SUMMER 2020

emphasis

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

YOUR DOUBLE GOLD AWARD WINNING MAGAZINE!

PULMONARY HYPERTENSION & COVID-19

Have your say

THE POWER OF POETRY

How it can help

"You don't have to give up your life because of PH"

Pamela's inspiring story

Celebrating a second chance

Pauline's transplant anniversary

Plus...

Exercise and PH
Rising to the 2.6 challenge
Making & baking whilst shielding

Together FOR THE JOURNEY

Specialist Provider Of Portable
& Medical Oxygen Solutions

pure O₂
'Dedicated To
Improving
Quality of Life'

FULL SUPPORT 24/7
FREE TRIALS
HOLIDAY RENTALS
BUY BACK & PART EX
ON-LINE RESEARCH CENTRE
BEST PRICE GUARANTEE

Why Choose pure O₂?

At Pure 02 we ensure that our services and products are second to none. Our portable oxygen concentrators have revolutionised the oxygen industry by offering users so much more confidence, reliability and efficiency, allowing long-term or ambulatory users to take small steps to have a better overall quality of life.

Our dedicated care team & technical support are available 24/7- we are always available to help you with any questions or queries you may have. We at Pure 02 pride ourselves on outstanding customer care.

Need finger tip advice? Why not view our research centre recognised globally as providing up to date information about all aspects of COPD and all other lung conditions. Questions/answers, real life stories & helpful tips, updated daily by our qualified medical staff.

Our show room is open Monday to Friday. Why not book an appointment to come and visit us. Pure 02 have for many years been providing patients and medical professionals with the opportunity to view all our medical oxygen ranges. Call our appointment line now on 0870 712 02 02. We look forward to seeing you.

- Free trials on all our POC's
- Buy back & part exchange available to all our customers
- Best buy guarantee with unbeatable discounts
- Back-up units always available

Pure 02 "We Care...."
Contact us now to arrange a full, free, professional assessment. From your first enquiry you will receive our complete undivided attention to ensure your needs are fulfilled to the highest level.

Our brochure has full details of all our Portable Oxygen Concentrators. Call now or visit our website to request your copy.

HOLIDAY RENTALS
AIR AND SEA APPROVED OXYGEN SOLUTIONS FOR HIRE

Pure O2, Viking House, 71 Princess Road, Urmston, Manchester. M41 5ST
Website: www.healthoxygen.com
Email: info@healthoxygen.com

Our Portable Oxygen Solutions

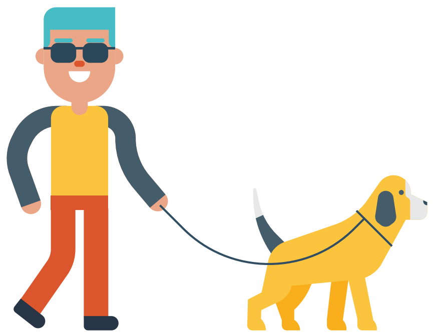
FreeStyle
Not only small & light but its new revolutionary oxygen generating system makes it the most reliable POC around!

Focus
With a weight of only 0.8kg (28oz) and standing just over 6" high the AirSep Focus is a true innovation in portable oxygen technology

SimplyGo
PHILIPS RESPIRONICS
Combining Continuous Flow and Pulse Dose oxygen delivery into a single ten pound device, SimplyGo offers an excellent all-round portable oxygen solution.

inogen INOGEN ONE® G3
The lightweight portable oxygen concentrator that offers up to 5lpm and weighs 2.2kg.

WHY NOT VISIT OUR SHOWROOM
CALL NOW TO MAKE AN APPOINTMENT
CALL 0870 712 02 02 (24 HOUR)
FREE PHONE - 0161 747 2617
Available 9 - 5pm Mon - Fri
Approved by Local NHS




WITH THIS ISSUE:
FREE! POSITIVITY CALENDAR
SPECIAL SURVEY: PH & COVID-19

Welcome...

...to the summer 2020 ssue of Emphasis. A lot has changed in the world since the last edition of this magazine, and I hope this message finds you safe, well and feeling optimistic for the future.

The PHA UK team has worked tirelessly to provide up-to-date information, guidance and support over the last few months and we hope it has helped. Ultimately, we really are ***'together for the journey'***, as our new branding reflects. I am truly proud of the whole PHA UK team; they are incredible.

You'll notice a couple of extra inserts with this issue. Firstly, we hope you'll spare a few minutes to complete our survey into the effects of the pandemic on people with pulmonary hypertension – you can find out more about this on *p17*.

It is so important that we understand the true impact of this pandemic so I would really encourage completing the survey as soon as you can. ***Your voice really does matter***.

Our 'positivity calendar' has been designed to boost mental wellbeing and aid the development of positive habits; do let us know if it helps.

As well as these additions, we've done our best to fill this magazine with interesting and uplifting content that includes something to appeal to everyone. You'll find features on topics as diverse as off-road scooters (*p20*), poetry (*p24*), holiday memories (*p39*) and rescue dogs (*p36*).

Plus, on *p48* we bring you a different kind of interview feature. Kevin Rowland has cared for his partner Julie since her diagnosis in 2012, and here he opens up about what he has learned. We'd like to thank him for being so candid.

Finally, we're inviting you to 'walk with us' in a virtual event designed to bring the PH community together and we'd love you to join us for something we hope will be really special. Turn to p45 to find out how to get involved.

> *"We've done our best to fill this magazine with interesting and uplifting content"*

Until next time,

Iain Armstrong

Iain Armstrong
Chair of the PHA UK
media@phauk.org

Together FOR THE JOURNEY

08

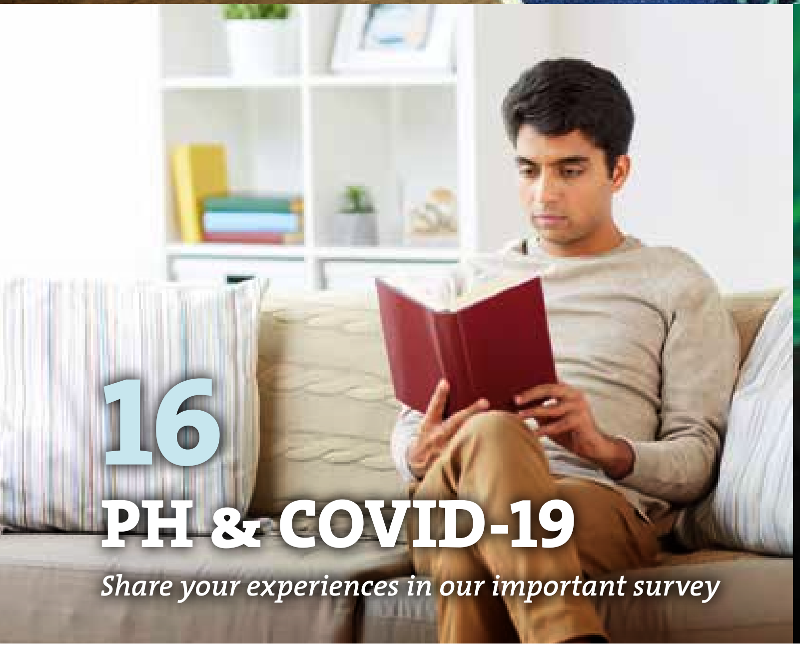
MAKING & BAKING

What you've been cooking and crafting whilst shielding

40

MAKING MEMORIES

Pam and Mike look back on their holiday adventures



16

PH & COVID-19

Share your experiences in our important survey

23

PLAYING IT FORWARD

Learning to make musical instruments has helped Jason navigate his grief

27

GREEN LEAF CREW

Our regular pull-out for young people with PH

45

WALK WITH US

Our virtual event to bring the PH community together

CONTENTS SUMMER 2020

Living with PH...

Latest News...

Regular Features...

YOUR DOUBLE GOLD AWARD WINNING MAGAZINE!

CIPR PRide Awards
'Gold' for Best Publication
2017 & 2019

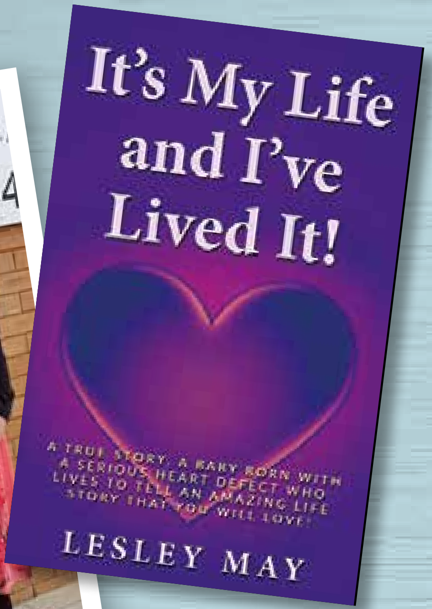
This magazine is printed on paper from sustainably managed sources

Emphasis ***exchange***

PUTTING IT **INTO WORDS**

PHA UK member Lesley Meek (pictured with son Ross) has written a book about her life - including her health problems and having a child via surrogacy.

'It's my life and I've lived it!' is available as a Kindle edition right now on Amazon, and all the money raised will go to our charity.


It's My Life and I've Lived It!

A TRUE STORY. A BABY BORN WITH A SERIOUS HEART DEFECT WHO LIVES TO TELL AN AMAZING LIFE STORY THAT YOU WILL LOVE!

LESLEY MAY

If, like Lois, you also enjoy bell ringing, please let us know by emailing office@phauk.org

AMONGST THE BATS IN THE BELFRY

Hi everyone,

I wondered if there were any other bell ringers in the PHA UK family?

My ringing hobby started back in the Millennium at St John The Baptist Church in Billesdon, Leicestershire. I would not class myself as a very good ringer, but I enjoy the friendship, and the exercise is good too.

I was diagnosed with CTEPH in the summer of 2012, and the team at my specialist centre soon had me sorted out with medication. I am very lucky that I am not too debilitated by PH and can carry on my active life almost as before.

There are 29 stone steps up a spiral staircase to our ringing chamber at church – nowadays I do have to hold tight to the rope and take my time to go up! And I need to allow about five minutes for my breathing to get back to normal when I reach the top. My ringing friends remind me to take a breather between the sets of ringing, and so I am still able to enjoy it.

So [before the pandemic] on Friday evenings and Sunday mornings that's where I could be found – amongst the bats in the belfry!

Best wishes

Lois Parker, Leicestershire

CELEBRATING ZOE

Dear PHA UK,

This is my companion, Zoe. We celebrated her 7th birthday recently and she is a great asset to all the family. She seems to have learned over the years that I can only go at a certain pace. She seems to know when I start to struggle with breathlessness and go blue, so she stops and refuses to go any further until we turn to return home. She's an important member of the family team!

Hope everyone is coping well during these difficult times, stay safe.

Ray Maule, Leeds

SAVE MONEY ON YOUR PRESCRIPTIONS

If you pay for prescriptions, an NHS pre-payment certificate could save you a significant amount of money. One prescription costs £9, but for a monthly direct debit of £10.40, you can get as many as you need - for no additional cost. So, if you have more than one prescription a month, it's guaranteed to save you money. Find out more, including how to apply, by visiting **www.nhsbsa.nhs.uk/help-nhs-prescription-costs/prescription-prepayment-certificates**

You can also ask your local pharmacy for details.

Social Media Highlights

As the pandemic took hold in April, we asked our followers what had made them smile amidst the chaos 😁

Lynn Pickstock
The birds busy making their nests and the blossom on trees...the most beautiful time of the year

Catmak1
I'm loving the sunsets at the moment

Jane Barker-Benfield
Captain Tom Moore and the amount he's raised for NHS charities. Makes me smile every time I see him on the news and hear him speak so positively.

Pandyusn50
I'm enjoying the sunrises and hearing the birds sing in the morning

Beverley Joanne
Doing a 'name that tune' live on Facebook for my friends. With a kazoo! Good exercise for the lungs! Got to keep spirits up 😁

Emmiluttu
Watching my daughter enjoying my plum puree this morning!

Sue Groves
How quiet it seems - no police sirens, hearing and seeing different birds coming into the garden

FOLLOW US...
Facebook **@PULHAUK**
Twitter **@pha_uk**
Instagram **@pha_uk_insta**
YouTube **@PHA ORG UK**

Making & baking whilst sheilding

Here's what you've been crafting & cooking whilst staying at home

The PHA UK's very own Shaun Clayton has been practicing perfecting a lemon drizzle cake

Comforting cottage pie by Lou Chadburn

"I'm making headbands to prevent the nurses ears from getting sore from the mask elastic. Glenfield Hospital is my local heart hospital and has looked after me since I was a child. It's nice to think I'm doing something to help."

