

SPRING 2020

# emphasis

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

## *Swimming and PH*

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### **A passion for fashion**

How Roshni learned  
to love herself

### **Plus...**

Single  
with PH

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Fundraising  
news

Meet the  
PH experts

...and much,  
much more!



## **THE NATIONAL AUDIT OF PULMONARY HYPERTENSION**

TAKING A CLOSER LOOK

*“Volunteering  
helps me feel  
more positive”*

*Viv's adventures  
with PAT dog Bobbi*

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# Welcome



Welcome to the spring issue of Emphasis – the first edition of a new decade! We're delighted to be starting it with almost 4,500 members, showing just how far we've come since the charity began 20 years ago.

We'll be rounding off our anniversary celebrations with our space-themed family weekend in May, designed to bring children with PH together to make special memories with loved ones and each other. Find out more about the event, which is for those under the care of Great Ormond Street Children's Hospital, on page 24. I'd like to personally thank volunteers Malcolm and Vee Willis who dedicate so much time and effort to ensuring the children's activities at our gatherings are so fantastic.

In this edition of Emphasis, we bring you inspiring stories from around our community. They include two members who have overcome challenges to enjoy swimming with PH, a young lady who has learned to love herself again through fashion, and a woman who is taking a different course in the quest for love.

Inspiration also comes in the four-legged form of Bobbi the spaniel, who spends his time helping people in

hospital to smile. Read about him and his dedicated owners on page 10.

Finally, it's a pleasure to bring you the story behind the Chesterwood Show, an equestrian event that has raised over £20,000 since it began 14 years ago (see page 34). We're constantly amazed by the extraordinary lengths our supporters go to in order to raise money for our charity, and we love sharing these endeavors as much as we can to give them the recognition they deserve.

**Do let us know if you plan anything over the next few months, no matter how big or small. Every penny really does make a difference.**

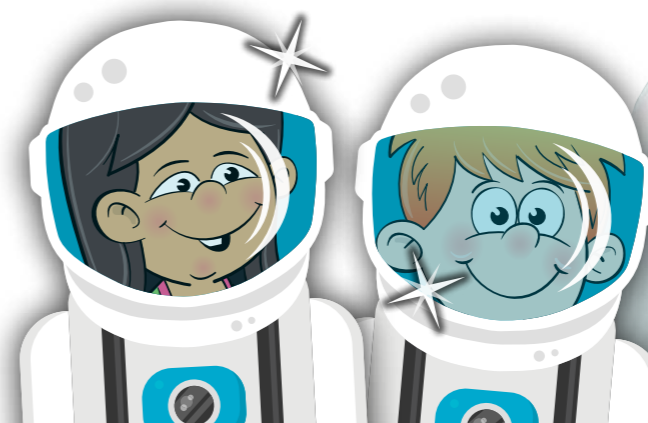
Until next time,

*Iain Armstrong*

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



**"We're constantly amazed by the extraordinary lengths our supporters go to"**



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# Emphasis *exchange*

## Sofia's story

Sofia Riaz is a mother of four living with multiple conditions, including pulmonary hypertension. She wrote to Emphasis to share her story.

Dear Emphasis,

I was diagnosed with PH in 2018, but because I have been suffering from pulmonary fibrosis (scarring to the lungs) since 2014 I thought the symptoms may have been down to that.

It wasn't until May 2018 that I had an echocardiogram which showed some abnormalities, and I was referred for further tests and diagnosed.

Having PH has changed my life dramatically. I used to say I wouldn't let it define me, but the honest truth is that it has, and I say I am not me anymore. I struggle with walking for more than 15 to 20 steps and I have to make sure I don't exert myself and take everything slowly.

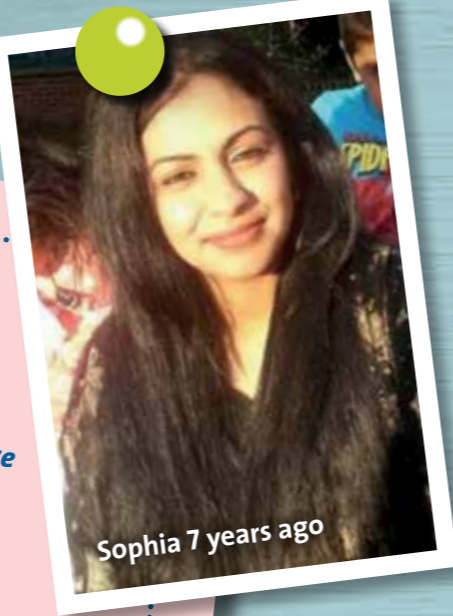
I have four beautiful children aged between seven to 13 who help me do so much and my husband makes it easier for me. It's still very challenging and hard, but knowing my family is there helps me to feel more positive.

My relationship has been impacted because I am restricted when it comes to taking part in activities or going out, and sometimes I feel bad because if I am struggling I have to ask for help - and I tend to get upset by this. It can be difficult not having 100 per cent independence.

I do get emotional and stressed to some level when I think how young I am and how I used to be, compared to how I am now. I often think how my life has completely changed. But at the same time, I have learned to be more patient and try not to worry about small things.

My advice for other people living with PH, particularly someone who has been recently diagnosed, is to research as much as you can and try to remain strong and positive.

Sofia, Leeds



Sofia 7 years ago



Sofia today



## Dear PHA UK,

I have suffered with PH for over 12 years now and am a patient under the care of the wonderful PH specialist team at the Royal United Hospital (RUH) in Bath - a satellite centre linked to the Royal Free Hospital, London.

The RUH Respiratory outpatients team who look after me during my clinical appointments and hospital admissions, have kindly sold books throughout 2019 to raise money and awareness for the PHA UK. I am delighted to say they have raised a fantastic £350!

We all hope this will be used to continue the fight against the disease.

Kind Regards,

Andrea x

Mrs Andrea Bown (nee Murphy)

## STANDING UP FOR THE PH COMMUNITY

We kicked off 2020 by meeting with a senior representative from Maximus, the company contracted by the Department of Work and Pensions to carry out assessments for Employment and Support Allowance.

We presented the results of our research into the financial impact of PH and showed recent videos filmed with members.

We took them to task on a number of things, and talked about how we can collaborate, for example by updating and improving their training materials on PH.

We'll keep you updated on developments, but please be assured that when you share your voices in our research or take part in our videos, as you can see, it really does make a difference!



## Social Media Highlights



@shargn39

Somehow, I managed a 100 mile walking challenge for the month of January. Each day I kept pushing myself to walk as much as I could, which in itself is a bit of a miracle, as winter isn't a good time for me with breathing and germs!



@CurlyTopAvery

Proud of all my friends and family who collectively donated £550 for @PHA\_UK in memory of my mum Clare Pickersgill who passed after battling PH for 10 years.



Tracy Harvey

The PH guides (produced by PHA UK) have helped me and my family so much, especially as a lot of our problems can't be seen.



@NHSOrganDonor

Excited to announce that our proposals for heart and lungs emojis have been approved and will hit keyboards this Autumn!



@phightertess

I'm starting 2020 as I mean to go on, listening to my body, putting it first and taking it day by day ❤️ #phighter #NoCureAlwaysHope



@kathrynangraham

Celebrating the gift of life with my family this weekend. Six whole years of wonderful and precious moments thanks to my donor and their family



@WHBTG

(Westfield Health British Transplant Games) Yesterday we visited @PHA\_UK to begin planning their support of the Games in Coventry. Lots to look forward to!



## FOLLOW US...

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## Remembering Brian

Dear PHA UK,

Please find enclosed a cheque for £900 – the second donation I have sent to you. The first one was from the church collection.

My late husband was Brian Toes, aged 67. Brian passed away in June 2019 after suffering with pulmonary hypertension for many years.

Brian's friends decided to get together and arrange an organised shoot day in his memory – an event which Brian had always been part of. This was held in January and called 'Stokes Shoot', after the farmer who owns the land.

Brian was a true countryman. He was brought up on a farm and enjoyed rural life all his life. He taught me and the children all about country life and the countryside – how to enjoy it and respect it, but also to understand it.

Brian's friends thought the world of him. He was always the life and soul of the shoot. They miss him very much and I'm sure they miss his humour too.

It was so touching and quite emotional too, to see Brian's friends stand together and have a picture taken and stand so proud in memory of him. (Yes, I'm shedding a tear at this point – it's ok to cry).

These are true friends that Brian was proud to know.

Thank you for all the good work you do.

Kind regards,

*Elizabeth Toes and family*

Sherburn-in-Elmet



## Award nomination for PHA UK co-founder

**PHA UK co-founder Iain Armstrong has been shortlisted for a prestigious national nursing award.**

Iain, who helped set up the charity 20 years ago, is up for 'Respiratory Nurse of the Year' at the British Journal of Nursing (BJN) Awards.

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

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

Iain has worked within the Sheffield Teaching Hospitals NHS Foundation Trust for 30 years and in 2005 became the first nurse consultant to work in pulmonary vascular disease.

He said: "It was an immense surprise to find out I was shortlisted for this award. I've seen working in respiratory nursing and it feels brilliant to be recognised in this way."

Chris Morley, chief nurse at Sheffield Teaching Hospital NHS Foundation Trust, said: "I am delighted that Iain has been nominated for this award, his dedication and care for our patients over the last 30 years is certainly worthy of this recognition. He is a credit to his team and the Trust and has made a huge difference to patients with pulmonary vascular disease both here in Sheffield and nationally."

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

## BACKING THE BRITISH TRANSPLANT GAMES

We'll be helping raise awareness of organ donation and pulmonary hypertension by backing the Westfield Health British Transplant Games for the second year.

The Games head to Coventry in July and the PHA UK is proud to be sponsoring the walking event, which sees participants cover a distance of between three and five km. As a charity, we'll also be taking part ourselves in the Donor Run, a

three-mile walk / run for anyone who wants to show their support for organ donation and life after transplant.

Last year, we sponsored the darts event at the Games held in Newport, South Wales.

The British Transplant Games have run for over four decades, taking place at a different UK city each summer. Look out for more on the 2020 Games in the next issue of Emphasis.

**Are you planning on taking part or attending the Games? Let us know by emailing [media@phauk.org](mailto:media@phauk.org)**



# Pawprints & PH

Living with pulmonary hypertension doesn't stop Viv Lloyd raising smiles in hospitals with her partner Denise and their therapy dog Bobbi. Mary Ferguson found out more about their volunteering and what it means to both them and the people they visit.

Viv (right) with Denise and Bobbi



Bobbi lending a paw to support last year's PH Week



Cheering up hospital staff



We are Dementia Friends



**V**olunteering has been a huge part of Viv and Denise's lives, since well before Viv was diagnosed with pulmonary hypertension in January 2019.

The Blackpool-based pair have been giving their time to others since taking early retirement over 15 years ago and spent a long time helping out as advisors at their local Citizens Advice Bureau.

But when King Charles Spaniel puppy Bobbi came lolloping into their lives, their volunteering path took a whole new direction.

*"We needed to dedicate more time to having a new dog, and because Bobbi had such a wonderful nature we thought we'd love to work with him in some way", says Denise. "I went on good old Google to research opportunities, found Pets As Therapy, and it all went from there."*

Fast forward three years and the trio now divide their time between two hospitals in Blackpool, working as a team to help people feel better during difficult periods.

Facilitated by the charity Pets As Therapy, they take Bobbi onto wards to meet patients for cuddles, comfort and companionship.

*"Lots of people in hospital miss their own pets", explains Denise. "It can be a long and lonely life, especially if you're in for a while, but Bobbi's visits give people something to talk to visiting relatives about – it provides a bit of normality, and friendship too."*

The volunteering has taken on a new meaning since Viv was diagnosed with PH at the Royal Hallamshire in Sheffield in early 2019. With three hospital stays before the diagnosis was confirmed, she experienced first-hand what it feels like to miss a pet – and the trio now visit the very ward she stayed on in Blackpool.

Viv says: *"I see it through different eyes now, from having been there myself. I know from experience what a wonderful job all of the hospital staff do – not just at the hospitals we visit but at my specialist centre too, where I continue to receive an overwhelming level of care and support."*

Coincidence has created poignant moments and memories for the pair through their volunteering. At one stage whilst visiting the children's ward at Blackpool Victoria Hospital, Bobbi

became a regular friend to a four-year-old girl named Lana.

