

SPRING 2016

emphasis

The magazine for supporters of PHA UK www.phassociation.uk.com

Work and pulmonary hypertension

A focus on working with this serious long-term health condition

Going from strength to strength

Glasgow PH exercise study underway

SWIMMING ALONG

The benefits of swimming for people with PH

Make Your Voice Heard

Take part in the PH patients survey

Business is blooming

Hollie Sassienie tells her PH business success story

Family Matters

Teenager Chris Straw remembers his sister Amy

Perseverance pays off

One woman's fight for Personal Independence Payments

Superheroes to the Rescue!

SUPERHERO ADVENTURE INSIDE THE HUMAN BODY!
MEDIKIDZ
EXPLAIN
PULMONARY/ARTERIAL HYPERTENSION

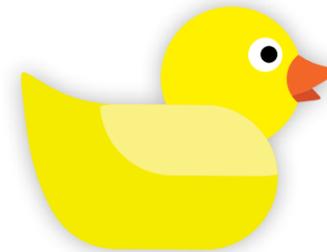


Limited edition
superhero comic books
which aim to explain
pulmonary hypertension
to kids are available
from the PHA UK
office.

Email office@phassociation.uk.com
to ask for your free copy while stocks last!

Actelion Pharmaceuticals UK Ltd sponsored the production of this educational resource, with no influence on the content, and have also sponsored this event.

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phaUK
pulmonary hypertension association



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This magazine is printed on paper
from sustainably managed sources

Join us online...

Don't forget the PHA UK website is always available for advice, resources, donation and fundraising support, plus links to the PHA Professionals website and much, much more!

www.phassociation.uk.com



Like us at www.facebook.com/PULHAUK
Follow us on Twitter @[PHA_UK](https://twitter.com/PHA_UK)
Call us on 01709 761450
Email us at office@phassociation.uk.com



Welcome

Welcome to the spring edition of Emphasis magazine. This issue focuses on a range of issues very important to people with PH, their families and loved ones.

We have a feature about working with PH and how the Equality Act 2010 protects the rights of employees with long-term health conditions like pulmonary hypertension. Another expert article from our partners at Turn2us looks at the benefits which may be available to carers. And, one of our readers, Myra Morrison, shares her experience of applying for personal independence payments (PIP).

Our Family Matters column is written by 17-year-old Chris Straw who looks back on his younger sister's fight against PH. And there is plenty of PH news, interviews and expert advice from across the UK.

We'd actually like to take this opportunity to thank all our members and supporters who, like Myra and Chris, are coming forward to contribute their stories and viewpoints to the magazine. PHA UK is committed to helping the whole PH community benefit from the mutual support we can gain through shared knowledge, insights and

experiences. We appreciate the input of all PH professionals, patients, family members and others who take the time to get involved in Emphasis.

You'll also notice we're printed on a new type of paper this time – don't worry it's the same price and has the same environmental credentials. We've just chosen this option to deliver a brighter magazine, which I hope you'll enjoy.

Iain Armstrong
Chair of PHA UK
editor@phassociation.uk.com



Don't forget to take part in our new national PH patients' survey, enclosed with this magazine – turn to page 17 for more details.



Emphasis *exchange*

If you have any news and views to share via the Emphasis exchange please e-mail editor@phassociation.uk.com and don't forget to keep in touch via Facebook and Twitter too.

BIG STRIDES FOR RESEARCH

A very big walk has attracted a huge amount of support raising £86,000 through more than 2,400 individual donations.

The Big Walk for lung disease research involved 21 people walking 286 miles along the Pennine Way from Kirk Yetholm in Scotland to Edale in Derbyshire; before being joined by over 100 other members of staff, students, Alumni and friends from the University of Sheffield for the final stretch of the walk into the city.

All the money has been donated to Pulmonary Vascular Research Group led by Dr Allan Lawrie, PhD, and will be invested in work to help those who suffer from pulmonary hypertension.

Dr Lawrie said: "We had a fantastic response and I would like to thank my fellow walkers, the organisers, the University of Sheffield and most of all the sponsors for their efforts and enthusiasm in supporting this initiative."



PHA UK has moved

PHA UK has moved but, don't worry, our e-mail address and phone number remain the same.

The charity's small core team, based in South Yorkshire, has moved from an office at Manvers in Rotherham to one in Chapeltown, near Sheffield.

*The full new address is
PHA UK Resource Centre,
1, Newton Business Centre,
Newton Chambers Road,
Thornccliffe Park, Chapeltown,
Sheffield, S35 2PH.*

We have arranged for post to be re-directed to us for six months though, so don't worry if you've just posted something to our old address.

Our phone number remains 01709 761450 and our email office@phassociation.uk.com

Shaun Clayton, director of membership support at PHA UK, said: "Our new workspace provides us with a better set up, not far from junction 35 of the M1 where we hope to be more than just an office but also a meeting place, training centre and resource in support of all PHA UK members and the PH specialist service in the UK."

LONDON CALLING

There is a support group in London for anyone who has been affected by PH, whether they are a patient, parent, partner or transplant recipient.

All are very welcome to come along on the first Wednesday of each month from 10am until 1pm.

Call Jocelyn Barker for more details on 020 77387085 or email jocelynab@gmail.com

Social Media Round-up

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



@PHA_UK Discussing how vital early diagnosis is. #agmconfuk #changingbeliefs #phauk



Chris Randall It's still amazing the Gp's don't know a thing about Ph!



@QPAFC Please support #Shaggy www.doitforcharity.com/LukePhillips @PHA_UK #LondonToParis @HampshireFA @DorsetCFA @DorsetFootball



wendy gin-sing *@wginging Pump and Chi here to promote the new Medikidz explain pulmonary arterial hypertension book @PHA_UK



@MediaplanetUK The UK's approach to #PAH is the envy of the world #LungAwareness #respiratoryhealth



Would your child like to be the next one to complete our Green Leaf Crew Q&A in Emphasis magazine?! If interested, drop our editorial team a line on steph@capitalbmedia.co.uk





Wake up call

Everybody knows the importance of a good night's sleep, but research now shows that it's also the point at which you wake up that can determine how tired you feel, rather than just the amount of sleep you get.

And a new app has been developed to help ensure you are woken at the perfect moment.

The Sleep Cycle app is an intelligent alarm clock that wakes you in your lightest phase of sleep within a time period set by you. It does this by analysing the sound and movements that you make whilst asleep.

The app allows you to set a certain period during which you'd like to be woken up, for example, between 7:30am to 8am, and will wake you up at your 'optimum waking period' during that time.

If you don't hit an optimum period, it will wake you up like a normal alarm clock at 8.

For the app to work, you need at least 50 per cent charge on your phone or your phone to be plugged in overnight, and then placed carefully next to your pillow or on your bedside table. The closer the phone is to your body the better.

The app also monitors your sleep over a period of time and puts it into graphs and tables such as sleep quality, time in bed and time you went to bed.



The app is downloadable for free on both iPhones and Android phones (a premium version is available at £1.49 with more features) Maybe you'd like to try it, and see if it can help you wake up feeling more refreshed!



FANCY A TOUGH CHALLENGE?

Are you tough enough to tackle a fundraising team challenge with a difference?

PHA UK has 21 free places available to take part in the Tough Mudder series of events across the country.

Tough Mudder courses challenge groups of friends and colleagues to get over an amazing array of demanding and muddy obstacles on 10 to 12 mile routes.

They build team spirit and muscles as well as cash for charities like PHA UK!

David Wright, PHA UK co-ordinator, said: "Tough Mudders are great opportunities for teams to pull together and do something very rewarding. Marathons demand great personal effort by an individual runner ofcourse, but the Mudders are very much more a team effort.

"Tough Mudder entrants really have to work together to help everyone over these obstacle courses. They're good to watch too!"

To apply for a place to enter one of the Tough Mudders, which are organised across the UK, contact David on applications@phassociation.uk.com or phone the PHA UK office on 01709 761450.

Perriwinkle Pioneers

Two PHA UK founders have been honoured as international pioneers in the fight to raise awareness of PH and help advance improvements in treatment, care and ultimately a cure for patients.

The USA's Pulmonary Hypertension Association has named 25 people and groups across the world as 'Perriwinkle Pioneers' to celebrate its 25th anniversary.

PHA UK trustee Kay Yeowart and Chair Iain Armstrong are amongst those identified as playing a 'unique and distinctive role in changing the history of PH.' They were nominated by the public and selected by a panel of judges.

The American PHA was the first in the world to be set up in 1991 and there are now 70 national PH associations today – PHA UK having been founded in 2000.

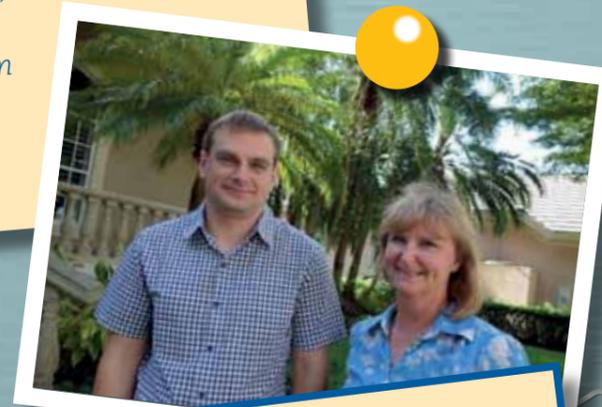
Kay said: "The PHA in America was a world-leader in advancing the cause of PH and a great inspiration and friend to us when setting up our own association in the UK.

"We have kept close links with them over the years and it is a great honour to be recognised in this way as part of their 25th anniversary campaign."

The periwinkle is the emblem of the PHA in the States.



Founder and Chair of PHA UK Dr Iain Armstrong in yet another pioneering moment, graduating as a Doctor of Medical Science in Professional Healthcare Practice at the University of Sheffield this year. He is the first NHS nurse specialist to have studied PH to this level and his thesis investigated the significance of hope in pulmonary hypertension. Congratulations Iain!



Kay Yeowart, a PHA UK founder and first volunteer secretary, whose kitchen table was the nerve centre of the charity's administration when it was established in 2000. Kay's son Lewis has PH and Kay travelled to the USA to seek treatment for his condition in the late nineties – she maintains strong two-way links with the PHA in America. She was awarded the MBE for her services to PH in 2014



Thank you letter

I'd just like to say a big thank you to everyone involved in the eleventh Chesterwood Showjumping and Pony Sports day, held in Northumberland in September 2015 which was the most successful to date, raising an amazing record sum of £2,164 for PHA UK.

We had lots of entries in each of the showjumping, handy pony and games classes and a prize, donated by Jackie and Josie Brown was again awarded to the most deserving rider – judged on whether they'd not cried if they'd fallen off or they'd improved their riding over the course of the day. The lucky recipient this year was Finn Marsden. Thank you very much to all the sponsors and helpers without whom the show couldn't go ahead. A special mention must go to Jools Howard from High Plains who generously donated some Woodland Ride vouchers and to Kate Marsden for kindly taking photographs. A massive thank you must also go to my sister Suzie Pigg for organising the show and her husband Graeme and Brenda and her team for the gorgeous food.

Many thanks again to you all.