Tina Pickering

All in a day's baking for Margaret Vickers

"I've been keeping busy doing some fretwork in my workshop"

Dave Jordan

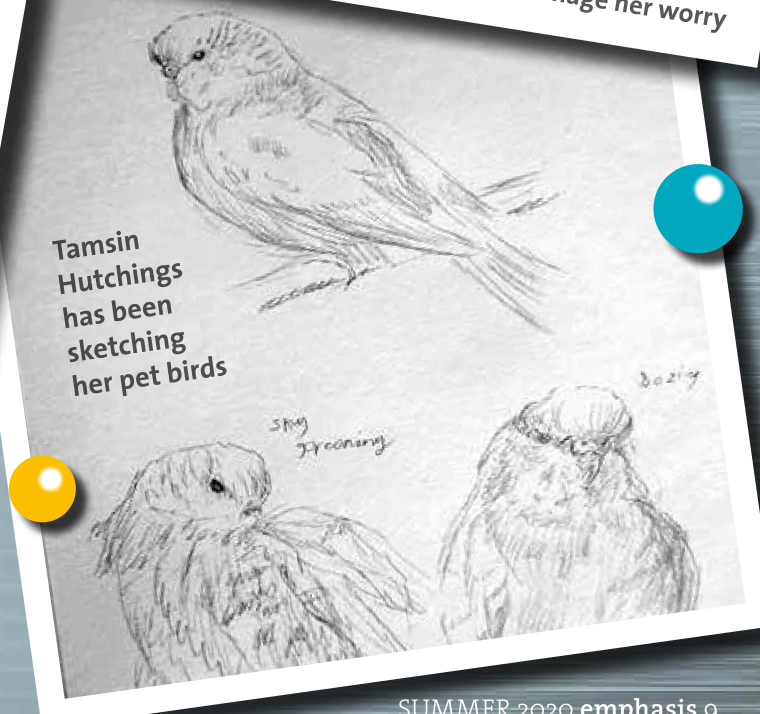
Liz McCleery's crochet creations

Adult colouring helped Tess Jewson manage her worry

Knitting clothes and blankets for her grandchildren has been keeping Pam Ellis busy

"Keeping busy during shielding by knitting blankets and beanie hats for my local Newborn Intensive Care Unit"

Nicola McCulloch



Tamsin Hutchings has been sketching her pet birds

FUNDRAISING focus

the 2.6 challenge SPECIAL

To help the charities losing money from cancelled fundraising events, the people behind the London Marathon had a brainwave. They asked supporters to complete a challenge based around the numbers 2.6 *(a marathon is 26.2 miles – geddit?)* in return for a donation to their chosen charity. We're proud to say our wonderful PH community rose to the challenge like true superheroes - and this is just a snapshot of that support. ***Thank you to everyone.***

Marathon for mum

Rory Sanger completed a marathon distance walk of 26.2 miles over the course of a week, using his permitted daily exercise to raise money in support of his mum (pictured together). He said: *"We are eternally grateful for the support and help that the PHA UK provides for PH patients, and this is of course especially important during the current pandemic situation."*

£205 RAISED

Stepping it up

£80 RAISED

Lou Chadbhurn, who is shielding due to her CTEPH, challenged herself to climb 26 flights of stairs at home – and sent us a photo of her sports watch to prove it! Her family also decided to hold a 'virtual bingo' game to celebrate her husband's birthday, raising even more money for our charity.

THANK YOU!

2 x 6 from Chris

Chris McCoy-Lavery challenged herself to take on a run in memory of her ex-husband, who died just two weeks prior to her fundraising. She said: *"I ran 12km (which is 2 x 6km) – not bad for an 'old' grandma of 66 years! Thank you for being there."*

£126 RAISED

SPVDU Super Slimdown

Our very own Iain Armstrong, Chair of the PHA UK, is taking on a 2.6 challenge with his Sheffield Pulmonary Vascular Disease Unit (SPVDU) colleague John Harrington. The pair are aiming to lose 26lb between them over a period of six weeks – and at the time of going to print, had already raised £1346.

Iain said: *"People living with pulmonary hypertension have had their lives turned upside down by the coronavirus pandemic and the PHA UK has pulled out all the stops to support them. However, as a charity that relies on fundraising to continue its work, our income has dropped considerably due to the cancellation of so many events. We work on the frontline of the UK's specialist pulmonary hypertension service and want to join our loyal supporters in raising money for the charity - and reinforcing that we really are all in this together."*

You can sponsor the pair by visiting ***www.justgiving.com/fundraising/iainandjohn***

Watch this space for further fundraising news from the SPVDU, as the ***pharmacy team*** take on their own special challenge...

Toby Butler made a £50 donation after completing a 2.6km walk and **Suzy Spencer-Boyce** challenged herself to walk 26 laps of her garden

THANK YOU!

COULD YOU RISE TO THE 2.6 CHALLENGE?

You don't have to be fit (or even leave your home!) to get involved with this fantastic fundraiser. You could...

- **HOST A 26-QUESTION VIRTUAL QUIZ**
- **COMPLETE 26 'SIT TO STAND' EXERCISES FROM YOUR ARMCHAIR**
- **BAKE 26 CUPCAKES**
- **READ 262 PAGES OF A BOOK**
- **FLIP 26 PANCAKES**

...The possibilities are endless! You'll find more ideas by visiting ***www.twopointsixchallenge.co.uk***

Don't forget to let us know what you're planning. Email office@phauk.org, call us on 01709 761450 or tag us on Facebook, Twitter or Instagram

the 2.6 challenge

Celebrating my second chance

April marked five years since *Pauline Ginn* received a heart and double lung transplant. Her story is one of unique numbers – she was her PH consultant's 100th patient, after just three months on the waiting list a match was found, and she was the first person her surgeon carried out such a transplant on.

Here, the mother-of-two from Bolton reflects on her extraordinary journey.

"My pulmonary hypertension diagnosis was confirmed when I was 42 and when I was assessed for transplant, I thought it was something that might happen in ten years or so. I had no idea just how quickly my condition was going to deteriorate to a crisis point and that I'd need a transplant within weeks.

I was in theatre for ten-and-a-half hours, in intensive care for five weeks, and on the rehab ward for two weeks - but it has all turned out well. I am here with my family and I'm not sure I would be otherwise.

The only thing I know about my donor is that she was a lady in her fifties.

She lost her life ***but saved mine.***

Life has changed totally for me in the last five years. I no longer need oxygen 24 hours a day and before having to shield I was able to go shopping without getting breathless, meet up with friends, and go out to restaurants with my family. There have been so many changes.

To be honest every day feels like a milestone for me, but in the last five years some of the things I have been so grateful to see include my son going to university and the birth of my grandchild. We are all looking forward to the next five years – and more.

My recovery is ongoing. I'm much better than five years ago but as I'm immune suppressed I tend to get a few chest infections, especially if I've been near someone with a cold.

The last chest infection took two lots of antibiotics and steroids to get rid of and I caught the norovirus at Christmas, which took a week to clear. Luckily, I've had no signs of rejection though.

Because I can't leave the house at the moment due to the pandemic, we celebrated my five-year transplant anniversary with a simple meal. My son and his girlfriend moved in with us last year, so they were there too, and we raised a toast to my donor. We'll celebrate properly as soon as we can.

I'm very excited ***about the future.***

At the moment we are staying safe, but when this is all over there will be lots of things to look forward to."

Pauline with her husband and grandchild

4 YEARS AGO

Mine & Terrys hero my surgeon Mr Venkat xxx

Pauline with her surgeon

How the law on organ donation has changed in England

From 20th May, England moved to the 'opt out' system of organ donation.

Max and Keira's Law – the Organ Donation (Deemed Consent) Act means that all adults in England are now considered as having agreed to donate their own organs when they die unless they record a decision not to donate, or are in one of the excluded groups.

Even though the law has changed, families will still be involved before any organ or tissue donation goes ahead. This means that unless your family know you wish to donate, they can stop the donation going ahead. And that's why having conversations about organ donation now are so important.

Wales already has an opt out system, after changing their law in December 2015. Jersey introduced the opt out system in July 2019 and Scotland will also be moving to an opt out system from this Autumn.

Do you feel **depressed or anxious?**

AnxietyUK
Here for you since 1970

PHA UK TRUSTED *Partner*

If you're having difficulties with your emotions or mental health, our partnership with Anxiety UK can help.

- Free counselling or therapy sessions
- Free helpline **0344 332 9010**
- Free email support service **phauk@anxietyuk.org.uk**

This service is open to PHA UK members and their families.

Please reach out.

Our partnership also gives you a free one-year subscription to mindfulness app **Headspace**

HEADSPACE

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

You can also contact Anxiety UK directly on *0344 332 9010* or at *phauk@anxietyuk.org.uk*

COULD YOU DESIGN OUR NEW *Christmas cards for 2020?*

Each Christmas, our cards raise vital income for our charity. And as lots of you have already been getting creative at home, we wanted to give you the opportunity to get involved.

THE WINNERS of each category will receive a £50 AMAZON VOUCHER

Simply submit your design and you could see it printed on our cards later in the year!

Here's how it works:

1 Design your card using crayons, paints, pens, or photographs – the choice is yours!

- Don't include any text; we'll add a festive message to suit your image
- Design your image to fit a square shape
- You can design it on paper or using a computer programme
- Remember to make it appropriate for Christmas *(a sunflower or beach scene won't work!)*

2 Take a photo of your entry and send it to us before 31st July

Email your photo (or computer file if you design it that way) to **office@phauk.org** with 'Christmas Card Competition' in the subject line. Remember to include your name, age and telephone number.

3 The PHA UK will draw up a shortlist and then ask the PH community to vote for their favourites via Facebook

Make sure you like our page – log in to Facebook and search **@PULHAUK**

4 The winners will be announced on 10th August

We'll make an announcement on Facebook and you'll also be contacted by telephone, so don't worry if you don't use social media.

Good luck!

If you have any questions about this competition please call **01709 761450** or email **office@phauk.org**

Age categories:

- Up to 9 years old
- 9-17 years old
- 18 years old and above

Don't forget to include your age on your entry!

HURRY! Deadline for entries is 31st July 2020

PH and Covid-19

Please help us by sharing your experiences

We know that the coronavirus pandemic has had a big impact on the PH community, and it's important for us to understand which areas of your lives have been affected the most.

It's also vital that we evaluate the support provided by ourselves as a charity and understand your experiences of support from other areas.

You'll find a detailed survey with this issue of Emphasis and we would be really grateful if you could take the time to complete it. By sharing your voice, you will help to shape future support and ensure the experiences of the PH community are heard.

The survey has been split into four key areas:

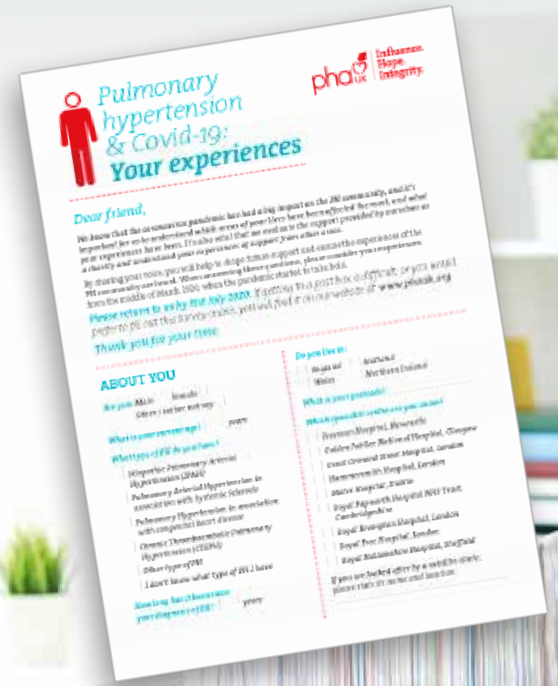
- *The emotional and psychological impact of the pandemic*
- *The physical impact of the pandemic*
- *The financial impact of the pandemic*
- *Support during the pandemic*

There is also space for you to add any other comments you would like to make, around anything at all related to the crisis. ***We're listening.***

You'll find a freepost envelope with this magazine, making it as easy as possible to return the survey. The postage is covered by us, so there is no need for a stamp.

If getting to a post box is difficult, or you would prefer to fill out this survey online *(which saves us the costs of postage too!)* you will find it on our website at www.phauk.org

Thank you for sharing your voice



Pulmonary hypertension & Covid-19: Your experiences

pha uk Influence Hope Integrity

Dear friend,

ABOUT YOU

Please ensure your responses reach us by 31st July

Find the survey online at www.phauk.org

You're not on your own!

Our private Facebook group enables you to talk directly to other people affected by pulmonary hypertension

- ○ **Safe forum to discuss the things that are important to you**
- ○ **Only members of the group can see who is in the group and what they post**
- ○ **Moderated by the PHA UK**

Want to join the community?

1. Log into Facebook and search ***Pulmonary Hypertension Association UK – official facebook group***
2. Click the ***+ Join Group*** button at the top of the page
3. You'll be asked a few screening questions – check your Facebook messages and don't forget to check the '***others***' folder
4. Once you've answered these questions, which are designed to protect privacy and make sure only people affected by PH are part of the group, ***you're in!*** 😊
5. Post questions, comment on other posts, or simply read what other people write. ***Use the forum your way.***

OVER 1,400 GROUP MEMBERS!

ME & MY JOB

Meet **John Harrington**, Ward Manager at the Sheffield Pulmonary Vascular Disease Unit. John took over the role from *Paul Sephton*, who is now the PHA UK's Research and Development Coordinator.

WHAT LED YOU TO YOUR CURRENT ROLE? *I started in vascular surgery in 2008 when I qualified, and it gave me a great basis for my career. Five years later I transferred to a cardiothoracic high dependency unit, where I was appointed to my first charge nurse post. Within a few years, I felt ready for a fresh challenge that would use some of my previous skills, and that's what brought me to the unit in Sheffield. Pulmonary hypertension is such a complex but rewarding area to work within and I'm lucky to be part of a great team.*

WHAT DOES A TYPICAL DAY LOOK LIKE FOR YOU AT WORK? (BEFORE AND DURING THE PANDEMIC) *The key features of my day remain the same, even throughout the challenge of Covid-19. My days can vary however, generally consisting of leading patient care on the ward, whilst balancing management responsibilities such as staffing, budget management and service improvement/updates in clinical practice. My role focuses on ensuring that everyone has what they require to work efficiently and effectively. I ensure that the clinic and elective capacity, with flow of up to 30 patients through this area each day, is maintained. This has been one of the biggest challenges throughout Covid-19; adapting our practice to provide a digital approach to the service.*

WHAT DO YOU ENJOY MOST ABOUT YOUR JOB? *I enjoy knowing that we can make a difference and rising to a challenge. It's like a jigsaw – and I love to solve a problem! The variety of clinical care and management responsibilities make my role enjoyable too.*

WHAT'S ON YOUR DESK? *Lots of post–it notes as reminders - and a coffee machine!*

TEA, COFFEE OR WATER? *All of them. I probably have too much tea and coffee, which is why there is a need for a coffee machine in my office. If I am out for drink, it's usually a flat white.*

CAN YOU TELL US A BIT ABOUT YOUR FAMILY AND WHAT YOU LIKE TO DO OUTSIDE OF WORK? *I have a beautiful wife, who is also a senior nurse. It's nice to have someone who understands the stresses of the role and provide moral support. I have two young children, George (7) and Evelyn (6) and a dog called Stanley. I enjoy mountain biking and running and I also occasionally play a round of golf... badly, some might say!*

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

John is undertaking a sponsored slim challenge with PHA UK chair Iain Armstrong.
See p11 for details

Off the beaten track

PHA UK member *Sarah Marshall* was frustrated by the difficulty of enjoying the countryside where she lives – so she found a solution. This is her experience of taking the plunge with an off-road scooter.

