

SUMMER 2019

# emphasis

The magazine for supporters of PHA UK [www.phauk.org](http://www.phauk.org)

**Move  
more this  
summer**

4-page special  
feature

**LOVE, PH  
AND US**

Andy and Lynsey  
share their story

**“I’VE LEARNED  
THAT I’M STRONGER  
THAN I THINK”**

Alysha looks back on  
a year since diagnosis

***Selexipag and  
the treatment  
jigsaw***

*Where does it fit?*

**Plus...**

Supporting  
the Transplant  
Games

Handheld  
fans and  
breathlessness

Our  
conference  
in pictures

Medical  
humanities  
explained

...and much,  
much more!

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# Welcome

Welcome to the summer issue of Emphasis. We hope the sun is shining as you're reading this – wherever you may be!

You'll notice a bit of a theme in this issue. An increasing amount of evidence points to the benefits of getting active with PH, but we know it's not always easy to get started. That's why we've dedicated a special feature to breaking down barriers and helping you to move more. Turn to page 27 and get ready to be inspired. Continuing the subject of exercise, we're delighted to bring you news of our sponsorship of the upcoming British and World Transplant Games. Read all about it and meet two participants from the PH community on page 22. It was great to see so many of our members and friends at our special 20th anniversary conference in May. The theme was #StrongerTogether and that's what the PHA UK is all about – so thank you for being part of our journey. As well as strength in togetherness there is also strength in making ourselves heard, so we've included a special survey with this issue.

We know that PH has an emotional impact, but it's important that we find out just how many people are affected, and how, so we can focus our support in the right places. We'd really appreciate you spending a few minutes sharing your thoughts and returning the anonymous questionnaire to us in the pre-paid envelope provided. **Enjoy the summer, whatever you get up to.**

*Iain Armstrong*  
**Iain Armstrong**  
 Chair of PHA UK  
[media@phauk.org](mailto:media@phauk.org)



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 Can you help by sharing your voice?



*"Thank you for being part of our journey"*



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# Emphasis *exchange*

## The evolution OF EMPHASIS

We were doing some digging around in the PHA UK office recently and came across one of our very early newsletters, from all the way back in 2001. We think you'll agree that Emphasis has come a long way in the last 18 years! The magazine you are holding in your hands today is an award-winning, much-loved publication and we are really grateful to everyone who contributes to its pages. Thank you!



**PH AWARENESS WEEK 2019**  
4-10 November

## Save the date for PH AWARENESS WEEK 2019

This year's PH Awareness Week takes place Monday 4th – Sunday 10th November and as always, there will be lots for you to get involved in. Look out for a special feature in the Autumn issue of Emphasis.

**DON'T FORGET!**  
If you have any news and views to share via the Emphasis Exchange please e-mail [media@phauk.org](mailto:media@phauk.org)  
Keep in touch via Facebook and Twitter too!



## Social Media Round-up

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

**f Laura Richards**

812 miles to cycle from Bilbao to Gibraltar. 221 complete, 130 miles to cycle today. Go James!



**@JimWhiteCurePAH**

Let's make all of our patients aware that increasing physical activity is safe and helpful for their energy, their symptoms, and their sense of well-being/independence.

**f Isla Dagg**

Before treatment and after! The left photo was taken before diagnosis, and the right was taken 22/4/2019. I push my body to the limits every day, and can't wait to see my team at Freeman to show them how far I've come!



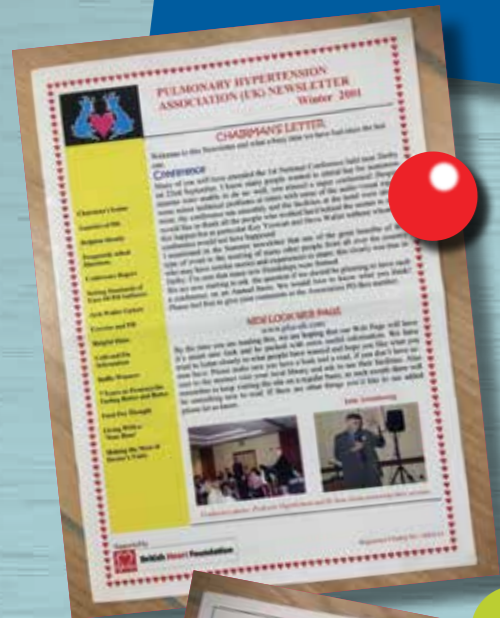
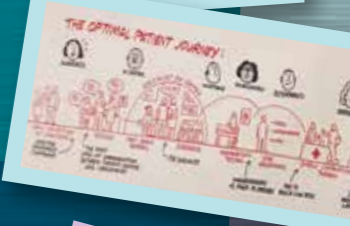
**@Lou26Chadburn**

Had a few friends and family over to raise awareness, and donations for taking part in a mini competition #phauk @PHA\_UK #minifundrasier



**@wginsing**

Our message to the #PH community at the @PHA\_UK conference on #WorldPHDay. A #PAHPatientCharter to improve outcomes for everyone with this rare disease #StrongerTogether



2001 NEWSLETTER



## Your Emphasis selfies!



## Celebrating Erika

DEAR PHA UK,

Please find enclosed a cheque donation of £120 which was raised by friends and family in memory of my daughter Erika Charlotte Cowie.

Erika had pulmonary arterial hypertension and this donation is in the hope of finding a cure.

I enclose a photograph of Erika when she received the Award for Endeavour at her school prize giving. She was nominated for this award because of her attitude, courage and determination throughout her illness and she inspired both teachers and pupils alike.

Since Erika passed away the school has now created The Erika Cowie Cup award which is given to pupils for their determination when dealing with adversity. It is a great honour that she is recognised this way and this photo reminds me that her illness did not prevent her achieving.

Kind regards  
RACHEL COWIE



Louise Gould with her sons

DEAR PHA UK,

As a child I knew my mum was ill. We'd see her taking medication, explaining to us that she needs stuff to help her heart.

Understanding as a child is hard but as far as we knew, mum wasn't well and needed her boys to help out and be good for her. We watched her trying her best day in, day out. Trying to be a mum when she couldn't.

It hurts me now, thinking about it. Now that I understand her illness. I'll never know what she went through physically and mentally, but I get that it must have been difficult. Imagine having a mum who wants to be a mum but can even walk up the stairs without running out of breath. Being pushed in a wheelchair when she wants to walk her children to school. Watching us play from a distance when she'd rather join in....

I treasure memories of my mum. I live every day missing her. Pulmonary hypertension took her life and this illness was so unknown to us until my mum suffered with it.

Now, me and my brothers openly talk about it and explain what it's like and how it affects you. My little brother fundraises for it and I aim to do so as well. My mum was a beautiful woman inside and out and she deserved to be the mother she wanted to be. But saying that, I'm proud of my mum for how she pushed to be a mum, knowing that it would end soon yet staying strong for her boys. It fills me with pride.

Louise Gould. A brave, strong, well-loved and caring mum. To all those in similar situations - take each day like it's your last day with your loved one suffering. Make them happy. Make everyone happy. You treasure those memories.

Adam

Dear PHA UK

I had a Pulmonary Endarterectomy in April and I would like to share my experiences. The surgery lasted about ten hours. I had been well supported and informed about the surgery both by Mr. Ng and the nurse specialist Lily so although very anxious, I knew exactly what would be happening.

Following surgery, Mr. Ng rang my wife to let her know that all was well and that she could visit me in an hour. I was intubated from that Monday until the Wednesday morning then given an oxygen mask. Staff tried to sit me in the chair that day but I was too weak, but managed to do so the next day. I remained on the intensive care unit until the Sunday and was discharged on the Tuesday.

My family just kept reminding me that it was "small steps" and that's something everyone should remember. I had various tubes, drains and wires in me but with the removal of each one I felt it was one step nearer to home.

I cannot thank or praise all the staff enough. They made what could have been a very frightening experience bearable.

As we live four to five hours from the hospital, we hired a large cottage so that our children and families could come and stay to support my wife and visit me. This proved to be an excellent idea - they are called Driftway Cottages (you can find them by searching on [www.cottages.com](http://www.cottages.com)) and the postcode is SG8 0BU. I can happily recommend them.

Kind regards

Chris Murray



## Shaping the future of care

Representatives from specialist centres across the country gathered at the PHA UK resource centre in May for an initial exploration meeting about the specialist PH service development and specification for the next five to ten years. The discussions were based around the NHS England peer review process, which took place in 2017/18. The PHA UK will play a central role in helping to shape the future of the specialist pulmonary hypertension service and we'll keep you updated on how things evolve.





*"An inspiration to nursing and medical staff"*

Dr Iain Armstrong, chair and co-founder of the PHA UK, has been recognised with a Fellowship Award by the Royal College of Nursing (RCN).

Iain, who also works as a nurse consultant within the Sheffield Pulmonary Vascular Disease Unit, was awarded the accolade at the RCN annual Congress in Liverpool in May. The Fellowship is given to individuals who have 'made an exceptional commitment to advancing the science and practice of nursing and the improvement of health care'. Only a small number of Fellows and Honorary Fellows are elected each year.

During his work as a nurse, Iain recognised the need for a charity to support people diagnosed with PH, so he co-founded the PHA UK with Kay Yeowart in 1999. The organisation now has 4,500 members and remains the only UK charity dedicated to supporting people affected by PH.

"I was genuinely surprised and humbled to hear about the award," Iain said. "To be recommended by your colleagues in the area you've worked in for 30 years is special – I don't think any recognition can surpass that."

"After leaving school with one O-level and being told I wouldn't make it, I'm very proud of what I've achieved."

Kay Yeowart, co-founder of the PHA UK, said: "Iain has dedicated much of his life to his patients and charity members' wellbeing, giving enormous amounts of his personal time to the PHA UK. Through the charity and his work, he has enhanced the lives of many patients and their families."

"Iain has the enthusiasm to continue working with others to ensure the success of the charity for many years to come."

Iain was the first nurse consultant to work in pulmonary vascular disease after enrolling as a nurse in 1982. He became a Doctor of Medical Science in 2015 after completing a PhD on pulmonary hypertension and the importance of hope in life threatening illness.

Carl Harries, clinical nurse specialist at the Royal Brompton and Harefield Hospital in London, who nominated Iain for the award, said: "Iain's commitment to patients and raising



PICTURED L-R: Dame Donna Kinnair, RCN Chief Executive and General Secretary; Professor Anne Marie Rafferty CBE FRCN, RCN President; Dr Iain Armstrong; Sue Warner, Chair of RCN Council.

**"I was genuinely surprised and humbled to hear about the award."**

.....  
awareness of PH as a rare condition has really stood out to me. He has a great understanding of their needs, and a huge determination to fight their corner."

Professor David Kiely, director of the Sheffield Pulmonary Vascular Disease Unit, said: "Iain is a fantastic colleague and I have been privileged to have worked with him for nearly 20 years."

"He remains an inspiration to nursing and medical staff both nationally and internationally and as the Chair of the PHA UK he has pioneered the development of a support network for people affected by pulmonary hypertension." ●

# Reducing breathlessness with a handheld fan

Research has shown that a cool draught of air from a handheld fan can be very helpful in reducing the feeling of breathlessness. Here's our guide to making the most of them.

Handheld fans can provide short-term relief if you are struggling with your breathing. When cool air goes in through your nose, receptors in your nose send a signal to your brain that reduces the sensation of breathlessness.

They can be useful after you have done activities which make you breathless, such as climbing the stairs, and provide relief in situations where being breathless causes you to panic. The time you take to get your breath back after physical activity can be shorter if you use a handheld fan. In a 133-person study carried out in 2017, 72 per cent of participants found some benefit and 11 per cent found substantial benefit from handheld fan use.\*

## Using the fan

When looking to buy a fan, it's important to make sure it has three or more blades, as these fans provide a stronger airflow, so they are more effective.

