

AUTUMN 2020

emphasis

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

#RareButThere

Putting pulmonary
hypertension under
the spotlight

PH AWARENESS
WEEK
2020
2-8 NOV



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#RareButThere

**PH AWARENESS
WEEK
2020
2-8 NOV**

Welcome...

...to the autumn 2020 issue of Emphasis. As I write, although things remain challenging, it's encouraging see the world moving in the right direction and I hope you are enjoying being able to return to some kind of 'normality'.

Like many events this year, our PH Awareness Week will look a little different, but the theme, #RareButThere, is more pertinent than ever. PH is an invisible condition and we know that brings unique challenges - including being part of the shielded group through the pandemic. We hope you can join us by putting PH under the spotlight between 2-9 November. Turn to p22 to find out how to get involved.

The awareness week follows our inaugural 'Walk With Us' event in August, which by sheer coincidence fell on the day that shielding was paused in England. It was wonderful to see so many of you come together (virtually!) and we loved receiving your photos from the challenge - can you spot yourself on p13? Thank you to those who so kindly raised money for our charity through collecting sponsorship or making a donation following the event.

I'd also like to thank everyone who shared their experiences of the pandemic in our recent survey. We received over 800 responses - the most we've ever had - and we'll be launching the findings soon, as well as including all the details in the next issue of this magazine (which will be out just before Christmas).

Speaking of Christmas, you'll find the winners of our card design competition on p21. We were very impressed by the standard of entries and we hope you agree that they are very deserving winners.

Finally, if you find it difficult to wear a face covering, you might find our cut-out-and-keep exemption cards useful. We've produced the front and back covers of this magazine in thicker material so they last longer in your purse or wallet - do turn this magazine over and make use of them if you can.

Take care and keep positive,

Iain Armstrong

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



"I hope you are enjoying being able to return to some kind of 'normality'"



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From CTEPH diagnosis to surgery, and learning to live with his experiences



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Emphasis *exchange*

Dear Emphasis,

I really enjoyed reading the article in the summer issue about Pamela Bayley and the joy she finds from her dogs. I moved to New Zealand from Surrey three years ago, with my two beloved Italian Spinone dogs Sid and Nancy (pictured below), and 18 months ago I was diagnosed with moderate pulmonary hypertension - following increasing difficulty walking on the flat and dramatic inability to get up the hills.

"The article reiterated exactly where I find myself - getting through each day doing very little but trying to ensure every day contains a little joy"

The joy of my life has always been my dogs and long walks, interspersed with bringing up four boys. I would like to think I was extremely energetic and always on the go. At 35kg each my dogs are gentle giants but strong. I call them my ponies! Because dogs are not allowed off leads in Wellington, I favour bush tracks, which have narrow paths, and steep undulating terrain. I navigate the tracks in order to avoid the people, police and park rangers - but I am always worried about being abused or fined.

The combination of these factors with PH is far from ideal. I walk for at least two hours a day and I know the walking is amazing for my PH, but the flip side is it is also all-consuming - my day revolves around completing the task. Household chores like cooking and cleaning come second, and the combination leaves me exhausted. I am ashamed at the amount of time I spend on the sofa and how little I achieve in a day.

I enjoyed reading the article about Pamela because it basically reiterated exactly where I find myself - getting through each day doing very little but trying to ensure every day contains a little joy. The biggest adjustment and only way to cope with the condition is to acknowledge that every task has to be done slowly.

I hope anyone else out there with PH is able to benefit from the description of how I feel and to know they are not on their own. For the overwhelming love of my dogs I walk them at least 7km each day, no matter what the weather. They need it and I am sure it's keeping me alive.

Thank you, Sid and Nancy, for keeping me going!
Sarah Hornabrook
Wellington, New Zealand



"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.

My four-legged family

My husband and I moved to New Zealand three years ago, and we have never had any other pets. Our four-legged family is our life. We have two Italian Spinone dogs, Sid and Nancy, and four boys. The dogs are gentle giants but strong. I call them my ponies! Because dogs are not allowed off leads in Wellington, I favour bush tracks, which have narrow paths, and steep undulating terrain. I navigate the tracks in order to avoid the people, police and park rangers - but I am always worried about being abused or fined.

Adapting to life with PH

I was diagnosed with moderate pulmonary hypertension 18 months ago. I was shocked and overwhelmed. I had to learn to live with a condition that was life-threatening. I had to learn to live with a condition that was life-threatening. I had to learn to live with a condition that was life-threatening.



Coming soon:
Share your thoughts about palliative care and PH

We know that palliative care supports people to live well with pulmonary hypertension, but to help more patients and families access this type of supportive care, we need to understand more about

how it is perceived and understood within the PH community. Later this year we'll be launching a short survey and we'd love for you to get involved. Please keep an eye on our website and

social media channels for your chance to share your thoughts about this important subject.

Turn to p32 to read our feature about palliative care and how it can help people affected by PH

Help to plan accessible days out

A free guide to accessible days out around Britain has been published online, just in time for autumn expeditions in the UK.



The new edition of The Rough Guide to Accessible Britain has been produced by Motability and includes reviews and detailed information about over 200 attractions, designed to help you plan trips and staycations wherever you live.

Destinations include markets, museums, sports stadiums, beaches, parks, cathedrals, activity centres, castles, gardens and even horse sanctuaries and a chocolate factory. For those who would prefer to avoid public places, the guide also includes scenic drives.

The publication can be read online or downloaded as a PDF, and the Motability website also features blogs about accessible days out written by people who have experienced them.

Visit www.motability.co.uk and search 'Accessible Britain'.

A SPECIAL THANK YOU

We'd like to say a special thank you to PHA UK member Anna Bowen, who has been independently organising and selling PHA UK branded hoodies and fleeces to raise both awareness and funds. Despite personal challenges over the last few months, she has continued to meet the high demand for the garments and we're very grateful for the money raised for our charity.



Social Media Highlights

@wecareforNHS This wonderful 28 Day Positivity Calendar from @PHA_UK sets out small daily tasks that can make a big difference to your mental #wellbeing. If you're feeling anxious in these difficult times, it's well worth downloading



Jozee Anne I loved doing Walk With Us ★ Felt very proud to be part of it

@itssophiemorris Whenever the #LondonMarathon goes ahead I'll give it everything in memory of Maddy and for the wonderful @PHA_UK. Receiving this today has made me even more determined of that! I'd hoped to write an "I did it!" piece but it wasn't quite to be. Soon! 🙌



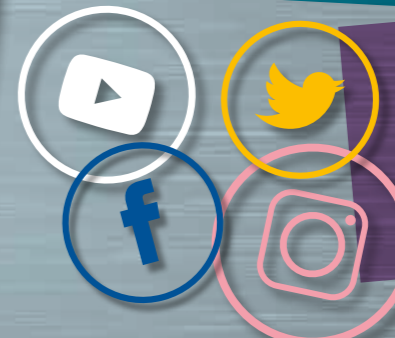
@breathlessness_beauty Thank you so much @pha_uk_insta for sharing my story in Emphasis magazine. Truly grateful! ★



@PulmonaryHIndia Indian #PHighter @roshnic29 featured in the Spring 2020 issue of EmPHasis Magazine (@PHA_UK). She talks about how she found a way around her illness and went after her dreams and how fashion blogging helped her learn to love herself. #phaware #pulmonaryhypertension #phindia #chd



@HarryBradford2 Killer bank holiday weekend training for my marathon and Ironman to raise money for @PHA_UK



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DON'T FORGET YOUR FLU JAB!



It's important to get your flu jab every year, but it's even more vital now. The best time to have the vaccine is between the beginning of October and the end of November and it's completely free if you have a medical condition like PH.

This year, the vaccine is also available for free to people living with someone who's at high risk from coronavirus. So, if you have PH, those in your household won't need to pay for a vaccine and should get one too if they can.

You can have your jabs at your GP surgery or local pharmacy. Find out more about the flu vaccine at www.nhs.uk

Have your say...

'Virtual' assessments for benefits applications: Your experiences

As a result of shielding measures, over the last few months many assessments for benefits applications moved online or were conducted over the telephone.

We'd like to hear from anyone in the PH community who has undergone one of these 'virtual' assessments.

What was the outcome? Were there any challenges? Did the process work for you?

Please let us know about your experiences by emailing media@phauk.org or by writing to **Emphasis, PHA UK Resource Centre, Unit 1, Newton Business Centre, Newton Chambers Road, Thorncliffe Park, Chapeltown, Sheffield, S35 2PH**

You can also contact us by phone on **01709 761450**.

We are in conversation with the organisations contracted by the Department of Work and Pensions (DWP) to carry out these assessments, and we would like to pass on your feedback and ensure people with PH are being treated fairly.

We will keep you updated as things progress.

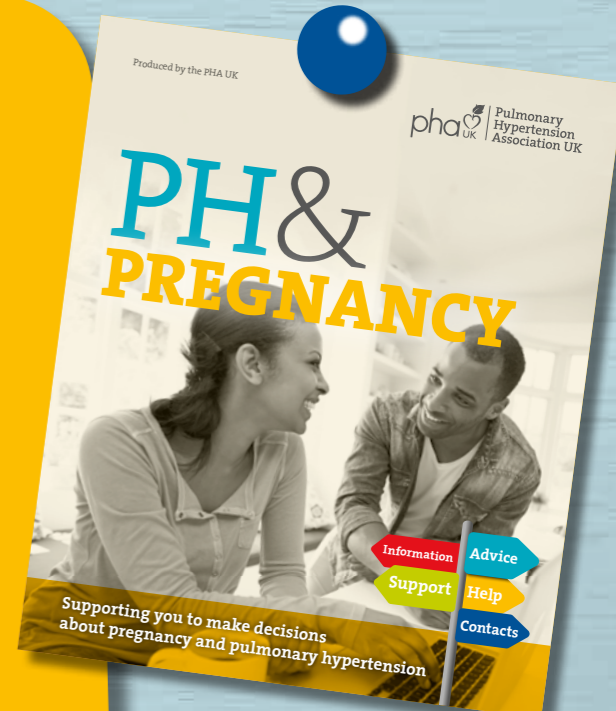
PH AND PREGNANCY: Supporting you to make decisions about pregnancy and pulmonary hypertension

We've been working hard on a brand new publication that tackles the sensitive subject of pregnancy and PH.

'PH & Pregnancy' is the first book of its kind and covers topics including the problem with pregnancy, contraception, unplanned and planned pregnancies, and other ways of starting a family - including adoption, surrogacy and fostering. The aim is to provide balanced expert information to help you understand your options and start conversations with your healthcare teams.

We have also included a number of accounts from people affected by PH, who have shared their experiences honestly and openly. We would like to thank everyone who offered to be interviewed for this important publication.

The book is available for free and will be published before the end of the year. To pre-order your copy for delivery when it becomes available please email office@phauk.org



Putting transplant under the spotlight

Organ Donation Week ran 7 - 13 September and we are grateful to PHA UK members Paula Massie and Catherine Makin for letting us share their experiences of their recent transplants online. You can read their accounts in a special feature in the next issue of Emphasis.

Member Michelle Hemmings also made the most of the opportunity to raise awareness of organ donation and PH by organising activities including an online concert, a walk and a bike ride.

Organised by NHS Blood and Transplant, the week was designed to celebrate and reinforce the importance of organ donation.



Avoid the crowds with Crowdless

This is one of the most useful apps we've seen for a while, and well worth downloading if you're worried about going to busy places.

'Crowdless' is completely free and enables you to see in real time how busy somewhere is - so you can choose to go shopping when queues are short or footfall is low.

Download from the app store on your phone or at www.crowdlessapp.co



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.**



Together
FOR THE
JOURNEY

THE DAY WE WALKED *together*

When we set the date for our Walk With Us virtual challenge, we had no idea it would coincide with shielding being paused in England, Wales and Northern Ireland. As it happened, 1st August marked a sea change in coronavirus restrictions and gave our virtual event even more meaning.

Designed to bring the PH community together during such a difficult time, we invited you to walk with us, wherever you were, at 1pm on 1st August.

Many of you walked with family or dogs, used a scooter or a wheelchair, pushed prams or paced your gardens. You took part to challenge yourself, to celebrate life, or to remember someone special. And we have been so touched to see how many supporters used it as a way of raising money for our charity too.

We have loved receiving your photos and hearing your experiences of taking part. [Turn the page to see a selection of what you sent us...](#)

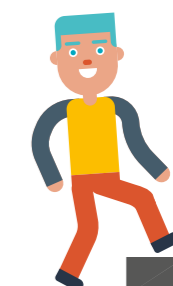
"Like most of the summer's sporting events, the Westfield Health British Transplant Games were cancelled, and as we were due to sponsor the walk competition, we thought we'd use the opportunity to bring the PH community together – at a distance – on the day the event was due to take place. It's been truly wonderful to see how many of our members and supporters got involved and it just shows that during the most challenging times that many of us will ever experience, we really are together for the journey."

Iain Armstrong, Chair, PHA UK

Check out our special Walk With Us highlights video, featuring your photos and footage, on our YouTube channel



Walk with us





In memory of Bobby

The family of Bobby Cloy took on two very different walks in his memory. Daughter Sandra, her husband Ian and sister-in-law Julie trekked up a hill in Scotland, while Bobby's son Brian and his grandson Liam walked a combined total of 48 miles - taking in sports stadiums along the way. Together, the family raised almost £2000.