Sarah and her dog Lottie – who she can now follow into fields!

Sarah and her **TGA Vita X** off-road scooter

“After seven years of illness, craving the countryside and missing out on muddy walks, I finally got my own off-road scooter. At last, I get to join my husband and my dog on their adventures.

Phil and I live in a beautiful, small village in South Northamptonshire. We love it here. It's the epitome of rural England, with its Cotswold stone houses, 17th century thatched pub, and tractors trundling through the main street. We're immediately surrounded by farmland and woods and meadows. Fields of crops and mud and long grass stretch for miles around us, joined together by a network of well-used rutted footpaths.

There's an ancient wood with logs to scramble over, and troughs to run in and out of. There's a hill to sledge down, meadows full of wildflowers, and a couple of rickety bridges over streams. There's a large pond full of geese and swans, and there's even the remains of an iron-age fort. We're surrounded by beautiful English countryside and it's perfect for us.

During the first six months of living here, Phil and I loved traipsing through the mud as we explored. However, shortly after we moved, I developed pulmonary hypertension – and suddenly those same fields became inaccessible to me. ***Overnight, my local countryside became largely unreachable, impassable and off-limits.***

For the past seven years, Phil and our dog Lottie have continued to explore every nook and cranny within a few miles radius of our home – without me. Between them, every footpath has been run down, every stile has been clambered over (or lifted over if you have four paws), and every mole hole studiously sniffed. At least once a day, they disappear together; returning with stories and photos and videos. Clips of Lottie following a scent, splashing through a puddle, running madly. Photos of scampering deer, glorious wildflowers, red kites soaring. Or tales of watching badgers, finding fallen trees, being chased by bulls. They love their adventures, particularly to their favourite bumpy spot – 'The Clumps'.

Although I loved to see them return with muddy paws and muddy boots and waggy tail, it also made me a little sad to have missed out again. ***We tried to get me into the local wilderness. We pushed my wonderful little scooter to its limits; but mud or battery or incline or camber always forced me to stop.*** *Consequently, family dog walks were restricted to hard path and road – just two routes that we alternated. Mud always trumps concrete for Lottie though... she tried to pull me into every field we walked by!*

Even though I loved and missed the countryside, for years I didn't want an off-road scooter. *Initially I lacked the strength and stamina needed to tackle muddy fields, so was perfectly content to stick to solid paths. Later when I grew stronger and more adventurous, I was disappointed with the off-road scooters available. They were amazing at traversing grass and mud and hills and rugged tracks, but I hated the look of them. The few models on offer were all big and bulky and heavy. Tanks. They screamed 'disabled person', they screamed 'different', they screamed 'look at me'. And they needed a big inconvenient trailer to be transported.*

Therefore, in a kind of 'cut off your nose to spite your face' way, I refused to have one. They were also pretty expensive, which helped justify my decision. ***As time passed, my want for wilderness exceeded my dislike of monster tanks and I decided I wanted one.*** *But then I was put on the transplant list, and it seemed pointless as we assumed I'd have new lungs within months. Later, when they paused me on the active list, I still couldn't decide.*

Then I finally agreed, and Phil wanted to buy me one for my approaching 40th birthday. So, we started watching videos, reading reviews, and even test-drove a few models. It was brilliant fun pushing them to their limits; though sometimes to the panic of the salesman! Off-roading when disabled must be niche though, as there are very few models available.

Some hardcore scooters are capable of clambering over big boulders and up very steep inclines. But we couldn't justify paying £17,000 just to reach a mountain summit once a year.

So, we picked a substantially cheaper one that would be perfect for us 99 per cent of the time – the TGA Vita X. It felt the nicest to drive and looks cooler than its compatriots – less tank, more quad bike.

I finally get to join in the adventures, traipse through the mud, and see the bumpy clumps. And when Lottie tries to pull me into a field, I finally get to follow her! ”

Sarah and Phil in 2014

This article is adapted from Sarah's blog. You can follow her posts at **www.wecanadjustthesails.blogspot**

The TGA Vita X starts from around £5,000 for a new model. Visit **www.tgamobility.co.uk**

Playing it Forward

Learning to make musical instruments has helped *Jason Cains* navigate his grief following the loss of his wife – and given him a new career to boot. Here, he shares his journey.

Struggling without yoy

“Sarah and I were childhood sweethearts. We met each other at 16 and by 18 we were married with a baby; it all just felt right. Now I am a widow at the age of 40.

Sarah had just turned 26 when she became ill, and it took over a year for her to be referred for tests for pulmonary hypertension. We didn’t really understand what the diagnosis meant at first and didn’t really contemplate the long-term consequences of it until a couple of years later.

Sarah died 13 years after being diagnosed, in February 2017. It was a complete shock. She died suddenly at home and I couldn’t go into that room for months. I had to move all of the furniture around in the house as I couldn’t stand to see the empty space where she used to sit.

I was angry. Over nothing ultimately, but I felt angry that life hadn’t given her a proper chance. She was a beautiful human being and only had good to bring other people. She helped me so much over the years with my own mental health issues and was always there to pick me up.

I helped her with her physical health issues and she helped me with my mental health issues. That’s how we got by. I miss that.

The loneliness was hard to deal with. I had grief counselling for three months and it was the best thing I did. I am also incredibly blessed with a big circle of family and friends and they were there for me constantly.

A WONDERFUL SURPRISE

For a few years I’ve been tinkering with guitars, taking them apart and fixing them up, and just learning as I went. But as the first anniversary of Sarah’s death approached, my friend Martin gave me a huge surprise – he had used his savings and borrowed money from friends and family to enable us both to take a residential guitar-making course.

He and my sister had organised it all behind my back. They knew it would help me get through the anniversary, and help me learn a new skill that I wouldn’t otherwise be able to afford to train in.

The course is run by Crimson Guitars in Dorset and we went for the three-month residential option, travelling from our homes in Portsmouth to stay in a cottage Monday to Friday. We were surrounded by nothing but sheep and an art gallery; it was beautiful.

Each day between nine to five involved intensive guitar-making in the workshop. **I kept a photo of Sarah on my bench, so she was there with me the whole time.**

ANNIVERSARIES AND FRIENDSHIP

The anniversary of Sarah’s death came a few days into the course. I tried my best to keep going, but about halfway through the day I went back to the cottage and went to sleep for a few hours. It was a very sleepy day, as I just tried to shut it out.

It was also hard on our wedding anniversary, which was just a few days beforehand. And shortly afterwards came the anniversary of her funeral, and then my birthday.

There were a lot of ‘firsts’ to deal with in a short space of time, but Martin and I had made friends by then, so we invited people round to our cottage and tried to keep the place busy.

I met some lovely people on the course. I suffer quite a lot with social anxiety but because everyone there was doing the same thing, it took a lot of the anxiety out of it because we all had something in common.

The course started in January and was due to finish in late April, but we had to stop a week before the end because of coronavirus. I’m looking forward to finishing it when we can.

FILLING THE HOLE

I would be lost if I hadn’t done this course. I spent the last few years of Sarah’s life as her carer, so with that gone, I found myself with little to do.

Making instruments is now what I intend to do as a career. I find it difficult working with the public, and the whole social anxiety thing can be a bit troubling for me. This way I can work from home too, so there are a lot of bonuses.

I’ve been using the skills I picked up on the course to keep busy during the coronavirus lockdown. I’ve been making ukuleles and I have my first build back home too, so I have been playing that. It’s a four-string fretless bass, quite thick and jazzy, and it’s dedicated to Sarah. I have another instrument - that I need to finish - which has her name written in Morse code down the fret board.

Things are much better now, but something I continue to find difficult is being a young widow.

I’m only 40, but the only people around me who really know what I’m feeling are my two nans. Being a young widow is an isolating experience; there is an expectation that young people live a long and happy life and there doesn’t seem to be many support groups.

With my depression, it would have been very easy for me to slide right down after Sarah died. But I had so many people rushing around to support me, even though they were suffering their own grief, and they offered so much love and kindness.

Grief causes a hole and that hole doesn’t shrink – you just fill it. I hope Sarah would be proud of me if she could see how far I have come in the last year.”

Jason would like to hear from other men with experiences of losing a partner. Please email **media@phauk.org** and we will put you in touch.

The POWER OF Poetry

Not everyone is a writer so if putting pen to paper isn't for you, ***reading*** poetry can bring many of the same wellbeing benefits. We spoke to PHA UK member *June Williams* about how it helps her manage stress, stay uplifted and even keep connected to friends.

Poetry has been part of June's life since she was a little girl and now, at the age of 72, it is still a close ally. During times of uncertainty, such as the coronavirus pandemic, it has been a lifeline.

"I find reading poetry out loud very uplifting and at times of stress, I get the poetry books out," she said. *"I find reading aloud helpful as I live on my own. I still have poems in my head from 60 years ago, and they pop up from time to time. A lot of them come from my childhood, from my father, who loved to read funny ones to me."*

June, who is a retired pharmacist, still has her father's poetry book from 1928. She's a big fan of children's poems, counting 'The Owl and The Pussycat' by Edward Lear amongst her favourites.

June likes to share the joys of poetry, and keep connected to people too, by writing out poems and posting them to friends – who then return the favour by sending something back.

She also copies poems onto cards and leaves them on her local vicar's doorstep, and he has left ones on hers in return. June was especially pleased to hear he had passed some of her cards onto his 93-year mother, so the words were spreading even further.

She finds poetry particularly helpful during periods of illness. *"I took my little book of poems in with me when I had to stay at my specialist centre for three days,"* she added, *"and I have read poetry to other people on the ward when I have been in hospital too."*

As well as reading poetry, June has discovered other ways of staying positive during difficult times. Finding knitting therapeutic, she regularly makes newborn baby hats for the hospital which houses her specialist centre, taking them with her to appointments. She also has the following advice for those who find night-time challenging: *"Every night when you go to bed, think of three positive things that have happened during the day. That stops you thinking about the bad things, and it will help you get to sleep."*

Do you find reading poems helpful?

Let us know your favourites by emailing media@phauk.org and we'll share them online.

These are two of June's favourite short poems for reading out loud. Why not give them a go?

KEEP A POEM IN YOUR POCKET

by Beatrice Schenk de Regniers

Keep a poem in your pocket
And a picture in your head
And you'll never feel lonely
At night when you're in bed.
The little poem will sing to you
The little picture bring to you
A dozen dreams to dance to you
At night when you're in bed.
So - -
Keep a picture in your pocket
And a poem in your head
And you'll never feel lonely
At night when you're in bed.

LIFE IS MOSTLY FROTH AND BUBBLE

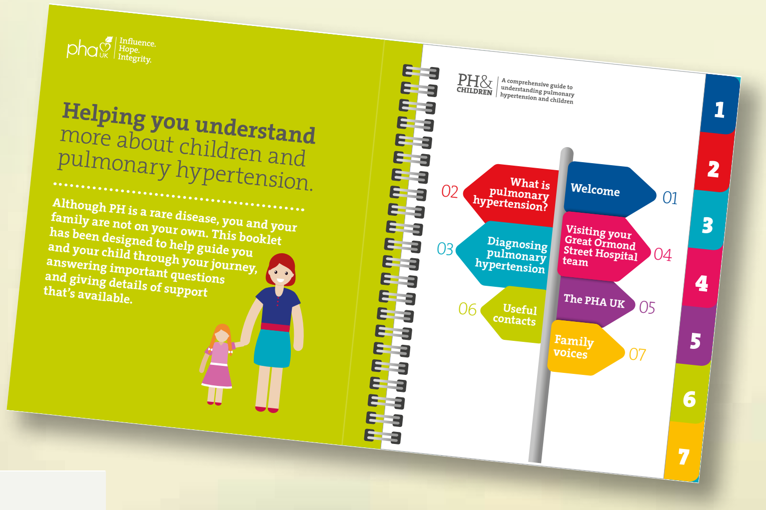
By Adam Lindsay-Gordon

Life is mostly froth and bubble,
Two things stand like stone.
Kindness in another's trouble,
Courage in your own.

PH & CHILDREN

New
RESOURCE

Published with the help of experts in paediatric PH and families living with the condition, this guide aims to help you understand more about pulmonary hypertension and the care and support available.



pha UK Influence. Hope. Integrity.

