SPRING 2019

emphasis

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

The financial impact of pulmonary hypertension

Research results revealed

ALLOTMENTS

Grow your own to
feel better this spring

A portrait of PH

The photography project in the frame

NEW LUNGS, NEW LIFE

Young Charlie's inspirational story

CONFERENCE IS COMING!

Looking ahead to
our anniversary
celebrations in May

Plus...

- The new rules around driving
- Medication and Brexit
- Health and wellbeing
- Working with PH
- ...and much, much more!

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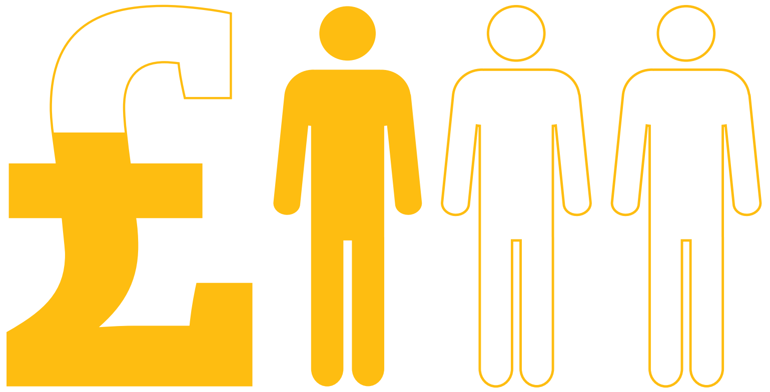

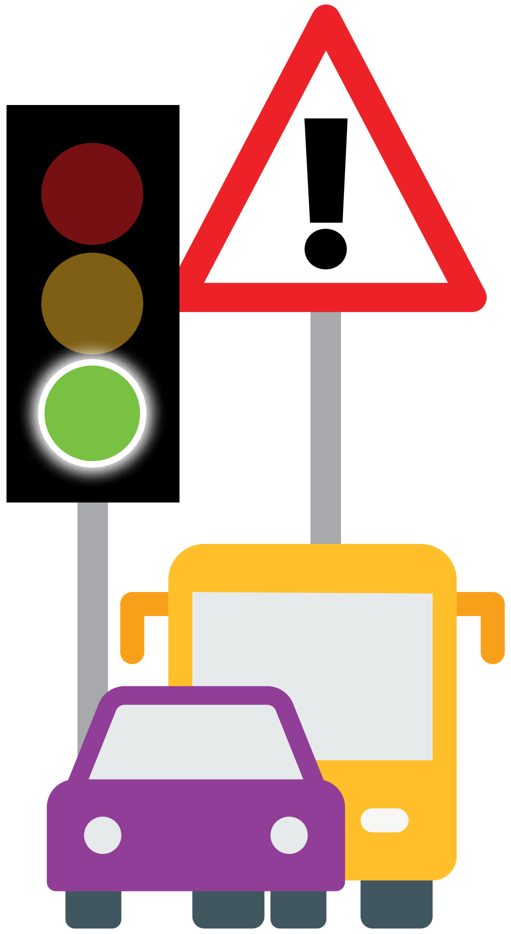

Welcome

Welcome to the first Emphasis of 2019. There's lots to look forward to this year as we begin to celebrate the PHA UK's 20th anniversary.

We now have over 4,000 members and I think we can all be proud of what we've achieved over the last two decades. As the organisation was formed in 1999 and registered as a charity in 2000, we'll be kicking off our celebrations at our conference in May and we can't wait to see lots of our PH family there. See page 24 for details.

In this issue of Emphasis we bring you the results of our research into the financial impact of pulmonary hypertension. We'll be using the findings as an important evidence base in our campaign for change, so once again, thank you to everyone who shared their voice.

I'd also like to draw your attention to the important information on page ten about driving with PH. Pulmonary hypertension is now a 'declarable condition', meaning you must tell the DVLA of your diagnosis. We worked hard to get to the bottom of this and bring the information to you as quickly as possible.

You may notice some things in this magazine look a bit different. We've refreshed the contents section to make it easier to find features and revamped our fundraising focus (we always have so much to say on these pages because you're constantly amazing us with your support!)

As always, we'd love to know what you think of this magazine. Keep your ideas coming.

Finally, we're delighted with the feedback we've been getting about our brand-new website www.phocusonlifestyle.org Take a look and let us know what you think!

Iain Armstrong

Iain Armstrong
Chair of PHA UK
media@phauk.org

> *"We can all be proud of what we've achieved over the last two decades"*

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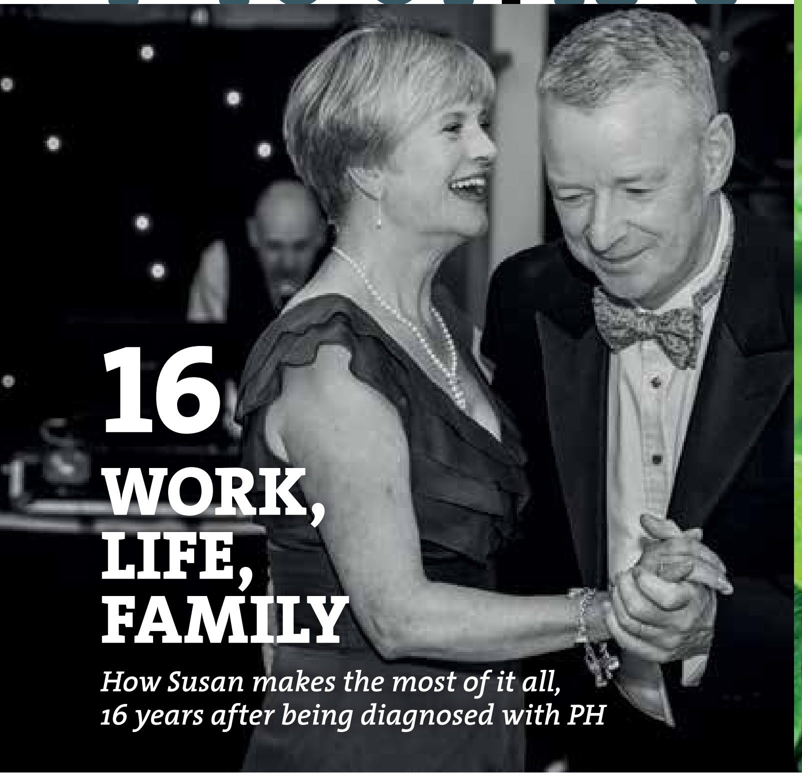
Important information about what you need to tell the DVLA



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This magazine is printed on paper from sustainably managed sources

Emphasis ***exchange***

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.

PRESTIGIOUS AWARD WINS FOR PAUL

Congratulations to PHA UK friend and advisor Professor Paul Corris, who has picked up two prestigious awards for his work in the area of pulmonary hypertension.

Paul, Professor of Respiratory Medicine at the Freeman Hospital and the University of Newcastle, was recognised with a lifetime achievement award by the International Pulmonary Vascular Research Institute at an awards ceremony in Barcelona earlier this year.

He also picked up the British Thoracic Society medal in December, awarded annually to individuals who have greatly contributed to respiratory medicine in Britain.

Paul, who recently retired from his role, was heavily involved in securing a national pulmonary hypertension service which was established in 2001.

He said: *"To be recognised for a lifetime's work in developing improving clinical care for patients and the quality of one's research by your international peers is very special."*

Paul is co-chair of PHocus2021, PHA UK's advocacy group which campaigns for changes to public policy.

Iain Armstrong, chair of PHA UK, said: *"It is fantastic to see Paul recognised with these two awards. His tireless work which led to the establishment of the pulmonary hypertension specialist centres is an inspiration and he has made a huge difference to so many people's lives across his career. He has always kept the patient's needs at the centre of his care. He has been an exceptional colleague and friend over the last 20 years and fully deserves these awards as he begins his well-earned retirement from clinical practice."*

Helping with hippos

Young Maddie Richards has been doing her bit for the PHA UK by selling a herd of cuddly hippos at her school. Maddie, who is nine, is supporting her dad's cousin, who has PH. You can read about the family's fundraising on page 46.

FIGHTING FOR OUR MEMBERS IN WESTMINSTER

As part of the PHA UK's continuing work to fight for what's fair for people with PH, two representatives of the charity attended a special meeting in Westminster to review the NHS England drug commissioning process.

Membership services director Shaun Clayton and associate John Smith were invited to take part in the Access to Medicines Hearing hosted by the All Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed Conditions. The meeting, the third of its kind, was held to talk about the NHS England commissioning process. It was an opportunity for the PHA UK to voice frustration over the lack of patient voices in the decision-making process.

Social Media Round-up

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

PHA UK

Member Victoria Sant has celebrated the start of 2019 by scaling the Sydney Harbour Bridge during a solo trip to Australia. Victoria, who was diagnosed with PH in 2016, told us: *"I used oxygen on the flight and completed the climb yesterday - the photo is me half way up. I don't know what my future holds but I am loving life and not wasting a day!"*

@LiamLawrence07

@stokecity and @swfc fans are walking between stadiums in time for kick-off between the two clubs on 30th March . I'm going to be joining them walking 17 hours and 55 miles all to raise funds for pulmonary hypertension and Sheffield's Hallamshire hospital.

Belinda Savage

I'd just like to say, how PHA UK has come on over the years... there's more knowledge of this disease out there. A job well done...thanks.

@NewcastleHosps

Prof Paul Corris – renowned lung specialist from Newcastle – has been honoured with a prestigious international Lifetime Achievement Award from @PVRI just weeks after receiving @BTSrespiratory Medal.

@kellystanley

My brilliant brother Mark has received a certificate from @PHA_UK to thank him for the money he raised when he did his 50km hike in 12 hours. Thank you so much to everyone who donated!

@MaryFergusonCBM

Loved meeting this little lady today whilst filming for @PHA_UK in Essex. Thanks @maritess_mt, Terry and of course Izzy for being such stars!

Vintage tea for Ally

Dear Emphasis,

Alison Whan was a faithful and enthusiastic member of our women's group at Spa and Magherahamlet Presbyterian Churches. We call ourselves Wonder Women and that just about sums up Ally. Although suffering from pulmonary hypertension for many years, she had a most positive and uplifting personality which infected every aspect of her life, inspiring people whom she knew.

Ally passed away in May 2017 and as a group we wanted to do something to celebrate her life. She was well known for her love of baking and fundraising for PHA UK so we decided to do something which would honour both those traditions. We organised a vintage tea in September 2018 to kick off our new season with scones and cakes, many recipes taken from Ally's Racy Recipe book, displayed on cake stands and old-fashioned china. We had waitresses in old fashioned aprons and pearls, music from the fifties playing softly in the background (so as not to disturb the conversations), balloons and bunting to decorate the hall and a play area for the children.

It was a wonderful day, and the atmosphere was super, with the 'workers' enjoying themselves every bit as much as the clientele. There was a constant flow of homemade cakes and scones, with delicious raspberry jam made by Ally's mum, Edna. No one left hungry and the compliments poured in. There were cakes and buns for sale and also handmade blankets. Instead of charging, we left a box for donations and made £1,668 on the day.

We all enjoyed the experience and felt that Ally would definitely have approved. Money continued to come in and we presented our cheque for £2,225 to Ally's mother Edna at our Christmas Dinner in December.

Margaret Broome

The Dromara Thursday Club in Co. Down has also been fundraising in memory of Ally. They celebrated their 20th anniversary by raising £160 for the PHA UK after selecting them as their charity of the year. The club offers arts and crafts for ladies over 50 years old. Thank you to everyone involved!

POST OFFICE Money®

READER RECOMMENDATION

Funeral plans through the Post Office

PHA UK member Rachel Bawden discovered an easy and affordable way of getting insurance to help with funeral costs. She contacted us to share her recommendation with Emphasis readers.

I've been living with PH since 2010 but when I turned 60 I started thinking about making my Will, and that made me think about getting insurance too.

I didn't want to pay a great deal of money and I wanted something simple, so I asked at my local Post Office and they told me about their Pre-Paid Funeral Plan (provided by Dignity Pre Arrangement Limited).

I pay £20 a month, but you can pay what you like depending on how much cover you want. You're covered straight away, as soon as you make your first payment, and the amount they pay to the funeral directors depends on how long you have been paying in for.

They don't care whether you have a long-standing illness like PH and they don't ask you complicated medical questions.

It was easy. All I had to do was fill in a form and they sent it off for me. It's not a huge or complicated form either, it's quite simple and easy to do. I preferred being able to do it all in person as although I use computers, I worry about putting my bank details in online because of everything you hear about fraud and hacking.

I've been paying into the policy for about a year. I think it's good for anyone, whatever their age, to know they can just pop into a Post Office to enquire about it rather than having to go to an insurance broker or online.

I know it sounds morbid thinking about your funeral, but for me it was about knowing I wasn't leaving arrangements to my family or my husband, who worries. I wanted to take it off everyone else's shoulders, and mine too, by not having to worry about how my funeral will be paid for.

We don't like to think that we are going to die, but you wouldn't get in your car and think 'I won't tax it or insure it today because I don't want to think about it'.

I'm glad I sorted this funeral plan as it gives me peace of mind and that's why I want to tell other people about it.

Do you have a recommendation that might help other people affected by PH? Let us know by emailing media@phauk.org

DRIVING WITH PULMONARY HYPERTENSION

The DVLA recently updated its medical guidance meaning you must now inform them if you have a diagnosis of pulmonary hypertension (PH) or congenital heart disease (CHD).

