WINTER 2018

emphasis

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

Life after transplant

8-page special feature

TRENDY MOBILITY AIDS

Did any of these make your Christmas wish list?

What a week!

A look back at our recent pulmonary hypertension awareness campaign

MERRY CHRISTMAS from all the team at PHA UK!

Plus...

Conference preview | Travelling by campervan | Research news | Expert interviews | ...and much, much more!

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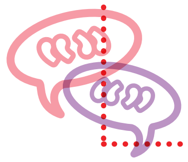

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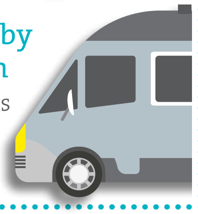
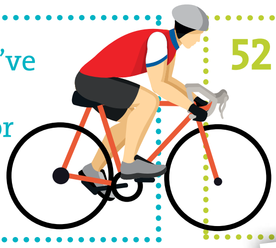




Regular Features...

With this issue of Emphasis:
4-page overview of the results of the **2018 National Audit of PH**

This magazine is printed on paper from sustainably managed sources

Welcome

Welcome to the winter issue of Emphasis. It's been a busy year for our charity and I speak for the whole of the PHA UK team when I say how proud I am of our members.

As a rare disease area it's important we work together to make our voices heard and there have been many examples of that this year – including PH Awareness Week in October. You can read our round-up of the campaign on page 24.

We've also been really impressed by the number of members who have backed our work to drive change by writing to their MPs to invite them to our parliamentary awareness event.

And, as always, we've been blown away by your fundraising support over the year. Your walks, bike rides, bake sales, BBQs, sky dives, marathons (and more!) have helped us continue our work and we are grateful for every penny and pound.

Our final Emphasis issue of 2018 is packed full of features, interviews and advice. Thank you to Kirsty, Asha, Dan and Kath who share their experiences in our special 8-page transplant spotlight. Talking about organ donation is incredibly important and we hope that our two-day focus during PH Awareness Week sparked some conversations around the topic too.

If the winter weather is leading to thoughts of holidays, have a read of Lois's tales of travelling in a campervan on page 28. It's given her the chance to see the world, and it could be an option for you too.

Finally, thank you to everyone who has contributed to this magazine throughout the year. We love receiving your letters, and you'll find a special selection over the page.

Here's to a peaceful festive season and a positive 2019.

Iain Armstrong
Chair of PHA UK
editor@phauk.org

> *"Thank you to everyone who has contributed to this magazine throughout the year."*

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.

LETTERS SPECIAL

Dear PHA UK

I am 52 years old and was diagnosed with Chronic Thromboembolic Pulmonary Hypertension (CTEPH) in August 2017 after probably 12 or more months of chronic fatigue and breathlessness.

My GP and local cardiologist were both prompt in sending me for tests, and eventually to see Dr Rachel Davies at Hammersmith Hospital. After yet more tests it was eventually decided I was a candidate for Pulmonary Endarterectomy. I saw Dr David Jenkins at Papworth and was placed on the wait list after being told that I would still suffer with residual pulmonary hypertension after surgery.

I am now nearly 18 months post-op. I still suffer with tiredness and get breathless on prolonged exertion but have certainly felt the benefits of surgery. On 29th September 2018, I got married to Adrian. As you can see we were blessed with beautiful weather and we shared our special day with family and friends. I would like to thank all those who continue with my healthcare.

Finally, a massive heartfelt thank you must go to my wonderful husband, who has been amazing in supporting me through this difficult condition - in sickness and in health!

Amanda Lucas

Do you have an experience of ***pulmonary endarterectomy*** that you'd like to share? We've had requests from people waiting for operations who want to hear real stories from others. Why did you have it? Why did you choose not to have it? How did you tell your family about it? Whatever your experience, we'd love to hear from you.

Please email media@phauk.org

Hi PHA UK,

I'd like to recommend the MyFitnessPal app to other members.

I came across this mobile phone calorie app quite by accident when looking for free mobile phone trackers for daily steps and weight loss.

I have been using it for two years and it has been the biggest aid in helping me lose weight. I have PAH, an under-active thyroid and walking is extremely limited.

I use the app to plan meals so I don't go above my target calories. I am now more aware of portion control and macros (proteins, carbs and fats) in foods.

This app is ideal for me as it is free and simple to do from home. MyFitnessPal has helped me lose three stone.

Zoe Armstrong

Social Media Round-up

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

Rivervale Leasing

We were delighted to help raise awareness for PHA UK by conducting the Rivervale fitness challenge. We're extremely proud of our efforts, managing to raise £510 for this amazing charity!

@kelly_stanley

2 months later than planned after 2 courses of antibiotics followed by catching hand foot and mouth, my brother Mark hiked 50k in 12 hours to raise money for @PHA_UK

@wginsing

Good to see a full room of enthusiastic doctors, nurses, physios and pharmacists at the @PHA_UK today learning more about pulmonary hypertension.

Karen Stokely

Living with PH but living the dream in Jamaica. Xx

@vickilou

I did a mini bake sale for my team at work for @PHA_UK. We raised £40!

Joanna Young

We had another coffee morning at the Freeman Hospital and raised £30... we are holding this the first Wednesday of every month 10.30-12.30, why not pop along if you are in clinic and have a cuppa and a chat?

@PHAToronto

It's very important to talk about PH because it is rare. Often it is an invisible illness so many people would not see it. We need to raise awareness!

LETTERS SPECIAL

Dear PHA UK,

Here is a picture of me and my sister Kate Lewis on my wedding day recently. My sister was diagnosed with PH in February 2017 and with all the ups and downs we have had along her journey she has been amazing and pushed on through and helped me plan the most amazing day of my life. She is the least selfish person I know so I thought she deserved a little shout out to you.

Charlotte Moreton xx

RESEARCH OPPORTUNITY

Dear PHA UK

I'm an MSc student at Brunel University studying pulmonary hypertensive patients and their physical activity levels.

I'm asking people living with pulmonary hypertension (aged 18-69 years) to participate in my study.

There is a lot of research which has been conducted in intensive exercise therapy as either an in-patient or out-patient. However, it has been noted that implementing this is not always feasible for patients. Therefore, this study is being conducted to further understand patients' current physical activity levels, their perceptions about this and whether patients are meeting the government recommendations for physical activity. This is the first study to look at physical activity levels of UK pulmonary hypertensive patients.

It is hoped that this will inform a more patient-centred approach with quantifiable outcomes for daily life, rather the six-minute walked distance, to be able to inform research into possible exercise modalities for patients at home rather than attending as an in-patient.

Participating in the study will not require any traveling or changes to your daily habits. If you choose to participate you will be asked to wear an activity monitor for seven consecutive days. This will be worn on your right upper arm, in the same way an armband would. This will be worn for 23 hours a day. You will also be asked to fill in a physical activity questionnaire.

The activity monitor and questionnaire will be posted to you and you will be required to return these in the addressed pre-paid envelope.

Benefits of participating include a free assessment of your physical activity levels and you will be helping to inform research and treatment of patients with pulmonary hypertension.

If you are interested or would like more information please contact me by emailing ***1717256@brunel.ac.uk***

Kind regards
Siobhán Haran

Dear PHA UK

In September I joined 50,000 runners at the start line of the Great North Run, the largest half marathon in the world. I was taking part in this iconic race in memory of Ally Whan (pictured right) and to raise money for the Pulmonary Hypertension Association.

This was a race like no other. When the start gun went off at 10.40am so did Mo Farah and the rest of all the elite runners. However, such was the volume of people in the main race, it took me over 10 minutes to walk to the start line before my race could begin. The 50,000 runners set off from Newcastle-Upon-Tyne city centre for the 13.1 miles of road ahead. As the runners ran over the famous Tyne Bridge the roar of the Red Arrows fly by could be heard overhead. Moving on through Gateshead the noise from the mass of spectators never ceased as thousands of well-wishers lined almost every inch of the route. Not only did they offer their support by clapping and cheering but they had goodie bags of jelly baby sweets, ice pops and fresh oranges to provide a much needed boost to energy levels. The atmosphere was also enhanced by the enthusiastic music DJs, the many live bands and the African drum groups, who all entertained the runners with lively tunes as they ran by. The pounding of feet continued to travel on towards the seafront at South Shields and the wonderful sight of the finish line!

This was my first ever half marathon which I ran in just over two hours and I enjoyed it so much I smiled all the way from start to finish!

£1000 was raised and, as with all the thousands of pounds Ally had raised, this money will go towards vital research into this devastating illness.

It was an experience I will never forget and I was so proud to have ran it in Ally's memory.

I would like to thank everyone who kindly donated.

Deborah Whan

Dear PHA UK

I'd like to share my transplant story. I have suffered for about 21 years with Interstitial Lung Disease (Pulmonary Fibrosis) and mild pulmonary hypertension. I was on oxygen for about five years but was slowly deteriorating two years ago.

I learned to live with my condition and tried to carry on with life and my party planning business. My symptoms at this point were manageable and I just took each challenge at a time, along with thinking positively and with determination.

I tried to carry on with my life the best I could, but I noticed eventually I was getting more out of breath. At this time I was on the waiting list. But my consultants said I needed to be on the priority list. So, I was put on the priority list, in 2017 and I had two unsuccessful calls.

But then one night, mum and I were talking and I was saying that I was getting tired. Then all of a sudden, the phone rang. It was Papworth Hospital. They had found a match and I needed to be ready because the ambulance was on its way. I was surprised for a while. Luckily my case was packed from when I was put on the priority list. I slowly got dressed. My heart was beating, with happiness and fear at the same time. But I knew it was for the best. I don't think I had a lot of energy left. I was just getting by.

I am so blessed to have had the transplant and be doing so many things, which I was unable to do for so long. From the bottom of my heart I thank the donor very much, for giving me the chance! I am so very grateful to my consultants, surgeons, nurses and all the staff at the hospital. The transplant team have turned my life around!

I'm hoping in the future I'll be an inspiration to others, by telling my story.

Michelle Hemmings

LETTERS SPECIAL

Dear Editor

Many thanks for the autumn edition of Emphasis which, as usual, was full of interesting, informative news and advice.

When I read the story from Yasmin Swift it hit a nerve. Like Yasmin I have been fortunate enough to be given a Blue Badge, and although I haven't experienced a note being left on the car like Yasmin, my husband and I have commented that people would have wondered why we have a Blue Badge as looking from the outside we both look 'normal'. I commend Yasmin on her work highlighting the situation in the press and social media, and Emphasis for including the information cards to help promote #LetsTalkPH #PHWeek18 – particularly 'Not all disabilities are visible' which hopefully will create public awareness.

Another article which attracted my interest was the physiotherapy intervention. Earlier this year I was asked if I would like to join a group to get involved with some gentle exercise and information classes; I was happy to give it a go. It became apparent during the assessment that the healthcare assistant hadn't heard of pulmonary hypertension and the physiotherapist had heard of it but didn't know anything about it – nevertheless, I put my name forward for when a place became available.

The environment and people were very friendly and I managed to join in the activities but when it came to the information talks I felt out of it as most or all of the patients seem to be COPD or asthma sufferers.

Benefits advisor Shaun Clayton's article also resonated with me. I am a 71-year-old lady who was finally diagnosed with PH in January 2018 after going to see my GP in April 2017 to ask about a knee replacement. Along the way I was advised to apply for a Blue Badge, which is proving very useful. PIP was also mentioned, but when I made enquiries it turned out I was too old. I was told about DLA and was refused, and it was also rejected after appealing because my 'body functions' were okay and I had my husband to care for me.

I hope I don't sound too negative with comments about the articles and I hope it may help other people identify in a similar way. Good luck with future editions.

With kind regards

Norma Brook


Research shows early physiotherapy intervention is integral to managing PH

Benefits available to carers

Benefits Advisor

With Shaun Clayton

IN THE NEWS

LIVING WITH AN INVISIBLE ILLNESS

SPECIAL REPORT

SPECIALIST CENTRES CONTINUE TO **EXCEED TARGETS**

Every year since 2008, the UK's specialist pulmonary hypertension centres have been asked to provide information on what they do and what their outcomes are, to ensure high standards are maintained.

The ninth National Audit of Pulmonary Hypertension, based on data submitted between 1st April 2017 and 31st March 2018, shows even more targets are being met or exceeded.

The findings include:

- **96%** } **of patients have a quality of life questionnaire recorded at least once a year (an 8% increase on 2017)**
- **59%** } **of patients referred to a specialist centre attended a consultation or were discharged within 30 days (a 7% increase on 2017)**
- **96%** } **of patients had a right heart catheter before being given drugs to treat PH (a 5% increase on 2017)**
- **98%** } **of patients had a WHO functional class and six-minute walk or shuttle exercise test recorded before being given drugs to treat PH (an 11% increase on last year)**

Iain Armstrong, Chair of the PHA UK, said: ***"Again, we are seeing more improvement in even more areas - despite the many pressures facing the NHS. We have a network of specialist centres that make a big difference to people's lives, and that's something we should all be proud of. It's vital that these services are protected."***

The PHA UK played an important role in setting up the National Audit of Pulmonary Hypertension by funding its first year in 2010. The audit is now funded via NHS Special Commissioning in England and managed by NHS Digital in Leeds.

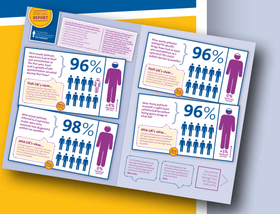
NHS Digital have invited centres who have areas needing improvement to complete local action plans and share them with patients and the public.

The full annual report and local action plans can be found here: **www.digital.nhs.uk/pubs/naph9**

Professor David Kiely has been appointed Clinical Lead of the National Audit of Pulmonary Hypertension following the retirement of Professor Simon Gibbs. David, who is Director of the Sheffield Pulmonary Vascular Disease Unit, said:

"I feel very privileged to have been appointed to this role following on from all the fantastic work that Simon and the team at NHS Digital have done over the last ten years.
Since its inception, the national audit has provided information on how many people in the UK have PH and how many people receive treatment. This is very important when planning services in the NHS. The audit also assesses the performance of individual centres against national standards, which ask questions about the appropriateness of PH services, whether people are receiving the correct treatment in a timely manner and information on outcomes. Importantly, since the introduction of these national standards there have been year on year improvements in the care that centres provide.
Over coming years, I look forward to working closely with people affected by PH, the PHA UK and my colleagues in the NHS to ensure that the national audit continues to help secure the care we provide for patients in the UK as amongst the best in world."