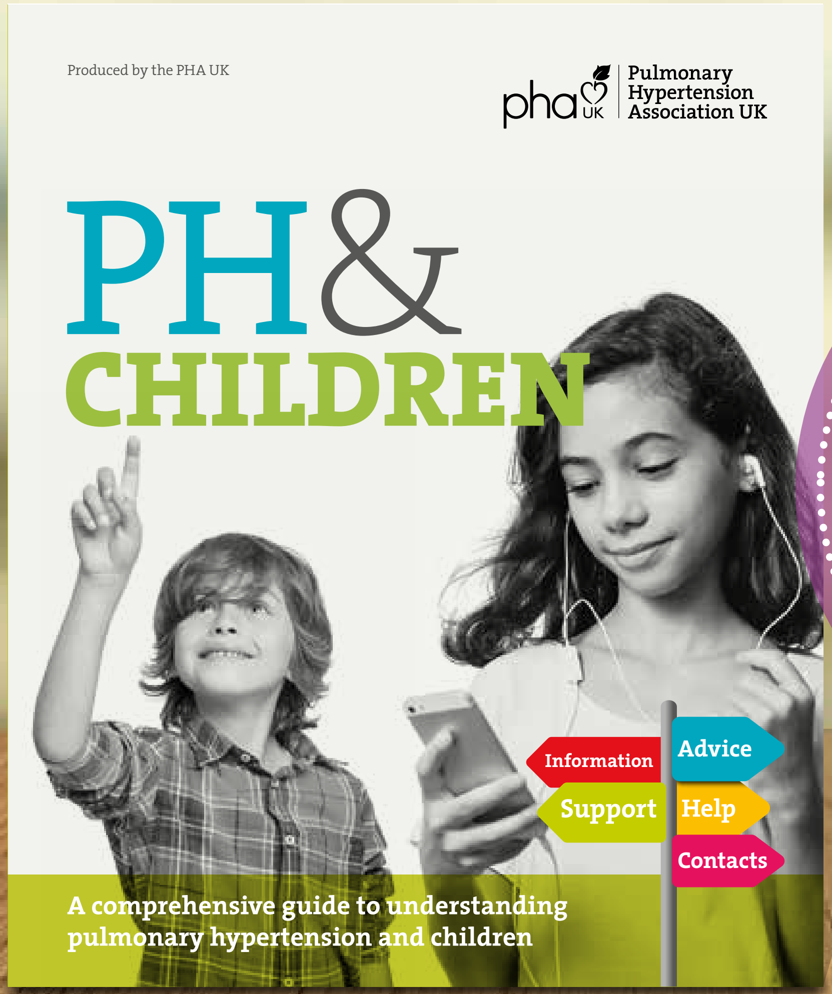
Helping you understand more about children and pulmonary hypertension.

Although PH is a rare disease, you and your family are not on your own. This booklet has been designed to help guide you and your child through your journey, answering important questions and giving details of support that's available.

PH& CHILDREN A comprehensive guide to understanding pulmonary hypertension and children

01 Welcome
02 What is pulmonary hypertension?
03 Diagnosing pulmonary hypertension
04 Visiting your Great Ormond Street Hospital team
05 The PHA UK
06 Useful contacts
07 Family voices

1
2
3
4
5
6
7



Produced by the PHA UK

pha UK Pulmonary Hypertension Association UK

PH& CHILDREN

Information
Advice
Support
Help
Contacts

A comprehensive guide to understanding pulmonary hypertension and children

FREE GUIDE

Order your FREE copy...
www.phauk.org
office@phauk.org
01709 761450

Green Leaf Crew!

4 PAGE PULL-OUT

Kaylee's Column

How to cope in the HEAT WITH PH

Kaylee Mynot is 19 years old and lives in Surrey. She was diagnosed with PH as a baby. In her latest Green Leaf Crew column, Kaylee shares her tips on coping with heatwaves during the summer if you have PH.

When having PH, it can be a lot harder to cope in the heat. The warm weather makes us more tired and breathless due to our bodies working hard to cool us down. Here are my top tips for coping with those hot summer days.

Drink plenty of water

In the heat our bodies use up a lot more water so it's important that we drink plenty of fluids to stop us becoming dehydrated and unwell. Water also helps the body to cool itself down when the temperature is high.

Buy a cool mat

Last year I got a cool mat to put on my bed at night to help me stay cool. The mat turns cold as soon as you put weight on it! I found out about these when my nan got one for the family dog, I thought it was so cool (excuse the pun!), so had to get one for myself.

Wear loose clothing

In the summer I try to wear thin and flowy type clothing and nothing that's going to feel tight on me. I live in jeans and hoodies, so when it comes to the summer, I have to change a lot about the clothes I wear. As much as I dislike wearing things such as dresses and skirts, it's definitely something I need to do in the heat because it makes a big difference when your body isn't confined in clothes.

Keep your room cool

I find it's always essential to have a room in the house that I keep as cool as possible, usually my bedroom. During the day I make sure that the curtains in my room stay closed to stop the heat getting in, and I have a reflective shade on the window. I also make sure the door is closed all day. A cool room makes a big difference!

Kaylee x

If you've got a question for Kaylee, let us know and she'll cover it in the next issue! Email media@phauk.org

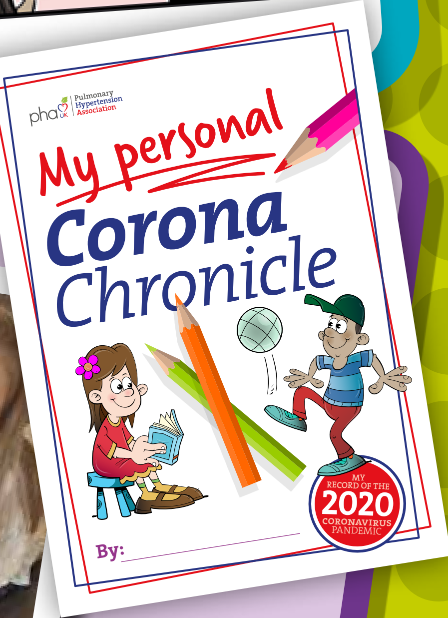
Zoom time...

by David Banks

Corona Chronicle for kids

Whilst living through the coronavirus crisis, you've been living through history! We put together a 'Corona Chronicle' journal featuring the Green Leaf Crew to help children keep a record of the time, write down thoughts and feelings, and have fun with puzzles too.

The journal is still available to download and print from our website - just visit www.phauk.org or email office@phauk.org if you don't have a printer.



Emily, who has PH, enjoyed filling in the Chronicle

Ready... set...bake!

BANANA ICE CREAM SANDWICHES

A delicious mix of peanut butter cookies with ice cream made from frozen bananas – yum! You'll need to ask an adult to help with this one. (Recipe and image courtesy of BBC Good Food).

INGREDIENTS

200g peanut butter (crunchy or smooth is fine)
175g golden caster sugar
75g dark chocolate, chopped into chunks
1 large egg

For the ice cream

3 bananas, peeled, chopped and frozen in advance
2 tbsp double cream
1 tsp vanilla essence

METHOD

1. Heat oven to 180C/fan 160C/gas 4 and line two large baking sheets with baking parchment. Put the peanut butter, sugar, 1/4 tsp fine table salt and chocolate chunks in a bowl and mix well with a wooden spoon. Crack in the egg and mix again until the mixture clumps together and forms a dough.

2. Break off chunks of dough (about the size of a cherry tomato) and arrange them, spaced apart, on the sheets. Press the cookies down with the back of a fork to squash them a little. (The cookies can be frozen for up to two months – to cook from frozen, add an extra 1-2 mins to the cooking time.) Bake for about 12 mins until golden around the edges and paler in the centre. Leave to cool on the trays for 5 mins.

3. Meanwhile, put the bananas, cream and vanilla in a food processor and blend until they make a thick ice cream. Scoop into balls with an ice cream scoop, and sandwich between the cookies.

Serve immediately and enjoy!

Lilia's support for PHA UK

Ten-year-old Lilia Sayer from Farnborough in Hampshire put her baking skills to the test to raise money for the PHA UK. Despite fracturing her foot the day before, the young fundraiser went ahead with her bake sale at Guillemont Junior School to raise £260, all in support of her grandma who lives with PH.

Lilia sent us this letter about the event:

DEAR PHA UK

The cake sale did indeed go ahead and we managed to raise £260. From the cake sale we made £100.60 and the rest from donations from friends and family. We were also lucky to have this amount matched by E.ON Control Solutions Limited who my mum works for. In the cake sale we also used the items from the fundraising kit PHA kindly gave us to use which sold very quickly. I was very happy to see other children be interested in PH and the information packs were taken for them to read. Usually in my school we have an information assembly before the sale where you talk about the charity you are fundraising for. To me I felt really pleased to spread the word to families in the school about this rare condition.

Yours sincerely

Miss Lilia Sayer
age 10

THE BEST Garden Games TO PLAY THIS SUMMER

If you have a garden, it's likely that you will be spending a lot of time in it this summer. Here are some of the best games you can play with your family.

Blanket Run

All you need for this game is an old blanket. One person sits on the blanket and holds it tightly, while the other person pulls them along as fast as they can. When you get to the end of the garden, swap roles and race back. First blanket back to the start wins!

SARDINES

We've all heard of hide and seek, but this game is the opposite! One person goes and hides while everyone else counts to 10. If you find the person hiding, you join them. The last person to find the hiding place is the loser.

SPUD

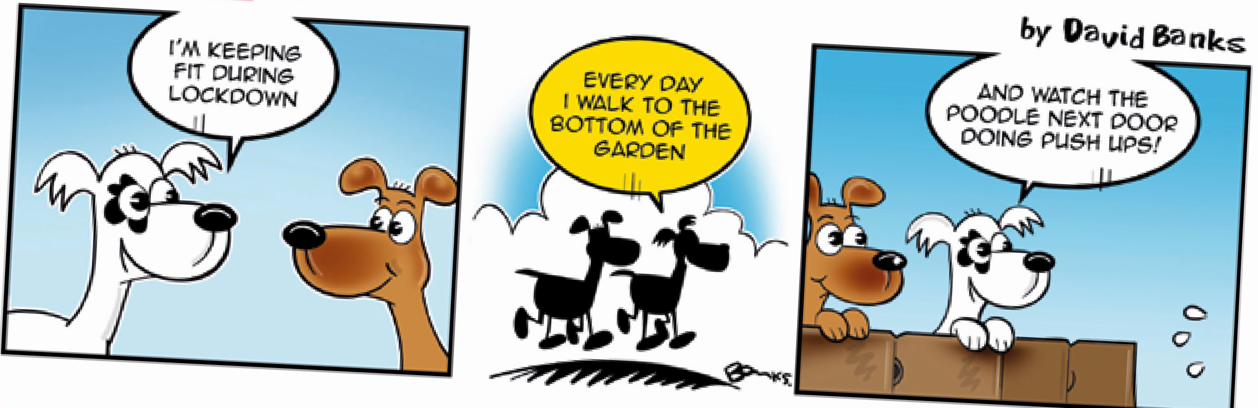
This game just requires a small ball. Each player crowds around the person who is 'it' for that round. 'It' then tosses the ball straight up and the other players run away. As the ball reaches its highest point, 'it' calls out the name of one of the other players and then runs away. The player whose name was called must run back and catch the ball, or chase after it if it has bounced. Once that person has the ball, they shout 'Spud!' and everyone else must freeze. The person with the ball must try to hit one of the players with it. If they do, that new person gets a letter (first S, then P, then U, then D) and is now 'it.' If they miss, the person who threw the ball is 'it' for the next round.

Red Light, Green Light

This game doesn't require any objects, so anyone can play it. One person is designated as the 'traffic light.' The traffic light stands with their back to the other players, who stand 5-6 metres away from them. The traffic light shouts 'green light!' which means the other players can begin moving towards them. Then the traffic light yells, 'red light!' and turns around. If any player is caught moving when the traffic light turns around, that player is out. The game is over if all the players are out before anyone reaches the traffic light or if someone tags the traffic light. If a player reaches the traffic light, that person gets to be the traffic light in the next game.

Patch

by David Banks



PHA UK LOTTERY • PHA UK LOTTERY •

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

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

- Choose to play as many times you like.
- Cancel when you want.
- No need to claim – if you win you'll automatically be sent a cheque.

WIN UP TO £25,000 EVERY SATURDAY AND HELP THE PHA UK AT THE SAME TIME

SIGN UP TODAY!

Visit www.phauk.org and search 'Lottery' or call 01709 761450

The PHA UK Lottery is operated by Unity Lottery. 50p of every £1 goes directly to the PHA UK with the rest covering prize winnings and administration costs. To contact Unity Lottery call 0870 050 9240. Unity is operated by Sterling Management Centre Ltd, registered as an External Lottery Manager by the Gambling Commission under the Gambling Act 2005 - www.gamblingcommission.gov.uk PHA UK Registered Charity No. 1120756

unity

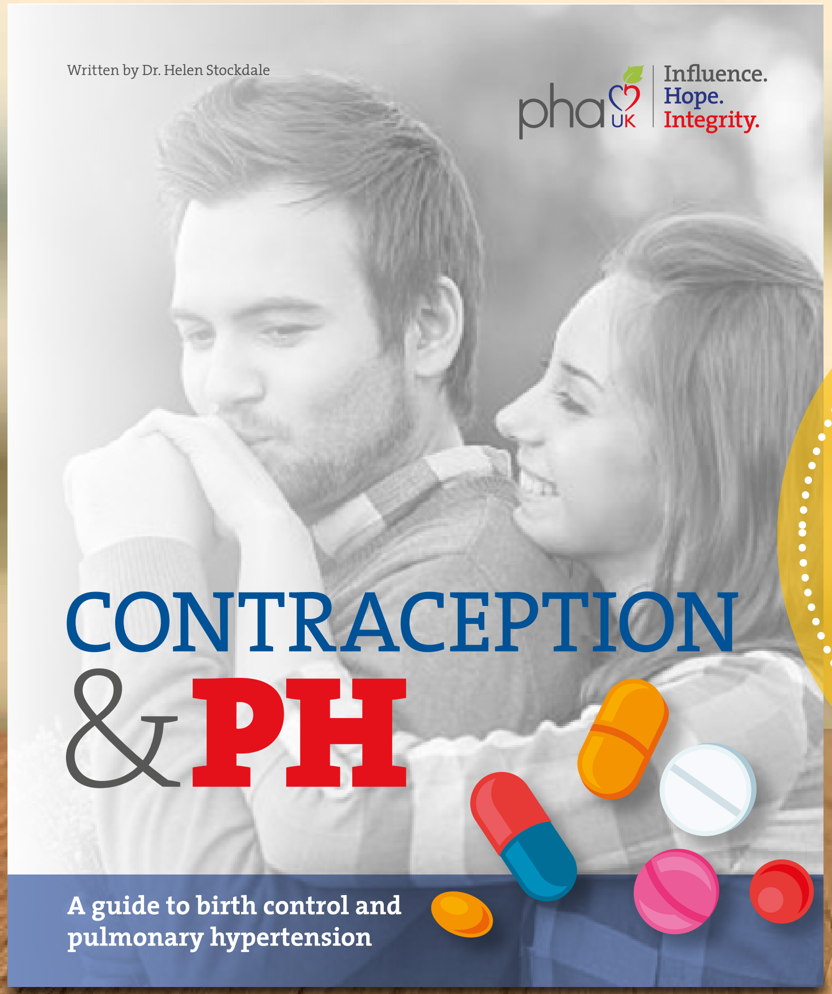
Contraception & pulmonary hypertension

Now AVAILABLE

A comprehensive guide to birth control and PH.