How do I inform them?

Call **0300 790 6806** and tell the agent you have PH or CHD and are under the care of a specialist centre. **Please be aware that the advice you are given on the telephone may be out of date and you may be told that PH or CHD is not a declarable condition**. The PHA UK made several test enquiries to the DVLA and received inconsistent advice before we eventually spoke to their senior doctor to clarify the definitive situation. **When you call the DVLA, be sure to make a note of the date and time that you called**, and keep this information in a safe place.

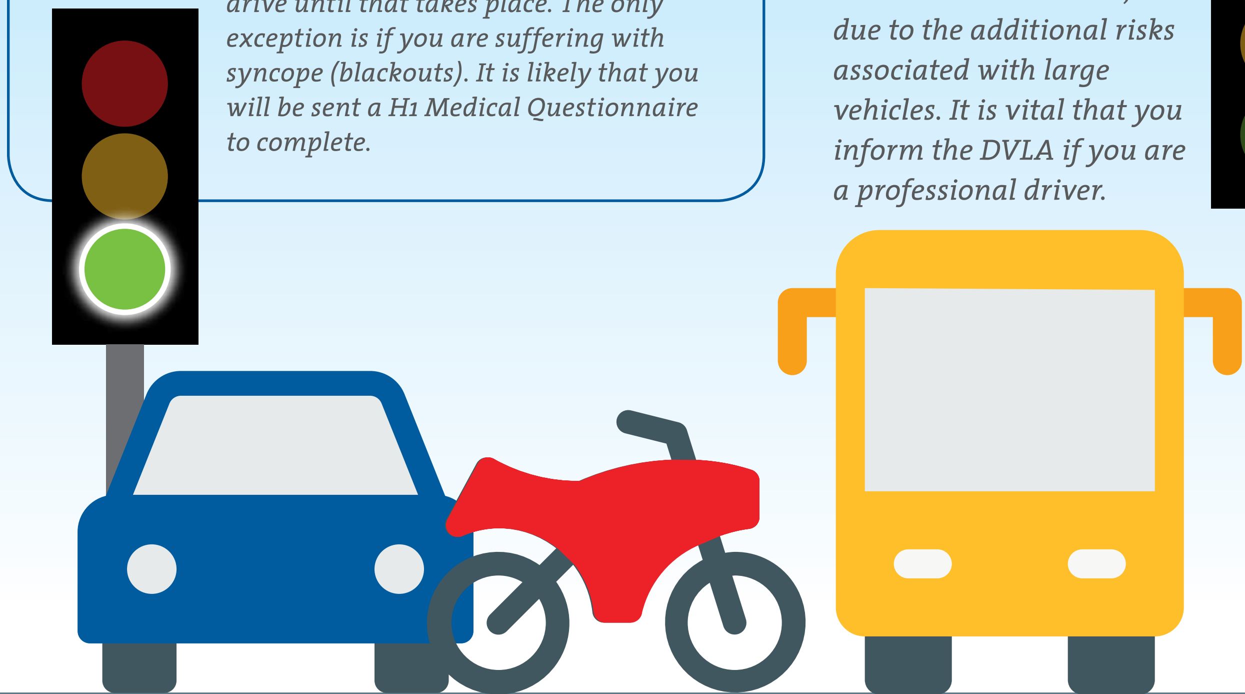
What will happen?

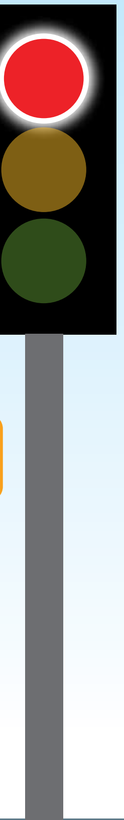
It is highly unlikely that you will have your licence revoked simply by calling the DVLA, so please don't worry. You may be required to have a specialist assessment, but you should be allowed to continue to drive until that takes place. The only exception is if you are suffering with syncope (blackouts). It is likely that you will be sent a H1 Medical Questionnaire to complete.

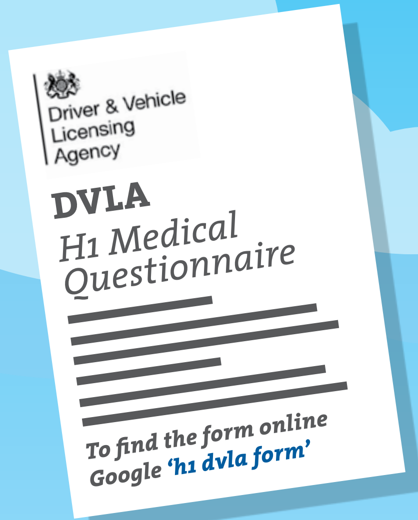
It is very rare for someone to lose their driving licence just because they have PH or CHD. If you think it may be unsafe for you to drive, DO NOT DRIVE!

What if I drive a large vehicle?

If you drive a large vehicle such as a HGV or bus, unfortunately you will be unable to drive until you have had an individual assessment, due to the additional risks associated with large vehicles. It is vital that you inform the DVLA if you are a professional driver.







Driver & Vehicle Licensing Agency

DVLA

H1 Medical Questionnaire

To find the form online Google 'h1 dvla form'

COMPLETING THE DVLA's H1 MEDICAL QUESTIONNAIRE

You may be asked to complete a H1 medical questionnaire after you have notified the DVLA of your PH or CHD diagnosis. Here's some advice to help you.

If you have any letters from your consultant that confirm you are fit to drive, include them with the form. Even though the form doesn't ask for clinical letters, it will help.

Most of the form is quite straightforward, however questions **1.3** and **1.4** need particular attention.

We advise that you carefully answer these on the basis of how you feel **when driving** (ie: sitting down), and not during physical activity.

Please be reassured that it is **very rare** for someone to lose their driving licence just because they have PH or CHD.

Want more guidance?

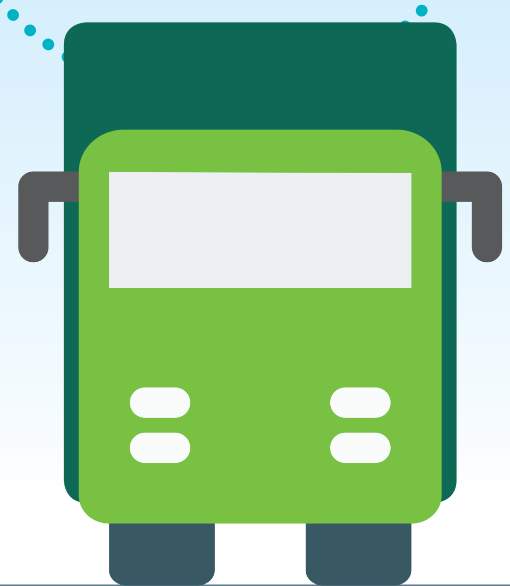
*Iain Armstrong, Chair of the PHA UK, offers his advice in a short film available at **www.phauk.org** and via our YouTube channel.*

*Download our quick guides to driving with PH and / or congenital heart disease at **www.phauk.org**. You can also call **01709 761450** if you'd like to receive one through the post.*

Questions?

The PHA UK are unable to advise on individual circumstances. Please contact the DVLA directly on **0300 790 6806** with queries about driving with PH.

Be sure to make a note of the date and time that you called, and keep this information in a safe place.



You can contact the DVLA at 0300 790 6806 or visit www.gov.uk/browse/driving

Lines are open Monday to Friday, 8am to 5:30pm. Saturday, 8am to 1pm

LIVE BETTER WITH PH

£ NEW REPORT

Beneath the surface

The true financial impact of pulmonary hypertension.

In 2018 we conducted a major survey into how PH affects people's finances – and some of the results were shocking. Now, we're using this evidence to campaign for change.

Over 170 people completed the survey, which asked questions about topics including changes in income, insurance, applying for benefits, and the day-to-day costs associated with pulmonary hypertension.

One-to-one anonymous interviews with people financially affected by PH dug even deeper and proved that, without a doubt, things must change.

Iain Armstrong, Chair of the PHA UK, said: *"Although we already knew that PH has an impact on people's finances to some extent, I think this evidence of the level and depth of the impact on people's day-to-day lives is quite shocking.*

"The qualitative research demonstrates the true emotional impact. These interviews reveal the effect on general health and wellbeing 'beneath the surface', in a disease which already carries a huge burden.

"This research now gives us an evidence base to engage support from commissioners and key stakeholders who are duty-bound to listen and act."

A SNAPSHOT OF WHAT THE SURVEY SHOWED:

76%

of patients under the age of 60 say their financial situation has declined since being diagnosed with PH. 40% reported that their financial situation had declined 'a lot'.

On average, patients in full time work at the time of diagnosis lose a third of their income.

84%

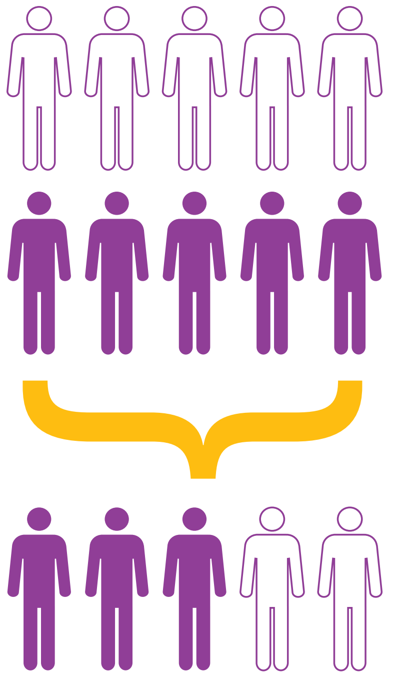
say life or travel insurance quotes are more expensive since being diagnosed with PH.

52%

of applicants were turned down the first time they applied for benefits.

62%

of those who appealed were then successful after appealing.



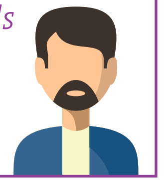
That means that eventually, 83% of everyone who applies for benefits gets awarded them in the end!

Breathless *not voiceless*

What our one-to-one interviews revealed

> *We went from two full time incomes to **living purely off benefits.***

> *I think that the system is stacked against people who have worked hard and then something like this comes along, which is through no fault of your own, and then **you're left to fall back on what you've got.** It feels very unfair.*



> *Sometimes my two children have to take care of me financially. They're only young people, they are starting their own lives and families, but I can tell that **they are bearing the burden of what's happening to me.***

> *We can't go abroad, because we can't afford the insurance. You pay for your holiday but on top of that **you have to pay a sky-high sum of money for medical insurance,** because I'm now deemed as a high risk.*

A summary report of the findings from the survey was included with this issue of Emphasis. For a copy of the full report, which includes all of the findings from the research, please email office@phauk.org or call 01709 761450.

FINANCIAL IMPACT ON FILM

We're bringing the findings of the research to life with a special video that highlights how PH affects the finances of families across the UK – and why change is needed now. We've been filming around the country and we'd like to thank the PHA UK members who have welcomed us into their homes.

The video will be available very soon at www.phocus2021.org – keep your eyes peeled!

Brexit and your prescriptions

By *Dr Neil Hamilton*, Consultant Pharmacist at the Sheffield Pulmonary Vascular Disease Unit

At the time of going to press, it feels as though the only certain thing about Brexit is the uncertainty! My Clinical Pharmacy Team at the Royal Hallamshire Hospital and our friends at the PHA UK are being asked ever more frequently about the potential impact of Brexit on their medicines. I am also aware of the amount of discussion on social media and the internet. I can completely understand everyone's anxiety and absolutely sympathise.

I don't have a crystal ball or any guarantees to offer. However to dispel some Chinese whispers and scaremongering that you may have heard from a very busy rumour mill, I wanted to give you some facts about the state of play nationally; firstly in general terms, and also what we have been doing within the PH community.

The prospect of a 'no-deal' Brexit has become more likely following the defeat in parliament of the Government's proposed withdrawal agreement. A national body, the Pharmaceutical Services Negotiating Committee (PSNC) has been 'deploying all necessary resources' to maintain supplies of medicines to patients when the UK leaves the EU at the end of March. They are focussing on contingency planning with the Department of Health and Social Care (DHSC) so the impact on community pharmacies is minimised.

Recently the Chief Pharmaceutical Officer, Dr Keith Ridge issued communication to summarise the work underway. His summary included the following plans;

- **Medicine Supply assessment** – a comprehensive assessment of medicines to identify those products made in the EU.
- **Six week stockpile** – how the government is working with the pharmaceutical industry to develop a six week stockpile of prescription-only medicines to ensure supply is maintained across the NHS. This involves securing additional warehouse space including refrigerated storage. This plan includes all prescription and pharmacy medicines, vaccines and unlicensed medicines.
- **Alternative transport routes** – the Government has reviewed current routes and made plans to re-route as necessary. Medicines and medical products will be prioritised to maximise the ability of securing supplies after 29th March.
- **Clinical research and trials** – participation and recruitment to trials should continue as normal. Trial medication will, just as with other medicines as described above, receive priority to alternative transport routes.