20k for Steph and Tim

Steph Dodge, who has IPAH, joined husband Tim for a 10-mile walk (20,000 steps!) that incorporated a pasty and a pint – their first in five months. The pair made it home for the FA Cup Final, rounding off an 'amazing' day.



Pacing the park

Julie Royle was joined by her friend Julie and grandson Oliver as they took to their local park for the challenge. They were cheered on by onlookers as they completed their laps and Julie felt so good that she even took another walk in a National Trust garden the day after. Thank you to 'Team Julie' for raising so much in sponsorship for our charity.



Celebrating Jenna

David Bird walked in memory of his wife Jenna Darch, starting at the location of their first date in Bath and ending ten miles later at their wedding venue.



Garden laps for Jane and Ginny

Member Jane Barker-Benfield completed 50 laps of her garden with Labrador Ginny for company. She said: "It was a great way to celebrate the end of shielding. I'm really chuffed as it was the longest walk I've done since lockdown started and equates to 1.1km"



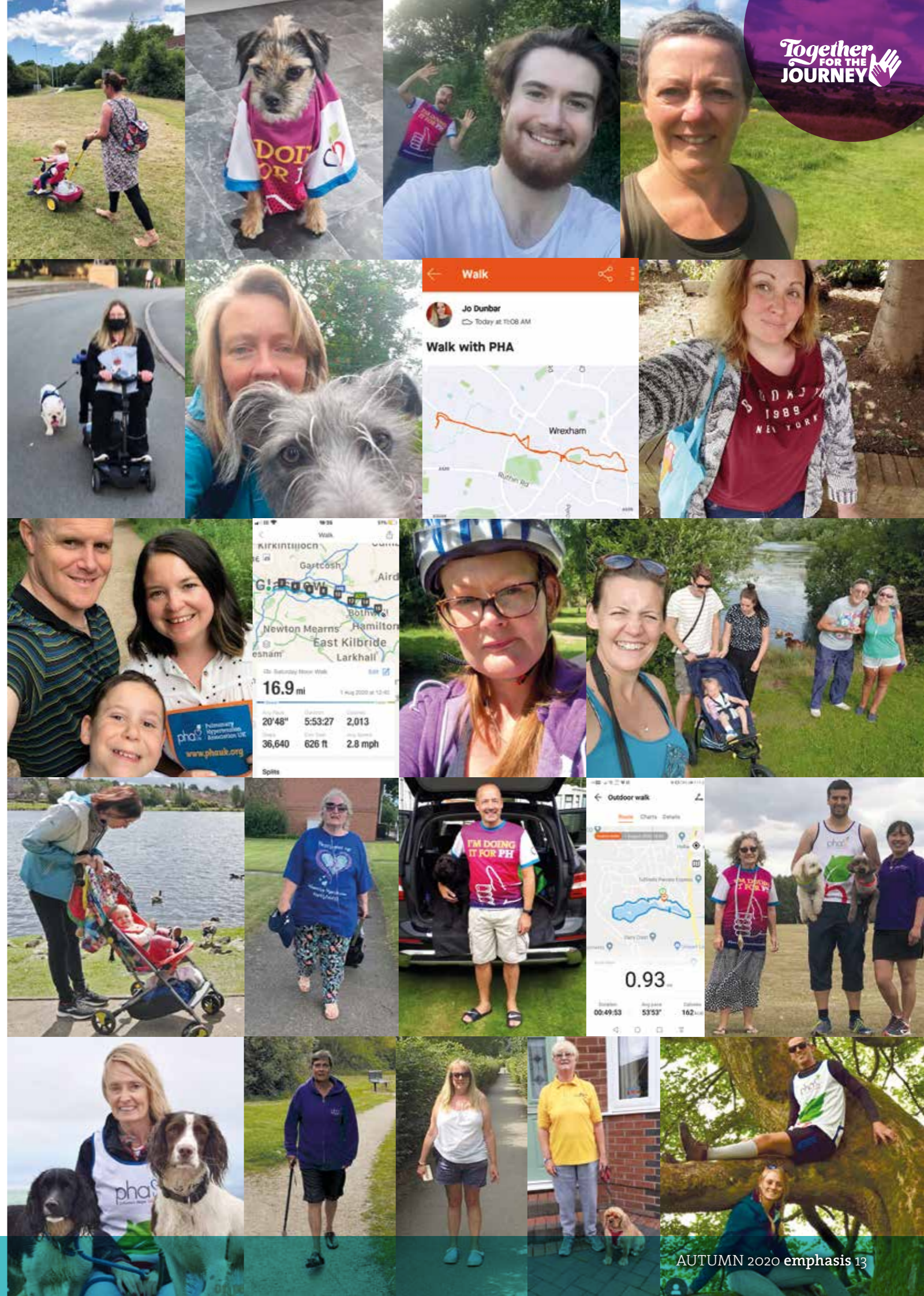
Little legs, big hearts

It was great to see infants getting involved with the challenge too. Isla, 16 months, had only just started learning to walk when she joined her mum Louise, who has PH. And Sharon took the opportunity to spend time with her five-month-old grandson, pushing the pram as she covered the miles.



Charlie's challenge

Young transplant recipient Charlie Beeton walked with his family on the day he should have been competing at the British Transplant Games. Charlie received a double lung transplant a few days before his 13th birthday, just a few months after being diagnosed with PH.



Meet the physio helping people with PH enjoy a better quality of life

Specialist physiotherapist *Katie Dowling* is dedicated to getting people with PH active, and funded by the PHA UK, she has spent the last eight months at the Royal Brompton Hospital doing just that. Emphasis caught up with her to find out more about her work.

A physiotherapist within a specialist PH service is still a fairly new concept. How did your role come about?

We know that exercise in patients with pulmonary hypertension is important and the PH team at the Brompton have been working hard for the last few years to get a physiotherapist in post to support their patients.

Following on from the successful work being carried out by Carol Keen, the specialist physio within the Royal Hallamshire's PH service, the PHA UK kindly provided funding for my post two days a week for two years. I started the role in January and during the rest of the week I work on the intensive care and cardiothoracic wards at the Brompton.

What does the job involve and what is your remit?

I love my role as I get to see such a varied range of patients at different stages of their journey. On my critical care days, I see patients on intensive care or on the wards following surgery. It is so rewarding helping patients improve and recover following a period of illness.

On my PH days, prior to the pandemic I was seeing patients with pulmonary hypertension in clinics or on the ward. Now, I am completing virtual or phone reviews with patients well as starting to see some face-to-face again.

My role involves talking to patients about what exercise they can do, how to implement exercise into their lifestyle and how to make it enjoyable! As one of the designated centres within the

national PH service, we see patients from across the UK. With this in mind, my work is varied and includes referring patients to local exercise groups or pulmonary rehab, implementing exercise programmes or offering support to be more active.

I am available to talk to patients on the phone or via email to offer support or advice whenever needed.

If a 'typical day' exists, what does it look like for you?

A typical day starts with a coffee and catching up on emails or any messages that have come in from patients. I catch up with the specialist nurses and doctors about new patients that they have seen during the week that they feel would benefit from some advice on exercise.



Ideally, I would like to see patients in person however at present, most of my work is done over the phone. I speak to new patients and catch up with patients that I have previously spoken to see how they are getting on. I complete any paperwork or referrals that I need to do and try to stay organised!

It's been eight months since you started the role within the PH service. How are you finding it so far?

So far so good! The team are a great bunch of people who balance working hard alongside having fun in the office. They are definitely very excited to have a physiotherapist within the team. The most rewarding part of my job is hearing feedback from patients about what they managed to do since our last conversation, or even just increasing their knowledge about how to exercise safely with pulmonary hypertension. Some patients have an element of anxiety about exercise and what they can and can't do, so it is really important to have those discussions and be a point of contact for them.

What I like about my role is the variety of patients that I see of all ages, with different underlying health conditions and different abilities. One patient who was in hospital in January and limited by breathlessness is now completing an exercise programme daily at home and walking more each week. We email or speak on the phone every few

months to discuss her programme and progressions. We encouraged another younger patient to get into the gym with a personal trainer, following discussions with the PH team. He was able to exercise a lot more than he originally thought and was really pleased.

Finally, why is physical activity so important for people living with PH?

Exercise is important for all of us! By exercising, you are working on your muscle strength and efficiency but also on your heart and lung function. More efficient muscles allow us to do more. Exercise also makes us feel good in ourselves and helps to lift our mood.

When you are living with a chronic condition such as PH and you are

already breathless, it can be scary to do something that makes you more breathless. Becoming a little bit breathless on exercise is normal and we encourage it, as long as it is the right amount. It is important not to push yourself too hard and to talk to your specialist team before starting any new exercise regime. ●

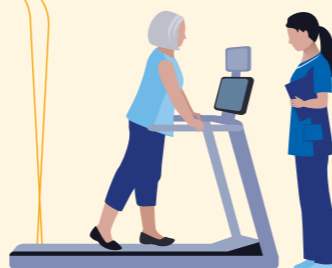


About Katie...

Katie grew up in Ireland and moved to England in 2007 to study physiotherapy at the University of Brighton. After spending five years working in hospitals in the South East of England, she felt sure that cardiorespiratory physiotherapy was the area for her, and in 2015 moved to London to start work at the Royal Brompton Hospital. Katie practices what she preaches; swimming regularly, taking part in exercise classes, and marathon training too. She also enjoys reading, travelling (when possible!) and the occasional gin and tonic.



"By exercising, you are working on your muscle strength and efficiency but also on your heart and lung function"



"It has been very clear for a while now that exercise is incredibly important for our patients, both in terms of what they can physically do, but also how they feel about themselves - including their mental health. The problem was, how could it be provided? The answer was Katie! Katie has transformed what we can offer as a service and I believe that a physiotherapist, like Katie, should be integral to all national PH services."

John Wort

Clinical Lead for Pulmonary Hypertension, Royal Brompton Hospital



TURN2US
FIGHTING UK POVERTY

STRUGGLING WITH MONEY?

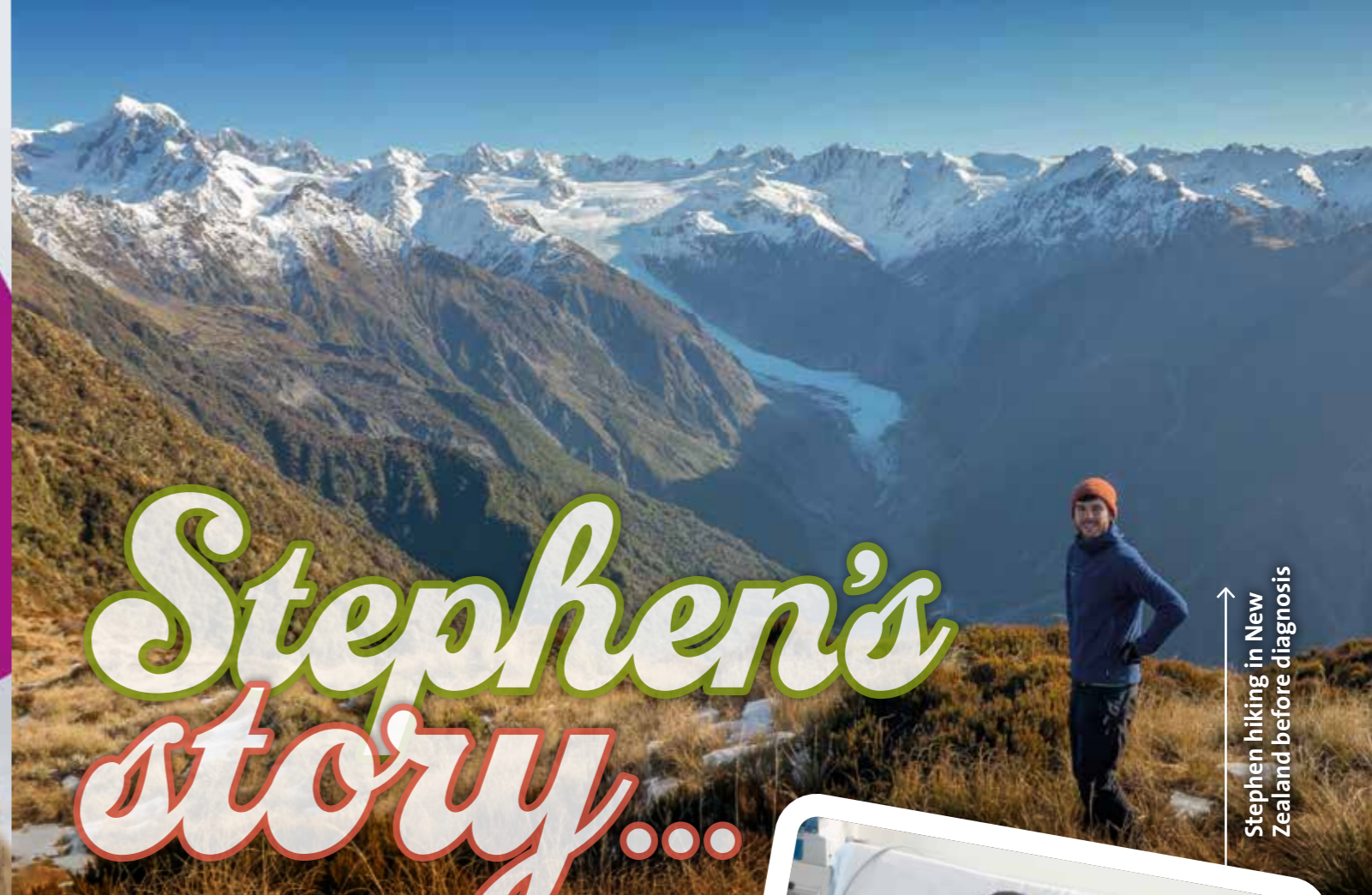
- Find out if you could access welfare benefits, charitable grants and other support that you might be missing out on.