- Get into a comfortable position such as sitting in a chair or leaning on a work surface when standing.
- Hold your fan approximately six inches (15cm) away from your face.
- Aim the draught of air towards the central part of your face so that you feel the draught around the sides of your nose and above your top lip.

Some people have to use the fan for just one minute before they feel their

breathlessness ease; for others it may take up to ten minutes. There is no limit to the amount of time you can spend using the fan, and it can be used at the same time as nasal oxygen.

It should be noted that using a handheld fan does not replace breathing exercises or other techniques taught by your physiotherapist to manage your breathlessness effectively. You should continue to practise these techniques so that you don't become too reliant on the fan, for example if you forget to take it out with you or the batteries run out.

Dr Janelle Yorke, Professor of Nursing at The University of Manchester, told *Emphasis*: "The advantage of a handheld fan is that you can take it with you wherever you go. It's a very easy and cheap method of getting a cool flow of air across your face."

"When patients feel breathless they often want to open a window to get that instant fresh air, but using a handheld fan simulates that in any environment."



PHA UK branded handheld fans are now available for just £3.99! Visit [www.phauk.org/product](http://www.phauk.org/product) to order online or call the office on 01709 761450. Batteries are included.

\*Contributions of a hand-held fan to self-management of chronic breathlessness. Tim Luckett, Jane Phillips, Miriam J. Johnson, Morag Farquhar, Flavia Swan, Teresa Assen, Priyanka Bhattarai and Sara Booth



# The year that changed my life

In May 2018, Alysha Sharma was told she had pulmonary hypertension. The 12 months that followed have been spent coming to terms with the diagnosis, adapting to life with the condition, and learning to look to the future. This is her story.

**M**y symptoms started when I was 21, just after my birthday. I collapsed whilst on a treadmill at the gym. I went to hospital, had tests, and was told I had an irregular heartbeat.

I didn't think much of it. From there, for about a year, I had more breathlessness and struggled to walk upstairs or walk the dog. Even standing up suddenly I couldn't do. It was debilitating.

I had lots of different tests at my local hospital for about a year. Half the doctors told me there was nothing wrong and the other half told me there was something wrong, but they didn't know what.

I was eventually referred to a rheumatologist, who referred me for a right heart catheter, and I was diagnosed with pulmonary hypertension. **I'll always remember the date: 1st May 2018.**

I was devastated. I felt lost. I didn't expect it to be something so serious. I thought I had something that could be fixed, or that could be made better. I suppose I didn't really accept it.

**The first few weeks after being diagnosed were a blur.** I just remember crying for weeks and not believing what the doctors were telling me. I hoped they had got it all wrong. I was frustrated, and scared about what my future was going to hold. I wanted to wake up and for it all to be a nightmare.

My family were amazing throughout this time, so supportive and positive. Some of my friends were amazing too, however some friends weren't so great. **I suppose if you haven't been through something like this yourself then it's hard to understand.**

Life feels quite different to before I got ill. Being young, I used to just be able to get up and go, but I can't do that anymore; it takes me about two hours to get ready in the morning.

I wanted to travel around Australia and New Zealand once I'd finished my degree, maybe even settle there. At the moment though, I don't think I could do anything without my mum. She is amazing, she does everything for me.

**Physically, I feel better than I did as the medication is helping.** Emotionally though, I have no confidence, I have anxiety, and I don't believe in myself anymore - which is really hard.

Despite all the changes, I do try to stay positive. **I take each day as it comes, as you never know what the future holds - whether you're well or not.** I always know there are people worse off than me and try and live each day to the fullest, as much as I can.

I'm at university, studying for a degree in occupational therapy, and love what I do - so that's a massive coping mechanism for me. **I live by the motto that I have PH, it doesn't have me.**

**I've learned that I'm stronger than I think.** My family and friends tell me all the time and I've just started to believe it! I know that whatever happens, I have tried to live life how I want to and be thankful for every day I have with friends and family.

My message to someone who has just been diagnosed with PH is this:  
**“I know it seems all bad and you might feel like you can't go on anymore. You probably feel lost and confused and nothing makes sense anymore. But you can do this, you can live life to the fullest. Whatever comes your way, never regret anything. Although there is no cure and probably no explanation, I believe everything happens for a reason - you just don't know what that reason is yet!”**



# 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.



**SIGN UP TODAY!**  
Visit [www.phauk.org](http://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](http://www.gamblingcommission.gov.uk) PHA UK Registered Charity No. 1120756



# Dancing for Matthew



Two dance schools in Chorley, Lancashire showed their support for a young member who has PH with a special performance at Empire Theatre in Blackburn. *Chris Coates* reports.

**Y**oungsters at Charlotte Killick School of Dance and drama and theatre school Starlight Kids put on a special 'One Night Only' performance on Saturday 27 April, raising over £1000 for PHA UK.

The showcase was organised by Charlotte Calvert, owner of the dance school, and her sister, Samantha Killick, who runs Starlight Kids. Over 60 children took part in the show performing a range of routines from ballet to modern street dance, as well as a theatre production and choir.

*"It was a fantastic evening and everyone who took part did amazingly well,"* Charlotte said. *"We also had great support from the audience – we raised over £500 from raffle and programme sales alone."*

Charlotte wanted to raise money for PHA UK because her three-year-old son Matthew was diagnosed with PH as a newborn.

*"Matthew was born with a hole in his heart which put pressure in his lungs, meaning the arteries at the bottom of his lung were not expanding properly,"* she said.

*"He is on seven nebulisers a day, and he has to have oxygen when he sleeps, as well as bosentan. At the moment, it is all under control with his medication. His nebulisers have reduced the pressure in his lungs but it is still there."*

Matthew joins in with the dancing lessons at Charlotte's dance school and made his debut performance in the One Night Only show with a Chick, Chick, Chicken routine.

***"He loves dancing and it is really good for him to develop his co-ordination,"***

*"He loves dancing and it is really good for him to develop his co-ordination,"* Charlotte added. *"He gets tired more quickly than the other children, but he powers through!"* Charlotte set up her dance school 15 years ago, and her sister Samantha launched Starlight Kids eight years later. *"Both of us have been dancers since the age of four and it was always our ambition to have dance schools. We just love teaching the youngsters and seeing them progress,"* Charlotte said.

The dance schools organise a charity show every other year to fundraise for worthy causes, with PHA UK being the nominated charity this time around.

*"We wanted to do this fundraiser to help PHA UK do research to find a cure,"* Charlotte added. *"In my experience most people assume hypertension is about blood pressure, but as we know it is completely different and not always visible."*



Matthew with Samantha (left) and Charlotte.



# Are you struggling with stress or anxiety?

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

- Dedicated helpline service 0344 332 9010
- Email support via [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk)
- Assessment and therapy provision for those who need emotional support
- Training and resources for PHA UK professionals and members



To find out more about how Anxiety UK can support the emotional aspect of having a diagnosis of PH contact us today on **0344 332 9010**, email us at [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk), or visit [www.anxietyuk.org.uk](http://www.anxietyuk.org.uk)



U3A

## BRINGING PEOPLE Together

If you're feeling isolated or are finding it difficult to cope with your diagnosis, getting involved with U3A could help. *Chris Coates* found out more.



Sue Stokes



**T**he University of the Third Age (U3A) is a national charity made up of retired and semi-retired people – of all ages! - who come together to continue their educational, social and creative interests.

U3A activity groups include everything from learning new languages, crafts, and writing classes to guitar lessons, belly dancing and computing.

Every U3A member is a volunteer, and people are encouraged to share their own skills as well as learning from others.

Sue Stokes, regional trustee for the charity's Yorkshire and the Humber region, said: "U3A is for people in their 'third age', but the important thing is that we never ask anybody's age – we have members as young as 40 and those in their hundreds."

U3A has over 424,000 members and there are 1039 U3A area groups

across the UK. "Our key principles are mutual benefit and learning," Sue said. "If you can do something yourself, can you teach other people to do it? Or, if you've always wanted to learn how to do something, are there people within U3A who can teach you or if not, can we as a collective find out how to do it?"

"The main commitment we ask for is that people contribute to the group they are in. But I can guarantee that U3A members get a lot more out of being in a group than they put in."

While U3A does not provide physical care, its work can support people with long-term illnesses like PH.

"We have people with all sorts of conditions, some of which are obvious and some which are not obvious," Sue added. "The point of U3A is you do as much as you want, when you want – you take it at your own pace."

It's very easy to join your local U3A –

membership fees vary but they can be as little as £10 per year.

"We find that people who gain the most are those that are looking for friendship, are recently bereaved, or have become isolated, whether that's for geographical, personal or health reasons," Sue added. "We have evidence that joining U3A has changed people's lives, and we have recently started working with medical professionals who are now recommending joining a U3A group for patients who would benefit from friendship, learning and exercise."

To find the nearest U3A in your area, go to [www.u3a.org.uk](http://www.u3a.org.uk)  
To watch a video of Sue Stokes talking about how U3A could help you live well with PH, head to [www.phocusonlifestyle.co.uk](http://www.phocusonlifestyle.co.uk)

4-6TH  
MAY  
2019

PHA UK CONFERENCE  
20<sup>th</sup>

# Anniversary Celebrations

Heythrop Park Hotel, Oxfordshire

# MAKING memories

There were smiles all round at our special conference to kick-start the PHA UK's 20th anniversary.

People with PH, and their family and friends, came together at the beautiful Heythrop Park Resort in Oxfordshire during the early May bank holiday.

As well as expert talks about subjects including transplant, wellbeing, CTEPH and drug treatment, visitors young and old enjoyed bingo, Tai Chi, crafts, mini golf and even beatboxing.

PHA UK member Tess Jewson delivered a special music workshop and a gala dinner brought everyone together to celebrate the association's 20th anniversary with delicious food and entertainment.

Thank you to everyone who made the weekend so special!



All of the conference talks are available to view online at [www.phocusonlifestyle.org](http://www.phocusonlifestyle.org) or by emailing [media@phauk.org](mailto:media@phauk.org)

A&L

# Love, PH and us...

When Lynsey Childs from Darlington and Andy Sweeney from Merseyside started chatting on the PHA UK Facebook group, they had no idea they would end up falling in love. This is their story.

**ANDY:** I had just got my new car through Motability, and I put a photo of me standing next to it up on the Facebook group. Lynsey commented that it was a nice car, and that was it. I replied and we started talking about medication. I then private messaged her and we spent a couple of weeks chatting online, as friends.



**LYNSEY:** We told each other we were single and that we weren't interested in meeting anyone because we didn't really see the point - you don't know how bad the illness is going to get and what's going to happen.

**A:** Yes, it's an upsetting illness. We chatted for a few weeks and then Lynsey asked about coming down and taking the car for a long drive.

**L:** Neither of us had met anyone else with PH, so I think at that point we were just interested in meeting another PH'er. We've now been together about seven months! We see each other as often as we can afford to. Neither of us work, but Andy tends to drive up to me and I go down to him by train. On average we see each other every couple of weeks. We both have kids and they have all met. I think they found it strange to begin with, as we both have the same illness, but they understand it now.



**A:** Our relationship works because we 'get it'. If you've got a partner who hasn't got PH it's difficult. If you're tired or you don't want to do something, they think you're being lazy, and you start to think that yourself. Whereas if I tell Lynsey I'm tired it's not questioned, because we both totally get it.

**L:** One day we may both be totally fine, and then the next day one of us might be flat out - we get the whole extreme of the condition. We have found out that our symptoms are quite different. For example, Andy can lift his arms, but I can't. I can't change a light bulb or anything like that, but my walking is better than his. It's been quite interesting to learn.

**A:** We both never imagined we would be with someone else with PH. I hadn't given up, I just didn't think it was worth it. In my head, putting somebody else through this just wasn't fair.