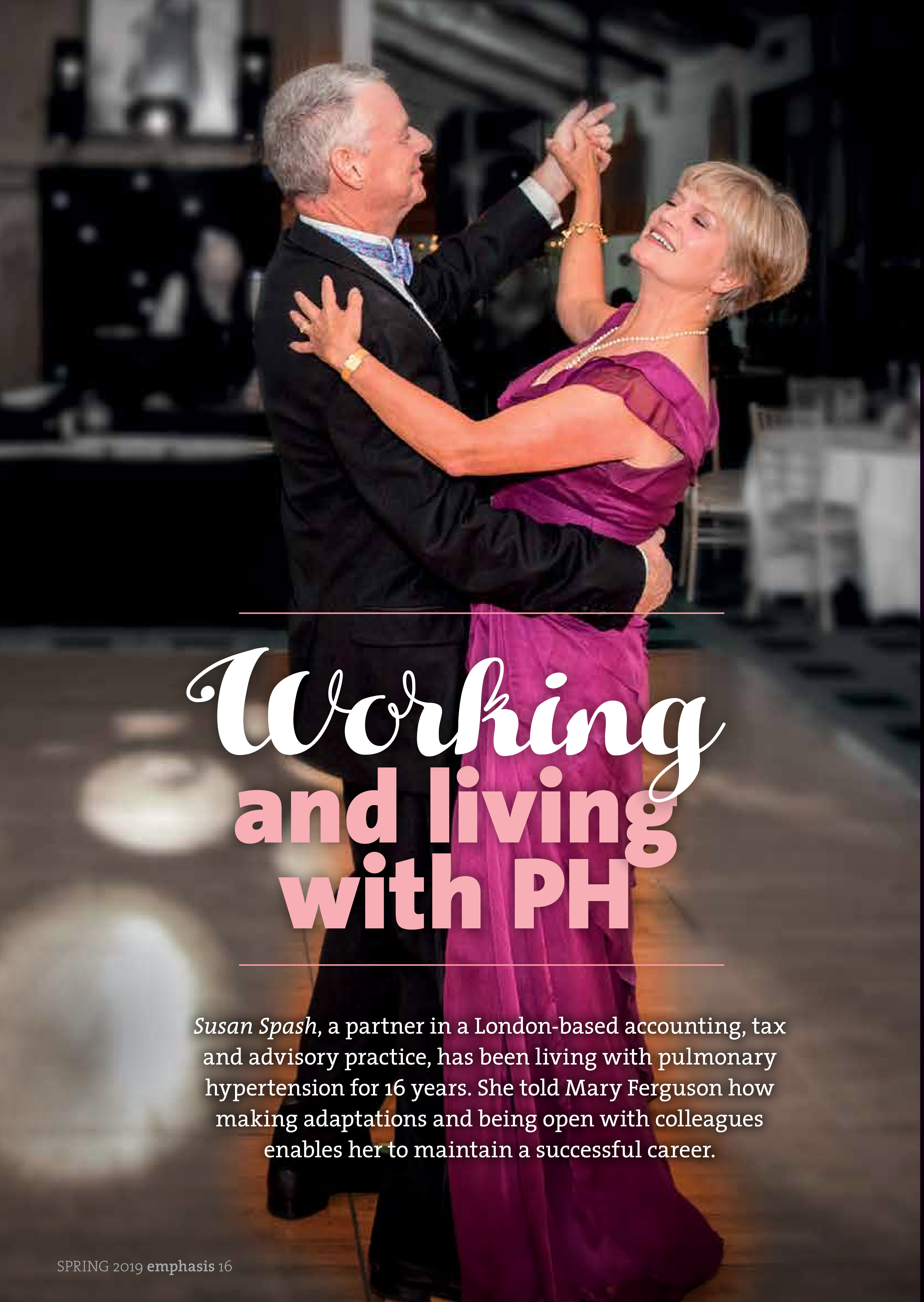
It is clear that a 'no-deal' Brexit will be an extremely challenging time but the focus of the Pharmaceutical Services Negotiating Committee (PSNC), the Department of Health and Social Care (DHSC) and the pharmaceutical industry will be to ensure that patients will be able to get their medicines and vaccines, regardless. For their part, a European body representing the industry is also calling on negotiators to agree a series of actions to protect patients. These measures include fast-track lanes for priority routes through ports and airports. I understand that they are even considering making raw materials exempt from border checks so as not to affect the production of medicines.

Dr Ridge emphasised that over-ordering and stockpiling locally by pharmacies is not helpful or appropriate. This would only add pressure on the availability of medicines for patients elsewhere. Please bear this in mind – even at your individual level.

Within PH, representatives from all the UK centres have met (and been reassured by) the homecare companies to ensure that they have plans in place to cope with maintaining supplies of the medicines, pumps and consumables needed.

My advice is to be particularly careful over your stocks and reordering of prescriptions to ensure that you have enough medication to get across 29th March. *However I do not advise stockpiling as this could deprive someone elsewhere access to their medication.* At this stage we just don't know what will happen and how it will impact us, but be reassured that there is a huge amount of work being done both here and in Europe to minimise the risk of medicine supply interruption over Brexit.

THE INFORMATION IN THIS ARTICLE WAS CORRECT AT THE TIME OF GOING TO PRINT ON 11TH MARCH 2019.



Working and living with PH

Susan Spash, a partner in a London-based accounting, tax and advisory practice, has been living with pulmonary hypertension for 16 years. She told Mary Ferguson how making adaptations and being open with colleagues enables her to maintain a successful career.

My work is very important to me. After I had my children in the mid-nineties, before I was diagnosed with PH, my husband and I made the decision that I would definitely go back to work. I enjoy being a mother, but equally, I really enjoy what I do in my work and I wanted to progress through my career to partner level.

As a private tax advisor I have many and varied clients, based all over the world. My job is mostly office-based and although I do have to travel locally and sometimes overseas, luckily it's not a job that involves an awful lot of rushing around.

I manage the travelling by giving myself loads of time, which also applies to my commute. I try not to get myself into a situation where I'm in a rush, and if I'm travelling around with colleagues I share that with them too. They know that if somewhere should normally take 20 minutes to get to, then I will ask for us to allow 40.

I have found that buses are brilliant for getting around London because they are above ground – so even when it's hot and stuffy and it's very difficult to breathe, I feel like I have a little bit more air than I might do on the underground.

When I was first diagnosed with pulmonary hypertension I was working for a very large employer and stayed there for another nine years. When I received a phone call one day about another job that may be suitable, I immediately wondered when I should explain that I have this illness.

Although pulmonary hypertension doesn't necessarily affect me on a day to day basis, there are some predictable times when I will be out of the office for medical appointments, and it may in the future restrict what I can do - who knows!

In the end I went to the interview with an open mind and happily I was offered the job. I think it was when we were discussing salary and terms and conditions of employment that I decided it was the right time to explain I had PH.

Their main question was whether it would mean unpredictable time off work and I was truthfully able to answer no. I have had time out of the office, but it has been predictable as it's been for medical appointments that I can plan into my diary.

For me, it really is just about getting from A to B. That's the only thing that really affects my work. I may get very tired and that might mean that I rest more at the weekends, or I have a sit-down when I get home at the end of the day. But in terms of my actual work, I really don't think PH has impacted what I do.

When I feel particularly fatigued I take advantage of the flexible working we are offered. So, if the morning isn't going quite so well for me, I can allow myself a little extra sleep and get to the office a bit later.

If you are worrying about how a diagnosis of PH might affect your job, my advice is to be open and honest with your employer and the people who are important to you in your office or work environment – that might be your boss, your mentor or a confidant.

You will have times, like I do, when you feel a little bit less able - but the more you share it the easier it is, and the more understanding people are. ●

You can watch a video of Susan talking about her life with PH by visiting **www.phocusonlifestyle.org**

Susan was diagnosed with PH in 2003 and credits her family for helping her to make the most of life and continue her career. She has two sons, Oliver and Edward (aged 24 and 22) and recently celebrated 30 years of marriage to her husband Mark.

"My family have been excellent, I have a very supportive husband and as a family we do try and get out and about. I really believe that in this day and age, with the treatments that are out there, you have a choice. Do you have an illness, or do you have a life? I have absolutely embraced life and despite having pulmonary hypertension I really wouldn't change it. Life is what you make of it – go for it!"

Home-grown veggies and a *place to de-stress*

The benefits of allotments are rooted far deeper than just providing fruit and veg. *Charlotte Goldthorpe* looks at the health benefits of this blooming trend.

Paul Harris in his shed

Before & After! Paul's Allotment

Some of the fruits of Paul's labours

TOP TIPS FOR MANAGING AN ALLOTMENT

- Share a plot with a neighbour or friend.
- Make sure you have a water source on site to keep those veggies growing.
- Be prepared to put the hours in, especially in the summer months.
- Get in touch with your local council and put your name down on a waiting list.
- Allotment Society website for advice on what to expect **nsalg.org.uk**

Having an allotment can be a rewarding thing to do, and for many provides an escape away from the stresses of every day life. From the satisfaction of growing your own fruit and veggies, to doing your bit for the environment.

An allotment is described by The National Allotment Society as an area of land, leased from a private or local authority landlord for the use of growing fruit and vegetables, and in some cases can be used to grow ornamental plants or to keep hens, rabbits or bees.

Allotments have been in existence for hundreds of years, with evidence pointing back to Anglo-Saxon times. However, today's allotments were rooted in the nineteenth century, when land was given over to the labouring poor for the provision of food growing.

The National Allotment Society claims that just 30 minutes of gardening on your allotment can burn around 150 calories. That's the same as doing low impact aerobics. Not only that but spending as little as 15 minutes a day out in the summer sunshine can build up your levels of vitamin D, if you are fair skinned. And for those whose skin is naturally darker, anywhere up to 90 minutes.

With all the fresh air, and exercise gardening provides, there's no denying that allotments can be good for our health. Plus, you should be able to get those all-important five fruit and veg a day.

If you don't have a particularly large garden, or simply want to do something sociable away from the house, then starting an allotment might be right for you. But how easy is it to get started?

Costs vary across the country, but council-run sites can cost between £50 to £110 for a full plot. Many people opt to split full-size plots in half to share with a friend or neighbour. The society recommends getting in touch with your local council to put your name on a list for a nearby plot but advises that there might be a long waiting list for this popular trend.

Budding gardener Paul Harris, aged 39, was diagnosed with PH in 2015. Coming to terms with his diagnosis took a toll on his mental health.

In April 2017 he started an allotment with his wife Diane after hearing about a plot of land near to his home in Kidsgrove, Stoke-on-Trent. He now spends hours each week on the allotment to help him manage his anxiety and live well with PH.

He said: ***"The allotment was perfect and just a three-minute walk away from home. The timing seemed right too. About a year or so after my diagnosis I had adapted aspects of my life to manage my physical symptoms, but I was struggling with my mental health, and needed an escapism."***

At the time Paul and Diane decided to start their allotment they had also recently gone through foster care training. The couple foster a three-year-old girl who loves spending time in the allotment, especially during spring and summer when she's able to pick raspberries and peas out of the pods and play with the frogs.

"We spend most of our time at the allotment during the late spring and summer for some quality family time – we're lucky that it's so close to home so it's more like an extension of our garden," said Paul. *"We invite friends over for BBQs or for a game of poker in the shed. In the winter we probably spend around two days a week making sure the beds are covered and the plot is tidy."*

It took a while to get the plot how they wanted it as no one had been on the land for 18 months. In fact, Paul recorded that they'd spent around 300 hours making the area safe and inviting, including recycling old palettes for new walls, plant pots and a shelter for the BBQ.

The allotment is part of an area of 25 plots, but each plot of land is enclosed so Paul can lock himself away and get to work on the next part of the project. Whether it's getting the spade out to dig beds or make a new roof.

"It's a welcomed distraction from my negative thoughts," he said. ***"I like to exert myself while working on the allotment too to test how much I can do. It helps get some of my frustration out, but on the flip side I can become frustrated that I can't do as much as I want to because of my PH."***

As well as having PH, Paul has lived with the auto-immune disease lupus for nearly 15 years. Around three years ago he first started to feel breathless and fatigued and one night he experienced abdominal pain too, which prompted a trip to A&E. He spent the next four months in hospital for various tests. Two of those months were spent at the Royal Hallamshire where he was diagnosed with heart failure and subsequently, PH.

It was a turbulent time for Paul and the family. With the lupus and heart failure, he was in and out of intensive care and lost three stone. He said: *"It took a long time for me to get walking again.* ***Having the allotment helped me get back on my feet and gave me a purpose in life.*** *Like many people with PH, day-to-day I get breathless easily, so I've had to adapt, for example, I sometimes can't do more than one flight of stairs in one go. However, I've been able to walk the 11 flights of stairs or so from B floor to the PVDU on M floor at the Royal Hallamshire Hospital!"*

While Paul experienced some physical symptoms of PH, having PH more so affected Paul's mental health and he struggled to come to terms with the fact that he might not be here in six, or seven years' time.

Along with working on the allotment to take his mind off the PH, he decided to contact the dedicated Anxiety UK helpline for PHA UK members and now attends sessions with a counsellor local to him.

Looking ahead, he's treating the allotment as speeding up the retirement process. He said: ***"It's been a great way to meet people and spend time with family and friends too.*** *There's a bit of politics involved, (as there can be with most things) but generally running an allotment is fun, and I love the swap culture too. I swapped a piece of guttering for around 50 tadpoles once!"* Paul has recently got together with other allotment enthusiasts to buy the land from the council and establish a society. The group plan to create a community garden project to give something back, inviting a local school to manage their own plot and sending extra produce to the Salvation Army. ●

Taking control **of your treatment**

Julia De Soyza, nurse specialist in pulmonary hypertension at the Freeman Hospital in Newcastle, is passionate about patient choice. Here, she discusses the importance of patients being involved in decisions about their treatment.

