

WINTER 2017

# emphasis

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



\*\*\*\*\*  
WISHING ALL OUR MEMBERS  
A VERY MERRY CHRISTMAS  
& HAPPY NEW YEAR!  
\*\*\*\*\*

## Looking back on 2017

Our year, your highlights

## TAKING CARE

*Dawn's experiences of  
looking after her mum*

## ADOPTING WITH PULMONARY HYPERTENSION

Physical activity and  
pulmonary hypertension

*"I feel more  
like the old  
me now"*

How Pauline has learned  
to live with PH

## PLUS...

Coping with winter viruses,  
financial advice, fundraising  
news and much more!



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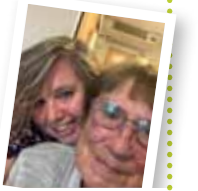


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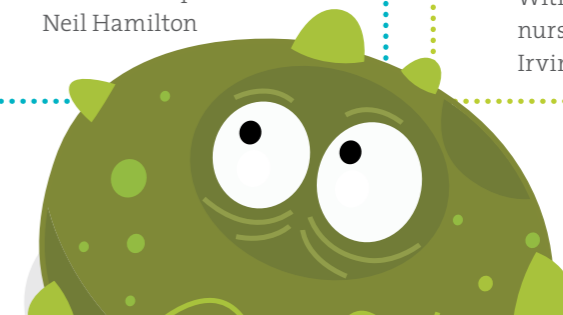
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This magazine is printed on paper from sustainably managed sources







# Play your part in the fight against PH

Clinical trials have transformed medical treatment for people with pulmonary hypertension – and more patients are needed to take part in research.

In the UK, before a new drug can be given to patients, it must be shown to be safe and effective in clinical trials, and must be approved by the Medicines and Healthcare Products Regulatory Agency (MHRA).

Before there were therapies available to treat PH, people diagnosed with the condition had an average life expectancy of about three years. Now, thanks to the approval of various new drugs, this life expectancy is much improved.

**Without clinical trials, and the patients who agreed to be involved in them, these drugs would not be available.**

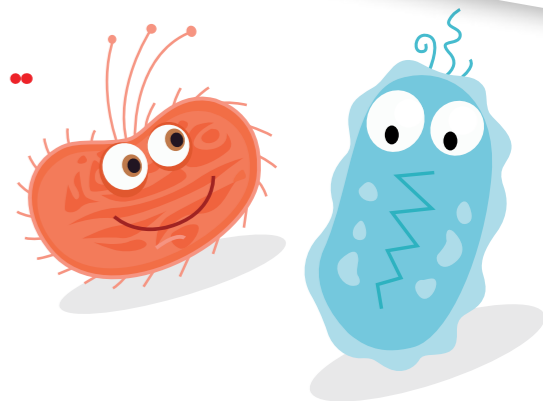
All of the specialist PH centres in the UK are involved in research, so you may be asked if you would like to take part in a clinical trial. If you can, please think about getting involved and playing your part in the fight against PH.

Interested in taking part in clinical research?  
*Let your specialist centre know!*



# Welcome

Welcome to the winter issue of Emphasis; the final edition of 2017. A lot has happened over the last 12 months, and on page 19 we share some of your highlights of the year.



For the team at PHA UK, a stand-out event was definitely the patient conference in May. Bringing patients, families and professionals together, it was the PH community at its best and we all learned something from each other. Thank you to everyone who made it so special.

As always, this issue of Emphasis is packed full of all the things that matter to you and to us. Pauline Harrison, Shani Fernando and Kevin McAllister all share their different experiences of **living with pulmonary hypertension**, and on page 14, Asha Sagoo reveals her tips for making everyday life with PH a bit easier.

PH professionals Joana Ford and Val Irvine give us an insight into their working lives and on page 38 pharmacist Neil Hamilton offers his advice on coping with winter vomiting bugs.

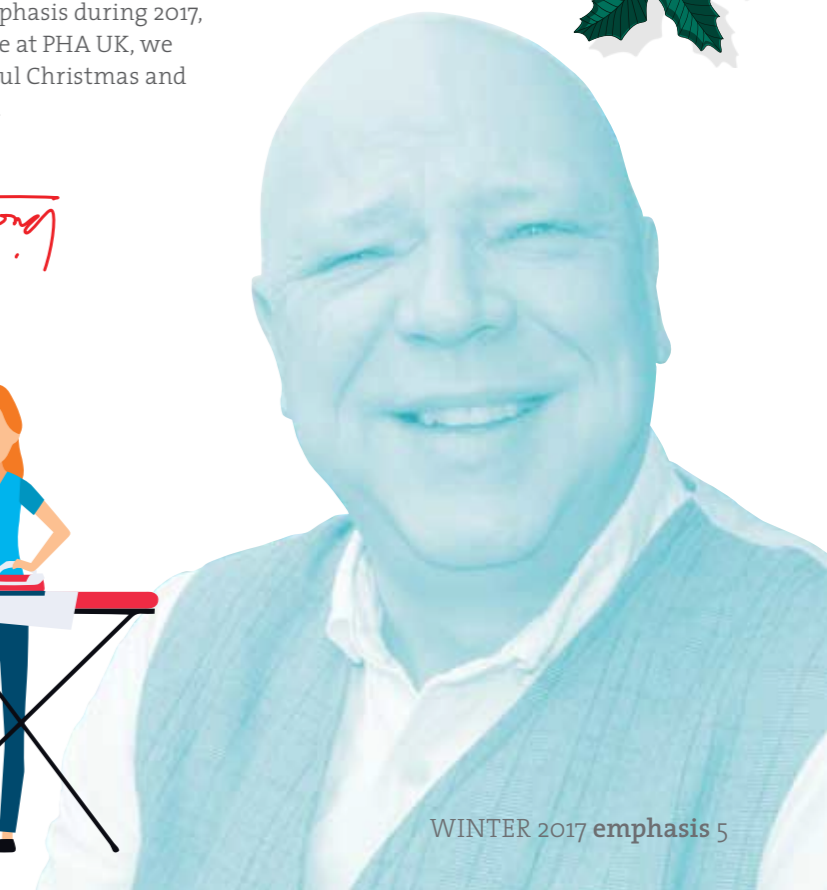
We'd like to say a special thank you to Sunil and Rinku Puri for sharing their experiences of adoption, and the difference their little boy has made to their lives.

Finally, as we look towards 2018, with your help we'll **continue our fight to make life better for people affected by PH**. A key focus will be on reducing the financial impact of PH, **so if you've received a survey through the post, please do fill it in and return it to us as soon as you can**. You can find out more about the research on page 20. Thank you to everyone who has contributed to Emphasis during 2017, and from everyone at PHA UK, we wish you a peaceful Christmas and a happy new year.

*Iain Armstrong*

**Iain Armstrong**  
Chair of PHA UK  
editor@phauk.org

**“we'll continue our fight to make life better for people affected by PH”**





# Emphasis *exchange*

If you have any news and views to share via the Emphasis exchange please e-mail [editor@phauk.org](mailto:editor@phauk.org) and don't forget to keep in touch via **Facebook** and **Twitter** too.

Dear Emphasis

I'd like to share my experience of using an electric bike. I have CTEPH and was diagnosed over five years ago, but long before that my husband and I had electric bikes. We have a campervan and spend a lot of time through the year touring in this country and in Europe. Our electric bikes are carried on the back of the van, and are another means of transport for us, if there are no local buses available.

We especially enjoy our cycling in Holland where there are plenty of cycle tracks, even with their own traffic lights. It is very safe for cyclists there as we have right of way!

The bike enables me to exercise as much as I want but the electric battery helps me up the hills. So, I can get plenty of fresh air, and as we live in a country area, I can enjoy the scents and sights of the hedgerows.

Lois Parker



emphasi**s**

Gardening as therapy



emphasi**s**

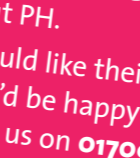
Let's talk about PH

Get Involved in PH Awareness Week 2017

TREATMENT THROUGH TRANSPLANT

Living with PH in my community

PHARMACY FOCUS



## Sharing is caring...

Sharing your copy of Emphasis is a great way of helping raise awareness and understanding of pulmonary hypertension. Perhaps you have a friend, family member or neighbour who would be interested in reading some of the articles? You could even offer it to your GP, to help them learn more about PH.

If you know someone who would like their own copy, let us know, and we'd be happy to send you an extra issue. Call us on **01709 761450** or email [office@phauk.org](mailto:office@phauk.org)

Don't forget you can also read every issue of Emphasis online at [www.phauk.org](http://www.phauk.org)

Would you prefer to receive Emphasis by email, instead of through the post?  
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## Social Media Round-up

Here are some top tweets and popular posts from PHA UK's Facebook and Twitter



**Stacie Leeanne**  
All ready for my sky dive thanks to my sponsor pack! It's been a real pleasure raising money for such an amazing charity!



**@amy\_good123turk** (Amy Gooding)  
Thanks @BobbyCNorris for the raffle prize donations for the @PHA\_UK fundraiser last night #rafflewinner #needitframed



**@HarryRozakis**  
It's very important to recognise the psychological as well as physical impact of PH #phaware



**Vickie Ridge**  
United Utilities team take on Tough Mudder 2017. In memory of our much loved and missed friend and colleague Sarah Mary Herron xx



**@MaryFergusonCBM**  
On location at Tesco today - filming the reality of life with pulmonary hypertension for @PHA\_UK with @visualisedit



**@wginsing** (Wendy Gin-Sing)  
An early happy birthday to the ever-young Dr Armstrong @PHA\_UK





## Family fundraiser for transplant recipient Mick

A charity night held in support of her brother-in-law Mick Noble helped Jan Chappell raise over £4,800 – with support from family and friends along the way. Jan, from Essex, organised the event with daughters Jade and Ria after her sister's husband was rushed into hospital, and after two months, fast-tracked for a double lung transplant in August. Mick had lived with PH for 17 years and celebrated his 40th wedding anniversary with wife Deborah two days before the operation.

Mick was determined to be well enough to attend the fundraiser at Paringdon Social Club in Harlow, and received a standing ovation on his arrival.

Entertainment on the night included local soul band 'Soul Crusaders' and a bottle stall, auction and raffle all helped to raise funds for PHA UK. Local businesses and TOWIE stars Amy Childs and Bobby Norris all donated prizes.

Jan's 80-year-old mum Brenda Unsworth also held her own raffle where she lives in Spain, raising 400 Euros.

Jan said: "It's been such a roller-coaster for the family since Mick went into hospital so for him to be able to make the event was fantastic. It was very emotional but he was so pleased he could be there and he even managed to get up and give a talk about PH.

"The support we have had for the event has been amazing and both Mick and Deborah have been completely overwhelmed. We hope and pray that we have raised awareness of PH and will continue to do so."

Mick and Deborah's daughter Leanne Noble is organising her own challenge, 'Hungry and Hairless', which will see her aim to lose two stone in return for sponsorship. If she succeeds, her husband will wax his chest.

**Jan's nephew Lewis Anderson has also raised money for PHA UK by shaving his head for sponsorship. See our fundraising map on p30 for details.**

Mick and Jan



Mick with his wife Deborah



Some of the prizes donated for the raffle



## Dear PHA UK

My amazing hubby Rich ran the New Forest 10k in September for PH and raised a whopping sum of cash - £1,506! I'm so, so proud of him and what he's achieved. He always looks after me and is so supportive in everything I do. He does chores around the house as well as doing his day job, and comes to all my appointments. I'm not easy at all and he copes with everything this illness throws at us. He has stood by me and fought with me every step of the way on our PH journey. I'm in absolute awe of the man he is and am so lucky to have him as my best friend, my soul mate, and my husband!