*"We saw her for the last time the day before her fifth birthday, and she was so poorly by this point that her birthday celebrations had been brought forward", remembers Denise. "Whilst I stayed with her and Bobbi, watching her cuddle him while her mum took photos, Viv got chatting and it transpired that, unbelievably, Lana had pulmonary hypertension too."*

*"She was so full of fun and always smiling", adds Viv. "I was really upset for her and unfortunately, she passed away just a few days after that visit. To come across a little girl with PH, who was so poorly, really shocked us."*

As well as comforting patients, Bobbi has an important role when it comes to helping hospital workers too. He makes one-off visits to boost staff morale and joins his humans when they speak about their experiences at nursing conferences.

For Viv, volunteering with Bobbi provides purpose and direction – even on the bad days with PH. She says: *"The side effects from the drugs I am on now give me muscle pains so I have to take pain killers before I go out for the visits, but they do give me a boost. They get me out there on the days when I could say I really don't feel up to it."*

*"I come away from the visits thinking 'this is it, this is what life's about'"*

*"It helps me, because sometimes I just focus on me and my problem, and I do get a bit black at times. But this helps me to feel more positive about things."*

Denise has noticed the positive effect that volunteering has on her partner too. *"There are obviously days where Viv doesn't feel so great and struggles to get*

*the will to go out and do stuff. But whenever we go out and do a visit, she says 'yep, that was a good day'."*

A lot of people with Pets As Therapy dogs make the visits on their own, but volunteering together gives Viv and Denise shared experiences – as well as helping the visits go smoothly.

Denise explains: *"It works well for us as Viv will go in first as the 'introducer' and check the patient wants to meet Bobbi, and I will be the one that picks him up and handles him, because Viv struggles with that due to her health."*

The trio go out twice a week, alternating between the cardiac and children's wards at Blackpool Victoria Hospital and a weekly visit to Clifton Hospital in St Anne's-on-the-Sea too. They also do 'special gigs' as they call them – including Christmas fairs, conferences, and visits to emergency department staff.

*"It's wonderful to see the difference it can make to patients"*

*"The volunteering for us is an absolute joy", says Denise. "As corny as it sounds, it's wonderful to see the difference it can make to patients. There have been occasions when someone has been laying in bed, not responding to anything, and when we have taken Bobbi up, they have put a hand on his head. Eyes have opened, a smile has appeared, and you think 'my goodness, I didn't even know you had that in you'. Sometimes we will see that same person progressing week after week. We get so much back from it."*

Both Viv and Denise agree that the volunteering puts things into perspective. Denise adds: *"PH is a lousy thing to live with but you realise there are a lot of other things going on out there in the world as well."*

Continued over the page →

Find out more about Pets As Therapy at [www.petsastherapy.org](http://www.petsastherapy.org) Cats can be registered as therapy animals too. All animals must be over nine months old and have lived with their owner for six months. They must also pass a temperament assessment to ensure they are suitable for visits.



*"The photos of Lana with Bobbi are my last memories of her being well and happy"*

Lana Driver died from pulmonary hypertension just a few days after her final visit from Bobbi. Here, her mother Susie reflects on the difference he made to her daughter.



*Lana was very poorly, and we knew she was going to pass away, but Bobbi cheered her up dramatically. Her face just beamed when she was with him. She could not stop talking about that little dog.*

*Bobbi was a calming influence and his visits gave Lana something to look forward to. Because she was so ill, her fifth birthday party was brought forward, and it was a coincidence that Bobbi was visiting the ward at the same time. She spent her last party laughing and for the hour that he was there, she was just a normal child cuddling a dog.*

*Watching Lana with Bobbi brought tears to my eyes; it was amazing to see her so happy. She got more out of it than you could ever imagine. She thought Bobbi was her best friend and she loved looking at the pictures I took of her with him.*

*She would be so excited to see them in this magazine. I can imagine her saying 'Look mummy, I'm famous'. The photos of her with Bobbi are my last memories of her being well and happy, as she died just a few days later.*

*Lana would want her memory to live on and I want to raise more awareness of pulmonary hypertension in her name. She was so loving and giving and touched so many hearts; there were over a thousand people at her funeral.*

*What Viv and Denise do with Bobbi is fantastic. Even though Viv has PH herself, they take time out of their lives just to go and visit sick children and adults and I think that's just amazing. I can't thank them and Bobbi enough for what they did for Lana.*



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You will be asked to fill out a short form giving permission for Anxiety UK to hold your details. Your membership starts once the form is returned.

For more information, call 0344 332 9010 or email [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk)



# A CLOSER LOOK AT THE NATIONAL AUDIT OF PULMONARY HYPERTENSION

The National Audit of Pulmonary Hypertension is more than an NHS tick-box exercise. *Professor David Kiely, who as a clinician works with the very experienced team at NHS Digital, explains...*

It's amazing to think the National Audit of Pulmonary Hypertension has been around for ten years, and I feel privileged to have taken over from Dr Simon Gibbs as its Clinical Lead in 2019. The annual audit, carried out by NHS Digital, looks at data provided by the UK's specialist centres and measures outcomes - including frequency of consultations, timeliness of diagnosis, administering of treatments and tests conducted.

More recently the results have been measured against specific targets, known as standards, but it wasn't always that way.

One of the big challenges at the beginning was trying to identify just how many patients actually had PH and were receiving treatment. So, ten years ago, it was very much about trying to uncover the day-to-day activity within the pulmonary hypertension service to help us plan for future services.

But medical audit is all about trying to improve standards of healthcare, so a few years ago, a set of standards were identified which reflected quality care measures. These were decided and refined in collaboration with the PHA UK, who involved their members - the PH community - in deciding which they felt were the most important. The standards were based on the areas identified by the PHA UK and their members as being most important. Each standard focuses on a specific area (for example, quality of life) and the top four standards were ranked in the order in the box below:

## OUR MEMBERS TOP 4 STANDARDS

**90%** of patients who have had at least one consultation (inpatient, day case, or outpatient) in the last year should have at least one quality of life questionnaire recorded in that time.

**95%** of patients whose referral letter was received over six months ago should have been seen, assessed and had a diagnosis recorded.

**95%** of patients receiving a pulmonary hypertension drug therapy should have had at least one consultation at a specialist PH centre within the last 13 months.

Patients receiving a pulmonary hypertension drug therapy should have the gold standard diagnostic tests performed and recorded before any treatment begins.

It was key that patients and their families had the opportunity to identify what they felt was important. Because we always want to do the right thing for patients, it's important to set standards that reflect what is important not only to healthcare professionals and the NHS, but also people affected by pulmonary hypertension.

## MEASURING IMPROVEMENT

Over the period of the last four years, we can see that the way centres have performed against these standards has improved year-on-year. You can see the latest results at

[www.digital.nhs.uk/pubs/naph10](http://www.digital.nhs.uk/pubs/naph10).

I think the audit has also been a huge success in terms of helping us to plan for the future, but it's clear that it has also been very important in driving up standards and improving care for people affected by pulmonary hypertension.

Sometimes a centre may not meet every standard and there may be very good reasons for this. If that is the case, that individual centre then has the opportunity to reflect on their own performance. It's invited to develop what's called a 'local action plan', based on feedback from the national audit, and these are then shared on the NHS Digital website. You can access them using the web address above.

It's a very important part of delivering a specialist pulmonary hypertension service to be able to demonstrate that people affected by this condition are receiving very high-quality care.

It's also important that within the NHS in general, the people who overview how your PH care is provided - the commissioners - see that the services in the UK are well organised and meeting these high standards.

And of course, it's vital that we look at identifying new standards that will continue to drive up the care we provide for people affected by pulmonary hypertension.

## UNDERSTANDING WHO CARRIES OUT THE NATIONAL AUDIT OF PULMONARY HYPERTENSION

The national audit sits within an organisation called NHS Digital, who are used to managing huge amounts of healthcare data.

We are very fortunate that within that team there are individuals who have worked on the audit for many years now, so they understand the condition and what's important to the pulmonary hypertension community. Having spent time with the team at

NHS Digital it is clear how passionate they are about providing care for people affected by PH.

They are still keen to find out more though, so we're delighted to be welcoming NHS Digital to one of the specialist centres soon, where they will see for themselves how the service works - and how centres are doing their best to provide high quality care.

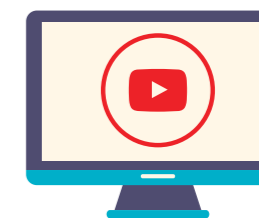
## The PHA UK's view

*"The PHA UK put up the initial funding for the formation of the national audit, paying for its first year. We wanted to ensure that the services being delivered in the specialist centres across the UK were meeting not just minimum standards, but high standards of care.*

*From our perspective, and from speaking to patients and their families, people are greatly encouraged by the existence of a national audit. And its results show that regardless of where you live in the UK, the standard of service is really high and consistent across the board. Plus, if there any issues, there is a process in which they are identified immediately and dealt with across the board.*

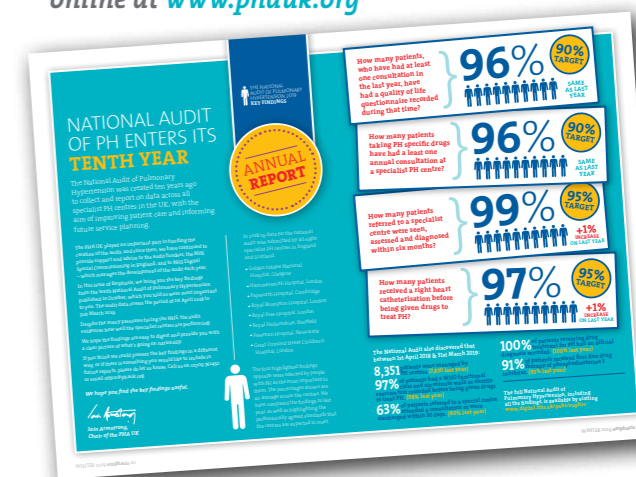
*Not only are centres striving to deliver high quality care in the UK - a high quality of care is actually being delivered.*

**IAIN ARMSTRONG**  
CHAIR, PHA UK



**YOU CAN WATCH A VIDEO OF PROFESSOR KIELY TALKING ABOUT THE NATIONAL AUDIT OF PULMONARY HYPERTENSION ON THE PHA UK YOUTUBE CHANNEL.**

To see the latest results of the National Audit of Pulmonary Hypertension, visit [www.digital.nhs.uk/pubs/naph10](http://www.digital.nhs.uk/pubs/naph10). You'll also find a summary in the last issue of *Emphasis* (Winter 2019), which can be viewed online at [www.phauk.org](http://www.phauk.org)



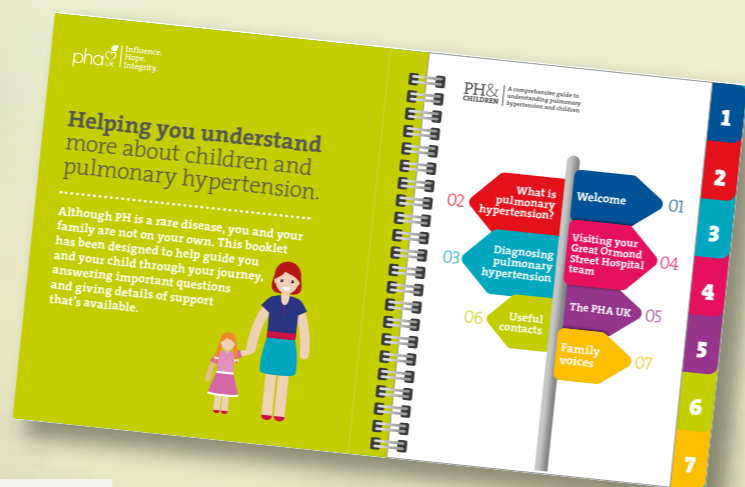
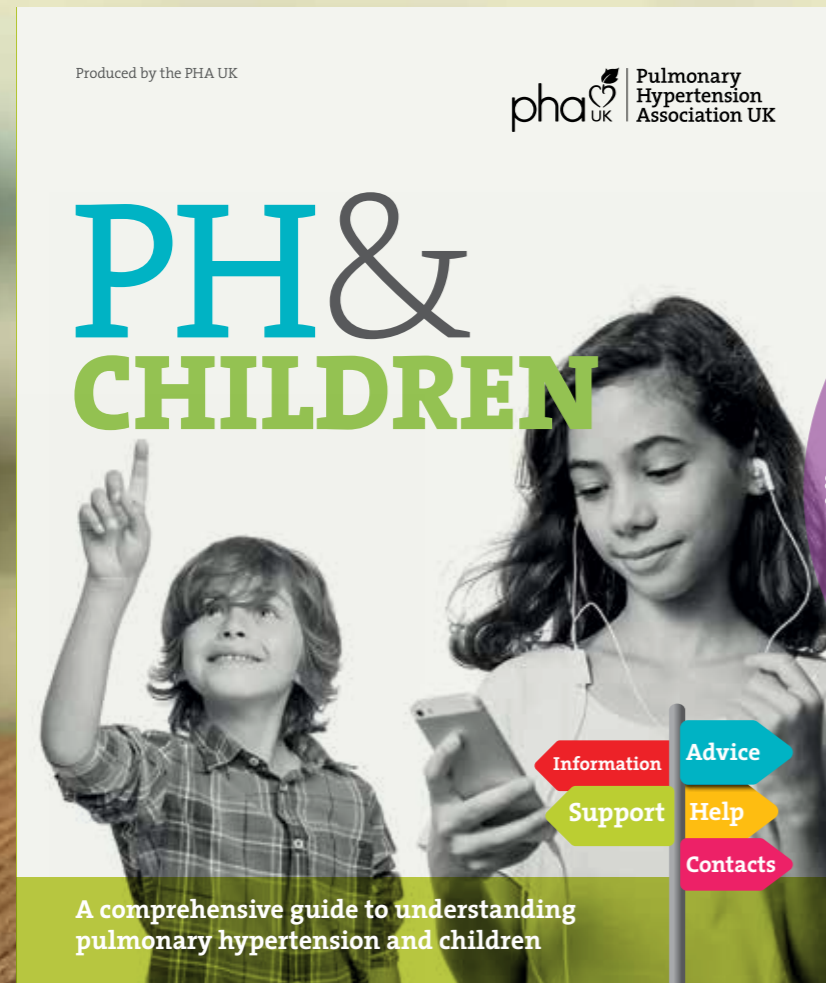
## A word of reassurance about your data

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# PH & CHILDREN

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



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# Swimming with PH

From increased strength to better mental health, swimming can hold many benefits for people living with pulmonary hypertension. Ready to dip your toe in the water? Read on for expert advice and inspiring stories to help you get reacquainted with the pool...