**L:** I think when it was clear we both liked each other, we were both a bit scared at first. We both took a step back and sort of said "can we do it, can we let ourselves go?" We just go at our own pace.

**A:** I think it also works because we're not with each other all day, every day. Although we do FaceTime each other several times a day! Lynsey is really kind and understanding, and always makes me smile.

"Andy makes me laugh, and he looks after me. He's a gentleman"  
**LYNSEY**

"Everyone has got something to give; why should this illness take that away from us?"  
**ANDY**



The picture that started it all off.

You can watch our interview with Andy and Lynsey in a special video online at [www.phocusonlifestyle.org](http://www.phocusonlifestyle.org)



## ME & MY JOB



Welcome to our regular column where PH professionals and associates tell us more about themselves and their work. This issue meet **Stuart Craig**, clinical nurse specialist in the Royal Brompton & Harefield specialist pulmonary hypertension service.

**WHAT DOES YOUR JOB INVOLVE?** I work as part of the CNS team at the Royal Brompton where I've been in post for the last year and a half. I've been at the Brompton though for over ten years, so I've been working with the patients and PH team for quite some time now. In my role I will see patients in clinic as well as when they are admitted into the wards. We're also in touch with patients by phone and email.

**WHAT'S THE FIRST THING YOU DO WHEN YOU GET TO WORK, AND THE LAST THING YOU DO BEFORE YOU LEAVE?** Check the answerphone and emails to see if anyone has been in touch. Patients and relatives often need to speak to us about issues regarding symptoms, medication, or general advice regarding their PH. A good cup of coffee also helps to start the day. The last thing is to turn everything off as we leave the office with maybe another coffee to steady myself for the commute home.

**WHAT DO YOU ENJOY MOST ABOUT YOUR WORK?** I'm lucky with the team of people I work alongside at the Brompton both in the PH team and the staff in the wards and clinics. The best thing about my work though are the patients and families we work with. They are an engaging group of admirable individuals and a real pleasure to spend time with.

**WHAT ARE YOU MOST PROUD OF IN YOUR CAREER?** There is no single aspect that stands out. Moments of great pride come when you don't expect it in conversations with patients and family, when you realise the difference that we can sometimes make.

**TEA OR COFFEE?** Coffee. Definitely coffee and ideally more than one.

**WHAT DO YOU LIKE TO DO OUTSIDE OF WORK?** Spend time with friends and family. I have three children and they manage to fill my time quite successfully!

**CAN YOU TELL US AN INTERESTING FACT ABOUT YOURSELF?** In my younger years I used to play the bagpipes in the local pipe band where I grew up in Glasgow. Thankfully now though my bagpipes are with my much more capable and musical nephew in New Zealand. Much better for all concerned.

If you work with people with PH and would like to answer our Q&A please e-mail [media@phauk.org](mailto:media@phauk.org)

# A SUMMER OF SPORT... *with a difference*

All eyes will be on Wales and the North East this summer, as participants from all over the world gather to celebrate organ donation and life after transplant.

**T**he World Transplant Games take place in Newcastle in August, with the Westfield Health British Transplant Games preceding them in Newport in July – and the PHA UK has been chosen to sponsor both for the first time.

Although they take part in different events, all the athletes have two things in common; they have received transplanted organs and are making the most of their gift of life.

**The PHA UK is sponsoring darts at the British Games, and Petanque – a ball game similar to boules – at the World Games.**

Iain Armstrong, Chair of the PHA UK, said: "This is a golden opportunity to raise awareness of pulmonary hypertension as a disease, to encourage organ donation, and, just as importantly, to talk about transplantation as a potential treatment pathway.

"We chose the events to sponsor carefully. Darts has a strong social element to it, with the added benefit of bringing people together, which is very important to us as a rare disease charity. And Petanque is accessible to most people, regardless of fitness levels.

"We're really excited to be supporting both the World and British Transplant Games, which both show that what might be impossible one day, can be possible the next."

More than 60 transplant teams from across the UK are expected to take part at the British Games, which are held every year. The World Transplant Games, held biannually, will see around 3,000 competitors from 70 countries descend on Tyneside for the sporting celebration.

In 2017 the World Games were held in Malaga, Spain, and 2021 will see them head to Houston in Texas.

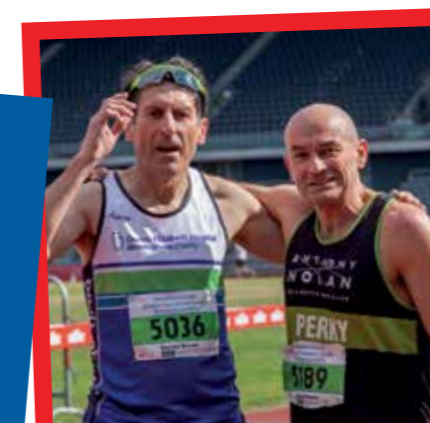
**"This is a golden opportunity to raise awareness of pulmonary hypertension."**

Professor Paul Corris, former Director of Cardiopulmonary Transplantation at the Freeman Hospital in Newcastle, and now Medical Director of the World Transplant Games, added: "Because pulmonary hypertension is a rare condition, sometimes it's difficult to engage with the public around it. This sponsorship gives a glorious opportunity to do that, to showcase PH, and show what we can do with modern medicine to restore health and vitality.

"The ability to work with PHA UK on this is perhaps the first step in what will become a long tradition of mutual support."

**WORLD TRANSPLANT GAMES**  
When? 17-24 August 2019  
Where? Gateshead, Newcastle, UK  
[www.worldtransplantgames.org](http://www.worldtransplantgames.org)

**BRITISH TRANSPLANT GAMES**  
When? 25-28 July 2019  
Where? Newport, Wales  
[www.britishtransplantgames.co.uk](http://www.britishtransplantgames.co.uk)



Turn the page to read about two people who have lived with pulmonary hypertension and are taking part in the British Transplant Games in July...



## OUR GAMES

Michelle Hemmings and Dan Peel are both taking part in the British Transplant Games in July, in very different events. The pair, who lived with pulmonary hypertension, received their transplants within a few hours of each other in early 2018.

A SUMMER  
**OF SPORT...**  
*with a difference*



*“I wanted to prove I could get back on my feet”*

*“I’m really looking forward to the buzz on the day”*

**Michelle Hemmings, 47** from Birmingham, is taking part in the walking event. This is her first time competing.

“I’d heard about the Games a few times and I always thought it could be me one day. They were in my hometown last year, in Birmingham, but I wasn’t well enough, so I’m really excited to be able to be part of them this summer.

My event involves walking 1.8 miles and my goal is to finish it. I know that on the day, I’m going to feel quite emotional.

I’ve been doing quite a lot of training. I started walking a few months after my transplant, initially with family and friends, but recently on my own too.

**I definitely think that signing up for the Games has given me the motivation to keep going with it and I now head out every couple of days.**

I tend to walk around the block, which takes around 20 minutes, or I drive to my local park and walk around there.

Walking helps boost my energy levels, helps my breathing, and helps to strengthen my muscles. It also helps me mentally. I don’t over-exert myself; I just do what I can.

I feel a sense of achievement when I finish a walk as before my transplant, I could only manage two or three minutes, carrying oxygen. It was hard to go out and about with it, as people would look at me, or ask me questions, and I just felt like going back home again.

But now, I don’t have to carry oxygen, I can breathe unaided, and I can walk for up to an hour with regular short breaks.

I’ll be heading to Newport in July with my daughter, my Mum and two friends. I’m really looking forward to the buzz on the day and seeing all the other participants.”



Michelle with her daughter, Nicole

**Dan Peel, 26** from Reading, is competing in the golf, ball throw, javelin, shot-put and 25-metre relay events. This is his second time taking part in the British Transplant Games.

“Last year I won gold in the ball throw and bronze in the javelin, just five months after my transplant.

I wanted to prove I could get back on my feet, and I’m doing it again because it’s a great chance to catch up with my team, who became like a little family.

Also, as a second-year competitor, it’s a good chance to see those who have had their transplants after me and to encourage them that they can also do whatever they put their minds to.

In terms of training, I’ve been playing cricket to help with my throwing and doing lots of cycling for general fitness. Before transplant I wanted to make sure my body was as fit as it could be to undergo the trauma of surgery and to get back on my feet as quickly as possible, which I certainly did.

**Post-transplant the training has been strengthening my lungs and getting my body back in shape. It also helps immensely with the mental side of things.**

I’m really looking forward to the Games and showing what can be done post-transplant. It’s really inspiring for those looking in and the Games are a great way of encouraging people to keep active - as ultimately that is one of the most important things you can do post-transplant to ensure a happy lifestyle.

At the Games I will be joined by my wife, parents, sister and friends. It’s a celebration for them to see me back to what I used to be doing, back enjoying life and back competing.

My message to those competing in the British and World Transplant Games is good luck, keep going and don’t give up. Just remember what you’ve been through, what you have achieved, and how much of a strong person you are because of that.”



Dan with his medals from the 2018 British Transplant Games

Visit our YouTube channel to watch our video interviews with Michelle and Dan.

Visit [www.youtube.com](http://www.youtube.com) and search ‘PHA UK’.



**FEELING INSPIRED?**

Turn over for advice on getting active with PH.



# Gaining fat The facts

In the first of a new series answering your questions about nutrition, **Shaun Clayton**, director of membership support at the PHA UK, looks at what to do if you need to gain weight.

**F**or the past 12 months I've been learning the art of nutrition from the Mac Nutrition Collective - the foremost authority when it comes to evidence-based nutrition. Nothing you will read in this or future columns is 'pseudoscience'; it's all information which is backed by research.

In the last issue of *Emphasis*, we asked if there were any questions people had when it comes to nutrition. Of the number of responses, one really caught my eye; from a young lady being told she needs to gain weight to be accepted onto the transplant list.

She's consulted Dr Google and he's offered her plenty of advice on how to lose weight or how to build muscle, but not actually how to gain weight healthily.

## ENERGY BALANCE

The best place to start is by explaining how we gain, lose and maintain our weight. By consuming more calories than our body requires, we begin to store that additional energy as adipose tissue (fat).

**For anyone looking to gain weight, that is your goal - consume more energy than your body burns.**

The healthiest and potentially quickest way to do that is to up your fat intake. People shouldn't be put off by the word 'fat' as we're talking about 'healthy' fats here and not adipose tissue (body fat). The reason I've identified fat as the main one to push is that it is the highest calorie macronutrient - one gram of fat equates to nine calories so it's very easy to overeat and force yourself into a calorie surplus.

Try to make a point of cooking foods in olive oil, and feel free to consume cheese, milk and nuts. There are also

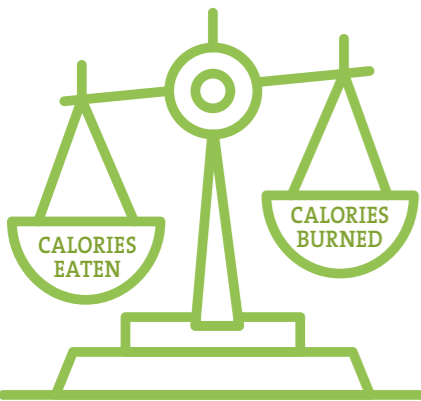
things like avocado and eggs. Eggs are fantastic as they are predominately a fat source but also come with a decent amount of protein. Protein is what antibodies in the blood are made up of, so consuming that will only be beneficial, particularly considering what may await with a potential transplant.

The dogma surrounding 'fat' mainly comes from the subgroup, trans saturated fat, or as we know it, things like doughnuts, burgers and pastries. They taste amazing but are not great for us!

But, as a doughnut lover myself, there is always a place for them in a healthy diet - it's just a case of not over-indulging.

Ultimately it's a case of taking ownership of your diet and making it work for you. There is no need to look for any fads. You already have a diet... it just isn't quite working, so adjust and adapt it to make it fit. Try implementing these few tricks and see if it helps.