A summary of the findings of the National Audit of PH was mailed with this magazine. To see it online, visit www.phauk.org. To request a printed copy, call 01709 761450 or email office@phauk.org.
The full report can be viewed at www.digital.nhs.uk/pubs/naph9



Trendy mobility aids for your last-minute Christmas wish list

Mobility aids don't need to be dull! PHA UK member *Justine Pearmain* from Ferndown in Dorset set out to find the best on the market to regain her independence.

Justine with her Rollz Flex shopper

Many online retailers and companies market mobility aids to the elderly which made my search for a trendy shopper-come-rollator somewhat difficult.

After spending a great deal of time searching the internet, I stumbled upon designed2enable.co.uk, a website which provides trendy living aids. My mission seemed complete.

Eager to try out one of their mobility aids for myself, in particular the Rollz Flex Shopper, I began searching my local mobility shops to see if they had the product in stock. I wasn't surprised to find that many of the mobility shops I visited hadn't even seen or heard of it. But they all agreed it was very trendy.

Luckily for me, I discovered a new mobility shop called CareCo was opening in Southampton, just a short drive from home. I visited the store on their open day and to my delight they had the Rollz Flex on display. Not only this but they had a wide range of rollators and walkers to choose from.

Being a savvy shopper (every penny counts), I shopped around online and found designed2enable offered the best value. I ordered the Rollz Flex the very next day and three days later it arrived fully assembled and ready to go.

It is fantastic and has allowed me to regain my independence. I can walk with it, it supports me as a rollator, it can carry my shopping, it provides a seat for when I need it, and most of all, it's fashionable! Trendy isn't cheap but any help to make my daily quality of life better is worth every penny spent.

Justine's Top Tip...

SHOP AROUND AND TRY BEFORE YOU BUY! SEARCH ONLINE AND ASK YOUR LOCAL MOBILITY SHOWROOM IF THEY CAN PRICE MATCH, OR GET PRODUCTS IN.

We know not everyone can afford a new mobility aid this Christmas. The British Red Cross is the biggest national provider of short-term wheelchair loans. Find out more at ***www.redcross.org.uk***

SAUSAGE DOG PERMIT COVER

Display your Blue Badge permit with confidence and style. The exclusive Hologram Safe design ensures that holograms on permits are never covered, protecting them from damage and complying with Department for Transport guidelines. Each wallet includes a free timer clock which is made with superior plastic cogs and can be dialed without removal. The chic dachshund design in pastel tones is sure to brighten your day. £18 from **bluebadgecompany.co.uk**

LET'S FLY ROLLATOR

Awarded the most beautifully designed product at one of the largest German mobility exhibitions, Let's Fly leads the way in terms of design and functionality. The frame is moulded entirely from aluminium in a contemporary design which gives it a unique shape and added strength. The stylish brown artificial leather seat is comfortable, while also being water resistant and durable. It comes in a range of colours including red, champagne, white and graphite grey. Expect to pay around £380 plus VAT. Purchase through **designed2enable.co.uk**

CARECO AIRLITE X TRAVEL MOBILITY SCOOTER

There are plenty of transportable and compact mobility scooters on the market, but you might struggle to find many with the lightweight and easy to manage design of the CareCo Airlite X. It comes in a cool blue colour and is perfect for shopping trips. Expect to pay around £390 plus VAT. Available at **www.careco.co.uk**

COMFY TABLET TRAY

Use your tablet in bed, on the sofa, while you eat and more with this comfy tablet cushion tray. There is a notch to hold the tablet upright and a non-slip surface for a drink or snack. The micro-bead cushion conforms to the contours of your lap making it super comfortable. £12.99 from **www.springchicken.co.uk** **01865 339 366**

ROLLZ FLEX SHOPPER

Described as your new 'best buddy for shopping and strolling around town', the Rollz Flex is a combined shopping and rollator with a modern design. It is available with a purple or grey bag. Expect to pay around £300 plus VAT. Available at **designed2enable.co.uk**

BLACK WATCH TARTAN WALKING STICK BAG

This stylish and compact storage bag for a folded walking stick is handy for use out and about or while not in use at home. It features a press-stud fastener to stop the stick from slipping out and a handy D-ring to hang from a coat hook or easily clip onto a handbag or wheelchair. Its traditional design has timeless appeal. Available in a variety of fabrics. Stick not included. £15 from **bluebadgecompany.co.uk**

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Life after transplant

For some people with pulmonary hypertension, having a lung or heart transplant – or sometimes both – can be an option when other therapies fail. There's a lot to think about, and it's not right for everyone, but for many it can feel like another chance.

In this special 8-page feature, Kirsty, Asha, Dan and Kath share their experiences of life after transplant.

"It's not a life without problems, but nobody's life is perfect."

In an honest account of her transplant journey, 43-year-old Tamworth racehorse trainer *Kirsty Smith* shares the story of her new lungs.

"I was living in Northumberland when I was diagnosed with idiopathic pulmonary hypertension back in January 2001. I'd started to get breathless and black out, and went through various tests with different doctors until finally, a right heart catheter at the Freeman Hospital in Newcastle showed what was wrong. I was sent up to the PH ward where I would visit for the next 15 years.

I'd gone from never being ill, riding horses and working non-stop, to bang, being struck down with this. I'm quite a resilient person, but at that point, the whole world just caved in. It was a horrible time.

After an operation to reduce the pressures in my heart, I was told I could start treatment. I vividly remember a nurse coming to my bed with a huge nebuliser, and putting this big box down next to me. I was told I would have to nebulise the drug every three hours, and I asked her to take it away.

I refused to have anything to do with the nebuliser, so I was given a Hickman line, which stayed in for 15 years. I was told I'd never ride again, but I did. I was told I wouldn't ski again, but I did. I stopped competing, but I still rode racehorses.

The first time I was listed for transplant was in 2013. I'd broken my leg badly in a riding accident and ended up having a nerve block while it was bashed around, pinned and plated – while I was awake. My heart couldn't cope with the trauma, so I was assessed and put on the list. *I didn't know it at the time, but no-one thought I would survive the weekend. Then, all of a sudden, two days later, I was fine and came off the transplant list. I don't know what it is inside me that just keeps on going.*

Two years later, I started going downhill quickly and went back onto the transplant list in January 2015. I had a suitcase packed and ready for when the call would come, as I never knew when it would be.

I was scared I wasn't going to get a transplant in time, but the call came four months later, on May 10th.

That morning I'd been over to a Point to Point race at Melton Mowbray, and it was mayhem. I remember leading one of the horses back from the winner's enclosure and I couldn't breathe.

I was living by myself at this point and at the end of the day I decided to go straight home to bed as I was so tired. I don't know what it was but even though I was exhausted I decided to have a bath and wash my hair – it was like I knew what was coming.

My head hit the pillow at 10pm and the phone rang. I was told that lungs had been found and a car would be with me in an hour. I called my mum and we were taken to East Midlands Airport where I was put straight on a private jet up to Newcastle. It was all very surreal.

During that flight I kept telling mum not to get too excited as sometimes the organs aren't right, or you're not right, and I'd heard so many stories of people being disappointed. I didn't want to get my hopes up.

I had the transplant at 7am, nine hours after receiving the call at home. Within a couple of days of having the operation I looked totally different. Everything was pink and white again because my body was now getting oxygen. It was incredible. It was literally a transformation – as if overnight, my body had healed.

> *"I thought I couldn't breathe because I'd spent 15 years struggling to breathe, and now I could breathe normally, but it felt wrong because I wasn't used to it. Mentally, it felt alien."*

Although I looked better, the first 48 hours after the operation were difficult. I thought I couldn't breathe because I'd spent 15 years struggling to breathe, and now I could breathe normally, but it felt wrong because I wasn't used to it. Mentally, it felt alien.

I freaked out and kept panicking. I also couldn't talk properly because my vocal chords had been damaged during the operation and I kept vomiting because of the anaesthetic. It was all just madness. Being honest, at that point, I was wishing I hadn't gone ahead with it all.

Soon though, everything calmed down and I got used to breathing normally. My voice came back and I left intensive care after 24 hours. My hair fell out - probably because of the trauma - but it did come back, although now it's curly!

I was put on anti-rejection drugs straight away and I will take them for life. I get a few side effects - mostly shakiness and achiness - but they affect everyone differently.

After a while, my lung function began declining and my body started rejecting the lungs, so I had intense radiotherapy. It made me lose a lot of weight, but it didn't really do anything. I think that like PH therapies, the treatments are so individual – they work differently for different people.

I am now having some new treatment, extracorporeal photopheresis, for chronic rejection and to try to keep my lungs at their current level. The decline doesn't happen with everybody, and it's something I don't think is fully understood yet.

Although my lung function has gone down, I do function quite well. I'm not going to run a marathon, but I can sit on a horse and go up and down the gallops, ride dressage tests and be absolutely fine.

For more information on organ donation, or to sign the register, visit ***www.organdonation.nhs.uk***

> *"I think of my donor often. There's a family out there grieving, while I'm living a life, but I hope they find some sort of solace in that she helped so many people."*

The lady who donated her lungs to me saved five people's lives with her organs. All I know is that she was 50, and that I probably wouldn't have made another month or two without her. After about six months I wrote to her family, via the hospital. I wrote the letter on the beach in Devon after I'd been kayaking. I never heard back, but I didn't mind – I just wanted them to know what she had done for me.

I think of my donor often. There's a family out there grieving, while I'm living a life, but I hope they find some sort of solace in that she helped so many people.

Three years on, yes, I've had ups and downs, but they are irrelevant. I've trained racehorses, I've lived a life, I've got a family – and I wouldn't have been able to without this. It's not a life without problems, but nobody's life is perfect.

Having a transplant for me has been wonderful as it's meant I can look forward again. I can plan things, whereas before I was just waiting - for the worst to happen, or for a transplant that would give me these years. It doesn't matter how many years you get really, as long as you've made the most of them.

Without the transplant I wouldn't be here now. I wouldn't be winning races with the horses, or seeing my nieces and nephews grow up. It means everything.

Why we need to talk about organ donation

Donating organs is selfless and I'm really grateful to my donor's family too, for respecting her decision. I think anyone who goes on the register is amazing, but the part the family play is vital too and people need to understand the importance of talking about their wishes. No-one wants to talk about death, but we need to have those conversations.

My transplant has inspired a huge number of my friends and family to sign the organ donation register, but it still took a lot of time for some to do it, even though it takes less than five minutes. It's easy for people to forget or put it off, and that's a shame.

If you needed a new heart or lungs, would you accept a donation yourself? If you would, you need to sign the register. Anyone could need a new organ, at any point. I never expected to need new lungs, but you don't know what's going to happen in the future."

Read Asha's, Dan's and Kath's transplant stories >>>

"I feel like what I've been through hasn't hit me yet."

Earlier this year mum-of-two *Asha Sagoo* from Leicester received a heart and double lung transplant. This is her story of a life-changing journey - with a few bumps along the road...

"**Life with pulmonary hypertension was hard, both physically and emotionally.** *I couldn't breathe. I was on oxygen 24 hours a day, I was in a wheelchair, I had a Hickman line and I was totally dependent on my family and my small little children, Ryen and Shanon.*

Last summer, because my organs had deteriorated so much, I was assessed for a heart and double lung transplant and told I wouldn't survive without it. I think I cried for about a week.

I expected to be listed at some point, but I didn't think I'd get the organs, because I'm a rare blood group and because I needed both heart and lungs.

I clearly remember jokingly saying 'well, miracles can happen', and I was told 'probably not in your case'.

I was officially listed for transplant in October last year, and my phone was with me constantly in case the call came.

It was always on my mind. If I was in the shower, I'd tell my children that they must answer the phone. Every time it rang I wondered if that would be it.

Because I had a Hickman line and was in a wheelchair and on oxygen, the kids could see I was sick. I told Ryen, my eldest, that mummy was poorly and couldn't breathe properly but that one day, when the doctor rings, it would be because there is a cure. So, he knew it was important to answer the phone.

In January this year, three months after I was listed for transplant, I developed sepsis out of the blue. *I was in intensive care for a week and all my organs were failing, so because of this, I was taken off the list. I was devastated. I was off the list for two weeks and convinced myself that the call would have come during that time. I felt so angry about it.*

After tests showed my organs were ok, I was relisted in February. A week later, I was playing board games with my family in the living room and my phone rang.

When I was told there was a possible match, my first reaction was to think it was a joke as the call had come so quickly. I was asked to get to the hospital within three hours.

Before setting off I took my children to the side one by one and told them what might happen. I said if they had found a cure, they'd see me in hospital after a couple of weeks.

The organs were a match and as I was wheeled to the theatre, I cried my eyes out. I didn't know whether I was going to come out, but I had to do it for my children. My son had to carry me up the stairs, he had to carry my medicines, and I couldn't live like that anymore. I had to take the chance.

Three weeks after the operation it was discovered that I had a blood clot. I was still in hospital, and I had to be un-stitched so they could sort the clot out, meaning I remained in intensive care for another two weeks.

I then went through rejection - my body wouldn't accept the new lungs and heart - and I was sedated for two and a half weeks. *I could hear some things, but I didn't have the strength to open my eyes. I also remember hallucinating a lot, which must have been the medication.*

Eventually I was moved out of intensive care onto the main ward, and in total I was in hospital for seven weeks. I was the third patient at the Queen Elizabeth Hospital ever to receive a heart and double lung transplant.

All I know about my donor is that she was female, and that she was 47 years old when she died. *She was on life support when the organs were taken as the heart had to be alive. That's a big thing for the family and I only found that out recently.*

Because of her, my life is now fantastic. I can walk up the stairs – which is amazing. I couldn't even cook a meal before, but now I'm cooking all the time.

I'm picking my kids up from school, taking them swimming, and we can go to the cinema together. There's no oxygen to carry around, and no wheelchair, which is massive for me. Being able to breathe on my own now makes me feel free.

In some ways I feel like what I've been through hasn't hit me yet. I've been invited back by the hospital to go through what actually happened, while I was there. I think it would stop me overdoing things, as the first year post-transplant is crucial. Once I realise what I actually went through, it might hit home.