**W**e talk a lot about the importance of moving when you have PH, and with good reason too. Exercise is vital for both physical and mental wellbeing and living with pulmonary hypertension doesn't mean you can't get active – you just need to find something that suits your lifestyle.

Swimming ticks so many boxes. It's gentle on the joints, you can go at your own pace, and it helps build endurance and increase fitness – as well as toning muscles and de-stressing the mind.

Some people, particularly those with other conditions that might cause them to be in pain, find it easier to move in the water. Swimming can provide a freedom to move that can't be felt on the land.

**DO YOU USE OXYGEN OR AN IV LINE? TURN OVER TO DISCOVER HOW PHA UK MEMBERS AMANDA AND YVETTE MAKE SWIMMING WORK FOR THEM... ▶▶▶**

**Carol Keen, clinical specialist physiotherapist in pulmonary hypertension, has the following advice if you're thinking of giving swimming a go this year:**



- Before you go for a swim, try and go along to the pool and have a look first. See how it is set up - what the layout is, where can you park, how far you have to walk to the pool, and whether you need change for the locker. That way, you know what to expect.
- Speak to the staff at the pool. Find out when might be a good time to swim, for example when it's quiet.
- Start very slowly and gently. You might only manage a very short swim (five or ten minutes) on the first occasion. Don't exhaust yourself as it might leave you feeling over-tired and put you off going again.
- Listen carefully to your body, particularly your breathing. In the pool you can't tell if you are getting sweaty, so you have to use your breathing to tell you how hard you are working.

**If you are a little short of breath but could still chat, then you are working at the right level – if you're any more out of breath than that, you should slow down or stop. Always stop exercising if you feel dizzy or experience chest pain.**

- Allow plenty of time to get changed before and afterwards so you don't have to rush. This can tire you out or make you feel anxious.
- Don't be surprised if you feel very tired after your first swim. Allow yourself some quiet time to recover.
- Get into a routine. Try and swim at the same time each week, meaning you are more likely to stick with it.
- Go with a friend or family member. It will make it more fun and again, you'll be more likely to stick with it.

# Swimming with oxygen

## AMANDA'S STORY

Amanda Goodman takes oxygen 24/7 but has found a way to continue swimming, thanks to a little imagination and determination.

*I began swimming at the age of 11 and until I got ill, I would go between one and three times a week – it was quite a big part of my life.*

*I was officially diagnosed with PH in 2013, and at first I was on low levels of oxygen and didn't need to use it all of the time. I used to go to water aerobics and have some oxygen before I got in the pool, and then some more after the class, before swimming six lengths. I just wanted to keep my swimming going.*

*As the years went on, I started to need more oxygen, and I started thinking maybe I should give it up completely.*

*Then I saw something on the internet that showed children swimming with oxygen, whilst someone walked the cylinder up and down the pool with long tubing reaching into the water. I had never considered this may be possible before!*

*My husband and I set about trying to find somewhere we could give it a go and found a children's pool we could hire for £12 an hour. I had a spare 15 metres of tubing, and we found that he could keep my oxygen in the trolley and sit and watch it to see when it ran out, and I would just swim up and down – we didn't need to move the trolley at all.*

*I turned the oxygen up to about 12 litres/minute (I normally take five to eight litres when I'm walking around).*

*I can only walk short distances on the land, but I found that in the pool I could walk up and down without a problem. I can even do star jumps in the water!*

*Eventually I had to stop using the children's pool as my knees got bad and I struggled to get up out of the pool using the ladder, as there were no steps down into the water.*

*Now, I go to a pool attached to a hotel (the Village Gym in Bury) and pay a monthly health club membership to use it.*

**“Swimming is a very important part of my life.”**



*I had to take my tubing along and show them just how long it was, so they knew what I would be bringing. The manager there has been extremely kind, and I'm allowed to have my very own lane.*

*When I first started at that pool, I had to take both my husband and carer – my carer would keep an eye on the oxygen and my husband would get into the pool with me to stop people tripping over the wire as it was difficult to see.*

*An idea then came to me to cover the tubing, which was clear, with electricity tape – so it's multi-coloured now, meaning it's more visible to other swimmers. This means my husband doesn't have to be there too anymore.*

*These days I go once a week for half an hour, with my carer, who I have two afternoons a week. I would go more if I could!*

*Swimming is a very important part of my life. It helps with the osteoarthritis with my knees, with exercising my lungs, and maintaining my weight. It clears my mind; any worries I have before I go into the pool seem to disappear after I have swum. It gets me out and seeing other people too, which is important.*

*When you become ill there are things you can't do anymore, so it's good to feel there is something I enjoyed before that I can still do now.*

# Swimming with a Groshong line

## YVETTE'S STORY

It is extremely important to keep your IV therapy line, pump and chest area completely protected against water to avoid infection. So, if you have a line, swimming is more difficult – but it's not impossible. Yvette Wilson was diagnosed with PH four years ago and uses a drysuit and an 'aquapac' to help her enjoy the pool and sea.

*I love going on holiday and the swimming pool and sea are a huge part of it for me. When I had my Groshong line fitted I couldn't let it stop me enjoying the water fun.*

*I searched the internet and found a website that sells aquapacs – waterproof cases for electronics with wires.*

*I always use the aquapac when I am down by the pool as it gives me the confidence that my pump is constantly protected around water. The aquapac is simple to use and has always been 100 per cent waterproof, plus it's clear so you can check on your pump.*

*It only protects the pump and a small amount of line that you place in the bag as well, it does not protect your site.*

*If I want to go into the sea or submerge myself in the pool I wear my drysuit too, which protects the pump as well as the site.*

*I purchased my purpose-made central line shortie drysuit from Hammond Drysuits. It was made-to-measure and cost me £300. The company is a small family-run business and I found them very helpful. I do need assistance to get in and out of it but it enables me to go snorkelling, which I love.*

*Having fun in the pool or sea is good exercise for me. I always stay within my depth, but it is lovely to be able to do some exercise - and best of all, be able to join in the fun with everybody else.*



Always speak to a healthcare professional before embarking on any kind of new exercise routine



## WHAT DO YOU LOVE ABOUT SWIMMING?

*"Swimming helps me work on my breath control. My lungs seem to work and feel better when I swim regularly. It's my favourite exercise!"*

Karen Hagerman Moseley

*"My 10-year-old has PH and has swimming lessons every week. He told me it helps him relax and stop thinking about hospital, and it makes him feel strong. He can keep up with people he can't normally keep up with when running."*

Helen Keith

*"I do a weekly Aquafit class that has helped with my strength in my body. I feel more motivated and able to do more."*

Lou Chadburn

*"I can only do gentle backstroke and breaststroke these days but I can manage 20 lengths and it's constant weightless movement so I'm working my whole body."*

Matt Whitlock

*"I have PH and my husband has COPD. We go to the gym together and always feel we have accomplished something after a gentle swim and 15-30 minutes on the treadmill."*

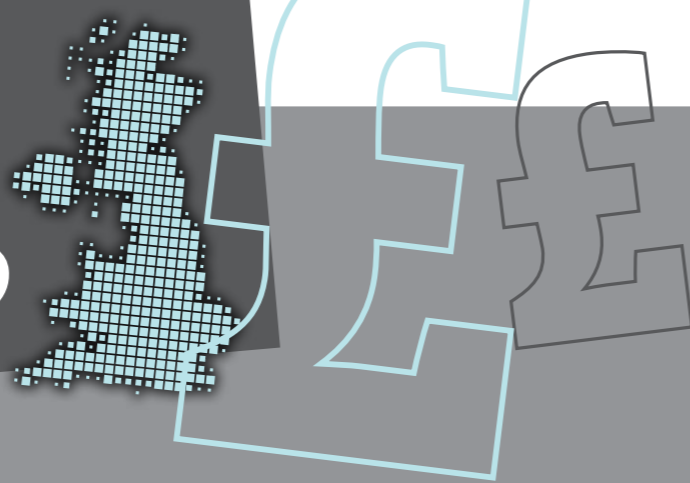
Margaret Vickers

*"Swimming has helped me so much. I started walking in the water and then started breaststroke while using a float... baby steps."*

Lynsey Childs



# FUNDRAISING focus



## Challenge for Charlie

Leigh Beeton completed the Milton Keynes winter half-marathon, raising £2069 for the PHA UK. Leigh's son Charlie was diagnosed with PH in 2017 and underwent a double lung transplant at Great Ormond Street in 2018. Writing on his Just Giving page, Leigh said: "I wanted to raise money for the PHA UK because they do incredibly important work in supporting PH patients, raising awareness and funding research into this rare disease. Charlie is now going from strength to strength after his transplant, and I am so grateful to my family and friends for their support and sponsorship for such a worthy cause."



## Knitting together funds

PHA UK members Joanna Young, Christine Pears and Michelle Hamilton raised £335 by selling knitted Christmas trees, snowmen, baubles, hedgehogs and owls. They set up a stall at the Freeman Hospital, and also sold items at a patient day at the Freeman back in October. Joanna said: "I made the knitted items along with my friend Ethel, who has PH. Christine, Michelle and I all suffer from PH and we are hoping to make some more knitted items for fundraising days next year."



THANK YOU!

## Baking for bucks

The PH specialist team at the Royal Papworth Hospital held a bake sale and information event to raise awareness of PH. They raised £335. Emily Knightbridge, clinical trial coordinator at Royal Papworth, said: "The whole of the Pulmonary Vascular Disease team got involved including the consultants, surgeons, specialist nurses, research team and admin team. It was a really positive day with so much interest from staff, patients and visitors and raised awareness of PH as well as fundraising for a great cause."



Another bake-off was organised by a group of PH researchers at Imperial College London to raise awareness within the college. Alex Ainscough, one of the students who took part, said "We had a lot of people get involved, and we were featured in the National Heart and Lung Institute newsletter which was great! We had several rounds across a few weeks, and then held a grand final just before Christmas - the competition was very high."



NOM!  
NOM!

## Carols for coins

Members of Faversham Choral Society in Kent raised £262 in just one evening by singing Christmas carols to commuters outside Faversham station. Stephanie Wolfe of the society, said: "Our son Alex suffers from PH, so we made the PHA UK our charity of the year. The commuters were very appreciative of our four-part renditions of the carols, particularly when we launched into the descants as well!"

If you're planning a fundraiser, don't forget to let us know about it! We will send you a free fundraising pack, and you might appear on these pages in the next issue. Email [office@phauk.org](mailto:office@phauk.org) or call us on 01709 761450.

# SPRING FUNDRAISING TIPS

Warmer weather can make fundraising much easier! Here are some ideas – and only one of them involves wearing trainers...

### VILLAGE FETE

If you live in a small community, a village fete offers something for all the family to get involved in. If you're not keen on organising the whole thing yourself, find out what fairs are taking place in your area and ask if you could have your own stall. You could sell cakes or PHA UK-branded merchandise, which would also raise awareness of PH in your community.

