

SUMMER 2017

emphasis

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

Pedal Power

How electric bikes can help you get out and about this summer

HOW MUCH IS TOO MUCH?

All about alcohol with Neil Hamilton

PHocus2021

The campaign calling for greater political PHocus on pulmonary hypertension

2017 CONFERENCE

Bringing patients and professionals together in Oxford

PLUS...

your letters and news, a new financial hardship fund, fundraising roundup and much more!

Keeping control

Karen's inspiring story



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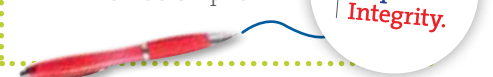
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This magazine is printed on paper from sustainably managed sources

With this issue of Emphasis:
4-page overview of the results of the **National Audit of PH**

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**



Welcome

Welcome to the summer issue of *Emphasis*, brought to you a few weeks after our latest conference.



It was great to see so many friends from the PH community come together in Oxford and we hope it was an enjoyable and informative experience for all. Take a look at our photo special on page 18 and see if you can spot yourself.

You'll notice this issue comes with a special supplement – an overview of the results of the National Audit of PH. This annual study of the UK's specialist centres shows that patients receive timely and high quality care, with many of the standards set by the audit being met. We've picked out the bits you told us were most important to you.

It's been an interesting few months for world politics, and we've been working hard here in the UK to encourage those with influence to listen to the voices of the PH community. To find out how we are helping put a political PHocus on pulmonary hypertension, turn to page 26.

This issue of *Emphasis* is also packed with news, views and patient stories, including a special feature on electric bikes. If you use one to get out and about over the summer, we'd love to see your photos.

Finally, a big thank you on behalf of everyone at the PHA UK to those who raise money to help support our work. The London Marathon round-up on page 22 is one of many great examples of the efforts people go to in the name of fundraising for the charity. We couldn't do what we do without you.

Iain Armstrong

Iain Armstrong
Chair of PHA UK
editor@phauk.org

“It was great to see so many friends from the PH community”



Emphasis *exchange*

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

"Mum is the strongest person we know"

Leicester-based PH patient Asha Sagoo said she was 'overwhelmed' to be nominated by her children as **'Mother of the Year 2017'** in a local competition. She was put forward in the Leicester Mercury contest by daughter Shannon, six, and son Ryen, nine, and the newspaper ran an accompanying article about pulmonary hypertension. In it, the children said: "Mum is the strongest person we know. Her heart is damaged but for us, it's the strongest heart a mum can have. She will always be the best and keep doing what she can to make us smile by playing games and tucking us into bed when she can because she can't walk up the stairs more than once a day."

"There are so many things we can no longer do together because of her illness. She is restricted so much but never gives up."

At the time of going to print, the outcome of the competition had not been announced.



ZARA'S LEAP OF FAITH

Zara Taylor and boyfriend Joseph Chamberlain took fundraising to new heights when they leapt out of a plane in aid of PHA UK.

The pair completed the 10,000ft sky dive at Skydive GB near Bridlington, in support of Zara's grandma Janet Mitchell, who has PH. They raised £2,000 by collecting sponsorship from friends, family, and customers at the pub where they work.

Zara said: "The sky dive was an amazing, breath-taking experience, and we'll definitely be doing another one! Nan was finally diagnosed with PH in 2010 after having been unwell for some time. She suffered heart failure in 2012 and is seen regularly at the Royal Hallamshire Hospital in Sheffield where she says the doctors and nurses are second to none. She is constantly battling her illness and believes if it wasn't for their expertise and dedication, she probably wouldn't be here."

Zara's grandma, Janet, watched the challenge with the family. She said: "We watched with bated breath as Zara and Joe fell from the sky at 120mph free fall, and landed perfectly just yards away from where we were all standing."



Social Media Round-up

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

f Donna Welch Just redeemed my Tassimo, biscuit wrappers and trigger spray recycling points for the last year, £210 coming to PHA UK in June x

f Joanne Slater Still can't believe it was me that raised over £2,000 by running Brighton Marathon. I'd do it all again too

f GlaxoSmithKline What is Pulmonary Arterial Hypertension? We chatted to Nurse Consultant Iain Armstrong, Chairman of PHA UK to find out more #WorldPHDay

t @CarolKeenPhysio Carol Keen First week in my new job as Clinical Specialist in PH - promoting physical activity in patients with PH #proudphysio

t @PHA_UK Congratulations to member @jewson_mt and new husband Terry!

t @davidnaghi_1 David Naghi My adopted daughter @wachiepoos at @PHA_UK stand at #Idconf in #York

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

JOAN'S COFFEE MORNING

Joan Hammond, from Bourton on the Water, organised a coffee morning in support of her grandson Will Acres, who was diagnosed with PH in 2016. The event, held at Joan's local Baptist church, raised £340 for PHA UK.

Joan's daughter Leah (Wills mum) said:

"All our friends and family are being so supportive. They all had a lovely morning and my mum was thrilled to receive a certificate."



BROMPTON HIGHLIGHTS RARE DISEASES

The Royal Brompton Hospital marked International Rare Disease Day with interactive stands and workshops to help increase awareness of rare diseases like PH.

Over 50 people attended the event and spoke with researchers about their work in rare disease research at the hospital. They also took part in activities including making DNA bracelets and extracting DNA from strawberries. A pancake recipe challenge enabled visitors to learn how genes play an important role in many rare diseases.

Dr John Wort, clinical lead for pulmonary hypertension at the Royal Brompton Hospital, manned a stand dedicated to raising awareness of PH. He is pictured helping school children learn more about the disease.



Hospital parking 'still too difficult'

Hospital trusts in England are still making it 'too difficult for people to pay to park' according to new research.

A freedom of information request from motoring organisation the RAC showed that many offer no option to pay by credit or debit cards, and others do not allow drivers to pay on exit.

Just a third of trusts (33 per cent) that have some degree of paid-for parking offer a payment by



card option at all their hospital sites, while a further quarter allow it at some of their sites. This means a large proportion of patients and visitors are still expected to carry loose change with them in order to pay to park.

Drivers' payment options are also limited at many hospitals by the fact that a third do not allow them to pay for parking when they leave. This means drivers are forced to guess how long their visit to the hospital will be and pay for a fixed period of time – and then risk either paying for more parking than they need, or having to run out and buy another ticket to avoid getting a penalty notice. Pay-on-exit provision is offered at some sites by one in three hospital trusts, and at all sites by nearly a third.

ico.
Information Commissioner's Office

Protecting your personal details

Members of PHA UK are being reassured their personal details will remain confidential after eleven charities were fined £138,000 for breaching the Data Protection Act.

The Information Commissioner's Office found charities including Oxfam and Cancer Research UK secretly screened millions of donors so they could target them for additional funds. Some charities also traded personal details with other charities, creating a large pool of donor data for sale.

Chair of PHA UK Iain Armstrong said: "We would like to reassure all of our members that their data will remain strictly confidential and under no circumstances will they be shared without their consent."

Leek club auction for PHA UK

Members of Coniscliffe Leek Club in Darlington raised £400 from a charity auction, in memory of long standing chairman Don Moody - who had PH. After their 45th annual Leek Show, fruits, vegetables and flowers were all sold to the highest bidders. Carol Marley, treasurer at the club, said: "The auction of show produce now enables the club to donate annually to local charities. One of the most popular items in the auction are the bags of mixed vegetables ready for a Sunday dinner".



RAISING MONEY IN SUPPORT OF REBECCA

A campaign by the family of a young PH patient in Wales has raised thousands for PHA UK.

Margaret Price and her family have been fundraising intensively in support of 11-year-old Rebecca Price, Margaret's granddaughter, who was diagnosed with PH just before Christmas.

Rebecca, who lives with her parents in Barry, is treated at Great Ormond Street Hospital.

At the end of April, along with friends, Margaret completed a sponsored walk up Pen-y-fan, the highest peak in South Wales. And on 13th May, a charity concert saw 200 people gather at the Con Club in Aberdare to enjoy performances by four musicians. The tickets sold out within days, and Margaret is already planning another event for those who missed out.

Staff and students from Cardiff and Vale College, where Rebecca's mum and dad both work, have also been

supporting their fundraising campaign. Their support includes a special needs student group auctioning a rugby shirt to raise £73.

Margaret said: "The family has been through hell and back but everyone has been so supportive, really marvellous. Rebecca is responding well to treatment, and you wouldn't think she was ill to look at her, but she has to carry a pump and oxygen wherever she goes."

Margaret's son Gavin, Rebecca's dad, set up a Just Giving page at the start of their campaign and in just one weekend, it generated over £500 in donations. At the time of going to print, the family has so far raised over £5450.



Emphasis *exchange*

If you have experience and ideas to share via the Emphasis exchange please email exchange@pha.org.uk and don't forget to keep it short! The Facebook and Twitter too.

Dear Emphasis readers,

I have enjoyed the last few days meeting and talking to you. I have been thinking about the last few days and how much I have enjoyed it. I have been thinking about the last few days and how much I have enjoyed it. I have been thinking about the last few days and how much I have enjoyed it.

The week of Emphasis is rapid and frequent. I have been thinking about the last few days and how much I have enjoyed it. I have been thinking about the last few days and how much I have enjoyed it. I have been thinking about the last few days and how much I have enjoyed it.

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In the Autumn 2016 issue of Emphasis, we printed a letter from member Graham Donald, who lives in Cyprus and was keen to connect with others with PH. Michael Tandy responded, and wrote to us to let us know how their friendship has helped him.