TURN2US.ORG.UK



PHA UK members can also use the Turn2us Benefits Calculator and Grants Search tool via **www.phauk.org**

Turn2us is a trading name for Elizabeth Finn Care. Elizabeth Finn Care is a charity registered in England and Wales No: 207812; and in Scotland No: SC040987.



Stephen hiking in New Zealand before diagnosis

As a sporty 26-year-old, Stephen Thompson was shocked to find himself with a diagnosis of Chronic Thromboembolic Pulmonary Hypertension (CTEPH). This is his story of acceptance, surgery, and learning to live with his experiences.

“**M**

y partner Beth and I moved to Newcastle from North Yorkshire at the end of 2017 and I started becoming symptomatic shortly afterwards.

I had a number of chest infections through the winter and was coughing up blood. I began struggling to run at my usual pace and to keep up with friends while hiking, and I also found going up steps and staircases difficult.

I was very active before becoming symptomatic, and I think that is why I recognised that something was wrong fairly early on; I was sensitive to any change in my physical capabilities. I went trail running, bouldering, and took part in long distance hikes and hill walking. When these activities started becoming more difficult for no apparent reason, alarm bells started to ring.

I knew something wasn't right and went to my GP surgery multiple times over six months, seeing a lot of different doctors. It was initially thought I was recovering from a particularly bad



In hospital following surgery

chest infection and then I was treated for asthma and given inhalers to use. My symptoms persisted and eventually I was sent for a CT scan which showed embolisms in my lungs. I was put on blood thinning medication immediately but after three months...

“I found it difficult to come to terms with my new limitations”

...I was told that the medication hadn't resolved the clots. After more detailed investigations I was diagnosed with CTEPH and referred to a specialist centre.

The diagnosis came as a big shock. I had been proactively working to recover from my symptoms for nine months by this point and had never thought my issue would actually be a chronic illness. However, the specialist nurses guided me through what the diagnosis meant and really helped me by planning out a roadmap for my treatment.

DEALING WITH THE EMOTIONAL IMPACT

Physical exercise is a big coping mechanism for me and has a great impact on my wellbeing. To be so physically limited felt like my body was letting me down and it was very hard to accept at first. I found it difficult to come to terms with my new limitations, which led to me getting very frustrated and upset at times. **I also struggled with the fact that this was an invisible disease; there were no outward signs that I was ill and to others I still looked like a fit 26-year-old. People sometimes didn't understand that there were things I couldn't do.**

Running was out of the question and walking up inclines and steps became increasingly difficult. I was still determined to stay as active as possible, but it was difficult to find a level where I could get out and about but not become ill.

I found a lot of solace in nature during this time, aided through my work with Durham Wildlife Trust, and slowing down allowed me to appreciate many areas of the environment that I had overlooked before. I enjoyed birdwatching and botany as well as making visits to smaller and more accessible nature reserves in my local area and across the country.

UNDERGOING SURGERY

Although I was fearful, I knew that pulmonary endarterectomy surgery was the best option for me. However, I was worried that the surgery would have negligible benefits as I was told I possibly had a lot of inaccessible disease.

The level of inaccessible disease I was considered to have meant that it was initially decided that I might not be suitable for surgery. When I was told this, it was the most heartbreaking moment of my experience. Thankfully, after further investigations and imagery this decision was reconsidered.

As I waited for a surgery date I experienced doubts and worries. It's a very scary procedure when you dwell on it, but I just focused on the fact that it was the best treatment for CTEPH. Beth would keep telling me that even if it didn't cure me entirely it would positively change my condition in some way and that could only be a good thing.

In September 2019 I had my pulmonary endarterectomy surgery at Royal Papworth Hospital which went as smoothly as it possibly could have. After ten days I was allowed to return home to Newcastle.

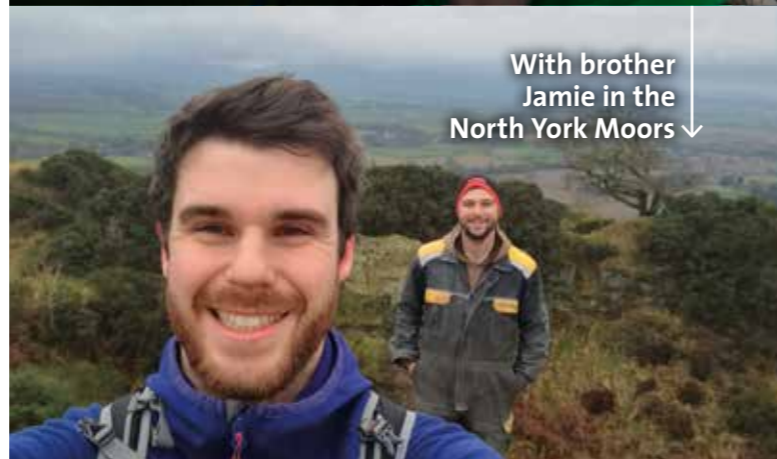
THE ROAD TO RECOVERY

Being patient was key in my recovery. I'm thankful to Beth for looking after me through the first few months. I began walking up and down my street for exercise and to build up my strength we would go to a church around the corner which has a convenient flight of seven steps. This was like Everest for me for a while.



Stephen & Beth

"I have learned how to slow down and appreciate the smaller things"



With brother Jamie in the North York Moors



Walking in Wales

About three months after the surgery I started to notice a real improvement in my breathing when walking and going up a flight of stairs. Since then I've kept trying longer walks and climbs and have been rewarded as my fitness has recovered and further improved my breathlessness. I can walk by those church steps with a smile now.

I was very lucky to have lots of emotional support through this journey. Beth looked after me and kept my head straight when I became frustrated or depressed with my condition. My family were there for me throughout and everyone at my workplace was also very understanding.

The staff at my specialist centre in Newcastle have all been brilliant and continue to be as I recover from my surgery.

MOVING ON

These days, I can breathe again! I'm symptomless when exercising; I have no heart palpitations or wheezing, just the

feeling of being unfit after nearly two years of limited exercise. I've been able to volunteer outdoors and continue with other projects I've been working on, with a view to gaining full time employment in the conservation sector. Beth and I have been on a number of hikes in the Cheviot Hills and the Pennines and I'm feeling great. **I'm also building back up to a 5km run. It's amazing how fast my body has recovered from the surgery, and it has also highlighted how severe my symptoms were before.**

Through my experience I have fully realised the value of physical health and that you truly don't know what you've got until it's gone. I'm just lucky enough to have got it back! I also came to terms my own mortality when facing major surgery, and also when the prospect of my surgery was unclear.

Spending so much time in hospital for investigations, surgery and clinics has given me a massive appreciation for the health service and the level of knowledge and skills required.

I have also learned how to slow down and appreciate the smaller things, whether that might be a study of nature or my relationships with family and friends.

I'm still not back to normal and maybe I never will be really, after going through such a traumatic experience. I take a positive view of this though as I have learned a lot about myself from it.

Although I no longer have PH I'm still not out of the woods with my health in regards to damage to my lungs, clotting and infection risks, so that still plays on my mind. However, I'm taking the best care of myself that I can.

”



With friends in the Lake District



Taking part in Tough Mudder before diagnosis

“You can make the best of a bad situation”

Learning from his own experiences, Stephen has the following advice for anyone newly diagnosed with pulmonary hypertension.

Keep as active and healthy as possible. Try and find or adapt hobbies and passions to fit with your limitations.

Be gently persistent with healthcare support for the information you need to understand your condition.

Read up on your health condition or procedures yourself. Although scary at first, it will help put your mind at ease in the long run.

Make sure you get the financial support you need! I had to put my misplaced pride to one side in order to get the financial support I was entitled to.

Try to talk to people about your condition. Most people will understand and offer support if they can.

You can make the best of a bad situation. When I was made to switch to desk-based work, I was disappointed but it has actually led to me building a whole new set of skills and experiences that I would have missed out on otherwise. I also made use of having more time to pursue other interests such as horticulture, photography, and film.



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

SEND AN *extra special card* THIS CHRISTMAS

Our PHA UK Christmas cards are now on sale - and this year there are some extra special designs to choose from. 30% from each pack sold goes to our charity so when you send one of our cards, you'll be raising money as well as festive cheer.

Meet the winners!

Over the summer we launched a special competition for our members and their families to design our Christmas cards for 2020. We were really impressed by your entries and it was a difficult job to decide on a shortlist! The PH community voted via Facebook and we're delighted to announce the winners below.



WINNER

9 YEARS OLD AND UNDER

'Rudolph'

IZZY PLATT, AGE 5

"Izzy is really happy to have won and we are very proud of her too. We couldn't resist the opportunity to also raise awareness for the PHA UK!"

Gaynor, Izzy's mum



WINNER

17-19 YEARS OLD

'Breathe Easy'

BROOKE THOMPSON, AGE 16

"I feel very happy I won. To be honest I didn't think mine looked good but seeing that other people liked it made me happy and gave me confidence."

I'm glad people like it and can't wait to see the design on the cards."



WINNER

18 YEARS OLD AND ABOVE

'Christmas deer foliage'

ALEX RUDGE, AGE 36

"During the lockdown I found painting in the evenings really relaxing. I heard about the competition on the PHA UK's Instagram account, which I follow because my mum was diagnosed with PH in 2017."

We'll be showcasing all of the shortlisted entries in the winter issue of Emphasis



The three winning designs, plus a selection of other designs are available to order now, at a cost of £5 for a pack of ten (P&P included) Buy online at www.phauk.org or email office@phauk.org

Let's put PH under the spotlight



This year, PH Week is all about raising awareness of pulmonary hypertension as an invisible disease – and helping people understand that even though it can't be seen, the condition still has a huge impact on those who live with it. Here's how you can get involved between 2nd – 8th November...

Take on a... PHfighter 20 challenge

Complete a challenge around the numbers **2020** and show the world you're a phighter!

These are just a few ideas. Choose a challenge to suit you or dream up your own – the possibilities are endless...

- Walk for 20 minutes every day during PH Week
- Complete 2020 steps over the course of the seven days
- Bake 20 biscuits and sell them for 20p each *Child friendly!*
- Complete 20 hours of gardening over the course of the week
- Read 2 books (or 200 pages!)
- Write down 20 things that make you happy (you could spread this out across the week)
- Draw 20 pictures for family and friends *Child friendly!*
- Do 20 minutes of housework a day
- Take on a 200-minute sponsored silence (that's over 3 hours!) *Child friendly!*

You'll find lots more ideas on our website – go to www.phauk.org and click on the PH Week tab at the top.

Everyone who completes a challenge will receive a thank you letter and if you want to turn it into a fundraiser, we'll reward you with a little extra...

- Raise over £20 and receive a special certificate (perfect for little ones!)
- Raise over £50 and we'll send you a PHA UK medal to wear with pride

Please let us know if you'll be taking on a challenge! To tell us what you're doing or request a fundraising pack, email phighter20challenge@phauk.org or call 01709 761450

#RareButThere
#PHWeek20

Get social



Social media is one of the best ways to spread the word about PH. Tell the world why you're supporting PH Week, share our posts, and snap your own selfies with the special photo cards included with this issue of Emphasis. You could even paint your face to show that PH may be invisible, but you're not! Don't forget the hashtags **#RareButThere** and **#PHWeek20**

The pledge wall is back!

Pledge your support for people with PH, and ask your MP to as well. Fill in a short online form and your words will appear for everyone to see at www.phauk.org. A template letter to send to your MP will be available soon – keep an eye on our website and social media channels.

Share your story

Your local newspaper, radio or TV station would love to hear about your reasons for supporting PH Week and it's a really effective way of raising awareness of the condition.

If you'd like to share your story with the media, email media@phauk.org and we'll guide you through what to do.

PLUS! Look out for...

- A new animation that lifts the lid on PH as invisible illness
- A series of podcasts dedicated to PH Week
- The launch of special car stickers to take the worry out of parking in disability bays

This is PH

Rare

Breathless

Will you be part of our special 'one word' video?

We want to tell the world what it's like to have PH and we need you to help us. We'd love you to send us a short video clip of you describing pulmonary hypertension in just **one word**.

Your clip may just be a few seconds long, filmed on your phone, but we promise that with them all edited together – and shared far and wide – it will make a real difference.