The transplant has definitely changed my perspective. I appreciate life more and I want to make every day important."

Read Dan's and Kath's transplant stories >>>

> *"The transplant has definitely changed my perspective. I appreciate life more and I want to make every day important."*

"My story is one of celebration, thanks and awareness."

Just months after his double lung transplant, 26-year-old *Daniel Peel* from Reading climbed Mount Snowdon and competed in the British Transplant Games. He told Emphasis what his new lungs mean to him.

"I was diagnosed with Pulmonary Arterial Hypertension (PAH) in 2012. Aside from the occasional bout of asthma I thought I was a fit and healthy 21-year-old. I played American football, cricket, squash and swam regularly, but after passing out while playing sport during my second year at university I realised this wasn't the case.

Over the next few years I began to decline, and in 2016 I was eventually told that my heart was under serious strain and may only last another year. A double lung transplant was the only remaining option to save my life.

The decision to opt for a transplant was not simple. Given the shortage of suitable organs there was no guarantee of getting off the waiting list and even if I did there were significant risks associated with the surgery itself, and then rejection post-transplant. *However, I realised I was out of most options and decided to sign up. Following a six month wait and three false alarms, a match was found in February 2018.*

My story is one of celebration, thanks and awareness. Celebration of the literal gift of new life, thanks for the support from family, friends and the NHS, but most importantly awareness. Awareness of a rare and often invisible disease that strips life from many of its sufferers. Awareness of the incredible skill and dedication of the staff of the NHS, most notably Royal Papworth Hospital, Royal Brompton Hospital and the John Radcliffe Hospital. Finally, awareness of the need for organ donation.

Before my transplant I couldn't walk up two flights of stairs without feeling breathless and having to stop. After it, I was determined to continue leading a normal life.

It was with this determination and a large helping of naivety that myself and some friends decided to climb Mount Snowdon. We started planning as a way to pass the time in hospital and set off for the summit exactly six months to the day after my operation.

While the climb was difficult at times we made steady progress and I was confident that the organs were working well when I realised I wasn't the only one having to work hard. I live by the motto that with a little hard work and dedication we can do anything we set our minds to. Reaching the summit was testament to that. I had set my goal while recovering in hospital and made sure I would make the best use of my new lease of life to reach that goal.

I also had the opportunity to compete in the British Transplant Games in August, taking part in the golf, ball throw, javelin and 100m relay. To be surrounded by hundreds of people who had been through a similar situation to me really brought it home that a transplant is a literal chance of a new life. The weekend was made even better by winning a Gold and Bronze, meaning I will now represent GB in the World Transplant Games next year.

Ultimately, I wouldn't be the person I am now without the support of my family and friends who have stuck with me through the good and bad. But, most importantly, I wouldn't be here without my donor."

"It is so important to discuss organ donation and share your wishes about it with your family"

Kath Graham, who was diagnosed with PH in 2010 and had a transplant two years later, is urging people to get talking.

Kath and grandson Freddie

"I was diagnosed with end stage Idiopathic Pulmonary Arterial Hypertension in 2010. I was immediately placed on a heavy regime of drugs, including intravenous drugs and was referred for a heart and double lung transplant within months of diagnosis. I waited two years on the transplant list before I was lucky enough to receive my gift of a new life.

It was all a massive shock and I made many adjustments to my lifestyle including giving up my career as a teacher. I lost my independence, but was happy to use a wheelchair so I could enjoy precious time with my family while I waited in hope for my transplant.

Since my transplant, life is very different. I've been able to celebrate and enjoy so many family milestones that I didn't dare dream I'd see. Rob, my husband, and I have been able to travel again and have visited many places, including celebrating our 25th wedding anniversary travelling on the Orient Express, which had always been a dream of mine.

I've been able to see both my daughters, Sarah and Rose, graduate and build their careers and Sarah get married. I now have a young grandson, Freddie, and another grandchild on the way. There's always so much to look forward to. Transplant has enabled me to share many special moments with my family.

> *"Since I started on my transplant journey seven years ago, the issues concerning 'family consent to organ donation' haven't changed."*

I'm an avid campaigner to raise awareness of organ donation and pulmonary hypertension and since my transplant have written and published a memoir, as I'd always wanted to write a book. I didn't ever think it would be a book about these subjects though! It's called 'Life is for the Living' and is available on Amazon. It aims to help others going through similar difficult circumstances and to promote these causes dear to my heart.

I have recently celebrated five years post heart and double lung transplant and it's still shocking to know that things haven't altered since I waited for my transplant all those years ago. Three people still die each day while waiting on the transplant list. There is growing confidence that this may change with the new 'opt - out system' the government is planning. I welcome any system that may improve the number of organ donors, but I do believe the situation is much more complex than this.

Since I started on my transplant journey seven years ago, the issues concerning 'family consent to organ donation' haven't changed. Families still have the right to override their loved ones wishes, even if the potential donor is a registered organ donor. Almost a third of families still say 'no' to organ donation. Sadly the proposed 'opt – out system' won't change this. This is why it is so important to discuss organ donation and share your wishes about it with your family.

My donor family told me they knew that's what my donor's wishes were and so the decision to donate was an easy one. I will always be forever grateful to them and my donor for giving me such a precious gift and a second chance at life and I will always advocate to 'have the discussion' and 'share your wishes' when promoting organ donation.

The more people we have openly discussing organ donation, the more it may encourage people to register as organ donors and the easier it may be for families to say 'yes' to organ donation."

Transplants are only possible because of people who donate their organs and unfortunately, signing the organ donation register isn't always enough.

Families are consulted after a loved one has died and their wishes are respected, so it's vital that people talk to those around them about what they want to happen. NHS figures show that at any one time there are around 6000 people on the transplant waiting list and on average three people die each day in the UK in need of an organ transplant. That's why we're encouraging people to talk.

Find out more about organ donation at www.organdonation.nhs.uk

Football fans walk the 'Peaks 4 PHA'

A group of football fans have raised over £9,000 for PHA UK through a series of inspirational walking challenges. *Mark Harris* from Rode Heath near Stoke-on-Trent was joined by six friends on three treks to raise money in support of his brother Paul, who has lived with PH since 2015.

In September the group completed their latest challenge, walking 55 miles in 17 hours from Stoke City's bet365 Stadium to Sheffield Wednesday's Hillsborough Stadium dressed in nurse's outfits.

Before arriving at the match, the group visited the Pulmonary Vascular Disease Unit at the Royal Hallamshire Hospital nearby, to say a personal thank you for the care that Paul receives there.

The group's fundraising efforts attracted the attention of the media and they were interviewed in several newspapers and on BBC radio stations in both Sheffield and Stoke.

In 2016 the group trekked the same distance across the Pennines from Alsager to the Royal Hallamshire Hospital in Sheffield, and last year, they completed the return leg.

The fundraisers now plan to walk the return journey from Sheffield Wednesday to Stoke City for their next match fixture on 30 March next year - aiming to smash their target of £10,000. They will be joined by six Sheffield Wednesday fans who will also walk in support of someone they know with pulmonary hypertension.

Mark said: *"The walk from Stoke to Sheffield Wednesday was incredible and we had a lot of support from both football clubs and the media. There was so much good energy, with fans from both sides well aware of what we were doing and why. Lots of people stopped to thank us, beeping horns and donating money. And our 'lap of honour' around the Sheffield Wednesday pitch at half time, in front of applauding fans, was really special!"*

As well as raising money, the group are hoping their walking challenges will raise more awareness of pulmonary hypertension.

Paul said: *"The support for all of the walks has been overwhelming. It's not just about the money, which will make a big difference to the PHA UK, but it's fantastic that the challenges have also helped so many more people hear about pulmonary hypertension. We're all already looking forward to the next challenge in March."*

Chair of PHA UK, Iain Armstrong, added: *"We're very grateful to Mark and his friends for taking on this challenge. It's vitally important that more people understand what life is like for people with pulmonary hypertension and events like this really help to get conversations going."*

To support Mark and his friends as they continue their walking challenges, visit www.justgiving.com/fundraising/peaks4pha

The team taking on the treks is made up of Mark Harris, Marc Fouldes, Rob Sandall, Mark Evans, Noel Scott, Julian Wilshaw and Laurence Greenhalgh. During each challenge, Paul and his father Steve drive ahead in a car filled with supplies, and park up every five miles to deliver refreshments.

Starting at Stoke City

Calling at the Sheffield PVDU

Finishing at Hillsborough

With Signal Radio

On the long walk

WHAT A WEEK!

PH
AWARENESS
WEEK
2018
22-28 October

PH Awareness Week 2018 ran from 22-29th November and we'd like to say a huge thank you to everyone who got involved. Together we made headlines, sparked conversations, got people thinking and reached thousands on social media.

It was fantastic to see so many people sharing their stories with their local media, and using their Facebook and Twitter accounts to help people understand more about PH.

We kicked off the week with a special animation that explained in a simple way exactly what PH is – and it was seen by 27,000 people online! If you missed it, you'll find it at www.phauk.org under the 'What is PH?' tab.

This year, we wanted to get people talking about organ donation too so we put a special focus on transplant stories during the final two days of the campaign. And we made a number of videos with members to help people understand exactly how PH impacts lives, and why we need to raise awareness.

We shared guest bogs from members keen to send messages to the world about PH (read Carole Ayrton's on page 32) and our Twitter chat drew in patients and professionals from the UK and beyond.

Encouraging Tea and Talk events helped people have conversations with colleagues, friends and family and it was fantastic to see so much support for the week from so many people. The Spinnaker Tower in Portsmouth even lit up purple to mark the campaign!

Thank you to everyone who held bake sales or fundraisers to celebrate the week. We've seen cakes that look like lungs (thanks Leeds General Infirmary!) press-up challenges (shout out to Rivervale Leasing!) and much, much more. Every penny raised will help us continue our work to support people living with PH.

These are just a few of the highlights from our third annual awareness campaign, which put pulmonary hypertension firmly under the spotlight. We're already looking forward to next year's!

962 SHARES ON FACEBOOK!

Daily Record

Cycling for awareness

Representatives from specialist centres across the country cycled from Sheffield to London to raise awareness of pulmonary hypertension during PH Week.

Riding under the name of 'Team PHenomenal Hope' their challenge saw them set off from the PHA UK Resource Centre in the north of Sheffield and make the 214-mile trip to Imperial College in London via Royal Papworth Hospital. Events at the PHA UK, Papworth and Imperial College marked the start, half way point and end of the three-day ride.

We'd like to say a big thank you to everyone who took part in the challenge. Some did the full three days and some took part in single stages - and you're all heroes to us!

THE RIDERS

David Welsh, Research Scientist,
Golden Jubilee National Hospital
Michaela Parr, PVDU Medical Secretary,
Royal Papworth Hospital
Luke Howard, Consultant Respiratory Physician,
Hammersmith Hospital
Jim Lordan, Consultant Respiratory and Lung Transplant Physician, Freeman Hospital
John Wort, Clinical Senior Lecturer and Consultant,
Royal Brompton Hospital
Robin Condliffe, Consultant Respiratory Physician,
Royal Hallamshire Hospital
Sean Gaine, Consultant Respiratory Physician,
Mater Misericordiae University Hospital
Charlie Elliot, Clinical Director of Respiratory Medicine,
Royal Hallamshire Hospital
Guillermo Martinez, Cardiothoracic Anaesthetist,
Royal Papworth Hospital
Jasvir Parmar, Consultant Transplant Respiratory Physician,
Royal Papworth Hospital
Hossam Fayed, Cardiology Senior Fellow,
Royal Free Hospital
PLUS... Helen Tracy, Laurence Stubbs, Edward Gore,
Kevin McDonagh and Robin Bhattacherjee
from Actelion Pharmaceuticals Ltd.

FULL SPEED AHEAD

At 73, *Jenny Blakeman* doesn't let her age or her pulmonary hypertension get in the way of living her life. She spoke to Mary Ferguson at her home in Tamworth.

Large personalised lorries are a common sight around Jenny and Graham Blakeman's house.

While some people in their seventies put their feet up, Graham restores old trucks, takes them to shows around the country, and runs a haulage repair business on the side.

And despite being on oxygen 24 hours a day, Jenny still plays an active role in the business by looking after the books from her office on the second floor of their home, which she reaches via a stairlift.

She also provides a vital service to her son by looking after his dog, a rescued crossbreed named Jessie, every day while he is at work. And painting watercolours, a hobby she took up in her sixties, is another way that Jenny keeps her life full.

"I keep positive because you've got to when you've got pulmonary hypertension," she said. *"You can't give in to it, so you've got to keep going and do the things that you normally do – or at least try to. If you didn't stay positive, you'd just get old and go into decline. You've got to live your life."*

Jenny was diagnosed with PH in 2016 after visiting her GP when she noticed she was breathless and had swelling in her lower legs. A scan revealed the right side of her heart was enlarged, and while waiting to be seen at a specialist centre she collapsed at home.

After six weeks at her local hospital, she was finally allowed home but has been on oxygen 24 hours a day ever since. Jenny admits that this is what she finds most challenging about life with pulmonary hypertension.

"It's something I just have to live with but I do find having the oxygen all the time is difficult. I have to be careful not to fall over all the tubes. I'm used to the constant humming of the machine now but it used to keep me awake at night.

"I use a portable oxygen machine when I go out and about. I can't walk far when I leave the house so I've got a buggy which I use if I need to. I get more panicky being on the oxygen, as I have to double think about everything. It makes me a bit more wary about going out."

Jenny still drives, but only when Graham is in the car with her. She has also had to adapt to looking different with her oxygen on, but has found things have got easier with time.

"When I go out, people look at me because I have the oxygen on, especially children," she said. *"I felt self-conscious at first but I got over it. You have to, otherwise you'd never go out, and it's important that you do."*

Painting and looking after Jessie are two ways in which Jenny relaxes during the day, and both help to take her mind off her illness.

"Since having pulmonary hypertension I tend to get a bit agitated over silly things which I didn't before, and painting the watercolours helps me relax and get back to normal. I like to paint sceneries mostly, sometimes freehand and sometimes from photographs.

"My son drops Jessie off every morning and she is good company for me while Graham is out. I can't walk her anymore, but she's a good friend and she looks after me during the day."