Mr Donald and I first became connected following an article he wrote which you published in a previous edition of Emphasis. In it he described his definition of how PH affected him. I was so impressed with this I showed it to my wife who had been continually asking me how I feel. I could not find the correct words until I read Mr Donald's description - it epitomised accurately how I felt and since then has been how I now explain my PH to other people. He also asked for other sufferers to contact him as he is a little isolated living in Cyprus, I did this and we have been in constant communication ever since. I have found this contact so refreshing and wonderful in helping me share often similar feelings, both mental and physical, and I now realise they are all part of the condition.

I have also shared with him a visit to the Hallamshire hospital, a centre of excellence in Sheffield of which I cannot speak too highly, and where I was cared for with courtesy and respect for my age. I learned far more here about my condition and the future than at any time in the last three years since I was diagnosed with PH. I am no longer frightened by what I have and am approaching it with confidence.

Michael J Tandy

Dear PHA UK,

I am writing to you with cheques to the value of £2000. Sadly my wife, Karen Clark, passed away in February after courageously battling pulmonary hypertension and, more recently, pulmonary occlusive veno disease. Karen had organised a 'Family and Friends' party in March and as promised, we went ahead with this to raise money for the PHA UK in her memory.

On the night we held an auction, which included a helicopter ride and a Ferrari ride. There was also a raffle with gifts donated from all of Karen's family and friends who attended.

Throughout her illness, Karen received incredible care from the PH team at the Royal United Hospital Bath and the outreach team at the Royal Free Hospital London, for which we are extremely grateful.

I am sure that this donation will be used towards the ongoing support and care given to other sufferers and their families and I hope that one day a cure can be found for this illness.

Kind Regards,
Don Clark



Pedal POWER

Sales of electric bikes have soared over the last year, with cycling now more accessible than ever to people with health conditions. Cycling fan *Luke Marino* takes a closer look at how e-bikes can help PH patients get out and about this summer.



e-bikes combine a standard bicycle with a battery and motor that helps out when you're pedalling.



In 2016, an estimated 80,000 e-bikes were sold in Britain, with ten times that amount sold in the Netherlands and Germany.

It's clear their popularity is rising, but how is an electric bike different? In short, e-bikes combine a standard bicycle with a battery and motor that helps out when you're pedalling, making it easier for climbing steep hills or for long-distance rides.

There are two slightly different types of e-bikes. One is known as the 'pedelec', which requires you to start pedalling in order for the motor assistance to kick in. The other type is the 'throttle' bike, which doesn't require you to pedal, and instead generates its power through a motor which can be activated by twisting the throttle or pushing a button on/off.

As with most motorised forms of transport, there is a maximum speed limit. Although you can buy e-bikes with motors that reach speeds of up to 50mph, to ride them legally in the UK, motors are restricted up to 15.5mph.

In terms of how long an e-bike battery will last, there's no definite answer,

as this depends on a range of aspects - including how much of the work you are doing yourself compared to the motor. However, a good rule of thumb is that an average rider on an average e-bike should get between 15-30 miles between charges. More advanced models can reach up to 80 miles.

All sounds great, doesn't it? The only downside is you'll have to dig deep into your pockets. If you're looking to get started, a simple city e-bike would

Heading out on an e-bike still provides you with a good amount of exercise, but the benefit is that there's a motor attached to provide that little extra oomph...

set you back around £450, whereas if you're in the market for a top of the range model, then you could part with as much as £8,000.

In today's world, e-bikes are fit for everyone. There is a whole range of them on the market, including hybrid, utility, standard road and even mountain bikes.

Heading out on an e-bike still provides you with a good amount of exercise, but the benefit is that there's a motor attached to provide that little extra oomph when you start to feel the strain - or when you want to keep up with family and friends!

E-bikes don't need to be insured, registered or taxed. As long as they meet certain requirements, you can also ride your electric bike on cycle paths and anywhere else pedal bikes

are allowed. However, you must be aged 14 or over to ride an electric bike on a public road in the UK.

For further information on the rules and regulations visit www.gov.uk/electric-bike-rules



The evolution of e-bikes...

Many think that electric bikes are a new concept, however, it may surprise you to hear that they were around in the late 1880s. As you can imagine, back then, they didn't travel very far or fast.

Fast-forward 125 years and a lot has changed. Continuous development and the rapid progression of technology has seen e-bikes appear trendier, lighter and quieter when in operation and with an improved range.

One of the latest innovations to enter the market are folding e-bikes, which have been a real hit with commuters. You can also now use conversion kits that allow you to convert a conventional bike into an electric bike.

One of the most popular conversion kits is the Copenhagen Wheel, which slightly differs from other electric bikes in that all components are elegantly packaged into one hub, meaning there is no external wiring or bulky battery packs. The wheel is controlled through your smart phone, meaning you can change gears, select how much the motor assists you, and view relevant real-time information.

1880

2017

What to consider when buying an e-bike...

There are now more e-bikes on the market than ever, so it's important to choose one that suits you best. According to Garf Taylor of E-bikes Direct (www.e-bikesdirect.co.uk) you should take into account the following:

- 1) Power output.** E-bikes have differing power outputs relating to the size of the motor, battery voltage and ampere that will determine how powerful the bike is and the distance it will travel.
- 2) Range.** Electric bikes have different ranges based on the mode of power, so it is key to check this prior to purchasing to ensure it suits your requirements.
- 3) Brand credibility.** Whilst in the main all are very functional, proven brands will have experience of the bike market and therefore will have adapted their specific brand to cut out any minor issues.



Read about Cas Lawson's experience with her e-bike...

Me & my e-bike



Cas Lawson lives in Kent and was diagnosed with PH in 2003. Earlier this year, she bought an electric bike to help her get out and about along the coastline.

“Since moving to the coast last year I’ve been trying to get more exercise, and have been building up my stamina by walking.

My husband is a keen cyclist and having seen many people using electric bikes locally, he suggested that I might like to get one as a way of increasing my exercise and going further afield.

I was a bit concerned about the cost and how much use I’d get out of it. My husband did a fair amount of research about the types available and I also discussed the prospect of getting an electric bike with the specialist nursing team at the Royal Free before I bought one.

Prior to moving to the coast, I used a mobility scooter a lot more, but the bike gives me the opportunity to go a greater distance (and faster!).



We visited the showroom of an online company which is reasonably local to us. **The salesman was helpful and informative and also showed understanding of my needs as he’d come across PH before.** I ‘test drove’ three different styles of bike and that convinced me to go ahead.

When making my choice I took into account the weight of the bike, that it has a clear LCD display showing speed, the level of power assist, mileage and so on. I also took into account that it has a restricted throttle (limited to 4mph) that you can engage if necessary which replaces the need for pedalling.

I bought my bike from E-bikes Direct (www.e-bikesdirect.co.uk) and it cost £800. It was delivered very well packaged and ready assembled; all we needed to do was put on the pedals, put the handlebars in the correct position and charge the battery for 24 hours prior to first use. The battery locks in position underneath the cycle rack and is easy to remove for charging.

Prior to moving to the coast, I used a mobility scooter a lot more, but the bike gives me the opportunity to go a greater

distance (and faster!) and also, unlike when using my mobility scooter, I feel less conspicuous.

As soon as you turn the pedals you feel the power assist kick in and can then put in as much or little effort as you are able to / want to.

Even just using my bike on the seawall and seeing some of the local coastline from two wheels has given me a feeling of greater independence. It means I can go out cycling with friends and no-one has to slow down to my speed, as they do when out walking. In fact, now it’s the other way around – in a head wind, I crank up the motor assist and away I go!



Putting it into words

Alisha Harding is a staff nurse on the cardiac intensive care ward at Sheffield’s Northern General Hospital. She sent us this poem in memory of her grandmother, Patricia Ann Othen.

Grandma

Working on a Monday,
Picking the grandchildren up
on a Tuesday,
Shopping on a Wednesday,
Tidying the house on a Thursday,
Fish and chips on a Friday,
Meeting up with friends on a
Saturday, cooking the family roast
on a Sunday.

To

Walking beneath the trees that shed
the autumn leaves before

Preparing the family Christmas meal
in the winter freeze

Walking through the clear spring
breeze

burning in the summer heat at
20 degrees

Here I am, this is me.

PH overtakes, the rest becomes
a myth,

Hospital appointments, blood tests,
surgical procedures not forgetting the
horrible shortness of breath

I look blue in the lips what’s
happening to me?

Help stop PH take over me

Haven’t seen my friends in a while,
I can no longer go out alone.

I rely on my family to look after me -
the roles have reversed and I am
no longer capable

PH has arrived and made my future
debatable.

Here I am,
this isn’t who I want to be

PH has overtaken and there’s
no cure for me,

Sadly I’ve died, but my spirit lives on,
in hope of a cure for those that live on.

Help me find an answer and put PH
to rest; it’s time we take over and
give our best.





A weekend to Remember!

The sun shone as members old and new gathered at Heythrop Park Hotel in Oxford for the 19th *pulmonary hypertension patient conference* organised by PHA UK.

From Friday 12th to Sunday 14th May, patients and their families enjoyed educational talks, entertainment and the chance to make new friends and share experiences.

PHA UK Chair Iain Armstrong opened the expert talks on Saturday morning, introducing a series of presentations by PH professionals from across the country.

Professor Paul Corris linked his love of Newcastle United with a detailed overview of PH, the tests, the treatments and the goals, and Neil Hamilton continued the football theme by sharing his thoughts around PH drugs based on a first team formation.

Dr Luke Howard, speaking for the first time at the conference, discussed the development of new technologies and the impact of exercise intervention.