**Please feel free to get in touch if you have any questions on this topic. ●**



Moving more  
with PH

# Let's get moving this summer

The sun is shining, and all the evidence points to moderate exercise being hugely beneficial for people living with pulmonary hypertension. So, what's stopping you?

*Maybe we can help...*

If you have a question about nutrition that you would like to see answered in a future issue of *Emphasis*, please email [media@phauk.org](mailto:media@phauk.org)

## Challenging the myths around exercise and pulmonary hypertension

When it comes to reasons for staying sedentary, Carol Keen, clinical specialist physiotherapist at the Sheffield Pulmonary Vascular Disease Unit, has heard them all. Here, she puts things straight.



### MYTH 1

**Exercise will make my BREATHLESSNESS WORSE!**

You might think that you are too breathless to exercise, or that being breathless means you shouldn't. That's not the case. It's ok to be a little bit breathless - in fact, it can be a good thing because it means you are training your body. The important thing is to be the 'right amount of breathless'.

What is the 'right' amount of breathlessness?

Imagine that we are going to go for a walk. We are going to start off really, really slowly, almost as if we are walking down the aisle in a church at a really slow pace.

We might increase our pace a little bit, a similar speed you may take when wandering around the shops. You're walking slowly so you can see what's in the shop window and you're stopping from time to time to see what interests you. You're walking and you're active and you're probably not breathless at that point.

If you increase the pace a little bit again you might be walking at a gentle walk for you (it will be different for everybody) and at that gentle walk pace you're not breathless. You might get tired after a while, but you are not breathless. And all of these are absolutely fine, but you're not exercising - you're being active.

If you increase your pace of a walk to the next step beyond that gentle walk you might start to feel that

you're a little bit breathless, but that's fine as well.

You should still be able to have a conversation, but maybe you're catching your breath here and there. That is perfect - that's the pace you want to be working at and how breathless you want to be, and that means you're exercising and training your body.

**When exercising, you should feel a little bit out of breath but still be able to talk**

This breathlessness at this point is not a symptom of your PH, it's because you're exercising at the right intensity. It's a good place to be.

If you walk a bit quicker than that and your breathing gets a little bit harder and laboured, and talking is too hard, then you're working too hard and you need to slow your pace back down again.

If you are walking so quick so that you're struggling and gasping for your breath then you really are working too hard and you need to stop, rest and recover your breath, and start again at a slower or gentler pace.



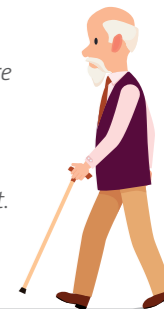
### MYTH 2

**Exercise is EXPENSIVE!**

People tell us that it can be too expensive to exercise and that they can't afford it. Joining a gym and buying fancy kit and trainers is an option, but you really don't have to.

There are lots of inexpensive and different ways you can get involved with physical activity. For example, there will be lots of charities and groups in your area that offer cheap and affordable ways to exercise, and clubs and societies that can be cheap to join.

Most councils have exercise schemes that they run with people for health problems where you can access their local gyms at a reduced rate and get support and advice around exercising. If you ask at your local gym they will be able to give you information about that. Walking is also a really good way of exercising and keeping fit, and it doesn't cost a penny.



### MYTH 3

**Exercise is NOT ENJOYABLE!**

Many people think exercise is not for them because they don't think they'll enjoy it, or that it will be painful and miserable - that doesn't have to be the case. If you find the right activity, you should be able to find something that you enjoy.

It's about taking small, incremental steps towards exercising. If you take up volleyball having done nothing for years, then of course it's going to hurt, but if you take some small steps towards being more active then it should be something that easily fits into your life.

The most important thing about being more active is that it can be fun. You can do things that you enjoy, do them with friends and with family and get the enjoyment of being in a group. And that means it's not just beneficial for you but also to the people around you - the more active you are, the more you can do with family and friends.

### MYTH 4

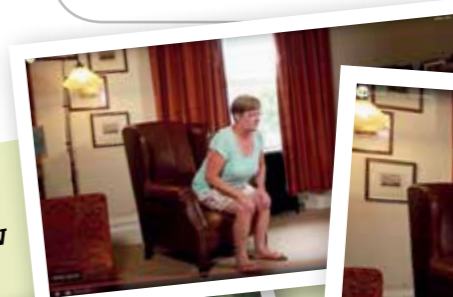
**Exercise takes TOO MUCH TIME!**

It's easy to think that you might not have the time to exercise, or that your life already feels full.

You don't have to spend huge chunks of time exercising. You can take small incremental steps by doing a little bit more today than what you did yesterday, and that way it will feel like it is fitting in with your life instead of taking over your life. You can exercise at home, in chunks of ten minutes, and that will still make a difference. And if you exercise with family and friends, then it's a way of socialising too and enabling you to spend time with people in a way that is enjoyable and making your life better.



You'll find lots of advice around getting active at [www.phocusonlifestyle.org](http://www.phocusonlifestyle.org), including a new series of videos, led by Carol, to help you feel more confident about moving.



Moving more  
with PH



*“Getting active has been life changing”*

Lynn Lilly, 66, started exercising to rebuild her confidence after being diagnosed with PH.

*“Before I was diagnosed with pulmonary hypertension, I had a physically demanding job as a care assistant for the elderly, with a lot of lifting, handling, and walking around. I also swam a lot and did a lot of running around after my two young grandchildren.*

*I went from doing all this and being independent to struggling to walk upstairs; just putting one foot in front of the other was awful. I lost my confidence, and that’s what hurt more than anything else. I was frightened of doing anything in case I collapsed and there was nobody there to help. It was fear that was holding me back from getting out and about.*

*With the help of the physiotherapist at my specialist centre, I set myself small goals. The first was to walk over the road from my house to my friend’s house. Taking part in pulmonary rehabilitation classes really helped. I did 12 weeks of them at the hospital and they were brilliant.*

*I then started aqua-fit at my local swimming baths and started adding in circuits classes once a week at my local gym. I’ve made friends from doing both. Getting active and doing these types of exercises has given me great energy and confidence.*

*I can go to town on my own with my granddaughters which is something I haven’t done in a long, long time – I was there for four hours with them recently. Plus, we did consider a stair lift but as I started to get stronger I realised I didn’t need one after all. Getting active really does help build your confidence up – it’s been life changing!*

*The advice I’d give to anyone who is in a rut and not really feeling great about doing more activity is to just try. When you get this disease, it can keep you indoors because you’re frightened of going out - but it doesn’t have to be like that.”*



How will you be getting active this summer?



*This is what you told us on Facebook...*

*Lorraine Me and my oxygen will be walking in the warmer weather. Yesterday was my first day out this year and I managed 500 steps in a few hours.*

*David I’ll be walking the dog at least once a day for up to five minutes. He is 10 now and getting on so luckily we walk at the same pace.*

*Jane I’ll be gardening. Sometimes I have the energy to do a lot, at other times not so much. Doesn’t matter either way as I just feel amazing benefit, both physically and mentally, from being outside.*

*Catherine I joined an adult ballet class 2 months ago and am really enjoying it.*

*Dave My wife and I will be out visiting National Trust places. I have my scooter (or a lot of them have ones you can book) and I can walk as little or as much as I can manage. Unfortunately going upstairs in the houses is a no-no but otherwise it makes for a nice day out.*

*Judy I’ll be walking my daughter’s puppy using my oxygen and joining the ladies at the gym for aqua.*

*Pauline Walking & tap dancing.*

*Sarah Walking my dogs, playing golf and swimming :-)*

*Hannah I already walk but I’m going to look into doing some cycling.*



# Research opportunity

Relatives of patients with IPAH needed to take part in study

CAN YOU HELP?



Carmen Treacy explaining the study at the PHA UK conference in May.

**T**he National Cohort Study of Idiopathic and Heritable Pulmonary Arterial Hypertension (PAH) requires relatives of patients to participate in its research.

The key objective of the study, which has been running since 2014, is to investigate the genetic causes of PAH, and how genetic mutations affect outcome and response to treatment.

Research study co-ordinator Carmen Treacy said: “The information we learn from the study will allow us to more accurately assess the risk of developing PAH to family members and identify new ways of treating PAH.”

Over 600 people diagnosed with IPAH have taken part in the study, but more blood relatives of patients who have a genetic mutation associated

with PAH or a family history of PAH are now needed. Only 50 relatives have taken part in the study so far, but we need many more relatives within the next four years.

For patients, taking part in the study does not involve any extra hospital visits of any kind.

When you go to your PH centre, you can pick up a slip for interested relatives to fill out. This must then be sent back to the hospital, and the research team will contact your relatives with more information.

Relatives can visit the same PH centre as you or go to their local PAH centre. They will be seen annually and will have tests including blood sample, an echocardiogram and a walk test. Travel expenses will be reimbursed.

The study is also looking for newly diagnosed IPAH patients, and all patients with IPAH who attend Great Ormond Street Hospital, to take part.

For further information please visit [www.ipahcohort.com](http://www.ipahcohort.com) or talk to your clinical team at your next specialist centre appointment.

## UPDATE

The current recruitment total is...

667

The number of samples so far in the biorepository is...

50,000





# SELEXIPAG

## Where does it fit in the treatment jigsaw?

After a lengthy battle for access, Selexipag was approved as a treatment for pulmonary hypertension across the UK in April. We caught up with Neil Hamilton, consultant pharmacist at the Sheffield Pulmonary Vascular Disease Unit, to sort the fact from the fiction.

### ? First things first, what exactly is Selexipag and how does it work?

Selexipag is a new therapy which works on the prostanoid pathway. It dilates blood vessels, allowing more blood to flow through the lungs and around the body.

The difference with Selexipag is that it is a tablet as opposed to the more complex forms of prostanoid that are currently available working on that pathway; which must be nebulised, continuously infused through an intravenous line or given subcutaneously.

So, there are some convenient advantages with Selexipag and lots of patients might prefer to take a tablet as opposed to some of these other difficult options.

### ? What has the clinical trial shown?

The clinical trial for Selexipag was the largest ever undertaken in pulmonary hypertension. It was a worldwide study and many centres across the UK were involved in recruiting patients. It showed that Selexipag could slow or prevent worsening for our patients.

In the study, patients could take Selexipag on its own or in combinations with other background treatments that they might have already been on - but whatever the combinations were, Selexipag showed a benefit over the placebo.

### ? Who is Selexipag suitable for?

It's not for everybody, and there will be some patients who won't be suitable because of the type of PH they've got. We are somewhat restricted by what the NHS commissions in terms of who we can prescribe it to, but those restrictions are born out of the data and the evidence that came from this big clinical trial, so there are good reasons for it.

It is for stable patients, to prolong their journey with PH and prevent them from getting worse. It's not a drug for treating someone who is declining.

Every case must be weighed up on its individual pros and cons. In the UK some patients must already be on certain therapies in order to be eligible to receive Selexipag.

So, it's not for everybody but it is a really important addition to the armoury of treatments available.

### ? Is Selexipag a replacement for IV therapy?

We don't see Selexipag as a straight replacement for either nebulised or IV therapy.

If patients are getting worse to an extent that we would consider them for an intravenous drug, or we're talking about other things such as transplantation, then Selexipag is not the right treatment for them.



However, this isn't a blanket rule and there will be exceptions – for example where it's difficult to give IV drugs or one of the more complex therapies. In these cases, a tablet may be the only thing that can be added in. It is worth stressing that we see those as very much exceptions, rather than the rule.

### ? What should I do if I think Selexipag may help me?

My advice is if you think you might want to give Selexipag a try and you think it might benefit you, have a discussion about it next time you're in clinic.

They are the experts and know you better than anyone else and will also have access to all your tests and all the results, so you can make a decision between you.

Selexipag isn't for everybody but it may stop some getting worse and needing more intense forms of treatment. It does give us a really important option to try and delay worsening.