Don't want to film yourself? You can write your word on a piece of paper and send us a photo of you holding it instead.

We'd love to see little phighters getting involved with this too; we want to show that PH affects people of all ages – including children. PH doesn't discriminate, but society can.

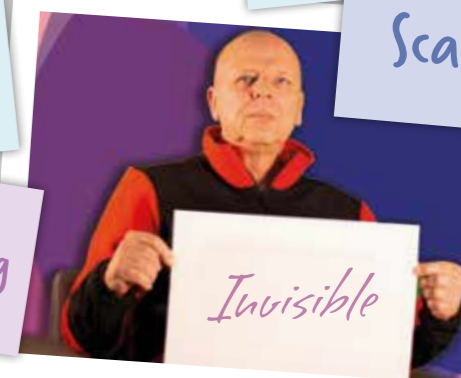
Send your 'one word' video clips or photos to media@phauk.org

Misunderstood

Isolating

Frustrating

Scary



We'll be using PH Week to launch the results of our research into how the pandemic has affected people with pulmonary hypertension. Look out for a full report including in-depth case studies, and a video that brings the findings to life.



Find out more about PH Week...

Access downloadable resources, including posters and social media graphics, at www.phauk.org

Got a question? Email media@phauk.org or call 01709 761450

FUNDRAISING focus

With big events cancelled and mass gatherings restricted, you've been finding other ways of supporting us over the last few months – and in these difficult times, each and every penny is appreciated. **Thank you!**

Mask-making magic

Nicola McCulloch spent the early stages of the pandemic making face coverings in exchange for donations, helping her friends and family keep safe whilst raising money for our charity. She said: *"Keeping busy making masks and knitting has helped me cope through some of the tougher days of lockdown."* Thank you also goes to Nicola Peach, who has been making and selling face coverings in memory of her mother-in-law Felicity.



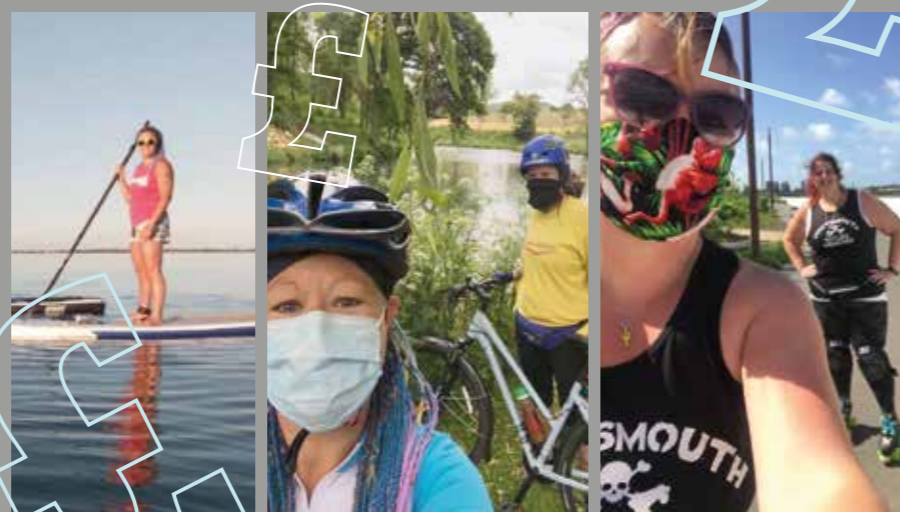
Remembering Keir

Supporter Angela Cran donated £100 to mark what would have been her son Keir's 16th birthday. Keir died in 2012, when he was eight years old, following a long wait for a diagnosis of pulmonary hypertension. Angela, who is planning to write a memoir about the family's experiences, said: *"We miss Keir every day and hope that this donation will help to continue the work to support others with PH."*

**£100
DONATED**

To Germany and back (sort of)

Roller derby team Portsmouth Wenches turned the cancellation of their international competition into a fundraising opportunity by travelling the equivalent distance to Munich by skating, running, cycling and rowing. The team were due to play the Munich Rolling Rebels in Germany in April, and when it was cancelled due to the pandemic, they took on the challenge to raise money for the PHA UK, PAPYRUS (Prevention of Young Suicide) and Southsea Skatepark. We'll bring you more on this challenge, and the reasons behind it, in the next issue of Emphasis.



Graham grabs super-cycle opportunity

As you're reading this (and if all goes to plan in these uncertain times!) PHA UK member Graham Timbers and two friends will have just completed a mammoth cycle from Lands' End to John O'Groats. Graham had a pulmonary endarterectomy operation at the end of 2019 following a CTEPH diagnosis, and due to shielding, spent lockdown training on a stationary bike in his shed. When he was able to get back out onto the roads, he made a decision. *"Life is for living and grabbing every opportunity you get"*, he said. *"I've always wanted to cycle from Lands' End to John O'Groats and as well as a personal goal, I wanted to raise funds for PHA UK. Apart from a few sponsored charity rides in the past I'm completely new to fundraising and I want this one to count."* The challenge saw Graham and friends Richard Mills and Paul Butler cover 1000 miles across nine days and climb a staggering 60,000ft in total elevation – the equivalent of cycling up Everest twice! At the time of going to print the trio had raised an equally staggering 1926 between them.

Harry's not giving up on his challenge

When Harrison Bradford decided to take on a marathon and an Ironman challenge in memory of friend Andrew Kitson, he had no idea that a global pandemic would thwart his plans more than once. Harry was due to run the Brighton Marathon in April followed by an Ironman in Switzerland in July, but both have been postponed due to the changing guidelines around mass gatherings and travel. You can support Harry, who is determined to complete the challenge when he can, via his online fundraising page at www.justgiving.com/fundraising/harrison-bradford3

**OVER
£1900
RAISED**



**Walk
with us**

TURN TO
PAGE 11 TO
FIND OUT HOW
YOUR WALKING
CHALLENGES
HAVE HELPED
US TOO!

FANTASTIC FACEBOOK FUNDRAISERS

Raising money via Facebook is a simple, effective way of supporting our charity, without having to take on a sponsored challenge. All you need is a Facebook account and a birthday!

HOW IT WORKS:

A few weeks before your birthday, Facebook will send you a message to see if you'd like to ask for donations to your chosen charity in celebration. All you need to do is select the PHA UK from the list provided and Facebook will automatically post it to your profile, so that it appears in the timelines of your friends.

It makes it really easy for your followers to donate, without leaving Facebook. You can select the target amount and include a personal message to encourage people to support your cause.

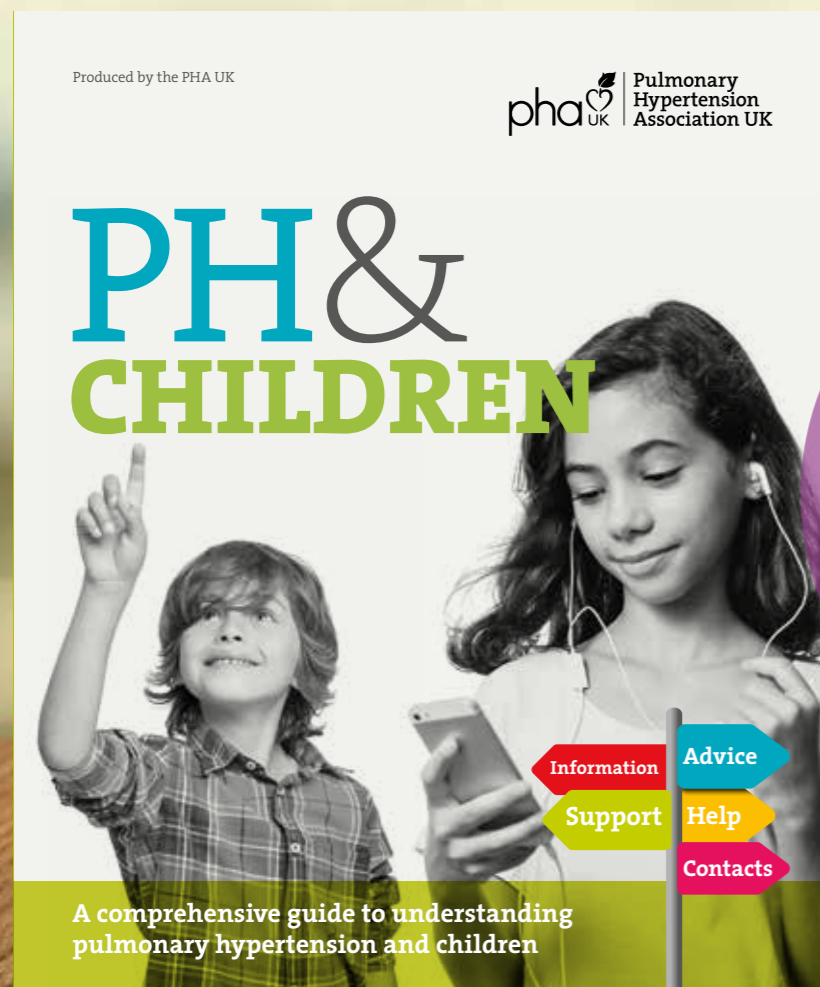
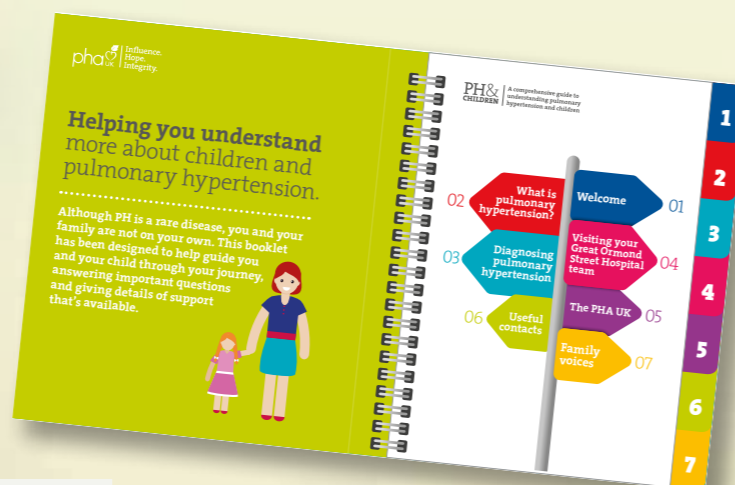
In the last year alone your Facebook fundraisers have raised almost £13,000!

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



PH & CHILDREN

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.



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



Green Leaf

Crew!



Kaylee's Column

STARTING SECONDARY SCHOOL WITH PH

4 PAGE PULL-OUT

Kaylee Mynot is 19 and was diagnosed with PH when she was a baby. She lives in Surrey and has a younger brother called Max.

As children return to school following a much-extended summer break, Kaylee looks back on her first days at secondary school and shares her advice for those making the transition with PH.

My first day at secondary school did make me feel quite nervous. It's a big move for anybody, especially for those of us with pulmonary hypertension. My parents had done all the paperwork beforehand, so my information and what to do in an emergency was already sorted. I think the teachers were more worried than me, all I had to do was turn up!

Remember that the first few days and weeks can be tiring until you know where you're going and figure out the quickest routes between class changes. For me, I was able to leave class just a few minutes earlier to avoid the rush in the corridors and walk at a slower pace to my next class with a teaching assistant (TA). It was decided that it was safer for me not to do PE, I have to say I was glad! But I did have a feeding tube in place, so it was definitely safer for me not to take part. Although saying that, the right level of exercise is good for you and your teachers should adapt things to include you.

"It's natural that new friends may have questions"

You will make new friends, and in time it's natural these friends may have questions about you. You can say a little bit or lots, it is absolutely your choice. On the plus side, if they do know your situation, it can help them to be more understanding.

You may see several teachers during your day at school, but you will always see the same form tutor every day, usually morning and afternoon. If you have any problems you need to talk about, or you're worried about anything, your form tutor or even a favourite teacher will always be able to help. And most importantly, your parents know you best and will always listen to you - on your good days and not so good ones.



Kaylee in her school days

Kaylee x

If there's a topic you'd like Kaylee to cover in her next column, let us know by emailing media@phauk.org

Back to school...

by David Banks



DON'T FORGET!

The clocks change on 25th october, meaning it gets dark an hour earlier. on the plus side, it gives you an extra hour in bed that night!

zzzzzzzzzz

Emily's top 5 LOCKDOWN MEMORIES

Ten-year-old Emily Gravenstede kept very busy whilst shielding, making the most of her free time to learn new skills and get creative. Here, she shares her top five memories from a time none of us will forget.

1. BAKING A 3D UNICORN CAKE

I did lots of baking and cooking during lockdown, but the unicorn cake I made for a school project was the best.

2. RIDING MY NEW BIKE

At the start of lockdown I inherited my sister's old bike. It is amazing and just like new and I love it.

3. CREATING FLOWERS USING TOILET ROLLS

I did a lot of art during lockdown. These blue, glittery flowers are my favourite and are now hanging on my bedroom wall.

4. HAVING VIRTUAL PIANO LESSONS

I was so lucky to have some piano lessons with my friend Tess, who raised money for the PHA UK by doing the lessons. I learned to play lots of tunes.

