met Dr Luke Howard, a respiratory consultant, and Prof Tulloh, who was a cardiologist. Both of them I found made a dynamic team.

During my first visit my six-minute walk test only lasted just under two minutes. I got very breathless and my saturations dropped well below 90 per cent. This led to my first hospital admission to Hammersmith, in June 2017.

After being there for four days, and undergoing a lot of tests, I was told I had blood clots on both my lungs.

After taking various medication without much success I was told by my PH

PTO



team that they were contacting Papworth Hospital in Cambridge, who specialise in removing clots. They believed that this was the best shot that I was going to get. However, I was informed down the line with hospital follow-ups that I was a 'complicated patient', because I had already got heart defects and surgery was high risk - but they were going to discuss it further.

I have since been told the operation is not an option for me. So, the medication which I am on now is what is keeping me alive and that is a wonderful thing in itself.

There are not many options left now. I have gone back to work, but not in the role I was in before. I informed my employers and they were supportive. I went gradually back to work on a phased return. Work is part of my independence, and I wish to keep that for as long as I can.

My symptoms include fatigue, dizziness, loss of appetite, nausea, tiredness and shortness of breath, with painful chest discomfort at the slightest task of walking from one room to another. My body feels like a dead weight. I also got a dry cough every day which makes me heave. It can sometimes be unbearable, and I feel frustrated and get very emotional. I have these symptoms most days and I deal with them by resting. But I find too much resting is no good either. I have to make an effort to keep going for my sake and for the sake of my partner. We both deserve it. Life is precious.

My partner, who is a wonderful and amazing man, helps me to wash, and on rare occasions, to feed me. He is a man in a million. We have worked out a strategy to do housework together, because it cannot be all on one person's shoulders - it is too much. As for work, I have found my own way of coping as an administrative assistant. You just have to carry on.

I have read some inspirational stories in *Emphasis* magazine. I get tearful as most lives have been changed through either medication or some other form. I am so happy for these people. But it does not happen for everyone and I want to emphasise this as I am sure I am not alone.

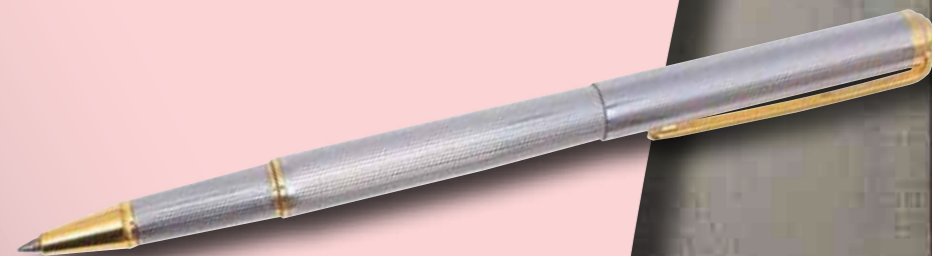
What about the carers who do an amazing job of looking after us, loving and supporting us? Who is looking out for them? They deserve a medal. Are they being recognised?

This is my story. The fight goes on for a cure.

Kind regards

*Maria Fernandes*

Swansea, South Wales



# Celebrating 70 years of the NHS

In a special feature for Emphasis, Michelle Rawlins reports on the evolution of a service that's put our nation at the forefront of medical care and welfare.

**I**n July, the National Health Service celebrated its 70th anniversary – an incredible feat by anyone's standards.

The service originally launched in 1948 after the Labour government announced that good reliable healthcare should be available to all, regardless of their financial situation – a core principle that remains at its heart today.

Spearheaded by the then health secretary, Aneurin Bevan, for the first time in the UK's history, hospitals, doctors, nurses, pharmacists, opticians and dentists were brought together under one revolutionary organisation.

Over the last seven decades the NHS has dramatically transformed the health and wellbeing of our ever increasing nation, continually evolving to serve the needs of all who access it. Over 17 million more people access the service now than when it first began.

*We have so much to thank the NHS for. Its achievements are nothing less than incredible and more pertinently, life changing.* Constant research and medical advances mean we can

all expect not only a much higher standard of care, but to actually enjoy life for longer.

## A timeline of care

From the very start, medical care was on the rise and it wasn't long before spectacular results were witnessed. By the late 1950s, the introduction of vaccines meant we were no longer at risk of polio or diphtheria and those with mental health disorders were given the care they needed - as opposed to being placed in Victorian style institutions.