Sheena Robinson, PHA UK member

BEWARE OF SALT

Did you know that 75 per cent of the salt we eat is hidden in the food we buy – some in places you'd least expect to find it?

National Salt Awareness Week, held last month, focused on raising awareness of the hidden salts in our food and issued a 'Low Salt Shopping Guide' to help us eat less.

The guide highlights foods that are usually high on salt and should only be eaten in moderation, such as pot noodles, pastry and cheese; ready-made

cook-in sauces, curry paste, ketchup, chocolate and sweets! It also lists healthier foods that don't contain much salt, for instance unsalted popcorn, dried fruits and porridge oats.

The recommended UK maximum daily salt intake is 6g for a healthy lifestyle and National Salt Awareness Week is backed by a host of health charities including the British Heart Foundation. The campaign also calls on food companies to provide us with more low salt options.

For more information and to download a A4 print version of the Low Salt Shopping Guide visit www.actiononsalt.org.uk



PH referrals up by more than 20%

The number of new referrals for patients with pulmonary hypertension has increased by over a fifth during the last five years, according to the latest National Audit report.

The Health and Social Care Information Centre (HSCIC) recently published its survey findings that show the number of new referrals for PH has risen from 1,789 in 2010 to 2,169 in 2015 - representing an increase of 21 per cent.

In addition to the increase in the number of new referrals, the data shows a 56 per cent increase in the number of patients being treated at the UK's eight specialist PH centres. It shows 6,671 were treated in 2015 compared to 4,287 in 2010, when the first audit took place.

In the last edition of Emphasis, we featured the nationwide audit which involves all PH centres and gathers statistical evidence which describes clinical practice; provides information for future service planning; and measures clinical outcomes.

The audit was founded by Dr Simon Gibbs, lead clinician and honorary consultant cardiologist for the National Pulmonary Hypertension Service at Hammersmith Hospital in London.

He said: "Today's report shows that despite pulmonary hypertension being a rare disease, the number of new referrals for treatment is steadily rising. The report also shows that specialist pulmonary hypertension centres are also having to deal with an increasing number of patients who need specialist treatments, reflecting

an ever increasing awareness of pulmonary hypertension.

"I hope that the information contained within this report will be useful to all eight specialist hypertension centres and commissioners to help plan services that meet the needs of patients over the next 12 months. It should also help patients themselves, providing them

“...despite pulmonary hypertension being a rare disease, the number of new referrals for treatment is steadily rising.”

with useful information about the clinical services available."

PHA UK played a vital role in setting up the National Pulmonary Hypertension Audit by funding its first year in 2010. The audit is now funded via NHS Specialised Commissioning in England, and managed by The Health and Social Care Information Centre (HSCIC) in Leeds. The full report of the 2015 audit can be viewed at www.hscic.gov.uk/ph



Simon Gibbs

Other findings from the National Audit of Pulmonary Hypertension 2015:

- The average age of patients treated with PH drug therapies in Great Britain was 59 years in 2015, the same as 2014.
- The number of people referred to a specialist centre for PH treatment in Great Britain represents just 82 in every million of the population – highlighting how rare the disease is.
- 43 per cent of patients seen at our specialist centres had their first consultation, or were discharged, within 30 days, and 89 per cent were managed in 90 days.





Glasgow exercise training programme inspired by pioneers in Germany

The Scottish Pulmonary Vascular Unit in Glasgow has just embarked on exercise programme for PH patients. The first of its kind in the UK, it has been inspired by a pioneering programme in Heidelberg, Germany. Here, research fellow *Dr Alison MacKenzie*, with PH specialist nurse *Joanna Ford* and PH consultant *Dr Martin Ford*, explains what it's all about.

Until recently it was common practice to recommend people with pulmonary hypertension avoid exercise. This was because of concerns of increasing the strain on the heart and worsening the condition. However, exercise has been found to be of benefit in many conditions affecting the heart and lungs and pulmonary hypertension is no exception.

Thanks to pioneering work performed over the last ten years in Heidelberg, Germany, it is now well established that exercise in pulmonary hypertension is both safe and beneficial when conducted under specialist supervision. A dedicated pulmonary hypertension exercise programme is now well established there and nearly 1,000 people from Germany and neighbouring countries have taken part.

The training programme that they run is highly original. It involves an initial three-week residential phase in a rehabilitation hospital with daily exercise training either one-to-one or in small groups supervised by physiotherapists. The activities include walking, cycling on a stationary bicycle, strength training, relaxation and there is lots of attention paid to breathing control.

The exercise is individually tailored to each person using heart rate and oxygen saturation monitoring. Often the exercises are performed with supplementary oxygen and high intensity / low intensity interval-training methods are used. Both are aimed at maximising the training effect whilst minimising the strain on the heart. Following this, there is a twelve-week home exercise programme. Therapists supervise this by telephone because of the distances involved. They are issued with equipment for home, including light weights, a stationary exercise bicycle and a pulse oximeter.

The results of the Heidelberg training programme are impressive. Improvements in exercise capacity judged by six-minute walk tests far exceed those seen in trials based on medication alone.

A team of us from Golden Jubilee Hospital visited Heidelberg in 2015. Having been impressed by the programme, we had several questions:

- **Could we reproduce this exercise programme in Scotland? Currently, no dedicated, established pulmonary hypertension exercise programmes exist in the UK.**
- **Why is this programme so effective? Is it because of its effect on the muscles, the heart, breathing control or something else?**
- **What are the parts of the Heidelberg programme which are most important and can we concentrate on these to make a Scottish programme even more effective?**

At the Scottish Pulmonary Vascular Unit in Glasgow, we have a long-standing interest in exercise and pulmonary hypertension. We therefore decided to set up our own training programme for people with PH based on the Heidelberg model to try to answer some of these questions. Before embarking on this project, we wanted to establish:

1. Whether the people who attend our unit would be willing to take part?
2. Are they willing to invest the time commitment?
3. Would they be prepared to have equipment in their houses?
4. What unforeseen barriers are there to taking part?

.....
It is now well established that exercise in pulmonary hypertension is both safe and beneficial when conducted under specialist supervision.
.....

On this basis, we performed a survey of people with pulmonary hypertension who attend the Scottish Pulmonary Vascular Unit. We described an exercise programme similar to that in Heidelberg, which involved both an in-patient and outpatient phase. We contacted 224 people of whom 43 per cent responded. 63 per cent were interested in all components of the training programme (inpatient and outpatient) with a further 10 per cent interested in outpatient training alone.

Most people were very enthusiastic about the programme and felt it would give them the confidence to undertake exercise and improve their quality of life. The most common reasons for not wishing to participate were:

1. The centre is too far from home, 19.4 per cent (7 of 36);
2. Work or carer commitment, 27.8 per cent (10 of 36);
3. Too old or too many other illnesses, 27.8 per cent (10 of 36);
4. Too big a time commitment, 5.6 per cent (2 of 36);
5. Active enough already, 8.3 per cent (3 of 36)
6. Equipment in their house would be unacceptable, 2.8 per cent (1 of 36)

Based on this positive response, and after taking on board the comments of those who did not initially feel exercise training was compatible with their lifestyle, we have started our study to assess the effects of exercise training in people with pulmonary hypertension. We have a dedicated team of doctors, nurses and a specialist physiotherapist working on the study and we have received training from the pulmonary hypertension rehabilitation team in Heidelberg.

The study will run for two years and we are very excited to have enrolled our first participants and started the training programme last month.

If you would like any further information on our study, please contact: **Dr Alison MacKenzie** or **Dr Martin Johnson** at the **Scottish Pulmonary Vascular Unit, Golden Jubilee National Hospital, Glasgow, 0141 951 5497, SPVUnit@gjnh.scot.nhs.uk**



Finding financial support as a carer

Are you caring for someone with pulmonary hypertension and struggling to make ends meet?

Every year, more than two million people become carers. Yet many of these people do not identify themselves as carers and are unaware of the financial support that could be available.

PHA UK has recently joined forces with Turn2us, a national charity that helps people in financial hardship in the UK. Turn2us provides a number of free services to help people access financial support and these are now available to access via the PHA UK website.

Here the charity tells us more about these services, and how they can help anyone who is caring for someone with PH and unsure of what financial help could be available to them.

Welfare entitlements

Being a carer for someone with a serious disability or illness can place a huge strain on household income and lead to financial difficulties. Help could be available in the form of welfare benefits.

For example, Carer's Allowance is money for people who spend at least 35 hours a week providing regular care for someone with a disability. To qualify, the person you care for must

be claiming a relevant benefit because of their disability, which in some cases has to be paid at a certain rate, and you must not be earning more than £110 per week or in full-time education.

Other benefits you could be entitled to depend on your household income and situation. Even if you have checked your entitlements to benefits before, it is worth checking again, especially if you have recently experienced a change in your circumstances.

The PHA UK website now includes the free and easy-to-use Turn2us Benefits Calculator to check what welfare benefits, tax credits and other support you could be entitled to. It also tells you the amounts you should receive and how to make a claim.

Anne is just one of the carers Turn2us has helped to access welfare support. Caring for both her daughter who had mental health problems, and then her husband who suffered an accident

leaving him unable to work, Anne gave up her full time job, and soon started to find things very difficult financially. The family's bills were mounting and they were struggling to pay for everyday essentials like heating and food.

Through the Turn2us Benefits Calculator, Anne identified that the family were able to claim Personal Independence Payment and Carer's Allowance, which has almost doubled their income.

Anne says: *"We don't have to live hand to mouth anymore. Being able to buy a weekly food shop is such a big relief, and it's given us some independence which is brilliant."*

Charity grants

Carers who are struggling financially may also be eligible for help from a grant-giving charity.

Every year, more than two million people become carers. Yet many of these people do not identify themselves as carers and are unaware of the financial support that could be available.

Turn2us also has a free Grants Search, available on the PHA UK website, which features over 3,000 charitable funds that give grants to individuals with a number of different needs and circumstances. The Grants Search also includes details of each fund's eligibility criteria and how to apply.

The funds award grants and other forms of support to those who meet their eligibility criteria. In most cases they have been set up to assist people in financial hardship that have something in common, for example those who have worked in a certain industry, have a specific illness or live in a particular area of the UK. Many funds also help the partners or children of the people their grants support.

One of the people who received help from the Turn2us Grants Search is Sheila – a carer for her granddaughter who has disabilities. To help Sheila cope with her caring responsibilities she cut down her hours at work.

Unfortunately this left her with very little money each month after household bills were paid and she became increasingly reliant on credit cards. When her granddaughter's bed then broke, she didn't know how she'd be able to afford to replace it.

On finding Turn2us, Sheila discovered a charity linked to her profession as a nurse and managed to make a successful application for a grant. She was awarded £500 for essential household costs and a new bed for her granddaughter and says this has helped her to feel much more positive about her situation.

Further information

Through its website, Turn2us provides a range of information and resources on welfare benefits, charitable grants and other support services. This includes a section on help for carers and more information about the different support they might be able to claim. For more information, please visit www.turn2us.org.uk

The Turn2us Benefits Calculator and Grants Search are available to use at www.phassociation.uk.com.





Join the PHA UK Lottery today!

A winner every week.

Raise vital funds to improve the lives of people with PH and fund research. Play for as little as £1 a week.