### SPONSORED CYCLE

Whether you're a keen cyclist or not, setting yourself a cycling challenge is a great way of fundraising. In the spring & summer months, a bike is a fantastic way to explore the UK countryside. Why not take a few friends along for the ride and run the event over several days, with a target distance to cover on each day?

### SKYDIVE

Doing a skydive is a spectacular way to fundraise. If you don't like heights, it's also a great way to face your fears, which might persuade people to give you extra money in donations. Tandem skydiving is the most popular type as you can let your experienced instructor do all the technical bits.

### CAR WASHING

Setting up a car wash is one of the easiest ways to fundraise – all you need is soap, water and elbow grease! You could contact your local school or church to ask if you could use their premises, and make sure you advertise well and have someone stood outside waving drivers in. You could also hand every customer an information leaflet about the PHA UK to take away.

# Understanding pulmonary artery changes

A presentation about why pulmonary arteries change in pulmonary arterial hypertension was the winner of a PHA UK-sponsored prize at last year's National PH Research Forum. Emphasis spoke to presenter *Angelos Anastasakis* about his work, his winnings, and the importance of medical research in rare disease areas.



## First things first, how did your research project come about?

I'm currently a fourth-year medical student at the University of Central London and during our third year of studies the medical school allows us to do a Bachelor of Science in a field that interests us.

I chose cardiovascular sciences and during this course we carry out a research project. Initially I investigated the immune cell response in pulmonary arterial hypertension (PAH). The project was very successful and I established a good relationship with the lab I was working at - Royal Free Centre for Rheumatology and Connective Tissue Disease. They offered me the opportunity to carry on researching in the field of PAH over the summer holidays - this time looking at metabolism - and I was delighted to be able to do this.

## Can you tell us more about the research - what did it set out to do and what did it discover?

The research I presented at the National PH Research Forum was from the above project and it was led by a final year PhD student called Jerry Abu-Hanna, who came up with the ideas which we investigated. We sought to understand why the pulmonary arteries in people with PAH become so thick and muscular. Hopefully by understanding these changes we can find a targeted drug to prevent them from occurring altogether.

All cells take up oxygen and glucose and use this to make energy in the form of adenosine triphosphate (ATP). This is called mitochondrial respiration. We wanted to investigate mitochondrial respiration in the muscular part of pulmonary arteries, which is made up of smooth muscle cells.

We looked at smooth muscle cells taken from the pulmonary arteries of PAH patients and from patients without PAH. We found that mitochondrial respiration was increased in smooth muscle cells from PAH patients, as they were taking up more oxygen and producing more ATP. This increased energy can then be used to make more smooth muscle cells, explaining why the pulmonary arteries are so much more muscular in PAH.

This energy or ATP is produced in mitochondria. Next, we wanted to see if mitochondria had an abnormal composition in smooth muscle cells from PAH patients to explain the increased energy production. We found that the mitochondria in PAH had an increased mass, which simply means they have more machinery which allows them to produce energy.

Our next task was to see why this mass was increased. The process which adds

mitochondrial mass to cells is called mitochondrial biogenesis, which we found was working at a higher rate than normal in PAH smooth muscle cells.

**The process which removes mitochondrial mass is called mitophagy, which we found was working at a lower rate than normal in PAH smooth muscle cells.**

The increased rate of mitochondrial biogenesis and decreased rate of mitophagy add more mitochondrial mass than there should be to smooth muscle cells in PAH. This gives them more machinery which then allows them to produce more energy. This energy is then used to make more smooth muscle cells - making the pulmonary arteries more muscular in PAH.

**Another feature of smooth muscle cells in PAH is a resistance to the normal cell death cycle, meaning they survive a lot longer than they should. This causes an overpopulation of smooth muscle cells making the pulmonary arteries very thick.**

To explain this, we looked at the levels of reactive oxygen species (ROS) that can disrupt the cell death cycle. ROS levels are normally tightly regulated, and the major source of its production is from mitochondria. We saw that the mitochondria were producing more ROS than they should be in PAH. This ROS allows the smooth muscle cells to survive, leading to thicker pulmonary arteries.

**Hopefully we might really be onto why the pulmonary arteries change in the disease, and we can understand even more soon.**

## Why is medical research in the field of PH so important?

The disease is rare and therefore as a result, fewer funds and resources are available for research when compared to something more common.

**Research is a necessity so we can find a way to improve patients' quality of life and reverse disease progression.**

Plus, the disease is very poorly understood which reinforces the need for research. Currently, treatment tries to widen the pulmonary arteries to increase blood flow through them and decrease strain on the right side of the heart.

Despite this, it doesn't change the progression of the disease - it only slows it down. **If through research we could find out exactly how the disease works, we could find an effective target that could stop the disease completely.**

**Your presentation won you £1000 towards developing your research. How do you feel about winning the PHA UK prize?**

To be honest I was completely surprised. Being one of the only students and presenting to a room full of leading researchers and clinicians in the field of PH, I was just nervous about getting the talk done!

It was a lovely and unforgettable experience, after which I had to run back to the Royal Free for some teaching. I got a text when I got back to the hospital telling me I had won. I couldn't believe it!

It's also great news that our theories about how PAH works made sense to someone other than us. It was a pleasure to be able to work with and learn from

**The National PH Research Forum takes place every year at the Chelsea Physic Garden in London. It brings together physicians, scientists and academics from all over the country and the PHA UK has provided sponsorship since 2012. The annual forum is an opportunity for those involved in developing better treatment for people with PH to share research, experience and ideas.**

**Watch a video of our interview with Angelos and others at the PH Research Forum on our YouTube channel.**



The pulmonary artery in a healthy person

The pulmonary artery in a person with PH

Jerry Abu-Hanna as part of this research. I must also mention Professor David Abraham, Professor Lucie Clapp and Dr Markella Ponticos. They were my senior supervisors, and nothing would have been possible without them.

## What will you be using the winnings for?

I would love to be able to go to an international conference on PH to present our findings. Fingers crossed we'll have more work to be able to present by then. This will probably be after my summer exams.

## Finally, what's next for you and your ambitions?

It's still early days and right now my goal is just to do as well as possible in medical school. Having said that, I would like to pursue a career in surgery. I couldn't tell you which branch with certainty, though cardiothoracic surgery has definitely caught my eye.

**In parallel with this I definitely want to continue carrying out research, as it's through research that we can continue to advance the field of medicine and improve the quality of care for patients.**

# THE PHA UK PHAMILY WEEKEND IS BACK!

WE'VE TEAMED UP WITH GREAT ORMOND STREET CHILDREN'S HOSPITAL (GOSH) TO HOST ANOTHER SPECIAL FUN WEEKEND IN OXFORDSHIRE, AND WE'D LOVE YOU TO JOIN US.

Taking place at the beautiful Heythrop Park Hotel in Enstone on bank holiday weekend 8th - 10th May 2020, the focus will be on fun and friendship, with plenty of activities on offer for both young children and teenagers. The event, which is fully funded by the PHA UK, provides a unique opportunity to meet other families outside of the hospital setting.

This year's space theme incorporates a large mobile planetarium and families are encouraged to embrace space-themed fancy dress for the gala dinner.

Former teachers Malcolm and Vee Willis have been involved in PHA UK conferences since 2001 and have been in charge of children's activities for five years.

Malcolm said: "Families can relax knowing that everything is provided for them and the children are in the safe hands of adults that many have come to know. Everyone gets their own private space - adults can join in, but they can also go off and have some time out if they want to."

The weekend allows connections to be made and friendships to be formed, and children can talk to others in similar situations - which is important for siblings too.

Malcolm added: "For children who have PH, it's a chance for them to see they are not on their own. It's about giving families time and space. It's wonderful to hear the conversations and see the smiling faces; that's what makes it so special."

Places are limited due to the costs associated with staging the event. Therefore, to be eligible to attend, your child must be currently under the care of the pulmonary hypertension team at Great Ormond Street Hospital or one of their national clinics.

For enquiries or bookings please contact Daisy Stewart at CFS Events on 01438 751519 or [daisy@cfsevents.co.uk](mailto:daisy@cfsevents.co.uk)

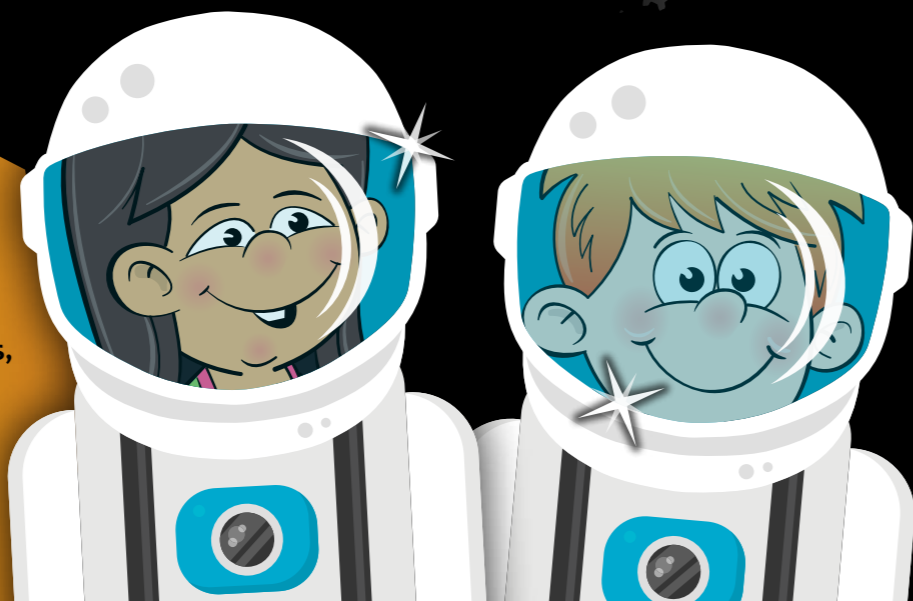
HEYTHROP PARK HOTEL,  
OXFORDSHIRE

8TH-10TH  
MAY 2020

LOOK OUT FOR  
SOME SPECIAL  
SURPRISES!

## WHAT'S ON...

NEW for 2020 is table tennis, face painting, t-shirt spray painting & more. PLUS Table hockey, table football, Lego workshops, soft play, arts & crafts, crazy golf, treasure hunts, films, bingo, pottery and model-making ...and much, much more!



# Green Leaf

Crew!

4 PAGE PULL-OUT

## Kaylee's Column HOW TO DEAL WITH EXAM STRESS...

Kaylee Mynot is 19 years old and lives in Surrey. She was diagnosed with PH as a baby. In her latest Green Leaf Crew column, Kaylee talks about coping with life at school and how to deal with the time of year every teenager dreads - exam season.

Exam season is coming up and I know that this can bring on a lot of stress and anxiety for anyone, let alone those with PH.

When it came to my exams, especially the GCSEs, I found it very tiring to be at school all day and then have to come home and study some more. I found it got me down a lot because I became so tired and worried about it all.

In the end I decided to make a revision timetable and made sure that I got all my studying done before I had dinner. That way I could spend time with my family and relax after dinner and forget about my exams for a while. Also giving yourself a day off sometimes helps a lot!

Many of you will know that being in school with PH can be quite challenging and tiring in general. From my own experiences, I know that feeling different from all your friends in school isn't nice, and your friends may not understand how PH makes your life different from theirs.

But I always used to think of all the positives that also came with having PH, such as not having to do PE (I used to hate getting changed and feeling

cold!). I also had a pass that I could use in lessons so that I could take some time out if I needed to.

I found that talking to my teachers and helping them to understand made them even more willing to adapt things for me so I could still take part. Remember that teachers are there to support and help you and they will always want you to do what helps you learn best, whether that's taking a break or doing something that's less tiring for you.

Good luck in all your exams!

Kaylee



If you've got a question for Kaylee or a topic you'd like her to cover, email [media@phauk.org](mailto:media@phauk.org) and she'll answer it in a future issue!

# Revision time...

by David Banks



## Zac meets David Beckham!



Two-year-old Zac Gunn was given a big surprise when a very famous face came to see him in hospital. David Beckham, one of England's most famous footballers, visited Great Ormond Street just before Christmas to meet children and staff, and Zac was one of the lucky few who had a kickabout with him. Zac, from Motherwell in Scotland, was diagnosed with PH in September 2019 and was in hospital because he was having a Hickman line fitted to help his breathing. Zac's

dad Gordon said: "It was amazing to see Zac forget his worries for a while by playing football with David. He wasn't fazed at all and got stuck in! David is such a nice person and really down to earth. He spent some time with us, posed for photographs and wished us well. It was an amazing experience and I can't thank him or the staff at Great Ormond Street enough."