Shaun Clayton, membership services director, also made his conference stage debut, with an insight into the welfare system. Offering practical tips and benefits advice, he ended by assuring patients that although they may have to fight for what they deserve, it's important not to give up.

Professor Janelle Yorke led an interactive discussion about managing breathlessness, and an expert panel debated questions posed by patients ahead of the conference.

After a relaxed buffet lunch, afternoon break-out sessions included Thai Chi, flower arranging, homeopathy and physical rehabilitation.

A workshop with Anxiety UK offered advice on managing the emotional impact of PH, and clinical nurse specialist Wendy Gin-Sing led a session on supporting loved ones during their PH journey.

Children's activities included creative crafts, crazy golf, magic and balloon modelling, treasure hunts and a sing-a-long show.

The day ended with a pirate-themed gala dinner and disco and as well as a packed conference programme, families were able to enjoy the extensive grounds and top class leisure facilities offered by the hotel.

The conference talks are available to view on YouTube; simply search 'PHA UK conference'.



SOUNDBITES FROM THE STAGE...

"You might be breathless but you're not voiceless; and many of you have proved that time and time again."

Iain Armstrong

"We're providing a lot of food for thought for the international community in terms of treatment for PAH."

Dr Luke Howard

"Breathlessness can be distressing and frustrating, but there are techniques and exercises that can help."

Professor Janelle Yorke

"You're going to have to fight for what you deserve when it comes to benefits."

Shaun Clayton

"There's been a huge change in the way we look at exercise in people with PH."

Professor Paul Corris

"There are frustrations, but we are fighting your corner the best we can, at a high level."

Neil Hamilton



Lots of people took to social media over the weekend, using **#PHpatientconf** to share their conference experiences:



@ukstressbusters A great day massaging at the PHA UK patient conference. #PulmonaryHypertension #breathlessnotvoiceless @PHA_UK



@CarolKeenPhysio Great early talks at #phpatientconf, good to see physio and exercise makes the 1st team for treatment. #letstalkph



@Jewson_mt (Tess Jewson) Thank you so much to @PHA_UK for a super weekend & conference!



Catherine Makin Fantastic weekend in Oxford for the conference. Enjoyed every minute. See you all again next time!



Pottering About I absolutely loved my time with everyone, it was the most rewarding day I have had for a long time.



RUNNING **roundup**

Here are just a few of our 2017 pavement-pounding fundraising heroes.

Lots of you have been lacing up your trainers for PHA UK over the last few months, taking on sponsored runs up and down the country.

Spartan Sprint

Sixteen-year-old Zac Brailsford from Nottingham completed the Spartan Sprint, which involved tackling over 20 obstacles, including walls and fire, to raise money in memory of his grandma Joan Horridge.



£595
RAISED

Great Birmingham 10k

Professional cricketer Mark Adair swapped his bat for the road to take on the Great Birmingham 10k. Mark, who plays for Warwickshire County Cricket Club, said: "My best friend recently met his girlfriend, and it so happens her mum suffers from PH. A life without my mum would be horrible and so I thought I'd help out and get involved with the cause." Mark is planning on doing more fundraising throughout the year.



£202
RAISED

Wolf Run

Family and friends of PH patient Alex Walker got muddy for money when they took on the Wolf Run in Leamington Spa, smashing their original target of £700. They are pictured before and after the race, which took them 10km across man-made obstacles in the countryside.



£2253
RAISED

Reading Half Marathon

George Lucas and Chris Duffy ran their longest ever distance when they completed the Reading Half Marathon in support of one of their close friends, who has recently been diagnosed with PH. George said: "We both felt a huge sense of achievement when we managed to finish the 21km, and it was all the more enjoyable to run in front of family and friends who came out to support us. We were both blown away by the generosity of donations and the sheer number of people who made the effort to sponsor us!"



£1600
RAISED

Brighton Marathon

Joanne Slater completed the Brighton marathon in just over six hours, taking on the challenge in support of her sister-in-law, Tara Sullivan, who has PH. She said: "Tara was planning to come and support me on the day, but unfortunately, she was suffering with side effects of her medication. She recently had her IV line put in - which she calls Ivy, her new best friend - and the plan was to have the three of us in the photo!"



£1170
RAISED

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

Conquering the capital

In April, a dedicated team of PHA UK supporters took on the legendary London Marathon. A huge thank you to everyone who ran 26.2 miles for us.



Alice Taylor-Gee completed the marathon in support of her little girl, Molly, who has PH. Molly answers our Green Leaf Crew questions on page 34.

Stephen Santry finished the marathon in a time of 5 hours 36 minutes.



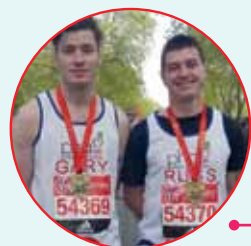
Darren Monette ran for us after gaining a ballot place. His father had PH, and he takes part in regular fundraising events.

Sian Owen and partner Gary Proven ran in support of Sian's friend Anna Bowen.



Steve and Vicki Beckitt completed the marathon together, raising £894. To aid their total, they also held a race night at their local pub in Rotherham.

Sunil Puri ran in support of his wife, who has PH. He said: "I wanted to run for PHA UK because of all the amazing work and support they provide to the people with this condition."



Brothers Gary and Russell Dean took on the London Marathon to mark ten years since their father Peter passed away. Gary said: "It was tough but we are both so proud we completed it and raised over £2,500 for PHA UK."



New fund to help people deal with financial hardship

The national poverty charity Turn2us has launched a new fund to help people facing financial hardship because of a life-changing event.

The **Turn2us Response Fund** is designed to help those who suddenly find themselves in difficulty – for example because of a medical diagnosis, job loss, or bereavement.

Grants are provided for specific needs which are essential to the financial stability, wellbeing, and independence needed to maintain normal daily living.

They could cover things like respite and convalescence, household goods, house adaptation (to accommodate mobility needs, for example) or funeral expenses. The life-changing event must have occurred within the 12 months prior to making the application.

Alison Taylor, Director of Turn2us Operations, said: "We see on a daily basis the devastating effects that a life-changing event such as job loss, bereavement, or long term ill health, can have on an individual or family's income in a short space of time and the turmoil this can cause. **We have set up this new charitable fund, to help people when they need it most** – and before there is a downwards spiral

from which it can be hard to climb up from. Through providing timely and compassionate financial support, we want to assist people as they move on and improve their situation."

Applications for the fund must be made via one of Turn2us's intermediary partners, who will check that an individual is eligible to apply to the fund and complete an application. The list of intermediary partners can be found at www.turn2us.org.uk.

The new Turn2us Response Fund will sit alongside the charity's core fund, the Turn2us Elizabeth Finn Fund, which has been providing grants to professional people in need for over 120 years.

The charity, which is a partner of PHA UK, also manages a further seven funds giving direct financial help to individuals. It provides a 'grants search' tool to enable people to seek support from over 3,000 charitable funds across the UK and Ireland, and has developed an easy-to-use benefits calculator. Both of these free tools are available via the PHA UK website.



To apply for a grant through the Turn2us Response Fund you must:

- Be over 18 years of age
- Have a household income below set limits
- Have £4,000 or less in accessible savings
- Be a British or Irish national or have the right to reside in the UK or Ireland
- Live at least half the year in the UK of Ireland
- Not be in full-time education at university or college studying for a undergraduate or postgraduate degree

For further information on the Turn2us Response Fund, visit www.turn2us.org.uk

My role in the fight against PH

PHA UK member *Carole Ayrton* is calling on fellow patients to take part in the *National Cohort Study of Idiopathic and Heritable Pulmonary Arterial Hypertension*.

“Are you still waiting for the cure, still hoping for new meds for this PH we all live with? Me too, which is why I decided to write this.

I have lived with PH for seven years and it has been a tough journey, but I am so fortunate to have an amazing ‘A Team’ behind me at the Royal Hallamshire in Sheffield. How blessed we all are that the medicines used to keep us here have come so far in the last 15-20 years.

I am a person who loves to trial new drugs that are hoped to be game-changers in treating patients with pulmonary hypertension. I like to think that the part I will play in drug research will make a difference. And maybe, just maybe, the vial of my blood that is now in many research laboratories holds the key - but we need more people to get involved in research too.

There is a missing piece in the jigsaw puzzle of pulmonary hypertension.

We have amazing teams doing research into the field. These researchers talk to our specialists and between them hope to learn more and more about all aspects of PH so that eventually the much longed-for cure is found. In the meantime, we need more drugs to keep us alive and in the best condition possible whilst we await this. Without our help as patients, research will flatline. There is only so much that the professionals can do without our input.

I know not everyone can be recruited for certain trials, but you can give blood for an important study currently taking place – the **National Cohort Study of Idiopathic and Heritable Pulmonary Arterial Hypertension**.

This particular study is for patients with IPAHA and in some

cases, some of their relatives, and the study will follow them up for several years. Although in IPAHA the cause of the disease is often unknown, in about 70 per cent of heritable and 15-20 per cent of idiopathic cases, there is a mutation in the gene that controls how blood vessels grow and function. This gene is called BMPR2. Although mutations in the BMPR2 are a risk factor for IPAHA, not everyone with this mutation gets the disease.

Sometimes, the researchers suspect that mutations in other genes are responsible for some cases of PAH. They are hoping that this study will discover new mutations and to determine what factors lead to poor outcome, and to understand what triggers disease in patients with mutations. In this way, information gained from the study could improve understanding of the disease and help doctors be in a position to continue to treat patients better in the future.