5. PLANNING MY NEW BEDROOM

I am going to get a new bed (which has a desk and wardrobe) and completely change my bedroom around. I am really excited about this.



Making a stand

We'd like to give a special Green Leaf Crew shout out to ten-year-old Charlie Keith, who managed to reach Health Secretary Matt Hancock with a question about the pandemic earlier this year. Charlie, who has PH, wrote to his local MP to express how unfair he felt it was that others were allowed

to go outside as much as they wanted while children who were shielding couldn't because it was so busy. He wanted to know if he and his family, along with other shielders, could have a 30-minute slot every day when they could safely go outside. His MP Daisy Cooper put the question to Mr Hancock in parliament in Charlie's name, and shared the video of the exchange on her Facebook page.

Well done Charlie!



Get busy in the kitchen!

Easy peasy two-ingredient fudge

This recipe is ideal for little hands and comes highly recommended by the PHA UK's Shaun Clayton (pictured). It's easy peasy, a little bit naughty and very, very tasty!

INGREDIENTS...

175g smooth peanut butter
175g chocolate spread

METHOD...

1. Melt down the peanut butter in a bowl over a pan with boiling water (make sure an adult is with you for this bit!) stirring until it is nice and runny
2. Add in the chocolate spread and mix together. Stir and stir until it is all a nice chocolatey brown and then spoon into a Tupperware box lined with parchment paper
3. Smooth the top with a spatula or the back of a spoon and put it straight into the freezer
4. After a couple of hours, it should be nice and hard. Now you can cut it into squares and enjoy!

If there is any left, keep it in the freezer until you're allowed some more 😊



Shaun's top tip...

Sprinkle some hundreds and thousands on top before freezing to make it more colourful!

Patch



Do you need help to manage anxiety, panic or worry?

We've partnered with psychology researchers at the University of Sheffield to trial a new self-help programme aimed at supporting people with pulmonary hypertension to manage their anxiety.

Anxiety is common in PH, with about 50% of those with the condition experiencing clinical levels of anxiety or panic.

We're inviting people with PH to take part in an important study to test its effectiveness, with the aim of making it available to all. Read on for the opportunity to help both yourself and others...

WHAT DOES THE PROGRAMME INVOLVE?

If you take part in the study, you will be asked to complete a series of online questions which will help us understand how suitable the study is for you. If you are accepted, you will be put into one of two groups at random.

One group will be asked to work through a series of workbooks based on a type of therapy called Cognitive Behavioural Therapy (CBT), used widely to help people experiencing difficulties with their mental wellbeing.

The workbooks include information about PH and anxiety and how the two can interact, and a range of techniques and skills to help you to better understand and cope with symptoms such as excessive worry, fear, panic, nervousness and stress.

The books have already been reviewed by a panel of people living with PH, to ensure they are the best they can be for the study.

You will be asked to complete the four workbooks over a period of four weeks, in your own time at home. At the beginning, end and part way through the four-week period you will be asked to complete a short online questionnaire – and your answers will help us understand how effective the programme has been.

If the study shows the programme is effective, we will make it available to all PHA UK members so they can

You are not alone

If you are struggling with anxiety, panic or worry but do not fit the criteria for this study please email us at office@phauk.org or call 01709 761450 and we will talk you through the support that's available.



benefit from this type of support too. People in the other group may receive the intervention at a later date.

TAKING PART IN THE PROGRAMME

To take part in the study we ask that you:

- Are over 18
- Have a diagnosis of pulmonary hypertension
- Can read and write English
- Are able to complete online questionnaires

Unfortunately, because we are testing the programme's effectiveness as a 'first stage' treatment, you cannot take part if you have received medication or therapy /psychological treatment for anxiety in the last 12 months, or are currently experiencing thoughts of self-harm or suicide.

HOW DO I APPLY TO TAKE PART?

The first stage is to complete a series of online questions. Please visit www.phauk.org and search 'anxiety panic worry' or email shaun@phauk.org for the link.



If you have any questions about the study, please contact lead researcher Gregg Rawlings at g.rawlings@sheffield.ac.uk



Supporting you to live well with PAH

Should palliative care be 'rebranded' as supportive care?

What does palliative care mean to you? It's likely that for some people reading this feature, the 'p' word itself is enough to evoke uncomfortable feelings – and this is where the problems begin. We spoke to researcher *Dr Sarah Woolcock* about what needs to change, and how the PH community can play its part.

Palliative care is about living not dying, but common misconceptions are preventing some people with PAH getting the supportive care they need.

Respiratory consultant Sarah Woolcock took two years out of registrar training to complete a PhD study into the delivery of palliative care in patients with PAH and uncovered various obstacles.

The aim of the study, funded by the PHA UK, was to explore the understanding of and attitudes towards palliative care amongst both patients and healthcare professionals.

Sarah conducted in-depth interviews which showed that for both patients

and staff, the term 'palliative care' was typically found to have negative connotations. For many healthcare professionals, the experience of receiving negative reactions from patients when discussing palliative care sometimes formed a barrier to discussing the topic earlier.

Uncertainty around the course of PAH was also cited as an obstacle, along with the difficulty of balancing active care (such as treatment with intravenous medications or transplant referral) and palliative care at the same time.

Sarah, who now works as a respiratory consultant at Royal Preston Hospital, said: **"Education of both patients and staff has potential to**

improve the way palliative care is discussed in PAH and improve patient experiences. We need to have more conversations about palliative care and address the misconceptions. So many people hear the term and think it means 'end of life' but there is so much more to it than that."

Palliative care is about living, not dying. It helps people who have an illness that cannot be cured, and some receive it for years. It takes a 'holistic' approach, involving psychological, social and spiritual support, as well as dealing with physical symptoms.

Sarah recognised the need for a study into its accessibility when she was working with the pulmonary

hypertension team at Newcastle's Freeman Hospital. **"I realised that our patients were getting palliative care, but it was very much at the end of life, and perhaps there were signs or symptoms beforehand that meant they would have benefitted from it earlier"** she said.

Supported via the PHA UK, Sarah interviewed patients under the care of the Freeman Hospital and healthcare professionals from across Britain. Some of the conversations, she said, were unexpected.

"I think I was quite surprised by the staff perceptions of palliative care. There was this fear of bringing it up with patients in case they interpreted it in a negative way. But when I spoke to patients, a lot of them said that actually they knew they were getting to that point [where palliative care was needed] and were waiting for someone to bring it up with them."

Sarah believes that as well as improving perceptions, recognising there is uncertainty in the disease trajectory for patients with PAH would also be helpful.

"People might enjoy a period of stability and then experience an exacerbation that sets them back – and it's difficult to tell whether that might be the start of a decline or whether they are going to get back to being stable again. That makes it very difficult to know when to have these conversations and I think ultimately

it comes down to raising awareness of what palliative care is and how it can make a difference."

Empowering patients to bring up the subject themselves is also important. And these conversations, Sarah says, can happen at any time.

"You don't need to wait until a certain point. One of the patients I spoke to compared having early conversations about palliative care to taking out house and contents insurance. It doesn't mean you need to use it now, but it's there just in case. And having those conversations when you're well can be easier than having them when you're in a decline."

Sarah hopes there will now be scope for further studies into the role of specialists in palliative care in PH, and perhaps the development of tools or frameworks that will help healthcare professionals recognise when to introduce the subject with patients.

For now, she is keen to keep the wider conversations going and will be working with the PHA UK to raise awareness of the benefits of palliative care.

"This is such an important area and it has potential to make a huge difference to patients and their families" she added. **"I'm very thankful to the PHA UK for the opportunity to carry out this study and of course to those who took part. Hearing the views of patients is vital as they are the ones who are going to shape how we do things better in the future."**

MYTH:
PALLIATIVE CARE ISN'T FOR FAMILY AND FRIENDS.

FACT:
Palliative care teams are aware that your illness may have a big impact on your family members and friends. Palliative care teams do what they can to help people cope.

www.mariecurie.org.uk



"Palliative care is about living, not dying... It takes a 'holistic' approach, involving psychological, social and spiritual support, as well as dealing with physical symptoms."

MYTH:
HAVING PALLIATIVE CARE MEANS I'M GOING TO DIE SOON.

FACT:
You can receive palliative care at any point in your illness. Some people receive palliative care for years, while others will receive care in their last weeks or days.

www.mariecurie.org.uk

Turn over to hear from the PHA UK's Paul Sephton

"Palliative care and end-of-life care are not the same"



The PHA UK's Paul Sephton is a registered nurse with many years of experience working in both palliative care and pulmonary hypertension.



"There are some serious misconceptions about palliative care and it's a real shame as it can make such a difference not only to people with PH, but to their families too.

The biggest issue is the belief that palliative care and end-of-life care are one and the same. They are very different! You can receive palliative care at any stage of your illness, and it doesn't mean you are dying. It's quite the opposite – palliative care supports you to live well and at the PHA UK we believe it's really important that people have access to this type of care as early as possible.

Palliative care is a holistic type of care. This means it addresses more than just physical symptoms; it supports your psychological, spiritual, social and other needs too, providing true 'wraparound' care to enhance quality of life.

And it's not just for someone with a diagnosis of PH. One of the most beneficial aspects of palliative care is that it is there to support family and friends too, for example with caring commitments, or their own emotional wellbeing.

We know- because our members tell us - that having PH can make some people feel like a 'burden', and they worry about the knock-on effect to close family and friends. Palliative care can help relieve some of that worry, as it is there to support those around the patient too.

Over the next few months, we will be running a series of articles in this magazine to help our readers understand more about palliative care. We'll also be working behind the scenes to find out more about localised support (as we know that services can vary) and explore opportunities to make a real difference 'on the ground'.

Ultimately, we want to help our members - and others - recognise that palliative care is about living, not dying. That way, more people can benefit from this supportive care and enjoy living well with PH.

"Over the next few months, we will be running a series of articles in this magazine to help our readers understand more about palliative care."



NEXT ISSUE...

We take a closer look at palliative care delivered by hospices and how they can help some people living with PH.

If you would like to share your own experiences of palliative care please email media@phauk.org

MYTH:
PALLIATIVE CARE IS JUST ABOUT TREATING PAIN AND OTHER PHYSICAL SYMPTOMS.

FACT:
Palliative care aims to provide a holistic approach to give you the best quality of life possible. This means caring for all your physical, emotional, psychological, social and other needs.

www.mariecurie.org.uk

Health app review

Emphasis editor Mary Ferguson tests the first online habit change programme to be commissioned by the NHS.

Have you used an app, read a book, or found a particularly helpful website you'd like to tell us about? Contact media@phauk.org or call 01709 761450

Second Nature

Formerly known as 'Our Path', Second Nature is a three-month programme, based on behavioural science, that's designed to help you lose weight and make long-term changes to the way you eat.

Daily support and accountability comes from a health coach (all are qualified nutritionists or registered dieticians) and you're placed in an online group with others taking the same journey. You can ask questions, chat to others and share your experiences via the app.

With the focus on reducing carbohydrate intake, you are encouraged to choose meals that keep you feeling full, and a five-day 'reset' plan at the beginning is designed to get you get off to a strong start.

Although it's mostly about food, the programme does also encourage physical activity by encouraging you to track your steps.

The good bits

I found the support from the health coach helpful and enjoyed being part of a group to share tips and experiences. The photo food diary element was particularly useful; snapping every meal and looking back at the end of the day made me think more about what I was putting on my plate and motivated me to cook nice-looking dishes. The app is easy to use so if you're not great with technology, it could be a good option for you (it's certainly simpler than the WW app I tried recently). I lost 7lb (which I was pleased with as my main aim was to get healthier) but as a fussy eater and a less-than-willing cook, I did find the plan quite restrictive at times.

The not-so-good bits

As someone who follows a vegan diet, I found the low-carbohydrate approach quite challenging, which probably explains why the weight went back on fairly quickly once I stopped. However, I do think that a meat-eater, or someone who can have eggs and cheese, would find this way of eating much easier.



The other downside is the cost; it's not cheap! However, if you're someone who usually spends money on takeaways or treats, you may find you end up breaking even.

What's the damage?

There are two packages to choose from with Second Nature.

1. The 'no tech' package at £40 a month

This gives you access to the programme via the app plus a recipe book and handbook delivered to your home. You'll need to have access to your own weight scales if you choose this option.

2. The 'tech package' at £60 a month

This gets you all of the above, plus digital scales (synced to the app) and a basic wearable activity tracker.

There is a two-week satisfaction guarantee so if you want to cancel within the first 14 days you can, with no questions asked. It's worth noting that once this time has passed, you are committed to paying your monthly fee for three months.

Top tip: Once the three months have passed, you are automatically moved onto a £10-a-month 'sustain' programme, so if you don't want this to happen, you must contact Second Nature to cancel at the end of the three months.

Thanks to its partnership with the NHS, it may be possible to access Second Nature for free via a referral from your GP. Please contact your surgery for details.

Find out more at www.secondnature.io

www.phocusonlifestyle.org

Our sister website to help you live well with pulmonary hypertension

Our online resource is designed
to support you with all aspects
of life with PH.

- Relationships
- Exercise and nutrition
- Complementary therapy
- Mental and emotional wellbeing
- Travelling with PH
- Welfare and benefits

...and much more!