Rich has now caught the running bug and has entered the Bath half marathon in March 2018 - again to help raise awareness and money for PHA UK.

Kind regards,

*Andrea Murphy*



## Dear Emphasis

I'd like to share a touching story.

Whilst I was having my Hickman line done at the specialist centre in Sheffield, unfortunately my aunt's father passed away due to kidney failure. My aunt and I have always been very close, ever since I was young. To me she's one of 'us girls'.

Sadly, I was unable to attend the funeral due to still being in hospital, and I became quite unwell there too. This made my aunt worry about me and despite her grief, on the day of her father's funeral she managed to raise £320 for PHA UK. She then surprised me with the funds when I was discharged from hospital.

This was so touching for me as she could have easily chosen to give the money raised to a kidney charity, but instead she felt she needed to help raise money and awareness for PH.

She educated most of the relatives and friends about what pulmonary hypertension is on the day of the funeral too.

I wish there were more people like my aunt, and I am so grateful for every penny that she raised on a very difficult day for her.

*Asha Sagoo*

Asha (right) with her aunt







Rosalyn, right, and friend Angie at the event

## Dear Emphasis

I held a coffee, shopping and therapy morning with a bike show to raise awareness for PH, and funds for both the PHA UK and the PH unit at Papworth Hospital.

We held a raffle and tombola with some fantastic donated prizes and had a reiki healer, hypnotherapist and reflexologist. We had beautiful handcrafted jewellery, crystals and fragrances for sale along with some very pretty fairy doors. The bike show went quite well considering the rain!

A good day was had by all. I also managed to blag myself two radio interviews - one with Cambridge 105 and the other with BBC Three Counties. Although nerve-wracking, these were a great way to raise awareness which also got me a few donations through my Just Giving page.

I was inspired to do this after becoming ill and being diagnosed with CTEPH, and then given a PTE operation. I wanted to help to raise awareness and some funds as a way of a thank you for all the good work that people do.

I raised a total sum of £700 which I have split down the middle; half going to the PHA UK and half to Papworth.

Yours faithfully,

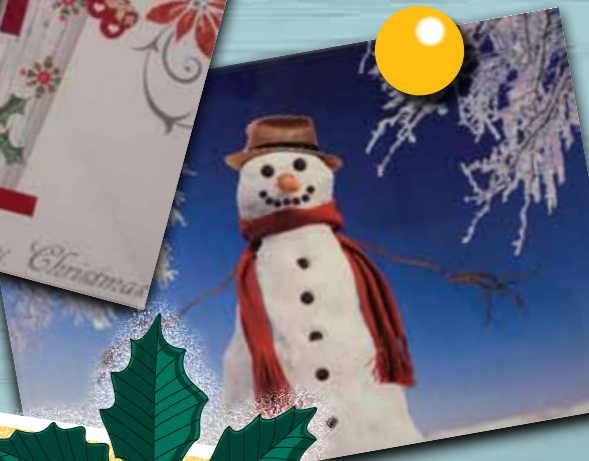
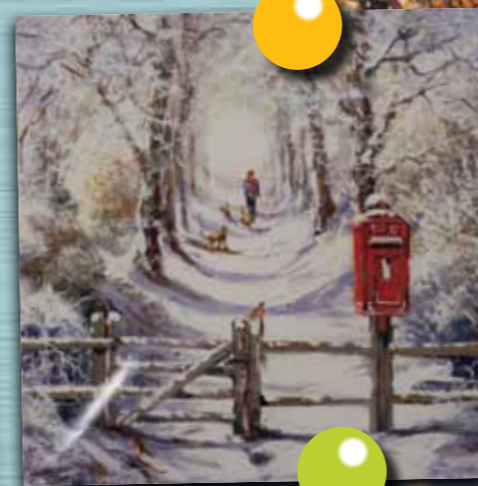
Rosalyn Knight



Raising awareness of PH at the event



The winners and judges of the bike show



Don't forget your PHA UK Christmas cards! If you need some last-minute Christmas cards, head to [www.phauk.org](http://www.phauk.org) where you can now order online. Choose from ten different designs and support PHA UK while spreading some festive cheer.





Call the Silver Line Helpline on 0800 470 80 90



# You're not alone this Christmas

Many older people suffer from loneliness and isolation, especially during the winter months. *Charlotte Goldthorpe* reports on a free and confidential helpline that can provide friendship and hope this Christmas.

**T**he Silver Line is a dedicated helpline providing support to people who are suffering with loneliness in the UK. Open every day for 24 hours, the helpline supports older people who just need someone to talk to, particularly those in their 70s and older.

Dame Esther Rantzen was prompted to set up the Silver Line in 2013 after the death of her husband. Since launching, the helpline has received over 1.4 million calls. Over two-thirds of these calls were made overnight or at weekends when no other helpline is available for older people who may be lonely, isolated or confused.

The Silver Line now receives around 10,000 calls every week from lonely and isolated older people; with 53% of callers saying they have no-one else to speak to.

The specially trained helpline team provide information and advice, offer regular friendship calls, link callers to local groups and services, and support those suffering abuse and neglect. Over 3,000 volunteer Silver Line Friends are making regular weekly friendship calls to older people.

The helpline relies entirely on voluntary donations to cover the cost of calls, the Silver Line's friendship services, and all other costs.

Iain Armstrong, chair of PHA UK, said: *"In today's fast-paced world and with cuts to social care funding, it's no surprise that some older people are feeling lonely and vulnerable. Having a long-term illness like PH can make things worse and it can become much harder to talk about your feelings."*

***"It's important to be aware of services like the Silver Line for anyone feeling like they need someone to talk to and to help make living with PH as an older person easier."***

## Become a Silver Line Friend

Volunteers are vital to the Silver Line's commitment to reduce loneliness and isolation and improve the lives of older people. Just a few moments of your time can make a huge difference to older people struggling with loneliness this Christmas.

Could you spare a few minutes each week to be a volunteer Silver Line Friend, and be a person to share an experience, joke or chat with? Or perhaps you could volunteer as a letter writer, providing friendship by post? To find out more about becoming a volunteer, email [volunteering@thesilverline.org.uk](mailto:volunteering@thesilverline.org.uk)



## Hallamshire PH consultant wins prestigious research award

A consultant based at the specialist PH centre in Sheffield has won a national award for his research around pulmonary hypertension.

**P**rofessor David Kiely, who has been the director of the Sheffield Pulmonary Vascular Disease Unit at the Royal Hallamshire Hospital since 2001, has been recognised for supporting high-quality research - facilitating the evaluation of new technologies and treatments for PH.

The award, from the NIHR Clinical Research Network and Royal College of Physicians, rewards outstanding research leadership in the NHS.

Professor Kiely's team provides specialist care for a population of more than 15 million people across Yorkshire, the North West and significant parts of the Midlands and Wales.

The team have participated in more than 40 studies, resulting in the development of drugs that are now used to treat pulmonary hypertension. Collaborating with colleagues in other specialties in Sheffield, they have pioneered PH diagnostic techniques such as MRI, making it safer and more comfortable for patients.

Professor Kiely said: *"Working with specialists from other parts of our Trust and the University of Sheffield has helped our goal of delivering more research for the benefit of patients. I also work with a great group of*

*colleagues and I am delighted that younger members of our team are spending time in the USA to increase our international research.*

*"We've also given patients more opportunities to be involved in research by setting up dedicated research clinics and working with patient groups, such as PHA UK, to understand what patients want from research and how best to get them involved."*

The drive to increase patient participation has led to new treatments for pulmonary hypertension.

Professor Kiely added: *"We've worked hard to give patients the opportunity to take part in research, ranging from taking blood samples and assessing new technologies, to trialling new drugs and catheter-based treatments."*

*"Over the last five years, we have recruited more than 600 patients to NIHR Portfolio studies. And working with a fantastic pulmonary hypertension research network in the UK, we are involved in studies funded by the British Heart Foundation, Medical Research Council and Wellcome Trust, which aim to find out more about why people get pulmonary hypertension."*

*"When I started in Sheffield there*



**NHS**  
National Institute for  
Health Research

Clinical Research Network

*was only one treatment for pulmonary hypertension, which required a line to be tunnelled under the skin and connected to a pump, containing a drug that had to be prepared by the patient every day.*

*"We have been able to develop new therapies for patients and most of our patients now take tablets. In Sheffield, as one of the largest pulmonary hypertension centres in the world, we have taken part in many of these studies and we are very proud of the contribution our patients have made."●*





# MY TIPS FOR EVERYDAY LIFE WITH PH



Asha Sagoo from Leicester was diagnosed with pulmonary hypertension in Spring 2016 and has learned to adapt her life to accommodate her symptoms. Here, she shares some of her tips for living more comfortably with PH.

## NEGOTIATING THE STAIRS

I avoid going up the stairs immediately after coming down so I bring everything I need down with me in the morning and only make one trip upstairs when I'm ready for bed.

## BUYING MILK

I used to buy six pint bottles of milk but found them too heavy, causing extra strain to my heart. I now only buy four pint milk bottles. This is the same for carrying all heavy groceries, and unfortunately includes children too!

## COOKING FOR YOUR CHILDREN

If you have kids like me, (mine are aged five and nine) you'll know how difficult it is to prepare a family meal. My chronic fatigue comes without warning so I cook as much as I can in the morning when my body has more energy to cope.

## DOING THE HOUSEWORK

I also do the housework in the mornings when my energy levels are at their highest, and if it can't be done I've learned to let it go. It helps me to sit on a small stool when doing the washing so I'm not bending down. I've re-arranged my kitchen cupboards to place items that I use daily at eye level, which avoids having to bend down.

## BAD HAIR DAYS

Greasy hair days are now inevitable – sometimes you just have to let it go and do it when you have the energy. For a long time I couldn't adapt to greasy hair days so I rang my local hairdresser and they only charged £5 for a wash and blow dry. It made a lot of difference to how I felt and saved some of my energy for my children.



## PLAN AS MUCH AS YOU CAN

I never used to plan before my diagnosis, but now I have to plan my week and even my day. For example, if I go into town on a Monday, the next day my body will need to recover so I might spend the day with a late morning watching a film in bed and take time off from phones and the internet.

## FOR THE LADIES

I've switched from carrying shoulder hand bags to small ruck sacks – there are some really stylish ones available. I found that this relieved the pressure from my shoulders and heart and I hardly noticed any discomfort with the ruck sack on my back. It also keeps my hands free.

## GETTING OUT OF THE SHOWER

After a shower I am extremely tired. To help, I find drying with a light weight towel works well before putting on a towelled dressing gown. I now try to shower in the morning as I'm exhausted if I have a shower in the evening or before I go to bed.

## GETTING A GOOD NIGHT'S SLEEP

I find drinking warm milk before bed aids good sleep, as does sleeping with two pillows and a v-shape pregnancy cushion, which is a godsend.

## TAKE YOUR TIME AND ACCEPT HELP

I don't rush through life, even if I'm having a good day. I never say no to help, even if I'm feeling ok, as it means I can save that energy for spending time with my children or doing other important things.

Do you have any tips you'd like to share with the PH community?

Email [editor@phauk.org](mailto:editor@phauk.org) or find us on Facebook (@PULHAUK) or Twitter (@PHA\_UK)



*"I feel like I'm accepting things now"*

Pauline Harrison from Inverness was diagnosed with PH when she was pregnant with her little boy. Seven years later, she's learning to make the most of life with her son.