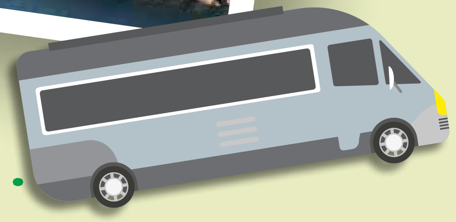
Although Jenny can no longer tend to the garden or do vigorous housework, it's still important to her that she maintains a routine and keeps positive.

She added: *"Every day I try to do the things I used to do. I get up, I shower, I make up the beds before I come down. I tidy round, I wash up, I get the dinners. Sometimes I have my off days but the majority of the time I try to be bright, cheerful and funny. For my own good, I find I've got to keep going."* ●

> *If you didn't stay positive, you'd just get old and go into decline.* ***You've got to live your life.***

Travelling by campervan with PH

PHA UK member *Lois Parker* enjoys regular foreign adventures with her husband, despite living with pulmonary hypertension. She wrote us this letter to share her experiences of travelling in a campervan - without the worry of flight oxygen, airport security or fit-to-fly letters.



Dear Emphasis,

The summer edition of Emphasis carried a very interesting article about travelling abroad with PH and this made me think how easy our own holidays are in our campervan.

My husband and I have always been keen campers, caravanners, motorhomers and now campervanners. So, when I was diagnosed in 2012 with pulmonary hypertension (CTEPH), we saw no real need to change the style of our holidays.

I remember well, sitting in bed at my specialist centre, having my medications explained to me, and saying "but we are due to go to France next week for a month in our motorhome"!

Everyone was very helpful, and before the diagnosis had really sunk in, we were setting off towards Portsmouth for our ferry to Santander in Spain. I had a whole month's supply of Heparin to self-inject as I couldn't start the Warfarin until we were back home, and able to have INR checks at my GP surgery.

We had a wonderful holiday, travelling from Spain over the Pyrenees, including walking in the Cirque De Gavarnie, which was beautiful. Of course, I had to pace myself and remember my medication, but it was well worth it. We continued up to Carcassonne – it was a bit tough climbing up the steep streets! And on to Bergerac and Cognac, where we had to taste the local brew. All too soon it was time for the ferry back to England.

Since then our annual trips have been to the French Alps, Holland, Germany, Denmark, Switzerland and Norway. *We returned a little while ago from a six-week adventure to drive our campervan up to and beyond the Arctic Circle in Norway. We went by ferry from Harwich to the Hook of Holland, drove across Germany and up into Jutland, Denmark, for another ferry across to Gothenburg in Sweden. Then a fast drive up to Oslo, continuing to Lillehammer, Trondheim and across the Circle to Bodo.*

It was cool, clear and sunny at the Arctic Circle Centre, where there was a small museum, café and shop. Apart from that, the area appears very barren, and windswept, with snowdrifts in places, and stone cairns left by visitors. From the top of the hills you can see for miles, but it is a hard, cold beauty.

We then started down the tourist route named the Kystriksveien, 650 kms, which would lead us back down across the islands and through the fjords to Steinkjer, a much prettier way and with lots of interesting places to see.

The scenery was magnificent, with forests, mountains, fjords and lakes at every turn. Bergen was our last big destination in Norway, with its fascinating museums and beautiful shops. Then it was several short hops to catch a ferry back to Denmark for the drive through Jutland, Germany and Holland. It was another brilliant holiday, travelling 4300 miles in total, staying on 30 different campsites, using 17 small and four large ferries over 43 days.

We use our campervan all year round, travelling around the UK, meeting up with family and friends. I don't have to worry about 'Fit to Fly' letters or taking all my medications through airport security, or booking oxygen for the flight. I take a small portable oxygen concentrator for night time use, and I did once drag it around at the top of the Jungfrau, making all the others with altitude sickness very jealous!

We always carry our EHIC cards so that if either of us becomes ill, we are entitled to healthcare in other European countries. *Obviously, we have travel insurance and our campervan is covered by a very comprehensive insurance too. Sometimes I have to organise an early delivery of my drugs and prescriptions from my GP, but that is no trouble.*

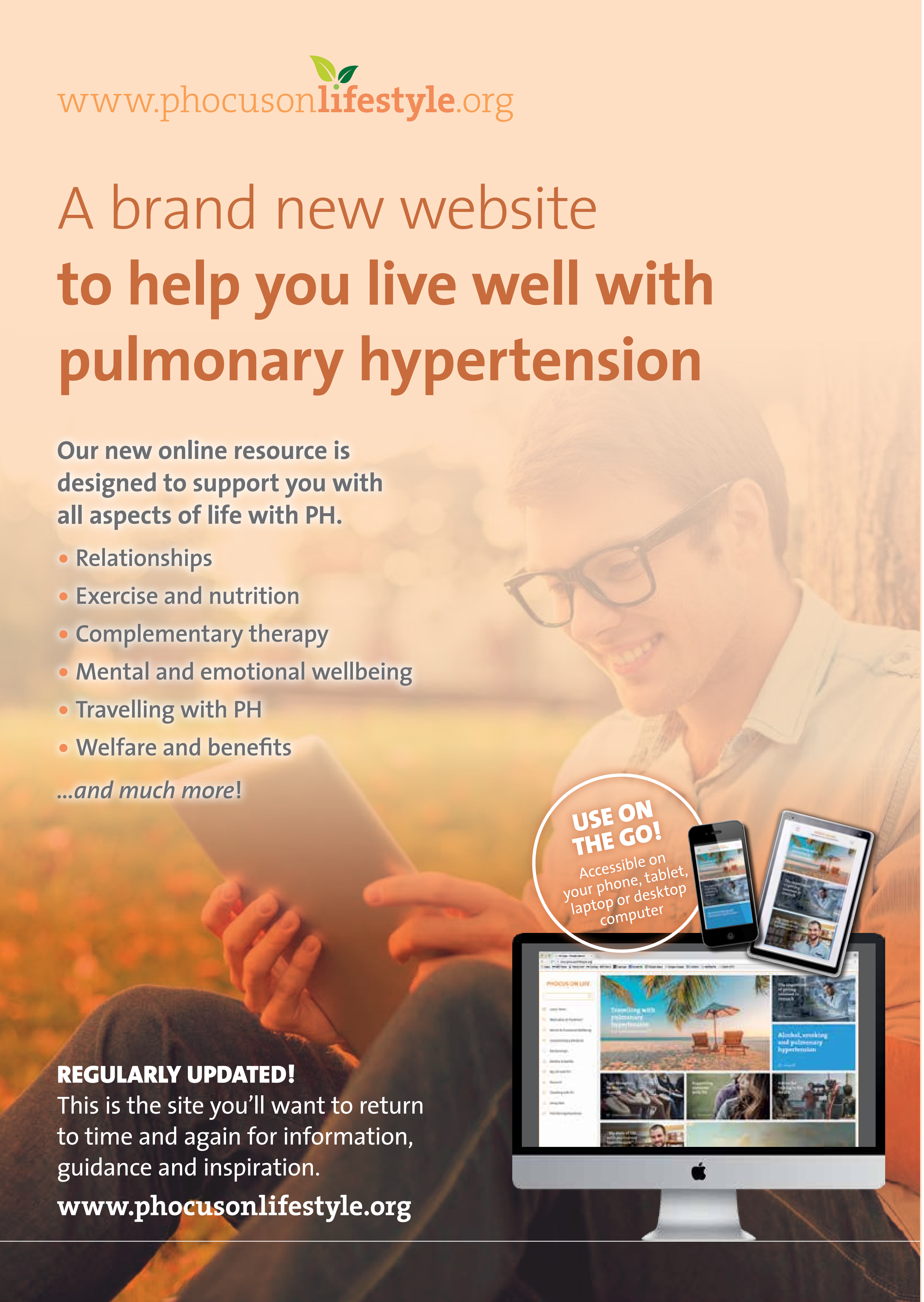
> **"Every day of our holiday is different, and we can do as little or as much as we wish. Our route is not fixed, so plans can easily be changed."**

Sometimes I have needed to ask permission from the specialist centre team for flying in a hot air balloon or climbing a mountain (by train!), and I hope we will be able to continue doing such things.

So, watch out for us travelling around – and think about doing it yourselves. It's a great life.

Lois x

Lois and her husband travel in an Autosleeper Warwick XL, affectionately known as 'Wanda'



Improving life for PH patients needing hip or knee replacements

Earlier this year, the PHA UK supported junior doctor *Mikaela Ming* to attend the European Respiratory Society (ERS) conference in Paris to present the work that Sheffield Teaching Hospitals has done to provide access to orthopaedic surgery for people with PH. Here Mikaela, who worked within the Sheffield Pulmonary Vascular Disease Unit as part of her job rotations, explains the difference it has made.

Due to advances in treatment, people are living longer lives with PH than ever before. This is great news, but it also means that some are now living with conditions more commonly associated with older age, such as osteoarthritis in the hips and knees.

IDENTIFYING THE PROBLEM

We are all aware of the physical and mental health benefits of keeping active. Living with a condition like PH can make this hard, and for those with arthritis too it can feel impossible. Similarly, living with two chronic health conditions causing pain and limitation in mobility can have a negative impact on one's quality of life, as well as their physical and mental wellbeing.

If conservative measures such as pain killers and steroid injections have failed to help improve the symptoms of severe arthritis, the next step of treatment is a hip or knee replacement.

In those without PH (or other heart, lung or kidney conditions) this is a relatively low risk operation lasting approximately an hour. However, people with PH are at higher risk of having serious heart complications when undergoing any form of surgery due to the stress that an anaesthetic and surgery puts on the heart. For this reason, non-emergency hip and knee replacements have not traditionally been offered to patients with PH.

PROVIDING A SOLUTION

At Sheffield Teaching Hospitals a new pathway has been developed to offer patients with PH and severe arthritis access to joint replacement surgery. The pathway has been pioneered between a close team of PH specialists, two anaesthetists and an orthopaedic surgeon. It involves carefully selecting patients for surgery, assessing their risk, and optimising their treatment before surgery. In most cases this means admitting patients to hospital several days before their operation to start them on a low dose of IV iloprost, even if it is not part of their regular PH medication. The operations are carried out under a regional anaesthetic if possible, for example a spinal anaesthetic, and all patients are carefully monitored to detect early signs of heart failure during and after their operation.

So far, 17 hip replacements and four knee replacements have been carried out on patients with PH. Of these, 16 were female, and 13 were in WHO functional class one. Four were in functional class four.

MEASURING SUCCESS

All operations have demonstrated good outcomes:

- **All patients were discharged home from hospital after an average stay of 13 nights.** The most common complication encountered was pain, followed by low blood pressure requiring medication to treat.
- **Everyone reported an improvement in mobility and reduction in pain when assessed six weeks after surgery.** All patients using walking aids before surgery reported a reduction in use of their aids after their operation.
- **The emPHasis-10 score was used to measure quality of life before and after operations and all patients reported either an improvement or no change.** The average pre-op emPHAsis 10 score was 29/50, which decreased to 20/50 after their operation. (Lower score represents a higher quality of life). ●

Professor David Kiely, Director of the Sheffield Pulmonary Vascular Disease Unit, said: *"In the UK, specialist centres are now performing elective operations to improve quality of life that would not have been considered two decades ago. Not all patients are suitable for an operation; some are improved without one, and for some patients the risks of surgery may be felt to outweigh benefits. However, I am really pleased that so many patients have now benefited from a big team effort and by carefully collecting data in the UK centres we are demonstrating that surgery in carefully chosen patients can be delivered safely."*

MEMBER BLOG

PHA UK member *Carole Ayrton* wrote this special guest blog for PH Awareness Week, to send an important message to other people with pulmonary hypertension.

Yes, we can live a life with PH.

I have lived with PH for eight years. Little did I know when first diagnosed and given six weeks to live, without medication and specialist care, that I would be here today and living a good life with this condition. Life is hectic as we are in the final stages of a house build. Who would have believed we would be doing this when first hearing the terrible diagnosis?

I feel sure that when most of you were told you had this devastating condition you looked on the computer to read what Dr Google had to say about it. Of course, most of the data on there is outdated but if you were like me you feared the worst.

Eight years on and I have come to realise we are, to a degree, masters of our own destiny. ***A person with a disability is still a person, a worthwhile person.*** *Many continue to hold down very worthwhile jobs and take care of a family. In essence, PH is NOT the death sentence it used to be. We have to have the belief in ourselves that we can live a full and satisfactory life with PH.*

Our lives have to change, of course they do. Some of us find things we could do easily before PH raised its ugly head are totally outside of our grasp now, but we need then to look and see what we CAN do, and not concentrate on the things we cannot.

Sitting on the couch all day feeling lonely and sad because life has taken us down this path is not the answer. *It does not change the diagnosis. This is where your family and friends can help you so much. It is important that because of having this disability we do not get left out of enjoyable things to do. Our family and friends need to remember that though we may not be able to do all we could before, we can still participate in lots of things, so if your loved one is suffering PH, please think of ways to include them in your life.*

I bought a scooter so I could still go 'walking' with friends. *This gets used less and less now that I have learned the importance of exercise but it does still get an airing on my bad PH days. I do not want to spend them in bed so my chair becomes my trusty steed to carry me off to the park or the shops.*

I think that upon hearing the diagnosis we all feared the very worst; an early death. Fortunately, as things move on, new medications have been discovered to help us, so this is not the case for most of us anymore. However, whilst the doctors can give us the meds that are so necessary to us, it is vital to help ourselves also. We need to help our bodies make the most of each day.

For me I have a belief; a belief that I will be cured and that PH will not take me, so I do my very best to stay on top of the game. *I take my meds religiously, I listen to all advice given by my specialists and take it all on board, never giving in. Of course, I have my bad PH days, I do not think it is possible for me to never have any. I also admit to sometimes doing too much, trying to prove to family and friends I am the person I was before PH. Of course, I then come crashing down to earth with the realisation I am not. Something has changed within my body so the game simply has to be played differently. That does not make me a worse person, or a less worthwhile one; just one that has to accept the limitations PH has placed on me. I am still stubborn and am determined to fight this disease with every bone in my body.*

Most of all, I think what keeps me going is the belief in myself and in my specialists. We make a great team and work together so I can make the most of this life whilst I await eagerly the day the cure is found for all of us.