1960 saw the first UK kidney transplant take place at the Royal Edinburgh Hospital. Just eight years later Britain's first heart transplant, only the 10th in the world, was deemed a huge success.

The swinging sixties also saw the launch of the contraceptive pill, playing a huge role in the women's liberation movement and sexual freedom.

The constant emergence of the most incredible pioneering

treatments continued through the following decade. In 1972 the first CT (computerised tomography) scans came to fruition, not only earning it's inventor, Godfrey Newbould Hounsfield, a Nobel Prize, but allowing doctors to diagnose a plethora of potentially life threatening conditions - including cancer and stroke.

The end of the seventies will go down in international history after the world's first IVF baby, Louise Brown, was born on July 25 1978, at Oldham General Hospital. This has led to more than one million children worldwide being conceived in a similar way – bringing untold happiness to parents across the globe.

The following year, the UK's first successful bone marrow transplant took place on a child at Great Ormond Street – the hospital that soon came to be renowned for its pioneering treatment on poorly children from across the world.

The eighties saw a plethora of advancements within the NHS. Keyhole surgery was used for the

first time to remove a gall bladder and in 1984, two-year-old Benjamin Hardwick became Britain's youngest liver transplant patient, giving him an extra 14 months of life.

Four years later, in a bid to reduce breast cancer deaths in women over 50, a national screening project was launched. Combined with improved drugs, including Tamoxifen and Herceptin, the number of breast cancer deaths was reduced by an incredible 20 per cent.

The nineties saw the emergence of NHS trusts, concentrating on care within local communities. But what stands out for this decade is the launch of the NHS Organ Donation Register, following a five year campaign by John and Rosemary Cox after their son, Peter, 24, died from a brain tumour. One of his final wishes was for his organs to be donated to help others.

The start of the new millennium saw 18-month-old 'bubble boy' Rhys Evans successfully treated with gene therapy, to cure him of severe combined immunodeficiency. And in 2006 we saw the launch of the pneumococcal meningitis vaccination of babies under the age of two. Two years later we witnessed the HPV vaccination begin to protect girls aged 12-13 against cervical cancer, which has now been extended to those up to 18.

The last decade hasn't been short of huge medical advances either. 2012 saw Mark Cahill become the first UK

recipient of a hand transplant and 2014 began with the NHS 111 phone service, giving people access to urgent medical healthcare.

Over the last two decades we have also seen the emergence of a network of specialist centres for those living with pulmonary hypertension - allowing patients to access the ever-evolving treatment and services on offer.

## Saying thank you

To celebrate their 70th anniversary year, the NHS, now one of the world's largest publically funded health services, announced a programme of events up and down the country. There was a huge party in the park in Peterborough, an afternoon tea in Birmingham, museum exhibitions, and hospital fun days - to name but a few.

And why? Because without our NHS a huge percentage of our population wouldn't be able to access the healthcare they need to live a full and healthy life. As founding father of the NHS, Aneurin Bevan recognised all those years ago: *'Illness is neither an indulgence for which people have to pay, nor an offence for which they should be penalised, but a misfortune, the cost of which should be shared by the community.'*

Everyone has the right to good healthcare and without this incredible service, our nation would be a much poorer place.

PHA UK members took to our Facebook page to wish the NHS a happy birthday...

*'Happy Birthday NHS! I just want to say thanks (for helping) me and my little boy when I was pregnant, thanks for saving our lives and for getting us back on track and all the ongoing support that you give us throughout my illness.'*  
Pauline Harrison

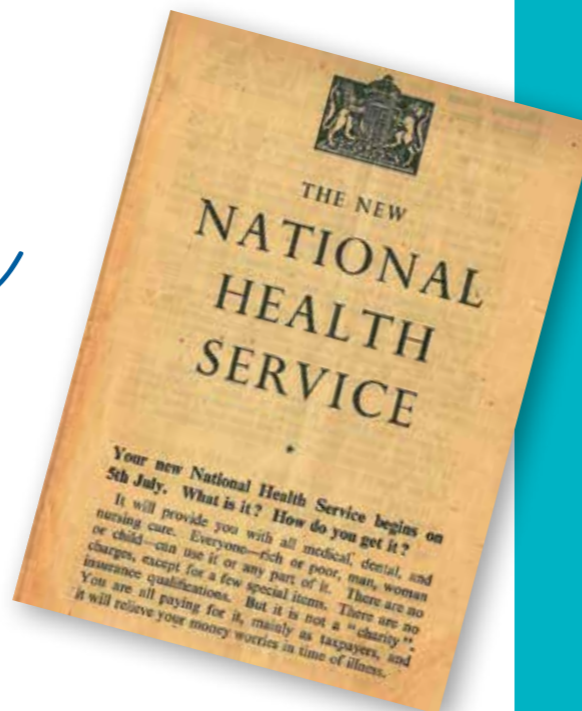
*'NHS well what can I say, I wouldn't be here without the amazing care and medication that I have received since diagnosis, truly amazing people and service. Thank you so much.'*  
Sarah Louise Moxon