"It was a lovely surprise to receive my winning cheque through the post – it was only for a tenner this time but it's all for a good cause!"

**Catherine Makin,
Lancashire**



It's easy to sign up! Visit PHA UK Lottery's page at www.unitylottery.co.uk to register and play. Or call the PHA UK office on 01709 761450 for an entry form.

TOP TIP: If you get a winning cheque through the post, take the whole letter with you to the bank. Please note, you must be 16 or over to enter.



Living with PH | 2016 Survey

MAKE YOUR VOICE HEARD

The PHA UK national patients' survey is underway. Have you taken part yet? This is your chance to help strengthen the voice of PH patients and make sure we are heard loud and clear in future debates about NHS policy and spending reviews.

Hundreds of patients with PH are now being invited to complete a new survey about their experience of living with pulmonary hypertension.

All completed questionnaires received before 25th April 2016 will be entered into a prize draw for a chance to win one of ten £25 gift vouchers!

It is open to every adult diagnosed with PH – you don't have to be a member of PHA UK to take part.

Chair of PHA UK Iain Armstrong says: "Our survey asks about your experience of diagnosis, PH treatment and care and also the wider impact of the condition on things like your family life, finances and mental health. It aims to gather important statistical evidence about issues such as the impact of drugs and the value of services.

"It's a vital piece of research into what it means to have PH in the UK today. We want to secure robust information about matters such as PH patients' quality of life, control of their

symptoms, the effectiveness of drugs; experience of NHS services and other important aspects of living with PH."

Iain says that the survey's findings will not only help PHA UK identify its own future priorities as a support organisation; but also really help the charity to represent the interests of people with PH in future debates about NHS policy and spending reviews.

"There has probably never been a more important time to make sure we are in a strong position to do this," says Iain. "It is going to become increasingly important to make our voice heard in coming years as the hard-pressed NHS reviews its spending on drugs and investment in services.

"For example, we know right now that a potential new drug called Selexipag, which could have enormous benefit for patients with PH, is under review and an initial poorly executed draft policy, which recommends against it being commissioned by the NHS for patients, has been drawn up with very little consultation. We want to fight this and the more people we can prove that we represent and the more evidence about our disease area we can present, the stronger and better armed we will be to do this.

"Similarly, we are aware NHS England is planning a review of specialised services in the near future. We are keeping an eye on that too, and want to have as much evidence as possible to protect and enhance our world-renowned network of PH centres.

"We will keep you posted on all such matters in future issues of Emphasis magazine – in the meantime please do complete the PH Patients Survey and add your voice to help ensure we are loud and strong enough as a patient body not to be ignored."

This survey is focused on PH patients using adult PH services. A separate survey dedicated to children and young people with PH will be organised in future.

If you would like to take part, please complete and return the questionnaire you have received with your Emphasis magazine, or complete the survey online at www.survey.phassociation.com

Call the PHA UK office on 01709 761450 with any queries. Your survey responses can be anonymous if you choose.

GROWING UP WITH AMY

Chris Straw, aged 17, lives with his mum, Jenny, dad, Ian, and brother, Andy, in Sway Hampshire. His little sister Amy was born with PH in September 2004 and passed away in June 2006. Here, Chris talks about growing up with Amy and his recent fundraising efforts in her memory.

“As an older brother of a sibling who suffered from PH obviously life was very different for me and my family during the period that Amy was alive. Though it was a slight struggle we all had our routines and we all managed to make it work.

The standard day would involve going to school in the morning with my brother, who was three years older than me, whilst mum stayed at home and looked after Amy, as after all she was only a baby, and Dad went off to work. We would all be home by around 4pm and would sit and lay with Amy in the living room whilst Mum prepared her medication and got her pump ready. Amy was always very good and at least 95 per cent of the time would stay perfectly still whilst Mum made sure everything about her pump was okay. I can only think of a few occasions when she was disturbed during the process which thinking about it, considering she was a one-year-old girl, this did always fill me with pride. Amy was always such a brave girl and always seemed to have a smile on her face whatever the situation was.

Due to me only being aged seven or eight at the time of Amy being alive, although I understood the situation and the possible consequences that could occur as a result of her condition I never really had a true understanding of her condition until I started secondary school and decided to research the condition and look with more detail into other families who have, or have had, similar situations to us. It was at this point that I realised I owe my mother a lot more credit than she gets. This, I imagine, is a statement a lot of teenagers would agree with, but for me even more so because of the fact that she, day in day out, worked her socks off for Amy and even today is just as committed to the rest of us.

One thing that I believe our whole family have taken from the situation is that it all happened for a reason. As a strong Christian family we've always felt that Amy was a gift to us as a family. Her constant happiness was not only contagious but also inspirational. It is impossible to imagine, especially towards the later stages of her being with us - with her being brought in and out of hospital at regular intervals - how much suffering she must have been going through, however, she always managed to smile and laugh and bring joy to our family and everyone else who happened to meet her. I remember whenever Mum came to pick us up from school she would bring Amy and she would always be surrounded by groups of children from the school who just loved her, and, even though you would imagine if a one-year-old was surrounded by loads of people bigger than her she would have been intimidated, she wasn't at all. She loved the attention she was getting - thinking about it she was a little bit of a drama queen. I am currently studying at Brockenhurst College doing maths, chemistry, history and psychology. Ever since Amy passed I've had the ambition to go into either pharmaceuticals or become a paramedic with the aim of helping people with diseases like PH in the same way that Amy received a lot of help from people like that.

The story behind my fundraising for PHA UK was a funny one. At my secondary school we had a charity week every year during which we would always raise money for a certain charity, however, due to us being in year 11 and about to sit our GCSEs our charity week got cancelled. This was to my thorough disappointment as PHA UK had been chosen as the charity for the week that year. So at first this wound me up a little bit. Then I was sitting having a conversation about it with one

of my friends when he suggested why don't we do something anyway, which was a very kind and supportive of him but he was probably assuming I would turn around and say "yeah good idea lets go run a marathon or something". I will probably never forget the expression of shock on his face when I asked if he would like to do the honours of shaving all my hair off in front of our year group. The support for my head shave was absolutely huge and enormously humbling. Within the first two days I had smashed my original target of £100 and by the end I had raised an astonishing amount of money - over £1,200 - which was remarkable considering at least 90 per cent of the donations were from ordinary students at a secondary school with me. It gave me a great feeling of happiness knowing that I had friends willing to give that much to a cause personal to me and my family and I will be forever thankful to them. I would genuinely recommend shaving your hair off to a friend as it makes washing, drying and generally styling hair a whole lot easier, however, if you aren't keen on the Phil Mitchell look for a few months then I would not recommend it. Before I sign off I would like to thank the PHA office for sending me a very large amount of merchandise to sell at my school as that was where the main source of funds has come from. I would also like to thank Great Ormond Street Hospital for the great work they did in looking after Amy whenever she

needed them, and lastly I hope that my story encourages other family members of PH sufferers to be able to speak out about their situation and maybe also help get involved with the PH fundraising appeal. ● ”

If you would like to share your family's PH story, please email editor@phassociation.uk.com



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
- 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** or visit **www.anxietyuk.org.uk**

Could you encourage donors?



For many, the possibility of a heart and / or lung transplant can mean the promise of a better life. And nearly 7,000 people in the UK are currently in need of a transplant. But many more people could sign up to the register and don't. What can we do to encourage more people to sign up to NHS Organ Donor Register?

1 TELL PEOPLE HOW EASY IT IS TO SIGN UP

Anyone can register to be an organ donor in several very quick ways:

- Fill in a form at www.organdonation.nhs.uk – which takes two minutes
- Call the NHS Organ Donor Register on 0300 123 23 23
- Text SAVE to 62323
- Or ask for a form to fill in at your GP surgery.

People also have the opportunity to opt to be a donor when they register for a driving licence; apply for a Boots Advantage card or register for a European Health Insurance card (EHIC).

2 ENCOURAGE PEOPLE TO CHECK IF THEY ARE ALREADY ON THE REGISTER

A lot of people signed up to be a donor sometime in the past, but have lost their dog-eared donor card and are not sure if they're on the electronic register now or not. It's very easy to check. You can call the Organ Donor Register on 0300 123 23 23 and ask. A very friendly person will ask your name and age and do a quick check. You don't NEED a donor card these days – being on the electronic register is enough – but if you want one in your purse or wallet, one can be posted to you.

3 REMIND PEOPLE TO TELL THEIR NEXT OF KIN

It is really important that when a person registers to be a donor, they talk to their loved ones about their decision. Although it's not something any of us like to think about, their family need to know that they wish to donate their organs after death. Even though they've registered for donation, their next of kin will still be asked to support that decision. Letting them know what they've decided in advance can make that decision easier.

4 REASSURE ANYONE WITH CONCERNS

Some people wonder if they are too old or ill to be an organ donor, but there is no upper age limit for donating organs and very few medical conditions disqualify you from donating. Some also worry that if they agree to donate their organs, doctors won't work as hard to save their lives. This is categorically not the case. Doctors focus on saving the life in front of them — not somebody else's. Another concern raised is about how the organs may be removed and how this will affect the body.

But the NHS process is handled with the utmost dignity. Specialist healthcare professionals remove organs and/or tissue with great care and respect in an operating room and carefully close and cover the surgical incision after donation. The arrangements for viewing the body after donation are the same as after death.

5 SPREAD THE WORD

Talk about organ donation and encourage people to go online or phone or pick up a form from their GP. Follow @NHSOrganDonor on Twitter and like the NHS Organ Donation page on Facebook. Share the stories and the news via your social media and boost the campaign to change and save lives.



This Working Life

*Employers and employees must work together to manage the implications of having a serious long-term illness like pulmonary hypertension. Here **Steph Pollard** takes a closer look at the world of work and PH.*



The Equality Act 2010 legally protects people with disabilities or long term health conditions from discrimination at work.

It replaces previous bits of legislation including the Disability Discrimination Act and requires employers to treat people with a chronic medical condition fairly.

Under the act, employers must, by law, make 'reasonable adjustments' to ensure its disabled employees can engage in their work successfully – alongside other workers.

These 'reasonable adjustments' may mean things like changes to an employee's work station, facilities and equipment; revised roles and responsibilities; and the introduction of flexible or part-time working hours to allow time for rest and hospital appointments and so on.

Terms of employment in general, including pay and benefits should not be affected by a person's disability or long-term illness. The law protects against discrimination of a worker's prospects for promotion, transfer and training opportunities too.

Finally, a person with a chronic condition like PH has the same rights as other workers in relation to recruitment and retention – plus the same protection against unfair dismissal or redundancy.

In this feature, three people with PH share their experiences of going back to work after a diagnosis of PH. Their employers have shown due respect to the principles of the Equality Act and there is excellent communication between bosses and employees.

We know this is not always the case. And because pulmonary hypertension is a rare, not widely known disease with invisible symptoms that people 'can't see' – it can lead to extra difficulties. In particular, the lengthy period it can

take to diagnose the condition can put a great deal of strain on the process as employees may be very ill but they - and their employers - do not know what they are dealing with for a long time.

sickness or disability. ESA replaces previous benefits including Incapacity Benefit. A person can apply for this when their entitlement to statutory sick pay has run out. In some cases,

A person with a chronic condition like PH has the same rights as other workers in relation to recruitment and retention

Nevertheless, under the act, employers have a duty to follow fair and legal processes and act accordingly.