Contraception, and the whole issue of pregnancy and PH, has changed a lot over the last 20 years. We've worked with experts to produce a guide that brings you the facts about birth control to help you make the decisions that are right for you.

Order your FREE copy...
www.phauk.org
office@phauk.org
01709 761450



Written by Dr. Helen Stockdale

pha UK Influence. Hope. Integrity.

CONTRACEPTION & PH

A guide to birth control and pulmonary hypertension

This book is supported by a trio of short films offering expert advice around contraception. Visit www.phocusonlifestyle.org to view them online.

FREE GUIDE

The University Of Sheffield.

To register your interest in being part of this study, please email Paul at **paul@phauk.org** or call him on **01709 761450**

Managing anxiety, panic & worry with PH

We're playing a key role in the development of a new resource to help people with PH manage anxiety, panic and worry. *Paul Sephton*, Research Support and Development Coordinator at the PHA UK, explains more.

We know that living with pulmonary hypertension can have a significant impact on mental and emotional wellbeing. In fact, research we carried out last year showed 92 per cent of people feel their emotional wellbeing has been affected, and 53 per cent have experienced or been diagnosed with anxiety or depression.*

As well as providing support to our members via our partnership with Anxiety UK (see p14 for details), we're now partnering with psychology researchers at the University of Sheffield to pilot a self-help intervention aimed at helping people with PH manage their feelings and emotions.

The intervention, which will initially take the form of a printed resource, is based on a type of therapy called Cognitive Behavioural Therapy (CBT), used widely to help people experiencing difficulties with their mental health.

CBT can help you make sense of overwhelming problems by breaking them down into smaller parts, and this resource will include information about pulmonary hypertension and anxiety and how the two can interact. It will also feature a range of techniques and skills to help you to better understand and cope with symptoms of anxiety - such as excessive worry, fear, panic, nervousness and stress.

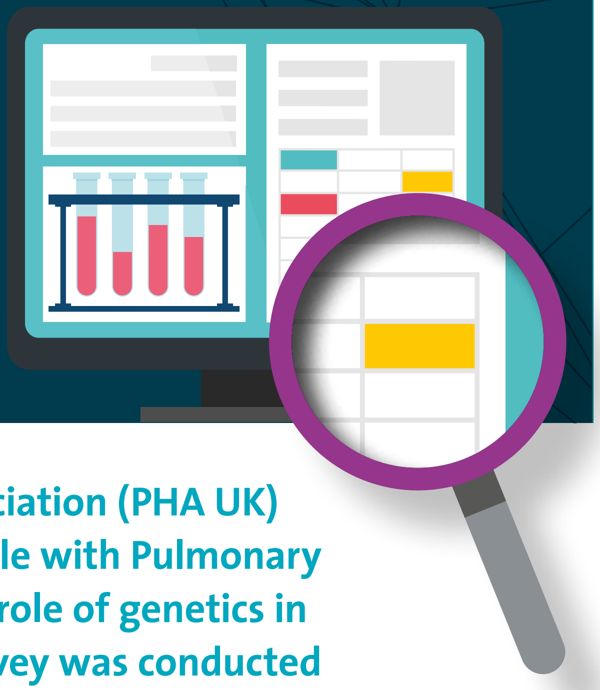
We'll be asking a group of volunteers to test the resource, as the aim of the study is to understand whether this type of intervention is an effective way of helping people. If you would be interested in being part of this pilot, please contact me using the details in the box at the top of this page.

We'll bring you more information on this in the next issue of Emphasis and will update you via our website and social media channels as things progress. ●

---

*'*The True Emotional Impact of Pulmonary Hypertension*' 2019. The full findings are available to view at **www.phauk.org**

Genetics and PAH
Research findings



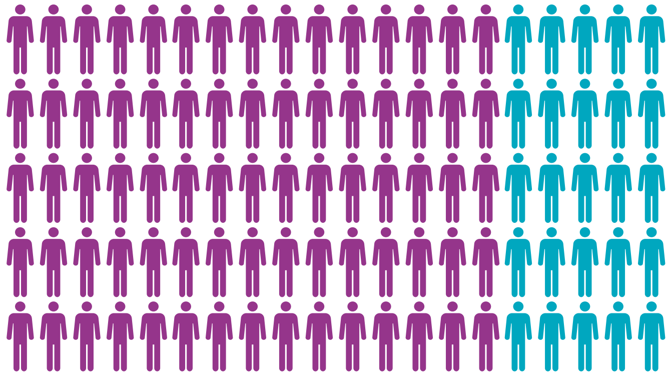
Earlier this year, the Pulmonary Hypertension Association (PHA UK) conducted an online survey to ascertain what people with Pulmonary Arterial Hypertension (PAH) understand about the role of genetics in PAH, and to identify any information gaps. The survey was conducted in collaboration with *Professor Nick Morrell*, British Heart Foundation Professor of Cardiopulmonary Medicine at the University of Cambridge.

HOW THE SURVEY WAS CARRIED OUT: *METHOD AND RESPONSES*

Online survey tool SurveyMonkey was used to carry out the research. Participants were recruited via the PHA UK's social media channels and via an e-newsletter.

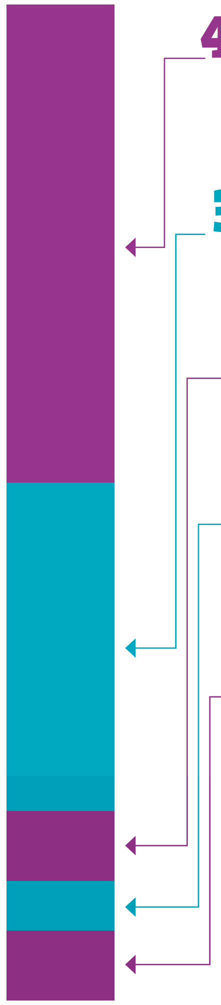
The survey consisted of 11 questions, with space for additional comments at the end. It was open for two weeks and only those with a diagnosis of Pulmonary Arterial Hypertension (PAH) were asked to respond.

207
PEOPLE RESPONDED



75% were female

25% were male



48% had idiopathic PAH

33% had PAH connected to another health condition

7% had hereditary (familial) PAH

5% reported a 'different type of PAH'

7% of respondents said they didn't know what type of PAH they had

The findings

AWARENESS AND UNDERSTANDING

50% of respondents were not aware that PAH can be linked with a fault in genes.

40% of respondents have had a discussion with a healthcare professional about the links between genetics and PAH, and the research and studies around it. ***Of those people, just 39% said they understood what was being discussed.***

INFORMATION NEEDS

78% feel there is not enough information available to them about the links between genetics and PAH, and the research and studies around it

98% of respondents said they would find clear and accessible information produced by the PHA UK vital, very useful, or useful. ***(31% vital, 49% very useful, 18% useful)***

GENETIC TESTING

74% respondents said they would want to be referred for genetic testing if they knew there was a chance of their PAH being caused by a faulty gene. ***20% said they 'don't know'***

80% of respondents said that if they found out they had a faulty gene causing PAH, they would want their family members to be offered genetic testing. ***19% said they "don't know"***

WHAT NEXT?

The results of this survey show a strong desire amongst people affected by PAH to understand more about this important subject. There is an obvious need for clear and accessible information. The PHA UK will now work with leading UK experts to produce resources that meet this need and that can be shared with family and friends. We would like to thank everyone who took part in our survey.

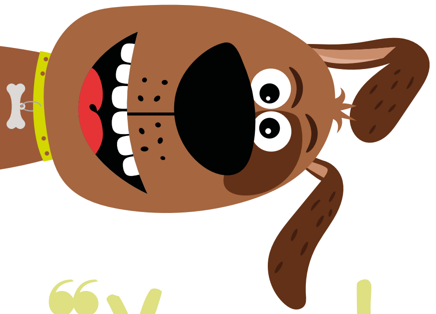
Iain Armstrong
Chair, PHA UK

We have known for some time that there is often a genetic cause for PAH, especially if more than one individual is affected in a family. This study is the first of its kind in a large patient population, and I'm delighted that the PHA UK has carried it out. The results show just how important the issue is to people affected by the condition. Ongoing research by experts is showing the importance of genetics in pulmonary arterial hypertension. It's important that more work is carried out to engage the patient population and their families to ensure the best care and management - for both the present and future.

Professor Nick Morrell
British Heart Foundation Professor of Cardiopulmonary Medicine

If you have any questions about this survey, please contact the PHA UK on 01709 761450 or media@phauk.org

In May we conducted a follow-up online survey to discover which subjects you wanted covered in the information materials we produce – and what format these materials should be in. *Thank you to everyone who responded. Watch this space!*



“You don’t have to give up your life because of PH”

Pamela Bayley has dedicated her life to dogs, and pulmonary hypertension hasn’t stopped her from enjoying them. She wrote this article to share her story of adjustment, prioritising, and how her furry friends have helped her through the bad times.

Six of Pamela's dogs - from left to right - Rooney, Fudge, Pepsi, Pippa, Daisy and Rolo

The other two of Pamela's dogs, Jake and Jonty

“Dogs have always been a part of my life. I was born in Derby and when I was a baby my mum would take me for a walk in my very large pram with our Yorkshire Terrier, Vicky.

Stopping at the local shop she would park me outside (you could do that in those days!) and put Vicky in the end of the pram knowing I would be protected while she shopped. I have loved that breed ever since.

I cannot remember a time when our family did not have a dog. They were usually ‘cast-offs’ from other people, and I have carried on the tradition.

My four-legged family

My husband and I moved 30 years ago to live somewhere with a field, taking five dogs with us, and we have never had less than that number. The most we have had was ten, and over these decades we have fostered or adopted from local rescue centres. For the last 14 years it’s been from our local RSPCA.

I seem to end up with the old ones no one wants, or ones that have ‘issues’! Sometimes if they are old, they are only with us a couple of years. Others are with us longer, but if I started on their stories, I'd never finish this article!

I have also helped to run a local dog club for the past 25 years, instructing the puppy class. We run eight classes over two nights and are very busy.

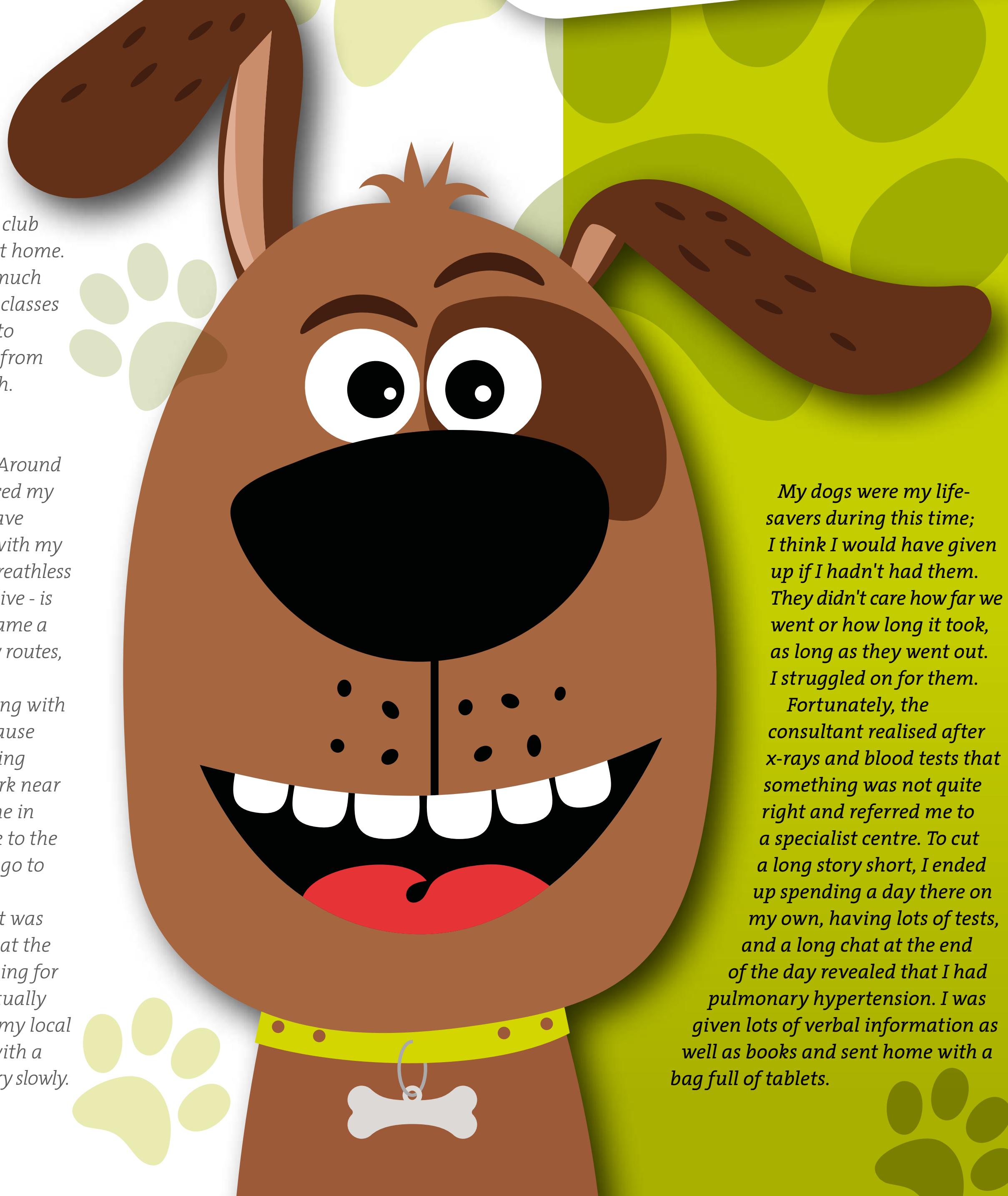
For the last 15 years I have also been teaching fun agility for our club members in our small paddock at home. It’s lovely in summer but not so much in winter. Recently I have cut my classes from four or five per week down to two because my PH prevents me from standing out in the cold too much.