Zac's family have raised £12,000 for the Great Ormond Street PH service after his treatment there.



©Joe O'Brien

### HAVE YOU EVER MET ANYONE FAMOUS?

Ask an adult to send a photo to [media@phauk.org](mailto:media@phauk.org) and you might just see it in the next Green Leaf Crew!

# GROW YOUR OWN TOMATOES!

As the spring weather arrives, it's a great time to start growing your own vegetables. Tomatoes are easy to grow, and you don't even need a garden to do it! A windowsill which gets plenty of sunlight will be fine.

## Here's our five-step guide...

First, you'll need a medium-sized pot filled with compost soil that is meant to live in pots (so not garden soil). Fill the pot with soil until it is 2-3cm away from the top of the rim. Then add a bit of vegetable fertiliser.

- Bury your tomato seeds deep into the pot and give them plenty of water to get them started.
- Place your pot in a warm place where it will get four to six hours of light per day, such as a kitchen windowsill.
- Water your pot every other day, or every day if the weather is hot.
- After two to three months your tomatoes should be ripe enough to eat. When they turn a deep red colour, you can pick them.



## VEG QUIZ

How well do you know your vegetables? It's time to find out!

Answers over the page >>>

- 1 This round orange vegetable is best associated with Halloween.
- 2 These small green ones like hiding away inside a pod.
- 3 These tasty round vegetables grow on a vine and are commonly red or green.
- 4 You'll find this one growing under the soil, and it's used to make crisps.
- 5 This strong round vegetable can make your eyes stream when you cut it.

### FUN FACT

Less than **ONE THIRD** of the Earth is covered by land.

# GREEN LEAF CREW Q&A

## Izzy Platt

Izzy Platt is four years old and lives in St Helens with her mum, dad, and her cat Salem. Izzy was diagnosed with PH in September 2019. Here she shares some of her favourite things.

**Q.** What's your favourite thing to do at school?

**A.** I enjoy anything to do with arts and crafts. I also like mirror play, playing on the swings, swimming and dancing!

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

**A.** I like going to see my two grandmas, two aunts and three uncles. I also enjoy going to the park to see the ducks and visit the play area. After that I like going to my local pub where mummy used to work because everyone fusses over me!

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

**A.** Sausage and mash with peas and gravy! I also like lasagne and chicken nuggets.

**Q.** What's your favourite film and TV programme?

**A.** I love Frozen and Shrek. When I watch TV, I like Scary Monsters, Paw Patrol, Bookaboo, Fraggles Rock, Wishenpoof, Vamparina and Monster High.

**Q.** If you could meet anyone famous, who would it be?

**A.** I would like to meet Elsa, Anna or Olaf from Frozen.

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

**A.** I would love to be able to heal anyone who is sick and find cures to rare diseases like mine.

**Q.** What is your biggest achievement?

**A.** I have learned how to walk by myself, which means I can walk down the aisle with mummy when she gets married to daddy in October.



**FUN FACT**

No words in the dictionary rhyme with 'orange'.

**QUIZ ANSWERS**

1. Pumpkin
2. Peas
3. Grapes
4. Potato
4. Onion

How did you do?

**Patch**



## ME & MY JOB



Meet **Paul Sephton**, who joined the PHA UK as research and development coordinator last year.

**WHAT DOES YOUR JOB INVOLVE?** I'm part of the small office team at the PHA UK that works to support members and ensure the smooth running of the charity. I am involved in researching and managing specific projects, and as a new role it is constantly developing and evolving, which is exciting.

**WHAT WERE YOU DOING BEFORE YOU CAME TO WORK FOR THE PHA UK?** For the last five years I've been ward manager of the Pulmonary Vascular Disease Unit at the Royal Hallamshire Hospital, and prior to that I was a clinical nurse specialist in pulmonary hypertension. I loved caring for patients and those close to them in both in the hospital environment and in the community, so working for the PHA UK is a perfect progression following my retirement from clinical work.

**WHAT'S IT LIKE WORKING WITH THE REST OF THE PHA UK TEAM?** The team is genuinely lovely! I've done bits and bobs of work with them in the past, so it's been great getting to know everyone better now I have this role. Iain Armstrong is the only one I've known for a long time—we used to work nightshifts at the hospital together back in the eighties! Everyone has been very welcoming and supportive.

**WHAT DO YOU ENJOY MOST ABOUT YOUR JOB?** I'm really enjoying getting to know more of the PHA UK members and helping them along their journeys. I love talking with people and putting all my years of experience in PH to good use.

It's a really great place to work – there's often a dog or two in the office! – and I love that I can see projects through from start to finish.

**WHAT'S THE FIRST THING YOU DO WHEN YOU GET TO WORK, AND THE LAST THING YOU DO BEFORE YOU LEAVE?**

I always start by making a coffee, checking my emails and getting myself set up for the day. Normally I've made a list the day before (I like to be organised!) and it's very satisfying ticking things off. Before I leave for the day, I make sure everything is tidy and in order for when we all come in the next day. I am very 'particular' about things like this!

**TEA OR COFFEE?** Black coffee. I also like to drink lots of water and aim for ten small glasses a day while I'm at work. It's not all healthy though – I do enjoy my Rioja at weekends!

**WHAT'S ON YOUR DESK?** I like my desk to be very organised. On one side I've got all the PHA UK publications and merchandise, and on the other side I have my in-tray and stationery. I always have my trusty list in a prominent place.

**WHAT DO YOU LIKE TO DO OUTSIDE OF WORK?**

I love to walk with my friend's dogs and I look after one a couple of days a week (he often comes into the office with me). My partner Paul and I really enjoy meals with friends. When it's our turn to host I tend to go for a salmon dish – with plenty of wine of course!

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)



# 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!*

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- Cancel when you want.
- No need to claim – if you win you'll automatically be sent a cheque.

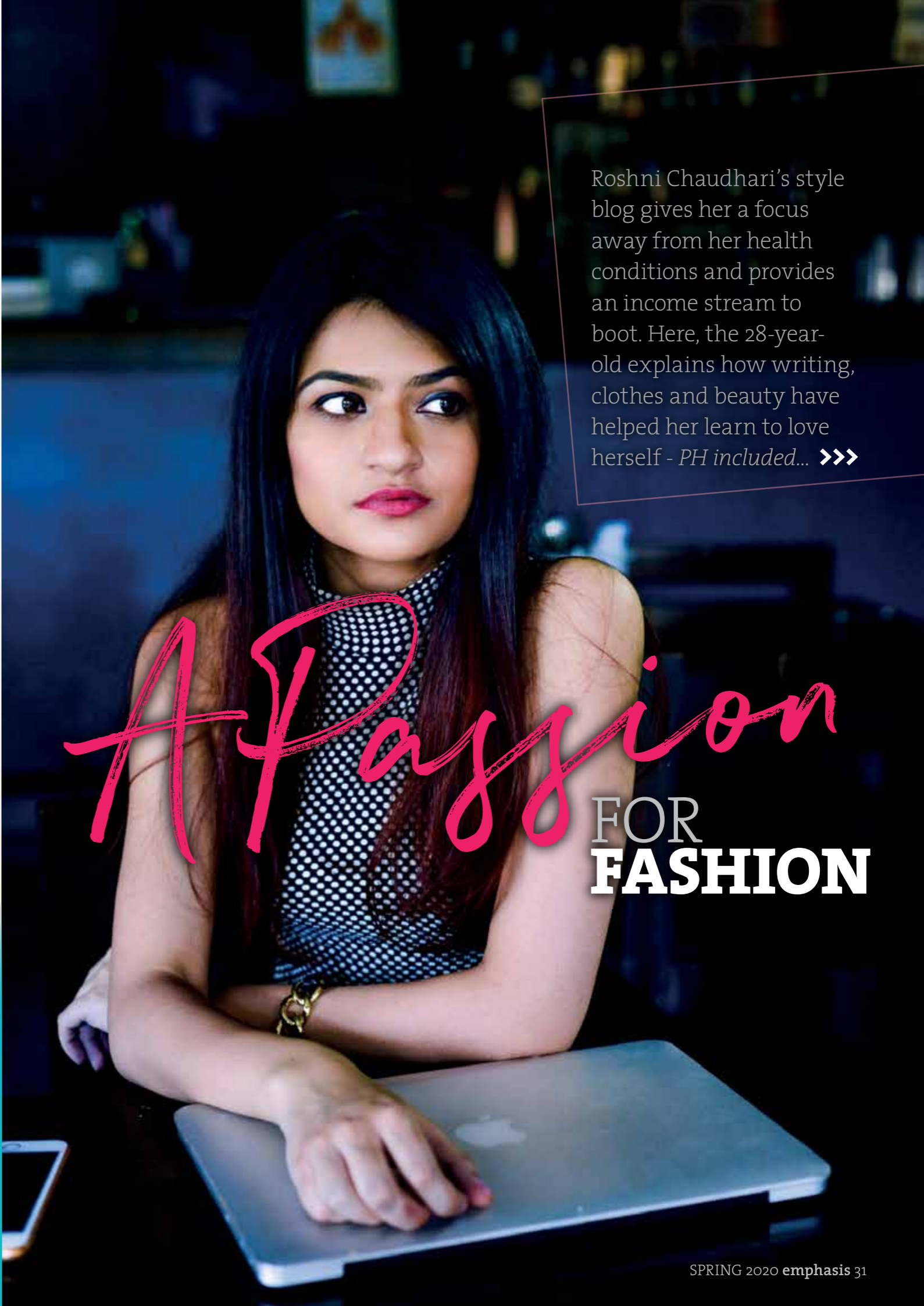
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EVERY SATURDAY  
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unity



Roshni Chaudhari's style blog gives her a focus away from her health conditions and provides an income stream to boot. Here, the 28-year-old explains how writing, clothes and beauty have helped her learn to love herself - PH included... >>>

*A Passion*  
FOR  
**FASHION**



# My BLOG

*My blog, Addicted To Lace, has always been my attempt at finding my voice amid the chaos all around me.*

*I share elements of my personal style, and everything that goes into making fashion what it is. I also cover posts on beauty and skincare.*

*It provides me with an income I wouldn't otherwise have too, as I promote brands including L'Oréal, Amazon, Converse and Budweiser – to name a few.*

*It was clear from the start that because of my health conditions, full-time work was not for me. I have had pulmonary hypertension pretty much all my life, getting my proper diagnosis around the age of eight.*

*I also have VSD (Ventricular Septal Defect) and Eisenmenger's syndrome. I couldn't participate in physical activities or sports in school and I*

*didn't even attend classes regularly to avoid getting too physically stressed out. But I was extremely passionate about my studies, so I did everything I could to end up with the best grades.*

*I was the typical 'studious nerd' who could not stand being average, so it didn't matter if I couldn't be in class every day; I still studied my ass off (keeping my health in mind though, I got proper sleep and good meals, thanks to my mum). Unfortunately, that's not something you can do when it comes to work.*

*I had tried my hand at a full-time internship, but I couldn't make it to the office every day and it had started affecting my immunity too. That's when I knew I had to do something of my own, and blogging has allowed me the liberty to do that.*

*I also write as a freelancer sometimes and the fact that I can do this from the comfort of my own*

*home makes it easier to cope with my health conditions. Although there can be some tiring days when I need to do a photo shoot outdoors or attend events, I usually plan it in such a way that I get enough rest and don't end up feeling exhausted.*

*gain weight because of my health conditions. The side effects of medications take a toll on my digestion often too.*

*Growing up, I went through so much 'skinny shaming' and people didn't care to ask why I was the way I was. They'd just pass comments like "You'll never find anyone to marry" or "You really need to eat more." This was the worst in high school - as we all know, teenagers can be very mean!*

*It was hard to ignore their comments or even try to explain it to them because even I wasn't sure why my body was the way it was.*

*It's not that I'm completely over it or that people still don't say things - they do, but I've adjusted to it better now because I get where they're coming from.*

*At the end of the day, I won't lie, these pictures do make me feel good about myself, however what makes me appreciate this life goes way beyond just 'looking good'.*

*You need to live with yourself, not people's opinions, and if you can't*

*love and appreciate yourself on the inside and out, what's the point?*

*What I realised was when you love yourself, you will do everything to look good and feel confident. Finding your own sense of style, taking care of your skin and body, and using makeup to enhance your best features are all forms of self-love, in my opinion. It's also an outlet to express yourself and boost your own mood. There are days when I feel down in the dumps but wearing my favourite top or jacket fixes that. Fashion can be great therapy!*