PHA UK has recently supported one woman with PH who has had a long, hard fight to challenge her dismissal from a large public sector employer. She was reinstated eventually as she proved she had been wrongly dismissed, under the Equality Act. The law had not been adhered to; due care had not been taken and key information had been missed leading to a decision made outside the law. The young woman, who had been very ill leading up to her diagnosis with PH, won her job back and her self-respect, but it was a difficult and challenging time for her on top of coming to terms with her condition.

If you need any help with work related matters you can:

- Call PHA UK's director of membership support Shaun Clayton on 01709 761450.
- Talk directly to your PH team.
- Visit www.citizensadvice.org.uk
- Visit the www.disabilityrightsuk.org
- Visit www.turn2us.org.uk

DID YOU KNOW?

Employment and Support Allowance may be available for people who have 'limited capability for work' due to

people may also claim ESA while doing a small amount of 'permitted work' which they can manage; for example less than 16 hours a week earning up to £107.50. To find out more about ESA and other work-related benefits visit www.turn2us.org.uk

DID YOU KNOW?

Working parents are entitled, by law, to take time off to look after sick children in an emergency. However, there is no legal requirement for the employer to pay employees for this time off, often called 'compassionate leave'. Some do, some don't. Check with yours.

DID YOU KNOW?

Parents of a child with a long-term health condition like PH are entitled to up to 18 weeks of unpaid 'parental leave' a year (as long as they've been working for an employer for a year or more). If your child qualifies for Disability Living Allowance, you are entitled to this unpaid leave up until their 18th birthday.

Read the personal stories of three PH patients...



Catherine Makin

Nursery Nurse, Lancashire

Nursery nurse Catherine Makin, of Whalley in Lancashire, was diagnosed with PH in 2014 at the age of 31. Before that, she was working full-time with three and four year-olds, from breakfast club in the early morning through to after school club at the end of the day. She went back to work six months after her diagnosis, but on reduced hours and with new ways of working. Here is her experience:

"I was really keen to get back to work as I was so bored at home. But I had to take the advice of my PH consultant at Sheffield about when the time was right, and when I was ready. I think that's a must for anyone who finds themselves in my position; your consultant knows best. My boss, the head teacher, was really good. She sat down and read the PHA UK materials I gave her, so she understood a bit more about what PH is and we talked through what would work best. I now work

14 hours a week across five mornings; I'm allowed to take rest breaks when I feel I need them and I'm not allowed to do any heavy lifting, running and so on. I keep her informed of any changes in my health, appointments and so on. My colleagues and family are really supportive too. And I found out about ESA (Employment and Support Allowance) through my employer, the Local Education Authority, so I get a little extra cash to boost my income through that now, which is very welcome because obviously my earning power has gone right down. Getting PH was such a shock and affected everything I do – I was very active before and it is so frustrating to not be able to handle the pace anymore. But I love my job, and it is great to be able to carry on working."



Toby Pettifor

Supermarket Manager, Sussex

Supermarket manager Toby Pettifor, who lives in Sussex, was diagnosed with PH four years ago, aged 21. He was a junior manager with Co-operative Food at its store in Newhaven when the condition hit him – and now he's been promoted to deputy manager. Here is his story:

"After six weeks in hospital following an emergency admission, I finally went home with PH drugs being pumped into my system 24/7. The new me took a bit of getting used to and I was signed off work for two months. But then I went back to the Co-op on reduced hours – three hour shifts – to ease me back in. My boss was very good, and we talked through everything. It was suggested I see the company doctor for their information, but I said they probably won't have heard of PH, which they hadn't! So work accepted all the details they needed

from my GP and PH consultant - and we worked with that. We did talk about what support I may need at work, but the best thing for me was that they trust me to manage my own capabilities. I was keen from the very start of my diagnosis, to accept the maximum levels of medication I could as quickly as I could, so that I could manage my PH as well as possible, and to keep strong and positive. My PH treatment is very effective and I feel in control, so I aim to go on working without boundaries. Although, of course, I do communicate with my GP, my PH team and my employer - they are all really supportive and all is going fine. I now work full-time and was promoted to deputy manager of the store a year after diagnosis. I am even responsible for staff rotas so I can easily plan ahead and make sure my hospital appointments fit around my work hours too!"



Laura Ling

UK Border Force, Kent

Laura Ling of Kent was diagnosed with PH in January 2013, age 33 when she was 23 weeks pregnant with her second child Rosie-May. Getting back on her feet - and back to work - was a challenge she and her family shared.

"I started working for HM Customs and Excise when I was 18 years old and I now work for the UK Border Force, which has evolved out of Customs and Excise.

I worked 24 hours a week before I was diagnosed with PH and I work the same hours now, but my role has changed. My previous post was very active and I am now office based.

My managers were very supportive when I went back to work and my colleagues are empathetic to my illness too and do not show me pity. They make me feel 'normal' and just another member of the team, not a poorly person.

That's key to me, continuing to live as 'normally' as possible and going out to work. When I was trapped in a bed for six weeks when first diagnosed I was going insane, quite literally! Along with the great support of my family and friends, my colleagues were there for me too, mainly teasing me and making me feel that 'yes' I would be ok. Some of my closest friends have been made through my job and that, for me, is priceless.

Living with PH and CVID (common variable immune deficiency) which means I have to have blood infusions every two weeks is tough and I would say that working is also one of the things that keeps my mind strong. Leaving the house for a purpose gives me strength, when I am not feeling overly strong.

I am covered under the Equality Act that protects workers with disabilities and health conditions so my hospital appointments are all covered. There are lots of employers who strongly support disabilities and I am fortunate enough to work for one of them.

My advice to others is to keep your mind strong and know your limits. I manage my expectations and take things at a slower pace. And I know I am very lucky that my employer offers opportunities to work in several areas so that I could find a new office role that best suited my needs. It is very important that you know your own limitations. Us PH patients are so very different and a physical job is not an option for me anymore. Working keeps me sane, the banter with others who treat me as an equal helps me live with this awful condition."



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Next time in Emphasis we'll be looking at what happens when your PH means you are unable to work anymore. Have you had to retire or stop working due to your condition? Contact editor@phassociation.uk.com

All going swimmingly

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“You have to be very rhythmic with your breathing when you’re swimming so it’s good. It helps me to exercise my lungs but in a gentle way.”
.....



Swimming can be a great way to relax and take gentle exercise. Here PH patient *Katie Somerfield* talks to *Deborah Wain* about her love of water – and there’s some expert advice for others who may be thinking of dipping their toe in the water.

Taking a dip in a pool is one of life’s simple pleasures and for events manager Katie Somerfield a swim has always formed part of her weekly routine.

A strong swimmer, Katie, 31, of Bristol, finds moving through the water meditative and freeing.

All that changed when Katie became unwell with what she later discovered was PH. Over the nine months prior to diagnosis as she struggled to find out what had caused a blackout and other debilitating symptoms, she could barely walk, let alone swim.

When Katie’s condition was eventually confirmed last summer, she was told she might need intravenous medication and that could mean she may not be able to swim again.

The news hit Katie hard – as hard, she stressed, as being told she would not be able to have children. At the time, she was trying for a baby.

“It broke me as much,” she recalled. “I think there are certain things you do in your life that form part of your identity and for me swimming has been one of them. For me it’s a form of meditation and I go into my own world.

“Also family summers have always been spent enjoying the sea at Weymouth and thinking I’d not be able to be part of that in the future was awful.”

For two weeks, while specialists at Bath’s Royal United Hospital tried her on a course of oral therapies, Katie seized every opportunity that she could to take to the water. Fortunately her treatment proved immediately effective. Today, Katie continues to swim weekly at her local pool and enjoyed the water during a holiday in Menorca last September. Katie believes the activity aids her breathing.

She commented: “You have to be very rhythmic with your breathing when you’re swimming so it’s good. It helps me to exercise my lungs but in a gentle way.

“I very much love swimming more than ever and the freedom to do so. My heart goes out to anyone who can’t though.”

Doctors used to think that people with PH should not exercise. They now recommend at least some exercise for people with the condition although it’s important not to overdo it.

When it comes to swimming, the advice is always to make sure you talk to a doctor before you start.

Carol Keen, lead therapist in specialised medicine at the

Royal Hallamshire, part of Sheffield Teaching Hospitals NHS Foundation Trust, said: “There are significant impacts on the body, and particularly on the heart, from being immersed in water. Anyone with PH who is thinking of swimming should seek advice from a doctor first.

“Once cleared by the doctor, they should begin, as they should with any form of exercise, very gently, doing only a small amount and gradually build it up.

“This is even more important when exercising in water, as it is much more demanding than exercising on land, and so it is easy for people to overdo it.”

Using a flotation device can be useful to help you to rest and catch your breath. It’s wise to exercise with a partner, too, in case you need help at any point. Also, stop when you need to rest or if you feel dizzy or breathless.

If your doctor has said it’s okay for you to swim, here are some pointers to help you to take the plunge:

What to wear?

The most important thing is to feel comfortable in the water. Make sure swimwear fits properly and you can cover-up if you like with close-fitting clothes. Goggles are a good idea if you want to protect your eyes from the chlorine and prescription ones can be purchased.

Where to go?

Contact your local authority for full details of facilities near you as well as timetables, special sessions and

lessons. Alternatively visit the following online link www.swimming.org/poolfinder

Water confidence holding you back?

Not everyone has learned to swim as a child but that doesn’t mean you can’t take to the water as an adult. Beginners’ classes will help you to overcome your fears.

KEEP IT DRY

- Swimming is not impossible for people with PH who have a Hickman or Goshong line.
- But it is extremely important to keep the IV therapy line, pump and chest area 100 per cent protected against the water to avoid infection.
- Bespoke dry suits tailor-made for each wearer must be worn and these are available from a couple of specialist UK suppliers who have proven experience of designing these suits for adults and children with PH and other 24/7 intravenous therapy patients.
- Please contact **Hammond Dry Suits** in Kent on 01474 704123 or Dan Lester at the **Scuba Diving Superstore** in Sheffield on 0114 248 8688 to find out more.





Caitlin in Cornwall.

Caitlin loves to swim

There's no holding 11-year-old *Caitlin Wilson* back when it comes to swimming.

Caitlin loves taking to the water every chance she gets, whether at her local pool in Sheffield or during family holidays to Cornwall.

Caitlin, who was diagnosed with PH in 2013, has a customised dry suit which protects her Hickman Line.

Mum Michelle said swimming is a great way for Caitlin to feel the same as her peers and enjoy freedom in the water.

"She just loves it and it keeps her happy and active.

We have a pool just five minutes from our house and we regularly go on Sunday as a family.

"When we're on holiday Caitlin body boards in the sea and as soon as we get back to the campsite she's in the pool there!"

Another advantage of swimming is that Caitlin is at less risk of injury than with some other activities.

Last year Caitlin fell over while playing football and knocked her line resulting in an infection around the entry point. This led to her needing an intensive course of antibiotics. Doctors at Great Ormond Street Hospital eventually decided to replace the line as she had been growing so quickly.