Carole Ayrton

JOIN US AT CONFERENCE

20th Anniversary Celebrations

Next year's conference will mark the start of our 20th anniversary celebrations as we return to Heythrop Park Hotel in Oxfordshire.

The celebratory event on 4th – 6th May (bank holiday weekend), will include interactive educational sessions, special keynote speakers and expert talks, as well as activities for children and the chance to meet and share experiences with other PHA UK members.

Activities for children will be provided at the 2019 conference, but on a reduced scale compared to the family conference which will take place in 2020.

Retired former primary school teachers Malcolm and Vee Willis will return to host the children's activities. Both have been involved in the conferences since they began in 2001 and have expanded the range of activities over the years.

Sessions in 2019 will include the ever-popular crazy golf, bingo, pottery and arts and crafts which are suitable for any age, as well as entertainers and several other activities tailored to the children.

Malcolm said: *"Over the years we've been able to cater for every child, giving them the opportunity to join in with their peers, have fun, learn new skills and make new friends. The activities allow children with PH and their siblings to be children – it's wonderful to see their smiles and they're always appreciative which makes it special."*

Malcolm and Vee will be joined by volunteers and fellow teachers Jean and Charlie Malsbury to run the activities.

"We're used to working with children of all ages and abilities; this means parents attending the conference for the first time can be relaxed when leaving their child with us, in the same way they would be when leaving their child at school."

Register to attend now using the form overleaf. Places are limited and are not guaranteed. Please book early to avoid disappointment.

Meet Malcolm and Vee

Q. How did you become involved with the PHA UK?

A. *Through family. Vee's sister is Kay Yeowart, a founding member and trustee of PHA UK. In 2001, a year after the charity was founded, we were asked to attend the first conference in the East Midlands. Back then there weren't any kids' activities, so the conference has really evolved over the years to cater for a wider audience.*

Q. What did you do before working with the charity?

A. *We were both primary school teachers for 40 years.*

Q. What is your most memorable moment at conference?

A. *There are so many! It would have to be seeing the sense of achievement on a child's face when they've done something for the first time.*

Q. Do you have any hobbies?

A. *We both volunteer as public footpath inspectors and enjoy travelling the world and spending time with our four-year-old grandson. Vee has a keen interest in local and family history and collects post boxes (300 plus and counting!), and I'm Chairman of my Local Civic Society and love photography.*

JOIN US AT CONFERENCE 20th Anniversary Celebrations

Attendee information

Name of booker:
Contact number: Contact Email:

Additional guests (not including booker)

Number of additional adults: ☐
Name:
Name:
Name:
Name:

Number of additional children: ☐
Name: Age:
Name: Age:
Name: Age:
Name: Age:

Dietary requirements:
Accessibility requirements:
Do you require a highchair? Yes ☐ No ☐

Room choices

Standard double:
Family rooms (2 double beds):
Interjoining rooms (where possible):
Accessible room:

A photographer will be present during the weekend.
Are you happy to be included in photographs? Yes ☐ No ☐

REMEMBERING OUR EXTRAORDINARY SOPHIA

Sophia Antognazza Hotson lived with pulmonary hypertension and Down's Syndrome, and amazed her family every day with her patience and courage. Her parents, Rosa and Howard Hotson, wrote to Emphasis to share this moving tribute to their daughter.

Our final family photo

Our precious and beautiful daughter, Sophia, died peacefully at home on 7 March 2018, surrounded by the love of her family. She was born on 31 May 1999 with Down's Syndrome and severe primary pulmonary hypertension. She bore her difficulties with amazing courage and astonishing resilience far longer than anyone thought possible, until her condition suddenly took a turn for the worse on Monday 5 March.

In trying to summarise in a few words the brief life of our daughter, the word which keeps reasserting itself is 'extraordinary'. This may seem a trivial observation of someone whose limitations and difficulties kept her outside the norm, but in Sophia's case disabilities were coupled with extraordinary gifts and abilities, way beyond the capacity of ordinary people. ***Continued overleaf >>>***

> "Even though every day was a struggle for her, she never stopped smiling."

From a purely physical, physiological perspective, there can be no doubt whatsoever that Sophia was extraordinary.

Anyone familiar with the typical physical manifestations of Downs Syndrome could recognise them in Sophia instantly.

To the benign external features were added the medical conditions associated with the syndrome – including a weak immune system and low muscle tone – as well as learning difficulties particularly manifest in the area of speech and language. And on top of these core limitations other problems gradually proliferated throughout her short life.

Due to a thyroid condition, our 'elfin creature' never grew above four feet tall. As adult teeth crowded into a child-size mouth, the danger of dental problems loomed which might eventually prove lethal. Worse still, in her teens she rapidly developed scoliosis which could not be treated without exacerbating her other conditions.

Rarest and most dangerous of all was her primary pulmonary hypertension. This condition first manifested itself when she was two-and-a-half years old. Fortunately, at that moment the Great Ormond Street Hospital opened an experimental clinic which provided Sophia with the newest medications. There was never any question of curing the disease, only of slowing its progression; but without their remarkable success in lengthening her life very little of what is recorded below would have been possible.

All told, Sophia's life was a continuous cycle of blood tests, doctor's appointments, and hospital check-ups. But – and this is the more extraordinary thing – it would be completely inadequate to define this little girl by her problems and limitations; for with these disabilities were intimately coupled with even more extraordinary abilities which also put her completely outside the norm, at least for those who knew her well enough to see them.

Perhaps the clearest example of this coupling of abilities and disabilities was apparent only to those who knew her day and night: namely, her parents.

> “Sophia's disabilities were coupled with extraordinary gifts and abilities.”

Her sleep was extremely difficult: whenever she lay down and fully relaxed, her airways shrank, depriving her of much-needed oxygen. For almost her entire life, she had to choose between sleeping and breathing. Watching Sophia's struggles to find a position in which she could do both simultaneously, we often thought that no normal person could endure for a single hour what she tolerated every night of her life.

But here is the turning point of this brief portrait: Sophia never complained. She tolerated this affliction with infinite patience, which was extraordinary enough; but somehow, she also managed to accept it, to transcend it, to rise above it. At any rate she could often be heard talking and laughing to herself as she tried to get off to sleep late in the evening; and we sometimes woke in the middle of the night to hear her singing to herself upstairs.

So here we encounter the first of several quite extraordinary virtues: inexhaustible patience, endurance, and courage.

What could possibly have produced this patience, endurance and courage in such a physically frail person? The best answer we can find is in the second cluster of virtues: a certain kind of selflessness and contentment which appeared to arise from a lack of envy.

> “What could possibly have produced this patience, endurance and courage in such a physically frail person?”

Perhaps Sophia's chief blessing was that she never compared herself with others, or with an imagined state of perfection to which she thought herself entitled. This was a stroke of utter genius, which enhanced her well-being immeasurably.

Here we encounter a wisdom which is not of this world, at least in the sense that it escapes the inclination to envy so deep-seated in human nature.

This second set of virtues was reciprocally related to a third: her remarkable capacity to extract happiness from the very simplest of things. Sophia did not compare herself unfavourably with others in part because she had a fundamental ability which so many of us lack: namely, an extraordinary capacity to extract the maximum happiness out of the few simple things which she was capable of doing.

And what she could do, she loved.

A few activities were out of doors: visiting the local play park and adventure playground, feeding the ducks at the pond on the way, swimming (in the arms of her family) at the local pool, or riding in a child seat or tag-along behind her father's bicycle.

Some were social and public: she loved her school days and the weekend ballet class which she attended for many years. When asked what her favourite thing was, she replied, 'Sound of Music at the theatre!'

For many years, she served at Mass every Sunday, and doing so was one of the chief delights of her short life. This role played to all her strengths: it was non-verbal, performative, ritualised, public, important, and clearly an act of service both to the officiating priest and to the parish community.

Other favourite activities were indoors, and played to her strengths as a very good visual learner: completing surprisingly complicated puzzles, writing and reading with a fluency one could not have expected given her very limited verbal abilities, watching and re-watching her favourite videos, and listening endlessly to music – which communicates meaning without words.

But the fourth and most important of her extraordinary capacities was the ability to give and receive love. This ability alone more than compensated for all the disabilities, and blessed Sophia – despite everything – with an extraordinarily happy life.

Perhaps the most eloquent documentation of this in our entire photo archive is the picture of her with her brother John (below), just after his return from a week in Italy.

She may have lacked words, but no words could possibly express her happiness at this reunion more eloquently than her little face.

Most eloquent of all was something that no camera can capture: the experience of looking into Sophia's eyes, upon returning home after a whole day of separation at school and work. She retained that gaze of perfect innocence and purity we all know from looking deep into the eyes of a baby, but to this she added three other things no baby is capable of: the awareness that she is one, unique, self-conscious person looking into the eyes of a separate, unique, self-conscious person; the awareness that the other person is reflecting back to her the outpouring of love that they see in her eyes; and the awareness that she is reflecting theirs back the same thing to them. It was, quite simply, the most beautiful thing in the world.

Sophia was a little person with special needs – but also and far more importantly – with very special gifts.

The greatest of these gifts was the capacity to love other people spontaneously and in doing so to evoke their love in return. Thanks to this gift, she experienced true bliss repeatedly, frequently, on a daily and hourly basis, and lived an extraordinarily happy and fulfilling life.

Sophia with John

Our first family photo

Sophia with Francesca

We would like to end with the words of her younger sister, Francesca – words which best capture what Sophia was for our family:

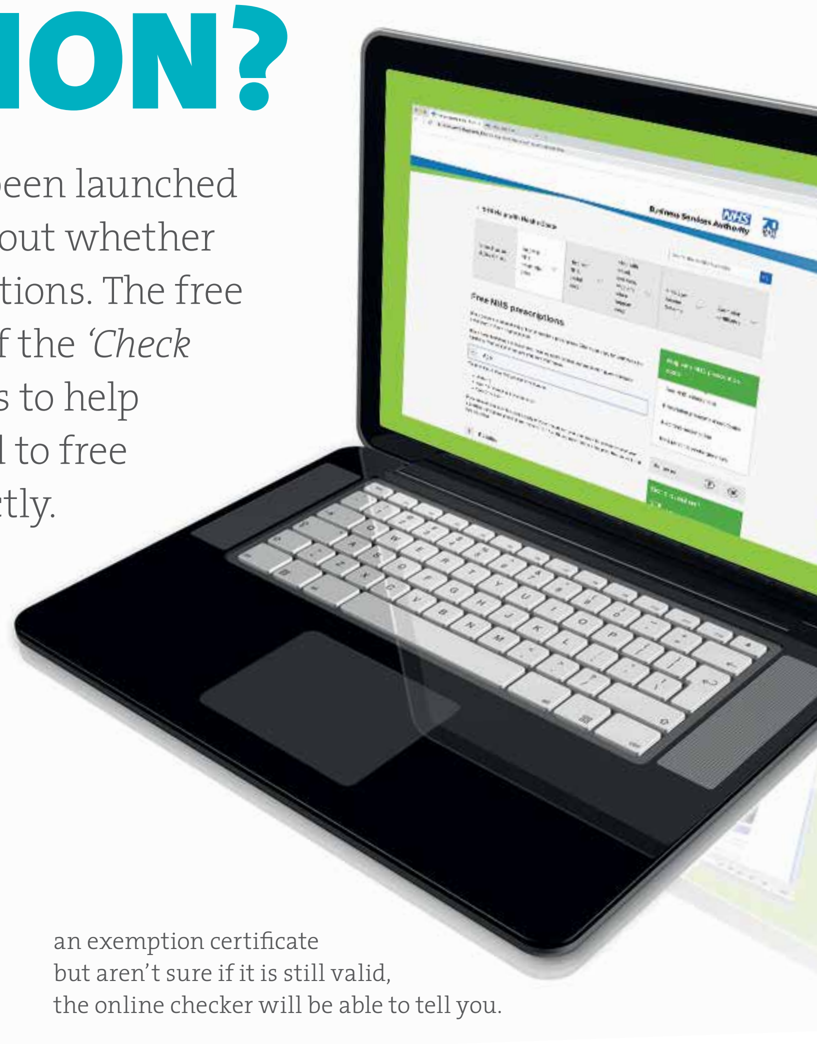
“Sophia shaped the way we lived our lives in the past and the present, and will shape it in the future. She was so precious not because of what she lacked but because of what she had to give to her family and friends. She gave courage, love, and strength to fight for herself, and keep the connection our family and friends shared with her until the end.

If someone who wasn't as close to my sister was asked who out of me and Sophia was the strongest, they would probably not choose the girl with a learning difficultly and a lethal heart condition over the girl who hasn't been hospitalised since the day she was born. I might be perfectly capable of running fast as I want to, or travelling wherever I want to, or being or saying whatever I want to. But in reality, and in my eyes, Sophia was much stronger and braver then I could ever be. Even though everyday was a struggle for her, she never stopped smiling. I often found myself bragging about my sister to my friends in school. She was truly the one I looked up to. I respect her more than ever and I see her as a hero.”

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

COULD YOU BE ENTITLED TO A FREE NHS PRESCRIPTION?

A new online eligibility checker has been launched by the NHS which allows you to find out whether you're entitled to receive free prescriptions. The free service has been introduced as part of the *'Check Before You Tick'* campaign which aims to help people understand if they are entitled to free prescriptions and how to claim correctly.



Who can claim free prescriptions?

Unfortunately, having pulmonary hypertension doesn't automatically mean you're entitled to free prescriptions – unlike cancer or some types of diabetes.

If you are aged under 16 or over 60, or aged 16-18 and in full-time education, you are automatically entitled to free prescriptions.

If you claim income support, income-based Job Seeker's Allowance or income-based Employment and Support Allowance, you are also entitled to free prescriptions. Your partner and any 'dependents' (e.g. children) aged under 19 can also claim free prescriptions as a result.

If you do not claim benefits but are part of the NHS low Income Scheme, you will be eligible for free prescriptions. Anyone can apply for the Low Income Scheme, but to be eligible you cannot have savings or investments worth over £16,000.