Across the UK, PH teams are dedicated to building relationships with patients - from diagnosis to treatment.

Having a good foundation for a relationship helps in the shared decision-making process and two-way conversation needed to enable healthcare teams to make a positive difference to patients' lives.

Whichever specialist centre patients attend, visits to clinics are vital and it's important to remember that PH teams are on the side of the patient.

People with PH deserve to be treated with dignity and respect, and this includes being involved in decisions about their treatment.

Therefore, it's important for all healthcare professionals to respect that patients can make decisions about their care and choice of treatments, even if that doesn't align with their professional view.

Most people are capable and willing to be involved in deciding how they will be treated. Shared decision-making involves spending time talking through all the options available to patients; the pros and cons of each treatment; and exploring patients' ideas, values and expectations, and what's important to them. It's about working together and puts people at the heart of decisions about their own care and treatment.

A particularly difficult choice to make might be starting intravenous treatment for PH. Health professionals might tell the patient about the strong evidence for its use and that it increases survival, but it's important to consider that IV treatment demands a lot of time and effort and can result in a significant burden for patients.

For patients to make an informed decision, the demands of treatment and its effects on wellbeing should be explored, along with the advantages.

Ultimately, some decisions may be a trade-off over quality of life versus length of life.

In the 2016 Living with PH survey, 86% of patients said the support they received from their specialist centre was 'excellent' or 'good'. This statistic was encouraging but there's still more we can do.

In my practice I've successfully used a shared decision-making model called the Ottawa Personal Decision Guide. The questionnaire explores the options available to patients by considering four elements: knowledge, values, certainty and support.*

The tool involves patients using stars to rate each treatment according to their understanding of the risks involved and the benefits that matter to them most. The process identifies their decision-making needs and how they feel about the choices available to them. They can either choose to make decisions alone or talk to a healthcare professional or family member. It gives patients control and ensures they feel involved. It is important patients are not pressured into a treatment and that they understand what it will involve.

The Ottawa Guide gives patients and medical professionals a chance to explore the options together.

The method takes into consideration what the patient knows best; their preferences, personal circumstances, values and beliefs, and what's important to them. It does this while also considering what healthcare professionals know best: the risks and benefits of treatments and evidence surrounding their use.

As a healthcare professional, hearing about patient values that influence decisions is one of the most valuable aspects of using this tool. Patients I've used this with have told me they found the process really helpful. ●

Julia encourages patients to remember the following:

- *Your healthcare team are there to help you, not judge you.*
- *Your visit should be a two-way conversation.*
- *Don't be afraid to tell your healthcare team about your worries and concerns. If you don't tell them they won't be able to help you.*

You can order our free patient guides: *Medication & PH* and *PH & You* via our website:
www.phauk.org/resources/publications/

**Ottawa Personal Decision Guide © 2015 O'Connor, Stacey, Jacobsen. Ottawa Hospital Research Institute & University of Ottawa, Canada.*

HOW YOUR DONATIONS **ARE USED**

As a charity we rely heavily on the kind support of fundraisers and we think it's important to tell you exactly how your donations are used. This is how we spent your money between October 2017 and October 2018.

For every £1 spent by PHA UK
96p
goes on charitable activities*

4%
££££

GENERAL RUNNING COSTS

A small amount of our income goes on general running costs to keep the charity operational.
Our office in Sheffield doubles up as a resource centre, which enables us to deliver educational workshops to medical professionals. It also hosts meetings between specialist centres and is the nucleus of our PHocus2021 activity, providing a northern base for collaborative working with strategic commissioning bodies.

30%
££££££££££
££££££££££
££££££££££

RESEARCH

Work in this area has included analysing the financial impact of PH to inform a major campaign; funding post-graduate research into the role of palliative care in PH; enabling junior doctor attendance at a major respiratory conference; and research around heart and lung transplants to underpin future PHocus2021 work.

27%
£££££££
££££££££££
££££££££££

MEMBERSHIP SUPPORT

This has included our first conference dedicated to children affected by PH, in partnership with Great Ormond Street Children's Hospital; the launch of a brand new support website, **www.phocusonlifestyle.org**; four editions of the award-winning Emphasis magazine; the re-launch of the flagship 'Understanding Pulmonary Hypertension' book; and support via telephone and email. Our partnerships with Turn2Us and Anxiety UK provided dedicated support for financial and emotional issues.

24%
££££
££££££££££
££££££££££

RAISING AWARENESS OF PH

This included our third annual PH Awareness Week; attending the World Symposium on Pulmonary Hypertension in France to raise awareness amongst the international medical community; media relations and social media; and producing short films. We have put a significant focus on raising awareness of organ donation and our medical education programme has continued to raise awareness amongst professionals in the UK.

15%
£££££
££££££££££

SUPPORT TO SPECIALIST CARE & NATIONAL DEVELOPMENT

Through our PHocus2021 platform we have helped secure access to the new drug Selexipag for patients in England, Scotland and Wales – making a major difference to individuals and influencing future commissioning processes. We have also supported specialised care through providing materials to specialist centres, lobbying NHS England and driving change via strategic collaboration.

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

AnxietyUK
Here for you since 1970

PHA UK TRUSTED Partner

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@anxiety.org.uk**
- Assessment and therapy provision for those who need emotional support
- Training and resources for PHA UK professionals and members

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

Working together to overcome anxiety

The PHA UK has been working with national charity Anxiety UK for several years to support its members experiencing anxiety, stress or anxiety-based depression. *Charlotte Goldthorpe* takes a closer look at the help available.

Many people with PH struggle with their emotional wellbeing and often don't know where to turn for help.

The PHA UK's partnership with Anxiety UK ensures that members can access a range of support services, wherever they live. This includes a free, dedicated helpline and email support service and access to talking therapies, and even acupuncture where appropriate, free of charge.

All the volunteers who work on the helpline at Anxiety UK are trained to support people who contact the charity for information and details of how to help manage their anxiety, stress and/or anxiety-based depression.

> *It's been a real lifeline for me. It took a while for me to realise I needed the support and to admit I was struggling*

Dave Smithson, services manager at Anxiety UK, said: *"When members of the PHA UK ring our dedicated helpline they will first speak to one of our trained volunteers, many of whom have experienced anxiety themselves so understand what it's like to live with these kinds of difficulties.*

"The volunteers are not clinicians, counsellors or therapists but they have a raft of lived experience of anxiety-related issues and around supporting individuals with anxiety."

The partnership allows accessibility at any time for individuals who are ready to seek support for their emotional wellbeing. The service is available for people with PH as well as their close family and friends.

Dave said: *"Whether someone has a physical condition or an emotional wellbeing difficulty, it's really easy to forget that it does impact on the rest of the family; it's not just about the individual living with PH. What's good about this service is that it's there for everyone – family, friends, carers and people with PH."*

As well as providing the dedicated helpline and email support service, Anxiety UK can refer PHA UK members for specialist support. This might involve face-to-face sessions with an Anxiety UK Approved Therapist local to them or accessing therapy through regular Skype or FaceTime calls in the comfort of their own home.

Anxiety UK Approved Therapists are subject to several pre-eligibility checks. All of them are members of a relevant professional governing body such as the British Association of Behavioural and Cognitive Psychotherapy.

The service is completely confidential, and Anxiety UK complies with data protection laws. Even the PHA UK won't know who has used the service.

People who seek support might be referred for Cognitive Behavioural Therapy (CBT) - a practical toolkit for people to address their anxiety which focuses on the here and now. Alternatively, counselling might be a more suitable therapy for longer-standing issues.

Paul Harris, aged 39, was diagnosed with PH in 2015. He has received counselling through the partnership to manage his anxiety. He said: *"After reaching breaking point, I contacted the dedicated Anxiety UK helpline for PHA UK members and within a week I started to receive free, face-to-face counselling sessions with a counsellor local to me.*

"It's been a real lifeline for me. It took a while for me to realise I needed the support and to admit I was struggling, but it was good to offload my feelings and learn coping strategies such as mindfulness. I now access the Headspace app through Anxiety UK at home as and when I need it. The more I've used the app, the more I've learnt how to manage my symptoms."

FREE HELPLINE AND EMAIL SERVICE

Members of the PHA UK have access to a free, dedicated helpline and email service run by Anxiety UK. If you or your family have concerns about your emotional wellbeing, call 0344 332 9010 or email phauk@anxietyuk.org.uk

4-6TH MAY 2019

JOIN US AT CONFERENCE

20th

Anniversary Celebrations

Heythrop Park Hotel, Oxfordshire

CONFERENCE *is coming!*

We're all looking forward to our conference weekend in May.

This year's event returns to the stunning Heythrop Park Hotel in Oxfordshire and will mark the start of our 20th anniversary celebrations.

Taking place during the first bank holiday of the year, 4th to 6th May, we're crossing our fingers for sunshine!

There will be lots going on, with interactive educational sessions, activities for children and the bit that everyone looks forward to – a special dinner on the Saturday evening.

There will also be specialist talks from Neil Hamilton, consultant pharmacist at the Royal Hallamshire Hospital in Sheffield, and Professor Paul Corris, clinical advisor to PHA UK who recently won a lifetime achievement award for his work.

The weekend is a relaxing and enjoyable way for the PH community to get together to share experiences, catch up with old friends, and of course, to make new ones too.

> ***"We always enjoy hosting our conferences because they're such a great way to bring the PH community together. It's important for patients and their kinship to meet with each other outside of clinic. PH can be an isolating disease so we come together each year to do something positive. We can't wait to see everyone there!"***
>
> IAIN ARMSTRONG
> Chair of PHA UK

Contact Daisy at CFS events on 01438 751519 if you have any queries about the event.

A Portrait of PH

Photography student Erin Lawson was so inspired by her mother Carolyn's journey with pulmonary hypertension that she decided to make it the subject of her university project. The work aimed to explore the impact PH has had on their family, capturing the seriousness and the positives through the lens of a camera and the words of Carolyn and her loved ones. Erin has kindly allowed Emphasis to reproduce part of the project for this special feature.

> *" I am really proud of what I have achieved. I think it's helped me not only as a photographer telling someone's story, but as a daughter too - reminding me how much my mum has been through and how strong we have all become. My favourite image from the whole series is my mum and I holding hands, the opening image of the series. I'm normally behind the camera so I never physically see us together in an image. It is quite surreal to see our relationship in a physical form of a photograph, but I think that's what impacts me more. This image, and the series as a whole, makes me reflect on my relationship with my mum and how close we have become in recent years - as well as the unspoken love we have as a mother and daughter. "*
>
> **ERIN LAWSON, CAROLYN'S DAUGHTER**

Life for Cas and her family in 2018 is vastly richer and more normal than I had thought it was likely to be when she was diagnosed in 2003, which is a statement to her strength of character. We have known each other since we were eleven, so we've seen each other through lots of different phases of our lives. From a practical perspective, adjustments have to be made, but I don't feel it's made a difference to the substance of that friendship.

Doris Braeburn, Carolyn's friend

Mum's illness has impacted her ability to be spontaneous. There always needs to be a plan when she goes anywhere or does anything. We, as a family, have to take into account the frustrations of having a limiting illness, being aware of not just the physical strain on Mum's body but her mental health too. I do not think pulmonary hypertension has limited Mum's happiness or ability to live a full life. I just think these expectations have been adjusted more to what Mum can actually do. PH has made our relationship stronger, especially in the last few years, and I now cherish the moments I have with her. I am so proud of my Mum and am proud to be her daughter.

Erin Lawson, Carolyn's daughter

My lovely daughter. It must be very difficult to live with this condition and the restraints it puts on daily life. I have been and remain ready to help in any way but Carolyn's determination to manage her life has meant that requests for help are few and far between. I am very proud of her and the way she is coping; from the girl who was always squeamish to the woman making her own cassettes. She is remarkable and never fails to amaze me.

Margaret Ray, Carolyn's mother

Mum ensures that pulmonary hypertension does not limit her life in any way. It's just resulted in some changes that we cope with as a family unit. Even though it is a big thing, I feel as though it has brought us closer in a way. PH is just a normal part of our lives. Although I may not say it to Mum often, I love her very much and if anything her illness has strengthened our relationship.

James Lawson, Carolyn's son

Cas having pulmonary hypertension makes me think about how precious life and good health is; how we should make the most of every day, every adventure and everyone we love as we do not know what fate may hold for us in the future.

The frustrations of PH have had both positive and negative impacts on our relationship over the years since Cas was diagnosed. It can make it difficult to share experiences together. On the other hand, I think it has made our bond stronger as we try not to let it impact our lives too heavily. Most importantly, PH doesn't change the person deep down who I fell in love with and married 26 years ago.

Adrian Lawson, Carolyn's husband

"I feel lucky to still be alive 15 years after diagnosis. I'm grateful that every time there's been a deterioration in my health there's been another treatment available for me to try.

What works for some doesn't for others. There are people diagnosed after I was who haven't responded to the treatment as well and have sadly died.

Because pulmonary hypertension is so rare and patients often look well, most people don't understand it, or what it's like to live with the condition. Awareness is low – it's not like cancer or diabetes or epilepsy. If you say 'pulmonary hypertension' people just think you have high blood pressure and dismiss it, but it's much more serious than that. I don't like to draw attention to my illness and hate the thought that when I say I can't do something people think I'm being lazy. Tiredness seems to exacerbate the side effects but it's hard not to over-do things when you don't want to miss out on activities or feel like you're 'giving in' to the PH.