### ? If Selexipag is right for me, what happens next?

Once we have agreed the decision with the patient to start Selexipag, we will begin something called 'titration'. By that we mean patients start out on a very, very low dose and build up steadily for a number of weeks, which might be eight to twelve.

The reason for building up slowly is because we know the treatment may cause side effects, such as headaches, or nausea,

or general tummy ache. By pushing up the dose slowly, these side effects can be managed and hopefully won't cause patients to stop their treatment.

They will likely have contact with their PH centre on a weekly basis during this time, which I think is really important.

This is exactly the same process we go through with titration of intravenous therapy but obviously that is taking place in a hospital bed rather than at home.

So, nothing new, nothing different, but managing the side effects and slowly increasing the dose is absolutely crucial.

Not everybody requires, or can tolerate, the same dose of Selexipag. There isn't a set target - what we are aiming for is the top dose which can be tolerated. This is the dose just one step down from where they are experiencing the side effects.



To sum up, Selexipag is an exciting treatment option that's now available for us to prescribe. It's not suitable for everyone, and it's not for those who are worsening, but it's an important addition to the other treatments that we have available. **If you think you would benefit from Selexipag, please discuss with the team at your PH centre next time you are in clinic.**



# Green Leaf

## Crew!

### GREEN LEAF CREW Q&A AARON GIBSON

Aaron Gibson is ten years old and lives in Portadown, Northern Ireland, with his mum, dad and big sister Rebekah. Aaron was diagnosed with PH in January 2018. Here he shares some of his favourite things.

**Q.** What do you like doing at school?  
**A.** I like maths, but the best thing is playing Zombie Tag in the playground.

**Q.** What's your favourite thing to do at the weekend and why?

**A.** Playing Fortnite! I get to have fun and talk to all my Fortnite mates.

**Q.** What's the best thing about the summer holidays?

**A.** Playing nerf wars, water balloons and going to the shop to buy blue slushies (mum hates my lips going blue though)

**Q.** What's your favourite food?

**A.** Dad's stew, it's the best!

**Q.** What do you like to watch on TV?

**A.** Alvin & the Chipmunks and my favourite YouTubers.

**Q.** What would be your dream job when you're older?

**A.** A lorry driver, a gamer or a road racer at the North West 200 bike race.

**Q.** Where do you like to go on holiday?

**A.** Portrush, because I don't have to fly there or take oxygen with me.

**Q.** If you could meet any famous person in the world, who would it be and why?

**A.** Fortnite YouTubers Ali-A or Ninja, because they're ace. Or any top riders at the North West 200, so they could show me how to ride a motorbike really fast.

**Q.** If you could have any superpower, what would it be?

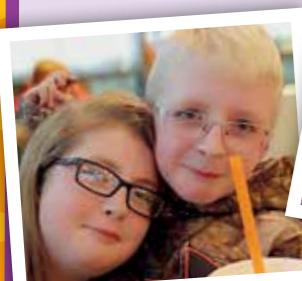
**A.** To see into the future so I could win the lottery and buy loads of V Bucks (Fortnite currency).

## EXPLORING ROCK POOLS



With the sunny weather (hopefully) upon us, it's the perfect time to head for the beach. While you're there, why not go exploring and seek out some rock pools? Here are five sea creatures you might find living there:

- **STARFISH** – look out for these star-shaped creatures at the bottom of the rock pool
- **CRABS** – some smaller crabs live in rock pools; watch out for their nip!
- **SHRIMP** – an orange lobster-like creature with ten legs
- **MUSSELS** – these will be stuck to the edge of the rock
- **BLENNY FISH** – these tiny fish have bright-coloured scales



AARON WITH HIS BIG SISTER REBEKAH



AT THE NORTH WEST 200 MOTORBIKE RACES

WATCHING THE NORTHERN IRELAND FOOTBALL TEAM

**FUN FACT** When you blush, your stomach also turns red!

### MADDIE'S HIPPOS >>>

You may remember 9-year-old Maddie from the Spring issue who sold all the PHA UK hippos at her school to raise money in support of her dad's cousin. We're delighted to say she raised £100!



## The GREEN LEAF CREW

BY DAVID BANKS

**SUMMER IS THE TIME TO GET FIT, GANG!**

**JUST RUNNING AROUND ON THE BEACH IS A GREAT WAY TO EXERCISE**

**AND WHAT BETTER THAN A SIMPLE GAME OF BAT AND BALL?**

**GREAT IDEA, LEXI! WE COULD PLAY FRENCH CRICKET!**

**OR WE COULD HAVE A GAME OF PIT-PAT!**

**OR A GAME OF REAL CRICKET!**

**OR HOW ABOUT A GAME OF ROUNDEES?**

**OR PADEL?**

**OR BEACH TENNIS?**

**OR FRISBEE?**

**THAT'S NOT A BAT AND BALL GAME, JUDE!**

**MUCH LATER...**

**OMG! I'M EXHAUSTED!**

**AND WE HAVEN'T EVEN DECIDED WHAT TO PLAY YET!**

**SWING BALL!**

**BASEBALL!**

**CROQUET!**

**GOLF!**

## Patch

by David Banks

**I'M DOING HIIT TRAINING!**

**IT'S PART OF MY NEW FITNESS REGIME**

**IT STANDS FOR HIGH INTENSITY INTERVAL TRAINING**

**ONLY IN MY CASE**

**INTERVALS LAST SIX MONTHS!**

### FUN FACT

The strongest muscle in the human body is the **tongue!**

# Reviews

Would you like to review an app or book which may be of interest to Emphasis readers? Please contact [media@phauk.org](mailto:media@phauk.org)

This issue we review an app to help you manage your walks and a book written by a unique trio of authors.

## MapMyWalk app

With the MapMyWalk app you can track and map every walk and get feedback and stats to improve your performance. Whether you're a beginner on your first long walk or a pro, it's useful for staying on track and being motivated along the way. The app syncs your data to other apps such as FitBit and Garmin, and you can take control of your nutrition by connecting it to MyFitnessPal for a comprehensive look at your calorie intake and burn. I particularly enjoy tracking my walks and workouts, and take my phone everywhere with me, so I found using the app a practical way of logging some of the longer walks I take at the weekend. As the name suggests, while you're walking the app maps your route using GPS. I like the fact that you can save your favourite paths and add new ones too. You can turn on audio feedback to hear your stats while you walk such as pace, route, distance, calories and elevation – it's a good way of making sure you reach your goals. The app also allows you to see what your friends are doing on your activity feed. I didn't use this part of the app as I prefer to set personal challenges, but I can see how it could be a good motivator and provide some healthy competition. Overall, I enjoy using the app and its features to track my walks, however the signal can sometimes be an issue. GPS also uses a considerable amount of battery life.

Reviewed by Chris Doyle

MARKS OUT OF 5

3.5

## How to Be Human: The Manual by Ruby Wax

Comedian and author Ruby Wax's latest book is described as the 'only manual you'll need to help you upgrade your mind'. I was compelled to order the book after seeing a tweet from Ruby and am so glad I did. In the book, Ruby is joined by a neuroscientist and Buddhist monk to answer every question you've ever had about: evolution, thoughts, emotions, the body, addictions, relationships, kids and the future. Neuroscientist Ashish Ranpura explains what makes us 'us' in the brain, and Buddhist monk Gelong Thubten explains how the mind works. Mixed with Ruby's ability to make you laugh out loud, it's a fascinating and joyful read which really made me think about aspects of my life and how I deal with negative thoughts and feelings. I found the book easy to read, with each chapter focusing on a different topic such as compassion and forgiveness. It's also easy to dip in and out of the chapters that relate to you most at a specific time in your life. All the topics lead to the practice of mindfulness, so at the back of the book you'll find some exercises to try out for yourself. Commenting about mindfulness, Ruby says: "Practising it is the only way I know to be able to find some peace in a world that's not peaceful." I would highly recommend this book to everyone. It's a practical and humorous manual to help guide you through life.

Reviewed by Charlotte Goldthorpe

MARKS OUT OF 5

5

# Spotting the signs of... breast cancer

Breast cancer is the most common cancer in the UK and according to the charity Breast Cancer Care, one in eight women will develop it in their lifetime.

## Whatever your age, it's important to check your breasts regularly for symptoms of breast cancer.

Each month is recommended. This can be crucial in diagnosing cancer sooner and getting more effective treatment. Breast cancer survival is improving and has doubled in the past 40 years, with almost nine in ten women surviving breast cancer for five years or more.

## Be breast aware.

We're all different so you should get to know how your breasts usually look and feel. Bear in mind how your breasts feel can depend on your menstruation cycle and age. For example, some women have tender and lumpy breasts, especially near the armpit, around the time of their period. After menopause, normal breasts feel softer and not as lumpy. If you spot any changes, report them promptly to your GP.

## If you have any concerns, see your GP.

Breast changes can happen for many reasons, and most aren't serious. Nine out of ten breast lumps are not cancerous. However, if you find changes in your breast that aren't normal for you, it's best to see your GP as soon as possible. You're less likely to need a mastectomy, breast removal, or chemotherapy if breast cancer is detected at an early stage. If you prefer to see a female GP, you can ask if one is available.

## Always attend your breast screenings.

Women are invited to routine breast screening - which involves having an X-ray or mammogram - from the age of 47 to 50, and it takes place every three years. However, it's important to always check your breasts in-between appointments.

## More help and information:

Breast Cancer Care is dedicated to informing people about breast cancer, supporting those affected and campaigning for better care. Anyone with concerns can speak to a Breast Cancer Care nurse for free by calling **0808 800 6000** or visiting [breastcancercare.org.uk](http://breastcancercare.org.uk)

**Coppafeel.org** is aimed at young people and has lots of advice on breast cancer, including a video on how to check your breasts, and you can also sign up to a boob-check alert.



## How to check your breasts

Look at, and feel, anywhere that has breast tissue - each breast and armpit, and up to your collarbone. You may find it easiest to do this with a soapy hand in the shower or bath, but it can be done anywhere. Also check your breasts in the mirror - with your arms by your side and then with them raised.

## What to look out for:

Breast cancer doesn't just show up as a lump. The NHS has the following guidance. **Check for:**

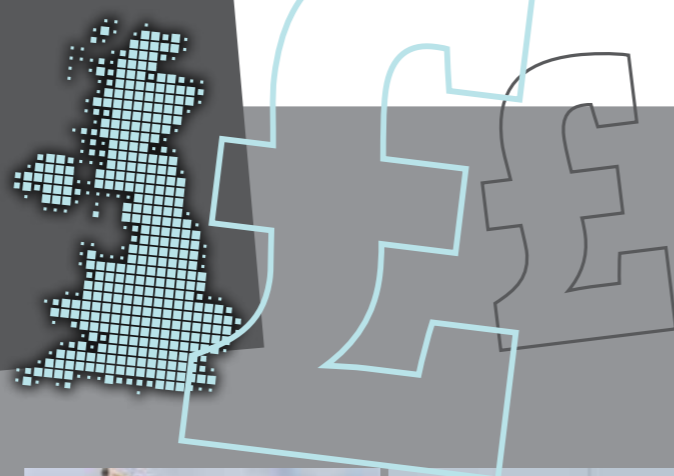
- A change in the size, outline or shape of your breast
- A change in the look or feel of your skin, such as puckering or dimpling
- A new lump, thickening or bumpy area in one breast or armpit that is different from the same area on the other side
- Nipple discharge that's not milky
- Bleeding from your nipple
- A moist, red area on your nipple that doesn't heal easily
- Any change in nipple position, such as your nipple being pulled in or pointing differently
- A rash on or around your nipple
- Any discomfort or pain in one breast, particularly if it's a new pain and doesn't go away

## BREAST CANCER AFFECTS MEN TOO.

Men also have some breast tissue in their chest and under their armpit, and almost 400 men are diagnosed with breast cancer in the UK every year.