The NHS will also allow you to claim free prescriptions if you have obtained a valid medical exemption certificate. To get one, you must fit into a certain criteria which will exclude some PH patients. However, for people with more severe forms of PH, you may be able to argue that you have 'a continuing physical disability which means you cannot go out without the help of another person'. This means you would be eligible for a certificate, and would in turn be able to claim free prescriptions. The certificate only lasts five years and then you must re-apply to renew it. If you have an exemption certificate but aren't sure if it is still valid, the online checker will be able to tell you.

How do I check if I'm eligible?

Visit **nhs.uk/checkbeforeyoutick** and complete the online questionnaire. You will be asked for details such as your date of birth, savings and investments and any current medical conditions you have. The checker will then be able to work out whether you're automatically entitled to free prescriptions or advise you on whether you could apply for exemption.

If you claim free prescriptions but are not entitled to them, you could be fined up to **£100**, even if it was an honest mistake. Fraudulent prescription claims cost the NHS **£256MILLION** every year, and increased checks are being carried out.

Green Leaf Crew!

GREEN LEAF CREW Q&A
JESSICA WAINWRIGHT

Jessica Wainwright is 12 years old and lives in Salisbury with her mum, dad, brother Harry, dogs Barnaby and Alfie, and hamster Perdy. Here Jessica, who was diagnosed with PH in 2010, shares some of her favourite things.

Q. Where would you most like to go on holiday?
A. *I'd love to go to Canada in the summer.*

Q. If you could be anyone in the world for a day, who would it be and why?
A. *I would like to be Wonderwoman so I could have her special skills and do really fun stunts!*

Q. Do you have a favourite film or TV programme?
A. *My favourite film is The Greatest Showman and my favourite TV programme is Heartland.*

Q. What would be your dream job when you're older?
A. *I would like to be an equine vet.*

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

Q. What do you like to do at weekends?
A. *I like to go horse riding, help out at the stables and spend time with my friends.*

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

Q. What do you enjoy most about Christmas?
A. *I really love Christmas dinner with my family, giving everyone presents and opening mine!*

MELTING SNOWMAN BISCUITS

Fancy doing some Christmas baking? Why not try whipping up these tasty festive treats!

Ingredients:
- 200g fondant icing sugar
- 6 white marshmallows
- 6 large cookies
- 24 mini chocolate beans
- 6 pretzel sticks
- Tube of black writing icing

Method:
- Put the icing sugar into a bowl. Add cold water a teaspoon at a time until the mixture is runny but thick enough to coat a spoon.
- Ask an adult to snip the marshmallows in half using scissors.
- Spoon a bit of icing onto each cookie and attach half a marshmallow. Using a little icing, stick the other half on top at an angle to make the head. Drizzle a little more icing onto the cookie to make melting snow.
- Break the pretzel sticks in half and place on the cookie for arms. Stick orange chocolate beans on for the noses. Stick three chocolate beans on each cookie to represent buttons.
- Using the writing icing, pipe small blobs for the eyes and mouth. Leave to set.

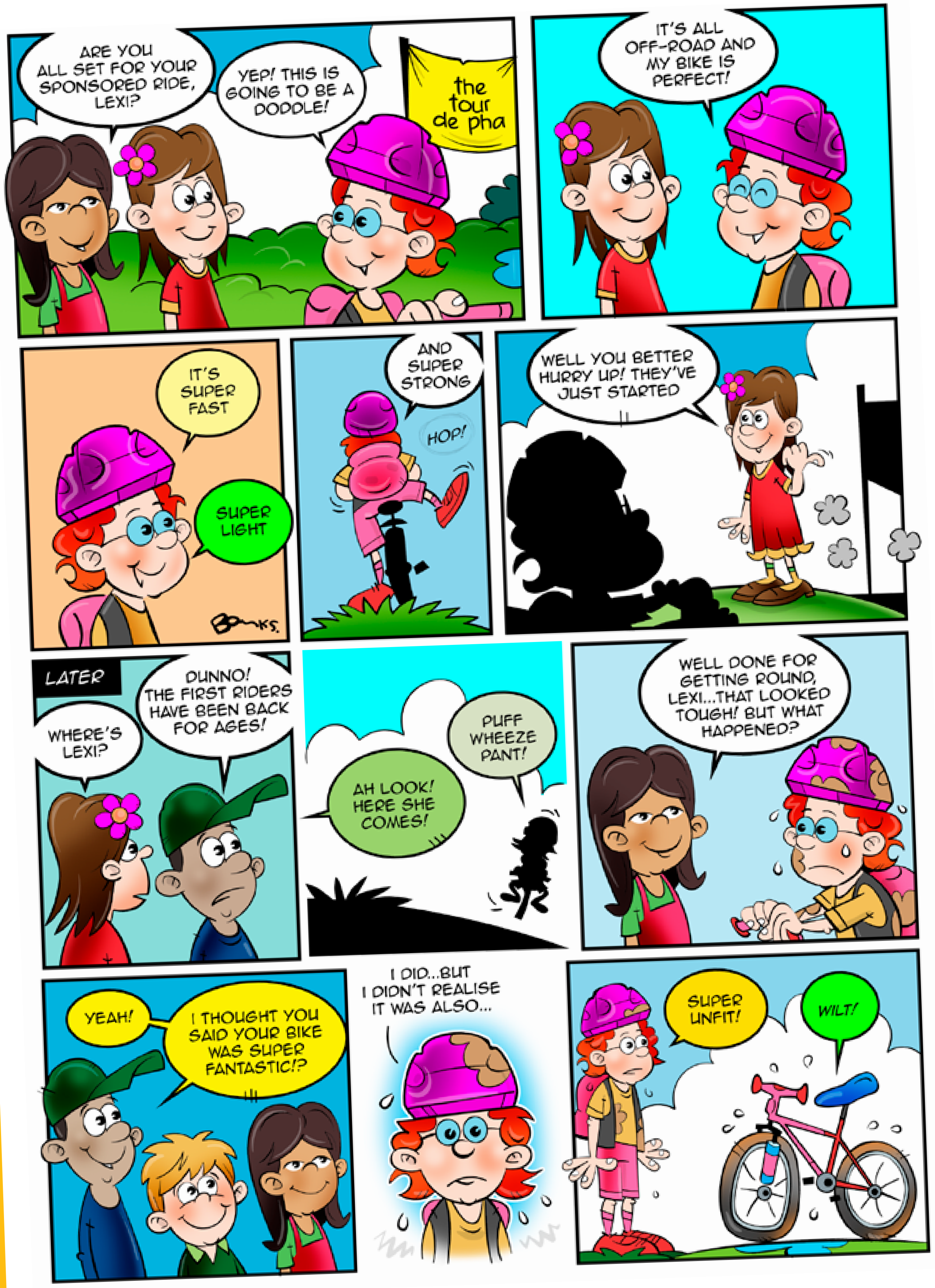
This recipe and image is taken from www.bbcgoodfood.com where you'll find lots more delicious festive recipes.

Patch

by David Banks

The GREEN LEAF CREW

BY DAVID BANKS



the*interview*

Professor of Clinical Pharmacology at Imperial College London

MARTIN R WILKINS

in conversation with

Deborah Wain

Martin R Wilkins is professor of clinical pharmacology at Imperial College London. He is Vice Dean (research) for the Faculty of Medicine, a role he combines with head of the Department of Medicine and director of the National Institute of Health Research/ Wellcome Trust Imperial Clinical Research Facility, which is based at Hammersmith Hospital While studying at Birmingham University, a travelling fellowship to St Louis in the United States in 1987 provided the platform for Martin's subsequent career in cardiovascular research.

For the past 25 years he has led a bench-to-bedside programme investigating the molecular basis of pulmonary hypertension and evaluating new treatments. His work, supported throughout by the British Heart Foundation (BHF) has contributed to the development of two new classes of drug for PH - phosphodiesterase inhibitors and soluble guanylate cyclase stimulators. More recently Martin's work has helped provide insight into the roles of iron and zinc in the healthy regulation of the pulmonary circulation. Martin was elected to the UK Academy of Medical Sciences in 2015. He holds a Liebig Professorship at the Justus Liebig University of Giessen and is an honorary member of the Kyrgyz National Academy of Sciences. Martin is also past president of the Pulmonary Vascular Research Institute, a global network of experts in the field.

Q. Were there any signs in childhood of the path you would follow in life?

A. *I have been interested in biology since my early days at school. Schoolteachers were a big influence. I became interested in the structure and function of cells more than the lifecycle of animals and plants. I didn't decide to do medicine until I had to make A-level choices.*

Q. What led you to research into PH?

A. *I was introduced to research in PH during my time in St Louis. I was there on a BHF Travelling Fellowship and interested in how the heart regulated blood pressure in the body. When I saw pictures of blood vessels, taken under the microscope, from patients with PH, it was clear to me that this was a much more aggressive and serious disease than the high blood pressure I came to the US to study. And one in greater need of new treatments. Maybe I am a 'visual person' but I was hooked. When I returned to the UK and started at Hammersmith Hospital, I was asked to supervise a PhD student interested in PH and that cemented my interest in this condition.*

Q. Is it all about hours spent in the lab?

A. *It used to be. When I returned from the US, I had to establish a new lab at Hammersmith. But nowadays it is all about having interesting conversations with some very smart people.*

Q. What achievement are you most proud of?

A. *I suppose it is the identification of the role of zinc in PH, which I hope one day soon will translate into a new treatment for this condition. We showed that a protein on the surface of cells that brings zinc into the interior of the cell is more abundant in the blood vessels involved in PH and that blocking this protein could help treat the disease. The discovery represents an original piece of research based on fundamental biology. It took the best part of 20 years to get to a stage where we could report the finding with enough confidence and sufficient evidence to persuade the scientific community that it was a robust observation. It involved problem-solving at different stages and drawing on a number of state-of-the-art techniques. It was dependent upon funding support from the BHF through successive grant applications and to their credit they invested in us. We are now working on finding a drug that can block this zinc transporter to treat patients.*

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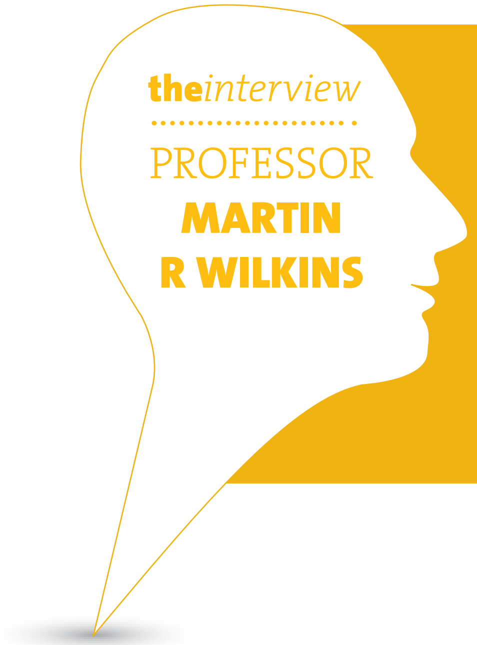


the*interview*

PROFESSOR
**MARTIN
R WILKINS**

> *“The UK is at the forefront of developing new [PH] treatments. The NHS centres around the UK that specialise in the care of patients with PH work extremely well together.”*

Q. Where does the UK sit globally in terms of advances in targeted therapies for PH?

A. *The UK is at the forefront of developing new treatments. The NHS centres around the UK that specialise in the care of patients with PH work extremely well together. This is very important for an uncommon disease. This organisation, together with the research opportunities funded through the NHS and BHF and the generosity of patients who give their time to research, makes the UK an enviable place to develop new treatments and long may that continue.*

Q. What are you excited about going forward?

A. *I am excited by the new technologies, coupled with computational tools, that allow us to better understand PH at the level of the molecules responsible for the disease and use that knowledge to develop personalised treatments. So the aim is not to treat everyone the same but find the best medicine for each individual. We are getting to the stage where we will be able to do tests in the clinic that tell us what is going on in greater detail than we have managed before and this will help clinicians make decisions based on the best available information. And we are beginning to use artificial intelligence to help us, with emphasis on help, rather than replacing us!*

Q. What is the best advice anyone ever gave you?

A. *I tell the story of giving advice on three separate occasions to a young fellow in the early days of his career. And in each case he did the opposite. He is now very successful. So the lesson here is to listen to my advice and do the opposite!*

Q. Who or what inspires you to do the work you do?

A. *The younger generation. I am continually inspired by the people I work with. The young scientists and clinicians that I am privileged to work with show the talent and the enthusiasm needed to push the boundaries and innovate. I don't think I would get a look in if I was starting out again.*

Q. And finally, how do you relax away from work?

A. *I am afraid to say that I watch too much sport. Mostly football, some rugby and occasional motor racing. I should do more exercise.* ●

Reviews

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

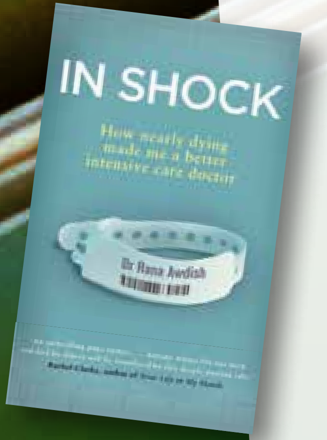
This issue, we review a thought-provoking book and an app to help you sleep.

Sleep Cycle

Described as ‘the natural way to wake up feeling rested’ Sleep Cycle works by allowing your phone to analyse your sleep and wake you up in your lightest sleep phase. It serves two functions: It's an alarm clock and a sleep monitor. Like many night owls, I was desperate to improve my sleep. The free app worked by tracking my sleep patterns and monitoring signals from my body. It recorded sleep quality and hours of sleep over days, weeks and months to get a good picture of my sleep pattern. The app required five days of data before it could collate my results, and after just a week I started to see a pattern emerging. I was going to sleep later and waking up later through the week too which I hadn't realised. This was impacting my sleep quality and by Thursday I could feel the negative effects on my mood. It's important to place your phone correctly; I placed mine screen down on my bedside table which uses the microphone to detect movement, but you can also place it on your mattress. The phone is required to be on charge through the night. While Sleep Cycle might not be the most accurate way to assess sleep, the upside is that it made me become more attuned to my circadian rhythm and the effect of sleep (or lack thereof).