I am not the same person my husband met and married. Our lives have definitely been changed by me having PH, but he has taken it in his stride and made the best of it for all of us. He is a good man. My illness has brought us closer together and made us realise that life is short and there to be lived. I'm not going to let it beat me.

Carolyn Lawson

Reviews

Would you like to review an app or book which may be of interest to Emphasis readers? Please contact **editor@phauk.org**

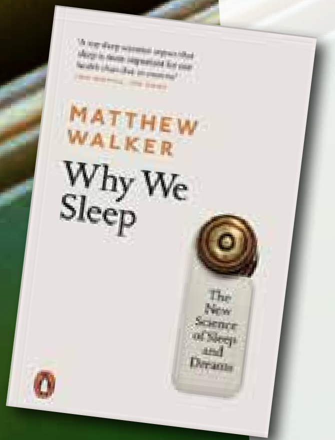
This issue, we review an app to help you keep track of your exercise and a book on the importance of sleep.

Strava app

With over 32 million users, Strava has a reputation for being the tool of choice if you lead an active lifestyle, but you don't have to be a fitness enthusiast to get the most out of its features. A year's subscription to Strava costs £47.99, but you can have one month's free trial to decide if the app is right for you. Strava's popularity has turned it into a social network, with users able to share their best times, running and cycling routes with friends and family. Strava performs well simply as a record of your weekly exercise. When you go for a walk, jog or bike ride, you can record your activity, and the app will track your route, recording the distance travelled and how many calories you've burnt. You can also link it to a smart watch so it can record your heart rate. It then adds up all your recorded time and produces a monthly report of your activity, with in-depth analytics. You then have the option to share your achievements on the app or keep it private. The app needs to be open during exercise to accurately track your routes, which can drain your phone battery.

Reviewed by Chris Coates

MARKS OUT OF 5? **4**



Why We Sleep

by Professor Matthew Walker

I was recommended this international bestseller by a friend (who kept telling me I looked tired!). I was sceptical at first, after all what was there to know? We go to sleep, wake up and start a new day, nothing to it. I can honestly say this book has been a real eye opener for me. I now see how sleep is utterly crucial to every aspect of our health, well-being, quality of life, life expectancy, memory function and so much more. Until very recently, we didn't know why we sleep, or why not getting enough is so damaging to our health. Compared to the other basic aspects of life, such as eating, drinking, and reproducing, the purpose of sleep remained a mystery. This ground-breaking book explores twenty years of cutting-edge research to solve the mystery of why sleep matters and busts many myths which cause lots of us to be making big mistakes. In pretty much every developed society around the world sleep is undervalued, with devastating consequences: every major disease in the developed world - Alzheimer's, cancer, obesity, diabetes - has very strong links to not getting enough sleep. You'll learn the best techniques to improve sleep and even delve into how other species sleep, and consider if sleep is one of the fundamental reasons why humans evolved so successfully - pretty big stuff for something we all just take for granted!

Reviewed by John Smith

MARKS OUT OF 5? **5**

THE POWER OF THE PATIENT VOICE

Sharing patient experiences was crucial to securing access to the new drug Selexipag last year, with the Living with PH survey providing vital evidence during the fight to overturn negative decisions. Here, *Dr David Kiely* and *Dr Neil Hamilton* of the Royal Hallamshire Hospital in Sheffield discuss why the patient voice is so important, and why we should continue working together to drive change.

Dr Neil Hamilton

Consultant Pharmacist, Sheffield Pulmonary Vascular Disease Unit

The decision to fund Selexipag for patients in England at the end of last year was long overdue, especially as it was already available for the rest of the UK.

The patient voice was absolutely crucial in terms of securing access. There was much less patient involvement at the start of this process several years ago, when we first heard that Selexipag was getting a licence.

A group of clinicians and PH professionals worked with NHS England to try and get the drug commissioned and it failed on a couple of occasions. That's been well documented. But what became increasingly important was the role that the PHA UK played in supporting the case, and NHS England began to involve the patient more and more.

I think that really was a momentum changer for the decision. Adding the patient voice created a narrative and a context for decision-makers at NHS England to better understand why the drug was so important, where it might fit in and what a difference it was going to make.

It is really important for patients to get involved with opportunities to share their experiences. As clinicians we have a long experience of working in this clinical area. We can interrogate and understand trial results. But we can't articulate as well as patients what it is actually like living with pulmonary hypertension and its impact on day-to-day activities.

> "Adding the patient voice created a narrative and a context for decision-makers at NHS England"

Understanding the goals and what people would want from the treatment might be very different sitting across from a clinician than it would sitting across from a patient.

Even if they have never come forward or spoken up before, patients and carers must always know they have a voice and the PHA UK is always happy to hear from people across the board. Everyone's take on something is going to be slightly different.

People shouldn't feel shy. Everyone has got a really important voice and it's great that so many did come forward to share their experiences for the Living with PH survey. It's clearly made a big difference this time around with Selexipag and almost certainly it will make a big difference again.

Dr David Kiely

Director, Sheffield Pulmonary Vascular Disease Unit

One of the great advantages of the patient voice is that patients are very capable of articulating their experiences in a language that individuals can understand.

I think we need to remember that the people making decisions about drug access are individuals in their own right. And to hear a patient story brings all the important aspects of how the condition affects people to life much more than a doctor talking about the hemodynamic and physiological effects.

Patients, families and caregivers bring a degree of reality that is often missed out amongst other descriptions of the illness. It is very important to understand what a huge impact pulmonary hypertension can have on people's lives.

I think patients, and ourselves as individuals, sometimes underestimate the impact that we can make on decision makers. We may believe there are other individuals out there who will be articulating our case, or putting forward our views, and actually I think we need to remember that we all have an important voice.

Within the NHS, the people that are making decisions are used to hearing from different groups, physicians and healthcare professionals lobbying for different treatments. To hear from the perspective of a patient or family member can be refreshing and provide another angle.

My colleagues and I have learned a huge amount from patients and their families over the years and we hope that makes us better caregivers, better doctors and better nurses.

I would like to say thank you to all the patients and their family members who gave their voice to the campaign to secure access to Selexipag.

I'd also like to remind people that it's important to continue sharing our thoughts and experiences. Working in partnership at multiple levels is one way that we can make a real impact in the area of pulmonary hypertension.

> "I'd also like to remind people that it's important to continue sharing our thoughts and experiences"

You can watch David and Neil being interviewed about the power of the patient voice by visiting www.phocus2021.org/latest-news

My Grandad *my inspiration*

After watching his grandfather live with pulmonary hypertension, 17-year-old *Will Pallett* was inspired to find out more about the disease – and he is now pursuing a career in medicine. He spoke to Mary Ferguson at the PHA UK resource centre in Sheffield.

Will was just 13 when he lost his grandfather Brian. The pair enjoyed a close relationship and it wasn't until years after his death of a heart attack that he – and the rest of the family – realised just how serious pulmonary hypertension is.

It was during the first year of his A-levels that Will decided to make the disease the focus of his Extended Project Qualification (EPQ), choosing the title 'Pathophysiology of Pulmonary Arterial Hypertension and the cost effectiveness of the modern medications used in treatment'.

The research enabled Will to discover more about his grandfather's disease, and sparked an interest in medicine that will now shape his future.

Until Will completed his research, neither he nor his family knew that PH was incurable. None of them had heard of it when Brian was first diagnosed, and they assumed it was a condition that affected lots of miners and steel workers. They had no idea it was so rare.

In fact, because Will's grandmother had been diagnosed with ovarian cancer two years previously, they worried more about her health – and Will's mum and dad felt the strain of having two elderly parents, both in ill health, living hours away from their family home in Morpeth.

"I knew grandad was poorly, but that was it really", said Will. "It wasn't until after he died that I realised he had PH. I remember walking to the pub with him to watch football every Boxing Day, but towards the end he couldn't even walk five feet. Even when he was ill though, he had a similar humour to me and we got on really well. I got used to seeing him with an oxygen mask on and I would forget about his illness and just enjoy spending time with him.

"We're a very tight-knit family and it was my relationship with grandad that spurred me on to do more research into pulmonary hypertension."

Will is now planning to go on to study medicine at university in September, and has big ambitions for the future.

"I'd love to be a consultant physician or surgeon one day, and also potentially do some lecturing and further research at the same time," he added. ***"Pulmonary hypertension has really caught my interest so working in the field of PH is an option that may be nice to go into, as I have a personal reason behind it. But I'm open to lots of avenues at the moment."*** ●

RAISING AWARENESS

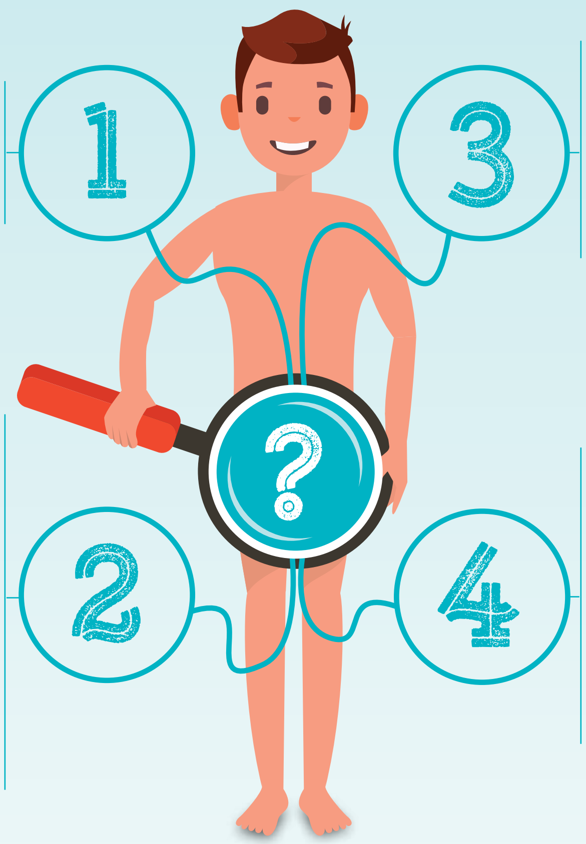
Choosing pulmonary hypertension as the subject of his Extended Project Qualification gave Will a chance to explain more about the condition to his friends. He said: *"When I told them I was doing my project on pulmonary hypertension they all asked what it was. If I'd told them it was on cancer, arthritis or Alzheimer's, for example, they wouldn't necessarily have needed to ask, as most people are aware of these conditions. Hopefully in the future, people will be more aware of PH."*

Will visiting the PHA UK resource centre

{ Checking for... testicular cancer }

"Unfortunately, having pulmonary hypertension doesn't mean you're less likely to develop another disease, so it's important to be aware of general wellbeing. We've been encouraged to start including a focus on general health in each issue, so we hope you find this guide useful."

Iain Armstrong, Chair, PHA UK



1. The best time to check yourself is after a shower or bath as your skin is most relaxed.
2. Examine one testicle at a time by taking the testicle between your thumb and first two fingers and roll with consistent gentle pressure. Feel for any lumps or changes in shape, size or consistency. A lump can be about the size of a pea but may be larger.
3. Familiarise yourself with the epididymis towards the back of the testicle. It should feel rope-like and tender to any pressure – this is a normal lump.
4. Most men have one testicle that is larger than the other or find that one testicle may hang lower than the other. This is very typical and is definitely not a reason to worry.

What should I do if I find a lump?
If you notice a change or you feel a lump, don't panic, but do have it checked by your GP. Research has shown that less than 4% of testicular lumps or swellings are cancerous, so any lumps you find could be completely normal, but it's still important to have them checked as soon as possible.

What if the lump is found to be cancerous?
The most common treatment for testicular cancer is an orchidectomy, which is an operation to remove the cancerous testicle completely. In most cases, no chemotherapy or radiotherapy is required, but you will be closely monitored for the next two to three years.

For more information on testicular cancer, visit www.nhs.co.uk

NEXT ISSUE: Checking your breasts

New lungs New life!


On holiday in Portugal in August 2017, before diagnosis


Charlie celebrating his 13th birthday in hospital, just 9 days after his transplant


First day at upper school, 9 months after transplant


Six weeks into his stay at GOSH


Charlie with his mum, dad and brother, January 2019


Claire and her Nordic walking club took on a special challenge for the PHA UK just before Christmas last year, completing an eight-mile walk to raise over £250. Claire said: "It's amazing that we were only aware of the PHA UK, and indeed pulmonary hypertension itself, for four short months between Charlie's diagnosis and his lung transplant. We can't thank the charity enough for the support they give and the awareness they promote."

Young teenager *Charlie Beeton* received a double lung transplant just a few months after being diagnosed with PH - and celebrated his 13th birthday in hospital just nine days later. Here, his mother Claire shares the story of his remarkable recovery.

We had never heard of pulmonary hypertension before Charlie's diagnosis in September 2017. The amazing paediatrician at our local hospital in Bedford knew exactly what he was looking at as soon as he had completed the ultrasound, but didn't go in to a great deal of detail at that point (for which I am very grateful). He did get Charlie onto the ward and hooked up to oxygen immediately, and we saw the improvement in his appearance straight away.

We knew that we were to be transferred to Great Ormond Street Children's Hospital quickly and it was once we were there that Charlie really started to deteriorate. We were immediately introduced to the transplant team. I was in equal parts devastated at the seriousness and severity of Charlie's condition, and relieved that we were finally dealing with a definite 'thing'. We knew that we were in the care of the best people and that whatever the outcome, it would be the best it could be.