Caitlin's growth spurt has also meant that Dan Lester, of Sheffield's Scuba Diving Superstore who designed her dry suit, has had to make some modifications.

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“She just loves it and it keeps her happy and active.”
.....

The suit has a special internal pocket on the back for Caitlin's Epoprostenol pump as well as extra waterproofing around the line.

Said Michelle, who also has PH: "Dan has put a panel in the suit and extended the legs and arms so it should last another year. I know Caitlin will be needing it when she goes to secondary school later this year and joins her friends swimming every week."

Under the microscope

A presentation about research into metabolite levels in blood samples from PH patients has won its presenter financial support to attend a medical conference.

Clinical research fellow Dr Pavandeep Ghataorhe of Imperial College, based at Hammersmith Hospital, spoke at last year's Pulmonary Hypertension Physicians' Research Forum in London.

This annual forum is an opportunity for those involved in developing better treatment for people with PH to share research, experience and ideas.

Pavandeep updated doctors, nurses and other health professionals from across the UK on her research project. This study involves measuring metabolites in the blood of patients with PH; tracing how they are affected by, and predict the course of, the disease - and how they can measure levels of PH treatments and medications.

The research works with donated blood samples from about 400 PH patients and aims to advance our knowledge and understanding of PH's impact on the body - and informs how we treat it.

Pavandeep's contribution was awarded the PHA UK prize for the Physician's Forum, which means she

will now receive a £1,000 grant to cover the cost of her participation in a national or international research event. The prize supports her ambition to share her research findings as far as possible.

Pavandeep said: "I'm very grateful to receive this prize from PHA UK which will enable us to take our research experience and its findings to an international forum and share it with other professionals.

"I'd also like to thank the hundreds of PH patients who donate blood samples to our biobank and make this long term analysis possible. The input of patients and the funding support from PHA UK is hugely significant and much appreciated."

Pavandeep is already booked to present at the American Thoracic Society conference in San Francisco in May. She hopes to publish her research study data within the next year.

Pavandeep is a cardiology registrar, who is currently studying for a PhD, and has worked with PH patients for several years. ●

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“The input of patients and the funding support from PHA UK is hugely significant and much appreciated.”
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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  

Retirement Gift

Gordon Mentiply and his wife Madge asked guests at Gordon's retirement party to make donations to PHA UK in lieu of gifts and raised £370. Their son Scott, aged 34, has PH which he manages with oral medication - and visits the Glasgow PH centre for check-ups. Gordon, who lives in Luncarty, Perth, retired after 26 years working on off-shore rigs as an electrician. He said: "We told people not to bring gifts but to make donations to PHA UK if they wanted to - they either brought along envelopes of cash or made donations online via Just Giving."



£370
RAISED

Party on with pasties for PH

When Zoe Armstrong's former colleagues, at cleaning products supplier Jangro, heard about her diagnosis with PH last year they swung into action and organised a charity night of dancing, raffles, pasties and peas. Zoe, from Bolton, said: "It was amazing and I just had to run up as the guest of honour." Generous donations from local shops, including the Tesco where Zoe first fainted with her condition, helped to make the fundraiser a triumph and Zoe, husband David and sons Lucas, aged nine, and Dominic, aged six, can't thank them enough for supporting the PH cause.



£2,500
RAISED

Curtain raiser for Kirsty

A variety show of comedy acts and musical turns raised a huge amount of money for PHA UK in Bournemouth. Ashley Garrett organised a bumper raffle as part of the drama club event which raised £1,700 in memory of her sister Kirsty Phillips, who was diagnosed with PH at the age of 22 and passed away just before her 32nd birthday last year. Ashley said: "Kirsty lived with PH for nine years - and as a family we are now doing everything we can to raise awareness of the condition and money for PHA UK."



£1,700
RAISED

Serena keeps on running

Energetic Serena Harrap entered a total of 28 sponsored events in 2015 to raise £432 for PHA UK. Serena said: "I set out to enter one a month but then it sort of spiralled out of control." Amongst Serena's weekend challenges were Tough Mudder obstacle courses in the Midlands and the South West and road races in Milton Keynes and London. Serena, who lives in Chesham in Buckinghamshire, chose to raise money for PHA UK after her friend Lynn lost her brother, Allan Davison, to PH, aged 40.



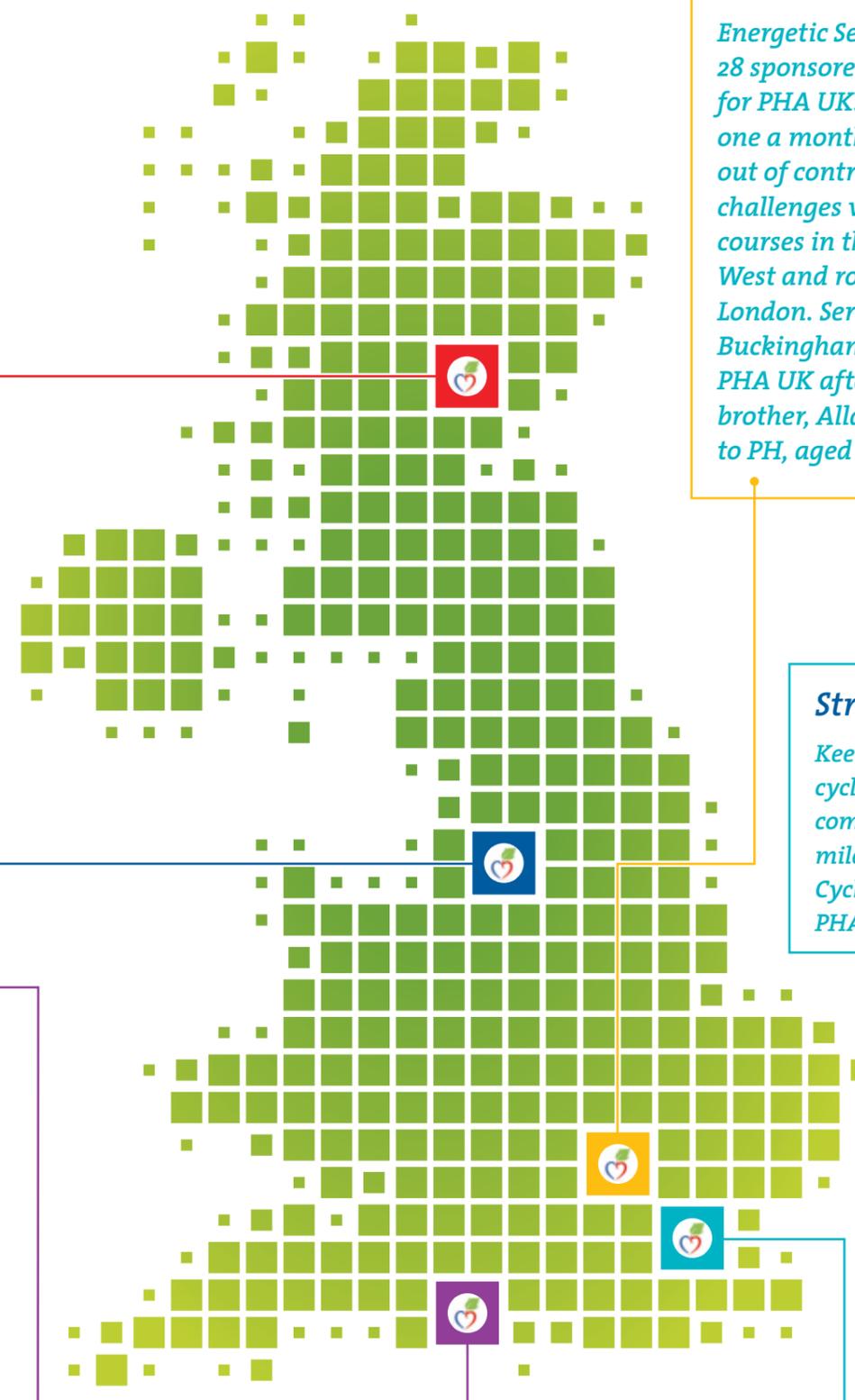
£432
RAISED

Streets of London

Keen cyclist Scott Sidley enjoyed cycling through the capital on completely traffic-free roads on the 100 mile Prudential 'Ride London-Surrey Cycle Challenge'. He raised £743 for PHA UK in support of his wife Clare, who was diagnosed with PH five years ago, after years of not knowing what was making her ill. Scott, of Reading in Berkshire, said: "Clare had a tough time before she was diagnosed and then it took a while to stabilise her condition on PH medication. Fundraising to raise awareness and invest in research is very important and personal aim for us."



£743
RAISED



If you have any ideas for raising money for PHA UK visit www.phassociation.uk.com. 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

Still sweating *over HRT?*

New NICE guidelines have been published for the use of Hormone Replacement Therapy (HRT). Here, consultant pharmacist *Neil Hamilton* considers the complex treatment in relation to women with PH.



Late last year, in November 2015, the National Institute for Health and Care Excellence published a guideline for the use of Hormone Replacement Therapy (HRT). The guideline summarises very nicely the evidence for prescribing HRT along with a clear explanation of the risks and benefits.

HRT has been the subject of much discussion, controversy and column inches in the press. Whilst the benefits to menopausal and post-menopausal women are well known, the potential for side effects has been well described. As usual, for our highly educated patient group, the publication immediately prompted calls and questions to the PHA UK office and indeed some in the clinic where I work at the Sheffield Pulmonary Vascular Disease Unit.

The menopause will affect all women at some point in their lives. Approximately 80 per cent of women experience some level of symptoms and current evidence shows that for some women these symptoms may last as long as 10 to 12 years. For some, the impact on their quality of life is huge. The symptoms of menopause can obviously affect all aspects of home, family, work and sex life. Hence, this is a very significant problem to tackle and one of the key messages of the guideline (to find it online, simply search for NICE HRT) is for women to seek advice from their GP in the first instance and receive the most appropriate treatment.



For women with Pulmonary Hypertension (PH) the situation is further complicated. All HRT treatments are either a combination of oestrogen and progesterone, or oestrogen alone. The new NICE guideline has answered some long-standing concerns and described clearly the pros and cons of treatment. However as with other chronic conditions, the interaction between oestrogen and PH is not fully understood.

Firstly, there are valid reasons why oestrogen may be beneficial, not least because it has a protective effect on the bones (it protects against osteoporosis). It can also provide relief from the flushes and psychological issues such as mood-swings.

However, oestrogens also have pro-thrombotic properties (in other words, they increase the risk of blood clots). This will have a varying degree of importance depending on the type of PH that you have. For example, if you have Chronic Thromboembolic Pulmonary Hypertension, any increase in the chance of having further clots could be life-threatening. However patients with PAH associated with congenital heart disease may be less concerned with risks of clots.

We don't fully understand the role of oestrogen in PH. As a result, there is a lot of research work underway looking at all aspects of oestrogen in PH. Such work includes looking at whether oestrogen may cause PH, whether high levels may be involved in making a diagnosis of PH more likely and even whether treatment with oestrogen-like compounds could be beneficial. If the investigators are able to draw some useful conclusions from their work, the picture may be clearer. However at the moment the evidence for taking oestrogens in any form remains very conflicting.