When you begin this particular study, procedures already taken as part of your routine care will be added to the database and there are no extra visits.

Even if you have a phobia about needles, and I appreciate some people do, there are times at your hospital appointments when blood has to be taken.

The needle is already in your arm and the vials of blood are already being drawn, so why not allow them to take a little more for research?

At each clinic visit the extra bloods needed for the study will be collected, along with a urine sample. So, all that is needed is your consent that data from all the previous tests may be used

in the study, a urine test and a few extra vials of blood.

There is also a lifestyle questionnaire to fill out. Initially this takes around fifteen to twenty minutes as you are asked questions such as have you smoked, where did you grow up and so on. The ones that follow are very short and really just ask if anything has changed for you with regard to your health. All information is kept confidential.

All it takes on your part is to tell your PH nurse at your next clinic visit that you want to be part of the study - and the wheels will be put in motion so that you will be able to play your part in furthering research into this condition. You can also contact your PH centre in advance to see if you are eligible.

Giving a few extra vials of blood seems so little to give in exchange for all the care and help we receive. After all, if we do not offer to help the research in this way, where will we be?

I would love it if, by writing this article, it opens someone's eyes to playing a vital role in helping the researchers to understand more about PH, which in turn will help towards them finding the cure we need.

What do I get out of being part of the study? For me personally, it's the satisfaction in knowing that I am giving something back in return for all the care I receive, and the knowledge that my small part plays an important role in the world of PAH.

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.”

About the study

The National Cohort Study of Idiopathic and Heritable Pulmonary Arterial Hypertension began in February 2014 and will run until at least 2018 – hopefully longer with further funding.

The key objective of the study is to investigate the genetic causes of PAH; to learn more about the mechanisms of the disease and the effects of potential new treatments. It involves patients over the age of 16 with idiopathic and heritable PAH in the UK. The study is also inviting relatives of patients to take part.

So far, the study has recruited over 500 patients and collected over 31000 blood and urine samples – but more participants are needed.

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

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



Putting a Political PHocus on PH

A new advocacy programme to ensure pulmonary hypertension receives greater attention from Government has been established by PHA UK.

PHocus2021 is a five-year programme with the aim of pushing for the changes to public policy that PH patients really want to see.

The group behind the programme is made up of representatives of PHA UK, plus leading medical professionals in the field of PH, academia and general practice and a special 'patient panel' made up of patients, carers and family members. Political relations experts, Decideum Health, are supporting PHocus2021 to achieve its strategic objectives and make an impact.

PHocus2021 was established last year and will run until 2021, working to:

- > Be an advocacy group for PH and a 'critical friend' to NHS England, lobbying Government on matters affecting the PH community;
- > Raise the profile of PH amongst Government, policy-makers and senior NHS decision-makers;
- > Actively protect PH from disinvestment and work to improve services across the UK;
- > Provide a forum where policy issues affecting the PH community can be raised and debated, and solutions proposed.

Iain Armstrong of PHA UK is co-chair of PHocus2021, alongside Professor Paul Corris of the Freeman Hospital in Newcastle. He said:

"The lack of transparency and proper consultation with senior figures within clinical and patient communities has led to the PHA UK leaving NHS England and setting up PHocus2021 to exert scrutiny onto a broken system - and to demand more for PH patients by pushing for change."

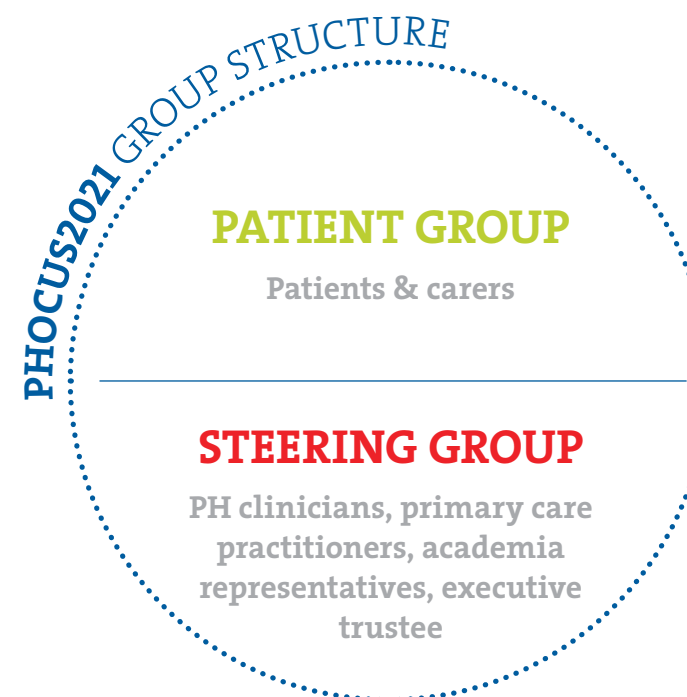
What does PHocus2021 hope to achieve?

The PHocus2021 programme has four main objectives, based around reducing time to diagnosis, emphasising the importance of patient quality of life, unblocking new treatments, and reducing financial hardship incurred by living with pulmonary hypertension.

As part of its work to reduce the time to diagnosis, PHocus2021 aims to educate professionals in primary and secondary care about the condition, its signs, and when to appropriately refer to specialist care.

This will be achieved via further research to understand the reasons behind delays to diagnosis, establishing an engagement programme with GPs and practice nurses, and exploring the possibility of PHocus2021 producing its own patient pathway or guidelines.

This area of work will be closely linked to the findings of the recent Living with PH survey, which highlighted



worrying statistics around time to diagnosis.

PHocus2021 will also work to ensure that NHS England and relevant health authorities update national commissioning guidelines to emphasise the importance of patient quality of life, as well as appropriate self-care. This will be achieved through establishing an engagement programme with key stakeholders to draw attention to PH and the risks associated with decreasing funding of its services, and developing a strategy for growing the membership of PHA UK.

The third key objective of the programme is to ensure PH patients get fair access to treatments by working to ensure new treatments are not blocked, and partnering with other relevant patient organisations to strengthen the case for funding.

The programme will also work to tackle the financial hardship incurred by PH patients as a result of their condition. Further research looking deeper into the financial impact of PH is planned for later this year.

Alex Ledger, deputy managing director at Decideum Health, said:

"Establishing PHocus2021, and a panel of patient, carer and family members to contribute their experiences into its work, is a major step forward for PH. PHocus2021 was formed because we were dissatisfied with how little we felt PH patients and their families were being listened to by national NHS bodies when reaching funding and other decisions affecting PH services. Having a strong and independent voice means that the PH community can stand up for itself where it faces problems and demand fair and equitable treatment from the NHS."

2021
PHocus

Positive change, our aims...

1

Reduce time to diagnosis for pulmonary hypertension.

2

Improve the overall health, wellbeing and quality of life of patients with PH and their kinship, based on their needs and preferences.

3

Ensure equity of access in the UK to evidence-based PH treatments for all.

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Putting a political
PHocus on PH

Early success...

As part of the work of PHocus2021, representatives from PHA UK are attending the major political party conferences to raise awareness of issues surrounding pulmonary hypertension.

In March, taking a stand at the Liberal Democrats Spring Conference in York saw successful meetings with a number of key political influencers. They included Tim Farron, Leader of the Lib Dems, Norman Lamb, Health Spokesperson for the Lib Dems; former Deputy Prime Minister Nick Clegg; and Baroness Brinton, President of the Lib Dems – who has her own personal connections to PH.

Norman Lamb was so inspired by the cause that he wrote a letter to the chief executive of NHS England, Simon Stevens, and sent it to him with the handouts the PHA UK team had created for the conference.

In his letter to Mr Stevens, Mr Lamb highlighted issues with delayed diagnosis, growing disinvestment and the blocking of drugs. He wrote: “This highly disabling condition can be better treated than is currently the case in our country and it is surely incumbent upon NHS England to lead the way in improving the experience of patients suffering from pulmonary hypertension.”

Direction from the newly established PHocus2021 committee is already helping increase education and awareness amongst medical professionals. With the objective of reducing time to diagnosis in mind, their guidance has led to the introduction of a series of PHA UK training days around treating breathless patients. The first one, held in April, was a huge success.

Keep up with the work of the PHocus2021 programme in future issues of *Emphasis*, online at www.phauk.org and by following PHA UK on Twitter and Facebook.

Liberal
Democrats

SPRING CONFERENCE



PHA's Shaun Clayton with Nick Clegg



Lib Dem Health Spokesperson, Norman Lamb



PHA's Paul Sephton with Baroness Tonge



Shaun with Baroness Brinton



Shaun & Paul on the PHA UK stand

Taking PH research across the pond

Last year, clinical researcher *Dr Pavandeep Ghataorhe* was awarded a grant from PHA UK to help her continue her studies into pulmonary hypertension. Here, she tells us how she's now working with a team at a top American university to continue the research.

Since winning the prize, I have submitted my PhD thesis, had my viva examination and been awarded my PhD.

I am delighted to say that the work I presented for the PHA UK prize was published in the journal *Circulation* in January this year, which has a very wide audience in the field of cardiovascular disease and beyond.

I presented the project at the American Thoracic Society in May 2016, which led to a collaboration with the group I am working with now at Harvard Medical School. In addition, I presented my work at Imperial College and won the Rising Scientist Award for the Department of Medicine.

The grant from the PHA UK has been used to help fund a short fellowship at Harvard Medical School. Here, I am working with leading clinicians

and scientists to use network analysis techniques on our data.