**“I don’t feel like I’m going through a dark tunnel on my own anymore.”**

## Getting a diagnosis

I knew there was something wrong right from the beginning. I fell pregnant in the January and was tired and drained, my skin was grey, and I was getting increasingly breathless. As the baby grew it got to the stage where I couldn’t walk up the stairs, dress or shower. I couldn’t walk more than the length of two cars before having to stop for breath and I was getting dizzy spells too.

**Each time I went to see a doctor about it they told me it was a normal part of pregnancy.** It was my first child so it felt hard to stand up for myself, having had nothing to compare it to. I knew something was really wrong but no-one would believe me.

I saw two or three different GPs and two consultants. One consultant told me it was part of being pregnant and I should just ‘get on with it’.

**It felt like I was banging my head against a wall and at times it felt like I was going crazy. I was so frustrated.**

When I was around seven months pregnant my symptoms had got so bad that I had to move into my mum’s bungalow because I could no longer manage the stairs in my house. I was getting blue lips and feeling dizzy, so I went to the doctors one more time, and saw someone I hadn’t seen before.

He could tell something was wrong and asked if I had ever had my oxygen levels checked – so referred me to the hospital. When there, **I struggled to walk to the lift and a consultant saw me, thought I was in labour, so insisted I was seen straight away.**

I stayed in for two days and had my oxygen levels checked and a chest x-ray. They showed there was something

wrong with my heart and **I was referred straight away to the Scottish Pulmonary Vascular Unit at the Golden Jubilee Hospital in Glasgow for further tests and that’s when things started to move.**

I had a right heart catheter the next day and at seven months pregnant, I was given the news that I had pulmonary hypertension.

I had never heard of it and I couldn’t get my head around it. All I kept thinking was ‘I’m dying’. I was told there was no cure, but that it could be managed with drugs.

**I was so scared. I didn’t know how long I had left.** I was bringing a child into the world, that I wanted so much, and I didn’t want to leave my baby behind. I cried 24/7. I felt angry. I had always looked after myself, so why this?

**A week after I was diagnosed, my son Ciaran was delivered early by caesarean section.** It wasn’t easy and I owe my life to the staff at the Golden Jubilee Hospital. I just can’t thank them enough.

## Fighting for what I deserve

I was working as a nursing auxiliary on a renal ward when I was diagnosed, but I had to give that up. My employers tried to help me find something less demanding, but no job in a hospital is easy!

I tried some office shifts but my partner is in the forces and was based down in England, so with a young baby and the fatigue associated with the PH it just didn’t work.

**When I was diagnosed I was awarded benefits for the next five years.** But problems began a couple of years ago when I had to apply for

Personal Independence Payments (PIP).

I had my car taken off me but I fought it in court and won. Then it happened again four months later and I had to fight it all over again. Again, I took it to court and won.

**When they took my car off me I thought my life was over.** I couldn’t walk very far and the thought of having to get a young child on and off a bus, with my symptoms, was awful. It felt like my whole world shattered. They had taken my lifeline.

**The last two years have been spent fighting for PIP.** I’ve now got what I’m entitled to and don’t have to be reassessed until 2021, but it makes me so angry that other people are still having to fight for what they deserve.

## Moving on

Ciaran is nearly seven now, and I feel like I’m accepting things. I still have good and bad days but I’m feeling a lot better as I’m learning more about the condition and I don’t feel like I’m going through a dark tunnel on my own anymore.

**I do still have a fear of ‘oh my god, I can’t leave my son behind’. But I’m positive that one day there might be a cure for PH.**

A year ago, I had a Hickman line put in, delivering medication straight to my heart, and I feel like it’s given me some of my life back. I have the motivation to do things now, and can manage everyday tasks like Hoovering much better. Before, I used to struggle to get even two rooms done.

**I feel more like the old me now. Sometimes I even forget there is something wrong with me – until my body reminds me!** ●



**“I’m positive that one day there might be a cure for PH.”**





# 2017 REVIEW

In our 17th year, we are proud to have stepped up our work to support everyone affected by PH, not just those with a diagnosis. Here, we share the highlights of our year so far.

After identifying a need for a publication that sets out what financial support is available to people affected by PH, in the spring we were proud to publish an innovative new financial guide. Titled *'What could my family and I be entitled to?'* the publication uses real-life scenarios to help people navigate the benefits system.

In May 180 people attended our patient conference, at Heythrop Park Hotel in Oxford, making it a weekend to remember. Patients and their families enjoyed educational talks, entertainment and the chance to make new friends and share experiences.

A key part of our activity this year has focused on greater Government focus for PH.

In the summer, we developed and launched a new website that focuses on the work of *PHocus2021* ([www.phocus2021.org.uk](http://www.phocus2021.org.uk)).

As well as launching a dedicated website, we have worked closely with associates to access influencers and decision-makers. We saw successful outcomes from our attendance at the *Liberal Democrat's Spring Conference* with meetings set up with a number of MPs.

We received some good news in July when we found out that *Emphasis*, your magazine, had been shortlisted for a prestigious communications award. We made the final cut in the 'Best Publication' award category at the CIPR Yorkshire & Lincolnshire PRide Awards.

In September, we published two reports into the results of the Living with PH survey.

To bring the survey to life and raise awareness of what it is like to live with PH, we commissioned a media relations campaign around the launch of the *Living with PH* survey results. Thanks to the help of PHA UK members, this resulted in extensive media coverage across the UK - in print, online, and broadcast, including ITV News.

As part of this work, we also produced an *18-minute documentary film on life with PH*, with separate shorter videos that focus on individual patient stories.

In November, we launched our second *PH Awareness Week*, building on the success of last year. This year's theme was breathlessness and to educate both PH professionals and the wider public about how breathlessness affects everyday life, we commissioned a short film through the eyes of PHA UK member Julie Royle.

Throughout the year, we have hosted a series of study days at our resource centre for medical professionals, which have been extremely well attended. We even had to organise a fourth session to meet the demand!

Between 30 to 40 per cent of people attending the study days have gone on to sign up for the full medical education programme *'Pulmonary*

*Hypertension Diagnosis and Management'* hosted by PHA UK in conjunction with Edge Hill University.

To understand more about the financial difficulties people face because of pulmonary hypertension, we recently launched a *financial impact survey*. Without a 'big voice' it's difficult to push for change, so we need as many people as possible to share their experiences before the 22nd December.

**The PH community is growing! Demand for our support is increasing, with 408 new members joining us between January and October – an average of 34 a month.**

**We'd like to thank all PHA UK members who have helped raise awareness of PH in 2017.**

## YOUR HIGHLIGHTS...

*"My highlight was attending the PHA UK conference in May. It was great to see patients and their families outside of the hospital setting, being the people they want to be."*

**Carl Harries**  
Clinical Nurse Specialist in PH at the Royal Brompton Hospital



*"My highlight was raising over £2,100 with the help of my mother Val Annett by running Tough Mudder in August. It was brilliant fun and it was great to be able to support the charity. My wife suffers from PAH and it felt great to contribute in some way."*

**Richard Annett**  
on Facebook



*"Professionally, in 2018, I'm looking forward to handing over the reins to my successor in June and the new challenges that the year will bring."*

**Professor Paul Corris**  
Director of Cardiopulmonary Transplantation and the Northern Pulmonary Vascular Unit in Newcastle



*"For me it has to be the birth of my beautiful grandson Freddie. With having PH and then a heart and double lung transplant - it is a dream come true."*

**Kath Graham**  
on Facebook



*"In 2018 I am looking forward to seeing how the physical activity programmes have benefitted the patients I've referred to them."*

**Carol Keen**  
Clinical Specialist Physiotherapist in PH at the Royal Hallamshire Hospital



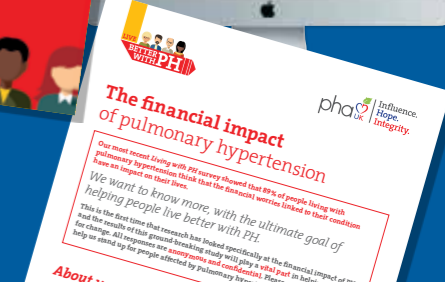
*"The highlight of my year in 2017 was being well enough to see my sister get married. It was such a fantastic day."*

**Catherine Makin**  
on Facebook



*"It was a two week holiday in St Lucia, a few months after my open heart surgery."*

**Deborah Waugh**  
on Facebook





# We need your help!

There's still time to help us understand more about the financial difficulties facing people with PH, to enable us to push for change.

We want to make sure that people don't face financial difficulties because of pulmonary hypertension, and to do that, we need to understand more.

Financial difficulties caused by PH seem to be getting worse. Last year, 63% of those who responded to our **Living with PH survey** said that financial worries had an impact on their lives, and the same number said their condition affects their ability to attend work or education.

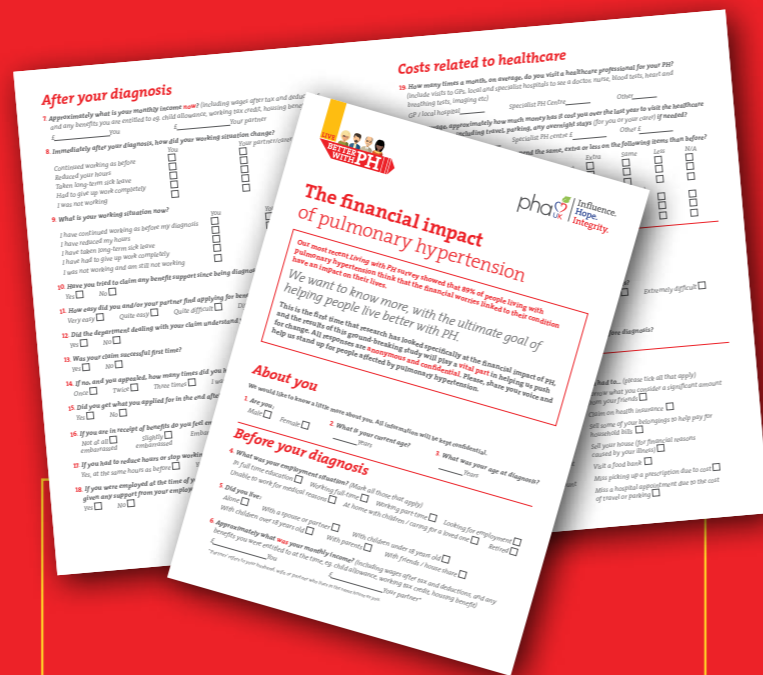
We want to build on these findings to find out which elements of people's financial stability are affected the most, and to understand the impact that has on their lives.

Without a 'big voice' it's difficult to push for change, so we need as many people as possible to share their experiences.

**You may have received a survey through the post recently, with a freepost envelope. We would really appreciate it if you could complete and return it by 22nd December, to help us understand more and provide an evidence base that will help us campaign for change.**

We understand that finances are personal, so we would like to reassure you that the information you provide will be kept completely confidential, and will only be used to input data. After that, it will be destroyed. You can also remain anonymous with your responses.

Without people like you sharing your experiences, we wouldn't be able to meet the needs of those affected by PH so as a thank you, we are giving away £10 Love2shop vouchers to 150 randomly selected respondents. These vouchers can be spent at over 20,000 shops, restaurants and attractions.



**If you haven't received a survey, but would like to take part in the research, please call us on 01709 761450. Just press 'option two' when prompted, leave your name and address, and we will post you one out. Alternatively, you can email us at [office@phauk.org](mailto:office@phauk.org)**

**The bigger the voice, the bigger the change.**

Please add your voice and help us support people living with pulmonary hypertension.