**USE ON
THE GO!**

Accessible on
your phone, tablet,
laptop or desktop
computer



REGULARLY UPDATED!

This is the site you'll want to return to time and
again for information, guidance and inspiration.

**Do you keep a blog
about your PH, or
would you like to
start one?**

**We'd like to
share your
words!**



The blog area of www.phocusonlifestyle.org
is a space to share your voice about anything
that matters to you.

Your blog post could be written especially
for us, or it could be something you've
already shared. Either way, we'd love to
hear from you!

You might want to talk about a specific
event or experience, or offer some advice
that you think might help other people
affected by PH. Maybe you just want to
share an opinion, or get something off
your chest?

We're happy to share creative prose and
poetry too, so it's a great chance to see
your work published online.

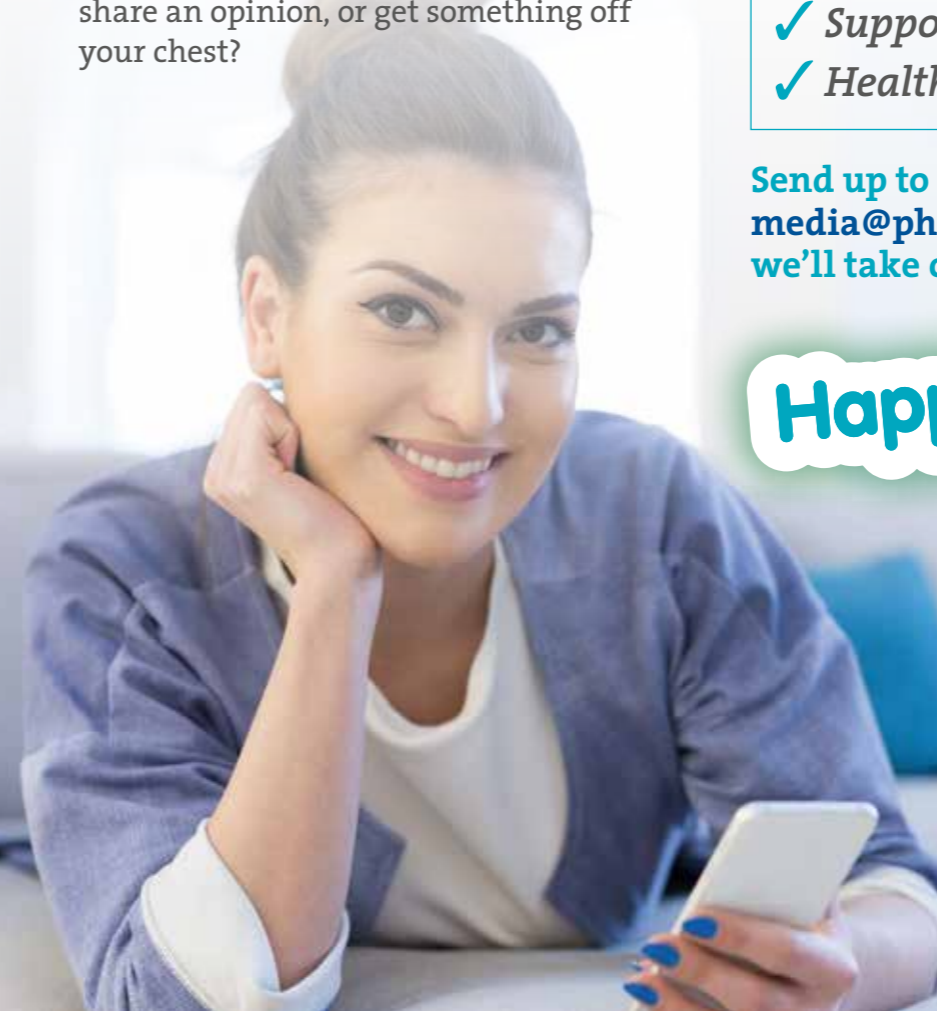
We can also include photos and videos
- but if you want to stay anonymous,
that's totally fine too.

We're looking for blog posts from:

- ✓ People with PH
- ✓ Carers and loved ones
- ✓ Supporters or fundraisers
- ✓ Healthcare professionals

Send up to 700 words to
media@phauk.org and
we'll take care of the rest :-)

Happy blogging!



Keeping **CONNECTED** through *Poetry*

Every Sunday during lockdown, PHA UK member *Maureen Jones* received a piece of poetry from her daughter *Catherine* – sent to provide comfort and hope during testing times.

For Catherine, poetry became a way of supporting her mother at the very beginning of her journey with pulmonary hypertension.

"It all started quite a few years ago, before the PH diagnosis, when my mum was very ill in hospital", she said. "She has always been an independent lady who loves life, nature, and the freedom of being outdoors so every morning whilst she was in hospital, I started to text her a little verse to keep her spirits up. It was to encourage her imagination to take her out of that hospital bed to wherever she wished to be. I then just fell into the habit of sending something every week on a Sunday. I have now written a few hundred as you can imagine!"

Eventually, six years ago, Maureen was diagnosed with pulmonary hypertension and is now on oxygen 24 hours a day

"She has fought to stay independent and adapt to each difficulty she has faced", added Catherine. "Each poem I emailed her whilst she was shielding during lockdown was dedicated to keeping her positive and giving her the determination to get through."

A 'poem of hope'

In June, the government announced that people could form 'bubbles' with loved ones. Maureen was so touched by the below poem she received from her daughter that week that she was moved to share it with us via email. *"I call it my poem of hope", she wrote. "I hope that one day I will come out of shielding and find my bubble."*

BUBBLES

By Catherine Jones

Floating high in the tangy aqua flavoured cosmic sky,
A crystal-clear shimmering bubble floats on by.
A little more freedom if you are alone and wish to escape,
But for many a challenge as it could be just a mistake.
Bubbles aplenty in our very own everyday life,
Always to be relied on if we wish to flee strife.
Bubbles protect but my favourite are those in my bath.
A scented steamy soak perfect just to unwind and relax.
Each and every day we are somewhat in our own little bubble,
Sometimes it is just so that we can stay well out of trouble.
Whilst for some this new bubble is certainly not one to be missed,
For others it still causes just far too much of a risk.
So, remember it is those who are with you in your bubble
not just physically but in your heart and your soul,
For they are the special loved ones that you cherish and
without them your being just would not be whole.



Catherine (left)
and Maureen

A dedication to my mum

Catherine has written this poem exclusively for *Emphasis*, as a surprise for Maureen when she receives this magazine.



Mum you simply mean the whole world to me
You were the very first thing of beauty my eyes did see.
You have always been there right by my side,
To know that you are my Mum fills my heart with pride.
You are such an inspiration to all who know you,
You exude grace and charm in whatever you do.
So pulmonary hypertension does not and will never affect
who you are,
For to me you are the brightest and most brilliantly
precious shining star.

We love receiving your poems. Send them to us at media@phauk.org and you might see yours in print or online!

More wonderful words

Our poetry feature in the last issue prompted some of you to get in touch with your creations. We were delighted to receive this ditty by member Brian Phillips, penned in 2012 after he collapsed

and was admitted to hospital. He said: *"This was an early diagnosis subsequently revised to PH. I had an operation at Papworth and am now fine. I hope it amuses you."* It certainly did!

Shove this on your finger,
While I stick this in your ear.
Don't move off the bed Sir,
Have I made myself quite clear?

Here's a push to call me,
Takes, say, half-an-hour a throw,
So for bottle or a bedpan,
Better plan your need to go.

Don't pull off the wires,
Makes the monitor upset.
(It's got two signals, loud and quick,
I hear the damn chimes yet!)

It's got three channels on its screen,
Pulse, oxygen and breath.
With space for yet another,
But I guess it isn't set.

Pulse and oxygen I can't control,
And generally they're fine,
But if I'm feeling naughty,
Hold my breath and then... Flatline!

You ought to see them run about,
Like anthill overturned,
But when the chaos does subside,
Well! Then my ears get burned.

"I've got this needle for your tum,
And this one's for your arm,
Let's not forget your thighs and bum,
Won't do them any harm!"

"Sharp scratch coming." Mercy me,
I just don't need to know.
I much preferred the older school,
Who came to jab and go!

"Can I listen to your chest?
Mmmm. Sounds, clear as a bell,
Tuned to Radio One, I think,
As near as I can tell.

Silly me, I've used me iPod
Not me stethoscope,
All these gadgets look the same."
(That really bolsters hope!)

They sent me for a CAT scan,
But the puss I didn't suss,
The operators ran and hid.
(Should I make some sort of fuss?)

But after all the pokes and prods,
The diagnosis comes.
Pulmonary Embolisms -
Blood clots in the lungs.

So now I'm on the Warfarin,
To take the clots away,
But I'm the biggest clot of all.
I hope it lets ME stay.



Genetics, PAH *and your data*



An update...

At the end of 2019, we asked PHA UK members for their thoughts about a research study which is aiming to discover whether looking at existing clinical data derived from people living with PH might help speed up diagnosis in the future.

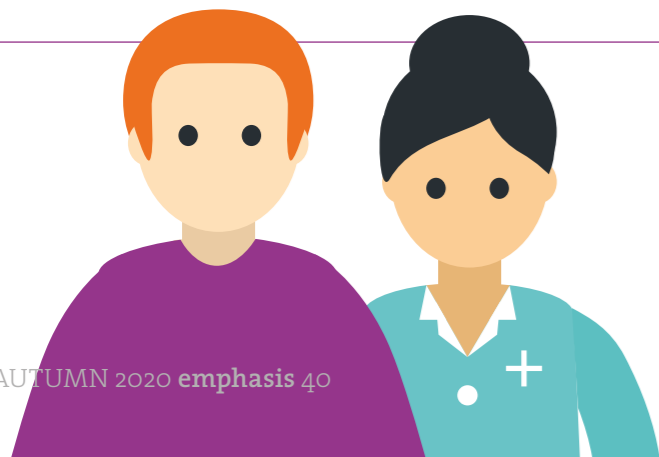
The study, led by The Royal Free Hospital in London and taking place across all of the UK's specialist centres, is aiming to paint a clear picture of the 'natural history' of breathlessness where pulmonary hypertension is suspected - allowing for earlier diagnosis and better outcomes.

This research involves accessing personal health records to obtain clinical data from tests you may have had at outpatient appointments; for example, echocardiograms, lung function, blood tests and walk tests.

Our online survey asked PHA UK members if they would be happy for data to be accessed in this way and 94% said yes.

Therefore, the researchers will not be seeking patients' consent to access previous clinical data but will be using the national opt out process to identify potential patients who may not wish for this data to be disclosed.

If you have any questions, or would prefer to opt out of the researchers using your data, please speak to your PH specialist at your next appointment or email rf.phphenotyping@nhs.net



94%



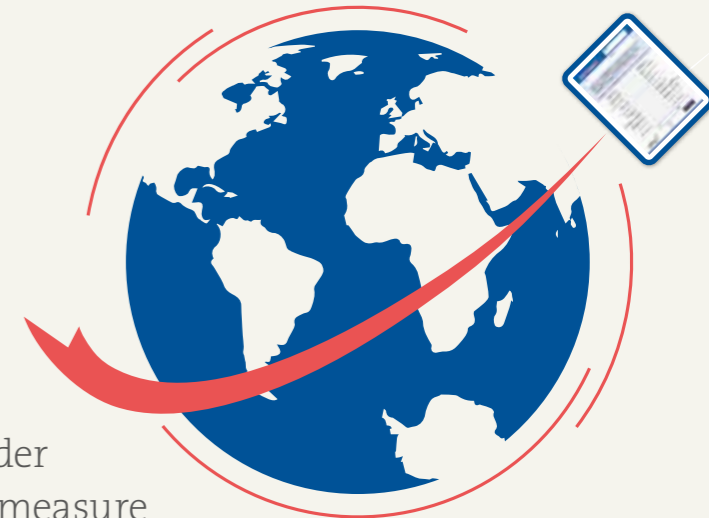
of respondents said they would be happy for their health records to be accessed without written consent.

96%



of respondents said the reassurances provided gave them confidence their data would not be shared inappropriately.

International audience for emPHasis-10 quality of life measure



The results of a study showing the broader value of the emPHasis-10 quality of life measure have now been published in a prestigious medical journal – grabbing the attention of medical professionals all over the world.

The emPHasis-10 questionnaire will be familiar to many readers as the short quality of life measure you are asked to fill in during clinic visits, designed to assess how well your treatments are working by understanding the impact of PH on your quality of life.

Your answers generate a number which can be used as a marker upon which to measure improvement.

The measure was developed during an 18-month research study led by Iain Armstrong, Chair of the PHA UK, and Janelle Yorke, Professor of Nursing at the University of Manchester. In the seven years since, it has since been translated into over 20 different languages.

A new study published in 2020, led by researchers in Sheffield, aimed to understand whether a lower emPHasis-10 score correlated with improved results in clinical tests, such as the six-minute walk test, incremental shuttle walk test, readings taken at right heart catheterisation and World Health Organisation (WHO) functional class.

The findings confirmed the correlations and the results have just been published in acclaimed peer-reviewed medical journal the European Respiratory Journal (ERJ) - raising awareness of the emPHasis-10 questionnaire amongst the international medical community.