The data we are using for this project comes from blood samples that patients have donated to the study, which allowed us to measure protein and metabolite levels in the blood. Without these samples, these studies would not be possible and they are of key importance for our research. Using network analysis, we can review which proteins and metabolites are central to the network, and therefore may be important in the development and potential treatment of pulmonary hypertension.

I am very grateful to all the patients who donate their samples and time to our studies and make this analysis possible. I am also very grateful to the PHA UK for funding a project which has led to an international effort in the research into pulmonary hypertension. ”

Dr Ghataorhe was awarded a grant from PHA UK following a presentation at the 2015 Pulmonary Hypertension Physician's Forum in London. The study she presented involved measuring metabolites in the blood of patients with PH; tracing how they are affected by, and predict the course of, the disease – and how they can measure levels of PH treatments and medications.

“I am very grateful to all the patients who donate their samples and time to our studies...”



How much is too much?

Consultant pharmacist *Neil Hamilton* addresses some common questions around alcohol and medication.



The great British public have a complicated relationship with alcohol. Drinking it is engrained in our culture and forms an intrinsic part of our social lives. This is the case, to a greater or lesser extent, across the Western world. However, unsurprisingly, the action of a few whilst under the influence of alcohol - for example some football fans - has given the British an especially bad reputation.

There are early signs that the average amount of alcohol consumed per adult in the UK has fallen slightly from its peak in 2004.

An annual BBC poll carried out since 2005 showed that of those surveyed, less people had drunk in the past week compared to 12 years ago. One of the reasons for this is the reduction in numbers of young drinkers. Young people were amongst the least likely to have had a drink in the previous week. Granted this is a small sample, but the

data suggested that higher earners and older age groups are now more likely to consume alcohol than the younger generations. Whilst this may not be highlighted in terms of anti-social behaviour, there are obvious impacts on health and wellbeing that could be equally problematic.

With that in mind, I am not going to write a pious and virtuous piece about the dangers of alcohol and alcoholism. Indeed, I am sure a good many of you, like me, will have enjoyed a drink whilst meeting with friends and colleagues at the fantastic PHA UK conference recently.

My aim here is to try and dispel some myths and bring some reality to discussions that I frequently overhear, and address questions we pharmacists get asked around drinking and medicine. Much of this advice is not unique to patients with pulmonary hypertension, and consists of general tips and considerations applicable to all.

"You cannot drink when you are taking warfarin"

This is false. Patients prescribed warfarin can safely consume alcohol, provided it is in moderation. A steady, regular intake of two units per day is preferable to 14 units in one night. Binge drinking close to an INR check may well affect the result, so be aware, and if you have drunk more than usual near to a blood test, just let the clinic know so they can interpret the result in context.

"You cannot drink when you are taking antibiotics"

This depends on which type of antibiotics. There is no blanket advice across antibiotics. As you may be aware there are many different medicines we treat infections with, so make sure you check with your doctor and / or pharmacist to be certain. The ones to definitely avoid alcohol with

are metronidazole and tinidazole. Others that can be problematic are co-trimoxazole, linezolid, doxycycline, nitrofurantoin and erythromycin. If you have access to the internet, the NHS Choices website has more helpful advice on this subject.

"I won't take my diuretics if I am having a drink, because I'll be in the toilet all day"

My advice here is to take care. Alcohol does have a 'diuretic' effect, causing you to pass more water. Patients with any tendency towards fluid retention should take care when drinking beer, cider or anything ordered in larger volumes. I would also urge some caution if taking diuretics when consuming significant amounts of alcohol as the added diuretic, and therefore dehydration, effects would be potentially damaging to the kidneys and blood salt levels if repeated regularly.

"I can't drink because I am taking painkillers"

This depends on which ones. Strong painkillers such as 'opioids' - which includes morphine, tramadol and codeine - all have the potential to cause

drowsiness and nausea. This will be enhanced by alcohol. Sensible advice here is to avoid alcohol altogether when starting a new painkiller and also immediately after a dose increase. This way you can assess how the change is affecting your body.

"I'm fed up and want a drink, but I've just started anti-depressants"

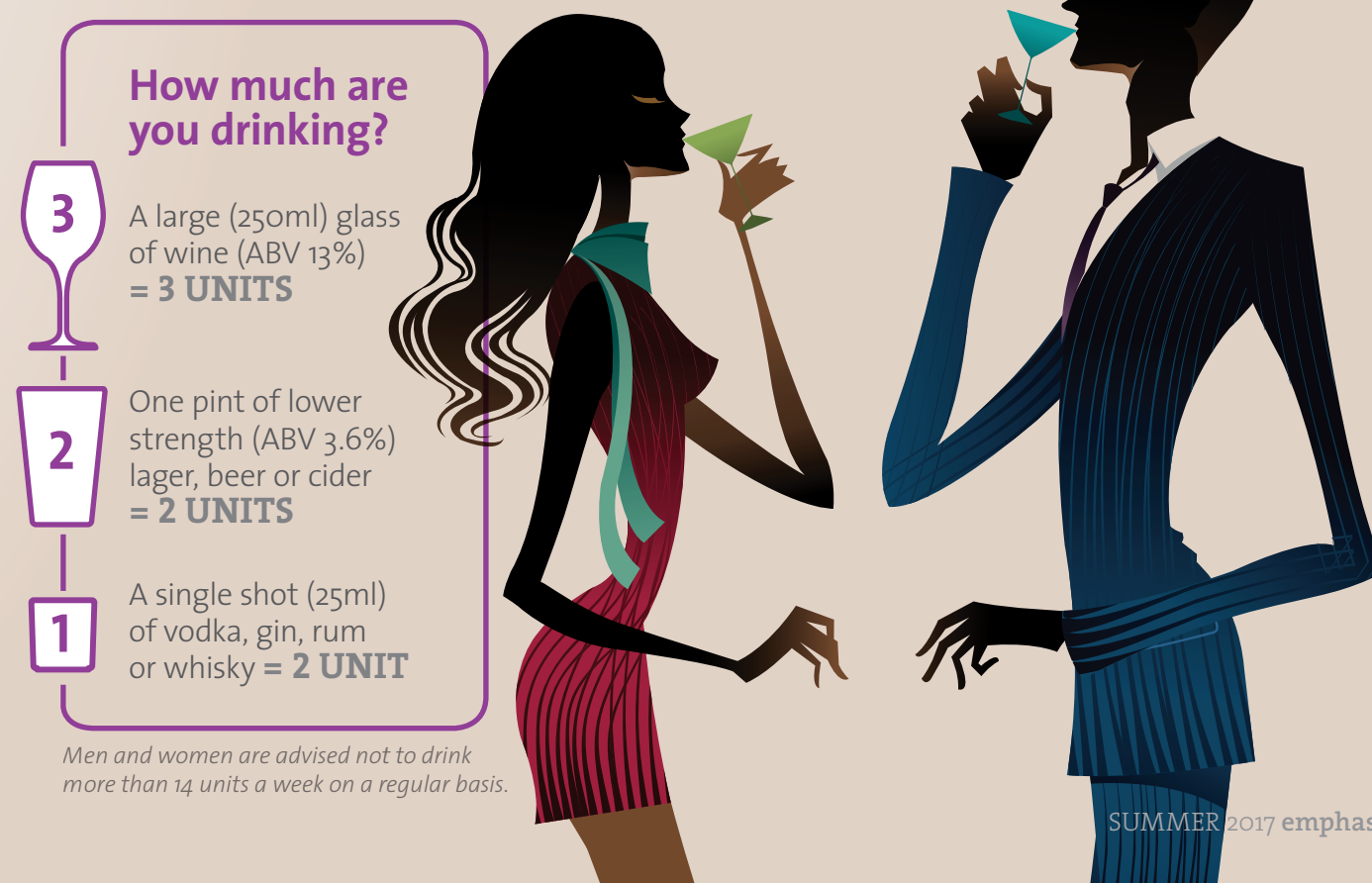
Coping with a debilitating condition such as PH can be stressful and cause anxiety, depression and other mental illnesses. There are some interactions between some of the older anti-depressants, but these are far less frequently prescribed nowadays. Newer treatments are likely to be preferable but it is always worth checking if in any doubt.

It is not my place to pass judgement and everyone has their own way of coping with whatever life may throw at them. Sadly for some people, coping with life involves excessive alcohol and as with all addictions, alcoholism is not easily overcome. Support is available locally at your GP surgery and through your specialist centre if this is something you want to access.

Thankfully for most of us, drinking alcohol socially is a pleasure, and

something we can enjoy without becoming reliant on. As with lots of things in life, enjoying a drink in moderation is unlikely to interact too much with commonly prescribed medication. Sticking to the government's safe alcohol limits of 14 units per week is applicable to us all, as the evidence suggests this reduces health risks. Your pharmacist, either locally or at your specialist centre, will be happy to advise on alcohol in relation to your specific treatments. ●

If you have concerns about your levels of alcohol intake, please speak with your specialist centre or GP, who can refer you to local support services. The NHS Choices website also contains lots of useful information about alcohol dependency, including links to helplines and organisations. Visit www.nhs.uk and search 'alcohol support'.



You have to have it in your head that you can do it.

When 56-year-old Karen Jones was diagnosed with PH after years of living with a connective tissue disorder, she prepared herself to juggle the many challenges the two conditions would bring. But with a penchant for finding ways to adapt, Karen is keeping control of both her physical and mental health. She shares her unique story with Emphasis.



“

I was diagnosed with the connective tissue disorder systemic sclerosis in 1999, and balanced bringing up two young children with hospital visits and regular inpatient care.