# Our adoption journey



When *Rinku Puri* was diagnosed with PH, she was terrified it would put an end to her dream of becoming a parent. But after deciding adoption was the right choice, 35-year-old Rinku and her husband Sunil are enjoying family life together at last. Here, she shares their journey with Emphasis.



## Our adoption journey



I was only 27 when I was diagnosed with pulmonary hypertension. It was a huge amount to take in and I felt utterly bewildered for a few weeks. I didn't want to grind to a halt. I had only just graduated and was working in a local hospital – the last thing I wanted to do was give up my career.

So, I decided I would try to build up my fitness levels as a way of making me physically stronger. I went back to the gym and began yoga and Pilates classes which really helped and I was eventually able to return to work.

But the one thing that my partner Sunil and I were very concerned about was if we would be able to have a family of our own. Just two months before I was diagnosed we got engaged. We are both from extended Asian families and having children is a huge part of our culture and something we both truly yearned for.

But I was warned the pressure on my heart and lungs during a pregnancy could kill me. I was devastated. Planning your wedding should be such a happy time, but we felt like our little bubble of happiness had been shattered. The thought of not having children of our own to love and cherish was just heartbreaking.

After we got married in 2010, we were referred to a fertility clinic to discuss what options we had. We were keen to see if my eggs could be harvested and go down the surrogacy route.

But after more discussions with specialists at my PH centre, we were told this wasn't an option as stimulating my ovaries was just too risky. Although part of me expected to be told this, it was still hard to take in and left me emotionally drained.

### Considering another option

It was then Sunil and I spoke about the possibility of adopting a baby. We both had so much love to give a child and desperately wanted to become parents. It felt right that if we couldn't have a child naturally, we should try and give a baby that desperately needed a home the chance to be brought up in a loving family unit.

So, we filled in the forms with social services and attended a three-day course. I would be lying if I didn't say it was daunting and intense but we were so focused on our hopes of becoming parents that we tried to take it all in our stride.

Afterwards began the process of being approved.

We had to be interviewed, provide references and prove what family support we had. At the time we were still living with Sunil's parents, but we bought our own home to show how committed we were.

We had specifically asked to be considered to adopt a child in the 0 to 3-year-old category. We felt we could teach a baby or toddler how to adapt to what I could and couldn't do, due to my health. We were asked how we would deal with certain situations including how we would cope with a very active child.

We explained Sunil and I were a team. That he would do the more physical stuff while I could do activities that were less exertive. We even made a video showing what I could and couldn't do. The social workers were very understanding and completely receptive to my needs and a year later we were approved to become adoptive parents.

We were absolutely elated. We couldn't have hoped for better news. We were enrolled on a national register where our profile could be looked at and we could view any children that had been placed for adoption.

### Finding the right match

The next four years were tough. We applied for hundreds of children but for one reason or another we weren't deemed the right match. It could be something as simple as not being in the right age or ethnic group.

With each rejection, it was hard to remain positive and there were times we felt very disheartened. We even looked at going abroad to adopt but the financial outlay was enormous. Most agencies specified an upfront payment of £15,000 to £20,000.

Then in December last year our social worker called and said there was a child that was a perfect match for our profile. We desperately wanted to get excited, but didn't dare get our hopes up again.

And a month later, we thought all our dreams had been dashed again, when we were told the baby's grandparents may be willing to take the little boy on.

Devastated, we assumed it wasn't meant to be. We even booked a holiday to Las Vegas and Florida for later in the year to give us something to look forward to.

But the very next day, we received the email that would literally change our lives, stating the adoption was back on.

.....  
It felt right that if we couldn't have a child naturally, we should try and give a baby that desperately needed a home the chance to be brought up in a loving family unit.  
.....

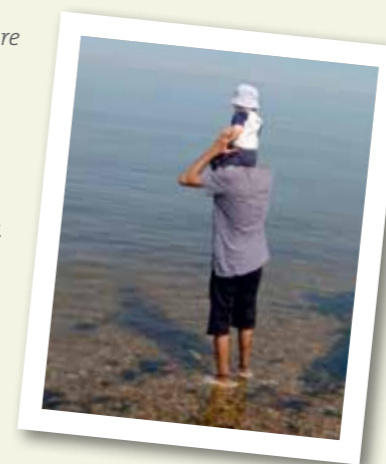
### Welcoming Kiaan

I cried and cried with happiness. It meant we had to cancel the holiday but it was a small price to pay and one we were more than willing to sacrifice.

In March this year, we got to meet Kiaan for the first time. He was just three months old. And as I held him in my arms, the bond was instant. It was an incredible feeling. We both loved Kiaan from the moment we set eyes on him.

We spent 13 hours a day with him and his foster parents for a week, getting to know Kiaan and his routine, before we brought him home. As Sunil carried him through our front door, I had never felt so happy. It was the best Mother's Day present I could have ever wished for. There couldn't have been a greater gift.

We had decorated a nursery and bought everything we needed for our son. Sunil had managed to secure five weeks off work and we enjoyed every minute as we settled into becoming a family.



### Family life

Kiaan is such a funny, happy and contented little baby. At the moment there is very little I can't do with him. I have a Hickman line in so I just need to be careful that he doesn't grab at that but I can pick Kiaan up, cuddle him and feed him. As he gets older, we will adapt to make sure Kiaan doesn't miss out on anything. Sunil will always be around to chase him around the garden and play football and when our son wants to curl up on the sofa with a DVD, I'll be ready and waiting.

Kiaan has completed our family and we couldn't be happier. And it just goes to prove that having PH doesn't mean you can't become a parent.

I would advise anyone to go down the adoption route if it's right for them. I would just say be honest about what you can do and expect that it might take a while. But we are proof that if you follow your dreams, they can come true. ☺

### Emphasis spoke to Adoption UK's chief executive Dr Sue Armstrong Brown about the benefits of adoption.

She said: "Adoption gives children a second chance of experiencing enduring family relationships when birth parents cannot care for them and no other reasonable options are available in the wider family. Adoptive parents provide stability, permanence, a new sense of identity and the love and nurture that all children need – and an opportunity to reach their full potential. "I would like to congratulate both Rinku and Sunil on becoming parents and it's heart-warming to hear that this couple's hopes of becoming a family have materialised through adoption." There is a huge need for adoptive parents. The most recent figures, released by Adoption UK, revealed that in England in March last year, 70,440 children were in the care of local authorities, compared to 69,540 in 2015. Dr Armstrong Brown, added: "This winter the number of children needing an adoptive home may outnumber those coming forward to provide that home. More still needs to be done to recruit adoptive parents who are willing and able to provide a forever home for children, especially those with complex health needs or disabilities, as well as those from BME backgrounds and sibling groups."

Please speak to your specialist PH centre if you have any questions or concerns about how pulmonary hypertension affects family planning.

For more information on adoption visit [www.adoptionuk.org](http://www.adoptionuk.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](http://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.

## FESTIVE FUNDRAISING GUIDE



### How to organise... a Christmas charity bake sale

A Christmas bake sale is a great way to get in the mood for the festive season. Shows like the Great British Bake Off have got the nation baking again, so why not get in on the act this Christmas and raise money for PH at the same time?

#### SET A DATE AND LOCATION

Decide where and when you would like to hold your bake sale. During the build-up to Christmas there are plenty of other events taking place that your sale could coincide with, such as nativities, Christmas markets and carol singing. Organising your sale where there is already a captive audience means you are likely to raise more money.

#### GET OTHERS INVOLVED

Encourage friends, family and colleagues to join in and give as much notice as possible. Not everybody likes to bake, but most of us know somebody who would be happy to put their baking skills to use for a good cause, especially at this time of year. If you don't have the time to bake everything from scratch, you can sell a few bought cakes.

#### ASK FOR SUPPORT

Update your social media followers on how you're getting on with your training. If you show that you are working hard, people are more likely to sponsor you. You can also raise awareness of PH when training by wearing one of our charity t-shirts. Give us a call on 01709 761450 and we'll send one out.

#### PROMOTION

As well as word of mouth, use posters, email and social media to spread the word about the date and time of your sale. Use festive hashtags to reach as many people as possible – see what's trending. If you're doing the sale at the same time as another event, you could ask the organisers to promote it on their social media account. After the event, you can also share the photos on social media and let us know how much you've raised.

#### DISPLAY

Make sure that your cakes are displayed as festively as possible. Going to town with tinsel, Christmas plates and a themed tablecloth will attract buyers to your stall, and in turn help you raise more cash.

#### DON'T FORGET...

Decide on prices for your cakes and clearly label them in advance or use a price board. Make sure you include allergy information with each bake.

#### LET US KNOW WHAT YOU'RE UP TO

We're always keen to know what people are doing to help raise much needed funds and awareness for PHA UK. If you're planning a Christmas bake sale contact Helen at [office@phauk.org](mailto:office@phauk.org) or on 01709 761450 and we'll send you a handy Fundraising Kit to help with your event.





# Ally's LEGACY

Alison Whan was dedicated to generating awareness of pulmonary hypertension and raising money for charity, supporting both the PHA UK and the Northern Ireland Transplant Association before she passed away in May. In a special article for Emphasis, her parents Edna & Davy remember their inspirational daughter.

“Organ donation and research was so important to Ally. She was diagnosed with pulmonary arterial hypertension when she was 22. This was a big shock to her and us as a family. Initially doctors gave her only two years to live.

When people would meet Ally it was difficult for them to believe that she was seriously ill. She was such a positive person and she would never let anything, not even a debilitating illness, prevent her from living life to the full.

Despite suffering from chronic fatigue, chest pains and a deteriorating immune system, Ally always managed to look on the bright side of life. She defied everyone's expectations as she held down a part time job at an accountancy firm, was a chairperson at the annual Castlewellan Agriculture Show, a prominent member of the local Young Farmers Club and was heavily involved in The Girl's Brigade.

Although there is no cure for pulmonary arterial hypertension, an organ transplant can often help prolong the life of people like our daughter. This was something that Ally was very aware of and so she fundraised for charities that supported people dealing with PAH and the Transplant Association in Northern Ireland. In fact, before she passed away she succeeded in raising over £40,000.

Since her death, that figure has exceeded £50,000 to date. Such was the response of the many people's lives that she touched with her positive outlook on life, they were all wanting to honour her in a way that would help to discover new medicines and methods of controlling this serious condition.

So many different events were arranged in memory of Ally. These included donations in lieu of funeral flowers, charity auctions, marathons, abseiling down prominent buildings, a vintage vehicle show and also donations instead of favours at weddings.

Such was her determination for raising funds for the PHA UK, a few years back Ally published a cookery book, 'Ally's Racy Recipes', which raised over £13,000. We are extremely proud of what Ally achieved.

Ally managed to live 11 years after her initial diagnosis and I believe this was because she never saw herself as a sick person. Shortly before she died she made a list of '101 things to do in 1001 days' and for us, it sums up her character. On it she has a list of places to visit, tasks to complete and people to help. She even had completely random things like 'lamb a ewe' and 'make a loaf of bread' on it. Every time we read it we smile as it is 100 per cent Ally, and with the help of her cousins, we hope to complete the list for her.

“Ally had an infectious personality, a beautiful smile and a kind word for everyone...our loss is Heaven's gain.”

We will always cherish the short time that we had with Ally as a family. Thanks to her we have a completely different outlook on what really matters and we hope that by telling her story we can persuade people to do something that can change someone's life; become an organ donor.

Ally had an infectious personality, a beautiful smile and a kind word for everyone she met and was sure to light up a room just by entering it. We as a family are so proud of all these memories and to have known her as our precious daughter Ally. Our loss is Heaven's gain.”

**Thank you to Ally's parents for sharing her story and to all of her family and friends for their incredible fundraising in her memory. ●**



Ally with her charity recipe book.