# FASHION AND MY body image

*I love to write about fashion. As a kid, I was always very picky about my clothes. I used to admire my mum when she would do her makeup, and I knew that when I grew up, I would get to try all that for myself someday.*

*I did not care too much about my style when it came to dressing up for school but the fashionable part of me started revealing itself once again when I was in college.*

*The images I have up on my social media and blog have helped me overcome my body image issues. It's always been difficult for me to*



# WRITING ABOUT my health

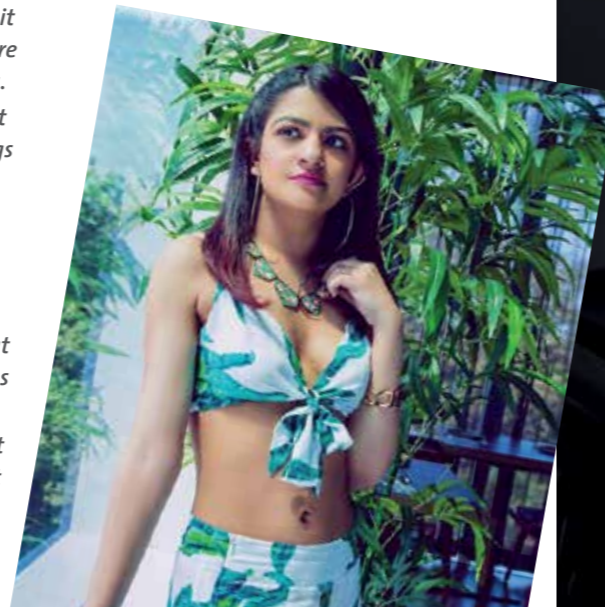
*I used to be very apprehensive about talking about my health conditions on my blog, mostly because I've seen people reacting oddly. Some people use me as a tool to feel better about their own lives and look at me with pity, while others question how I 'look so normal'.*

*I didn't want my two worlds to be merged at first, but I saw others sharing their stories online and that made me realise I wasn't alone in this battle. It also pushed me to*

*share my own story so that if, by chance, anyone who's dealing with a chronic illness like me sees my posts, they wouldn't have to feel alone either.*

*I actively talk about congenital heart disease and PH on Instagram and Twitter now, sometimes on my blog too, but I don't update that as often as I update my social media pages.*

*The 'shame' of living with PH has gone. The only way to normalise it is to talk about it so much that we are finally recognised as human beings with hopes and dreams, just like everyone else!*



YOU CAN READ ROSHNI'S BLOG AT [WWW.ADDICTEDTOLACE.COM](http://WWW.ADDICTEDTOLACE.COM)

# “We’ll keep going as long as people keep coming”

An annual equestrian event to raise awareness of PH has generated over £20,000 since it began 14 years ago – and there are no plans to stop now. *Mary Ferguson* spoke to the sisters behind the shows.

**E**very September, a large field in Northumberland is filled with poles, ponies, and a dedicated team of people determined to make a difference.

Chesterwood Show, which takes place in Hexham, sees young riders take part in showjumping competitions and games with the aim of raising money and promoting awareness of PH.

The event is the brainchild of Suzie Pigg, whose sister Sheena Robinson was diagnosed with the condition in October 2002. It has been held annually since 2004, with the only exception of 2018 – when plans were halted at the last minute due to Sheena undergoing a double lung transplant.

The most recent show in September 2019 boosted total fundraising to almost £21,000 - but Sheena said it's not just about the pounds. *“It's more about raising awareness than money”,* she explained. *“It's a different way for people to know what PH is. It took quite*

*“It's about people coming and having a go and enjoying it, rather than being overly competitive”*

*a long time for me to be diagnosed, so the more people that talk about it the better. I think because you look well, people don't understand that it can be quite a debilitating disease.”*

Each show is supported by an army of sponsors and volunteers, including 2019 supporters AW Jenkinson Forest Products, Carrs Billington Agriculture and High Plains Livery and Equestrian Centre.

The event always ends with a prize presentation and a speech by Sheena, where she talks about her pulmonary hypertension. Supporters Jackie and Josie Brown continue the annual tradition of donating a handmade jump – which is usually awarded to a child who has fallen off but not cried, shown patience with a naughty pony, or improved their riding throughout the day.

*“It's about people coming and having a go and enjoying it, rather than being overly competitive”,* said Sheena. *As well as the jumping competitions we have pony games that are all about having a laugh – we do have a few tumbles, but that's par for the course when you've got kids and ponies!”*

The show is held at Chesterwood Farm, owned by Suzie's husband. Money is raised through entry fees and the selling of cakes, sandwiches and quiches – which are all donated

by supporters. Suzie said: *“Everyone gives their time for free to help with the show. We have a lot of good friends and family and we get local businesses that we know to sponsor the classes, which covers the cost of prizes. It's hard work, but everyone mucks in. We'll keep going with the shows as long as people keep coming.”*

As well as looking forward to future events, the sisters have fond memories of those gone by.

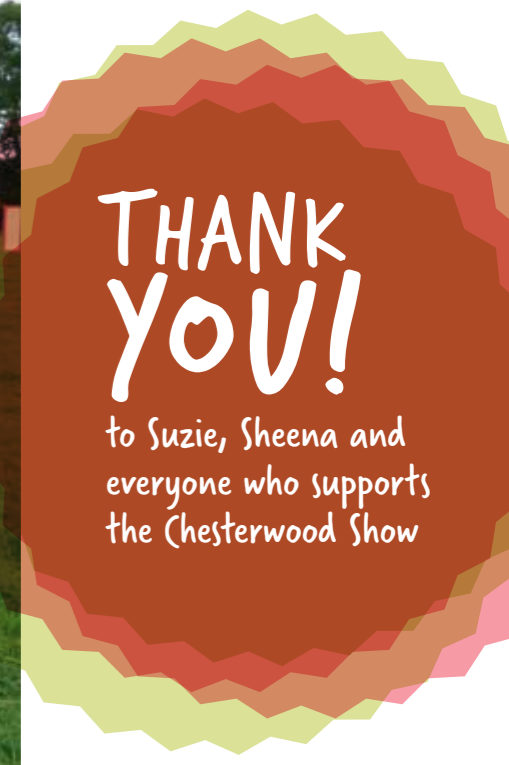
*“I think all of the shows are special; there's always something that makes them memorable”,* said Sheena. *“I remember one year, my cousin's daughter entered one of the pony classes on her little Shetland. My brother-in-law was leading her, and he's very competitive, so when Emily fell off right at the start, he didn't even realise and carried on regardless – leading a pony with no rider! We still laugh about that now.”*

As well as hitting a cumulative fundraising total of £20,833, the 2019 show was extra special because it was the first since Sheena's transplant.

Suzie added: *“It was a bit surreal – for all those years she could hardly walk from A to B, and at the last show you saw her walking around and taking photographs, which she couldn't do before. The event felt like a celebration; everyone there saw the change in her. They have been on the journey with her too, watching her struggle for so many years. I don't think people could believe the difference!”* ●



Suzie (left) and sister Sheena





# Together for CTEPH

Healthcare professionals from all over the world will come together in June for the fourth International CTEPH Conference.



**H**eld every three years, the International CTEPH Conference (ICC) is dedicated to Chronic Thromboembolic Pulmonary Hypertension (CTEPH) and this year, 450 delegates are expected to attend the event in Bad Nauheim, Germany.

Organised by the International CTEPH Association (ICA), ICC 2020 aims to educate physicians on the latest developments in the field; including diagnosis, patient management, medical therapy and interventional treatments.

It will bring together healthcare professionals and patient organisations from around the world to benefit from global networking and collaborative opportunities.

The inaugural event was held in Cambridge in 2011, followed by conferences in Paris in 2014 and in Leuven in 2017. In 2023, the event will head to San Diego.

Dr. Joanna Pepke-Zaba of Royal Papworth Hospital is part of the scientific committee underpinning the organisation of the conference.

She said: *“The event aims to capture the developments and innovations*

*in this rapidly progressing area of pulmonary hypertension specifically in CTEPH, and to further improve awareness of CTEPH among physicians and health professionals.*

*“Networking is a vital part of the programme. It allows people to exchange their experiences, explore joint projects, invigorate old acquaintances and make new ones too. There is nothing else like this in the world for CTEPH, on an international stage; it's really quite unique.”*

As well as a programme of talks and presentations, an exhibition area will showcase the latest products and innovations.

Researchers are being invited to submit abstracts (overviews of research projects) and to display their findings in the form of posters. There will also be the opportunity for four abstracts, selected by the abstract review committee, to be presented as talks to delegates during a plenary session.

Dr. Pepke-Zaba said: *“The call for abstracts is a very important part of the event, as we hope to stimulate young investigators by allowing them to present their work in CTEPH.*

*“The number of abstracts we have received has hugely increased since the first conference. We had over 80 at the last event, and the quality of those posters was absolutely fantastic.”*

She added: *“The management of patients with CTEPH is steadily progressing and we have different treatment modalities now, each delivered by different specialists. So, it's very important that all these people coming from different specialities come together and discuss up-to-date discoveries and approaches - and take that knowledge back home. Ultimately, this event will be of benefit to patients all over the world.”* ●

**The International CTEPH Conference will be held on 20th June 2020 at the Hotel Dolce in Bad Nauheim, Germany.**

**Visit [www.cteph2020.org](http://www.cteph2020.org) for more information about how to submit an abstract or to register for the event.**

# Single with PH Shana's story



PHA UK member *Shana Hindle* was diagnosed with pulmonary hypertension two years ago at the age of 45. This is her honest experience of looking for love with a chronic illness – and changing the course of her search...

*them - I blame Leonardo DiCaprio! My milkshake stopped bringing the boys to the yard about 15 years ago.*

*I decided to move on to a different type of group which concentrates on bringing single people together for informal group meet-ups in places like coffee shops or pubs. The idea is that rather than looking for love, I am looking for companionship and letting something develop organically through that.*

**“A**t the point of being diagnosed with PH I had been single for three years and my main concern was not about finding a partner but accepting my diagnosis and dealing with the massive impact on my family, work and friends.

At the beginning it was just about dealing with the here and now. But as time went on, I accepted the illness and adjusted to it day-to-day, so a year ago I had a change of mind and thought I might be ready for romance.

I decided to dip my toe into online dating and as a novice, decided to try a free service first. It was a total waste of time and frankly scared me! I was that person who sent a picture of my cat when I was asked for a certain type of photo. The conversations were not what I was looking for and I promptly deleted my profile.

I then decided to have a look around Facebook for friendship groups. I found one local to me and spoke to a few men on there. Some were typical of single men of my age (they don't know what they want!) but I confided in a few about my illness. I wanted to have the conversation early on and be honest and upfront.

Unfortunately, initial responses included things like: 'I am not wanting to look after someone who is ill' or 'My interest is walking and how can you keep up? I am not going to keep stopping'.

Someone told me he doesn't date people that don't work, and another asked me if I was 'allowed' to get sexually excited.

It's difficult at my age too because men in my age bracket (with a pulse) want partners 20 years younger than

*The group I found has a great mix of people and personalities. I find it very healthy and a positive step towards maybe getting into a relationship, at a pace that I'm comfortable with.*

*My advice to other single people living with PH is not to give up. I am not going to, but I'm going to look for companionship instead, in group dating / meeting settings.*

*Join people that have being single in common and you will find more understanding and tolerance.*

*Always be honest from the beginning. Explain it the best you can, don't dress it down, and if rejection comes, don't take it personally. It's their problem, not yours. And it's not you, it's the illness.* ❣️

**Would you like to share your dating experiences with us?  
(You can stay anonymous if you wish!)  
Email [media@phauk.org](mailto:media@phauk.org)**

**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.



## FINANCIAL SUPPORT WHEN YOU NEED IT MOST

*Liam Evans, campaigns and communications officer at Turn2us, explains how the charity can support people affected by pulmonary hypertension.*

*Turn2us has been a charity since the 1800s, and while our name has changed a few times our mission has always remained the same – to help people who are struggling financially. So what help is available? Turn2us provides practical financial help. If you are struggling financially we may be able to help you in one of three ways.*

1

**Firstly, we can help you access welfare benefits.**

Our Benefits Calculator can work out what welfare benefits or tax credits you are entitled to. Every year billions of benefits are unclaimed, for example, over 1.3 million people are not claiming the Pension Credit they are entitled to, meaning they are missing out on around £2,500 every year. We want to make sure anyone who is struggling with money is getting the money they are entitled to.