The condition, an autoimmune disease that causes abnormal growth of connective tissue, caused painful ulcers on my fingers and toes and led to partial amputations of my fingertips. These days my hands are very sore and often bandaged, which along with my missing fingertips drastically affects what I am able to do.

Vascular manifestations of systemic sclerosis include pulmonary arterial hypertension, so as someone at risk, I was already known to the PH service at the Hallamshire hospital when I started to become breathless in 2002.

My symptoms were monitored, but it wasn't really until 2012 when they started getting worse, and a right heart catheterisation showed the pressures had gone right up. I was officially diagnosed with PH.

I was absolutely devastated to be diagnosed with another serious condition, but at the same time it was a relief that it explained a lot, such as why I couldn't walk very far, or get dressed very quickly. As time went on, more medication was introduced. I was already taking iloprost for my sclerosis, and I now also take it for my PH - so it has become my friend over the years.

It's not always easy to do things independently, but it's important for me to try.

I've recently had to start taking it via a nebuliser, which I've found very fiddly because of the limitations with my hands.

I had to stay in hospital for a few days to learn how to use it and the medical professionals were concerned I wouldn't be able to because of my fingers. For me though, I saw a nebuliser as a much better alternative to a Hickman line, so I was determined to find a solution.

I like routine, as it helps when the rest of life feels chaotic with hospital visits and changing medications.

One of the things I found difficult was breaking the ampoules (the capsules containing the iloprost), but I used Google to research what could help, and found that you could get little cutters, which made a big difference. The internet is great in terms of helping me find handy solutions and ways to adapt.

It's not always easy to do things independently, but it's important for me to try. A nurse even once jokingly called me 'Miss Do-It-Yourself'.

I believe though that the best person to manage your condition is yourself and for me, it's about self-preservation as much as anything else. It's about recognising that something will probably be difficult, but trying to do it anyway.

When it comes to overcoming hurdles, you have to have it in your head that you can do it. I try and concentrate on what I can do, not what I can't.

One of the challenges for me is when plodding along on an even keel I can think things are under control, but then something will change with one of the conditions and throw new challenges up. So, I may have finished dealing with one thing, but I then have to find new coping strategies for another.

There are positives though. There is so much patient information available for both of my conditions and I've found the internet to be very useful, as well as various helplines. It's good to know there is help there when you need it. I also feel lucky that the healthcare professionals involved in each of my conditions are all so committed and helpful, and I receive great care wherever I am.

I live near Wigan with my two sons, Thomas, 24, and James, 19 and they are a big support to me. I was divorced in 2007 so it's been me and my boys together for a long time. My youngest is currently at university, but he chose a local one so he could stay at home, and my eldest son is a musician, so although he is often out at night, there is always one of them around. I use the nebuliser seven

times a day and it needs washing and cleaning too, but the boys assist me with it and help me keep on top of medication deliveries. They are happy to push me in my wheelchair too.

It has all definitely had an impact on their lives though. Over the years, I've missed birthdays and Christmases, and always had to rely on other parents to give them lifts. There is a lot of guilt that comes with these illnesses.

In October, I started having morning carers coming in to help and that was difficult to deal with at first, but I've accepted now that I need the help.

I can't walk upstairs, I can't get dressed easily, and I can't decide to simply go out for a stroll. I've lost freedom of movement and that has been particularly challenging psychologically. Disease progression is tough to deal with too.

But there are little things I do that help me cope, such as planning. I write things down a lot and when my fingers hurt too much to write or type, I use voice technology to dictate what I want to say.

I find it especially useful to write down when I take my medication and I would encourage others to do the same. As well as helping me keep track it also helps me feel in control, and I write to-do lists for the same reason.

I like routine, as it helps when the rest of life feels chaotic with hospital visits and changing medications.

I've visited the transplant unit at Wythenshawe Hospital twice but because of my sclerosis, they don't think I will do well. Although I've not had a direct 'no', I don't think transplant is an option, so it's important to me that I continue with my current PH treatments with a positive mindset.

I've had some clinical counselling sessions which have helped, but ultimately, I've realised it's down to me, as the manager of my own mental health.

Even when faced with something horrendous, I believe we all have it in us to be positive in the end. ”



Crew!



A. *I like playing babies with my friends at school and I like dressing up at home.*

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

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by David Banks

The GREEN LEAF CREW

BY DAVID BANKS



DEALING WITH IT TOGETHER

Sophie Carpenter-Richards was diagnosed with PH in March this year, just eight days after first visiting her GP. It was a shock for both her and her girlfriend Alex Smith, who she lives with in Milton Keynes. Here, they share what the diagnosis means to them and their relationship, and how support from family is helping them both.

Sophie's story

“Before my diagnosis, the only symptom I had was shortness of breath after walking up a flight of stairs or two. Sometimes it would really take my breath way, and it would take me about five to ten minutes to recover. But I just thought I was becoming unfit.

From my first doctor's appointment to my diagnosis, it took just eight days. I originally went to my local GP after pulling a muscle in my back after overdoing it at the gym. Whilst there, I mentioned that I was struggling to breathe when using stairs and walking long distances. He examined me and came to the conclusion that this wasn't normal for a relatively fit and healthy 24-year-old.

So, he referred me to my local hospital for a scan and some blood tests, and from there it all escalated. I eventually got transferred to the Royal Brompton in London for further testing, where I finally got my diagnosis of PH. I had never heard of pulmonary hypertension before, but I was relieved that I finally had a diagnosis and I could go home! I hated being stuck in hospital. It was the first time I'd ever been admitted.

Alex was with me when I was diagnosed and was by my side every day. She would travel up from Milton Keynes by train and then travel back home that evening, to do it all again the next day. We've been together three years now, after meeting on social media, and have lived together for over two of them. I've only had to make very minor changes to my everyday life. I don't go up and down the stairs as often as I would; if I need something from upstairs, generally Alex will go for me. Some

house chores such as putting the bins out and carrying shopping has had to stop too. I've also had to make some changes at work – I'm a waitress, and I now do shorter shifts, and don't replenish stock as that entails heavy lifting. Luckily, my employers have been very supportive.

Alex has been there for me every step of the way. She took some time off from her job as an emergency ambulance dispatcher to be with me when I was in hospital and I couldn't have asked for a better partner throughout all of this.

“We take every day as it comes and live life to the fullest.”

We take every day as it comes and live life to the fullest. Fortunately, my symptoms don't restrict me at the moment but I know later in life they will, so we spend more time with each other, going places and spending more time with family, who have been so good to us too. Even though they live far away, everyone has been there for us both. If we need anything they're just a phone call away. At first, my grandparents found it very difficult, but I think that's because they didn't understand what was happening. However, once we spoke to them properly and explained everything, and gave them the good news that I'm a responder and should respond well to treatment, they were okay and dealt with it. My mum has also been really good and was there most days with me in hospital as well. I couldn't have got through it all without her either.”

Alex's story

To be honest, when Soph first started experiencing shortness of breath I wasn't that worried. Just like her, I thought she was just getting unfit.

I was devastated when she was told she had PH. Her consultants threw multiple different possible diagnoses our way in the beginning, so for the first week in hospital we had no idea and were a bit oblivious to how serious it was. When they finally

“I think that, if anything, Soph's diagnosis of PH has brought us closer together.”

came back with a definite diagnosis of pulmonary hypertension I cried my eyes out. Thankfully the specialist nurses and doctors at the hospital put my mind at ease and told me that although she has this very serious and rare disease, they've caught it early and she should respond very well to treatment.

Before the diagnosis, at home Sophie would put the bins out, change cat litter, cut the grass and so on. But now, so she's not over-doing it and putting strain on her heart, I do that for her. If she ever forgets something upstairs, so she's not going up and

down the stairs unnecessarily, I'll go. It's just the little things around the house that I took for granted before, that I now do. I think that, if anything, Soph's diagnosis of PH has brought us closer together. When someone you love gets ill, it reminds you just how much you care and adore them, and how you would do anything for them. When Sophie was in hospital and first diagnosed, she told me she would understand if I didn't want to deal with it and left her. But I told her that was silly. She's stuck with me. Forever.

Luckily, I have an extremely close and supportive family too. Even though both my parents live in different countries, they are always there at the other end of the phone - no matter what time of day or night. I'm also close with Sophie's family, and her mum especially has been a massive help and support to us both during everything.”

If you would like to share your family's PH story, please email editor@phauk.org



Sophie is keeping a blog about her PH journey, which you can read by visiting www.sophieccdd.wordpress.com

Protecting Royal Brompton Hospital's world class services

A campaign to prevent the closure of congenital heart services at Royal Brompton has been gathering momentum since they were threatened last year.



Carl Harries

Dr John Wort

On 18th March, nearly 2,000 patients and their family members, supporters, hospital staff and other campaigners marched along the famous Kings' Road in London to protest against NHS England's plans to decommission congenital heart disease (CHD) services at Royal Brompton Hospital.

The march formed part of a campaign, spearheaded by charities that support the hospital, to contest the plans which – if they went ahead – would not only mean the closure of Royal Brompton's CHD services, but also its paediatric intensive care unit, specialist respiratory services (including cystic fibrosis, for which it is the largest centre in Europe) and pulmonary hypertension service.

The background

NHS England claim Royal Brompton Hospital does not meet one standard out of approximately 470 new rules for hospitals providing CHD services. This standard is called 'co-location', and requires certain children's services – such as stomach and general surgery – to all be permanently based in the same building as the CHD service, rather than on neighbouring sites.

As Royal Brompton is a specialist heart and lung hospital, these additional services are based at the neighbouring Chelsea & Westminster Hospital, just a few minutes' walk away.