Ally, left, as a bridesmaid for Jemma.



Jemma Roleston.

## Abseiling for Ally



Ally's friend Jemma Roleston is one of many people who have raised money for the PHA UK in her memory. In September, four months to the day since Ally's death, Jemma faced her fears to abseil 120 feet down the Europa Hotel in Belfast, raising £1271.

Jemma said: "Ally was my oldest and best friend. We grew up together. I am 12 days older than her - of which she reminded me at every opportunity! We have a lot of happy memories growing up and she was my bridesmaid when I got married. She was such a strong person and took everything in her stride. Even after her diagnosis she continued on where many others would have given up. Ally's main goal was to try and raise as much awareness of PH as possible and I decided that I would complete my abseil in her memory to continue to raise awareness on her behalf.

"An abseil is not something that I would normally do, so people knew it was something close to my heart. A lot of those who sponsored me did not know anything of PH so it was exactly what Ally would have wanted. It also gave me the chance, in my own way, to say thank you to Ally for being my friend."





# Building trusted partnerships

Living with PH can have a knock-on effect on finances and mental and emotional wellbeing, so, PHA UK has built two charity partnerships to ensure members have access to specialist advice and support. *Charlotte Goldthorpe* looks at what is available.



## Navigating financial support with Turn2us

**If you're struggling with your finances, you're not alone. Of those who responded to the Living with PH survey, 63 per cent said that financial worries had an impact on their lives, and the same number said the condition affects their ability to attend work or education.**

Living with a chronic condition like PH can have a big impact on family finances and personal purse strings. There are many hidden costs that can be associated with the condition, including the cost of travelling to and from hospital, an increase in electricity bills from using an oxygen machine, or the minefield of dealing with a benefits system, which doesn't understand PH.

To help members deal with the financial burden, PHA UK has teamed up with national financial hardship charity Turn2us, which helps people gain access to welfare benefits, charitable grants and support services. As a trusted partner of PHA UK since 2014, Turn2us offers a range of free tools to help you search for grants and calculate benefits. Simply by filling in your personal details and circumstances, the tools flag the benefits that are likely to help you and how you can access them.

The benefits calculator, available to

access through the PHA UK website at [www.phauk.org](http://www.phauk.org) by searching 'benefits calculator', allows you to find out what welfare benefits, tax credits, and other support you may be entitled to, based on your situation. It takes into account where you live, and can identify local benefits such as discretionary housing benefit or emergency funds. You can also find out if you are eligible for additional support through charitable trusts by searching 'grant tools'. Turn2us has over 3,000 of these funds listed on its database and the tool makes it easy to find the right one for you.

**As a trusted partner of PHA UK since 2014, Turn2us offers a range of free tools to help you search for grants and calculate benefits.**

Another useful source of information can be found on the Turn2us website at [www.turn2us.org.uk](http://www.turn2us.org.uk) where the 'your situation' tab at the top of the homepage provides advice for those who are ill, injured or disabled.

Not everyone has access to the internet, so support through Turn2us is also available through a free Turn2us helpline on 0808 802 2000 between 9am and 8pm, Monday to Friday. Its team can help you access all the support found on the website. Calls are free from landlines and major mobile network providers, but do check with your provider before calling.

Shaun Clayton, director of membership support at PHA UK, said: *"Financial hardship can have a debilitating effect on those already struggling with the physical and emotional impact of living with a chronic condition like PH."*

*"This is an area we are focusing on which is why we are carrying out further research and working with partners like Turn2us to offer specialist advice."*

*"I'd encourage anyone experiencing financial hardship to make the most of our partnership with Turn2Us by using the free online tools and accessing support via their helpline."*

**For further information on Turn2us services, visit [www.turn2us.org.uk](http://www.turn2us.org.uk) or call the free helpline on 0808 802 2000**

## Accessing emotional support through Anxiety UK

**People living with PH cope with the condition in different ways. While some struggle to come to terms with the diagnosis, others are more accepting and are able to cope better.**

In our most recent Living with PH survey, an overwhelming 80 per cent of people said that PH had an impact on their general mental and emotional wellbeing. This highlights a need for more resources to help people living with this serious condition and to raise awareness of how it affects people's quality of life.

Leading mental health charity Anxiety UK has been a trusted partner of PHA UK since 2012. Through the partnership, members can access free services to help them deal with feelings of anxiety, stress and anxiety-based depression.

Dedicated telephone helpline and email support services are available to PHA members, completely free of charge. If you're struggling with stress or anxiety, or if you or your family have concerns about your emotional wellbeing, call the dedicated helpline service on 0844 332 9010 between the

hours of 9.30am and 5.30pm, Monday to Friday. An email support service is also available by emailing [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk).

**Through the partnership, members can access free services to help them deal with feelings of anxiety, stress & anxiety-based depression.**

PHA UK members may also receive free assessment and therapy provision if more emotional support is needed. This may be accessed directly through the helpline or via referrals from PH teams working with pulmonary hypertension patients and their families.

For those accessing therapy, a limited number of free subscriptions to lifestyle app Headspace are also available. Headspace is a digital tool, accessed via a computer or smart

phone, which uses proven meditation and mindfulness techniques to help users train their minds in order to reduce stress and anxiety.

Iain Armstrong, chair of PHA UK, said: *"We know that many of our members struggle with the associated psychological impact of a PH diagnosis. Our partnership with Anxiety UK gives patients and their families access to a dedicated helpline and email service, providing vital support for their emotional wellbeing."*



*"Understanding what anxiety is and how its symptoms can be managed, allows those faced with a diagnosis of pulmonary hypertension the ability to focus on moving forward with their diagnosis and lead a fulfilled life."*

**To access support from Anxiety UK, call 0844 332 9010 email [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk) or visit [www.anxietyuk.org.uk](http://www.anxietyuk.org.uk)**



# Fundraising **roundup**

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

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

## Toughmann to support mum

Michelle Towers from the Isle of Man took part in the island's Toughmann event – a 10k obstacle course designed to test physical strength and mental courage. Michelle's mum has PH and finds support through PHA UK and Emphasis magazine. She said: "I have never done anything like Toughmann before but was given the opportunity and thought what better time to raise awareness of PH and raise money for something that is so close to the family."



£788.75  
RAISED

## Peaks 4 PHA

Mark Harris and a group of friends have completed the return leg of their fundraising walk across the Peak District in support of Mark's brother Paul who has PH. Dressed as nurses, the team walked 55 miles from the Royal Hallamshire Hospital in Sheffield to the Broughton Arms in Rode Heath. Mark said: "The medical and support staff at the specialist pulmonary hypertension unit at the Hallamshire hospital are absolute heroes. They have supported Paul through some extremely tough times with their continued expertise, dedication and support."



£3,885  
RAISED

## Ridgeway ramble

Niki Vallance and her husband Wayne joined Niki's office colleagues at Nationwide Building Society to take part in a 23-mile sponsored walk. The team walked nine hours from Nationwide HQ in Swindon along the Ridgeway to Hampley Hollow in Calne, Wiltshire. Wayne was diagnosed with PH in January 2016 and receives treatment at the Royal Brompton Hospital. Niki said: "We hope the money raised will help raise awareness of this disease and help towards research to find a cure."



£493  
RAISED

## Edinburgh Rough Runner

Dugald Scobbie completed Rough Runner in Edinburgh in memory of his late wife Gillian. Friends and family joined him for the 10k charity fun run to help him raise money for PHA UK, the Scottish Pulmonary Vascular Unit (SPVU) and Scottish Adult Congenital Cardiac Service (SACCS), which all played a part in supporting and treating Gillian. Dugald said: "I hope the money raised can help fund research and help others who require support and advice from these services."



£2966  
RAISED

## Lewis' hair-raising challenge

Lewis Anderson took part in a hair-raising challenge to generate awareness of PH amongst his colleagues at Ipswich Building Society. Far from a typical day in the office, Lewis had his head shaved to raise money for PHA UK in support of his uncle who has been living with PH for 18 years. Lewis set up a stall where people could find out more about the work of PHA UK and gave out goody bags with PHA branded gifts. He also organised a cake sale on the day to raise additional funds.



£813.17  
RAISED

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



# Life with PH in my twenties.

Shani Fernando was diagnosed with PH as a baby. Now 26, she tells *Emphasis* about studying for a degree, planning for the future and how social media is helping her inspire others to live the best life they can.



**“**When I was diagnosed at just nine months old, like most other people, my parents had never heard of pulmonary hypertension.

People are shocked when I tell them I have a serious illness but I don't blame them for their reaction. For me, PH is an invisible illness; it's not until I climb a lot of steps or do something really physical like running a long distance that my breathlessness becomes obvious and I know that I'm lucky in that respect.

I've been taken off the transplant list twice, and when the PH was at its worst I have been in and out of hospital for six or seven years of my life. However, for the last three years things have been relatively normal for me. Don't get me wrong, I do have my down days where I just curl up and watch Netflix all day, but I guess we all feel like that at some point in our lives.

**As I've grown older, I've learnt how to cope and manage my illness and not let it consume me. I always try to make time for the things I enjoy such as spending time with family and friends.**

I also try to keep fit and healthy and enjoy going to the gym. I used to have a personal trainer who I would train with twice a week with a

special programme to suit my condition, but it started getting a bit costly. I'm now more confident exercising on my own and I think it's important to try to stay as active as possible.

Over the last six years, I have kept my brain active too by studying full-time for a degree in aerospace engineering at Kingston University in London. It has taken me much longer than the average undergraduate due to my PH and fitting studying around my treatment. The course has also been incredibly intense, which led me to being admitted to hospital for stress. At that point, I knew I needed to listen to my body and not overdo it and am grateful to the university for being so understanding.

**I truly believe that if your mental health is suffering, your physical health will be affected too.** Luckily, I have a great support network. Living with a rare disease is difficult and I try to surround myself with positive people. Having PH certainly gives a new perspective for me and I see it as a second chance at life.

## The future...

My PH has definitely affected past relationships I've been in with people who struggle to understand the condition and how it affects me from one day to the next.

I try not to think about it, but I do worry about finding the right person in time to start a family - it's something that's always in the back of my mind. Having PH doesn't give you a long-lasting life and as I approach 30, I become more and more concerned about whether I'll be able to have children with someone I love.

I was aware of the risks of pregnancy, not just for me but for my baby too, so I took medical advice from doctors and decided to have my eggs frozen. This has helped put my mind at ease a little, but the possibility of the surrogate mother

bonding with the baby does trouble me. I suppose I will have to cross that bridge when I come to it.

**As a student who will be graduating in January 2018, I'm worried about the prospects of getting a job and being able to afford to live with PH.**

Currently, I receive disability allowance, but I fear that the government will take it away, and the pain of applying and then reapplying for financial help scares me. I'm also worried about finding an employer that understands my condition and offers flexible working hours if I need them. But for the moment, I'm trying to stay positive.

## Keeping well...

I visit the specialist PH centre at Brompton Hospital for check-ups every six months and I am grateful for the care and support I receive.

**Over the past few years, I have felt in total control of my illness and the medication I am prescribed, but if my condition goes downhill I know the doctors will deliver the appropriate care for me.**

However, when I was put on an epoprostenol pump around three years ago it was a very different story. This is where the drug is administered through a surgically placed central venous catheter - a constant reminder of my PH.

I'm a very free-spirited person so I decided to take charge of the situation by coming off the medication. It was a big decision because the drug did improve my symptoms, but it was

holding me back from living the life I wanted to live.