# FUNDRAISING focus



## Manchester Marathon for mum

Clare Chappell, her husband Dan, Sharon Watt and Lindsay Cameron completed the Greater Manchester Marathon to raise £1000 for PHA UK because Clare's mum has PH. Clare said: "I am not sure yet if I enjoyed it, it was so much harder than any of my training runs but it's done. Training for a marathon, with two small children and a full time job is one of the hardest things I have ever done, but when I found it tough I thought of those who would love to walk or run and remembered how lucky I am to have the opportunity to even do this."



## Cycling between the capitals

Rob Macdermott and Robin Hamilton, brother of The Sheffield Pulmonary Vascular Disease Unit's consultant pharmacist Neil Hamilton, completed the London to Paris 24-hour sportive, raising £1588. "Rob and I both cycle very regularly but cycling 300 kilometres in just 24 hours was very much out of our comfort zone!" Robin said. "We made it in under 23 hours with a top ten finish out of 120 - very pleased with that. Thanks to everyone who donated for all the awesome support."



## David takes on Liverpool 10k

PHA UK member David Stott ran the Liverpool 10k in May. David, who was diagnosed with PH in 2013, said: "Since diagnosis I have focused my energy on getting fit and fighting PH to ensure that my girls have a father to walk them all down the aisle. My condition has improved so much that doctors have called me remarkable, and I am able to do lots of gym work. The run was my challenge to myself to face my fears and try to raise money for those with my condition that are not so lucky. I completed it in one hour 2 mins - it was so hard mentally and physically."

## Farmers club raises four figures for PHA

Spa Young Farmers Club raised over £6208 for PHA UK after various charity events were organised by the club throughout the year. PHA UK was chosen in memory of past member Ally Whan who sadly passed away in May 2017. The club held a tractor run, treasure hunt and table quiz during 2018, and all money raised from their 75th anniversary dinner in November 2018 was also donated to PHA UK. The Spa Young Farmers Club would like to thank anyone who helped support their efforts throughout the year.



## Golfers club together for PH

Marlene Danter and her friends at Derby Golf Club raised £2608 for PHA UK after a year of fundraising events, including raffles, cake sales and a coffee morning. Marlene, who was lady captain of the golf club in 2018, said: "It was a pleasure to raise money for this worthy cause which is very dear to my heart having lost my husband Philip to PH in July 2014 aged 62. I hope the charity continues to thrive and that, in a small part, I've raised awareness."



## TOP FIVE FUNDRAISING IDEAS FOR A... SCHOOL FUNDRAISING EVENT

A school fundraising event gives you easy reach of a large group of people, increasing the amount you could raise. Providing the school with information about PH and PHA UK is important – they need to see that the money is going to a great cause. Please make sure you get permission from the school to hold your event.

- 1 **DRESS DOWN DAY/FANCY DRESS**  
How about donating £1 - £2 to wear whatever you like to school for the day?
- 2 **SPONSORED EVENTS**  
Almost any sporting event can be sponsored – walking, running, swimming, cycling etc. And don't forget the non-sporting events such as read-a-thons, sing-a-thons and sleepovers too.
- 3 **CONCERTS/SHOWS**  
You could organise your own disco/fashion show/festival and charge for admission.
- 4 **GUESS THE AMOUNT**  
Filling jars with sweets and charging participants to guess the amount is an easy way to generate funds. The winner can take the contents of the jar as their prize.
- 5 **SALES**  
Cake sales or bring and buy sales are popular events at schools. Pupils can get their families involved in baking and get rid of unwanted items from home.

IF YOU ORGANISE A SCHOOL EVENT, DON'T FORGET TO LET US KNOW ABOUT IT. YOUR EVENT COULD FEATURE IN THE NEXT ISSUE OF EMPHASIS! EMAIL [office@phauk.org](mailto:office@phauk.org)

We love hearing about your fundraising adventures!  
Email [media@phauk.org](mailto:media@phauk.org) for a chance of seeing yourself on these pages.

**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.

## Partnership spotlight

# Turn2us



*Kyle Clayton* takes a closer look at the tools available to help PHA UK members find information about benefits and grants.

Access the benefits calculator and grants search tools for free at [www.phauk.org](http://www.phauk.org)

**T**he PHA UK's own research has shown that many people living with PH struggle to stay financially stable once they have received a diagnosis. Their partnership with Turn2us aims to help.

Turn2us is a non-profit organisation that has been working with the PHA UK since 2014 – and the partnership is as strong as ever. Here are the tools that are available to help you:

sent anywhere, and unless you give permission, it won't even be seen by Turn2us.

If you would like to ask questions or get help about the questions asked on the survey, you can either ring Turn2us on **0808 800 2000** or visit [www.turn2us.org.uk](http://www.turn2us.org.uk)

### Benefits calculator

The benefits calculator is a free to use, simple survey that will ask you a series of questions, some quite personal. Once all boxes have been ticked and data has been filled, it will show you the benefits that you are entitled to claim. I can say without doubt that the information you provide will be safe. It will not be

### Grants search

If a large sum of money is needed to purchase something one-off, you could be eligible for a grant. This tool will help you identify what could be available to you. Eligibility criteria will be based on considerations such as the jobs you've had, your age, and of course, your health condition.

The grants search will also ask you questions similar to the benefits calculator, but don't worry, this will all be kept confidential too.

*“Turn2us offers a hugely valuable resource in a time where it's becoming harder and harder to receive honest advice around something so important as benefits. My hope is that this makes it easier for members to receive the support they truly need.”*

**Shaun Clayton,**  
Director of membership support,  
PHA UK

# Demystifying medical humanities

Ever heard the term 'medical humanities' but been confused about what it means? Here Professor *Ian Sabroe*, co-director of Medical Humanities Sheffield, explains all.

**E**ssentially, 'humanities' are the subjects that study human life and experience - so philosophy, music, arts, history and English are all areas of knowledge that would be described as humanities in academia.

'Medical humanities' very broadly describes that area of overlap where you use the lens of one thing to look at the other.

You can use humanities to look at what medicine does and that's a very traditional medical humanities approach. That can encompass a huge range of different disciplines; so you can, for example, use a 'narrative analysis' to collect stories of people who have experienced illnesses and look at the words they use and the experience they have, and do all sorts of different analysis to understand what illness means to people. (See the Autumn 2017 issue of *Emphasis* to read about a project supported by the PHA UK that did just that!)

*"Humanities can challenge doctors to think about how they make decisions and help people."*

There are a lot of challenges and assumptions and different types of narrative that people have when they talk about illness - the 'quest narrative' of finding a goal, the 'restitution narrative' of getting back to normal, and the 'chaotic narrative' of an illness journey being deeply unpredictable.

An academic called Susan Sontag talked about everyone inhabiting, at different points in their lives, 'the

kingdom of the well' and 'the kingdom of the sick' - and the journeys we all make through these things.

Another aspect of medical humanities involves looking at the philosophy of medicine and how doctors make decisions and what it's like to be an expert.

So, the humanities can look at how people experience illness, help doctors listen to these stories and understand them, and challenge doctors to think about how they make decisions and help people.

## USING CREATIVE ARTS

Another aspect of medical humanities is to use arts to interpret illness.

For example, if you decided that you wanted to interpret pulmonary hypertension using theatre, or painting, you might be using humanities to explore medicine.

If you are doing it from an intellectual view you might research how well that is communicated, and study whether or not that has communicated the experience of medicine. I have colleagues who work in music and who are studying how music engages with memory, for example in people with dementia.

The vast majority of people who work within medical humanities are not doctors or nurses - they will be people in departments of English or literature, history or philosophy, who look outside of medicine and critique it.

There are clinicians who take an interest in it but it's a fairly small number, because it's not a very traditional skill taught at medical school, even if it's incredibly important.

## MEDICAL HUMANITIES FOR EDUCATION

I'm very keen that you can also use the humanities to teach doctors different skills. You can take the languages of humanities and use them to teach medical students about medicine in general.

For example, in America they have long courses in narrative medicine to listen to the experience of being ill. I've recently been awarded a Churchill Fellowship which will see me spend six weeks out there, looking at how they use humanities in the teaching of medics.

## WHAT IT ALL MEANS FOR PEOPLE LIVING WITH ILLNESS

People with illness may come across medical humanities if they take part in research projects that explore the experience of illness and you could argue that there might be a space for medical charities to consider lobbying for more research to happen within the domain of humanities to explore what illness means to people.

*"How we listen to people with illness and share their experiences really matters."*

I would like to think if doctors had been trained to use and understand knowledge gained through humanities, they might have a different set of skills that might help them to understand the patient's journey, and understand themselves better to be able to cope with a lifelong career that is very challenging.

*Ian Sabroe is Professor of Inflammation Biology at the University of Sheffield and Honorary Consultant Respiratory Physician at Sheffield Teaching Hospitals NHS Foundation Trust. He is also co-director of Medical Humanities Sheffield ([www.sheffield.ac.uk/mhs](http://www.sheffield.ac.uk/mhs))*



## Medical humanities in research

I often supervise medical students who are doing research, and the two projects I supervised last year are examples of medical humanities.

### GRACE ELLIOTT

*Grace Elliott looked at women and their narratives of postnatal depression. She looked at the last 120 years of women's writings about their mental health after having children and matched them to changes in scientific thinking about postnatal depression. Grace is going to write about how women were strong at finding ways to communicate their distress, even when there was no model for them to do it, and how the origin and development of new models allowed women's mental health to be discussed more available and freely.*

### AMY WILSON

*Amy Wilson looked at a different side of life as a doctor, because there's a high rate of depression, mental illness, and suicide in the medical profession. She showed how narratives of doctors writing about their own mental health were suppressed by the stereotype of what a doctor 'should' be and found how difficult it was for doctors to describe and share their illness.*

### SALLY MATHER

*This year, Sally Mather is looking at the problem of uncertainty in medicine; where it comes from, who it creates stress for in terms of the patients and*

*doctors, when we're prepared to talk about uncertainty, and whether or not uncertainty has been increased or decreased by technological advances in medicine. These research projects show how humanities like philosophy, literature and history can be used to explore and understand what it is to be ill, or to deliver clinical care, or to discover different ways of communicating what illness is like.*

# A brand new website to help you live well with pulmonary hypertension

Our new 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.

# Walking the peaks to raise £10k for PHA UK

A group of football fans who completed several walks across the Peak District have raised over £10,000 for PHA UK.



**T**he fans have walked the 55 miles between the stadiums of Stoke City and Sheffield Wednesday four times in the past two years, and their latest trek took place at the end of March, coinciding with the two teams playing each other at Stoke's bet365 Stadium.

The walkers, made up of Stoke City fans, Sheffield Wednesday fans and former Republic of Ireland international footballer Liam Lawrence, left Hillsborough stadium in Sheffield at 7pm on Friday evening. They stopped off at the Royal Hallamshire Hospital, one of the PH specialist centres, before trekking across the Peak District through the night. They arrived in Stoke in time for the 3pm kick-off.

The challenges have been organised by Mark Harris, whose brother Paul has PH. "We walked from Stoke to Sheffield in September last year and were completely overwhelmed by the support from everyone; hence the return leg!" Mark said.

"We were delighted that Sheffield Wednesday allowed

us to start the walk from the pitch at Hillsborough, and we managed a very slow lap of half the pitch at half-time when we arrived in Stoke 55 miles later!"

Mark's brother Paul, 39, lives in Kidsgrove in Newcastle-under-Lyme. He was diagnosed with PH in September 2015.

Paul said: "The effort the lads have put in for the walk has been great. It can be challenging trying to explain to people the unfortunate outcome of living with PH especially as I look so well now. The walks have increased awareness and raised some money for PHA UK as they, along with family and friends, have been fundamental in supporting my wellbeing."