Reviewed by Charlotte Goldthorpe

MARKS OUT OF 5? **4**



In Shock: How Dying Made Me a Better Intensive Care Doctor

by Dr Rana Awdish

The author, Dr Awdish, is the Director of the Pulmonary Hypertension Service in Detroit with many years' experience as an intensive care doctor. I had the great pleasure of meeting this remarkable lady and witnessing her special interaction with patients at the American PHA conference in June. While pregnant with her first child, Dr Awdish suffered a rare catastrophic medical episode leading to a near death experience, with an extremely long road to recovery, treatment by medical staff is indeed shocking and it is her experiences that have shaped the way she now practises medicine herself, treating patients with immense empathy. The book is a highly personal account of her illness and recovery. Her experiences have shaped the way she now works with her patients, listening and respecting their wishes. She is keen to encourage doctors to regard patients as human beings and not treat them in a detached clinical manner, which is often encouraged at medical school. I would encourage both patients and medics alike to read this book, it's thought-provoking and sheds a unique light on both patients and the views of medical professionals.

Reviewed by Kay Yeowart

MARKS OUT OF 5? **4**

Sorry PH, you picked the wrong warrior!

PHA UK member *Peter O'Brien* is celebrating after completing an inspirational cycle challenge the length of Britain. Deborah Wain spoke to him about his adventure.

Peter and his wife

Peter, 56, finished the gruelling 980-miles ride from Land's End to John O'Groats in just nine days.

At one time Pete needed help to complete the simplest everyday tasks, however his life has been transformed by surgery.

He hopes his achievement will encourage others with PH to reach for their own goals, whatever they are. Sponsorship has been flooding in for the PHA UK.

It was 2014 when Pete, from Oldham, went from doing regular boot camp-style exercises, along with wife Yvonne, to struggling to climb the stairs. His condition deteriorated and that Christmas he found himself very seriously ill in his local hospital, where it was discovered he had blood clots on his lungs and one on his heart. Remarkably the clot on his heart disappeared overnight through a congenital hole in the organ that he never knew he had, possibly saving his life.

After months of hospital visits and tests Pete was eventually referred to the Sheffield Pulmonary Vascular Disease Unit at the Royal Hallamshire Hospital where he was diagnosed with chronic thromboembolic pulmonary hypertension (CTEPH). He was later given the news that he was suitable for surgery to have the clots on his lungs removed. Pete underwent the pulmonary endarterectomy procedure at Papworth Hospital, in Cambridge, and its success was immediately noticeable despite the after-effects of more than eight hours of surgery. In the weeks that followed, Pete's condition dramatically improved. He was well enough to return to his job as a security officer by the September and began cycling the several miles to work each day, which he found hugely beneficial.

Pete decided he would like to take part in the ***Deloitte Ride Across Britain*** after someone he knew completed it last year. The challenge is considerable for anyone, let alone a PH patient. But with the backing of Yvonne, who bought him a new bike, and the couple's two grown-up children, Pete signed up. He trained on the roads near his home and on a static bike in his bedroom.

> *"Just a couple of years ago I needed help to walk to the toilet so to be able to complete the challenge was a massive achievement"*

Earlier this year Pete flew down to the south of the country and lined up with several hundred other cyclists from all over the world for the epic ride.

The group covered over 100 miles each day and stayed at campsites overnight when Pete proudly wore a red t-shirt with the slogan: ***'Sorry Pulmonary Hypertension, you picked the wrong warrior'.*** It prompted many questions from other cyclists and helped him to raise awareness.

While the route followed by the riders is often breath-takingly beautiful, the terrain can be tough. By the seventh day the punishing ride started to take its toll on Pete and suffering from sore muscles, extreme fatigue, and a tight chest, he started to doubt whether he would get to the finish line - but he was determined to press on.

He said: *"One of the medics from the ride rode with me and he said if I wanted to stop I had already done amazingly but that was like a red rag to a bull. I wanted to do it!"*

When Pete got to the end, he was overcome by emotion. It took him a while to physically recover.

He said he considers himself very lucky to be fit enough to have taken on the ride and hopes his efforts will inspire other people who have PH that "anything is possible".

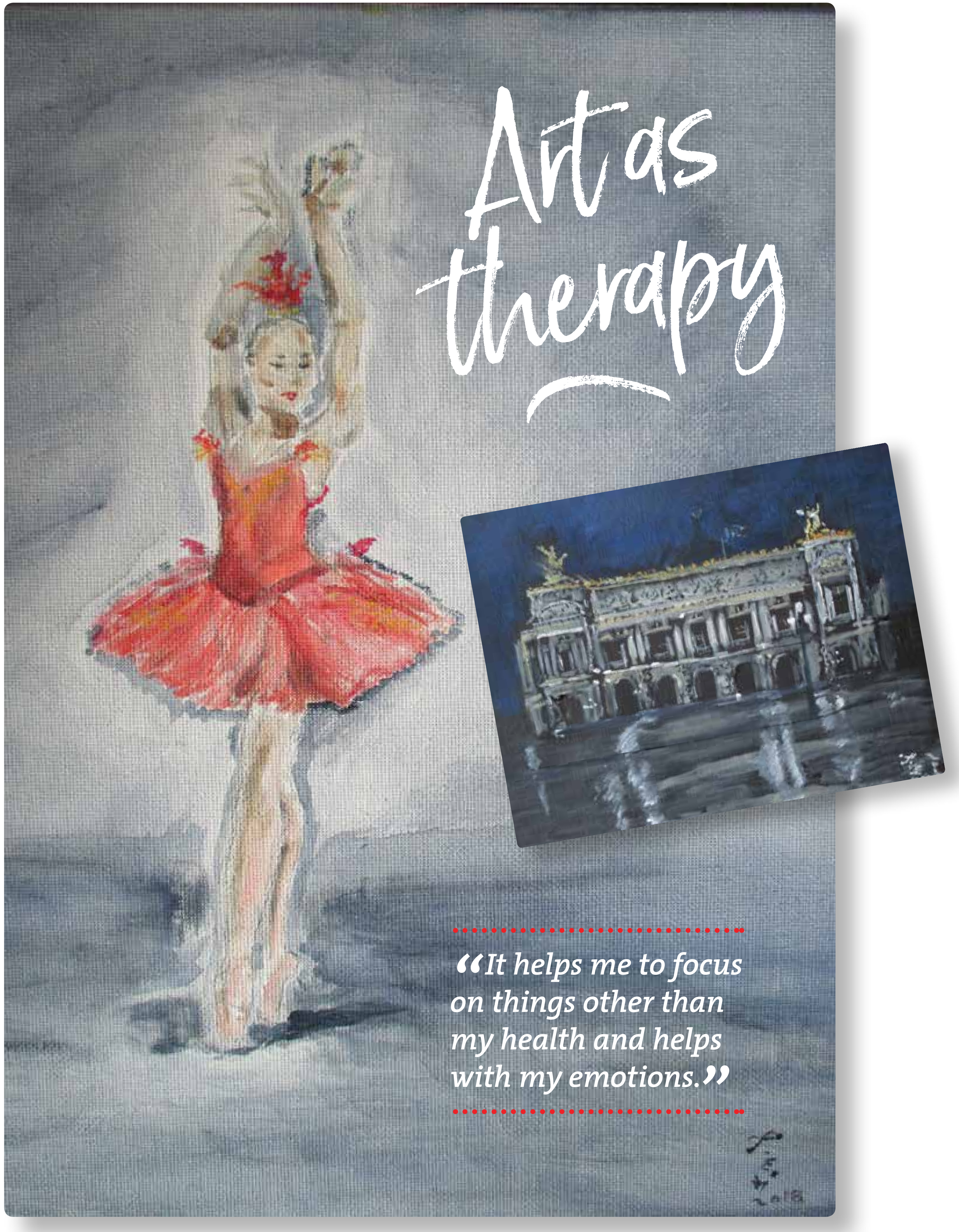
"I broke down at the end of the ride. Just a couple of years ago I needed help to walk to the toilet so to be able to complete the challenge was a massive achievement," he said.

Sponsorship from colleagues, friends and family has already raised more than £1,400 for PHA UK. As well as receiving support from the charity during his time in hospital, Pete has found its online forums beneficial. In fact, the t-shirt he wore during the challenge was made for him by fellow forum member Ros Knight, nee Blatch.

He said: *"PH is an illness you can't see and people don't understand it. They question it. You find yourself having to explain all the time. I've found the forums have been a fantastic help in making me feel less isolated."*

Pete, who currently takes blood-thinning medication to prevent further clots from forming, is looking forward to cycling many more miles.

To donate, go to Peter's fundraising page at:
www.justgiving.com/fundraising/petersride



Art as therapy

For *Tamsin Hutchings* there is nothing more enjoyable than picking up a pencil or a paintbrush and letting her creativity flow. She told Emphasis how her talent for art helps her to cope with living with pulmonary hypertension and other health conditions.

> **“It helps me to focus on things other than my health and helps with my emotions.”**

Tamsin, 28, has produced an impressive collection of over a hundred pieces since she took up the hobby.

She posts images of her art on the photo-sharing website Instagram and other online platforms and gets great feedback.

Tamsin first began to show symptoms of PH when she was aged around three when she repeatedly caught colds and suffered from a phlegmy chest. The condition began to make her more breathless around the time she started at senior school, leading to her diagnosis. Up until recently she was treated only with aspirin, but she is now prescribed Sildenafil.

Tamsin explained: *“It was diagnosed quickly. I didn't have oxygen until I was 24. I only just started on medication.*

“I went to mainstream schools. I left plenty of time to get there, to allow for breaks when I needed to catch my breath. My secondary school was very understanding and gave me a pass to use the lifts, and time to get to lessons.”

Also in her early teens, Tamsin developed scoliosis, a condition where the spine twists and curves to the side. In addition, she has Eisenmenger's Syndrome, which affects adults born with congenital heart disease.

Despite her challenges, Tamsin achieved 98 per cent attendance at school and was one of the top pupils in her year.

Tamsin's interest in art was sparked by a childhood visit to a museum when she was captivated by artefacts from Ancient Egypt. She went on to paint craft sets featuring plaster busts of Egyptian art. Later she began to experiment with drawing Chinese dragons, again inspired by items she had seen during visits to the museum.

As yet Tamsin hasn't sold any paintings or drawings but says she would only consider selling commissioned pieces as she admits she ‘gets emotionally tied with the art’. Instead she likes to give her artworks to relatives and friends as gifts.

Tamsin works from both photographic references and from life and it can take her anything from a week to six months to complete a piece depending on the size, level of detail and the medium. She uses pencil, colour pencil, acrylic, watercolours, ink and pastels. Over the past few years, she has begun to paint with oils.

> **“My art has become more realistic, but the backgrounds have become simpler.”**

“I have branched into different subjects, over the years. Whenever I have an art block, my art tends to change,” she commented.

At the moment Tamsin is focused on drawing and painting birds. This includes portraits of her own colourful pets – a baby canary called Hikariand and two budgies called Sky and Bertie. Tamsin had a third young budgie called Natsu but she sadly died a year ago.

Tamsin said: *“Sky is white, and pale blue. He's a shy little budgie who loves his music. Hikari loves playing with tassels, and his baths. He looks like a fluffy pom-pom when he has fluffed himself up. Bertie, who is green and yellow, has a trill that sounds like a crystal bell. He even trills when he sleeps.*

“I always love drawing and painting them, as it always cheers me up and they are little characters.”

Tamsin also creates portraits of actors and characters from theatre. She is a fan of award-winning Broadway and West End actor and singer John Owen-Jones, and has presented the stage star with some of her work.

Most recently Tamsin has finished a portrait of a ballerina, as the Firebird, and a painting of the Paris Opera House which she visited.

Tamsin said, like her, others with PH might find a creative hobby therapeutic. *“I would recommend doing something creative like this, as it can be very relaxing and enjoyable. There are many different ways, to suit everyone. It helps me to focus on things other than my health and helps with my emotions. When Natsu became unwell and passed away, it helped me with my sadness of losing her. I drew and started painting our other birds, and made needle-felted versions of them.”*

In addition to her passion for art, Tamsin has been interested since school in Japanese culture. Although she hasn't been able to travel to Japan as the journey is too demanding, she is learning the Japanese language.

She has a collection of beautiful vintage Japanese Kimono and their accessories, which she buys from a specialist shop in Bristol, where she lives. Made from silk and silk-crepe, the garments have usually been dyed and decorated before being hand sewn together. ●

Help yourself **and help the NHS**

Consultant pharmacist *Neil Hamilton* urges us all to look after ourselves - and our NHS - this winter.

Regardless of whether you voted remain or leave in the referendum, the spectre of Brexit casts an uncertain shadow over us all. The NHS benefitting to the tune of £350m per week seems somewhat unlikely as I write, but as an eternal optimist I live in hope!

What seems clear amongst a huge deal of uncertainty is that we must all do our best to use NHS resources wisely as they become ever more scarce. I am sure many readers will, just as I did recently, face a long wait for the next available GP appointment at your surgery.

Many of our patients relay to me the difficulty and delay in even booking into phlebotomy or nurse clinics just for blood tests. Local surgeries are struggling to cope with an ever-increasing demand on their services.

The newly appointed Secretary of State for Health, Rt Hon. Matt Hancock, added his weight behind the ***'prevention is better than cure'*** ideal - encouraging all of us to take steps in our daily lives to do whatever we can to live healthier. Keeping healthy through sensible lifestyle and dietary choices is good advice for anyone with or without long-term conditions.

> *"Amongst the range of self-care topics frequently mentioned is visiting your pharmacy for minor ailments."*

The NHS in different areas of the country is tackling this in different ways, but I notice a common theme emerging; that of self-care.

For example, NHS Derbyshire has launched an initiative called ***'Stay Well Derbyshire'***. They say that self-care 'refers to the actions we take to recognise, treat and manage our own health. It's about doing small, everyday things for yourself to keep healthy and happy'.

By searching for 'Stay Well Derbyshire' on the internet, you can visit their website with plenty of useful advice and materials.

Their aim is to encourage self-care as it is estimated that this could save the NHS £136m every year. These schemes aim to make NHS resources available more readily where they are really needed. This can only be achieved by diverting the less crucial demands to more appropriate locations.

They use an example of obtaining some paracetamol and it is almost unbelievable how the costs increase depending on your route:

59p	Self-care (buying yourself from a shop)
£31.88	GP prescription and pharmacy
£40.13	Walk-in centre
£63.59	A&E

Similar examples include basic hay fever remedies and treatment for blocked noses / colds.