## Helping others...

It saddens me to meet other PH patients who let the condition get the better of them. This spurred me on to do something that would help give other PH patients hope for the future, so with encouragement from friends, I set up a vlog (short video clips, like a blog).

**My idea is to make weekly vlogs about how to achieve a positive mindset to cope with PH and to share how I deal with my bad days and make the most of my good days.** My posts will cover everything from socialising and exercise, to relationships, travel, fertility and depression.

**I would encourage other people affected by PH to watch my vlog and I welcome any questions they may have. I would also be happy to keep in touch via Facebook and Snapchat. Social media is such a powerful tool these days and really does help raise awareness.”**

Shani will be posting her vlogs on her Facebook page - search 'Shani Delphina'. You can also follow her PH journey on Snapchat, where she posts as **Phighter90**.





# Green Leaf

## Crew!

### GREEN LEAF CREW Q&A DALE LEITCH

Dale Leitch is 13 years old and lives in Midlothian, Scotland, with his mum Sharon, cousin Angela and his two dogs. Dale was diagnosed with PH when he was 18 months old and is cared for by Great Ormond Street Children's Hospital and the Royal Hospital for Children in Glasgow. Here, Dale shares some of his favourite things.

Q. What's your favourite subject at school?

A. I love all the sciences, especially chemistry as I want to do pharmacology or biochemistry when I leave school.

Q. Where would you most like to go on holiday?

A. Canada or Ireland.

Q. If you could be anyone in the world for a day, who would it be and why?  
A. Usain Bolt, so I would be first in line for my lunch at school every day.

Q. Do you have a favourite TV programme?

A. Top Gear and Tom and Jerry.

Q. What is your dream job?

A. I'd love to be CEO of McLaren cars.

Q. What do you like to do at weekends?

A. Tae Kwon-Do training or playing on my Xbox.

Q. What's the best thing about Christmas?

A. The presents, the food and spending time with my family.



Would you like to answer the Green Leaf Q&A? Contact us at editor@phauk.org



Congratulations to five-year-old Amelia Kelly who completed a 'scootathon' to raise over £260 for PHA UK. Amelia wanted to support a family friend who lost his daughter to PH.



### THESE CHRISTMAS CRACKERS ARE PERFECT TO WATCH TOGETHER WHEN IT'S COLD OUTSIDE.

- 1 HOME ALONE** - EIGHT-YEAR-OLD KEVIN MCALLISTER IS LEFT TO PROTECT HIS HOME FROM A PAIR OF BURGLARS.
- 2 ELF** - BUDDY, AN ADULT HUMAN WHO WAS RAISED AS AN ELF IN THE NORTH POLE, LEAVES TO TRY AND FIND HIS REAL FATHER IN NEW YORK CITY.
- 3 HOW THE GRINCH STOLE CHRISTMAS** - WHEN THE GRINCH ATTEMPTS TO STOP CHRISTMAS IN HIS VILLAGE, RESIDENTS REFUSE TO BE DEFEATED.
- 4 POLAR EXPRESS** - A YOUNG BOY EMBARKS ON A MAGICAL TRAIN JOURNEY HEADING TO SANTA'S OWN SPECTACULAR WORKSHOP.
- 5 MRS MIRACLE** - NANNY MRS MERKLE TAKES CARE OF TWO RASCAL TWINS AT CHRISTMAS, BECOMING A CHEF, FRIEND & MATCHMAKER.

### Patch

by David Banks



### The GREEN LEAF CREW

BY DAVID BANKS





## TAKING CARE OF MUM

*Dawn Shelley from Sutton became a full-time carer for her mum, Christine Codd, after she was diagnosed with PH in 2012. Her experiences of struggling alone have led to her setting up a Facebook group, 'Carers for PHighters', to help other carers access support and advice. Here, Dawn shares her story.*

**“M**um was officially diagnosed with pulmonary hypertension associated with Scleroderma at Hammersmith Hospital, and she also had the connective tissue disorder 'CREST'. Her first symptoms were in 2007, when she had problems with swallowing, and she was diagnosed with esophageal disease. A year later she was diagnosed with Reynaud's phenomenon. We then noticed Mum had blotches like broken veins on her face, but her GP said it was 'just old age'. In around 2010 she started to get a bit breathless, but we were told it was 'probably asthma'. For about 18 months Mum tried various different inhalers, before she finally saw a different GP who referred her to our local hospital. Here she saw the Respiratory Consultant, who by chance had recently attended a conference that covered PH. Unfortunately, by the time she was diagnosed, Mum was already at stage three. She was immediately started on treatment. Following a chest infection in December 2014, Mum became unwell and after a trip to our local hospital she deteriorated. She was admitted to Hammersmith and after three weeks was discharged with 'end of life' care. By this time, she was in a wheelchair, and on oxygen 24/7.

**“Being a full-time carer for a loved one is hard and I suffered physically, financially, mentally and emotionally.”**

*Mum initially had carers in place through our local social services and she hated it. We also found they weren't giving her 'proper' care, so after a week I decided I would give up my job as a children's nurse to care for her full time. We also*

*paid for a private care company to provide us with additional help a few times a day. With the joint efforts of the carers and myself, Mum started bouncing back and for a few months she seemed a lot better. She started going to the local hospice for craft sessions and to have lunch with the other patients, and we started going out for meals together again, and to the local garden centre. We also went to see Lionel Richie in London in July; something Mum had always wanted to do.*

**“As a carer I felt isolated and alone.”**

*Everything was great until July 14th 2016 when she suddenly seemed to deteriorate. I managed to persuade her to let me call an ambulance and she was admitted to hospital. After a three-day stay the doctors discharged her home 'to die' and she was now bed-bound, which she found very hard. At this point I was living with her, as she wasn't coping very well. She did bounce back again briefly before finally giving up the fight on the 1st September 2016. She died in my arms, surrounded by close family. As a carer it was tough. I did Mum's medications, attended all her hospital and doctors' appointments, and attended to all her personal and basic care. As well as giving up my career, I also ended my marriage and moved in with her after her hospital stay as she needed someone there 24/7. My marriage was on the rocks anyway and seeing Mum deteriorate made me realise that life's too short. Being a full-time carer for a loved one is hard and I suffered physically, financially, mentally and emotionally. My only income was carer's allowance and Mum gave me attendance allowance. Everything took its toll and I was diagnosed with depression. In front of Mum I had to pretend everything was ok, so my suffering was in silence. I hid it from friends and family.*



Mums 69th birthday meal, April 2016.



Mum & me before our Lionel Richie concert.



Mum in January 2015.

**“Mum was my best friend and we were very close.”**

*The only support I received was from the hospice's counsellor, who was amazing. As a carer I felt isolated and alone. No-one understood what I was going through and people assumed I was fine - which was partly my fault, as I didn't want to burden people. And besides, compared to what Mum was going through my problems seemed insignificant. Mum was my best friend and we were very close. Watching her going through what she did was hard and I had no one I could really talk to; I found there were groups for people who had PH but nothing to support people like me. Before I set up the Facebook group I used to go on various PH forums but I felt guilty 'moaning' about my problems to a group that was full of people suffering themselves from an illness that I was moaning about. It didn't sit right. Carers for PHighters is a group where we as carers can talk*

*about anything that needs talking about - whether it is PH related or not. As I found, there are lots of other issues that come when caring for a loved one.*

*There are no rules to the group - except that it is strictly for carers of people with PH only, not patients themselves. We have parents, siblings, friends and partners on there, and they can talk about anything, confidentially. I want the group to be a place where people can open up and discuss anything that is worrying them. I want them to feel that they are not alone, to ask for advice, and to come and rant about anything that has happened to them that day. I know more than anyone how damaging it can be not to talk to someone. I now have good days and bad days. I'm still on antidepressants and am arranging to see a counsellor, but I have no regrets about caring for Mum - I feel I did the best I could to ensure she had a good quality of life.*

**.....  
If you would like to share your family's PH story, please email [editor@phauk.org](mailto:editor@phauk.org)**

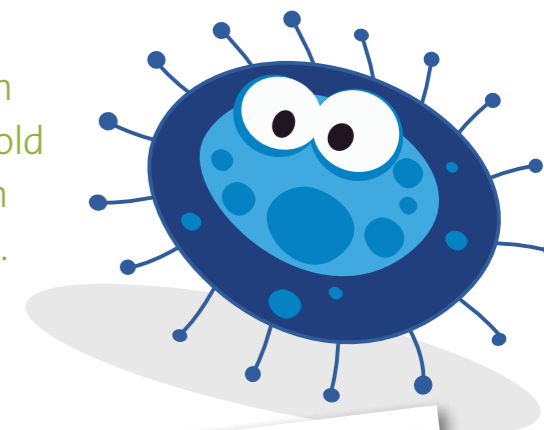


Dawn's Facebook group, Carers for PHighters, is a private forum where people who care for a loved one with PH can share experiences and access advice and support from others. Search 'Carers for PHighters' on Facebook to send a join request.



# Coping with winter vomiting bugs

It's common knowledge that winter weather can increase your chances of catching illnesses like cold and flu, but you're also more likely to contract an unpleasant stomach bug at this time of year too. Consultant pharmacist *Neil Hamilton* offers his advice on how to cope.



**V**omiting bugs can theoretically occur at any time of year but are more common in winter. There are many different strains, the most common of these is called **Norovirus**.

Norovirus is a highly contagious stomach bug causing a high temperature, stomach cramps, vomiting and diarrhoea. It is estimated that annually it affects up to a million people in the UK.

Whilst this is highly unpleasant for anyone, it is usually a very short-term problem lasting only a few days and virtually everyone will make a full recovery without needing to see a GP or visit A&E. In fact, I would advise patients to definitely not go to the surgery unless symptoms persist more than 72 hours. If this is the case, contact them by phone for advice. This is due to the highly contagious nature of the bug, meaning that contact with others could almost certainly spread the infection.

To reduce the chances of passing on stomach bugs to others, extra care with hand hygiene is essential. This means frequent hand washing, not sharing flannels or towels and maybe using alcohol hand gel if you want to make really sure. These measures are particularly important if you have either small children or older people in the house.

PH patients do not cope with any infection well. The body diverts all its attention to fighting off the infection so patients often notice an increase in

breathlessness. This is likely to be made all the more significant if the stomach bug means that usual medication doesn't 'stay down'.

In addition, patients who take diuretics (which are absorbed despite the bug) may notice more problems with thirst and dehydration. Careful management is needed because light-headedness or dizziness may be down to either dehydration or the PH. If these are occurring at rest, they are far more likely down to norovirus than PH.

If this is the case for you, there is no specific advice to cover all eventualities. However the most vital consideration through the (hopefully short) time of the bug is keeping well hydrated and keeping blood sugars as normal as possible. This is achieved by gentle sips of clear fluids. Rehydration sachets can be helpful to replace valuable salts.

Paracetamol can help with the symptoms of stomach cramps but there is little else that can be taken to treat norovirus. The bug will run its course in only a few days. If possible I would advise against the use of loperamide or other agents for diarrhoea. These can prolong the duration so should be avoided.

In terms of PH medication, I would simply apply common sense. In general, tablets are absorbed from the stomach into the system within about an hour, but that depends on many factors and will vary hugely. However if you are sick after taking your medication we

cannot be sure how much has been absorbed or not. I would not 'double up' by taking more just in case. I would concentrate on keeping up your hydration and blood sugars and try again when your next dose is due. *As this is only likely to be a short-term problem there are more risks from taking too much of your medication than missing a few doses whilst poorly with a stomach bug. However, if you are unfortunate enough to catch norovirus and you have any specific concerns or questions, don't hesitate to give your PH centre a ring.*

## **DON'T FORGET YOUR FLU JAB!**

**Flu vaccination is available every year on the NHS to help protect adults and children at risk of flu and its complications.**

According to the NHS website: "Flu vaccine is the best protection we have against an unpredictable virus that can cause unpleasant illness among at-risk groups, including older people, pregnant women and those with an underlying medical health condition." Contact your GP or pharmacist to make an appointment now, and make sure you're protected.