Charlie was on the transplant list for just two months.

We were advised that because of his blood type, donor organs were easier to match to him and that it would be fairly quick - we weren't expecting it to be that quick though! In those two months we were called into hospital twice with possible matches before that third and final call that ended in a very successful transplant.

The incredibly quick turnaround of just four months from diagnosis to transplant really didn't leave much 'coping' time at all. I have not had the opportunity to speak to other families who have experienced a child or other relative being on a transplant waiting list, but I would imagine that our situation is quite unusual.

At the time of Charlie's transplant, we were still in shock and if I am to be perfectly honest it was hard to celebrate it in the same way that a family who has endured a long and arduous wait might.

Although vastly improved by the constant epoprostenol (epo) infusion, Charlie was still very poorly and we simply couldn't envisage anything beyond him being wheeled in to theatre. We knew that he was in amazing hands, that the surgical team were world class and that Charlie would not have been listed in the first place if they were not confident of a successful outcome, but we couldn't imagine anyone surviving that operation.

To say that Charlie is a different child post-transplant would be the understatement of the century!

He looked better that he had in years immediately after coming out of surgery, despite all the tubes and gubbins. He was lovely and pink! He was out of bed within 36 hours, outside of the hospital for a wander about in a week and home on the mainline train just two weeks post-surgery.

He has continued his recovery without a single setback; not a cold, a sickness bug or any time off school at all, apart from for clinic appointments.

It took Charlie a long time to realise how very poorly he had been; he had just adapted to his failing health as the years had gone by. His acceptance that he was in fact ill, and that he does in fact now feel much better, has been key in his continued improvement.

He just has so much more 'about' him now. It is not just his energy, fitness and improved physical health and appearance. It is his amazing personality that is growing all the time. He is enjoying life so much more now, as are all of us. We had not realised how much we were missing out on as a family before Charlie's diagnosis and subsequent treatment.

Charlie developing idiopathic pulmonary hypertension is devastating, but that's our lot, and we must accept it.

We count ourselves as so incredibly lucky that it was diagnosed and treated in time, and that we are currently enjoying the most 'normal' and happy times as a family that we have ever wished for.

CLAIRE'S ADVICE FOR OTHER PARENTS

- *We were very busy with clinic appointments, medicine deliveries, visits from the community nurses and goodness knows what else. I tracked down online and printed off an A4 week-to-view calendar. Lots of room to write everything clearly, and there really was something to deal with most days.*
- *It helped us to keep all correspondence, discharge letters and appointment letters in a folder just for Charlie.*
- *If your child is about to begin using the epo, do not underestimate how much room the medicine, syringes, needles, pumps and goodness-knows-what-else will take up in your home!*
- *We were advised by another parent to invest in a baby monitor to help us if the CADD pump went off overnight. I am really pleased to say that we did not have any problems with any of the pumps at all, but it was good to have that as a back-up just in case.*

Keeping busy with PH

Lucinda Duxbury-Smith from Kent is determined to keep busy and live her best life with PH. She told Charlotte Goldthorpe about how her hobbies help her maintain a positive outlook.

Lucinda was diagnosed with PH in 2004, six years after first experiencing symptoms. After becoming ill, she had to leave her job as the head of a healthcare assistant agency which left her feeling isolated.

She'd always managed to keep busy, but as her symptoms worsened, she was frightened to go out or do any exercise.

It wasn't until three years ago, when studies on the benefits of exercise and PH had been published, and with advice from her consultant, that she felt confident enough to give exercise a go.

Now a keen swimmer, she completes 32 lengths each morning. She has also taken up ballroom dancing and joined a Rock Choir; performs spiritual healing at her local church, and even makes her own jewellery.

Lucinda's enthusiasm for exercise and wanting to learn new things has helped her remain positive, which, in turn, has helped her cope with her PH.

She said:

"I try to keep as busy as possible, within my limitations. When I feel unwell it's difficult to be motivated and I struggle to lose weight when I'm not able to go out. I live on my own so it can be lonely too.

"Like many people living with PH, I have good days and bad. Over the last few months I've felt very out of breath and not my usual self, but generally I enjoy a good quality of life."

Lucinda dances twice a week when she feels well enough. *"I'm a beginner, I'm not a ballroom dancer, but that doesn't matter. I enjoy keeping active and being sociable,"* she said.

Lucinda also attends her local sports centre every morning to swim and socialise. She said: *"I go early in the morning, which is a lovely start to the day. Some mornings I don't feel like going but once I'm in it's ok and I'm glad that I did it. I've met some new friends there and after our swim we move to the baby pool to sit and chat. Once a month we also get together for a meal."*

"Exercise is so important. It makes me feel healthier, happier and good about myself. The team at my specialist centre taught me how to breathe when I'm swimming to get rid of the carbon dioxide, which has helped me a lot and no one can see me do it. I avoid the front crawl or other strokes which are too energetic and stick to doing breast stroke slowly.

"For the first time in 12 years I've come off oxygen at night and I'm sure that swimming has helped. My next step is to lose the weight so I don't need to use a sleep apnoea mask anymore."

As well as exercising, Lucinda has many hobbies to keep her busy, including making jewellery as part of a college course. Five years ago, she enrolled on a course to become a spiritualist healer and now practices at her church every Thursday afternoon and Friday evening.

Lucinda is also part of a Rock Choir which combines the power of music, meeting new friends and performing at events. In August she will be performing with the choir at the Edinburgh Fringe Festival.

Last year she sang with 4,000 Rock Choir members during a concert of 10,000 people at London's Hyde Park with Michael Ball. *"I've never experienced anything like it before. We all stood up and sang – it was wonderful. It was hard work and I found the walk quite far, but my friends waited for me and helped pull my trolley along,"* she said.

"I would advise others with PH to try to do as much as they can. I've made lots of friends through my interests and without my hobbies I would be lost." ●

Green Leaf Crew!

GREEN LEAF CREW Q&A
CONNIE PRICE

Connie Price is five years old and lives in Rayleigh, Essex with her mum, dad, big sister Lucy and cats Poppy and Red. Connie was diagnosed with PH aged three. Here she shares some of her favourite things.

Q. What do you like doing at school?
A. *Playing games with my friends like 'tag'. I like hide and seek because I get to stop and rest.*

Q. What's your favourite thing to do at the weekend?
A. *I love movie nights with mummy, daddy and sister Lucy.*

Q. What's your favourite food?
A. *Chicken nuggets and chips*

Q. What's your favourite TV show?
A. *Peppa Pig*

Q. What do you want to do when you grow up?
A. *I'd like to be a chef and bake cakes. And maybe climb a really big mountain.*

Q. Where do you like to go on holiday?
A. *I like to go to France and stay in a villa. I also like Center Parcs and Legoland.*

Q. What famous person would you like to meet?
A. *Snow White.*

Q. If you could have any superpower, what would it be?
A. *I'd like to be able to make water bombs to throw at the baddies. It would stop them chasing me.*

CONNIE WITH HER BIG SISTER LUCY

HOW TO... GROW A BEAN PLANT

If you have a garden, as the warmer weather arrives you'll see plants starting to grow. So why not grow your own plant? Broad beans are easy to plant and you can watch them grow in as little as a week. Here's our step-by-step guide.

What you'll need...

- a broad bean seed
- a saucer
- some water
- a glass jar
- a piece of kitchen roll or a napkin

How to do it...

- Soak the broad bean seed in some water on a saucer for one hour.
- Swirl some water around in your jar then tip it out but leave the jar wet – don't dry it.
- Roll up a piece of kitchen roll or a napkin and put it inside the jar, pressing it against the glass. Then, slip your bean seed in between the napkin and the glass.
- Stand your bean on a sunny windowsill and use a plant spray or spoon to sprinkle a little water on it every day.
- Your bean should sprout after about four days.
- After about ten days, your bean seed should have grown roots, a stem and leaves.
- To make sure your bean continues to grow, add some soil to the jar and water it often. It should then grow enough to produce beans for you to eat!

Credit: Great Grub Club.