Getting my diagnosis

So, now we come to the PH bit! Around 12 years ago when I retired, I noticed my breathing was not quite right. I have always loved walking, especially with my dogs, and realised I was getting breathless going up hills. As Wales - where I live - is not known for being flat, this became a bit of a problem! I had to plan my routes, so they were not all up or down.

As it got worse, I stopped walking with friends as I felt embarrassed because I was slowing them down. Shopping became a problem; I learnt to park near the trolley park so I could take one in with me and not have far to walk to the car after. I decided it was time to go to my local doctor.

After two years of telling him it was not COPD or Emphysema, and that the inhaler he gave me was not working for the asthma I hadn't got, he eventually referred me to the chest clinic at my local hospital. By then I was walking with a stick, managing about one mile very slowly.



My dogs were my life-savers during this time; I think I would have given up if I hadn't had them. They didn't care how far we went or how long it took, as long as they went out. I struggled on for them.

Fortunately, the consultant realised after x-rays and blood tests that something was not quite right and referred me to a specialist centre. To cut a long story short, I ended up spending a day there on my own, having lots of tests, and a long chat at the end of the day revealed that I had pulmonary hypertension. I was given lots of verbal information as well as books and sent home with a bag full of tablets.

Adapting to life with PH

The meds had an almost instant effect on my breathing, but it took me a lot longer to get my head round all the information. I have never been a ‘pill popper’ and I found it hard taking tablets at a regular time each day. If I went out, I had to remember to take them with me. I'm more organised now but it took a long time to sort myself out.

Apart from a few friends and family I didn't tell anyone about the PH, I just set about getting myself and my dogs fitter. We gradually lengthened our walks, still going slowly - especially up the hills - but you do see more of the scenery when you have to stop to get your breath!

Three years on I walk at least two miles each day, sometimes four, and very occasionally five or six. I usually walk in the mornings as I have more energy and then I rest for at least one hour at lunch, sometimes longer. My dogs enjoy this routine, and then we have a short walk around 3pm. The meds have enabled me to carry on with instructing my classes at the dog club - although I do get very tired and I am in the process of handing over some of the responsibilities to the younger people.

Because I felt ‘better’ thanks to the meds, I initially thought I could do all the things in a day that I used to. Gradually I've realised I have to 'prioritise' (a very popular word!). Dogs and I are most important - does it matter if there is a bit of fluff or dog hair floating round the kitchen floor? No, it doesn’t! My mop only gets an outing when I have the energy and my dusters are collecting dust in the cupboard.

We have eight dogs at the moment, four who are very elderly and need very little exercise. In fact, one sleeps under a blanket most of the time and only comes out for dinner and a wee! The other four go walking with us to the beach or the woods.

I am doing the things I enjoy, getting out in the fresh air with the dogs and meeting people when we're out. It’s amazing how many people will stop and chat if you've got a dog, but they walk by you if you haven't.

I have always been a busy person and find PH quite frustrating, but you don't have to give up your life because of it, you just need to adjust. My attitude now is that I can do things, they just may take longer. I may be tired, but I can still do it.”

DO YOU HAVE AN ANIMAL THAT HELPS YOU WITH YOUR PH?

We’d love to hear your stories – and see your photos too! Please email
media@phauk.org

Making memories

Before the coronavirus pandemic, PHA UK member *Pam Hodkinson* enjoyed regular short breaks around Britain with her husband *Mike*. As she looks forward to a time when travelling can resume, she looks back on some special memories – and shares her advice for others hoping to holiday when they can.

> *I was diagnosed with PH in 2018 after a gradual decline to the point that I was unable to even wash my hair without becoming severely breathless. In the 15 months prior to being referred to my specialist centre, the decline was so pronounced that my family and I were fully expecting that I would die before the end of the year. At that point I certainly never thought I would go on a holiday or a short break again. But with the incredible kindness, support and treatment from my PH team, things have become more manageable and I try and get as much out of life as I can.*

TURN OVER FOR MORE >

Making memories

A ferry crossing at Oban, during one of Pam and Mike's favourite holidays in Scotland

Domestic bliss

“When I became ill, I composed a ‘ucket list’, which included a hot air balloon ride, driving a boat across Windermere, riding a steam train, riding a horse and going to a Star Trek convention. These boxes have been ticked and I keep adding to the list, including going on different holidays.

My husband Mike is also ill, with neuromuscular disease, reactive arthritis and a heart problem, but in healthier times we had many ‘typical’ family holidays, including trips abroad as well as in the UK.

The logistics and holiday insurance costs are too much to consider going abroad now, so we stay domestic. Plus, I'm not sure I would have the confidence; if one of us becomes unwell when we are on holiday in the UK we can just go home early - and that gives us reassurance.

We generally choose holidays in detached properties that are quiet and either single storey or with downstairs bathing and sleeping facilities. It's also important that the property is warm, because of the additional Scleroderma and Raynaud's that I have.

Some days I don't feel well enough to leave the property so I always like to have a nice view to admire from a window. Our other must-haves are access to a good chippy, proper cappuccinos, and local homemade ice cream!

We don't stay in hotels as I generally have poor sleep due to my breathing issues and Mike requires portable medical devices that are quite noisy through the night -so we would be concerned about annoying other guests.

Planning ahead

We keep an extensive checklist on the laptop of things that we need to take with us when going away. Most items can be stored in plastic storage boxes throughout the year and are ready to go when we are, so that we don't feel overwhelmed at the thought of preparing for a holiday. It also makes it easier to book things last-minute.

We always plan ahead and use online home delivery grocery services wherever we go, so that we don't need to take food.

We have had one medication hiccup where I forgot to pack my selexipag – and we only realised when we arrived in Cornwall. We investigated same day delivery from Royal Mail but at £500 decided we would drive back for it instead. We were not going to be beaten! The moral of this story is to check and re-check whether you have packed your meds.

From Scotland with love

One of my favourite holidays was in Scotland last year, where we stayed in a property near Argyll and Bute that felt like a rock star's mansion. It had a ten acre garden with a hot tub (pictured right) and from it we could witness sea eagles hunting over the loch and beautiful mountains in the distance.

Forests were a stone's throw away with golden eagles in flight above the peaks. These views were perfect when bad days meant I was limited to being indoors, as I still had a choice of beautiful views to focus on from every room.

Scotland suited our illnesses perfectly as it is no exaggeration to say that around every corner is another lovely view to stop and admire.

Sitting with a bag of chips on my knee, a coffee in my buggy basket and an ice cream in my hand, watching the sun dropping into the sea at Oban was awesome. As was having a red deer eating apples out of my hand... I could go on about this holiday, but it would fill an entire magazine.

A record of our memories

We tend to keep a written daily diary and photo diary of each place that we go to. On New Year's Eve we then put all the photos on a memory stick, pop it in the TV and watch how the year unfolded for us.

It is so easy to convince ourselves we are housebound a lot of the time, and that we don't achieve much because of our illnesses, but the photos prove that we do create good memories. It's the little things like this that help put us in charge of the illnesses, instead of the illnesses being in charge of us.”

“Holidays have been modified rather than lost

MIKE'S VIEW

“When Pam first became ill, we didn't plan anything as her confidence in being away from the house took a hit. We had to build up slowly, with trips just five minutes up the road, and eventually we decided to book a short break so that we had something to hope for.

Our holidays have changed in different ways. In the past we would have been very active, with lots of walking and swimming, and little time to stop and admire the views. Now we do a lot of sitting and watching and we are ok with that.

We throw in the occasional little flat walk dependent on how Pam is, and of course the trusty little mobility scooter is always there.

We have discovered the joys of fishing and Pam likes to sit there watching the wildlife while I attempt to catch a tiddler or two. Holidays have been modified rather than lost. It's surprising how, when you move slow and stop often, you see more.

Our holidays remind us what we fight to live for. Illness often makes us spectators of life rather than participants in it, and it's nice to shake the shackles free every now and then. During those times when we are at our lowest, we can look back on the photos and videos and they remind us what we have achieved. Mentally that makes a real difference to our lives.”

OUR ADVICE FOR happy holidays

“We plan or book holidays even if we think we may not be able to go, as it gives us something to focus on. We never know until the actual day of travel whether we will be going, or how long we will be able to stay, but that's ok for us.

When we plan a holiday but do not manage to go, or have to come home early, then we take the loss and accept it as part of the package. ‘Yo-Yo’ days are common with PH so we just plan and hope for the next opportunity.

THESE ARE OUR OTHER TIPS FOR UK HOLIDAYS WITH PH:

- *Plan plenty of stops along the way. Toilet breaks are a must because of our water tablets and regular stops break the journey into manageable chunks to stop it becoming overwhelming.*
- *Keep a holiday box prepared in advance. This means you can go on last-minute trips without the daunting feeling of having lots of things to get ready.*
- *Keep a daily diary of places that you go to. Use it with photos to look back on the holiday and it may remind you that you did more than you remember. Illness can be an overwhelming cloud that just sits above you and stops you focusing on anything else, so this way you're ensuring time doesn't get lost along the way.*
- *Pack light. Don't take lots of unnecessary clothes and items with you. We take very little and just use the washer and drier facilities in the properties we rent. Don't forget your medications!*
- *Research the location. Make a list of the places you would like to visit while you're away, and check whether they are accessible. Look up the local health facilities in case of emergencies and make a note of their numbers.*

Days out, or even afternoons out, are just as important as holidays. Sometimes we just drive to our nearest coast or woods and watch the scenery, and if we do it two days in a row it feels like a little holiday in itself. It gets us away from our four walls and provides a pleasant distraction from our illnesses.”

Keeping Maddy's memory alive

The London Marathon might have been postponed, but PHA UK supporter *Sophie Morris* is determined to keep on running for childhood friend *Maddy Hardman*. Here, she explains how their friendship group is keeping her memory alive by spreading awareness of pulmonary hypertension and raising money to support others.

Chloe completed her first ever triathlon alongside her Dad for the PHA UK

One of Maddy's oldest friends Elle faced her fears and took part in a skydive for the PHA UK

Kate, Sam and Rhiannon spent months training for their London to Brussels charity cycle ride

Maddy with her friends

You can support Sophie's fundraising for the PHA UK at **www.justgiving.com/fundraising/sophiemorris21**

Sophie having completed her first ever 10K race a month into her marathon training.

*“**I met Maddy at secondary school, and as part of a group of girls who used to get the school bus in together each morning, we quickly became friends.***

She had the most mesmerising long, flowing waist-length blonde hair, an incredibly angelic singing voice and a quirky fascination with skulls which always used to make me laugh.

Maddy was one of those effortlessly funny people and we spent many bus journeys travelling into school and back home again in fits of laughter which left our stomachs hurting.

But as we all moved away to various universities and colleges across the UK, Maddy got sick. In December 2014 she was diagnosed with pulmonary hypertension. I'd never heard of PH but was told it affected the heart and lungs.

Maddy was due to have intravenous treatment in January 2016 followed by a lung transplant later on in life, but tragically lost her battle unexpectedly and passed away on 29 December 2015. She was just 20 years old, two months away from her 21st birthday.

Her death was a complete shock to all of us. I knew Maddy was sick but hadn't comprehended the concept of losing her.

Maddy's passing immediately made all of us realise how important it is to not take life for granted and to always challenge yourself and try new things while you are fortunate enough to have the opportunity to do so.

With this firmly in our minds, we set a goal to raise as much money for the PHA UK as possible in memory of our friend and to help others like her.

I imagined writing this having completed the London Marathon which I've been training for over the last eight months, but sadly, due to coronavirus, that has been postponed.

I'd decided to challenge myself to run a marathon as when we were at school, the most exercise Maddy and I ever did was run from the sports hall to the school bus - via the canteen to buy a chocolate brownie!

We were not the most athletic group of girls, and many of us were made to go to fitness club at school after failing to run the cross-country route in a speedy enough time. Maddy of course, although she did not know it at the time, was impacted by her health condition. The rest of us were just lazy!

Starting from scratch following a leg injury, I almost completed the full marathon training plan and have so far raised over £1,000 for the PHA UK.

My wonderful Grandad made it his mission to collect donations from market stall traders, members of his community groups and even the local vicar. And with another few months to go until the marathon at least, I'm hoping to raise even more.

The training so far has been tough, particularly competing with Storm Dennis and Storm Ciara, but at the end of February I somehow battled the elements to make it around 18 miles.

I work as a political journalist, so fitting in running between key Brexit votes, a December general election and the initial outbreak of coronavirus has also been quite a challenge!

As upsetting as it was to hear the London Marathon would not be going ahead in April after all the training, at the beginning of March I had begun to have my doubts over running during the pandemic and I'm glad that the health of the nation has been put first.

Despite my lack of belief that the event would go ahead, I persevered with my training, and it was almost comical when Virgin Money announced the marathon's cancellation just four minutes after I arrived back home following my final 18 mile run!