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



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Research  
Physiotherapist  
**JOANNA FORD**

in conversation with  
**Deborah Wain**

.....



Joanna Ford is a Research Physiotherapist at the Golden Jubilee National Hospital, Glasgow. She gained her BSc (Hons) Physiotherapy degree at Glasgow Caledonian University in 2003. She has extensive knowledge in a variety of clinical specialities and vast experience in the rehabilitation of patients suffering from advanced heart failure.

Joanna was appointed as a Research Physiotherapist for the Scottish Pulmonary Vascular Unit (SPVU) in 2015 to be involved in a study to assess the effects of exercise training in PH patients. It is the first project of its kind in the UK and is inspired by a pioneering programme in the German town of Heidelberg.

The study involves an initial three-week residential phase with individually-tailored and supervised daily exercise training either one-to-one or in small groups. Following this there is a 12-week home exercise programme supervised over the phone and by email.

.....  
**Q. How did you become involved with this project?**

**A.** Since embarking on my physiotherapy career 14 years ago I have worked in a wide variety of clinical specialities. For over six years I worked as a Senior Physiotherapist providing specialist care within cardiothoracic surgery and the advanced heart failure service here at the Golden Jubilee National Hospital. Patients with advanced heart failure have similar symptoms to those suffering from PH therefore I was well placed to take on my current role when the job opportunity arose two years ago.

.....  
**Q. Can you tell us what's been achieved so far in numbers?**

**A.** We have had 24 participants through the exercise programme. We have several more participants lined up over the next few months and a total of 40 patients will participate in the study. We aim to have the study completed by next summer.

.....  
**Q. How are you involved with an individual patient, from initial contact?**

**A.** All participants undergo a detailed assessment of their exercise capacity, heart, lung and muscle function, before and after completion of the programme. This involves a cardiac MRI, a cardiopulmonary exercise test, muscle strength testing, a six-minute walk test and pulmonary function tests. These

tests allow us to determine if the therapy has a beneficial effect on participants' overall condition and establish how the therapy works.

Participants stay at the Golden Jubilee Conference Hotel for three weeks and undergo four exercise sessions daily, Monday to Friday, under the close supervision of myself or Dr Alison Mackenzie. Each programme aims to reduce symptoms, improve quality of life and heart function. These sessions involve bicycle training, weight training, outdoor walking, respiratory training and relaxation sessions. Every timetable is personalised and developed for each individual. This ensures that patients are exercising at the correct level and within their safe limits.

In addition to this, I schedule regular education and goal-setting sessions while the patients are here. During these sessions we discuss expectations and set realistic goals to work towards. This helps patients to have a focus and to understand their role in the process, which is key to the success of the programme. I educate, reassure and motivate people who are often frightened or reluctant to exercise. Additionally a significant part of my job is counselling patients and their relatives on lifestyle changes to help them manage symptoms, build self-confidence and return to their daily life.

After the residential phase participants begin an exercise programme at home, with regular telephone and email physiotherapy support. At the end of the 12 weeks, the patient returns to the Golden Jubilee for a final assessment. >>>



theinterview  
Research  
Physiotherapist  
JOANNA FORD

“It has been shown in other European countries that exercise training can improve symptoms, heart function, exercise tolerance and quality of life to a greater degree than many of the drugs available.”

at home. The majority of participants have enjoyed it so much that they do not want to finish at the end of the programme!

**Q. How do you work with the rest of the team?**

**A.** The study is being led by Dr Martin Johnson, along with a fantastic research team which includes nursing and medical staff from the SPVU. We work very closely as a team to ensure that we are providing a safe, effective and patient centred service. We also work in collaboration with other allied health professionals, the Golden Jubilee Research Institute and the Golden Jubilee Conference Hotel who we could not perform the study without.

**Q. What is the significance of the study?**

**A.** The causes of reduced exercise capacity are not fully understood in PH. It has been shown in other European countries that exercise training can improve symptoms, heart function, exercise tolerance and quality of life to a greater degree than many of the drugs available. Exercise therapy is not established for people with PH in the UK. It is unclear what changes in the body are responsible for the improvement in symptoms and exercise capacity seen with exercise therapy. Understanding these changes would help to deliver the best type of training programme specifically for people with PH in the UK.

**Q. What sort of results are you seeing so far?**

**A.** We are delighted with the progress of the study. Initial results have shown significant improvements in exercise capacity, quality of life and breathing function and going forward we hope to gain more insight into how the therapy is benefiting patients.

**Q. Have there been any surprises for you?**

**A.** I am amazed by the commitment of the participants – three weeks staying here, then a further 12 weeks of independent exercise

**Q. Have there been any inspiring moments?**

**A.** There have been many! For example, one of our patients had a successful lung transplant last year. She believes that she would never have got through the process had she not had the prehabilitation of our programme. Another chap had been housebound, but managed to walk up the 164m (539 ft) Blackford Hill, in Edinburgh, within a month of going home from here. One of our ladies managed a 5k event, jogging and walking, and just last week a chap started running again on the treadmill in our gym. He hadn't run for years and years and was positively glowing when he finished his residential programme.

**Q. How will these results be used at the end of the two years?**

**A.** The results of the study will be analysed and published in scientific journals (hopefully!), as well as being presented at scientific meetings. We have already presented some of our initial results at the Pulmonary Hypertension Forum, in Vienna, and the European Respiratory Society Congress meeting, in Milan, this year. In the long term, the aim is to establish a dedicated rehabilitation service for this specific patient group.

**Q. And finally, what's the most rewarding aspect of your job?**

**A.** We have a fantastic group of motivated, inspiring participants who we really enjoy working with. Many of our patients have been unwell for a long time and have significant exercise limitations. Watching them learn how capable they are and gain confidence in their bodies again is very rewarding. Seeing participants achieve their goals is phenomenal. I feel very proud. ●

## Important definitions when applying for welfare support

# Benefits Advisor

With Shaun Clayton

I have found during my time helping members navigate the welfare system that there are particular phrases that the Department of Work and Pensions (DWP) look for in applications.

These words and phrases are what the DWP themselves use to decide whether to award benefits, so by including them in your application, you'll be speaking in their language – giving you a better chance of success.

If you feel like these key words may help describe your situation then please use them wherever you feel appropriate when completing your application, but make sure you understand what they mean as you may be questioned about it later.

**Frequent** is defined as 'several times, not just once or twice in a 24-hour period.' For example: "I frequently experience breathlessness or light headedness when going up and down the stairs."

**Continual** does not mean 'non-stop', but simply 'less than continuous'. For example: "I'm continually breathless when I'm up and about making a meal, but fine whilst eating it."

**Supervision/supervised** can mean precautionary ('in case of' or 'safely') or anticipatory (in case something may happen; for example, blackout trip and fall). It doesn't mean that someone eliminates the danger; merely that their presence reduces the risk of harm.

**Night/day time** is defined by when the 'house' shuts down. When the last adult goes to bed night time starts, and when the first adult wakes day time begins.

**Prolonged** is defined as at least 20 minutes. For example: "I experience prolonged palpitations or light headedness (dizziness)."

**Repeated** means more than once during a period of 24 hours.

**Significant** refers to length of time, not the importance of the occurrence. Experiencing symptoms for a 'significant' period of time, for example, means an hour or thereabouts and can consist of one or a number of periods during the day.

**Consistently** refers to whether you can always carry out a particular activity. For example: "I cannot consistently bath myself without the aid of supervision."

**Reliably** refers to whether you can reliably complete an activity. For example: "I can walk to the shop but I cannot always reliably walk back." In this case, you may be able to get to the shop one day but because of your symptoms you cannot get back – even if on the previous day you could. Or: "Today I could cook my breakfast but due to symptoms suffered throughout the day, come dinner time I couldn't cook my dinner. Therefore, I couldn't cook reliably and safely."

Our free guide to navigating potential financial support is available now. For your copy of **Financial support: What could my family and I be entitled to?** please contact **01709 761450** or email **office@phauk.org**



Shaun Clayton is Membership Services Director at PHA UK, and specialises in helping members navigate different aspects of the benefits system. If you would like a particular subject covered in a future issue of Emphasis, please email [editor@phauk.org](mailto:editor@phauk.org)





# Could you support us by playing our PHA UK Lottery?

At PHA UK we rely on our supporters to continue our mission to improve the lives of people with PH. Playing the PHA UK Lottery is a fantastic way to support our work through a small regular donation.

Iain Armstrong, Chair of PHA UK, said: "It's free to join PHA UK so our Lottery is a great way for supporters to contribute a little money on a regular basis to support the charity's work. We need to raise money to fund better treatment plus support PH patients and their families and every little helps."

**For just £1 a week, you can play the fundraising PHA UK Lottery.**

So how does it work? Each week PHA UK Lottery players are allocated a six-digit number and the winning numbers are selected every Saturday. Cheques are then

posted to winners directly – there's no need to check your numbers or make a claim yourself.

- Match six digits to win **£25,000**
- Match five digits to win **£1,000**
- Match four digits to win **£25**
- Match three digits to win **£5**

You can increase your chances of winning by purchasing more than one entry.

### Signing up is simple!

Go to either [www.phauk.org](http://www.phauk.org) and search 'Lottery', or [www.unitylottery.co.uk](http://www.unitylottery.co.uk) and search 'Pulmonary Hypertension Association UK' or complete the form attached to the Leaflet enclosed with this magazine.

"It's nice to support the PHA UK with a regular donation, with the added bonus of maybe winning a prize."