The formal arrangement has been in place for several years, and means that expert opinion can be gained within a short timeframe across a number of areas both during and outside normal working hours, without patients needing to move.

The public consultation

Last October, we ran an article in *Emphasis* to reassure patients that PH services would continue as normal during the consultation period. Since then, NHS England launched a public consultation on the plans, inviting members of the public to submit their views.

The consultation, launched in February this year, had been paused for the general election at the time *Emphasis* went to publication, and is now expected to end sometime in July.

The Brompton Fountain, a charity which supports children and their families at the hospital, continues to campaign

hard to fight the plans. As well as the march, they have been calling on supporters to submit consultation responses and write to their MPs, and have been liaising with the media to make their voices heard.

The impact on services

Official figures show that Royal Brompton operates the UK's largest congenital heart disease service, and consistently has among the best patient outcomes in the country. Clinical teams help over 12,500 patients, treating many from birth through childhood, adolescence and adulthood. It also has exceptionally high patient satisfaction levels, with over 98 per cent of patients saying that they would recommend the cardiology service.

Dr John Wort, clinical lead for PH at Royal Brompton Hospital, told *Emphasis*: **"Our work at Royal Brompton has transformed patient care in the UK and the rest of the world. Our expertise in congenital heart disease sets us apart from our national counterparts in PH. It makes no sense to try and improve care by closing one of the biggest, well-performing services, or by destroying research teams that are leading the way in finding new treatments for the future."**

Carl Harries, clinical nurse specialist in PH at the hospital, added: **"As one of the seven centres that make up the UK's national pulmonary hypertension service, this continues to be an unsettling time for patients and staff. The adult congenital heart disease and PH services here remain committed to ensuring we provide the highest clinical care throughout the entire process."**

How you can help

Visit Royal Brompton & Harefield Hospitals NHS Foundation Trust's website (www.rbht.nhs.uk/chd) to find out more about the review.

Visit NHS England's website (www.engage.england.nhs.uk/consultation/chd/) to take part in the consultation.

I realised the only way I'd be happy was to confront the illness head on.

As theatre manager for a hospital cardiac unit, *David Stott* from Preston was used to being around patients, but unprepared to become one himself. He tells *Emphasis* how his PH diagnosis triggered depression - but why he's coming out of it stronger.

“I was always an active person, but in 2012, following a lay-off from a sporting injury, I started to try and run again and I couldn't run 50 metres without feeling like my chest was caving in. I couldn't walk upstairs and talk at the same time and because I was quite fit, I noticed quite quickly that something was wrong.

I went to see my GP thinking it was asthma or hay fever, but was surprised to be referred to hospital for echocardiograms and CT scans. When I was told my heart was enlarged due to significant pressures in my lungs, and I had idiopathic PAH, it all went hazy.

I did what any 21st century boy would do and I asked Dr Google

I had never heard of pulmonary hypertension and there was little information in the hospital I was in, so I did what any 21st century boy would do and I asked Dr Google. And that's when it all went black.

Feeling breathless on exertion was the only symptom I had prior to being

diagnosed. But after being diagnosed, I fell into a depression and was having chest pains and palpitations which screwed my nights up. I'd just sit every night watching films over and over. It later turned out to be nothing more than heartburn reflux (a common side effect of the drugs I was given) which yet another tablet would resolve - but it goes to show that not every bump and ache would be due to my heart.

After I was diagnosed, I was too scared to move. For months, I counted and limited every step and breath as if it was my last and let myself be overcome by a black shadow. I'd dream that I was having cardiac episodes or dying and they were so vivid that I would scream in my sleep. I really feel bad for how little I spoke to my wife and kids, although I do know that I was battling depression.

I have since sought counselling and emotional support due to the condition. I took very little time off after diagnosis, and then bottled everything up and compensated with activity and work to keep my mind busy. But after a while, I identified that I needed help, as I was becoming anxious and very stressed.

Again, this was pushing me away from my family and friends.

Although I was still able to exercise, I had not looked after my emotional wellbeing in the same way. It was offered immediately after diagnosis, but at the time, someone telling me to 'focus on the now' was a very difficult mindset to have when I thought I had only days or months to live.

I slowly picked myself up and started to go back to work, first two days a week, then three, then four. I eventually started going back to the gym again and have since completed charity runs.

These days, the only real physical symptom I notice is not having the exercise capacity I once had. I find that I have great endurance, but no explosive exercise capacity. I don't black out, but my body just tells me to stop.

If anything, it is the mental strain that I have suffered from more than the physical symptoms. It's a draining condition that, unless you look to get support for it, has the potential to drag you down.

I couldn't have coped emotionally without my wife and four girls. When my daughter Lorien was born, seven months after I was diagnosed, she reminded me

Completing an exercise test

that life is never hopeless if you don't lose hope. My children help me manage my condition by making me smile more than anything or anyone can - even when I don't feel able to.

Being able to get physically active again really helped too. I realised the only way I'd be happy was to confront the illness head on - and I started waking up knowing I was fighting, and going to sleep ready to recharge.

That's not to say I'm arrogant; this condition and the days after diagnosis still haunt me and the black cloud still lingers. I occasionally tear up and want to cry, and I know that I'm still hard to get talking and prefer to be out of

I couldn't have coped emotionally without my wife and four girls

crowds, but I've accepted this challenge.

I'm lucky that I don't get out of breath or symptomatic, and I don't need oxygen or many drugs, just 25mg of Sildenafil, and Warfarin. I go to the gym three times a week for at least two hours at a time. I now do interval training and have pushed myself as hard as I ever had done.

My consultants have called me remarkable and I have been discharged to yearly appointments at the Royal Hallamshire Hospital in Sheffield. So, all in all, I know PH is not the best thing to happen to me - but I'm still alive. ”

Being interviewed for his local TV channel

David performing in his band outfit

David with his four daughters

Earlier this year, David organised a fundraising gig for PHA UK in conjunction with the Sanctuary Rock Bar in Burnley. His theatrical circus metal band, **Ward XVI**, joined five other groups on the line-up and over **£900** was raised through entry fees, a raffle, CD sales and proceeds from merchandise sales.

“” spreading the wordabout PH.....“”

A Cumbria-based pulmonary hypertension patient is aiming to encourage earlier diagnosis by raising awareness of the condition.

Des Walmsley, who lives in Kendal, was diagnosed with PH six years ago, and also lives with Raynaud's and Scleroderma. He is organising a fundraising night at his local pub, headed by local classical singer Lizzie Curwen, and will also be speaking to local groups about PH. **His aim is to help people understand the signs and symptoms of the condition, and what it's like to live with an invisible illness.**

Des, 63, is under the care of the PH unit at the Royal Hallamshire Hospital in Sheffield and also attends Salford Royal Hospital – who initially referred him for tests for pulmonary hypertension. But it took three years from Des first experiencing symptoms to receiving a diagnosis. He said: “Even some medical staff I met had not heard of PH, or if they had, didn't know much about it. In terms of my day-to-day symptoms I experience shortness of breath and I've lost around 37 per cent of my lung capacity. I also have a lot of aches and pains but people look at me and don't realise there is anything wrong with me. **If I had a leg missing, it would be obvious. People find it hard to believe that my condition is life-limiting, because I don't look ill.**”

Des wants people to push their GPs to consider PH if they go to see them about feeling breathless. He added: “**I have a three-year-old granddaughter and it concerns me that even children of her age can have the condition, but that it may not be picked up.**”

Des, who is self-employed, still works as a salesman, which involves travelling around garages in the north west. And as well as keeping his business going, he is also keeping busy by organising the fundraising evening at The Heron pub in Kendal.

The event, planned for 10th June, will feature performances from local singer Lizzie Curwen, who offered to help after hearing about his condition. A raffle and a collection will aim to raise funds for PHA UK and Des plans to use the event as a way of encouraging people to find out more about the signs and symptoms of PH. He added: “*I knew nothing about pulmonary hypertension when I was initially told I may have it. I certainly had no idea how serious it was, until I asked how long I had left. It upsets me to think about not being able to see my grandchildren grow up, and I'm determined to help raise awareness of the condition so that more people are diagnosed earlier.* I don't want people to be fobbed off – they need to push their doctors to consider PH, but they need to understand what it is first.”



Join our PH family for free today

Be part of a 3,500-strong national support network.

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

Join today and benefit from:

- Support and advice
- 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

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 3,500 members in a unique network of support and inspiration.

Join **FREE** today at www.phauk.org
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FLYING THE FLAG FOR PH IN THE NEWS...

Victoria's journey

Victoria Sant told her local Sussex lifestyle magazine, etc, that five months after her PH diagnosis, she is determined to keep positive.

In the article, titled 'Living life to the full', Victoria said: "People always say life is short but very few do anything with it. I don't know what my prognosis is and I try not to think about it too much as I don't want to waste my time being miserable. I do have down days but I try and keep positive and there are so many things I want to be able to do as I'm only 31." Victoria shared her journey to diagnosis, which involved her believing that her breathlessness could be down to lung cancer. But following tests and ECGs at the Royal Brompton Hospital, she was diagnosed with pulmonary hypertension and connective tissue disease - which consultants said linked PH with her existing condition of autoimmune hepatitis. She said: "When the consultant first told me it was a lot to take in. I had so many family members asking me questions that

I just couldn't answer so I told them about the PHA UK website as there was so much information out there." The article in etc. also included information about the signs and symptoms of PH, who it affects, and where to find support. Victoria's story was also shared in the magazine's sister publication, the Crawley Observer, and on its website. Victoria told Emphasis: "Seeing myself in the 'etc' article and unexpectedly in my local newspaper, made me feel proud. It was good to know that I was helping raise awareness for something I didn't even know existed before October 2016. It's good for people to read, especially friends and family, as they can understand what I'm going through. As always with these things I would have loved more detail, but I know I can't have a book! The journalist was very easy to talk to, she made me feel at ease and told me how

interesting she found this story. I know a lot of people struggle to talk about PH but for me talking is like therapy and putting it out there into the world is my way of coping - and if I can help someone then all the better!" ●



Andrea's 'insight' into her condition

Andrea Murphy, a staff nurse from Bath, recently featured in her hospital Trust's in-house magazine, Insight, to talk about ten years of living with pulmonary hypertension.