The NICE guideline does a great job of raising the importance of appropriate management of menopausal symptoms. It goes a long way to clarifying and describing the long-term risks of taking HRT, which will allay some commonly held misconceptions.

However, HRT has not suddenly become the treatment of choice for all ladies with PH who are experiencing symptoms of menopause. Careful evaluation of oestrogen, and the likely benefits and risks is necessary in all cases. This can be done best by your GP, with advice from the specialist centre on hand if needed. ●



Green Leaf

Crew!



GREEN LEAF CREW Q&A DAMIEN MESAQUE

Damien Mesaque is 8-years-old and lives in West London with his twin brother Isaac, big sister Tyra, mum Helena and Dad Mesaque Camucumba. Damien was diagnosed with PH as a baby but it doesn't stop him singing, swimming and running about the park.

Q. What is your favourite biscuit?
A. I don't like biscuits. I like salt and vinegar crisps.

Q. Where do you like to go on holiday?
A. Spain and Portugal. Especially Malaga.

Q. What football team do you support?
A. Chelsea.

Q. What superpower would you most like to have?
A. I am already brave and strong. I'm always telling my brother that.

Q. What is your favourite meal?
A. I like semolina, my Mum makes it with beans, spinach and a tomato sauce.

Q. What's your favourite thing to do at school?
A. I love to go swimming, but I have to behave in class or I don't get to go.

Q. What do you like to do at home?
A. I like to sing all the time! I am learning the guitar. I like to get out of the house and go to the park.

Q. What's your favourite TV programme?
A. Everything on Cbeebies.

Q. What famous person would you most like a selfie with?
A. Mr Tumble.



Would you like to answer the Green Leaf Q&A? Contact us at editor@phassociation.uk.com

LONDON LANDMARKS

Trips to London are part of life for many kids with PH. Great Ormond Street Hospital is one of the most famous buildings in London – with the bronze statue of Peter Pan outside the entrance! Here are five more facts about famous London landmarks you may spot:

- The London Eye can carry 800 people at a time and more than 3.5 million people go for a ride every year
- The Shard is the tallest building in Western Europe, standing 306m high
- Over 40,000 people cross Tower Bridge every day
- About two thirds of London's drinking water comes from the Thames
- The world's first traffic light was erected outside the House of Commons in 1968. It blew up the following year, injuring a policeman.

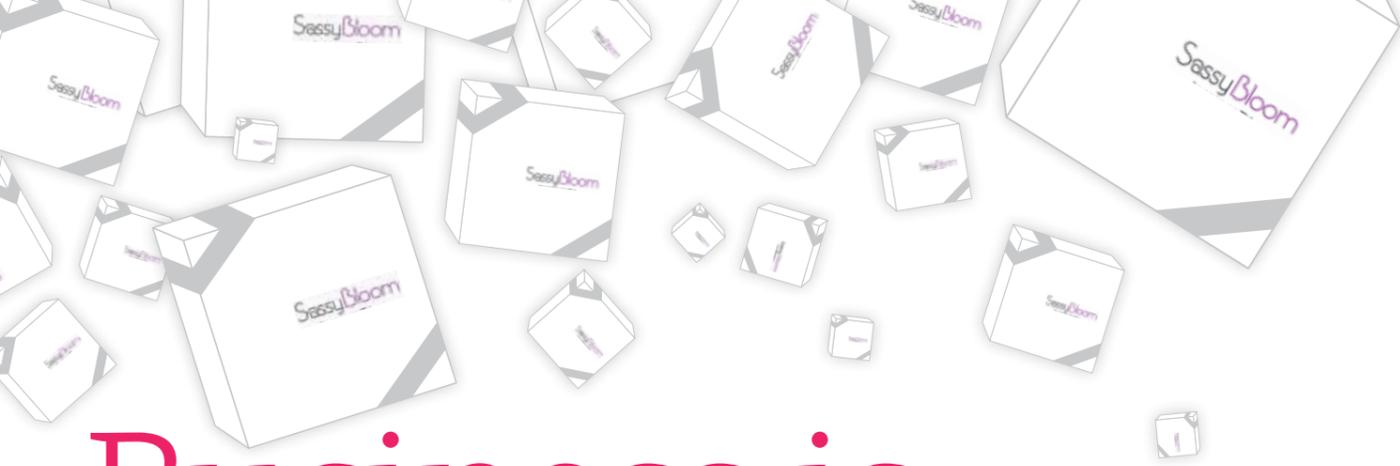


The Green Leaf Crew

by David Banks

Patch

by David Banks



Business is Blooming!

A mum has success wrapped up with the online baby box business set up after she developed pulmonary hypertension during pregnancy.

Hollie Sassienie fell seriously ill while expecting her daughter Gabriella.

In hospital, following Gabriella's early delivery, a friend presented Hollie with a box of useful baby items to help her through the coming weeks - and the kind gesture sparked an idea for a business.

That was in 2012. The following year, Hollie and husband Darren set up Sassy Bloom providing new parents with home deliveries of luxury baby supplies.

The couple felt all parents could benefit from their service, not only those with additional health needs like Hollie had.

Boosted by an appearance on BBC entrepreneur challenge show Dragon's Den, Sassy Bloom has since gone from strength to strength.

It has already won 13 awards, has a dedicated social media following, and a string of celebrity fans.

Hollie said: "If I'd had a normal pregnancy and birth, I don't think I would have had the idea for the business."

"The way Sassy Bloom has grown has been amazing. People love the convenience and the surprise element of receiving their boxes. But it's also about the supportive online community we've built up around it with mums who love the brand and want to get

involved. They share their advice, thoughts and photos and it's lovely."

As well as highlighting PH through telling Hollie's story on Sassy Bloom website and in the media, Hollie and Darren are raising money for PHA UK.

They credit the organisation's support and advice at the time they most needed it as helping them to come to terms with Hollie's condition.

Customers are given the option of making a donation to PHA UK every time they make an order. Donations made to date have totalled more than £500.

“I'm not going to let PH control what I do. Really I do as much now as I did before I was diagnosed.”

Women with PH are generally advised by doctors not to have children because of the risks presented by pregnancy.

Hollie believed it was her asthma causing increased breathlessness while carrying Gabriella. However when she began passing out, having fits and could barely catch her breath it became apparent something more was wrong.

At 31 weeks pregnant, Hollie was

rushed into Watford General Hospital and later transferred to the Hammersmith Hospital PH unit for tests which immediately diagnosed her condition.

Hollie was reassured her baby was safe but she and her family were warned of the dangers the condition posed to her own life.

She remembers the dreadful moment when her mother, brother, sister and Darren all sat around her hospital bed looking gravely concerned.

"All I could think was that I was going to be leaving my husband behind alone with our baby," she recalled.

Fortunately Hollie responded well to the Epoprostenol which was being pumped directly into her heart and her condition stabilised. She gave birth to Gabriella, weighing 5lb 2oz, at 34 weeks.

Hollie now manages her condition with oral medication under the care of Hammersmith PH centre.

Hollie says she is careful to look after herself and rest if she needs to as she juggles running the business and looking after Gabriella, who turns four in May. At the same time she is determined not to allow PH to stand in her way.

She said: "I do have to pace myself and step back sometimes. I know I'll be



“The way Sassy Bloom has grown has been amazing. People love the convenience and the surprise element of receiving their boxes.”



of no help to anyone if I get ill. Because I have asthma as well, the winter months can be hard, when I get chest infection after chest infection.

"However, I'm not going to let PH control what I do. Really I do as much now as I did before I was diagnosed."

Although their time in front of the television 'dragons' didn't bring investment for Hollie and Darren, positive feedback gave them confidence in the potential of their idea and helped them to develop their brand and reputation.

They now have a small team helping them run Sassy Bloom from their base in Hertfordshire.

Boxes are packed with high-quality, age-appropriate items for babies and toddlers and people can buy them as a one-off, as a gift say, or sign up for a monthly delivery.

Because parents were asking for boxes designed for older children too, the company has now expanded its range to offer crafty Kids Boxes for youngsters aged three to eight.

The company recently took an order from the Queen's granddaughter Zara Phillips and celebrities who have raved about their products online include Danny Dyer, Peter Andre, Vanessa Feltz and Edith Bowman.

At www.sassybloom.com when customers go to the check out, they are offered the option of upping their payment to a round figures or making a donation of their choice to PHA UK. They are also able to turn their customer reward points into a donation to the charity if they like.

Visit Sassy Bloom via their website, Facebook page or Twitter to find out more details.



Don't give up!

One woman's bid for support

Myra Morrison of Frome in Somerset was diagnosed with a type of PH called CTEPH in March 2014 at the age of 61. She applied for Personal Independence Payments (PIP) and it took her a year of letters and appeals - plus a tribunal hearing – to finally be deemed eligible. Here, she shares her experience and encourages others to persevere and pursue the support they are entitled to.



I'd had a cough for ages and just ignored it, then people at work started saying how ill I looked and I went home early one day thinking I'd be right in a couple of days. By that evening I couldn't manage the walk from the lounge to the kitchen without becoming severely breathless. My GP referred me to hospital and I was diagnosed with CTEPH following a pulmonary embolism within weeks. This came on top of my existing condition, rheumatoid arthritis (RA), which I've had since 2008.

A few months later, in November 2014, I decided to apply for PIP. My PH, on top of my RA, has had a dramatic effect on my everyday life. Every single task takes twice as long and I'm always having to sit down for five minute rests; take the stairs in two goes for example. Many people with PH know exactly what I'm talking about. I can't lift heavy things and there are a lot of jobs I can no longer do by myself, so I rely much more on my husband and family for support. I know I am so much luckier than many people with PH, but I also know the impact on what I can do has been significant, so I decided to apply for that extra bit of support to help me and my husband cope.

“No one in authority says ‘okay you may be able to get this’ so I had to work it out for myself.”

No one in authority says ‘okay you may be able to get this’ so I had to work it out for myself. After checking with the DWP, Citizens Advice Bureau and PHA UK, I duly completed and sent back the lengthy forms needed to apply for PIP. After some time, I was invited to a face-to-face assessment carried out by ATOS healthcare.

After another wait, I got a letter from the DWP stating I did not meet the criteria so would not be awarded PIP. I challenged this decision – especially on the grounds that I felt my ATOS assessment only took into account RA and did not consider my PH symptoms.

A further wait and then another letter of explanation detailing each point of the assessment and how the decision had been reached. I have to say there were times when I thought about giving up and just letting it go. It was hard to keep taking the responses I was getting, but, no, I decided to go on and appeal. This meant taking my application to tribunal.

I was asked to supply further evidence to support my case and this included a letter from my consultant and a letter from the PHA UK too. I hoped they would look at all this additional evidence and give me a ‘paper decision’ but, no, I was told they



“It was definitely worth sticking to and I am very grateful for the support PHA UK gave me in this process.”

couldn't agree a decision, and I was invited to attend a tribunal to be held in Bristol in December 2015.