Although at first I considered still running 26.2 miles on the 26th April from my front door, I realised how important it was to follow the social distancing guidelines and run limited distances in quiet areas. Knowing that those living with PH have been advised to shield reaffirmed this even more.

So, writing this in April, I'm currently ticking along with small runs here and there past our old school and Maddy's memorial tree - and am looking forward to getting back to training as soon as it's safe to do so. But it's not just me running the marathon that has helped to raise money and awareness for PHA UK.

Since Maddy's death, as a group of friends we have raised almost £10,000 in her memory - from Elle crazily jumping out of a plane and completing a sky dive, to Chloe completing a triathlon and Kate, Sam and Rhiannon cycling from London to Brussels.

Plus, Sophie has been selling her amazing home-made candles and cakes at our old secondary school's seasonal fetes and elsewhere.

Nothing we do can bring Maddy back, but we have such wonderful memories together and are determined to continue to raise as much as we can to help others who are in a similar position.

I continue to wear my PHA UK training shirts with pride while I go for some short runs around where I live and I can't wait to wear one on that London Marathon start line, whenever the race may be, to raise awareness for such a fantastic cause.

I am so grateful for the many kind messages of support from members over the past few months and will continue to update people with my progress on social media. But for now, it's time for us all to take care and look forward to better times ahead.”

Intimacy & pulmonary hypertension

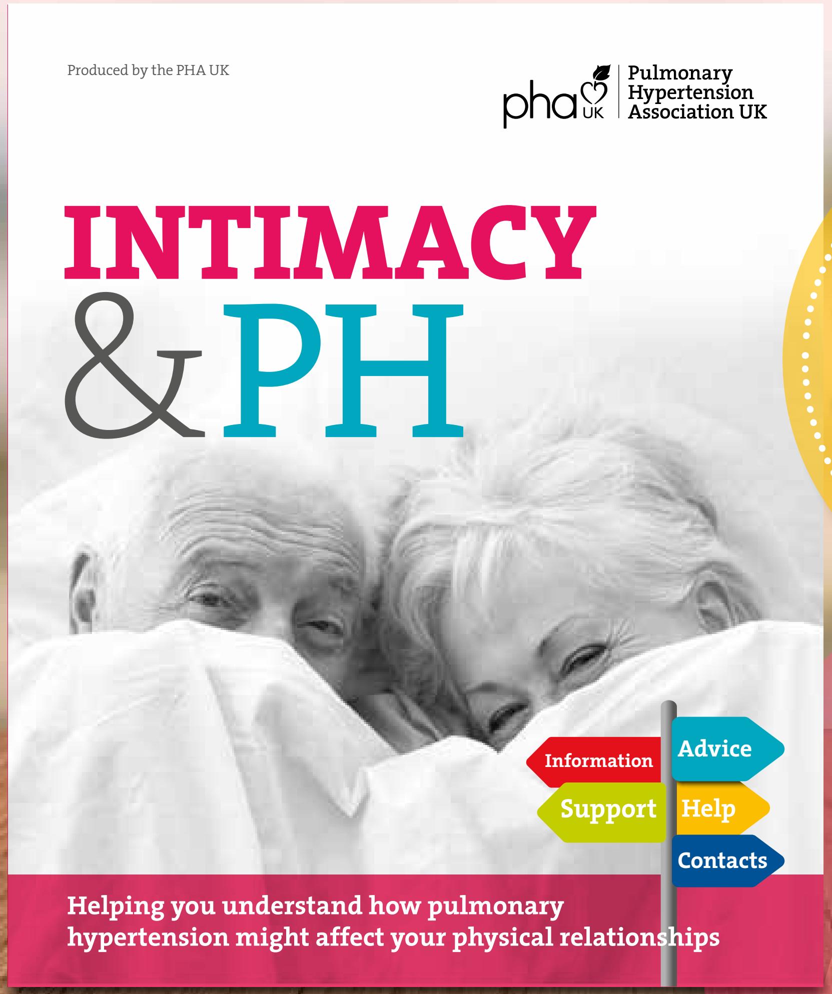
Helping you understand how PH might affect your physical relationships.

Many people diagnosed with a long-term condition will have some issues with intimacy and sex at some point, and even people without an illness can have similar experiences.

This guide explains how PH and its treatments can affect you as a sexual and intimate person and discusses ways of dealing with problems that may arise. After all, you haven't changed – only your health has!

Coming soon!

For any sexual orientation, gender or age


Produced by the PHA UK

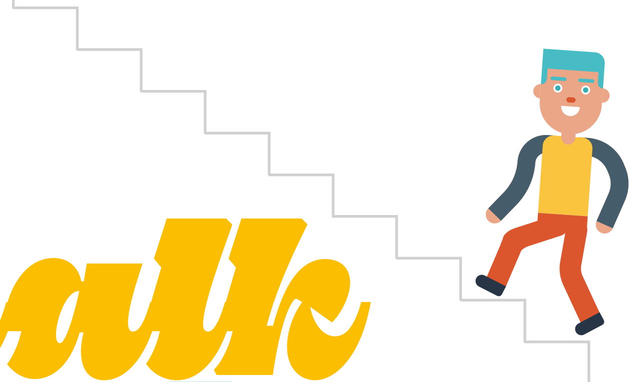
pha UK Pulmonary Hypertension Association UK

INTIMACY & PH

Helping you understand how pulmonary hypertension might affect your physical relationships

Featuring interviews with people affected by PH

Add your name to the waiting list for a copy
Email **office@phauk.org**
or call **01709 761450**.
Copies can be ordered directly from **www.phauk.org** when they become available.



Walk with us

Our virtual event to bring the PH community together

Like most of this summer's sporting events, the Westfield Health British Transplant Games have been cancelled – but we're making the most of the opportunity to bring the PH community together.

The PHA UK had agreed to sponsor the walking competition at this year's games, so on the day the event was due to take place, we are inviting you to walk with us - wherever you are – in the virtual company of our PH family.

When?

Saturday 1st August 2020 at 1pm

Where?

Anywhere you can!

You could complete laps of your garden, pace up and down the stairs, or stroll around your local area if you're able to get outside. You can even walk on the spot in your living room.

How Far?

It's completely up to you!

The official walk event at The British Transplant Games is a choice of 3km or 5km, but there are no rules here. Walk for as long as you like or as far as you can manage, knowing there are hundreds of others touched by PH who are doing the same thing at the same time.

The aim of this event is to encourage a sense of togetherness at a time when some people may be feeling alone.

If, however, you would like to take the opportunity to raise money for our charity, every penny will be appreciated. Perhaps you could make a donation after your walk, or invite friends and family to sponsor your endeavours? For advice or a fundraising pack, please call **01709 761450** or email **helen@phauk.org**

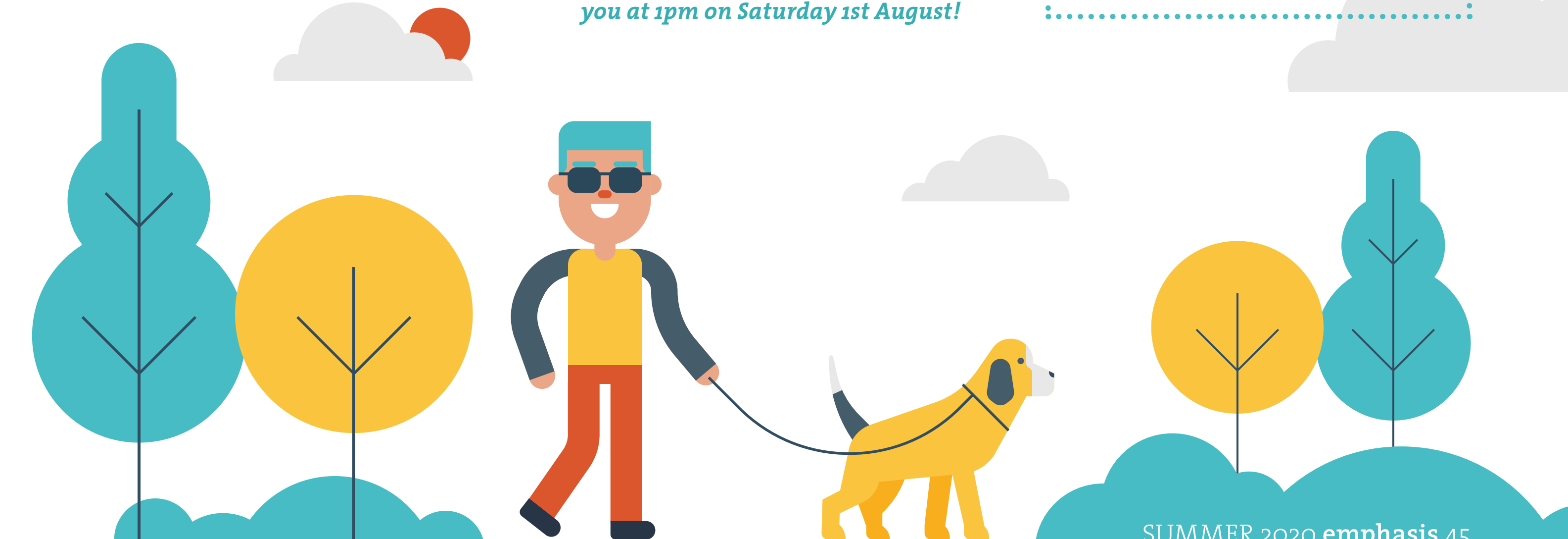
We're looking forward to walking with you at 1pm on Saturday 1st August!

Together FOR THE JOURNEY

*Share your walking photos on social media using the hashtag **#WalkWithUs** – and don't forget to tag us in! You can also email photos to* **media@phauk.org**

the Westfield Health
BRITISH
TRANSPLANT
GAMES

The Westfield Health British Transplant Games were due to take place in Coventry from 30th July until 2nd August. They will be held in Leeds next year and will return to Coventry in 2023.



Exercise with PH

Last year, the PHA UK supported post graduate student *Siobhan Haran* to carry out a study of physical activity levels amongst people with PH – with the ultimate goal of improving advice and treatment. We caught up with her to find out what happened.

CAN YOU EXPLAIN A BIT MORE ABOUT WHAT THE STUDY SET OUT TO DO?

This research was conducted to explore the physical activity levels of people with pulmonary hypertension. This was assessed using both a questionnaire (the International Physical Activity Questionnaire Short Form – known as the IPAQ-SF) and by asking volunteers to wear an activity monitor for one week.

We then looked at whether there was any difference between the activity levels recorded by the monitor and the amount of activity the volunteers self-reported when completing the questionnaire. The study also aimed to identify whether the volunteers with PH were meeting the UK government recommendations for physical activity of 150 minutes per week.

WHY DID YOU CHOOSE THIS SUBJECT FOR YOUR STUDY?

There is very little evidence showing what activity levels people living with PH are achieving and whether this links in with what is being self-reported. There is also not much evidence to say what the best way is to improve activity levels, and what the 'best' type of exercise for people with PH is.

SO, WHAT DO THE RESULTS OF THE STUDY SHOW?

The results show that there was no link between the assessed severity of pulmonary hypertension and either the activity levels the volunteers recorded using the questionnaire, or the activity levels recorded using the activity monitor.

There was a link between the activity category produced by the questionnaire (low, moderate or high activity levels) and the amount of time the volunteers spent being active - as recorded by the activity monitor. For example, patients that were being more active and doing more steps, tended to have a higher activity level rating on the questionnaire. This may mean that the activity questionnaire we used might be an accurate tool to identify activity levels in people with pulmonary hypertension.

Over the week that the volunteers wore the activity monitor, almost 82 per cent of the 11 patients participated in the recommended 150 minutes of moderate physical activity. ***This is great news!***

Despite this, the overall physical activity levels of the volunteers that participated in this study were deemed to be low in terms of their daily step count. A high level of participation in sedentary-based activities were also recorded, meaning there may be more work to be done in promoting safe physical activity for people living with pulmonary hypertension.

WHAT HAPPENS NEXT?

As this study only involved a small number of people, the results can't be generalised to all patients with pulmonary hypertension. Further work with more patients would need to be done to prove the link between the IPAQ-SF questionnaire and measured activity levels.

It does, however, provide a good basis for future work investigating the best way to monitor and assess physical activity in patients living with PH.

The IPAQ-SF may also be useful for measuring patients' response to medical treatment, both in research trials and in the clinical setting. This knowledge will help to improve the advice and treatment we provide to patients.

HOW IMPORTANT WERE THE PARTICIPANTS TO THIS STUDY?

The participation of the patients, all of whom were recruited by the PHA UK, was hugely important to be able to further research and gain insights into a small population within respiratory medicine. To be able to treat and support patients with PH in a more tailored way to meet the needs of their condition is invaluable.

I am extremely grateful to those who volunteered to participate; they generously gave up their time to engage with the study and to allow the results produced to be possible.

