

AUTUMN 2016

emphasis

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

**“Let’s talk
about PH”**

**Get involved in
PH Awareness
Week 2016**

Let’s get people talking about
pulmonary hypertension

**All about
oxygen**

Your essential guide to
oxygen therapy

**TREATMENT
THROUGH
TRANSPLANT**

What to expect from those
who’ve been there

**‘Living with PH
in my community’**

Rukhshana Khalifa shares her experience

**PHARMACY
FOCUS**

How to make the most
of your pharmacist



Could you support us by playing our PHA UK Lottery?

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

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

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

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

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

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

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

Signing up is simple!

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

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

Sarah, Oxfordshire

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

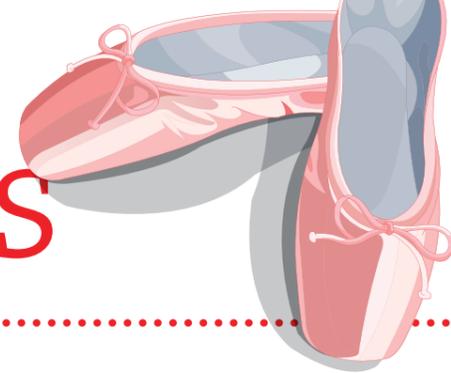
Darren, Glasgow

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

Catherine, Lancashire



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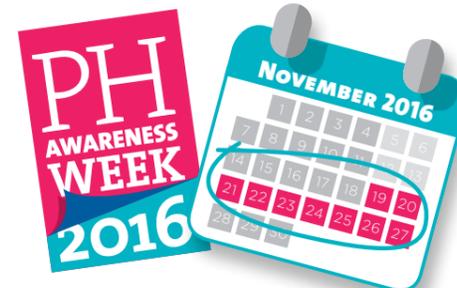
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See enclosed PHA UK Lottery leaflet for details of how you can play!



TURN2US
FIGHTING UK POVERTY

STRUGGLING WITH MONEY?

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

TURN2US.ORG.UK



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

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



PH
AWARENESS
WEEK
2016
19th-27th Nov

Welcome

Welcome to the autumn edition of Emphasis. This issue tells you all you need to know about our first ever PH Awareness Week, and we'd love everyone to get involved.



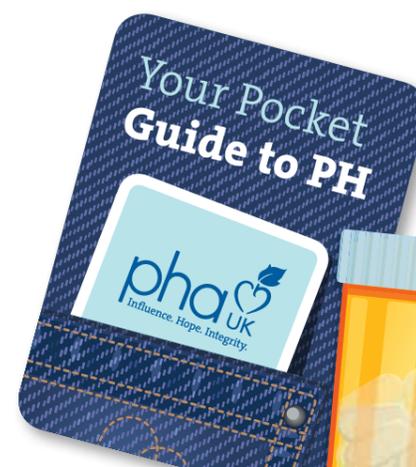
This week will run from 19th – 27th November and aims to help generate awareness and understanding of what it is like to live with PH. You can read all about it in our centre spread. We've also got plenty of news, features and insights from across the PH community including a report from the International PH Conference in Texas; a closer look at the NHS cardiac services review, and a look-back at the PH patients day held in Glasgow. We're very grateful to Pauline Ginn and Jocelyn Barker for sharing their experiences with us in our special transplant feature, which aims to prepare you for what to expect if this becomes a possible treatment option for you. And Jocelyn's

daughter, Hope, tells us how it felt for her to watch her mum go through the process in our 'Family Matters' column too. Also inside is an essential guide to oxygen therapy. And Rukhshana Khalifa tells us about her experience of living with PH. Thank you to her and everyone who shares their stories with us; this is your magazine and it's great to hear from you.

Iain Armstrong

Iain Armstrong
Chair of PHA UK
editor@phauk.org

Our transplant feature aims to give you insight into this treatment pathway.



Emphasis *exchange*

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

Dear Emphasis readers,

I wake up around the same time every morning and lay there wondering what sort of day it will be. I'm not referring to the weather (not least because I live in Cyprus so it's usually sunny!). It's because I have PAH, so I'm never quite sure what to expect. I may have been disturbed by cramp in the night, and when I wake, I can find that I feel dizzy, and my feet and lower legs and sometimes the fingers of my hands will tingle with pins and needles.