I was very nervous about this, but it was honestly not as daunting as I was expecting. Everyone there was very nice and understanding. The panel consisted of a judge, a medical doctor and a person with expertise in daily living activities. They said my husband could come in with me if I wanted – but I decided to go in by myself. The panel asked me questions about the assessment process and then they asked for more details of how CTEPH and RA have affected my life. This took about half an hour and I was then asked to wait for fifteen minutes before being called back in and told they had reached the decision to allow my appeal. And I was thanked for being open and honest with them.

So, I now receive PIP and the added bonus is that it was backdated to my original claim date a year before. I receive the daily living component but not the mobility component, which means I don't get a blue badge so we have to plan journeys to take into account parking and where I can be safely dropped off.

The whole process took over a year and at times I felt like I couldn't be bothered and would give up, but then something inside me was saying, ‘fight it, it's what you believe, they're not listening to you.’ At the tribunal, I finally felt someone was listening and taking on board how my lifestyle has changed and all the adjustments I've had to make.

I know not everyone is the same and experiences are different, especially if there are other health factors involved, but for me it was definitely worth sticking to and I am very grateful for the support PHA UK gave me in this process.

My case is up for re-assessment again in November this year (2016) which feels quite soon, but I'm hoping this will just be a paper re-assessment through which I have to let them know of any changes – and as I have two progressive conditions that won't go away, I hope this will be straightforward.

It wasn't easy applying for PIP and at times I thought I couldn't be bothered anymore but I really was determined. I've worked in the NHS and social services all my life, most recently working with carers of adults with learning disabilities, and I believe that people should get any benefits they are entitled to. I would like to urge others with PH to persevere. ●

Turn the page for some advice regarding PIP from PHA UK benefits advisor Shaun Clayton.



A closer look at Personal Independence Payments

Benefits Advisor

With Shaun Clayton

Applying for Personal Independence Payments can be daunting and often dispiriting – it is the benefits issue we take most calls about at PHA UK. I hope Myra's experience (previous page) will help, if you are applying for this support. Here are a few more tips which may help you to put your case:

- It is very important to be as clear as possible about the impact of your condition in every question you are asked. Give as much descriptive information as possible about how PH affects your ability to do things like prepare a meal, get yourself ready in a morning or plan and carry out routine journeys. How long does it take you to do specific tasks? How many breaks do you need? Take time to notice and record these things. Provide real examples about things like climbing stairs, loading the washing machine, hoovering the lounge and so on. Describe what you need to do to manage your health.
- If a question offers simple multiple choice options, always use the box provided for extra comment – write your answer in more depth.
- Don't assume knowledge. PH is not well-known so describe your symptoms eg breathlessness, as graphically as possible both on paper and at your face-to-face assessment.
- Study the Department for Work and Pensions section of www.gov.uk and download their Personal Independence Payments handbook.
- Get support from the experts who know you and your condition best – when the DWP asks for evidence in support of your application speak to your PH specialist centre team about a letter or medical report.
- Contact us at PHA UK too. We can provide personalised letters explaining the condition, its symptoms and the significant impact it has on people.
- Don't be afraid to challenge your initial decision. Lots of PIP claims are rejected first and then granted at tribunal stage, where the applicant is able to talk through their situation with a panel including a judge and a doctor.

- Visit the Turn2us welfare rights website www.turn2us.org.uk for free advice on your ways to challenge your PIP decision.
- Talk to me at the PH UK office. We are here to support you. Request a copy of 'Signposting for Potential benefits' via publications@phassociation.uk.com
- Take it steady and pace yourself. The DWP admit the PIP assessment process is taking longer than anticipated. But if your claim is successful, your payments will be backdated to when you originally applied. Persevere.

WHAT IS PIP?

PIP is the UK benefit for adults of working-age who have a long-term illness or disability. PIP replaced the Disability Living Allowance for new adult applicants in 2013. It aims to provide help towards some of the extra costs a person might have because of their condition. PIP is made up of a 'daily living component' which takes account of how your condition affects your ability to take care of yourself; and a 'mobility component', which takes account of how your condition affects your ability to get around. You may be awarded one or both of these components. PIP is awarded at either a 'standard' or 'enhanced' rate depending on whether the DWP assesses your abilities are 'limited' or 'severely limited' by your condition. ●



Shaun will look at different aspects of the benefits system in future issues of Emphasis. If you would like a particular subject covered please e-mail editor@phassociation.uk.com



PH AWARENESS WEEK 2016

PH Awareness Week to be launched in 2016

Following on from our 15th anniversary celebrations last year we have decided to step up our campaign to raise awareness of PH in 2016.

PHA UK plans to launch an annual PH Awareness Week between November 19th and 27th this year. And we want you to get involved.

Proposals for the new week include a media and social media campaign; plus a letter writing campaign targeted at GPs and other members of the health community.

We would like you – PH patients, families, friends and professionals – to get involved. Template press releases, letters and other communication tools will be developed and made available to all before the week.

Chair of PHA UK Iain Armstrong said: "Raising awareness about pulmonary hypertension is a 365 day job for the charity, and our many supporters. We appreciate and celebrate everyone's efforts all year round.

"We've now decided to step up this activity with the launch of a PH Awareness Week, following the buzz

of our anniversary year, plus on-going feedback from members about the desire to make more people aware of PH. "We hope it will provide an additional annual focus for our consolidated efforts.

“It will be a chance to pull together, share our stories and focus our efforts on raising awareness of PH.”

"PH Week won't be a big-spend fund-raising extravaganza with expensive resources, but a chance to pull together, share our stories and focus our efforts on raising awareness of PH."

During our first PH awareness week, the charity proposes to focus on making more frontline health professionals aware of the condition. The more GPs and consultants, working across disciplines, who are aware of the disease, the more likely it will be that they spot early indications of PH

symptoms and refer patients to PH centres for assessment. The swifter people are diagnosed, the sooner they can start treatment and the better their prognosis.

It is also hoped the week will provide an opportunity to share more awareness and understanding of PH amongst family, friends and work colleagues. Look out for more information in future Emphasis magazines and on our website, Facebook and Twitter.

If you have any comments or suggestions about our first PH Week, please get in touch with us via office@phassociation.uk.com ●

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theinterview
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Professor
JANELLE YORKE

in conversation with
Deborah Wain

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Last year Janelle Yorke was appointed Professor of Nursing at the University of Manchester, rated as the leading nursing unit for research in Europe. Janelle began her nursing career in Australia and specialised in heart and lung transplantation for many years. She was nurse consultant for the transplant programme at St Vincent's Hospital, in Sydney, before moving to the UK in 2004. That was to be her last clinical role as she went straight into teaching and research and completed her PhD in 2009 investigating the experience of breathlessness in a range of cardiac and respiratory conditions.



Janelle was made nurse researcher of the year by the Royal College of Nursing in 2007 and developed a programme of work around symptom experience and self-management in chronic respiratory conditions which now includes a significant amount of work in pulmonary hypertension. She worked with PHA UK on developing the emPHasis-10 questionnaire, a tool to help clinicians assess and improve management of PH by measuring the impact the condition has on a person's life and how this changes over time. Janelle's current role is unique for nursing in that it is a joint Chair between the University and The Christie NHS Hospital, so she works for both organisations.

.....
Q. Growing up, did you ever imagine being where you are now?

A. *I cannot remember a time when I did not want to be a nurse. My mum made me a nurse's uniform for my seventh birthday and that is what I wore to my party. I remember feeling so proud. So I guess there was no turning back from there. Although I always imagined being a nurse, I never imagined that I would become a Professor.*

.....
Q. How are you enjoying your role?

A. *I am really enjoying being back in the NHS and working with clinicians to develop and conduct research that is clinically relevant and has the potential to have a real impact on patient outcomes and experience. To me it is the perfect job – I still have my academic role and responsibilities but I can dovetail that with the work that I do at The Christie so my research remains focused on patient care.*

.....
Q. How does your nursing background inform your research?

A. *My nursing practice always guides my research – from initial idea through to publishing and disseminating the results. My research is also patient centred – by that I mean; it is related to the personal, social and psychological factors of living with a long term health condition. I am interested in exploring how people (patients and family members) respond to illness*

and how we can use research to better understand this and find ways that can help people to live better with a long term condition. I have a particular interest in how people experience breathlessness and developing techniques for people to self-manage this symptom and improve quality of life.

.....
Q. How did you first come into contact with PH patients?

A. *I first came into contact with PHA UK and Iain Armstrong through networking at conferences – my work on symptoms and quality of life made us the perfect match really. I started working with PHA UK about six years ago and we have achieved a lot in that time, including developing the emPHasis-10 questionnaire.*

.....
Q. What do you think are the challenges of living with PH when set against other respiratory conditions?

A. *Living with PH brings a number of challenges and this is evident in the research that I have conducted with PHA UK. Some of the specific challenges reported in our research include: PH is a relatively rare condition – so the majority of the general public have never heard of it. This can lead to frustration for people with PH as it can be difficult to explain the condition to people and inform people about the seriousness of the condition. My research has also shown that people living with PH describe it as "living with an invisible illness". Patients have described how people (friends, family and strangers) often... >>>*

theinterview

Professor
JANELLE YORKE

“Most of all patients and their families inspire me – that is what keeps my research (and me) grounded.”

comment on how well they look but they are in fact feeling very poorly, or are putting all their energy into today, but it will take many days to recover. This has often led to feelings of frustration at trying to explain their condition. Similarly, many health care professionals are not familiar with PH and many GPs may only come across one or two patients with PH during their career – so we still have a lot of work to do about raising the profile of PH. It can still take two to three years before someone receives an accurate diagnosis of PH. So that is a real challenge that PHA UK are working hard to address. Some of our research has focused on the patient’s journey to diagnosis and was published in the British Medical Journal Online in 2012.

Q. What is the most important thing you’ve learned about PH during the course of your research?

A. The resilience of people never ceases to amaze me.

Q. What positives are there going forward?

A. PHA UK and I have just completed a large piece of work, the ImPHact study, which followed patients up over 18 months to explore how the condition affects people’s daily lives. This study will provide important information about symptoms and quality of life that have not been investigated in this way before. This work will help us to better understand the condition and enable us to develop new and better ways of providing health care services and interventions to enable people with PH to live better for longer.

Q. Who or what inspires you?

A. Learning new things about how people experience illness and then developing and testing new ways to help people better manage their condition. Most of all patients and their families inspire me – that is what keeps my research (and me) grounded.

Q. And of what achievement are you most proud?

A. Development of emPHasis-10 – we have received some great feedback about the usability of the questionnaire and how it has been used by patients and clinicians to guide consultations.

Q. Back to the ImPHact study. When can we expect to see the findings?

A. Data analysis has recently finished so we plan to publish the results in early spring this year.

Q. How would you like to see it make a difference?

A. I hope we gain a much deeper understanding of the experience of living with PH and how this can improve PH services and lead to further research that has the potential to really impact on the lives of patients and their families.

Q. Finally, how important is the role of PHA UK?

A. PHA UK are advocates for the PH community – patients, families, friends and health care professionals. Everything that they do is patient centred – it is all about aiming to improve the experience of everyone living with or affected by PH. They are a vital part of the jigsaw puzzle. ●

Apology. In the Winter edition of Emphasis, we printed some out-of-date biographical details about our interviewee Professor Paul Corris. We’d like to apologise and point out that Professor Corris is in fact Past President of the British Thoracic Society and the current President of the International Pulmonary Vascular Research Institute.