2

**Secondly, we provide grants.**

Grants are a financial award you don't have to pay back. For example, through one of our funds, you could get £1,000 for a new recliner, £500 for a new oven, or £2,000 to make renovations to your home. Last year we gave over £4 million in grants. In addition to this, we also have a Grants Search database which means if you aren't eligible for one of our grants, we can help you access grants from other charitable trusts.

3

**Thirdly, we provide help, support and information through our website and helpline.**

We have guides on everything from the basic state pension to winter fuel payments. These resources have been put together by experts to help make it as easy as possible to maximise your income.



Liam Evans,  
Turn2us

To find out if Turn2us can help you financially, you can ring us on **0808 802 2000** or visit **www.turn2us.org.uk**

.....  
**theinterview**  
.....



.....  
Clinical Nurse Specialist  
at the Freeman Hospital

**RACHEL CRACKETT**

in conversation with  
**Mary Ferguson**

.....

Rachel, who hails from Whitby, has been in nursing for over 30 years. She has spent the last 19 of them as Clinical Nurse Specialist within the Northern Pulmonary Vascular Unit at Freeman Hospital in Newcastle.

Previous roles have been in the cardiothoracic department in surgery, medicine, transplantation and research and during her time in PH, Rachel has completed a Masters degree in Nursing Science (Research Methods), gained a Nursing Practitioner RCN Award, and become an Independent Nurse Prescriber. Her current role as Clinical Nurse Specialist has given her the opportunity to be part of the development of the pulmonary hypertension service both locally and nationally. She has presented at educational programmes, is a member of the PH Professionals Group, and served as the Northern Senate representative on the National Commissioning Reference Group - which advised on national policy.



.....  
**Q.** Have you always wanted to be a nurse?

**A.** No! I fell into it really. I had no idea what I wanted to do when I left school and ended up doing beauty therapy. From this, I discovered I liked working with people, but I enjoyed the therapeutic side more than the beauty side. I was floundering a bit, unsure what I wanted to do, so decided to visit the Job Centre to ask for advice. Nursing was suggested to me as a career and that's how it all began! The Freeman was my first choice as I had family in Newcastle, and I started my training there in 1988.

.....  
**Q.** Did you find PH, or did PH find you?

**A.** A lot of my allocations during training were in the cardiothoracic unit, so when a job became available in coronary care, I went for it. I then moved onto a role on the transplant unit, before issues with my back meant I had to do some research work for a while. Just as my back began improving, I saw the advert for a nurse specialist in the pulmonary hypertension service. I knew Professor Corris – who headed up the unit – from the work I had done in transplantation, and all my research was in heart / lung transplantation. Plus, I had nursed PH patients post-transplant, so I thought this would be an

opportunity to get them better before surgery too. I knew, quite early on in my career, that I didn't want to be an A&E nurse. I like stories, and seeing people through their journeys, and getting to know them well. I knew PH would give me that. It was a new area of medicine at the time, so I knew it would be an interesting place to be. I started the role in April 2001, and 19 years later I am still here!

.....  
**Q.** What does a typical day or week in your job look like?

**A.** I like to get into work early, I cycle to work (seven miles each way) which I find is good thinking / planning time, so getting in early gives me some time to shower, have some breakfast and prepare for the day ahead. I check my emails and have a cup of tea before phones start ringing! Even though I plan my day, you never know what's going to happen and things can change quite dramatically. You can have urgent referrals, or poorly patients, and that always takes priority. What I like about my job is that no two days are ever the same. On Monday's I do a nurse-led clinic in the afternoon. Tuesday's are a telephone clinic in the morning and Wednesday's are a very busy clinic day, with ward rounds too. Thursday's are a catch-up day from the clinic... >>>



**“I still remember people I nursed right at the beginning of my career. They stay with you.”**

...the day before, checking results and making time for ongoing development and education.

On Friday's we get together as a Multi-Disciplinary Team and do ward rounds. That tends to be a busy day. I'm quite clinically 'hands on' and I do spend a lot of time talking to patients over the phone. At the Freeman we are the first point of call for outpatients so if they have a problem, they phone us first, and then we triage that – directing them to where they need to be.

**Q. Who or what inspires you in your work?**

**A.** This might sound like a cliché, but it's definitely the patients. I've been in nursing over 30 years, and in this job for 19, and the reason I have stayed where I am and not gone into management is because promotion takes you away from the patients. And I became a nurse because I like interacting with people and making that difference. That's what inspires me. I still remember people I have nursed right at the beginning of my career. They stay with you. And I still bump into transplant patients who I nursed through their operation 25 years ago! I am able to tell patients, during the initial diagnosis chat, that I still have patients who were diagnosed 18 years ago – and that is reassuring. I find it really helpful that I've done the job for so long that I can say that.

**Q. Do you have any standout moments from your career?**

**A.** Getting my Masters degree (in Nursing Science) was a stand-out moment for me. I never thought I would get a degree, never mind a Masters degree! I'm proud of being part of the International Society for Heart and Lung Transplant. I've had work accepted and I've presented on the other side of the world and that's quite an achievement, I think. I have standout memories too. One of the earliest was as a student nurse, when I came back from a few days off to a card and present from a patient who wanted to thank me for caring for her. I still have that card to this day, in a box of keepsakes. I still get nice cards from patients, and I look at them on bad days. I especially like to keep the handmade ones, and I get them back out to look at year after year. Last Christmas I had a thank you card from someone who was transplanted 22 months ago. She was still thinking about me and for me, that is the epitome of what I do.

**Q. What is the best piece of advice you've been given, and who was it from?**

**A.** I was told by my mother, very early on in my career, to never burn my boats. (You may have also heard it as never burn your bridges!) The idea behind it is that you never know when you might need to get back in your boat to leave the place you're in. You don't know whether you might meet the people you passed on the way up, when you're on your way back down. I've always stood by that. I worked with my current line manager 30 years ago – and I had no idea she would be my manager one day! Treat everyone like you would want to be treated yourself, as you never know when the roles will be reversed. My mum also told me, when I went off to start my nursing training, to remember that everyone I care for is someone's daughter, father, brother or sister.

**Q. What are the biggest changes you've seen whilst working in the field of PH?**

**A.** The biggest change has been the introduction of targeted oral therapy. I spent the first few years in the job mainly teaching people how to use nebulised or intravenous (IV) drugs but I do a lot less of that now. It's benefitted patients because they can have a better quality of life if they are not having to do something six times a day, or be attached to a pump. Some nebulised or IV treatments are still gold-standard and are very valid for the right people – but often not quite so soon.

**Q. And what do you expect to come next?**

**A.** I think triple therapy will eventually become standard, like it is now for heart disease and some other conditions. It's already starting to happen; we're already using upfront combinations where we never thought we would, and I think in the future when drugs become generic (when patents are lost) pretty much everybody will get triple therapy. At the moment there is still criteria around who can have triple therapy. But in the years to come, I think that as long as the therapies can be tolerated, everyone will end up with one from each pathway. It will be standard practice. In terms of the PH service as a whole, I would like to think that in the future it will still look like it does now, with designated specialist centres. The service is highly valued by patients and I truly believe that specialist care is the way forward. We're 20 years into targeted therapy now, which is still quite young in a disease process, and specialist knowledge is invaluable in managing this difficult condition.

**Q. What do you like to do away from work?**

**A.** I'm quite busy when I'm not working. I play a melodeon (a bit like an accordion), and I sing in a community choir, which has performed at patient days at the hospital. I like to visit my mother down in Whitby and I'm president of my local Women's Institute. My husband of 25 years is also very musical, and we play and sing folk music together. Music is my life – and my therapy! ●

# Our sister website to help you live well with pulmonary hypertension

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

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

...and much more!



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

## Online weight loss programmes: Save or splurge?

You or a loved one may have kicked off 2020 with a resolution to lose weight, but with so many online programmes available via specialist apps, how do you know which are worth spending money on? We tested a budget and a premium version, and here's what we found...



### WW

(formerly Weight Watchers)  
From £9.95/month

[www.weightwatchers.co.uk](http://www.weightwatchers.co.uk)

WW (the new Weight Watchers), is a weight loss programme in the palm of your hand and is an alternative to attending weekly meetings.

I first signed up for the WW digital membership plan around nine months ago when my partner and I decided to motivate each other to make healthier food choices.

When you sign up to digital membership, you'll have access to the WW app which comes with a whole host of features. You'll first be matched with a plan colour (blue, green or purple) and given daily SmartPoints to 'spend' on food tailored to you. For extra flexibility, you'll get a custom list of ZeroPoint™ foods too, which you can eat freely.

Among the many features of the app is a handy barcode scanner which is useful when out food shopping. It not only tells you the SmartPoints value but also the nutritional content too.

There are over 1,000 recipes in the app for breakfast, lunch, dinner and snacks, as well as meal

plan ideas, and you can even check the SmartPoints value on the menus of your favourite chain restaurants.

If you're doing WW on your own and need some motivation to keep going, you might like the 'connect tab' where you can join online groups. There's also a 24/7 live chat function where you can talk to a WW coach.

I connect the app up to my Fitbit to collect FitPoints® which I can choose to use towards my weekly points goal. If you have an iPhone, the app can also sync to your Apple health.

Each time you track your weight you'll build up WellnessWins™ to choose a reward - which might be a gym pass, drinks bottle or wireless headphones.

If you're looking for an app which can help you reach your eating and exercise goals, then I'd recommend giving it a go. WW is available for Apple and Android. Details on the plans can be found at [www.weightwatchers.co.uk](http://www.weightwatchers.co.uk)

Tested by Charlotte Goldthorpe  
Emphasis contributor



### NOOM

From £26/month  
[www.noom.com](http://www.noom.com)

Like many people I was targeted on Facebook by adverts for the NOOM weight loss programme. I ignored it for some time but as I did want to lose some weight, I investigated the reviews and signed up for the 14-day trial. I'm glad I did, as it's been the only diet that has significantly worked for me.

NOOM is a health app designed by behavioural psychologists and it's great for users of tablets or mobile phones. It focuses on making tangible, sustainable lifestyle shifts rather than encouraging more extreme styles of eating. I found it really good and lost 18 pounds in two-and-a-half months.

The main benefits of NOOM are:

- You can track the foods you eat by searching a database or scanning barcodes. This logs the calories and sorts them into red, green and yellow categories which I found helpful. You weigh yourself daily and plot the readings on a graph. This certainly focuses the mind!
- Log exercise, weight, blood pressure, and blood sugar if known. I just logged exercise and weight. This was great as the calories calculated by exercising are automatically added to your allowed daily intake.
- Receive in-app 1:1 health coaching during business hours. You also become part of an online support group of people following the programme at the same stage as you. You can interact with this as little or as much as you like, but it's helpful to feel part of a community.



- Stay motivated with interactive articles and quizzes. I really like these; they take a few minutes to go through every day and keep you focused. I feel this was a key part to my success.

The app is designed to 'trick' your body into developing healthy habits; for example, snack on strawberries rather than biscuits, eat from a smaller plate and so on.

To summarise, I would recommend the NOOM diet. I paid £1 when I signed up for the 14-day trial and then £79 for a three-month plan. Once that finished, I cancelled my membership but have kept the free weight tracking app. The diet does not involve buying expensive fancy foods or supplements so although at first glance it looks expensive, it turned out for me to be good value.

Tested by Kay Yeowart  
PHA UK co-founder



Kay before and after completing the NOOM weight loss programme



If you have PH, please speak to a healthcare professional before making changes to your diet or embarking on a weight loss programme.

### FREE ONLINE TOOLS

MyFitnessPal is an effective free way of tracking calories, nutrition and exercise. There is no expert support, although you are able to interact with other users via a chat forum. Search in your app store or visit [www.myfitnesspal.com](http://www.myfitnesspal.com)

Other free online weight loss tools include the NHS Weight Loss Guide, a 12-week diet and exercise programme developed with the British Dietetic Association. The downloadable plan includes weekly goals, tips and food and activity charts. Visit [www.nhs.uk](http://www.nhs.uk) and search 'weight loss plan'

Have you found a weight loss tool that works for you? Let us know by emailing [media@phauk.org](mailto:media@phauk.org)

# Why medication doesn't always **make you feel better**

Although PH therapies often do a great job of slowing disease progression, you can't always 'feel' the benefits - as consultant pharmacist *Neil Hamilton* explains...

Trust me, I'm doing my job! :)



I don't 'feel' any different?



**Taking a tablet with long-term benefits that may not make you feel better is not a new idea.**

**I**wonder how many of you made New Years' resolutions, and more impressively, stuck to them? For many people, the start of the year is a time for a fresh start, not least with their own health. Parties and get-togethers with families and friends over Christmas are great fun but often result in putting on a few pounds!