The onset of tiredness is rapid and frequent. How will my body react to being 'on the go?' Will it perhaps be 'on the slow?' Some days, the first hour or two would seem to be perfectly normal and people may remark on 'how well I look'. A trifle annoying when in fact you feel inside like a piece of bedraggled seaweed washed up by the tide!

I am 76 years old and have led an active and sporting life all my days. I have a loving wife and grown up children but cannot plan for the future. I used to enjoy the carrot of holidays and trips out and about, but now I am lethargic and confused.

As you read this you will be feeling that this is all rather negative. But it doesn't need to be, and my message is one of positive hope that, by interacting with each other as real patients, we will be able to encourage and support each other through difficult times.

Best wishes,
Graham Donald,
PHA UK Member
Cyprus

Graham is interested in chatting to others with PH via email and can be contacted on donalds@cytanet.com.cy. He is also planning on joining the PHA UK Facebook group, and can be found on LinkedIn.



David faces fears to complete 10k charity run

For PH patient David Stott, training for the Mersey Tunnel 10k run gave him a focus that took his mind off his condition. With the careful support of his doctors, David, who lives in Preston, completed the challenge in June in 63 minutes – raising almost £800 for PHA UK.

He said: "I have focused my energy on getting fit and fighting PH to ensure that my four girls have a father to walk them all down the aisle. My condition has improved so much that some doctors have called me remarkable. The run was a challenge to myself to face my fears and try to raise money for those with my condition who are not so lucky."

If you have PH, it is very important to talk to your care team before embarking on an exercise routine.



FANCY DRESS TREK IN SUPPORT OF BROTHER

PHA UK member Paul Harris cheered on his brother and friends when they trekked 55 miles across the country dressed as nurses, in recognition of the PH team at the Royal Hallamshire Hospital in Sheffield.

Mark Harris rounded up friends to join him in his Peaks4PHA challenge, which saw them cross the hills from Cheshire to Sheffield with a target of raising £5,000 for PHA UK.

The group set off from Alsager at 2am and finished at 9pm at the Royal Hallamshire Hospital in Sheffield where Paul is treated for his PH. He was diagnosed in September last year and spent nearly three months in hospital. Paul said: "I think it's great that the walkers dressed as nurses in recognition of the fantastic team at the Hallamshire. I've had so much support from them - everyone from the cleaners and catering staff, to the physio's, doctors, nurses and consultants, have been fantastic. Their emotional support has been really important to me. You develop good relationships when you're admitted for such a long period of time, and it makes such a difference that I feel so comfortable going back for appointments."



Social Media Round-up

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

 @PHA_UK Congratulations to PHA UK member @maritessdunn who now has a Masters in Music Therapy!



 Bunty Cloy My hubby got his copy of Emphasis today... very interesting and informative.

 @robertireson Thanks for the information pack @PHA_UK, received today and now ploughing through it.

 Anxiety UK We work with PHA UK to provide support and information to its members #AnxietyUK.

 @KagGraham Great to receive Emphasis mag today and see the article about my book 'Life is for the Living'. #PHAware @PHA_UK



 @dk92 (Danielle) Bake sale was an absolute hit at work, so much was made and sold which raised £200 for the charity @PHA_UK - so thrilled with the outcome.



 @RHFFans Have a look at the great work @PHA_UK do, raising money and awareness for pulmonary hypertension

Join in the conversation online! Tweet us @PHA_UK and like our Facebook page at www.facebook.com/PULHAUK

Kate and Maddy



POUTING IN PINK FOR PH

A 'selfie challenge' designed to raise awareness of PH was organised by Kate Jones in memory of her best friend Maddy Hardman, pictured together, left.

Kate, who lives in St. Alban's, Hertfordshire, set up a Facebook photo campaign to raise money for PHA UK and generate awareness of the condition. She asked friends to upload photos of themselves wearing pink and pouting, with a caption describing PH and its symptoms. People posting selfies were also encouraged to include details of how to donate £3 to PHA UK by texting 'MADZ95 £3' to 70070.

The hashtags #PinkForMaddy and #PoutForPH were used alongside the selfies, and the campaign caught the attention of Kate's local newspaper, who published a story about it. Text donations totalled almost £400.

Maddy, who lived in Shenley, Hertfordshire, died in December last year aged 20, a year after being diagnosed with PH.

Kate said: "I was sitting on Facebook one day looking through old photos, and one popped up that showed Maddy and I on a school visit to Iceland back in 2011. I realised that she had been displaying signs of illness on that trip, but it took another three years for her to be diagnosed, and it hit home how important it is to raise awareness of PH and its symptoms. That's when I had the idea of the selfies."