Dr Robert Lewis, Speciality Registrar in Respiratory Medicine (pictured right) led the study and wrote the published paper. He said: *"The ERJ is one of the most prestigious respiratory journals in the world and publishes high quality research that may lead to a change in practice. By having this work published in a journal that has such a reputation and an international readership, it means that our findings are likely to be seen by PH physicians around the world and will hopefully encourage others to place more importance on quality of life scores."*



Dr Lewis had expected the results of the study to show there would be correlations with measures that tell you how well you are doing - such as WHO functional class and exercise - but the research also shows that emPHasis-10 is effective as an independent marker of life expectancy for people with pulmonary arterial hypertension.

He added: *"We were really fortunate that we were able to get data from almost all the UK specialist centres for the study, and it was a collaborative effort. Colleagues from other centres had to put work in to extract the data from their clinical databases and the paper wouldn't have been possible without their help."*



Janelle Yorke
Professor
of Nursing

"The success of emPHasis-10 is one of the most significant outcomes of the PHA UK since it was formed 20 years ago"

CELEBRATING JOSH

October marks a year since Josh Parker died at 21, and his family are determined to make the most of every day in his memory. Here, his mother Sally shares what made him so special and the lessons they have learned from his life.

“Josh was the youngest of three children and as a child he was very excitable and active. He loved dogs and would spend hours teaching ours tricks and reading them books.

When he got older, he had a wicked sense of humour and was great fun to be with. He had a huge love of the outdoors and enjoyed spending as much time as possible outside. He was very mechanically minded and spent many hours restoring a Landrover which he completely re-built.

Josh had a great love of farming and tractors and from a very early age he had decided he wanted to drive tractors for a living. In 2015 he attended Plumpton College in Lewes, East Sussex, to study Agricultural Machinery. During his time there he made a lot of good friends and they spent many hours together getting stuck in muddy situations and repairing their various vehicles.

After college Josh worked for a local farmer as a tractor driver where he was in his element. He bought himself a Springer Spaniel called Sid, who became his co-driver and went to work with him every day.

Josh was born with Transposition of the Great Arteries which was discovered when he was eight weeks old. He was transferred to hospital as an emergency, undergoing several life-saving operations, and spent the next 13 years without any kind of medical intervention. However, in 2011 during an annual check-up, he was diagnosed with pulmonary arterial hypertension.

This was a huge shock to us all, especially as Josh hadn't really shown any signs of having the disease. He was fitted with a permanent IV pump but in spite of this, quite inspirationally, Josh continued as he always had as he was determined not to let it stop him doing anything.

“In his short life he taught us a lot, particularly the importance of going for our goals. **”**

As a family we discovered that there was always a way around things, and we made sure that Josh didn't miss out on anything he wanted to do.

He went on mountain biking holidays in the Alps, swam in the sea with a dry suit, went camping and kayaking and learned to drive. Josh's school was incredibly supportive, but he was quite private about his condition and it was only a few close friends who knew the whole story.

By November 2018 Josh's health had really started to deteriorate. He spent Christmas at home with his family and in January 2019, after being admitted to hospital for further tests, he was placed on the emergency transplant list. This all came as a huge shock and it took us some time to get our heads around it.

As part of the assessment, the day before his 21st birthday, Josh had a liver biopsy which unfortunately caused major internal bleeding. He stayed in hospital for three months and at the beginning of June last year, we were told he was no longer suitable for transplant and only had days to live. He came back home to spend those days with us on the farm.

Miraculously, Josh stayed with us for just over four months and during this precious time he went on a family holiday to Cornwall, spent a week in Exmoor, camped in the New Forest, visited Harry Potter World and Cadburys World, made it to his Grandad's funeral, attended a family wedding and was able to spend time with his friends.

We invested in a stair lift for the house and a 'go anywhere' mobility scooter. Inventive as ever, Josh sourced a van so that we could also 'go anywhere' with the scooter!

As he was less able to do physical things Josh reinvented himself and became an accomplished chef, keeping busy by looking up recipes, shopping for fresh ingredients, visiting farmers markets and food festivals and cooking gourmet meals for us each day.

Sadly, Josh's life was cut short and in October last year he passed away peacefully at home with all of his family around him.

The lives of his family and friends will never be quite the same but he leaves us with a lot of very special memories. In his short life he taught us a lot, particularly the importance of going for our goals and making the most of every day - as Josh himself did.

In his final months he made it clear that he wanted to help other people with PH in the hope that one day a cure will be found - and so we are all now trying to do our best to raise awareness and funds.

Josh's Landrover has gone to his old college and students have been finishing off the project that he started. The college also gave permission for us to plant a tree in the grounds with a memorial plaque. So, in February we braved the wind and horizontal rain to plant a red beech which is now looking beautiful - a fitting tribute to an amazing young man.

Generating funds and awareness

A memorial in Josh's name has already raised over £5,000 for the PHA UK and determined to raise more, a group of his friends plan to complete a sponsored European road trip next year. By driving from Calais to Istanbul in a Skoda that cost £350, as well as generating funds the group will be ticking off an item on Josh's bucket list that he never managed to complete.

Perry Hockin, part of the team taking on the challenge, said: "Josh was one of the nicest people I've ever met. He had a heart of gold and was an inspiration to all who met him because of his resilience, kindness and vivacity.

Josh's struggle with pulmonary hypertension was a private one, however as a group we were aware of how hard he had to fight every day to maintain a normal lifestyle. By raising money and awareness for the PHA UK, we hope to donate to a cause that helps those in need."

Plumpton College is also dedicating a full day to fundraising in Josh's memory. Thank you to everyone who is doing so much to support our charity in his name.



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**

National nursing award for PHA UK co-founder

Iain Armstrong, co-founder and chair of the PHA UK, has been named **Respiratory Nurse of the Year** at the prestigious British Journal of Nursing (BJN) awards.



The award recognises Iain's work with our charity and in his role as nurse consultant within the Pulmonary Vascular Disease Unit at the Royal Hallamshire Hospital in Sheffield.

He was announced as the winner during a virtual ceremony held online at the end of August which, like many events this year, was slightly different from the original plans. The ceremony was due to be held in London in March but was postponed and moved online due to the coronavirus pandemic.

The BJN Awards aim to showcase nursing excellence, highlighting the critical contribution that nurses make to healthcare.

Iain's commitment to innovation was also highlighted during the ceremony, with the hosts citing his leading role within the development of the emPHasis-10 quality of life measure – which is now used across the world.

Iain said: "This award was completely unexpected, and I'm thrilled and humbled to have received it. **My motivation for my work has always been the patients, who are at the centre of everything.** Those I have had the privilege to nurse over the years probably won't remember my name, but I hope they remember how I made them feel.

I have worked in the rare disease area of pulmonary hypertension for 25 years and in that time, I've seen it evolve into a major service that I'm very proud to be part of.

This award feels even more pertinent following the challenges of the last few months and it highlights the vital role of nurses across the NHS.

Iain co-founded the PHA UK 20 years ago and has worked within the Sheffield Teaching Hospitals NHS Foundation Trust for 30 years. In 2005 he became the first nurse consultant to work in pulmonary vascular disease.

Dr John Wort, chair of the UK PH Physicians Group and clinical lead for pulmonary hypertension at the Royal Brompton Hospital in London, said: "**This is well-deserved recognition for someone who has dedicated decades to nursing and pulmonary hypertension.** Iain has played a pivotal role in developing the UK's specialist pulmonary hypertension services and his commitment to patients is second-to-none. On behalf of the UK PH Physicians Group, I'd like to congratulate him on this award which recognises all of this hard work."

In May 2019, Iain was awarded a Fellowship from the Royal College of Nursing in recognition of a professional career dedicated to supporting people affected by pulmonary hypertension. ●

BJN
British Journal of Nursing
**The Awards
2020
Winner**

When inviting nominations for the Respiratory Nurse of the Year category, the British Journal of Nursing said: "*This award will be presented to a nurse who has achieved excellence, or shown a flair for innovation, and translated this into measurable improvement in patient care in respiratory care.*"

Find out
more about the
global success story
of emPHasis-10
on p41



Medicines and the *pandemic*

Consultant pharmacist *Neil Hamilton* looks back on a challenging few months and offers advice on saving time and money when it comes to prescriptions.

The past six months has seen unprecedented change for us all. The COVID-19 pandemic has touched every aspect of our lives and will continue to impact us for the foreseeable future. I know that regrettably we have lost some of the UK PH community to coronavirus and our thoughts go out to the families. However on a more positive note, I also know the great lengths that all our patients have gone to in order to keep themselves and loved ones safe and well throughout the pandemic.

Whilst we are undoubtedly over the first wave, our efforts must now focus on avoiding a second wave whilst rebuilding those parts of normal life that have had to be shelved for most of 2020. From the regular communications between the centres, it is clear to me that wherever you go for your care, very detailed plans are being implemented. This will ensure that any clinic, test or inpatient stay is as safe as can be for the team - but more importantly, for yourselves.

We understand everyone's anxieties about coming to hospital having been shielded for so long, but please remember that your appointment will

be necessary to ensure your ongoing health and wellbeing is maintained.

The UK PH centres have worked more collaboratively than ever before, and I have been privileged to be part of this great collective effort. The groups of doctors, nurses and pharmacists have worked really hard to ensure that high standards were maintained throughout.

Keeping medicines going

From a pharmacist perspective, there were several really important strands to our work - firstly, ensuring that nobody went without their medication whilst in lockdown. All homecare delivery companies have been understandably stretched but rose to the challenge and continued delivering as normal.

Alongside homecare deliveries, there were fears over medicine shortages. Fortunately these did not reach critical levels either, meaning aside from rare brand-name substitutions, nobody went without.

Some of the biggest anxiety centred on patients prescribed intravenous treatments, not least because their 'PPE equipment' (gloves, hand gel, sterile wipes and so on) were suddenly in so

much demand elsewhere in the NHS. Again we have ensured that our PH patients were prioritised so that crisis was avoided. I am still monitoring stocks of these items at the homecare companies on a weekly basis for reassurance.

I hope that none of you reading this have experienced any interruption or issues with your medication during the pandemic. Whilst the pharmacists at your centre will be happy to help with queries regarding PH medication, your local pharmacist may be able to help with your access to medication prescribed by your GP. I know that virtually all of your local pharmacies offer deliveries if you cannot get to the shop and can also collect prescriptions (or receive an electronic prescription) if the surgery is only open for emergencies.

Managing prescription charges

Given the financial impact that we know a diagnosis of PH has - in addition to any impact on income from COVID-19 - it would be worth considering prescription charges to ensure you get the best value if you usually pay for medication.

"The UK PH centres have worked more collaboratively than ever before, and I have been privileged to be part of this great collective effort."



In an ideal world, PH would be one of the named conditions which entitles all patients to free prescriptions, but in the meantime please make sure you are entitled to an exemption before ticking the box on the back of your prescription.

Last year's 'check before you tick' campaign was aimed at cutting down on prescription fraud, and more checks than ever are taking place - so please don't get caught out.

There have been several sensationalised reports in some areas of the media. If you are genuinely exempt you do not need to worry at all, but I expect that you may be

increasingly expected to show proof of your exemption at the pharmacy in order to avoid paying.

For those of us that pay for prescriptions, myself included, a recent article on the Martin Lewis 'Money Saving Expert' website may be of interest. They found that over a million patients in England last year could have saved an average of £40 with an NHS pre-payment certificate. If you have not heard of these, they are like season tickets for prescriptions. You can buy a pre-payment certificate for 3 months (£29.65) or 12 months (£105.90 as a lump sum or ten direct debit instalments of £10.59).

Given that a single item now costs £9.15, you only need to pay for 12 items in a year to make the season ticket a cheaper option.

Indeed, if you have four medicines each month, an annual certificate will save you over £325 per year against paying for each item individually. Your local pharmacy can answer any questions that you may have about this. Whilst a single item charge may seem expensive when multiplied up, there are ways to save.

The quickest way to buy a pre-payment certificate is online. Visit www.nhs.uk/using-the-nhs/help-with-health-costs/save-money-with-a-prescription-prepayment-certificate-ppc/ or simply search for 'NHS Prescription Prepayment Certificate'. Once you've ordered it, you will be emailed with the certificate so you can

print and use it straight away. If you don't have access to the internet you should call 0300 330 1341 and they can make the transaction on the phone.

Looking ahead

It feels to me that September will be operation restart for most people; with children going back to school, offices and workplaces reopening for those not able to continue working at home, and for us in the NHS gearing up to clinics restarting. Most of us have used video chatting, phones, iPads and apps like never before to stay in touch during the pandemic. With a fresh start, there would be no better time to make sure that you make best use of technology in terms of accessing your medicines. You could use this time to explore technology for requesting repeat medication; this may save unnecessary trips to GP surgeries and result in a quick visit to the pharmacy once your medicine is ready - therefore avoiding any waiting around.

As always, the team at the centre and your local pharmacy will be happy to help with any medication-related queries you may have. Hopefully I may have given you some ideas that can save you some time, effort and maybe even money when it comes to getting your medicines.