*'Thank you to all our amazing NHS teams who make such a massive difference to their patients' lives and also their loved ones. Thank you for all my specialist care since diagnosis two and a half years ago. Forever in your debt.'*  
Vesta Poulston

*'Many thanks for saving my daughter's life and looking after her and her complex health condition heart / lung for the last 25 years and hopefully more to come. She wouldn't be here otherwise I am very eternally grateful for sure.'*  
Nichola Stukalo



Aneurin Bevan, first day of NHS  
5th July 1948 ©Park Hospital Manchester



Nurse study group  
©Queens Nursing Institute



A District Nurse gives an insulin injection to a patient 1949  
©Queens Nursing Institute



Community Midwife on bike  
©Queens Nursing Institute

**NHS 70**



# Prepare early to protect yourself from 'flu

With a new season beginning, it's time to start thinking ahead about winter illness, writes consultant pharmacist *Neil Hamilton*.



*If you are like me, you will have loved the hot and sunny summer weather - provided you didn't have to be at work! Our office has a great view of the city of Sheffield but no air conditioning whatsoever, so it has been like working in a greenhouse.*

**S**adly, now the holidays are over and everyone is back to school or work, autumn and winter are not far off. Beautiful countryside walks and colourful leaf drops are something to look forward to, but with them often comes a turn in the weather. And for many people, this colder weather brings concerns over colds, flu and other illness.

As a result, this is the perfect time of year to plan ahead and think about how you can help defend yourself against the prospect of suffering a bout of the flu. You can do this quickly and easily by having the flu jab (flu vaccine). ***I can tell you from personal experience that since I had full-blown flu once, booking in for an annual flu jab has been a priority just as soon as my GP surgery has this year's batch in.*** Making sure everyone has a flu vaccine has become a priority for the NHS and there are national advertising campaigns reminding everyone, with very good reason.

**“ PH puts you at greater risk of catching flu ”**

Flu is an extremely debilitating and unpleasant viral illness for the fittest in society and unfortunately those people with other conditions will fair even worse. Having pulmonary hypertension (PH) may not only put you at greater risk of catching flu, but will have a far greater impact on you.

Indeed, your body may really struggle to fight it off and this will almost inevitably have an impact on your breathing. ***I cannot emphasise enough how sensible it would be for PH patients to ask their GP, nurse, pharmacist or specialist centre about flu jabs.***

**“ It is also possible to protect yourself against pneumonia and shingles (amongst other conditions) ”**

There are very few reasons why you wouldn't be able to have it on medical grounds. The main exception is those of you taking medication that dampens the immune system. The flu jab is a very tiny dose of the flu virus so if your immune defences are down, the effect of the little dose is magnified. Please be aware that the vaccine itself contains egg proteins, so if you are allergic to eggs, just check with the clinic if they can obtain an egg-free version (these are not available every year).

Not many people have serious reactions or side effects, but obviously as this is a tiny dose of the virus, some people feel a bit 'fluey' for a day or two. This can often be easily controlled with a few doses of paracetamol if necessary.

Although flu jabs are the most common vaccine that most people have these days, it is also possible to protect yourself against pneumonia and shingles (amongst other conditions).

The pneumonia vaccine gives protection against serious chest



infections, and may be recommended for 'high-risk' groups, but not everyone would need one. If in any doubt, just ask your GP, nurse or pharmacist. Unlike the flu jab, this is a one-off vaccine usually giving life-long protection.