PHA UK Chairman contributed an article about pulmonary arterial hypertension to a special supplement on respiratory health in the Guardian newspaper. If you missed it, here is the feature reproduced in full. The supplement was produced by Media Planet Health Awareness. Visit www.healthawareness.co.uk to see more articles.

Leading the way in Pulmonary Arterial Hypertension

PULMONARY ARTERIAL HYPERTENSION
A lot can happen in 15 years as has been shown by developments in the way Pulmonary Arterial Hypertension (PH) is diagnosed and treated in the UK.



Iain Armstrong

Chairman, PHA UK and Nurse Consultant, Royal Hallamshire Hospital

15 years ago The Pulmonary Hypertension Association (PHA UK) was set up to support those living with the rare condition. The initial focus of the charity was to provide peer-to-peer support for those living with PAH. A lot has changed since then and the charity’s chairman, Iain Armstrong, who was one of the nurses who started the charity, describes the UK’s response to PAH as the “envy of the world.”

Back in 2000 there was no cure or licensed treatment for PAH and life expectancy was just two to three years. Very little was known about PAH, which occurs when the walls of the pulmonary arteries are thick and stiff or blocked by blood clots, making it difficult for them to expand and allow blood through, placing greater pressure on the right hand side of the heart.

Today, whilst there is no cure, there is treatment, investment in research and, with a life expectancy of six to seven years, PAH has been reclassified as a chronic rather than an acute disease. There is even a national audit so everyone diagnosed with the condition, which currently stands at around 7,000 individuals in the UK, is identified and can access specialist care.

“So much has changed over the past 15 years,” recounts Iain, “But the two major breakthroughs have been the licensing of a specific treatment and the development of specialist centres to care for those with PAH.” Those diagnosed can now receive medication that helps to relax the arteries, allowing blood to flow more easily, and get support from one of eight specialist centres around the country. The breakthroughs in treatment have also stimulated further industry research.



Risk of misdiagnosis

Whilst progress has been great, there’s still a lot to do. PAH can affect anyone, of any age and with unknown causes and vague symptoms, it can take up to two and a half years to diagnose. “The symptoms are so similar to those of asthma or chronic obstructive pulmonary disease, that people are often misdiagnosed,” says Iain. However, he is confident that the UK is in a better position than ever to continue advancing the care, research and general awareness of PAH.

“In terms of awareness, there isn’t the same public narrative that there is around, say, some forms of cancer, even though the outcome is just as bad, or even worse,” explains Iain. “This places a huge stress on individuals when claiming benefits, talking to employers or even their friends about the condition.”

Perhaps the most neglected area that comes with any rare condition is the wider on the general wellbeing of a patient. PHA UK continue to lead the way here, providing resources and connecting patients and families to ensure that those living with PAH have, as Iain says, “the right tools at the right time to make the right decision.”

Embrace the anxiety

Claire Eastham talks about her decision to accept her feelings of anxiety. Despite what anyone says it is nothing to be ashamed of – and support is out there.

I imagine lying in hospital with two broken legs and hearing the doctor say, “what’s wrong with you? You’re pathetic. Can’t you just pull yourself together?” Anyone would feel outraged! If only a broken leg could be healed with a few stern words, the NHS would be under less pressure.

But the reality is very different. The body needs time and patience to heal itself.

Now imagine having a panic attack or feeling anxious, suddenly it’s more acceptable to be so harsh and unfeeling. The majority of the criticism comes from within ourselves. We feel frustrated and embarrassed by mental problems and often try and suppress them. If we can ignore those nasty thoughts and feelings for long enough then hopefully they’ll go away. Sadly this is one of the most damaging things that anyone with a mental condition can do. Rather than disappearing, the problems will only get worse.

Many people feel ashamed about their anxiety, and I used to be one of them. I thought that I was weak and a loser, and I wasted so much energy trying to act ‘normal.’ But eventually things came to a head, my body couldn’t take anymore punishment and I had a mini breakdown.

Despite feeling devastated that my secret had been exposed, I realise now that it was a very positive thing, because it forced me to face my problems. I’d been trying to walk on broken legs for years and now I was finally giving myself time to heal.

Think about it, would you feel embarrassed about a cold? Would you be ashamed of admitting that you have a headache? Of course not, you didn’t ask to fall ill it just happened, so why is anxiety any different? The more that I began to accept this idea, the stronger I grew.

The truth is, facing up to any illnesses is a daunting prospect. It takes time and great courage, but it can be done.



“Facing up to any illnesses is a daunting prospect. It takes time and great courage, but it can be done.”



Here are a few things that really helped me to embrace my anxiety

TELL SOMEONE.

Whether that be a family member, friend or colleague. Talk to someone who you trust and explain to them what you’re going through. Be sure to pick the right time, don’t try and talk to your spouse right before they dash off to work, as you won’t get the attention that you need. I made a list of symptoms in advance to help myself be concise. Being honest with someone will help to ease the burden instantly. I also directed family members to the Anxiety UK website for extra information. And if you need someone else to talk to, don’t forget you can even ring the Anxiety UK helpline.

BE PATIENT AND KIND TO YOURSELF.

Accept that for now certain situations will be harder for you to deal with than most people. Social interactions for example were a struggle for me. So whenever I went to a party or meeting, rather than criticising myself I made

an effort to say, “ok, this is difficult but you’re doing really well. You should feel proud of yourself”. (Naturally do this in your head to avoid any strange looks)! After the event treat yourself to something nice, you deserve it.

REMEMBER THAT YOU’RE NOT ALONE.

On average one in every four people in the UK will experience a mental health condition at some point in life. It’s much more common than you think and people will therefore be more accepting than you feared. The moment that I started being honest about my anxiety I was overwhelmed with support and similar stories by everyone from close family to random colleagues in the kitchen.

EMBRACE IT AND ACCEPT IT.

There is nothing to be ashamed of. **FACT.**

Claire Eastham writes about her experiences with anxiety and panic attacks on her blog www.weallmadhere.com

Recommended reading: ‘Understanding Anxiety’ – a guide produced by Anxiety UK, priced £3.99, is available via www.anxietyuk.org.uk/products or by calling 08444 774774.



If you would like to speak to someone at Anxiety UK, please call them on 0844 332 9010. This is a free dedicated Anxiety UK helpline for PHA UK members if they are feeling depressed or anxious and need someone to talk to. The helpline is open from 9.30am to 5.30pm Monday-Friday. You can also visit www.anxietyuk.org.uk

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 **phassociation.uk.com**

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.

THE PROFILE



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

NAME: Carl Harries, but I answer to Carl, Carlos, Carly, 'Mr H' or if you're a Brompton consultant - they call me Professor Harries with a big tongue in cheek!

PLACE OF WORK: Royal Brompton Hospital, London.

JOB: Lead clinical nurse specialist in pulmonary hypertension, aka 'Agony Uncle' and an honorary good friend to patients, their friends and family.

LENGTH OF TIME IN JOB: 13 years, well past the seven year itch.

HOW LONG HAVE YOU WORKED WITH PH PATIENTS: 18 years. I first started nursing patients with PH as a staff nurse on Paul Wood Ward at Royal Brompton. It really only seems like yesterday.

BEST THING ABOUT YOUR JOB: Meeting new patients is always special; giving them an answer as to why they've been unwell and, if we can help with treatments, seeing them hope for a better future. There is also something amazing about seeing patients year after year. I also work within a dedicated and passionate team. We have an amazing administrative gang, the consultants are superb experts and approachable on all levels. What more could a nurse ask for - another nurse maybe? One final 'best thing', my partner in crime, Lisa - Lindfield nee Parfitt - yes she's got married!

FIRST THING YOU DO WHEN YOU GET TO WORK: Greet the girls in the PH office with a big 'GOOD MORNING', put the kettle on, check the answer phone and emails and catch up on any office gossip.

WHAT DO YOU LIKE TO DO OUTSIDE WORK: I could say marathon running and mountain trekking but that would not be very truthful, so I'll say that it's like seeing seven magpies in a row, 'a secret never to be told'...

TELL US ABOUT A KEY DEVELOPMENT YOU'VE SEEN FOR PH PATIENTS: The easier access to medicines through the NHS commissioning document has had a huge impact. People will not know or have forgotten that all therapies had to be applied for and agreed before we could start them in the past, which could take weeks if not months. Commissioning does not come without rules, but it has broken down huge barriers to access PH treatments.

PROUDEST MOMENT AT WORK: Setting up shared care with other hospitals linked to our service and making sure there is a strong nursing element at each. Patients have fantastic support from the shared care specialist nurses at Southampton, SASH, Oxford and St George's and they bring calm to chaos. I am really proud of what we've set up together.

TEA OR COFFEE? Coffee. I'm fussy though, a Latte has to be nice 'n' sweet, but I don't take sugar in other coffee. I don't like weak or cheap stuff - and definitely no chicory. Black or white is fine by me though!

If you work with people with PH and would like to answer our Q&A please e-mail editor@phassociation.uk.com

Join us free today
and be part of a 3,000 strong
national support network.



*The only charity in the UK dedicated
to people with pulmonary hypertension.*

Are you living with PH? Do you have family or friends who are? Are you interested in knowing more about the treatments available? Would you like to get involved with fundraising or stay up to date with the latest PH news and events? If so, we are here to support people like you.

At PHA UK we are committed to helping improve the lives of people with PH, and supporting the PH community across the country through funding research, raising awareness, and helping our members in their day-to-day lives. Our website provides useful advice, access to publications, audio and video presentations, plus ways to get involved with the organisation.

*Our quarterly **Emphasis** magazine keeps people informed and engaged with all things PH. In addition our friendly, knowledgeable office staff are just a phone call away with one to one advice. But most importantly it's our 3,000 members who form a unique network of support and inspiration to each other. We think of it as one big family and there's always room for new people.*

Join FREE today at www.phassociation.uk.com, call us on 01709 761450, email us at office@phassociation.uk.com



Support, advice and much more...

- Be part of a nationwide network
- Advice & support for patients, friends & family
- Fundraising ideas
- Latest news & events
- Regular supporters magazine
- FREE membership



PHA UK Contact Details

Office hours: 9am to 3pm, Mon to Fri for general enquiries
Tel: 01709 761450
Web: www.phassociation.uk.com
Email: office@phassociation.uk.com
Address: PHA UK Resource Centre,
Unit 1, Newton Business Centre, Newton Chambers Road,
Thornccliffe Park, Chapelton, Sheffield, S35 2PH

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

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 access support; and provides a range of information and resources on welfare benefits, charitable grants and other services via its website: www.turn2us.org.uk. Through our partnership with Turn2us, PHA UK members can also use the Turn2us Benefits Calculator and Grants Search on our website at www.phassociation.uk.com.

Do we have your correct details?

Please email us on office@phassociation.uk.com 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?

Next time in Emphasis...

The next issue of Emphasis is due out in **summer 2016** and we have planned features about oxygen therapy, invisible illness and the therapeutic effect of pets!

To get involved, give feedback and ideas, contact editor@phassociation.uk.com

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Free support & advice...



If you would like copies of any of our publications please contact the PHA UK office on 01709 761450 or email us at office@phassociation.uk.com