Paul and his father Steve drove ahead in a van filled with supplies

and parked up every few miles to deliver refreshments as the walkers trekked through the night.

Former Stoke and Republic of Ireland footballer Liam Lawrence, who joined the walkers for the first time, said: "Big respect to the guys that did it, they're proper mentally tough."

"Unfortunately, at about 4:30am and after around 30 miles, I had to stop because of blisters on my feet. I was gutted, but it was like walking on glass and I couldn't slow the other lads up, so I jumped in the van and helped with the catering. I might join them for their next venture, as long as it's not walking!"

To support the challenge, visit [www.justgiving.com/fundraising/peaks4pha](http://www.justgiving.com/fundraising/peaks4pha)



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# theinterview

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Consultant  
respiratory physician

**ROBIN CONDLIFFE**

in conversation with  
**Deborah Wain**

.....

Robin Condliffe is a consultant respiratory physician in the Sheffield Pulmonary Vascular Disease Unit, at the Royal Hallamshire Hospital. He went to medical school and completed his early training in Edinburgh and Glasgow and then spent a year working in Dunedin, New Zealand. Robin undertook his registrar training in and around Sheffield and it was during that time that he first worked with PH patients. Soon afterwards he embarked on his Doctor of Medicine (MD) qualification.

The first year was based at Papworth Hospital, in Cambridgeshire, compiling UK registries in chronic thromboembolic pulmonary hypertension (CTEPH) and pulmonary arterial hypertension (PAH) associated with Connective Tissue Disease (CTD), which increased the understanding of outcomes and prognostic factors. His second year was spent at Sheffield using cardiac magnetic resonance and cardiopulmonary exercise testing.

Robin became a consultant in the Sheffield pulmonary hypertension (PH) unit in 2009 and has seen the service grow significantly since then with over 1,000 patients now being treated. Robin has been a member of the Pulmonary Vascular Clinical Reference Group, the Fifth World PH Task Force and is current chair of the British Thoracic Society (BTS) specialist advisory group. He was also part of the BTS guideline group for the outpatient

management of patients with pulmonary embolism (PE) - blocked pulmonary arteries in the lungs. Robin has developed a shared-care service of about 300 patients in large regional adult congenital heart disease centres.

He has also set up a local hereditary haemorrhagic telangiectasia (HHT) service. HHT is an inherited genetic disorder that affects blood vessels in the lung, liver, brain and nose. A typical week for Robin consists of several PH clinics, reviewing many elective patients coming in for investigations, and performing right heart catheterisations. He also has clinics relating to his other areas of expertise.

Despite his workload, Robin manages to find time for research, publishing many articles on PH outcomes and radiological assessment and enrolling patients into therapeutic studies as well as into the UK Cohort study and the Sheffield PH Biobank - a growing store of blood and other products being analysed by scientists.

Last October Robin was among cyclists who rode over 200 miles from the head office of PHA UK to London during UK PH Awareness Week. He has a wife, who is a GP, and two children, aged 13 and 11.



.....

**Q.** As a child, what did you want to do when you grew up?

**A.** From an early age I said a doctor, but I can't remember why as I come from a very non-medical family. I'm glad I made that choice, however.

.....

**Q.** What engaged you so much about work around PH?

**A.** Although doctors can often focus just on the lungs or just on the heart, the lungs and the heart don't work in isolation. PH is a fascinating area with marked progress over the last two decades. I work in a great team, and within the UK there is great collaboration between all the centres.

**Q.** How does your work in other areas help inform your PH work and vice versa?

**A.** There is a big overlap between patients with CTD-related lung disease, for example pulmonary fibrosis, and pulmonary hypertension (PH) as many PH patients with rheumatological conditions will also have a degree of lung disease, and sometimes both the lung disease and the PH need treatment. Some two per cent of patients following an acute PE will develop chronic thromboembolic PH. Many other patients have some degree of persistent breathlessness. A small proportion of HHT patients develop PAH. A higher proportion of patients with HHT can also develop other... >>>



the interview

Consultant respiratory physician  
**ROBIN CONDLIFFE**

“PH is a fascinating area with marked progress over the last two decades. I work in a great team, and within the UK there is great collaboration between all the centres.”

...forms of PH and there are some novel treatments which can help some of those.

**Q. What achievement in the field of PH are you most proud of?**

**A.** Probably my first two papers as a research fellow which showed what can be produced by collaboration between our UK centres.

**Q. To what extent are PH patients helping to improve treatments?**

**A.** The involvement of patients in different types of studies, including new drugs, new interventions, new ways of monitoring blood samples for biobanks and assessment of impact on quality of life is absolutely vital to improve outcomes.

**Q. What should PH patients be encouraged by going forward?**

**A.** Multiple new drugs targeting novel pathways are currently being assessed in studies which have the potential to improve outcomes above what we achieve with our current medications. Also, looking to the future, we can be positive about the increasing roll-out of interventions through the UK, including balloon pulmonary angioplasty as well as better local monitoring of patients using technology.

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

**A.** I enjoy getting to know patients over the years, and seeing

their responses to PH therapies and interventions. I'm happiest when I see a patient back in clinic who has clearly improved following starting new PH therapy. It's also rewarding to work in a great team and within a collaborative UK set-up. The main challenge is to manage the demands of a very large service and also find time for research.

**Q. Can you sum up what it was like to do the PH Awareness Week bike ride?**

**A.** In one word - sore. In more than one word it was great fun to ride with friends and colleagues from around the UK and I hope it had a positive impact on awareness of PH.

**Q. How do you spend your time when you're not working?**

**A.** With my family, also running, and of course cycling. I can often be found wandering round the unit in cycling gear! I'm also involved in my local church and I have an interest in music. I recently wrote and put on a musical in a large city centre theatre. I'm also in the band Five Rivers, on vocals and bass. We play a wide range of covers plus self-penned songs, and we're available for weddings, birthdays and bah mitzvahs at a very reasonable rate.

**Q. So, finally, who is your own musical hero?**

**A.** Our band sings an eclectic mix but we do a few Beatles songs, and I think Paul McCartney is probably the greatest songwriter of them all. ●



"It's a great feeling...

Knowing you've probably saved someone's life"

Teenager Billy Smith recently gave blood for the first time, following in the footsteps of his dad John (who designs this magazine!). Here Billy, 17, shares his experiences.

**"As soon as I hit 17, it was time to sign up to give blood. It runs in our family, as my dad John has done it for over 25 years and is now approaching his 80th donation.**

I donated at a community centre in Barnsley. You can check online to find the nearest donation centre in your area.

**The first time was a bit daunting because I'm not a fan of needles (who is?).** On arrival, I was greeted by a nurse who was surprised to see someone my age giving blood. Apparently, most people who do it are over 30. To check my blood was suitable for donation, the nurse pricked the end of my finger and tested to ensure that I had enough iron in my blood. I also had to be tested for malaria because I'd been to Africa in the past year. My blood passed the test and I was then taken for my donation.

It really is such a simple process. The nurse placed the needle into my left arm and then just under a pint of my blood was taken. I was asked to keep clenching

my fist to maintain blood pressure and help my body recover, but once the needle was in my arm, I felt relaxed and it didn't feel like a medical environment at all.

Afterwards, I was told to help myself to free coffee and biscuits. The nurses advise you to sit down for 15 minutes and have two drinks before leaving, to allow your body time to recover. It probably took a bit longer for me than somebody like my dad who has given blood for years. For the rest of the day I felt lethargic, as though I hadn't had enough sleep, so it's a good idea not to do any intense exercise until the following day. I felt a little bit of pain in my arm for a few days afterwards but nothing more.

**One of the best things about giving blood is that the NHS send you a text to let you know where your blood has been sent.** Mine had gone to a hospital in Manchester. Receiving that text brought it home to me that giving blood is such an easy thing to do but the effect it has on someone else is huge.

Now that I've given blood, I've managed to persuade some of my friends to sign up. I don't think there's very much advertisement for giving blood, especially among young people.

**The amount of donations in the UK has fallen by 11,000 since 2016 so there's definitely a need for more donors.**

I'll be back in three months to donate again. I've worked out that by the time I'm 50, I'll have reached 100 donations! It's so rewarding to think that just by giving away a pint of your blood, you could save someone's life. ||

**The NHS Blood and Transplant unit is in urgent need of more blood donors.** Although you can't donate if you have PH, please consider showing this article to someone who is able to. Find out more at [www.myblood.co.uk](http://www.myblood.co.uk)



# Medication for PH

## Why do we have homecare delivery?



Nearly all PH patients in the UK benefit from homecare delivery – where medication is brought to your home. Why do you receive it that way and what are the benefits? Consultant pharmacist *Neil Hamilton* explains.

**Depending on the severity of your pulmonary hypertension, you may be prescribed long-term oxygen therapy, oral medication or more complex treatments needing a nebuliser, sub-cutaneous pump or intravenous infusions given through a Hickman line.**

The vast majority of our patients across the UK have their PH medication delivered to their home address. This article describes why we use homecare services, how they have come about, the main advantages and also what to do if you experience any problems with your delivery.

*There are currently five different homecare companies used by the PH centres; Healthcare at Home, Polar Speed, Lloyds Clinical Pharmacy Homecare, Pharmaxo and Healthnet.* All these have been carefully selected jointly by representatives from each PH centre together with NHS England. The quality of the service is constantly monitored to ensure high standards are maintained. Details of these and others can be found on the NHS

website, if you would like to know any more information.

If you don't receive medicines via homecare delivery, it is inevitable that you will pick up a supply at the outpatient pharmacy at the PH centre instead. This is because NHS England restrict supplies of PH medication to the expert prescribers (doctors, nurses or pharmacists) at your centre. GPs and local hospital doctors are not allowed to prescribe these medicines unless there are exceptional circumstances such as an emergency local admission.

At our centre in Sheffield, the Pharmacy team manages the prescriptions for over 1,200 PH patients. This makes up nearly a quarter of all the patients across the whole Trust receiving homecare prescriptions for a whole range of illnesses.

Homecare delivery has evolved quickly across the NHS in the past 15 years since we first used it for PH medication. There are several reasons for this massive expansion. Firstly we have seen a shift in the way care is delivered across the NHS.

Many services have evolved from hospital-centred care where treatments were given in a clinic to being given at home, either by patients self-administering or nurses coming out to patients in their own environment. Although PH homecare simply delivers supplies, other services have homecare (rather than NHS) nurses giving infusions and taking bloods at home.

Secondly, the NHS saves money by using homecare as medicines dispensed by this route do not incur VAT, hence a 20% saving against all medicines supplied in the hospital. Lastly, and most importantly, homecare delivery allows for specialist medicines to be prescribed by the experts despite you living a long way from the centre.

It is unlikely (and maybe unnecessary) that you would need to go to clinic as frequently as you need a medication delivery. *Homecare allows for medication to be delivered at an appropriate frequency without the need to involve GPs who often know much less about the management of PH.*

You will of course still have to attend regular appointments as instructed by your specialist team. These are essential to ensure that your prescription is still at the right dose for you, that you are benefitting as much as you and we would like and that side effects are not unmanageable for you.

### How do I receive homecare delivery?

Your specialist centre will discuss the option of homecare delivery during your visits to clinic. When you start on a PH treatment which will be sent to you via homecare delivery, you will be asked to sign a consent form. Once this has been accepted by the Pharmacy Homecare Medicines team at your specialist centre, your medication prescription will be sent to one of the homecare companies mentioned earlier.

You will then be contacted by the provider who will ask you to specify an address to deliver the medication (it doesn't necessarily have to be your home address) and the date and time that is convenient for you. It is very important that you are able to accept delivery of the medication because it has to be signed for – it cannot be left on your doorstep or with anyone who has not been specifically authorised by you to receive on your behalf.