Please take care and stay safe over the winter. This is always the busiest time for the NHS and this year may be especially challenging. ●

"In an ideal world, PH would be one of the named conditions which entitles all patients to free prescriptions"



theinterview

Lead Pharmacist at Imperial
College Healthcare NHS Trust

TOM COOPER

in conversation with
Mary Ferguson

Tom Cooper is Lead Pharmacist (Cardiology) at Imperial College Healthcare NHS Trust, where his role has evolved to help provide a pharmacy service in the area of pulmonary hypertension.

Tom fell in love with pharmacy as a teenager, motivated by the difference that medicines can make to people's lives. He has since completed an undergraduate degree, Master's degree, postgraduate diploma and independent prescriber course, devoting his career so far to Imperial. He has been Lead Pharmacist (Cardiology) for almost four years.



Q. Can you describe your journey from student to lead pharmacist?

A. I studied Pharmacy at the University of Nottingham and graduated in 2013. I undertook my pharmacist pre-registration training year at Imperial College Healthcare NHS Trust and have remained there since. During my initial year as a junior pharmacist I gained experience from various clinical and operational based rotations whilst also participating in a residency on-call service. I then moved to a permanent medicines information pharmacist role which provided me with some valuable skills and experiences. During these roles I completed a postgraduate diploma in advanced clinical pharmacy practice with Queens University Belfast. The next role in my career was as a cardiac pharmacist. I have grown further and developed within this role and became an independent prescriber in June 2018 after completing a course with Medway School of Pharmacy.

Q. Did you always want to be a pharmacist, and have you always had an interest in cardiology?

A. I initially thought I wanted to study medicine, but after gaining work experience in a community pharmacy after

studying my A-levels I realised I had an interest in medicines, how they work and how they can be used to make a real difference and impact on patients' lives. From covering a range of wards as junior pharmacist I found cardiology the most interesting area, with conditions that affect such a large number of people.

Q. What does a typical day at work look like for you?

A. The first thing I do is check for any handover from the day before or from the on-call pharmacist. I spend the rest of the morning on a cardiac ward; joining ward rounds and board rounds, reviewing patients, communicating with colleagues around any pharmaceutical care issues and speaking to patients to both gather information and educate them on a range of medications or medication related issues. Afternoons can include a range of tasks; including follow-up on outstanding tasks from the morning, screening homecare PH prescriptions or responding to prescription queries, completing other admin-based tasks, reviewing guidelines, or teaching junior rotational pharmacists. One afternoon each week I also provide a heart failure clinic service, with a focus on optimising medication. >>>

“I’ve learned a lot about the impact that PH can have on the lives of patients and those around them”

Q. What are the rewards and challenges of your job?

A. The rewards include getting to work with a wide range of people, learning from others and benefitting from a multi-disciplinary team environment. I enjoy being able to make a difference to patients’ lives, even from simple things such as a patient thanking you for explaining about a new medication.

Q. Who or what inspires you in your working life?

A. Colleagues within the pharmacy department and within the wider Trust. Working at a large Trust and teaching hospital has given me the opportunity to work alongside some amazing healthcare professionals and specialists that are experts within their fields. I have the pleasure of working within a great, supportive pharmacy department and with fantastic doctors and nurses – notably with those in the heart failure team and pulmonary hypertension team.

Q. What’s the best piece of advice you’ve been given career-wise?

A. Never be afraid of new opportunities or challenges and stay committed in continuing to learn. Oh, and always be nice to nurses!

Q. What are you most proud of in your career?

A. I think if I had to pick one single thing it would be becoming an independent prescriber. It’s something that has opened up great opportunities going forward and has also allowed me to feel like I can make even more of a significant impact on patient care.

Q. In what ways has your role changed during the COVID-19 pandemic?

A. During the peak of the pandemic, due to some previous Intensive Care Unit (ICU) experience my role changed to becoming a temporary ICU pharmacist, or at least helping to support our ICU pharmacy team. Since then, the main change has been the implementation of more remote reviews. At the moment (August 2020) my current heart failure clinic is mainly telephone and virtual consultations.

Q. What are the biggest things you’ve learned since working in the field of pulmonary hypertension?

A. How much there is to learn! I’ve also learned a lot about the impact that PH can have on the lives of patients and those around them – and how useful it is to have a group of PH professionals to learn from and discuss things with.

Q. What do you predict for the development of PH therapies over the next few years?

A. Tough question! I’d guess further oral prostacyclins options (to add to selexipag) and perhaps having a subcutaneous (under-the-skin) prostanoid option to help overcome some of the challenges and difficulties with IV prostanoid therapy. I also expect there to be a continuation of a more individual patient opinion-based approach to treatment plans.

Q. Finally, how do you relax away from work?

A. I’ve always been interested in sport and fitness, so I like to keep active. This includes keeping active at the gym but also playing tennis a couple of times a week. I also enjoy my food and drink and have found myself enjoying wine more in recent years. I enjoy socialising with friends and eating out but also relaxing with my girlfriend – we have a favourite wine bar in Tooting, South London, where we live. ●

A pharmacist independent prescriber is responsible and accountable for the assessment of patients with diagnosed or undiagnosed conditions, and for decisions about the clinical management required – including prescribing.

Ten islands on Two wheels

Initially thwarted by lockdown, in July Jonny Burns and his friend Kevin Sommerville were finally able to complete their Hebridean Way cycle challenge – raising over £1300 for our charity. Jonny looks back on a weekend that made memories as well as money, including an impromptu sheep rescue along the way...



I have been a keen cyclist for a number of years now and have had a love for the beautiful landscape we have in Scotland since I was a boy. I had seen a few videos and read a few blogs about the Hebridean Way cycling challenge and had put it on my ‘bucket list’. My friend Kevin, who has completed various cycle events with me, was also keen.

We decided to do it to support the PHA UK as in late 2017 we lost my father-in-law Derek Rennie after a short battle with pulmonary veno occlusive disease (PVOD), which is a subset of pulmonary hypertension. **Derek was another lover of Scotland’s beauty and was intensely passionate about the country, so it only seemed fitting that I completed the challenge in his memory.**

We had originally planned to do it in May but due to the lockdown it had to be postponed. The weather that weekend was almost perfect – with glorious sunshine and little wind – so it was a bit of a blow. We took the earliest opportunity after the islands reopened to start the challenge.

The cycle went well although we did have a few issues to overcome with some restrictions still in place. Our accommodation was limited to tents and

we had to plan our food and water stops to make sure we had plenty of fuel to keep us going.

The weather was also rather windy and although most of the time it was helping us along, there was a section on day one where we were battling a crosshead wind for several miles and had to seek shelter in a bus stop.

Something we will always remember is when Kevin jumped to the rescue of a sheep which had become entangled in a wire fence in quite a remote spot on Harris. He had to pin the sheep down and cut the wire free from around its neck using a multitool I had taken along. That, I am pleased to report, was the only time we had to use any tools on the trip as we didn’t even suffer a puncture!

Overall, it was a special experience and will take a bit of beating. If it wasn’t for the temperature it would be easy to mistake some of the beaches as being somewhere in the Caribbean. And we were certain that Derek was looking down on us as the weather was mostly in our favour.

I am sure Kevin and I will be signing up to more challenges in the future, and we already have some rough plans to walk to the most remote pub in Scotland and back. Watch this space! ●



Setting off for the challenge



Jonny (right) and Kevin



Derek Rennie



Some of the stunning scenery



The Hebridean Way cycle route takes riders through the length of the Outer Hebrides, covering 185 miles across ten islands.

Find out more about how people have been supporting the PHA UK in our Fundraising Focus on page 24.

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!

New
RESOURCE

For any
sexual
orientation,
gender or
age

Featuring
interviews with
people affected
by PH

INTIMACY & PH



Helping you understand how pulmonary hypertension might affect your physical relationships

Order now for free
at www.phauk.org

You can also order by
emailing office@phauk.org
or calling 01709 761450.

And finally... 

Another reminder about getting a flu vaccination!

Colder weather is on its way and if you have PH, it's vital you get your flu vaccine.

Where?

You can get your vaccine free on the NHS at your GP surgery or a local pharmacy offering the service. Some community pharmacies now offer flu vaccination to adults at risk of flu, including people with long-term health conditions and carers. If you have your flu vaccine at a pharmacy, you do not have to inform a GP. It's up to the pharmacist to do that.

When?

The best time to have a flu vaccine is in the autumn, from the beginning of October to the end of November. But do not worry if you have missed it, as you can have the vaccine later in winter. Ask a GP or pharmacist.

Find out more about the flu vaccine at www.nhs.uk



In your winter issue of Emphasis...

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

PH and the pandemic

The results of our major survey

Lifting the lid on hospice care

How this type of supportive care can help

Our year

A look back at 2020 in the life of the PHA UK

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

You can get involved in Emphasis too:

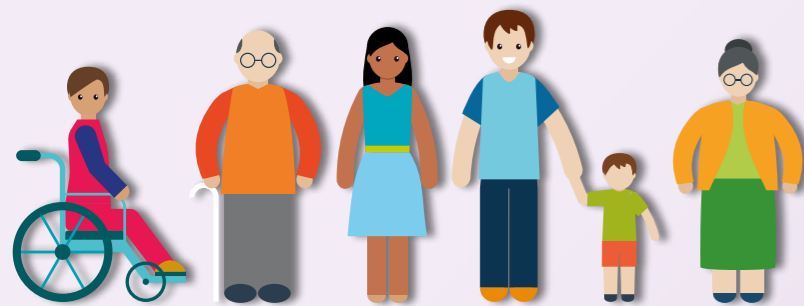
Emphasis Reviews - read a book, used an app or seen a film you think other readers may be interested in? Tell us about it!

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.

Little phighters - do you know a child who would like to be part of our Green Leaf Crew?

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.*

*Are you living with PH, or do you
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 4,500 members in a unique network of support and inspiration.

Join **FREE** today at www.phauk.org
Call us on **01709 761450**
Email us at office@phauk.org
Or simply fill in the form below
and return to us.



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



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? _____

**Influence.
Hope.
Integrity.**

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 financial advice from qualified professionals via our partnership with Turn2Us
- Fundraising ideas and guidance

PHocus2021

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

STRATEGIC PARTNERSHIPS

Turn2us
Ashtree Communications
(communications)
Creativesmith
(design & branding)

OTHER CHARITIES
(National & International)
Collaborative working and learning

EXTERNAL SUPPORT

Bookkeeping & Financial Auditing
Communications and design
Pharmaceutical & Industry
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TRUSTEES

Sue Townsley
Tracie Parnell

PHA UK
How we're structured

PHA UK Contact Details

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Email: office@phauk.org
Address: PHA UK Resource Centre,
Unit 1, Newton Business Centre, Newton Chambers Road,
Thornccliffe Park, Chapeltown, Sheffield, S35 2PH
Registered Charity Number: 1120756

Anxiety UK

PHA UK works closely with our partners at Anxiety UK. To speak to someone about how you are feeling, call the dedicated PHA UK helpline on: **0844 332 9010** or email: phauk@anxietyuk.org.uk

Turn2us

PHA UK has joined forces with Turn2us, a national charity that helps people in financial hardship in the UK. The charity aims to help people in need to access support; and provides a range of information and resources on welfare benefits, charitable grants and other services via its website: www.turn2us.org.uk. Through our partnership with Turn2us, PHA UK members can also use the Turn2us Benefits Calculator and Grants Search on our website at www.phauk.org

Do we have your correct details?

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

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

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

CUT-OUT AND KEEP

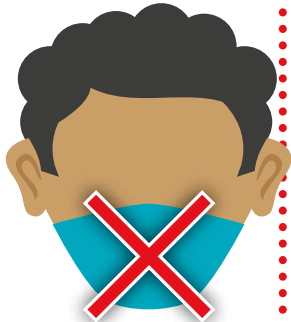
Mask exemption notices

If you have pulmonary hypertension, you do not have to wear a mask or face covering if it affects your breathing or makes your symptoms worse. You are exempt even in places where wearing a mask is required, such as on public transport or in shops. We understand that PH is an 'invisible illness' and therefore those around you may not understand why you are not wearing a mask. That's why we have designed these cut-out-and-keep notices that you can carry with you in your pocket or purse, and display if you are challenged. We hope you find them helpful!

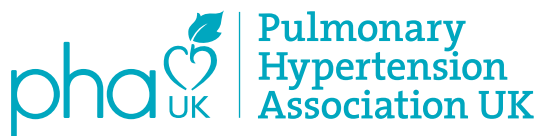
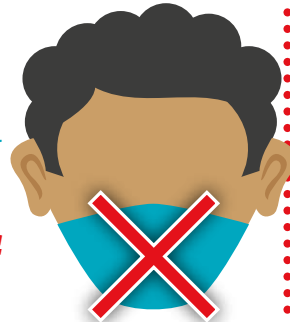
You can print out additional copies by visiting www.phauk.org



I AM **EXEMPT**
FROM WEARING
A FACE MASK
BECAUSE I HAVE
**BREATHING
PROBLEMS**



I AM **EXEMPT**
FROM WEARING
A FACE MASK
BECAUSE I HAVE
**BREATHING
PROBLEMS**



I AM **EXEMPT**
FROM WEARING
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