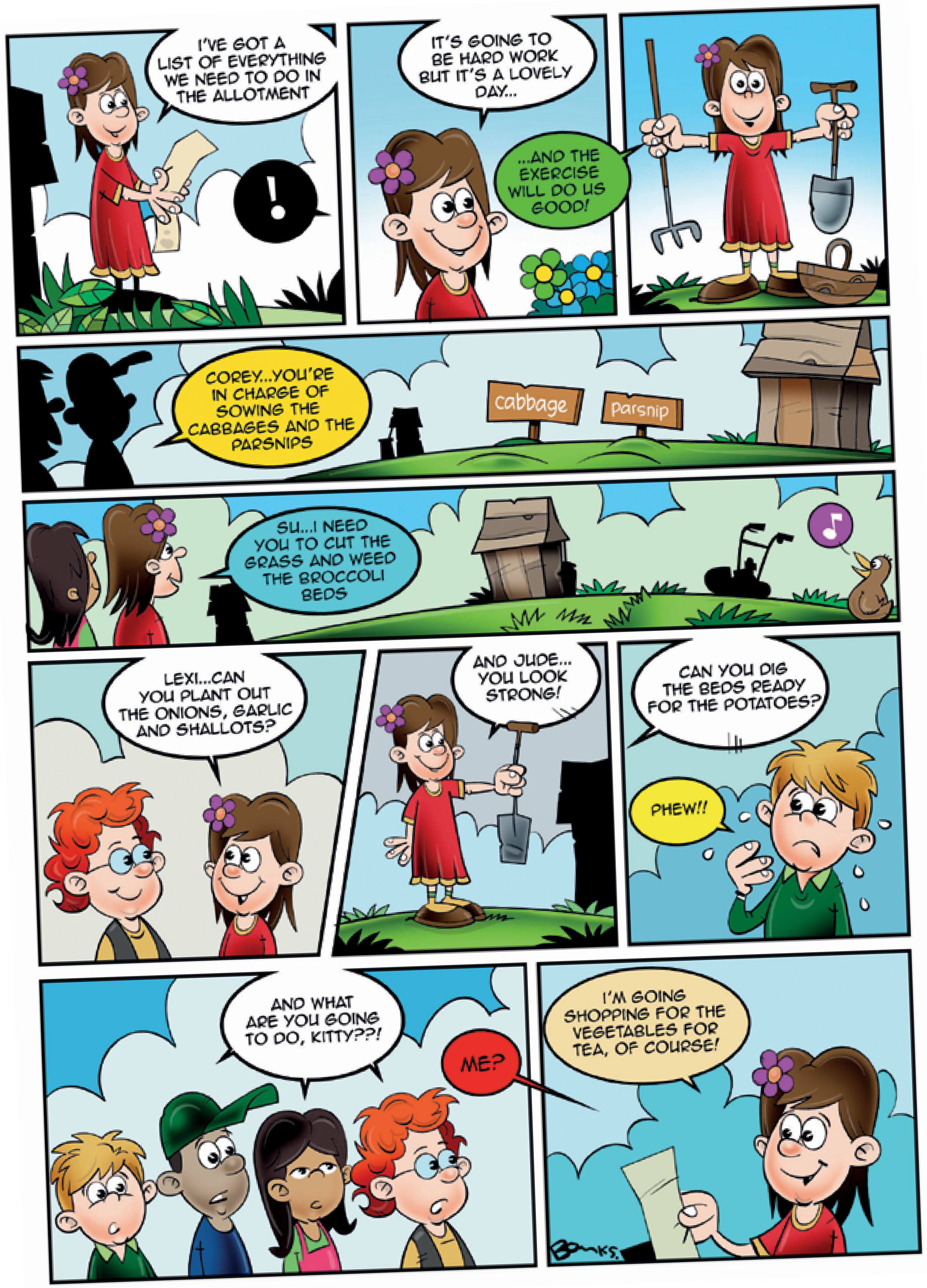
HOMEGROWN BEAN SPROUT

Patch

by David Banks

The GREEN LEAF CREW

BY DAVID BANKS



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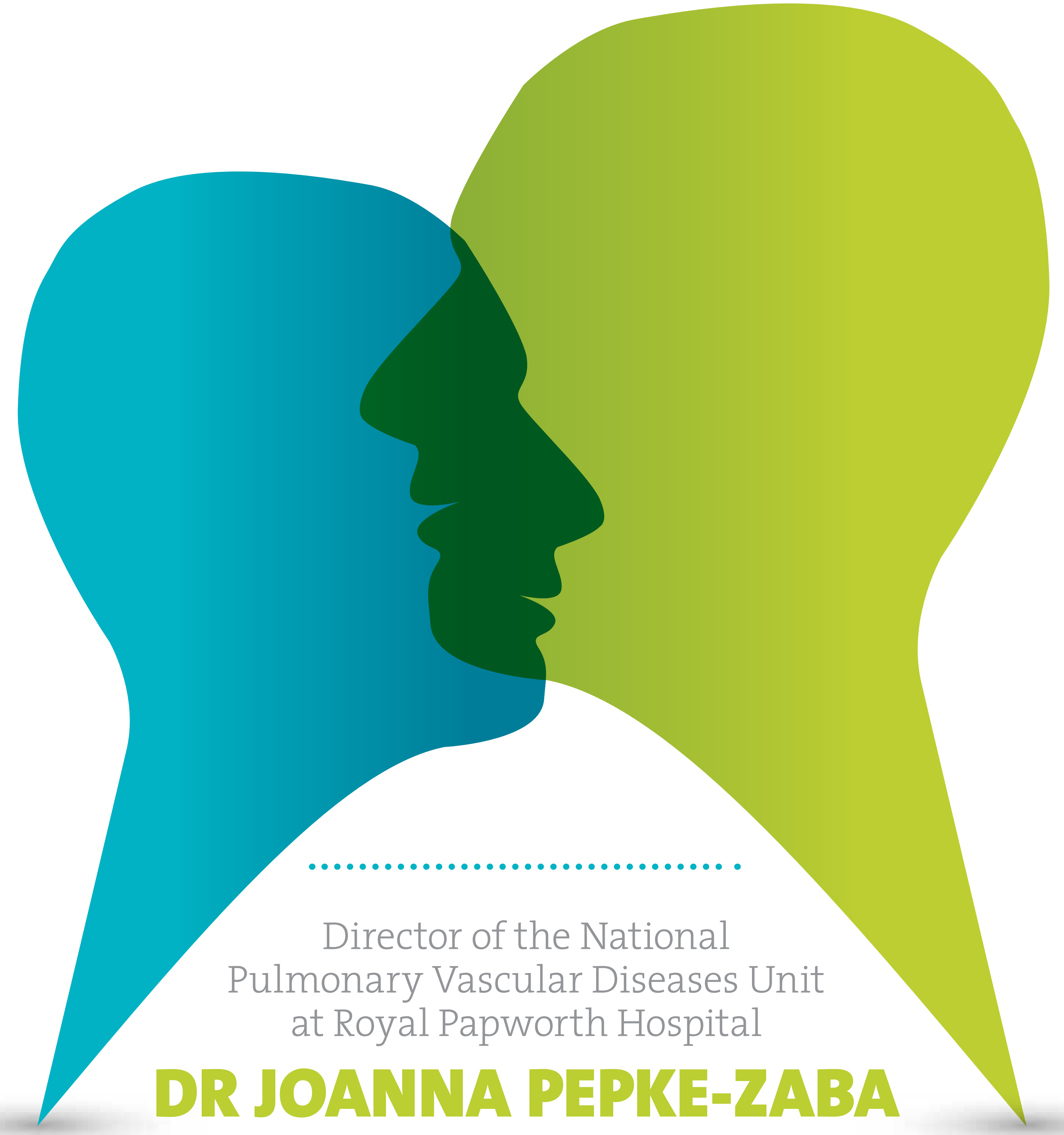


Director of the National
Pulmonary Vascular Diseases Unit
at Royal Papworth Hospital

DR JOANNA PEPKE-ZABA

in conversation with
Mary Ferguson

Joanna graduated from Warsaw University School of Medicine in Poland before undertaking a fellowship in respiratory physiology at Royal Papworth and Addenbrooke's Hospitals, University of Cambridge, which resulted in a PhD.

She is the lead physician and Director of the National Pulmonary Vascular Diseases Unit at Royal Papworth Hospital. She leads the National Chronic Thromboembolic Pulmonary Hypertension (CTEPH) programme together with cardiothoracic surgeons (pulmonary endarterectomy) and with interventional cardiologist (balloon pulmonary angioplasty) services. Joanna has published over 150 papers in peer review journals and book chapters in the field of PH and serves on various educational and scientific international committees. She is a founding member of the International CTEPH Association and has been Honorary Senior Visiting Fellow at the University of Cambridge and School of Clinical Medicine since 2011.

Joanna played a key part in establishing the pioneering balloon pulmonary angioplasty treatment for CTEPH patients in the UK.

Q. What does a typical day at work look like for you?
A. *There's no such thing as a typical day. It's always busy – that's typical! A huge part of my job involves direct contact with patients and their families. I am very much a 'hands-on' physician. My role is to keep the service up to the top standard, so that patients receive the best care possible.*

Q. When did your interest in medicine begin?
A. *My interest in medicine began even before I started my school days. As a small child I had a recurrent illness and I remember feeling fed up of sitting at home doing nothing with a sore throat. I decided there and then that I would grow up and be a doctor and find a cure!*

Q. What led you into the field of pulmonary hypertension?
A. *It's a very long story. I came to Cambridge from Poland as part of a research scholarship and I was introduced to Dr Higenbottam, who was the leading researcher into pulmonary hypertension and lung transplantation in those days. I started working with him in the field of researching into PH.*

This was a good few years ago and led to my PhD. It was one of the most exciting times of my life.

We started introducing epoprostenol and nitric oxide; I was the first person in the world to give nitric oxide to a pulmonary hypertension patient. It was exciting to be at the forefront of developing treatments for pulmonary hypertension.

Q. Can you tell me about your current research interests?
A. *I'm very much interested in translational medicine, which covers lots of projects. I'm particularly interested in the basic mechanisms of underlying pulmonary hypertension and specifically, Chronic Thromboembolic Pulmonary Hypertension (CTEPH) and idiopathic PAH.*

At Papworth we are very much involved in all the projects related to mechanisms in those two specific sub-diagnostic groups of PH, including treatments and innovation – like the balloon pulmonary angioplasty (BPA) procedure for CTEPH. (A pioneering procedure which uses a balloon to widen blocked or narrowed blood vessels.)

Q. Can you tell me more about your involvement in bringing balloon angioplasty to the UK?
A. *The procedure was developed in the 1990s in the USA but it was then refined by Japanese colleagues who truly established it as a procedure for patients with CTEPH.*

It was clear in 2012/13 that this procedure was offering patients with a distal distribution of vascular occlusion a significant improvement in functional status, and in pulmonary pressures in lung vessels.

The Pulmonary Hypertension Physician's Committee UK and Ireland agreed that this procedure should also be established here. I was the one who led the project and introduced it to the service in this country, with the treatment being made available on the NHS in the spring of last year.

It took years to go through all the loops and hoops of the National Institute of Clinical Excellence (NICE) innovation...

>>>

the*interview*

DOCTOR
JOANNA
PEPKE-ZABA

> *“It was exciting to be at the forefront of developing treatments for pulmonary hypertension.”*

...group, and the different stages of NHS approval, but it’s finally been achieved and now we have a balloon angioplasty service in the UK that’s been a huge success.

Q. What difference is the treatment making to patients?
A. *It gives an alternative to those patients who would not benefit from the pulmonary endarterectomy. Even with drug treatment they are often still limited and have significantly elevated pressure and vascular resistance, but with the balloon angioplasty we can reduce pressures and vascular resistance in the lungs. Symptoms can be significantly improved by this procedure which is opening the vessels in the lungs to improve flow of the blood through the lungs. We’ve carried out over 130 balloon angioplasty procedures so far. The BPA service has been established alongside its ‘bigger brother’ pulmonary endarterectomy - we performed our 2000th pulmonary endarterectomy operation in February 2019 which is a great achievement not only for Papworth, but for the country.*

Q. What inspires you in your work?
A. *The patients. That’s a very simple question! I am inspired by seeing the patients feeling better, even if they are not cured. Seeing improvement is one of the most wonderful things that can happen in a doctor’s career. And seeing the survival curve improving from decade to decade is something which really keeps me going and driving forward.*

Q. Do you feel a sense of pride that you have played a part in improved survival?
A. *It’s funny because things are always so busy day-to-day that you don’t think about it; there’s not much time to reflect from a personal perspective. Interviews like this are a good way of reflecting! I feel like I have been one of the luckiest people in the field because I have been involved in the development of so many drug therapies, something which is very special.*

Q. What’s the best piece of advice you’ve ever been given?
A. *Always do what you think is the most important for the patients. That sounds very broad, but it’s what makes everything meaningful.*

Q. And finally, how do you relax outside of work?
A. *I like cooking for family and friends. In my opinion, cuisine is like art and I adjust what I make according to things like the weather and how I feel. The idea is to have everyone around the table, enjoying good food and talking about life. I do lots of walking and cycling, especially alongside the river, which is very beautiful. I also enjoy diving – ideally in warm seas!* ●

NHS Digital

The National Audit of **Pulmonary Hypertension**

How your data is used

What is the National Audit of Pulmonary Hypertension?

The National Audit of Pulmonary Hypertension is a clinical audit carried out by NHS Digital, a government organisation set up to collect and study information on health and social care.

The audit measures the quality of care provided to people referred to pulmonary hypertension services in England (including patients referred from Wales) and Scotland, with the aim of improving patient care.

By looking at what is being done now, the audit can help to improve care for people with pulmonary hypertension in the future.

The Pulmonary Hypertension Association (PHA UK) played a vital role in setting up the National Audit of Pulmonary Hypertension by funding its first year in 2010.

How does the audit measure quality of care?

The audit measures against professionally agreed standards for the quality of care provided by pulmonary hypertension services.

These standards include:

- ✓ Patients should receive a timely diagnosis
- ✓ Patients receiving a PH drug should have an annual consultation
- ✓ PH centres should see a sufficient number of patients
- ✓ Patient quality of life should be recorded

How does this improve care?

The audit publishes annual reports which show how the participating PH centres measure against these standards. These reports identify where improvement is needed and showcase good practice.

Centre results have improved since the standards were introduced and they are invited to share their good practice for publication in the annual report.

All of the reports are available on the NHS Digital website by visiting **www.digital.nhs.uk/ph**

What health information does the audit collect about you?

The audit collects identifiable information about you and your treatment to track your care wherever you receive it.

Only information that is normally recorded in your medical notes is used. This identifiable information is linked to Office of National Statistics information.

The data within the published audit report is anonymised, which means that a patient cannot be identified because their personal information is removed.

You can find a full list of the information collected in the audit by visiting **www.digital.nhs.uk/ph**

How is your information safe and confidential?

NHS Digital has been given permission to use and store patient information in order to carry out this audit in line with strict regulation under Acts of Parliament.

You can learn more about how they keep your information safe by visiting **www.digital.nhs.uk/ph**

Your right to say no

If you do not want your information to be used in the audit, please contact our enquiries team by emailing **enquiries@nhsdigital.nhs.uk** or calling **0300 303 5678**.

They will talk you through the process of having your data removed.

Please be assured that this will not affect your treatment and care in any way.

Want to know more?

If you would like more information about the National Audit of Pulmonary Hypertension please get in touch with NHS Digital in the following ways:

Website:
www.digital.nhs.uk

Email:
enquiries@nhsdigital.nhs.uk

Telephone:
0300 303 5678
Calls to this number will be charged at the same rate as standard landline numbers

Regular as *clockwork*

By consultant pharmacist *Dr Neil Hamilton*. Before you start to read this edition's 'advice from the pharmacist' section, be aware that we are talking about bowel habits. So if you're about to eat – you maybe want to enjoy that first then come back to us!

Incontinence and constipation may seem trivial but both can make people feel terrible, so the impact of them is not to be underestimated. Both are potentially major issues, which may be remedied or potentially avoided by lifestyle changes. However if you are struggling then accessible advice is always available over the counter at your local pharmacy with very few treatment options being "prescription-only". If it is any reassurance, and you experience bowel problems, you are not alone.

An NHS report from last year estimated that 6.5 million adults in the UK suffer some form of bowel problem.

An NHS report from last year estimated that 6.5 million adults in the UK suffer some form of bowel problem. Nearly 1 in 10 of the population are affected by faecal incontinence and 0.5-1% adults experience it regularly enough to affect their quality of life. Whilst faecal incontinence is closely associated with age; it is reported to be affecting 15% of the over 85s living at home and even more common in residential and nursing homes. However this is not only a concern of adults, with 900,000 children and young people in the UK suffering bladder or bowel problems too.

It is also worth bearing in mind that these figures may be an under-estimate, as people may not seek advice because they are embarrassed.

As with many common ailments, some people feel uncomfortable asking for advice about their bowel habits; whether their problem is going too often or not enough. This reluctance is unfortunately misguided, and either way the problem is often easily rectified. Where simple remedies are not successful, early intervention of more serious issues is highly likely to improve the outcome in the long term.

Having put this hugely common complaint in a national context, I will now give some ideas for people who may be suffering in silence and yet to seek help. More good quality advice can be found on the NHS Choices website. Whilst the web can be immensely helpful if you know to look in the right places, tapping into "Dr Google" can also throw up millions of results, many of which link to unverified, poor quality information. Be warned!

Constipation

If you do ask for advice on constipation, the first stage will always be support and encouragement for self-management. In short, this means;

- *Optimising the quality of your diet; eating a healthy, balanced diet and having regular meals. The meals should include whole grains, fruits & juices and vegetables. Aim for 30g fibre per day.*
- *Ensure that you drink adequate amounts of fluid, especially if you are at risk of dehydration.*
- *Ensure that you stay as active and mobile as you are able to.*

Public Health England's "The Eatwell Guide" is a great source of information on how to maintain a healthy balanced diet.

Incontinence and constipation may seem trivial but both can make people feel terrible, so the impact of them is not to be underestimated.

Ensuring appropriate hydration and fluid intake is especially challenging for PH patients who suffer fluid retention or take diuretics (water tablets). Fluid restriction (which means limiting your liquid intake) to avoid fluid retention (often called oedema) can itself cause problems for the kidneys. Everyone taking water tablets will need blood tests periodically to check the kidneys, and salts in the blood, are within safe limits. Maintaining the right dose of water tablets to control oedema without causing dehydration (a common cause of constipation) requires expertise. Patients are advised not to alter their own doses independently without discussion with doctors.