As everyone becomes more familiar and comfortable using technology, there are a wide array of apps for smart phones and websites aimed at self-caring, including NHS choices.

Here, you can find a wealth of well-written pages on a massive range of illness and medicines. Anyone without access to the internet can get medical help and advice by dialling 111. This line is definitely not to be used in the event of an emergency but may be useful if your query is non-urgent.

Amongst the range of self-care topics frequently mentioned is visiting your pharmacy for minor ailments. Most, if not all, pharmacies now have a private consultation room where you can speak in private and receive quality, confidential advice, which can often spare a trip to the GP. Best of all, you can walk in at any time without any delay for appointments.

Staying on the theme of doing the right thing for both yourself and the NHS, I noticed the 'check before you tick' campaign – you may have seen the adverts on TV. Emphasis brings you more information about it in this issue on *page 39*.

It is a very easy tool to use and easy for everyone to access. In an ideal world, PH would be one of the named conditions which entitles all patients to free prescriptions, but in the meantime please make sure you are entitled to an exemption before ticking the box on the back of your prescription.

Check before you tick will help avoid prescription fraud, and more checks than ever are taking place – so please don't get caught out. There have been several sensationalised reports in some areas of the media. If you are genuinely exempt you do not need to worry at all, but I expect that you may be increasingly expected to show proof of your exemption at the pharmacy in order to avoid paying.

If you are not entitled to free prescriptions but need a number of medicines, the best option is to buy a pre-payment certificate. This is akin to a prescription 'season ticket', giving you unlimited prescriptions for the duration of the certificate. These cover either three or 12 months.

It is even possible to pay the annual fee by direct debit over 12 months to save a big outlay all at once. If you have three medicines each month, an annual certificate will save you over £210 per year against paying for each item individually. Your local pharmacy can answer any questions that you may have. Whilst a single item charge may seem expensive when multiplied up, there are ways to save.

Please look after yourselves through the winter. This is always the busiest time for the NHS. Make sure you are not wasting valuable time and resource for some paracetamol (or similar minor ailment /remedy) - after all, it could be you, a loved one or fellow PH patient that can't be seen when they really need to be as a result.

Fundraising r£undup

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

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

£621 RAISED

Cardiff Half Marathon

Ellen Seagan completed the Cardiff Half Marathon to raise money for PHA UK after her mum Joanne underwent surgery for PH in 2015. Ellen said: "It was my first ever half marathon so I was quite nervous on the morning of the run but it was a beautiful day and the crowds were amazing. My mum came to cheer me on and every mile was worth it for her."

Moondance Ball for Will

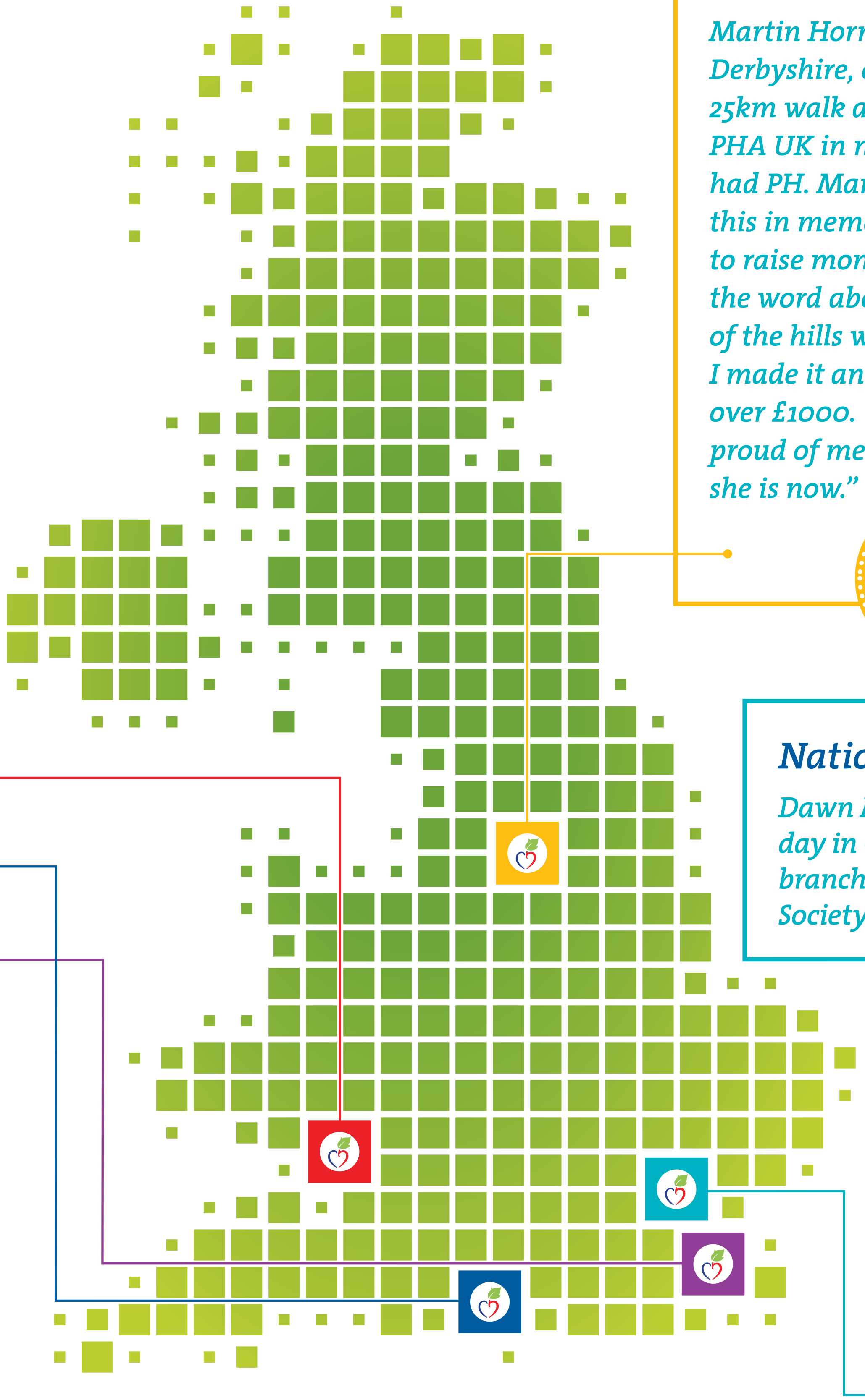
Julie Turner organised the third annual summer ball in Emsworth, Hampshire, to raise money for PHA UK in memory of Will Acres who passed away aged just 22. Julie said: "We had 300 people attend a fabulous black tie picnic with live music and a charity raffle. We managed to raise over £3,000 which we hope will go towards further research and support for people with PH."

£3,255 RAISED

Taking to the skies

Lily Nash from Dartford in Kent completed a skydive at Headcorn Aerodrome in memory of her cousin Lucy Clarke. Lily said: "I couldn't be more proud of myself for actually going up 12,000ft to jump out of a plane! I wouldn't change it for the world, it was an amazing experience and I enjoyed every part of it knowing that I had raised money for PHA UK in Lucy's memory."

£1,300 RAISED



Trekking the Peaks for PH

Martin Horridge from Swadlincote, Derbyshire, completed TrekFest, a 25km walk across the Peak District for PHA UK in memory of his mum, who had PH. Martin said: "Not only was this in memory of my mum, I wanted to raise money for PHA UK and spread the word about PH. I must admit some of the hills were gruesome, but I made it and in doing so raised over £1000. Was my mum proud of me? I hope she is now."

£1,010 RAISED

Nationwide Charity Day

Dawn Martin organised a charity day in October at the Hornchurch branch of Nationwide Building Society in Essex, where she works. The branch was officially opened by local Mayor Dilip Patel on the day. Dawn said: "My four-year-old cousin Connie was diagnosed with PH so I wanted to do something for her. We had a fantastic day and our head office has agreed to match the total amount we raised."

£490 RAISED

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

ME & MY JOB

This issue meet Nadine Turner, Advanced Clinical Pharmacist at the Scottish Pulmonary Vascular Unit (SPVU).

WHAT DOES YOUR JOB INVOLVE? I am a prescribing pharmacist so I am responsible for prescribing and supplying patients in Scotland with their medicines for pulmonary hypertension. I often advise other healthcare professionals such as doctors and nurses on the best choice of medication for patients taking into account a number of different factors. I also educate patients on their medicines which often aids them when taking them at home.

HOW LONG HAVE YOU WORKED WITH PH PATIENTS? For about a year and a half. I initially started working with SPVU as a secondment then my job became permanent about a year ago. Prior to this, I worked with patients with various respiratory conditions so this was a good progression into a more highly specialised area of respiratory.

WHAT'S THE BEST THING ABOUT YOUR JOB? I am lucky that a large part of my job is working directly with patients, be it on the ward, at clinic or telephoning them to discuss their medicines. They are always so receptive and keen for knowledge about their medicines. It's nice to be able to give them this information, be part of their experience with PH and see the effect these medicines can have on their lives.

WHAT'S THE FIRST THING YOU DO WHEN YOU GET TO WORK? Have a coffee! Then I will plan the various tasks I need to carry out that day.

WHAT'S ON YOUR DESK? My laptop, a phone, a pile of paperwork and maybe some sweet wrappers!

WHAT DO YOU LIKE TO DO OUTSIDE OF WORK? I enjoy hill-walking and just generally being outdoors in the Scottish Highlands. I try and go up north or to Loch Lomond most weekends in the summer (if the weather is ok!).

IF YOU COULD HELP THE WORLD UNDERSTAND JUST ONE THING ABOUT PULMONARY HYPERTENSION, WHAT WOULD IT BE? I would like to help people understand what it is like for someone to live with pulmonary hypertension. I don't think there is enough awareness among the general public of the impact it can have on people's lives and I think it's really important to increase understanding of this.

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

Flying the flag in Italy for patients

In October, *Tess Jewson* represented the PHA UK at a medical conference in Rome. Here, she shares her experiences of making patient voices heard in front of an international audience.

Thanks to all my online awareness campaigns, I was invited to be a speaker by the organisers of the International Chronic Obstructive Pulmonary Disease Conference, and on 22nd October, my husband Terry and I flew out to Italy.

We had the honour of representing the PHA UK and it was a real privilege to stand in our purple branded tops, proudly talking to doctors and researchers from around the world about why we were there.

On the first day of the conference, we found it was really daunting as we were the only non- medical people there. It was a very serious event, with everyone suited and booted, looking very smart!

During the welcome talk we found it really interesting to hear where in the world people had travelled from. ***There were people from China, Bulgaria, Greece, Malta, France, Belarus, Italy and, closer to home, Wales.*** *We listened to many presentations that day, learning about using inhalers properly and other breathing topics. The first day was very much about different breathing problems and COPD. Some of the talks were quite interesting, as I also have Bronchiectasis and Emphysema, so I could relate to what they were saying.*

On the second day of the conference, I gave my talk. I was very nervous, but the nerves soon settled and I really enjoyed speaking about PH, telling the room about my own journey and how PH affects people in the UK.

I had practiced my presentation a lot and so I was confident in what I was saying. I used facts and figures from the PHA UK's 'What it means to live with PH today' survey, and clips from videos produced by them. It was wonderful being able to speak from a patient's point of view because as much as we love to hear about the medical advances, I felt it was very important to help the doctors to understand what it is like for us having the condition.

My talk went down very well, ending with a rapturous applause and great feedback, so I was extremely happy.

I also mentioned the PHA UK a lot in my talk and told them about all the amazing work they do for us here in the UK.

I want to say a huge thank you to those who sent me good luck wishes and for all of their support. I received so much and it definitely helped me for when I was giving my talk. I was very proud to represent all of you!

> *"It was wonderful being able to speak from a patient's point of view"*

Terry and I decided to stay on in Rome after the conference to do some sight-seeing. We had a wonderful time looking at the main attractions, such as The Colosseum, Trevi Fountain and Vatican City. I took my Blue Badge with me, which proved I had a disability, allowing us to gain free entry and skip the long queues for each attraction.

We did a sight-seeing tour on Segways - which was a lot of fun! - and we also took a day trip to Pompeii. It was so interesting and full of history. Unfortunately, it's not very accessible, so I had to walk around the park, but Terry piggy-backed me round some of it when I got tired - especially the hilly parts.

We had a super time in Rome and can't thank the PHA UK enough for this amazing opportunity and for all those who followed my trip on my social media. ●

You can follow Tess's PH journey on social media and at **www.phighter.co.uk**

Available now

New guides for people newly diagnosed with PH

(and for anyone who wants to find out more!)

PH & YOU

This comprehensive information guide provides a vital introduction to pulmonary hypertension. Sections include defining the disease, tests and diagnosis, specialist centres, useful contacts and what to expect from your hospital visits. This book is given to all new members of the PHA UK, along with its sister publication, 'Medication & PH'.

MEDICATION & PH

A guide to treating and managing pulmonary hypertension using drug therapies. Sections include conventional or supportive therapies (including oxygen), and targeted therapies including those taken orally, intravenously or via a nebuliser. This book is regularly reviewed to keep the information as up-to-date as possible.

Edited by Dr. Iain Armstrong

pha UK Influence. Hope. Integrity.

PH & YOU

Information
Advice
Support
Help
Contacts

A comprehensive guide to understanding pulmonary hypertension

Edited by Dr. Neil Hamilton and Dr. Iain Armstrong

pha UK Influence. Hope. Integrity.

MEDICATION & PH

A guide to treating and managing pulmonary hypertension

Order your free copies now at ***www.phauk.org*** *or email office@phauk.org*

How we spend *your money...*

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

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

For fundraising support...
call the PHA UK office on **01709 761450**,
or email **office@phauk.org**

In your Spring issue of Emphasis...

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

The financial impact of PH
Study results and how we're pushing for change.

PH in pictures
Erin's photography project.

Handheld fans
How they can help breathlessness.

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).

Influence.
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Integrity.

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**.

Free PHA UK publications for support and advice

Available to order online!

If you would like copies of any of our publications go to **www.phauk.org/publications** call us on **01709 761450** or email us at **office@phauk.org**