The shingles vaccine is a very safe

way of protecting older people from developing this reactivation of the chicken-pox virus. You must be aged 70 to 80 years old to be entitled a shingles vaccine (the vaccination seems to be less effective in the 'over 80s'). It is a one-off jab with no repeat doses necessary and research suggests that the vaccine will give you at least five years protection.

If you have access to the internet, there is lots of helpful information on these vaccines on the NHS website at [www.nhs.uk](http://www.nhs.uk). Just type 'vaccinations' in the search box at the top of the page.

If you can't get onto the website, just ask a healthcare professional who will be more than happy to advise you.

***I would suggest that 'fore-warned is fore-armed' and with a bit of planning you may be able to save yourself the risk of nasty viruses this autumn and winter. Hopefully once you are prepared, you'll be able to look forward to leaf-kicking and snowball fighting!***



## ME & MY JOB



Welcome to our regular column where PH professionals and associates tell us more about themselves and their work. This issue, meet **John Smith**, PHA UK's associate graphic designer. John works with the media team and designs this magazine.

**HOW LONG HAVE YOU WORKED WITH PHA UK?** Just over three years – my first project for PHA UK was to give *Emphasis* magazine a revamp for Spring 2015. This issue will be my 14th edition.

**WHAT DOES YOUR JOB INVOLVE?** I design all communications material, from the magazine you're reading now to the pocket guide to PH and the publications given to patients such as financial support. I also get involved in strategic planning for future projects and campaigns and I help run PHA UK's recurring PHocus2021 meetings.

**WHAT DO YOU ENJOY MOST ABOUT YOUR WORK WITH PHA UK?** I enjoy working in collaboration with other people such as the PHA UK media team to produce work together that genuinely makes a difference to people's lives. I also enjoy working with PH patients because I receive great feedback from them about the impact my work is having on raising awareness of PH.

**WHAT DO YOU LIKE TO DO OUTSIDE OF WORK?** I'm a member of the local Mountain Rescue Team. We're on-call 24/7 and it is totally unpredictable so it can be a very quiet month and then three call outs in a weekend or one in the middle of the night. I also enjoy a spot of fell running and I'm saving up my pocket money for a motorbike to fulfil a childhood dream.

**TELL US AN INTERESTING FACT ABOUT YOURSELF?** In the 90s, when I worked for an advertising agency in London, I was once paid to fly out to Mauritius and spend a fortnight taking photographs of sunsets for an extravagant corporate client, and I wasn't even the photographer! I took a guy with a camera with me who did all the 'hard work'...

**TEA OR COFFEE?** Either, as long as it's decaf with soya milk.

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

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### In your Winter issue of *Emphasis*...

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

**Modern mobility aids**  
Fashionable meets functional

**Travelling by campervan**  
Alternative holidays for people with PH

**Life after transplant**  
Kirsty shares her story

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

You can get involved in *Emphasis* too:

**Emphasis Reviews** - read a book, used an app or seen a film you think other readers may be interested in? Tell us about it!

**Family Matters** - let us know if you'd like to tell us about your family's PH experience in our regular feature.

**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.

We always love to hear from you – contact [editor@phauk.org](mailto:editor@phauk.org) with any feedback or ideas.

# Join our PH family for free today

## Be part of a 4,000-strong national support network.

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Are you living with PH, or have friends and family who are? We're here to support people like you.

Being part of PHA UK also enables you to participate in important research, and our friendly office staff are just one call away when you need advice. Join our PH family and you'll be joining 4,000 members in a unique network of support and inspiration.

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### Join today and benefit from:

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- Helpful printed information and resources
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- Free access to emotional support from qualified professionals via our partnership with **Anxiety UK**
- Free access to financial advice from qualified professionals via our partnership with **Turn2Us**
- Fundraising ideas and guidance



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Are you a Patient  Carer  Parent  Medical professional

Other (please state) \_\_\_\_\_

Are you willing to take part in PHA UK surveys? Yes  No

Which **specialist treatment centre** do you attend? \_\_\_\_\_

Pop your completed form into an envelope and return to us for free to **FREEPOST, PHA UK** (no stamp needed).