Andrea, 38, works on the Eye Unit at the Royal United Hospital in Bath and was diagnosed with PH in 2007. In the beginning, things looked very bleak and Andrea was told to take medical retirement. But instead of being consumed by the things she couldn't do, she fought back with a self-driven determination not to let her illness define her. Andrea told the publication how she balances her illness with working life. She said: "Work is my saviour. When in my uniform, I am Andrea the nurse. Most of my patients have no idea I'm ill. I work because it's good for me - I need to feel part of something bigger, and I want to make a difference. On the Eye Unit, we work miracles by restoring peoples' sight. Work helps to keep life 'normal'." Andrea also took the opportunity to share her advice with others diagnosed with PH, and Insight featured the following tips:

'OWN YOUR CONDITION'
"It's been really important to me to own my condition. As it's so rare, I have had to become my own expert and my own advocate. The team of specialists who have helped keep me alive for over ten years are amazing - but it is a team effort of which I am part. As a nurse, it surprises



me how easily some people hand over control of their conditions and their lives. It is my PH, and I like to have control over it as much as possible."

'DON'T GIVE UP ON LIVING'
"When I was diagnosed, I thought my life was ending. Since then, I've married my amazing husband Rich and maintained a fulfilling career. Don't give up on living. Put dates in the diary - you may have to cancel, but never stop making plans. Take each day as it comes, and celebrate your achievements - some days these may be as big as getting married and some days as small as brushing your teeth."

'DON'T LET THE ILLNESS DEFINE YOU'
"Andrea the patient' lives in a box under the bed. I am so many other things first: 'Andrea the wife', 'Andrea the friend', 'Andrea the nurse'. The illness has taken many things from me, but I refuse to let it define me." Andrea ended the article with a plea to readers. She said: "Please, if you haven't already done so, sign the organ donation register. Some lucky PH patients' lives can be transformed by transplants. Life can change in the blink of an eye - donation is one way to bring something positive out of tragedy." Andrea told Emphasis: "I was poorly

last summer and spent ten days in intensive care. My family was told to prepare for the worst, but thanks to the wonderful care I received I went back to work after a four-month recovery. My colleagues held a charity cake sale to raise money for PHA UK, and I took the opportunity to raise awareness of PH - it's so rare; gets little publicity; and most people don't realise just how serious and life threatening it is, given the 'invisible' nature of the disease. "I try not to focus on my illness every day, so seeing myself in print was slightly surreal. I also didn't expect so much interest - life is difficult for lots of people, but the positive feedback from colleagues, staff members and patients has been truly overwhelming. Life remains a challenge, and there have been considerable lows, but I continue to focus on living in the 'here and now' and enjoying each day as it comes." ●

Thank you!
to Victoria and Andrea, and everyone who raises awareness of PH through their local media. Please share your stories with us by emailing editor@phauk.org

Are you struggling with stress or anxiety?

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

- Dedicated helpline service 0844 332 9010
- Email support via phauk@anxietyuk.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 **0844 332 9010** or visit **www.anxietyuk.org.uk**



Go Mediterranean for mental health

Nutrition expert *Sarah Dash* explains how the Mediterranean diet can boost mental health by reducing inflammation.

The principles of the Mediterranean diet are based on common healthy concepts; eat plenty of fruits and vegetables, whole grains, healthy fats, fish and occasional meats and avoid processed, sugary foods and beverages.

The diet is high in fibre and antioxidants, and has been shown to reduce levels of inflammatory cytokines in the blood, which can compromise gut function, damage tissue and disrupt important signalling pathways. This causes chronic inflammation, which has been linked to commonly occurring mental disorders such as depression and anxiety. Happily though, what we eat can help to reduce it.

The principles of the Mediterranean diet are based on common healthy concepts.

The foundation of the Mediterranean diet is the consumption of plant-based whole foods. The diet is packed with healthy fats, which help to make this dietary pattern both enjoyable and healthy. Here are a few ways you can incorporate Mediterranean-style meals into your life.

Breakfast...

- Sourdough toast topped with avocado, tomato and feta, drizzled with olive oil
- Bowl of Greek-style yogurt topped with seasonal fruit, oats or low-sugar muesli
- Omelette – eggs with veggies and olives

Lunch...

- Mediterranean chickpea salad – chop cucumber, cherry tomatoes, red bell pepper, red onion and olives and toss together. Add chickpeas, and top with crumbled feta. Dress with olive oil and lemon juice.
- Salad sandwich on wholegrain or sourdough bread – fill with sliced cheese and an array of veggies such as spinach, shredded carrot, beetroot, sliced tomato, or avocado. Add an egg or small can of tuna for extra protein.

Dinner...

- Grilled salmon, brown rice and veggies
- Tomatoes stuffed with cous cous and goats cheese
- Roast lamb with mint tzatziki
- Sweet potato with salmon fish cakes

If you're still hungry, try Mediterranean-style snacks such as a handful of nuts (avoid flavoured or salted options), Medjool dates, fresh fruit or vegetable sticks with houmous. ●



SARAH TIPS:

Dress vegetables with olive oil – not only does this healthy fat make them taste delicious, it can help with the absorption of key nutrients too.

Choosing frozen vegetables can cut costs. They are equally nutrient-rich and will keep for longer.

Explore ways you can add plant-based protein to meals – lentils, chickpeas and beans are all excellent sources.

Enjoy plenty of water, tea and black coffee, but avoid heavily processed foods and sugary drinks.

ME & MY JOB

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

NAME: Joana Barbosa.

PLACE OF WORK: Brompton Hospital, London.

JOB TITLE: Clinical Nurse Specialist within the PH service.

HOW LONG HAVE YOU WORKED WITH PH PATIENTS? I worked for the Royal Brompton and Harefield NHS Foundation Trust initially for 4.5 years from 2009, and returned in September 2016 following time on the Overnight Intensive Recovery (OIR) unit at St. Thomas' Hospital.

WHAT'S THE BEST THING ABOUT YOUR JOB? It's really nice to be able to see patients at the start of their treatment and be with them on their journey. It's very different from my previous nursing roles.

WHAT'S THE FIRST THING YOU DO WHEN YOU GET TO WORK? I turn on my computer, check to see which patients will be admitted that day, and check the phone for messages. Then I will make a cup of tea and fill up my bottle of water ready for the day ahead.

WHAT'S ON YOUR DESK? My diary, computer, phone and notebook. I also have a copy of Emphasis on there today too.

WHAT MAKES YOU PROUD ABOUT WORKING WITH PH PATIENTS? I feel proud that we can make such a difference by supporting them, and that they know we are here for them. I also feel proud when I see patients improve along their journey.

WHAT DO YOU LIKE TO DO OUTSIDE OF WORK? I spend my spare time seeing friends, going to the cinema and travelling. I'm originally from Portugal and my favourite place to visit is Asia, but there is still lots more of the world I want to see.

IF YOU COULD MAKE THE WORLD UNDERSTAND ONE THING ABOUT PULMONARY HYPERTENSION, WHAT WOULD IT BE? That you can still have a good quality of life with PH. And that although it is a life limiting disease, we see many people live much longer than the average life expectancy you may find by looking on Google.

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



How we spend your money...

Thank you to **everyone** who raises money to support the work of PHA UK. With your help, we can continue to improve the lives of those affected by pulmonary hypertension.

And when you raise money for PHA UK, you can be confident that it's being spent in the right way. An independent assessment of our charitable activities has shown that for every £1 we spend, 96p goes on charitable activities.

For fundraising support...

call the PHA UK office on 01709 761450, or email office@phauk.org

£1

For every £1
spent by PHA UK

96p
goes on charitable
activities

Source: Charity Choice (www.charitychoice.co.uk)

In your Autumn issue of Emphasis...

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

PH Week preview – how you can get involved in our second awareness week.

Exploring adoption – experiences and advice.

Me and my music – Chris Johnson on how singing helps him manage his condition.

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 with any feedback or ideas.

Free PHA UK publications for support & advice



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



PHA UK Contact Details

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

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. Through our partnership with Turn2us, PHA UK members can also use the Turn2us Benefits Calculator and Grants Search on our website at www.phauk.org

Do we have your correct details?

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

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



Support us by playing our **PHA UK Lottery.**

For just £1 a week, you can play the fundraising PHA UK Lottery.

So how does it work? Each week PHA UK Lottery players are allocated a six-digit number and the winning numbers are selected every Saturday. Cheques are then posted to winners directly – there's no need to check your numbers or make a claim yourself. You can increase your chances of winning by purchasing more than one entry.

Match six digits to win **£25,000**

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Signing up is simple!

Go to either www.phauk.org and search 'Lottery', or www.unitylottery.co.uk and search 'Pulmonary Hypertension Association UK'.

"I play the PHA UK Lottery to support the charity in their research. Plus, I've won some money a couple of times too!"

Catherine, Lancashire