It may be preferable for your local pharmacy to accept on your behalf, in which case you need to discuss this with the pharmacy and communicate the details back to the homecare company. If you think you might miss a delivery, for example if you go on holiday, please let your provider know as far in advance as possible

and they can make arrangements to move the date or send a double supply as appropriate. *Homecare delivery companies are using technology similar to that used by supermarkets and online retailers to schedule deliveries*, so patients can receive delivery slot confirmations and reminders by text and/or email. It is likely that soon there will be apps and websites to enable stock checks and delivery slot choices to be made at patients' convenience rather than following a call from the company.

### What if I have a problem?

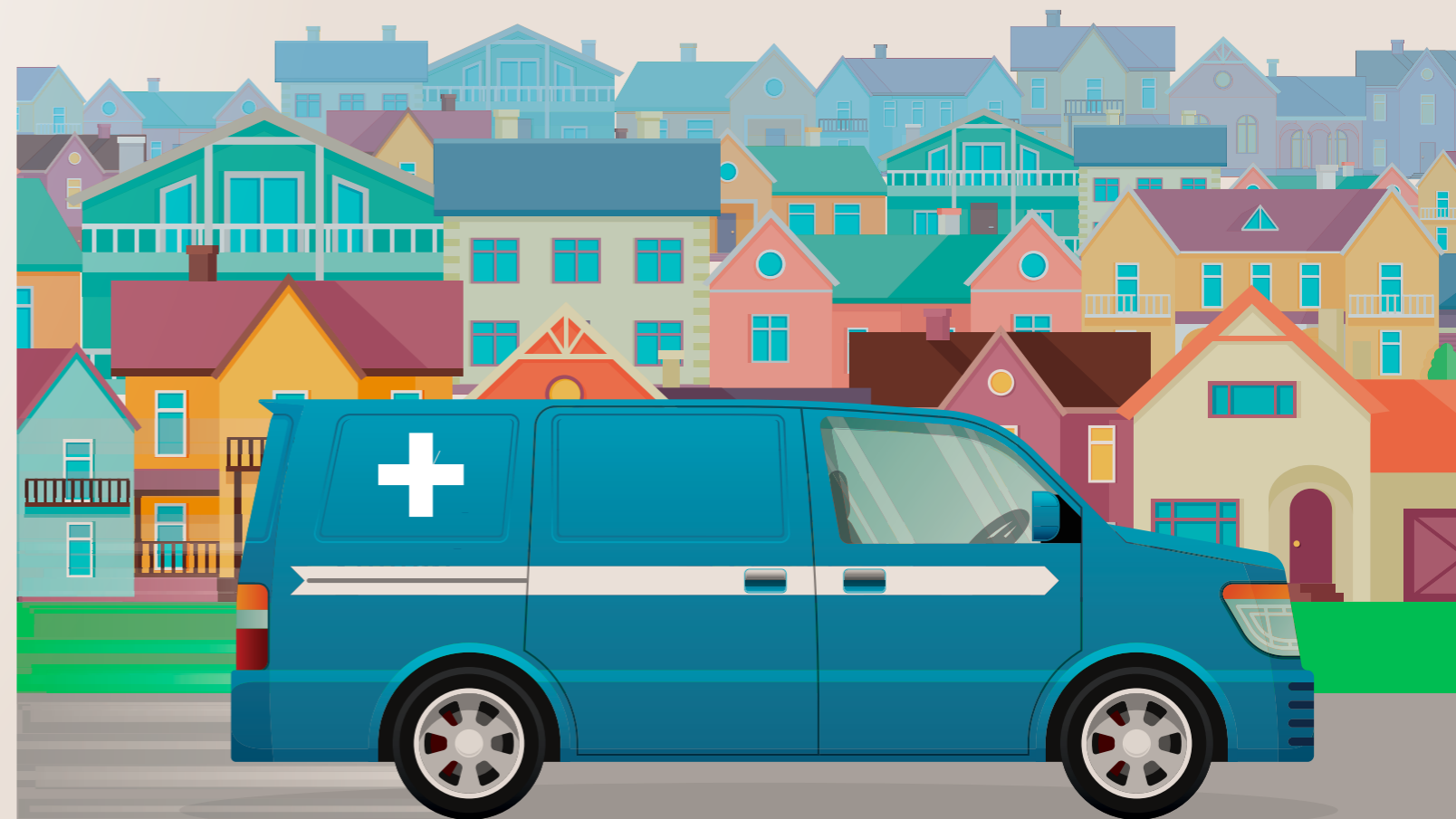
If you experience a problem with your delivery you must first contact the delivery company. The sooner you report an issue after a delivery, the quicker they will be able to resolve it. All patients on complex treatments must check their delivery for accuracy and completeness on arrival (just as you would groceries or any other online shopping). Do not leave the box unopened until you have run out of the previous month's, only to find an error has missed out the item you need. If the homecare company are unable to help you, get in touch with your PH centre and they will resolve the matter

for you wherever possible. The PH centres meet with the homecare companies regularly to ensure that high standards are maintained and any complaints or incidents are thoroughly investigated.

### What are the benefits?

There are huge benefits to patients on complex treatments as the lines, syringes and everything else is brought direct to the door. Faulty pumps are exchanged very quickly, sharps bins exchanged and patients needing blood tests have kits sent out with their tablets. None of this would be logistically possible directly through the NHS.

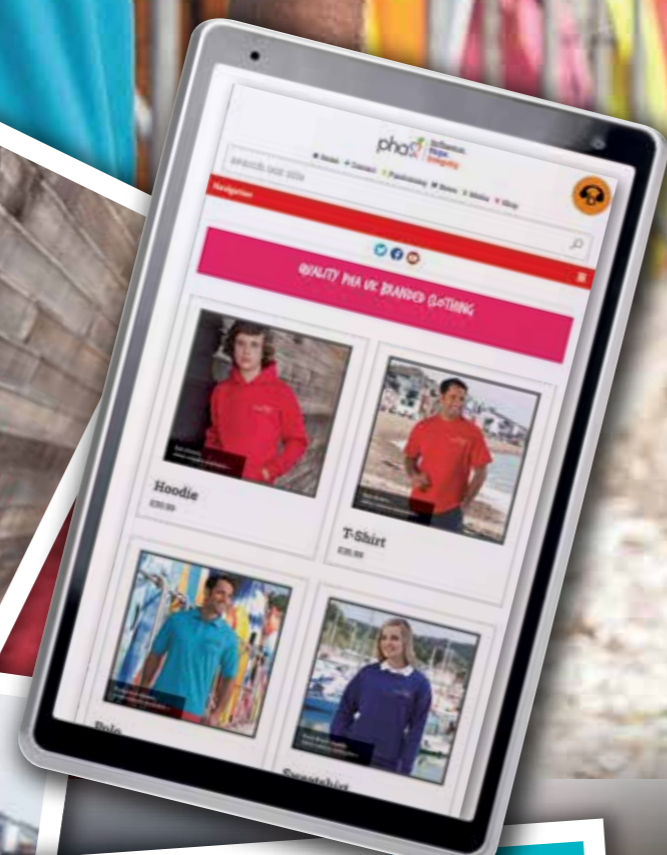
*In summary, convenience for all should be the main benefit. By using homecare your PH centre can oversee every prescription carefully and ensure that doses are correct and side effects managed carefully. We live in an age when online shopping and home delivery is ever more commonplace, so medication delivered to home should fit in easily. The services offered to PH patients are flexible enough such that nobody should feel inconvenienced by their deliveries.* ●



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

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

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



**Order online**

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or call 01709 761450

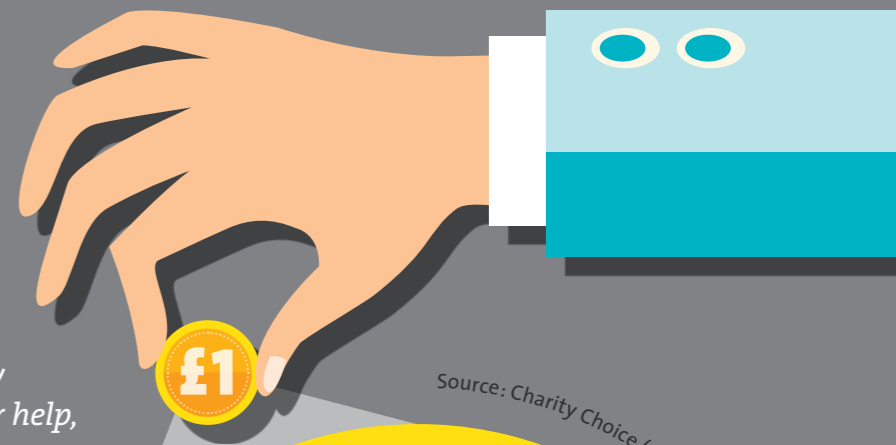
## How we spend your money...

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

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

### For fundraising support...

call the PHA UK office on 01709 761450, or email [office@phauk.org](mailto:office@phauk.org)



Source: Charity Choice ([www.charitychoice.co.uk](http://www.charitychoice.co.uk))

### In your Autumn issue of Emphasis...

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

**PH Week 2019 is coming!**

Our annual awareness-raising extravaganza.

**Alcohol and wellbeing**

How much is too much?

**All new Green Leaf Crew**

Our kids pages are getting a makeover!

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

### You can get involved in Emphasis too:

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

**Family Matters** - let us know if you'd like to tell us about your family's PH experience in our regular feature.

**In the News** - let us know if you raise awareness of PH through the media.

**Take the biscuit!** - and please get in touch if you'd like to answer the Green Leaf Crew Q&A.

We always love to hear from you - contact [media@phauk.org](mailto:media@phauk.org) with any feedback or ideas.

# Join our PH family for free today

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

**Influence.  
Hope.  
Integrity.**

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

Being part of PHA UK also enables you to participate in important research, and our friendly office staff are just one call away when you need advice. Join our PH family and you'll be joining 4,000 members in a unique network of support and inspiration.

Join **FREE** today at [www.phauk.org](http://www.phauk.org)  
call us on **01709 761450**  
email us at [office@phauk.org](mailto:office@phauk.org)  
or simply fill in the form below and return to us.



### Join today and benefit from:

- Support and advice
- Helpful printed information and resources
- Emphasis magazine delivered to your door four times a year
- Free access to emotional support from qualified professionals via our partnership with **Anxiety UK**
- Free access to financial advice from qualified professionals via our partnership with **Turn2Us**
- Fundraising ideas and guidance



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

**phaUK** | Influence.  
Hope.  
Integrity.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Postcode: \_\_\_\_\_

Email: \_\_\_\_\_ Telephone: \_\_\_\_\_

Are you a Patient  Carer  Parent  Medical professional

Other (please state) \_\_\_\_\_

Are you willing to take part in PHA UK surveys? Yes  No

Which **specialist treatment centre** do you attend? \_\_\_\_\_

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

**phaUK** | Influence.  
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Integrity.



### PHA UK Contact Details

**Office hours:** 9am to 3pm, Mon to Fri for general enquiries  
**Tel:** 01709 761450  
**Web:** [www.phauk.org](http://www.phauk.org)  
**Email:** [office@phauk.org](mailto: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](mailto: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](http://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](http://www.phauk.org)

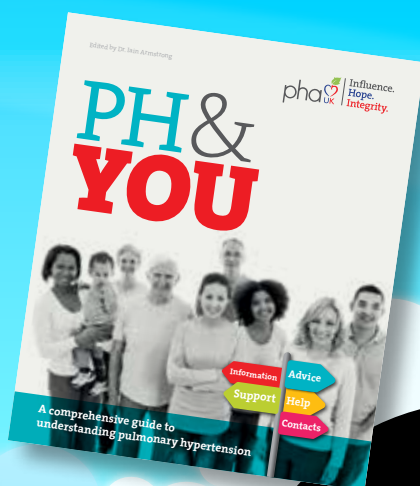
### Do we have your correct details?

Please email us on [office@phauk.org](mailto: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?

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