There are many ways to work these off and many will try healthy diets; maybe something ethical such as reducing meat intake might appeal, or some people try cutting down on alcohol.

Whilst an intense gym class might not be possible for those with PH, everyone is encouraged to do some more exercise at a level suited to their abilities. I know how many people have benefitted from the advice of Sheffield's in-house PH physiotherapist, Carol Keen, to understand the best ways for them to get fitter and feel better.

***This got me thinking about the medicines that we prescribe, and how patients would usually expect that their medicines would always make them feel better.***

Huge progress has been made in research in the UK and across the world to search for a cure to PH. Despite this, unless you can have an operation for Chronic Thromboembolic Pulmonary Hypertension (CTEPH), unfortunately none of the current medical treatments are curative.

The past 20 years have seen a wide

range of treatments aimed at reducing symptoms of breathlessness and increasing exercise capacity approved, but no medical cure as yet.

The most recent medicine to be approved by NHS England in 2018 for prescription, selexipag, is approved for a slightly different situation. ***The evidence supporting prescription of selexipag is of preventing deterioration without necessarily an obvious clinical improvement.***

Some may feel better with selexipag, but this is not by any means guaranteed. This may be hard for some to understand, especially as the increasing doses mean that adverse side effects are common.

Taking a tablet with long-term benefits that may not make you feel better is not a new idea. Those of you familiar with statins will know that these lower cholesterol levels in the blood. This is not something that anyone can actually 'feel' but will reap huge health benefits for people at risk of heart attacks and stroke, for example those with high blood pressure or diabetes.

Essential hypertension (high blood pressure) itself is a condition that people would rarely feel themselves, but left untreated can be catastrophic. Huge numbers of the population are treated with medicines to lower their blood pressure (BP). These should always be given alongside lifestyle advice to help patients make better choices to help

lower the blood pressure.

***Honestly though, without the BP check at the clinic, nobody can know or feel if their blood pressure is raised, or being lowered by the medicines.***

Selexipag for PH can only be used in patients who are already prescribed two oral treatments; sildenafil or tadalafil, plus one of bosentan, ambrisentan or macitentan. This means that patients are receiving a treatment which acts on all three different pathways in the body. We have a growing number of patients prescribed selexipag and I can see from our experience to date that side effects are common. For this reason, everyone goes home with medicines to help counter these adverse effects. However, the regular calls from the PH centre, maybe weekly until the best dose has been found, provide considerable support and reassurance.

Selexipag will not suit everyone, but offers an alternative option in a growing range of treatments available for PH. It may help patients remain 'stable' for longer and in turn avoid more complex options such as the nebulised or intravenous infusions.

If you are on two oral treatments already, you could ask about whether you would be suitable for selexipag next time you come to clinic.

***It may be a good option and help prevent you getting worse...just don't expect it to make you feel a lot better in the process!***



# Contraception & pulmonary hypertension

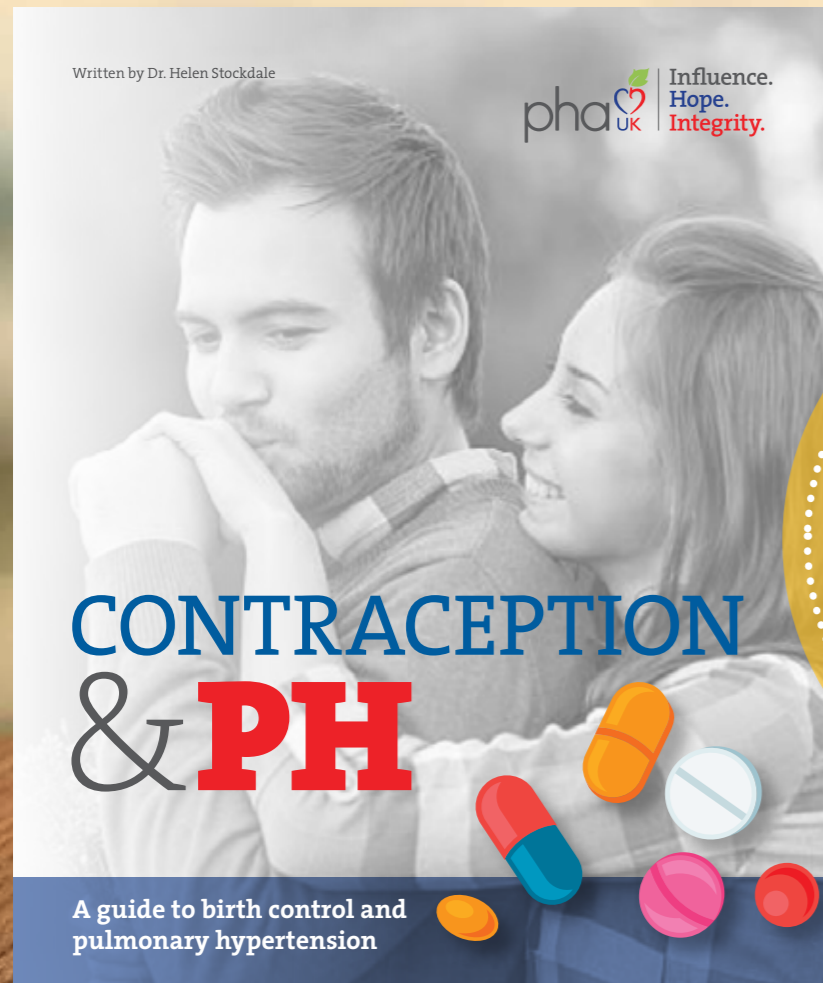
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## How we spend your money...

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

And when you raise money for the 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)



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

**Travelling in the UK**  
Tips for a summer staycation.

**British Transplant Games 2020**  
Looking ahead to our sponsored event.

**Fundraising Focus**  
What you've been getting up to in support of the PHA UK.

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

You can get involved in Emphasis too:

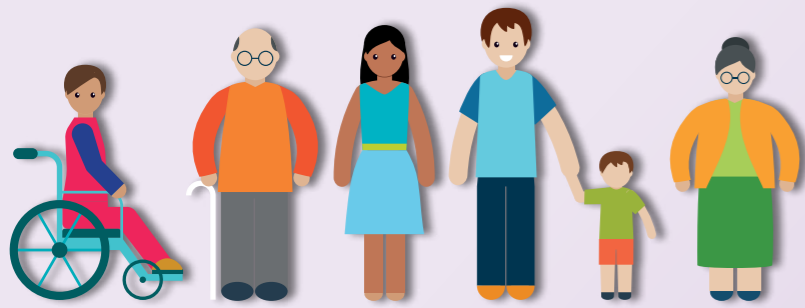
**Emphasis Reviews** - read a book, used an app or seen a film you think other readers may be interested in? Tell us about it!

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

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

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

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



# Join our PH family for free today

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

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

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

Join FREE today at [www.phauk.org](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.



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



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

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

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

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

Are you a Patient  Carer  Parent  Medical professional

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

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

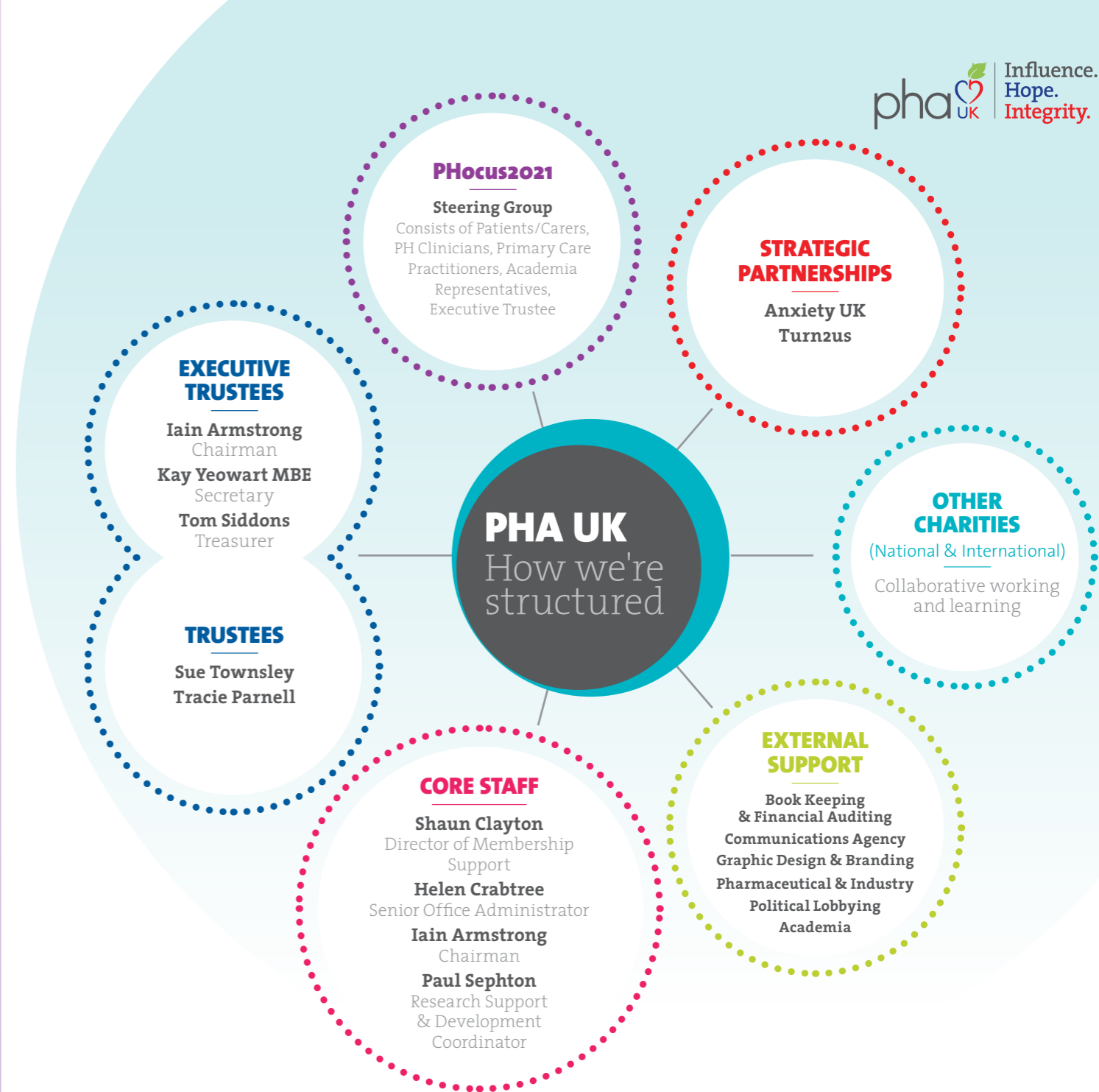
Which **specialist treatment centre** do you attend? \_\_\_\_\_

### Join today and benefit from:

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

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



### 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

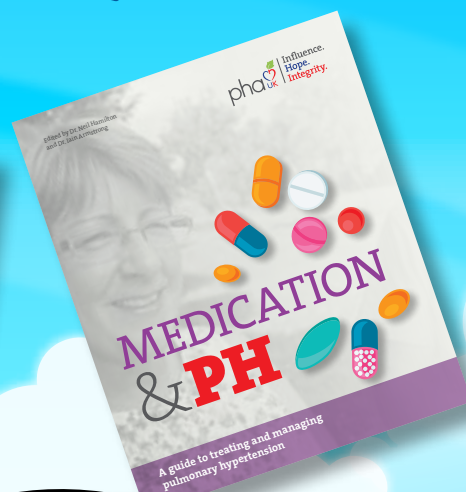
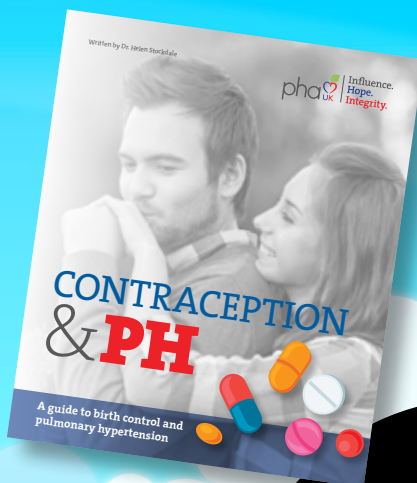
PHA UK has joined forces with Turn2us, a national charity that helps people in financial hardship in the UK. The charity aims to help people in need to access support; and provides a range of information and resources on welfare benefits, charitable grants and other services via its website: [www.turn2us.org.uk](http://www.turn2us.org.uk). 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?

# Free PHA UK publications for support and advice Available to order online!



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