> “*I am extremely grateful to those patients who volunteered to participate*”

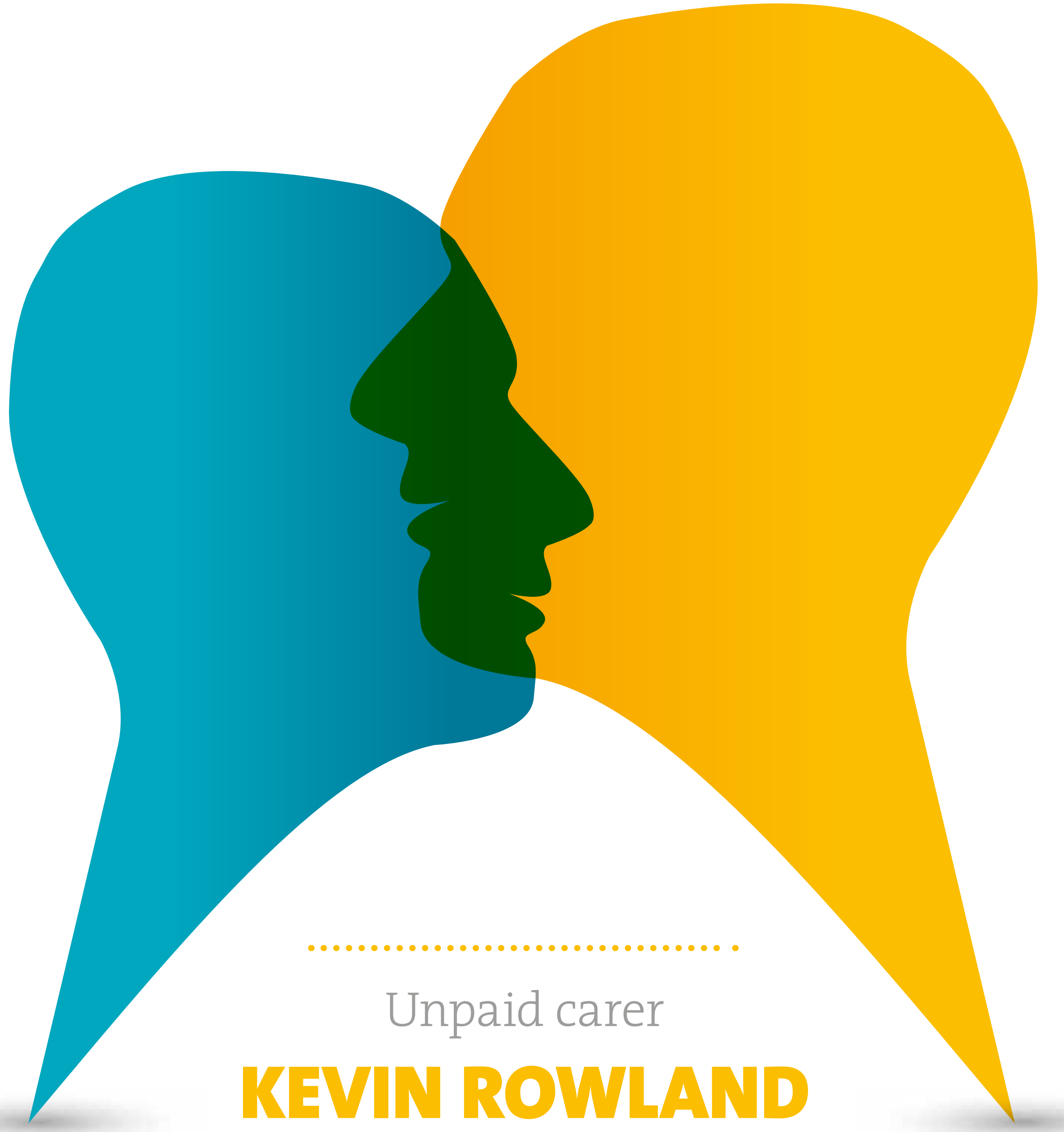
WHY IS IT SO IMPORTANT THAT PATIENTS GET INVOLVED IN STUDIES AND TRIALS?

Studies allow learning opportunities to test treatments and interventions and assess the appropriateness of tools used by clinicians. They are important to inform future research and to help clinicians meet patient needs and improve services. It's also an amazing way to get feedback from the very people that treatments are designed to help!

I am very grateful to the PHA UK for their support throughout the study, from advertising for participants on a number of platforms including Facebook and this magazine, and for generously purchasing the SenseWear activity monitors used in the study. These not only benefitted this study, but will be invaluable in future research too. ●

Siobhan Haran is a post graduate student based at Brunel University, London. She carried out the study in conjunction with the Royal Brompton Hospital. The PHA UK supported her study by assisting with the recruitment of participants and providing the activity monitors used.

the*interview*



Unpaid carer

KEVIN ROWLAND

in conversation with

Mary Ferguson

We're doing things a bit differently in this issue of Emphasis. This feature is normally reserved for healthcare professionals, but those who care for loved ones with PH have a role that is just as important.

Kevin Rowland lives with his partner Julie Royle in north Manchester and a year after she was diagnosed with PH in 2012, he retired from his job in education to become her full-time carer.

Kevin started his career at the age of 16 as an apprentice bricklayer, before becoming a self-employed builder. At the age of 46 a chance meeting gave him the opportunity to work in construction education and after working his way up he ended his career as curriculum head manager at a college.

Q. What does your role as Julie's carer involve and what does a typical day look like for you?

A. *My role as Julie's carer changes day-to-day. If she has a bad day, she will need me constantly (and I try my best). if it's a good day, and as Julie is a very independently-minded person, she will attempt to do things for herself. On these days and always, I am Julie's shadow - which can annoy her but gives me peace of mind. I do this in an attempt to protect Julie. For example, if she has a shower, I will let her go and get started but then I follow her upstairs on the pretext that I'm looking for something. Julie has tackled me about this as it's happened many times that she's noticed, so I had to admit to her that I was checking up on her to see if she's ok. She now always keeps the door open so I can hear her, and she's also said she loves that I'm so considerate even during these simple tasks. I believe Julie's health depends on her confidence, so I try to be as discreet as possible!*

Q. How do you balance being a carer with looking after yourself?

A. *This involves an infrequent game of golf with family or friends or going to visit my daughters and grandchildren, one of whom lives a long distance away. For this daughter a visit may not take place if Julie is particularly unwell, although she is quite insistent that I go as she feels it's important for me to be with my family whenever I can. When I do go, I'm constantly concerned about Julie being home alone and can't wait to return. I look after my emotional wellbeing by talking to close friends and family regarding Julie's condition as it changes daily, and we never know from one day to another how it will be. It also helps me to keep a very good sense of humour, which is essential during tough times when Julie is feeling scared or uncertain – such as during the Covid-19 crisis.*

Q. What support do you have as an unpaid carer?

A. *Financially, I receive no support as I have a small pension from work. I have looked into what I could get but it appears it would have a detrimental effect on the benefits that Julie receives. Julie's son and daughter live very close by and offer lots of emotional, physical and even financial support to both of us - which we are extremely grateful for. However, Julie finds the financial support hard to accept as she is very proud and believes they need it for themselves and their families.*

>>>

the*interview*

KEVIN ROWLAND

> *“I’ve learned how to balance both our needs without losing my free spirit”*

Q. What are the main challenges you face as a carer?
A. *The main challenge that I face is balancing Julie’s independence with my need to shelter and protect her, which has emotional consequences. For example, I cancel visits to my daughter who lives more than three hours away if I consider Julie to be unsafe without me - even though she insists that I should go as she feels it’s just as important for me to have respite time to myself.*

Q. What are the rewards associated with caring for Julie?
A. *I am Julie’s carer, but first and foremost, I have unconditional love for her. Julie is a retired chef and teacher and one of my rewards is her desire to keep us both as fit and healthy as she can with a sensible diet, which I believe has helped her combat many aspects of this disease. My ultimate reward will always be for us to enjoy a lengthy period of time together now and in the future.*

Q. What are the biggest things you have learned about being a carer over the last few years?
A. *Patience, and understanding of another person’s needs, are two things I have learned and am still learning. I’ve learned how to balance both our needs without losing my free spirit, which we constantly laugh about together - and it’s something I’m teaching my grandson all about! I believe that as a result of living with someone with PH, I have become a much more caring and sensitive person - as rumour would have it, more than I was before! Julie’s condition has made me more reflective as a person and I also now value time more. It is precious and should be spent with people I love and care about.*

Q. Do you have any advice for someone who has started caring for someone recently diagnosed with PH?
A. *Firstly, quickly get rid of any anger you feel towards this disease. You will be more effective as a carer if you can focus on the here and now and not what’s happened. Secondly, learn to listen to the professional advice, the patient’s feelings, and any other information given. Never be afraid to ask for help! Ask questions, no matter how silly you may think they are. Share your own thoughts and feelings with someone you trust – but not the person you’re caring for if you think it might affect their wellbeing. However, you should always talk to each other about everything you feel able to as not discussing worries or concerns can be worse. Always remember you are not perfect, and the person you’re caring for doesn’t expect you to be. You may make mistakes - as we all do anyway in life - but remember that whatever you do, your efforts are immensely appreciated by your loved ones.* ***Finally, never ever lose your sense of humour!*** ●

If you’re struggling with your emotional wellbeing, help is available via our partnership with Anxiety UK.
Turn to p14 for details.

MAINTAINING A HEALTHY *state of mind*

PHA UK member *Kaveeta Sunan* lives with depression and anxiety, as well as pulmonary hypertension and congenital heart disease. Here, she shares some techniques that have helped improve her mental health.

Have you ever felt so low that you just cannot pick yourself up and whatever you do, you feel like you are just sinking more and more into emptiness?

I had suffered from depression and anxiety for many years and to be honest I do still have my bad days. But I have learnt how to deal with the feelings, and I wanted to share some of the things that have helped me over the years.

Self-help books: *There is one book in particular that has truly changed my life; ‘The Secret’ by Rhonda Byrne. It is about the law of attraction and the theory that if you think positive things, then positive things will happen.*

For so long I was thinking ‘why am I in such a deep dark place?’ and I used to question why I was so negative. Why do all the bad things keep happening to me?

When I realised I could change the way I thought about things, I discovered I could be happy.

I also kept a journal listing all the things that I was grateful for in my life and I wrote down clear visions and goals of where I wanted to see myself in the future.

Meditation: *I would meditate every day and it would really help me to relax. It made me feel super calm and also helped me with my anxiety.*

Learning to be by myself: *I think for me, most of my problems came from caring about what other people thought of me and the way I saw myself. It took me a long time to truly feel happy about myself, and I am still working on this, but learning to be by myself taught me that I can enjoy my own company without having people around me all the time.*

Doing what I love: *I started taking up art classes and I found this was very therapeutic. It made me forget about everything and calmed my mind. I also bought myself adult colouring books.*

There is so much help out there for us and I want everyone to know that you are not alone. For me personally, depression was a hard thing to overcome - but I believe the one person that can change your thoughts is yourself.

Kaveeta keeps a blog to help raise awareness of long-term health conditions. You can follow her posts at **breathlessnessbeauty.com** and on Instagram at **breathlessness_beauty**

Could you provide **your expert input** into research studies?

A team of researchers from the UK pulmonary hypertension centres are looking for a small group of PAH patients and carers /relatives to be part of a new ***PAH Clinical Trials Network.***

You will sit on a steering committee alongside doctors, nurses, scientists and researchers to shape clinical trials across the UK's seven specialist centres.

You will be asked to ***attend quarterly teleconferences***. In the future this is also likely to include ***at least one face-to-face meeting a year***. The meetings might be anywhere in the UK but your travel and expenses will be covered, along with those of your carer if necessary. You can dial in to the teleconferences from home using your phone or computer. Before each meeting you will be sent materials to review, which you can do in your own time. You will be asked for your input on subjects such as study design and the best ways of making trials work for patients too.

This is a fantastic opportunity to represent the patient voice and influence important PAH trials.

The opportunity is ideally suited to those with experience of evaluating evidence (for example those with a scientific or engineering background), as it will involve reviewing rationale and methodology for research studies and clinical trials. However, we would be interested in hearing from anyone interested in being part of this project.

If you would like to find out more about this opportunity, please email shaun@phauk.org and he will put you in touch with the team behind the network.

A message *from Tess*

PHA UK member Tess Jewson is offering online piano lessons to others, in exchange for a donation to our charity.

Tess delivering a 'virtual' piano lesson to young PHA UK member Emily

Hello fellow PHighters!

The last few months have been very difficult for many of us due to being in isolation.

I am a musician and I play and teach piano, trumpet and cello. I love being able to play my piano throughout isolation and I wanted to share my passion for music with you. As a music therapist, I know that music is very good for helping us mentally.

I've seen people suggest taking up new hobbies to keep them busy during this time and so I wanted to put my teaching skills to use and offer four weeks of piano lessons, for members of all ages.

I don't ask for payment, but a donation to the PHA UK instead - as a thank you for everything they continue to do for us.

As someone with PH, it's lovely to help others within the PH community and I really hope that these lessons help people start a new hobby and feel better too.

I hope you all keep as strong and positive as possible – and one day we will play music together again!

Tess x

To enquire about the piano lessons, please email **media@phauk.org** and we will pass your enquiry on to Tess. You can make your donation at **www.justgiving.com/fundraising/musical-phighters**

The next issue of Emphasis is due out in September and planned content includes...

PH Week preview
Our annual awareness week is back!

Meet the physio
The PH professional helping patients get moving

PH and the pandemic
How the coronavirus crisis has affected you – the results of our research

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

You can get involved in Emphasis too:

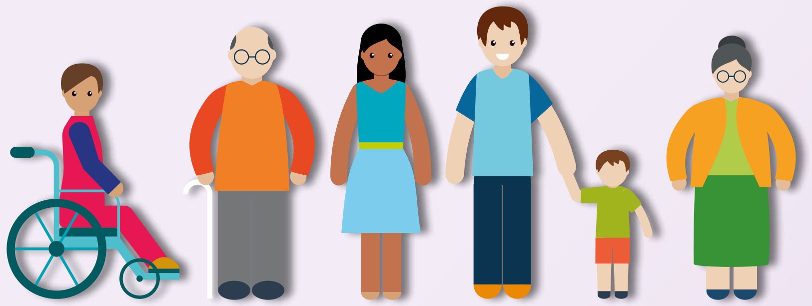
Emphasis Reviews - read a book, used an app or seen a film you think other readers may be interested in? Tell us about it!

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 media@phauk.org with any feedback or ideas.



Join our PH family for free today

Be part of a 4,500-strong national support network.

Influence.
Hope.
Integrity.

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

Being part of the 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.

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*

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

pha UK Influence. Hope. Integrity.

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).

---

pha UK Influence. Hope. 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 & 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
Paul Sephton
Research Support & Development Coordinator

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**