If the constipation does not ease despite these lifestyle modifications, there are various types of medicines available, which can help. The best one to use depends on first diagnosing the likely cause of being 'bunged up' in the first place.

Medication that can cause constipation may include (not exclusively);

- *Aluminium-containing antacids*
- *Diuretics*
- *Iron or calcium supplements*
- *Opioid analgesics e.g. morphine, codeine, tramadol etc.*
- *Antimuscarinics, e.g. oxybutynin, procyclidine*
- *Antidepressants, especially tricyclics e.g. amitriptyline*
- *Anti-psychotics e.g. quetiapine, clozapine*
- *Anti-epileptics / neuropathic painkillers e.g. gabapentin, pregabalin*
- *Anti-histamines, especially hydroxyzine*
- *Anti-emetics, especially ondansetron and granisetron*

Where constipation is opioid induced, patients should continue with healthy dietary choices but may also need an osmotic laxative, such as macrogol (e.g. laxido®) and maybe a stimulant (e.g. senna or docusate).

Where opioids are not involved, a suitable first choice is a bulk-forming laxative such as ispaghula (fybogel® or similar). A popular choice in my experience is senna for occasional use. Senna is a stimulant laxative and has its effect about 12 hours after the dose. If this works for you, then there is no need to change to an alternative. Note that some laxatives, especially osmotic laxatives will not give an immediate effect, may take a few doses to work and so should not be taken as single doses to help relieve short-term problems. They need to be taken regularly in the minimum dose needed to maintain a regular bowel habit. In any event, try and improve diet and hydration in addition to any medication to try and prevent ongoing issues. Once normal stools are being formed and easily passed three times a week, the laxatives can be stopped.

I cannot emphasise strongly enough (without stating the obvious!) how vital maintaining normal bowel habits can be. Excessive straining during episodes of constipation poses additional risk for patients with PH. It is not unheard of for our patients to feel very dizzy and worse still black out when straining on the toilet.

Incontinence & diarrhoea

A more frequent need to open your bowels is every bit as distressing as constipation and with some more serious causes. If you notice diarrhoea / incontinence which has persisted for more than four weeks you need to seek medical advice. Clearly if you notice more worrying signs such as potential blood in the stools and unexplained weight loss these need to be investigated more urgently.

Usually, diarrhoea is short-lived and may be down to eating the wrong thing, short-term infections such as norovirus or drinking local water/ice when you're travelling. These are usually self-limiting and taking medication such as loperamide (Imodium®) if absolutely essential may provide sufficient relief.

Some medications, most notably the prostanoids used in PH can cause loose motions. If this is the case, discuss with your specialist centre for personal advice. Temporary symptoms may be managed with loperamide but ongoing issues may warrant a reduction in the dose of one or more medications. Always check with the experts if you have concerns. ●

Whilst we may not all be taking up Dry January, Stoptober or increasing our time exercising, simple lifestyle changes in terms of eating more of the right things at the right times can help keep us all 'regular as clockwork'. This is a new year's resolution that we would all be better off sticking to in 2019!

FUNDRAISING focus

Walking in Derek's memory

Yvonne Rennie, her two daughters and three grandchildren took part in the 10k Edinburgh kiltwalk in memory of Yvonne's husband Derek, who lost his battle with PH in 2017.

Pauline Stirrat, Derek's daughter, said: *"Derek's passing has left a huge hole in our lives. He proudly walked my sister down the aisle without oxygen in June 2017 despite being terminally ill and unable to walk easily. He was also an extremely proud grandad to all of the grandkids, egging each of their little personalities on. Sadly he never got to meet Ruraidh, his fourth grandchild who was born in March 2018. My mum has been working hard to raise awareness of PH, the silent symptoms and any treatment available. We were proud to raise £1,500 for PHA UK, a charity which is now very close to our hearts."*

Spanish cycle for PHA UK

James Richards is cycling 724 miles across Spain to raise money for PHA UK after his cousin Julia was diagnosed with PH in July 2018 aged 48.

James said: *"My little bike ride is nothing compared to the challenges that PH sufferers have to contend with on a daily basis and to have no cure is definitely heartbreaking. So, with some grit and determination I would like to raise some cash to donate to this amazing charity, which is now very close to my heart."* James has already smashed his £1000 target, well before he sets off on his seven-day ride from Bilbao to Gibraltar on 18 May.

Remembering Will through music

Rye Milligan organised a fundraising concert in London in partnership with the British and Irish Modern Music Institute to raise money for PHA UK in memory of his friend Will Acres, who died in February 2018. At the concert, there was a showcase of 'Body and Soul', a song Will, a DJ, wrote but never released. Will's sister Annie also spoke at the event and a stall selling chocolate eggs raised even more money. *"The event was a huge success and so many people had an incredible night – the feedback has been unbelievable,"* Rye said. *"The venue said we had over 300 people through the door which is amazing."* The event raised £1,555 for the PHA UK, with the same amount going to Royal Brompton and Harefield Hospitals.

Multiple half-marathons

Kerry-Jane and David Clary from Kent are running three half-marathons in three months to raise money for PHA UK in memory of Laura Ling, who died in summer 2018. The pair have signed up for the Lydd and Hackney half-marathons, with the third one yet to be arranged. *"Dave and I have run one together before, so we wanted to up the ante and set a real challenge. Doing them within three months will be a real challenge for us,"* Kerry-Jane said.*"Laura used to refer to the friends she made through PHA UK as the silver lining to her PH cloud. They helped her immensely after her diagnosis. The conferences are so vital in bringing sufferers and their families together, so we wanted to just do a little something to help the charity continue with their work."*

We love hearing about your fundraising adventures!
Email ***media@phauk.org*** *for a chance of seeing yourself on these pages.*

HOW TO ORGANISE A... QUIZ NIGHT IN 5 SIMPLE STEPS

A quiz night is a popular way of fundraising because it's easy to put together and fun to be involved in. Here's PHA UK's quick guide to organising quiz night.

1. *Decide on a date and venue, such as a pub, local hotel, social club or village hall.*
2. *Invite friends, family and colleagues. If you've arranged to stage the event at a pub, for example, make those who are regulars aware of the quiz night. Promote the event further via social media and posters.*
3. *Pick a quiz host who is entertaining, funny and will get the crowd going. Make sure there are a variety of questions and throw in the odd PH-related question to help raise awareness.*
4. *Cover the cost of your event in the ticket price and add a few extra pounds to go towards the fundraising total. You could also do a raffle on the night and set up a JustGiving page for your quiz to raise even more funds.*
5. *Promote the success of the event on social media afterwards. This will encourage further donations through your JustGiving page and ensure that your fundraising does not stop when the quiz ends.*

IF YOU'RE THINKING OF ORGANISING YOUR OWN QUIZ NIGHT, EMAIL **office@phauk.org** *AND WE'LL SEND YOU A FREE FUNDRAISING PACK. LET US KNOW HOW YOU GET ON AND YOU COULD BE IN THE NEXT ISSUE OF EMPHASIS!*

30% of all clothing sales go towards the PHA UK's charitable activities

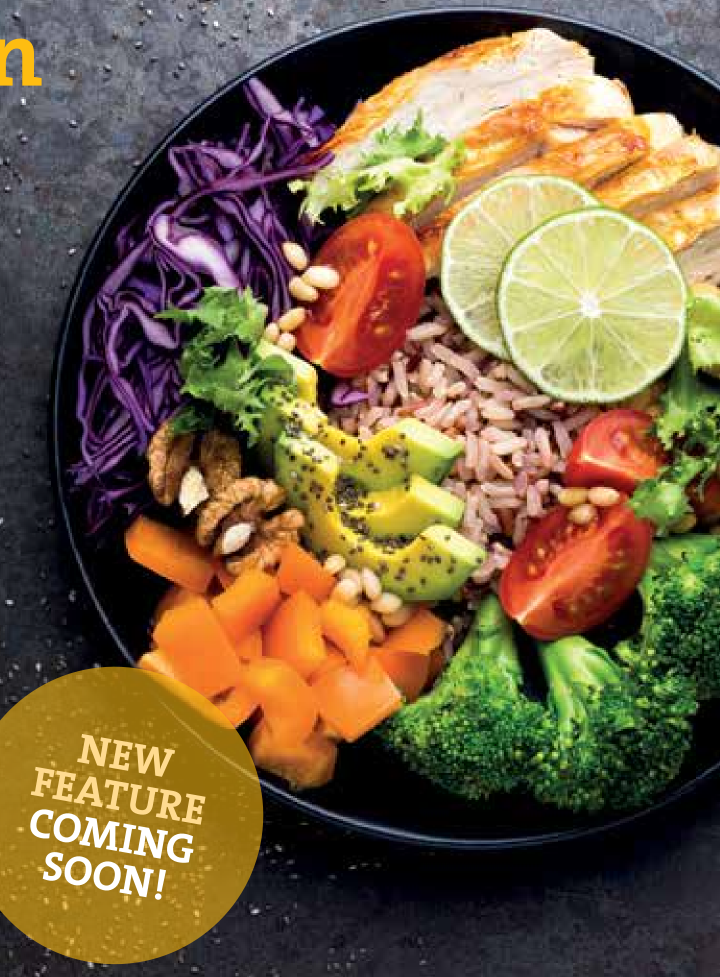
Fly the flag for PH awareness in one of our new PHA UK tops

Choose from t-shirts, polo shirts, sweatshirts and hoodies, for adults and children in a range of colours.

Order online
www.phauk.org/shop
or call 01709 761450

All about nutrition

What would you like to know?



NEW FEATURE COMING SOON!

Healthy eating is vital for overall wellbeing, but with so much information out there, it can be hard to know where to start.

We're planning to introduce a regular feature that addresses the questions you have about nutrition. Maybe you want to lose weight? Build muscle? Have more energy? Or maybe you just want to know what you should be eating to live as well as you can.

We want to give you the information you're looking for, so please let us know what topics you would like to see covered, or what questions you'd like to see answered.

Email ***media@phauk.org***
or tweet us ***@PHA_UK***.
You can also contact us via our Facebook page ***@PULHAUK***

In your Summer issue of Emphasis...

The next issue of Emphasis is due out in June and planned content includes:

World Transplant Games
The competition in Newcastle this August.

Happy birthday PHA UK!
A look back at our 20th anniversary conference.

The story of EmPHasis-10
The quality of life measure making a difference worldwide.

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.*

Join our PH family for free today

Influence.
Hope.
Integrity.

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

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*
- *Emphasis magazine delivered to your door four times a year*
- *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 4,000 members in a unique network of support and inspiration.

Join FREE today at www.phauk.org
call us on 01709 761450
email us at office@phauk.org
or simply fill in the form below
and return to us.

YES! I'd like to join PHA UK for FREE.

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Name:
Address:
Postcode:
Email: Telephone:
Are you a Patient ☐ Carer ☐ Parent ☐ Medical professional ☐
Other (please state)
Are you willing to take part in PHA UK surveys? Yes ☐ No ☐
Which ***specialist treatment centre*** do you attend?

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

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PHA UK
How we're structured

PHocus2021
Steering Group
Consists of Patients/Carers, PH Clinicians, Primary Care Practitioners, Academia Representatives, Executive Trustee

STRATEGIC PARTNERSHIPS
Anxiety UK
Turn2us

EXECUTIVE TRUSTEES
Iain Armstrong
Chairman
Kay Yeowart MBE
Secretary
Tom Siddons
Treasurer

TRUSTEES
Sue Townsley
Tracie Parnell

OTHER CHARITIES
(National & International)
Collaborative working and learning

CORE STAFF
Shaun Clayton
Director of Membership Support
Helen Crabtree
Senior Office Administrator
Iain Armstrong
Chairman

EXTERNAL SUPPORT
Book Keeping & Financial Auditing
Communications Agency
Graphic Design & Branding
Pharmaceutical & Industry
Political Lobbying
Academia

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,
Thorncliffe 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?

Emphasis magazine is produced by **PHA UK**. Content by **Capital B Media**. Design by **Creativesmith**.

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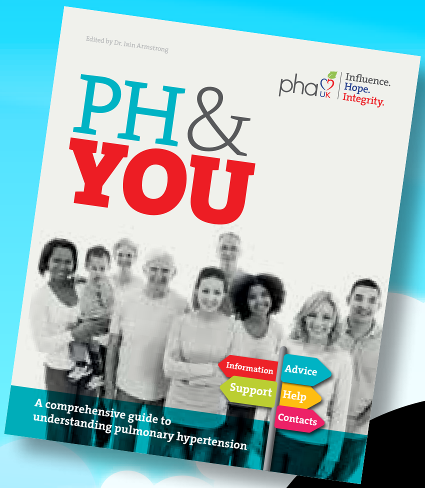
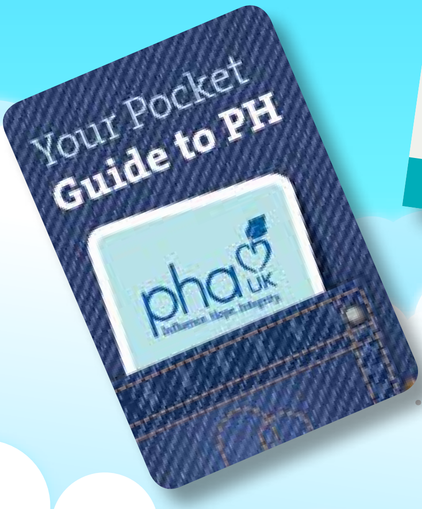
Available to order online!





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