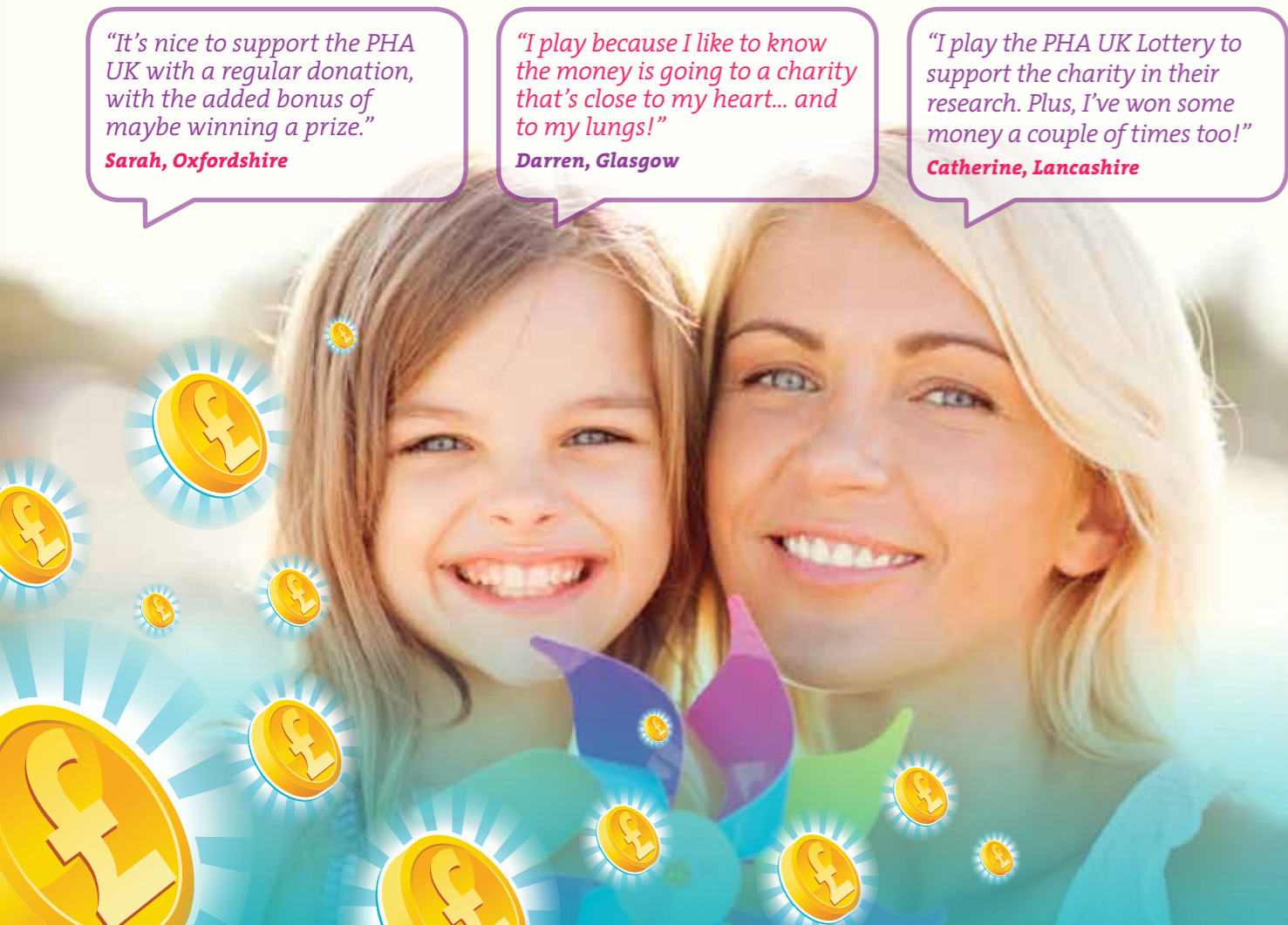
**Sarah, Oxfordshire**

"I play because I like to know the money is going to a charity that's close to my heart... and to my lungs!"

**Darren, Glasgow**

"I play the PHA UK Lottery to support the charity in their research. Plus, I've won some money a couple of times too!"

**Catherine, Lancashire**



# Growing through PH

Kevin McAllister from Newcastle was diagnosed with PH at the age of three. Now aged 43, he's started to notice his body's limitations but won't be defeated.

### How does PH affect your daily tasks?

Nowadays, I get out of breath putting socks on and climbing stairs. It's frustrating but I'm still independent and I will continue to push my body. When I was younger, I had ambition to become an artist and after almost 20 years, I started painting again. It helps me switch off from the world and my condition.

I always suffered with shortness of breath but since my late thirties and early forties, I have seen a massive change in my breathing and the ability to do daily tasks. Day-to-day activities such as shopping for food or browsing retail stores are nearly impossible unless I am just going out for a few items.

### How does PH affect your relationships with family and friends?

Over the last ten years in particular, my PH has had a huge impact on my social life. My friends meet on a regular basis in Newcastle city centre but I'm restricted as I cannot walk the distances anymore, so I often meet them at home.

My eldest child fusses over me a lot and encourages me to rest. She has a better understanding of my condition as she used me as case study during her media degree for

a project entitled 'blind to disability'. It focused on how people view disabilities and their reaction to people with PH who appear healthy on the outside.

My wife is the one affected most by my condition. She's a businesswoman, a mother and a carer for me – and I know it all takes its toll. If I get the flu or seem breathless for consecutive days, her brain goes into prevention mode and she restricts my normal daily activities.

Every day we spend together as a family, even if it's just for a few hours, is a day I feel blessed.

### How do you live life to the fullest?

I remain as active as possible and enjoy life with my family. Having lived with PH for most of my life I know my limits and can recognise any warning signs.

My advice to anyone reading this is to keep fighting. There are no re-runs and life is a one time only gig. We are all dying from the moment we take our first breath – it's what you do in-between that determines if you're celebrated long after your last breath.

Kevin uses painting as a way of coping with his PH. Pictured are some of his pieces of work.





# Are you struggling with stress or anxiety?

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

- Dedicated helpline service 0844 332 9010
- Email support via [phauk@anxiety.org.uk](mailto:phauk@anxiety.org.uk)
- Assessment and therapy provision for those who need emotional support
- Training and resources for PHA UK professionals and members

To find out more about how Anxiety UK can support the emotional aspect of having a diagnosis of PH contact us today on **0844 332 9010**, email us at [phauk@anxietyuk.org.uk](mailto:phauk@anxietyuk.org.uk), or visit [www.anxietyuk.org.uk](http://www.anxietyuk.org.uk)

# Life after Hammersmith

Dr Simon Gibbs, Lead Clinician and Honorary Consultant Cardiologist for the National Pulmonary Hypertension Service at Hammersmith Hospital, retired from clinical practice in August. He spoke to Mary Ferguson about his time at the specialist centre and what he'll miss most about working directly with patients.

Although Simon has stepped down from his clinical role, he is still a busy man. As founder of the National Audit of Pulmonary Hypertension he remains as audit lead, and is continuing his roles as a member of the UK Specialist Respiratory Clinical Reference Group, and as board member of the European Reference Network's project around rare diseases of the respiratory system (ERN-LUNG).

Simon is also still involved in international clinical trial committees and remains a close friend of the PHA UK, playing a key role as part of the PHocus2021 steering committee.

Simon joined Hammersmith in 1997 and on the day he arrived, there were just seven PH patients. Now, the specialist service manages over 1300 each year.

He said: "When I started at Hammersmith the national PH service didn't exist and we tried for four years to get it established. So, a real standout

moment for me was actually seeing the launch of a designated national PH service back in 2001. As a professionals group we worked so hard to get it up and running."

Simon said the biggest thing he's learned about PH patients over the years is just how determined they are to make the most of life.

"It's something I really admire. These people have inspired me, and plenty of others, to develop the PH service, do more research and find better treatments to improve the clinical service. The patients are just amazing. I will miss them, and the satisfaction of seeing them feel better under our care. That's what has driven me."

As well as keeping busy with his other projects, Simon will be using his semi-retirement to spend time with his wife, daughter and Miniature Schnauzer Flora. But he will always remember his years in clinical practice with fondness and pride.

He added: "Meeting so many extraordinary people has definitely been a highlight of my time at Hammersmith, as well as appointing and working with such a fantastic team. It's been great fun, and hopefully we've done some good."

Dr Gibbs trained at Christ's College, Cambridge and St Thomas's Hospital Medical School. He completed London training in cardiology at the National Heart Hospital, Royal Brompton Hospital, Westminster Hospital and St George's Hospital. ●



## Patients helped by Dr Gibbs shared their thanks on Facebook

"Simon treated me for seven years and was amazing. He and his team kept me alive long enough to get my transplant and did everything in their power to give me a great life to live. I cannot thank him enough for all he ever did for me."

**Stacie Pridden**

"Thank you so much for all the help and support you've given me, I will truly miss you and your incredible knowledge."

**Suzy Spencer-Boyce**

"Dr Gibbs is the type of doctor who fills you with hope and positivity about your condition whilst ensuring you know all the facts. Whilst I'm saddened that his vast knowledge, experience and expertise will no longer be available to us PH patients, I wish him a long and enjoyable retirement."

**Hayley Maggs**

"Dr Gibbs is an amazing consultant, he will be sadly missed by his team and all the patients he has treated. Dr Gibbs diagnosed me with PH back in 2000 - thank you for all you have done."

**Christine Banks**



## ME & MY JOB



Welcome to our regular column where PH professionals tell us more about themselves and their work.

**NAME:** Val Irvine.

**PLACE OF WORK:** Golden Jubilee National Hospital, Glasgow.

**JOB TITLE:** Senior Research Nurse with the Scottish Pulmonary Vascular Unit (SPVU).

**HOW LONG HAVE YOU WORKED WITH PH PATIENTS?** For 20 years now. I started as a staff nurse on the respiratory ward, and in 2004 became a research nurse for the SPVU research portfolio. With the help of patients, we've run studies contributing to the licensing of nearly all of the modern PH specific medicines. A large part of my role now concerns the big genetics research studies in collaboration with Cambridge University and all of the PH centres in the UK. It has been a complicated project; challenging, but with seriously awe-inspiring aims, which I am proud to be associated with.

**WHAT DOES YOUR JOB INVOLVE?** Busy times would generally be associated with taking patients through research activities, and as this is a lot more exciting than the desk-based parts of my job, I look forward to it. But there is a lot of data handling, one way or another, which isn't as dull as you would think since it concerns people I have met - who all have an interesting clinical story.

**WHAT IS THE BEST THING ABOUT YOUR JOB?** Undoubtedly, the patients. One particular joy is to know patients who were at the very start of their PH journey when I first met them in the early years. I get to spend a lot of time with individuals taking part in certain studies, which is a distinct bonus of the job.

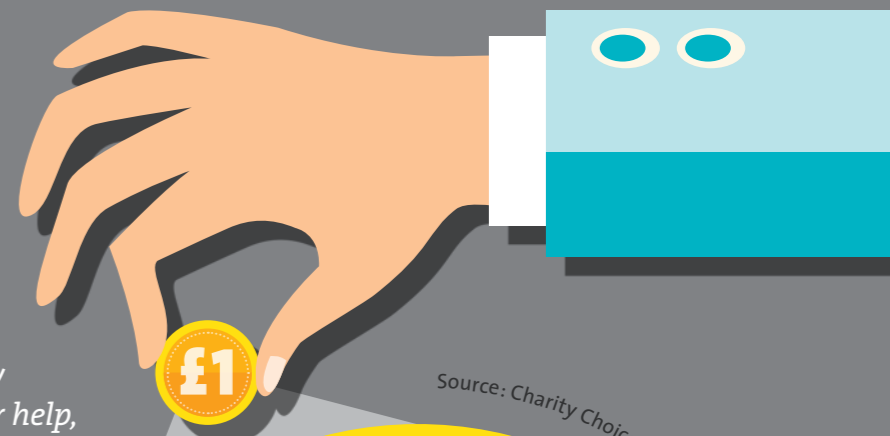
**WHAT'S ON YOUR DESK?** Lots! Laptop, project files, filing pending, in-tray, and of course my paper diary and some scrap paper and notebooks. There's also my tea cup, water bottle, and currently a copy of the PHA UK Financial Support booklet. The overall look is not minimalistic.

**WHAT DO YOU LIKE TO SNACK ON AT WORK?** I bring a pear or an apple to quell hunger pangs between meals, but when I'm with patients I'm a lot less distracted by hunger and thirst.

**WHAT DO YOU LIKE TO DO WHEN YOU'RE NOT AT WORK?** I enjoy cooking and baking, reading, and exercise classes. I have ambitions to foster more worthy projects, such as further education, and to put my new(ish) sewing machine to good use - instead of letting it gather dust in the corner!

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

## How we spend your money...



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

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

### For fundraising support...

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



### In your Spring issue of Emphasis...

The next issue of Emphasis is due out in March 2018 and we have planned features about:

**Physical activity and PH** – How exercise can help.

**Your charity** – A closer look at PHA UK.

**Mental health** – Taking care of emotional wellbeing

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 3,500-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 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 3,500 members in a unique network of support and inspiration.

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

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



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

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

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

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

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

Are you a Patient  Carer  Parent  Medical professional

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



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



**PHA UK Contact Details**

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**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 & advice



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