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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](http://www.phauk.org)  
**Email:** [office@phauk.org](mailto:office@phauk.org)  
**Address:** PHA UK Resource Centre, Unit 1, Newton Business Centre, Newton Chambers Road, Thorncliffe Park, Chapelton, Sheffield, S35 2PH  
Registered Charity Number: 1120756

### 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 or email: [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk)

### 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 to 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](http://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](http://www.phauk.org)

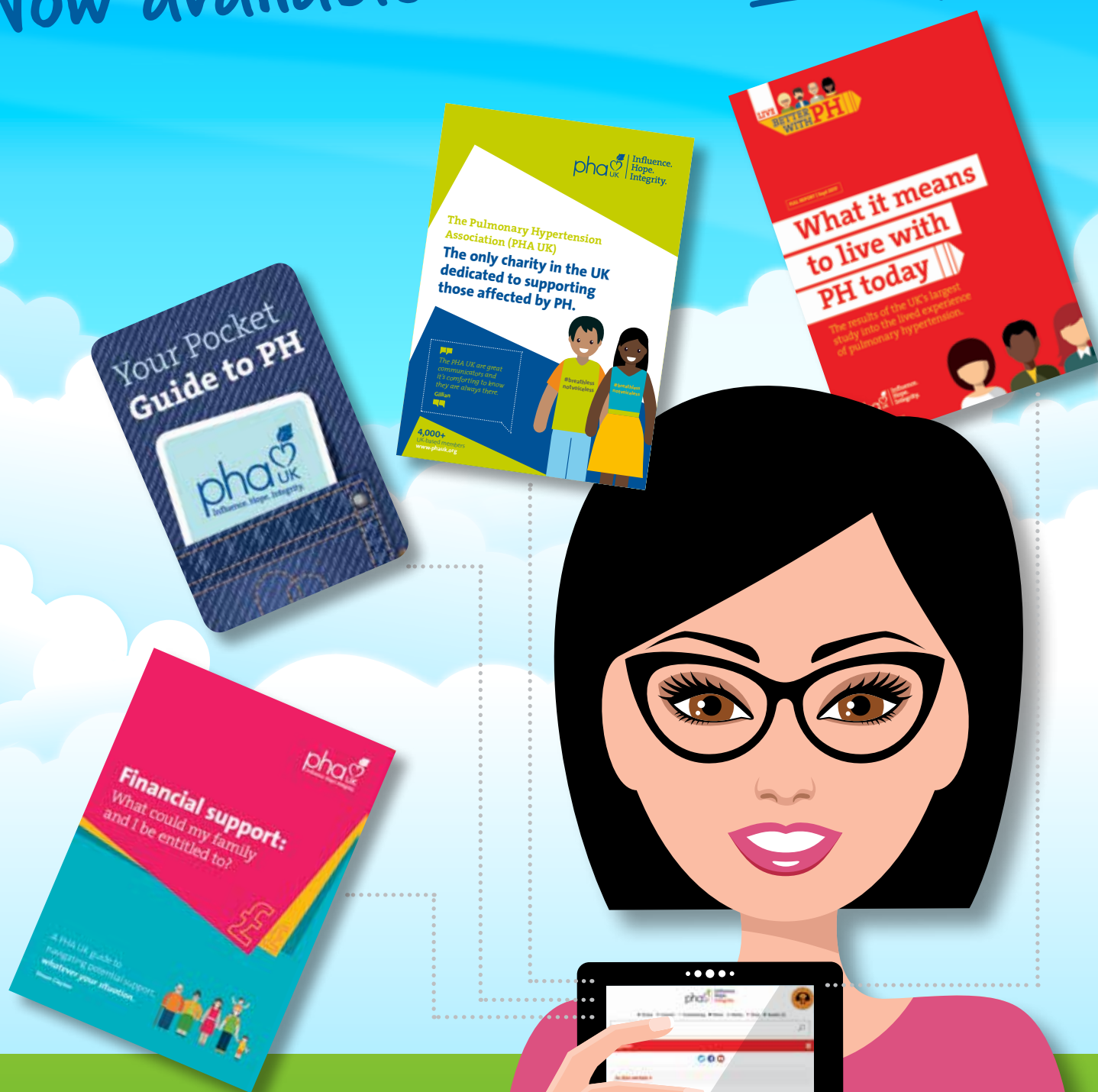
### Do we have your correct details?

Please email us on [office@phauk.org](mailto: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?

Emphasis magazine is produced by PHA UK. Content by Capital B Media. Design by Creativesmith. This magazine is intended only to provide information and not medical advice on individual health matters. PHA UK will not be responsible for readers' actions taken as a result of their interpretation of this magazine. We encourage readers to always discuss their health with their doctors and medical team.

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