Kate set up a JustGiving page when Maddy died and along with launching her Facebook campaign, she took part in the Rock Solid 10k mud run in Exeter earlier this year. Altogether, including general donations and with help from Maddy's family, the page has raised over £5,000 with gift aid for PHA UK.



The daughter of PH patient Mandy Noble has written a letter to the editor of Emphasis about her Mum's experience of the condition and urges us all to carry on raising awareness and understanding.



Dear Emphasis readers,

My mother lived with Pulmonary Hypertension for approximately 23 years before her death a year ago. I believe she was one of the longest survivors of the disease in the UK and wanted to write this letter to share her story. Mum was one of the most courageous people I know. My parents were given this life sentence / diagnosis of PH in the early 1990s as, unbeknown to my mum, she had been living with a hole in the heart since birth, which only started to present itself when she reached her 40s. It was when she was on an excellent trip to see Michael Jackson live in concert that my mum started to feel breathless. She then visited the GP who, following tests and a mini admission to a local cardiology unit, diagnosed my mum with heart disease. She was given ten years to live there and then.

Over the following years my mum visited many hospitals including the Freeman Hospital in Newcastle for their specialist treatment and tried many different medications to help alleviate her symptoms. She was then referred to a transplant centre, for transplant assessment. This was approximately 10 years ago. But whilst awaiting a heart and double lung transplant, my mum had a long term intravenous line fitted to enable an IV pulmonary dilator to work alongside the two oral medications she already took. This was a harrowing experience overall. I remember it well. Not only had the IV line been inserted just above her nipple, but the initial response to the IV proved distressing. She complained of feeling sick, suffering headaches and generally feeling awful. Then, over the days and weeks, my mum's condition seemed to improve as this toxic drug that had initially made her feel so poorly began to make my mum feel better. It kept her alive another 10 years.

Unfortunately, last year, my darling mum could no longer fight the disease, and passed away on 9th July 2015. Although my father, sister and I knew we didn't have my mum forever, it was still an unexpected tragedy when she died. Over the years, my mum gained a huge interest in campaigning for more awareness of PH and helped to raise money for PHA UK to promote knowledge of the disease, how it could be prevented and if too late, treated. My mum was an amazing woman who I will always aspire to be like. Thanks for reading my letter. I hope it helps others to understand more about living with the disease.

Cassandra Noble,
Newcastle-upon-Tyne



Gym membership for the mind

A digital tool designed to improve mental and emotional wellbeing is being recommended to PHA UK members, by our partners at Anxiety UK.

Headspace, the lifestyle app known as 'gym membership for the mind', uses proven meditation and mindfulness techniques to help users train their minds in order to reduce stress, encourage better sleep and improve focus and relationships.

Users are encouraged to listen to the app for ten minutes each day, enabling them to take time out to relax and focus their thoughts.

A subscription to the app, which can be accessed via computer, laptop, tablet or mobile phone, is available from £4.99 a month.

Anxiety UK is a national charity that helps people with anxiety. Through our partnership with them, PHA UK members receive free access to their dedicated helpline on 0844 332 9010.



They also receive free assessment and therapy provision if emotional support is needed, and training and resources. For those accessing therapy, a limited number of free subscriptions to Headspace are also available.

You also have the option of joining Anxiety UK yourself for more individual benefits if you'd like to. Members receive access to reduced cost therapy and peer support through an online community and pen-pals programme, plus a free 12-month subscription to the Headspace app and a full subscription to their quarterly magazine, *Anxious Times*.

Membership of Anxiety UK costs £30 a year and family and group memberships are also available. To find out more, call their team on 0844 332 9010 or visit www.anxietyuk.org.uk.

You can find out more about Headspace by visiting www.headspace.com.

App fan Chris Parkinson, a newcomer to mindfulness and meditation, tested Headspace on behalf of PHA UK. This is what he thought.

"The app features a variety of meditations, including focused sessions which help to deal with problems like anxiety and a lack of sleep, which can both be issues for people with PH. Plus, there are other specific areas such as improving generosity in relationships. The app even allows users to connect with one another to track and share their mindfulness progress.

It can take discipline to listen to something every day, but I tried to think of it like listening to a couple of songs – at whatever time of day suited me best, when I wouldn't be disturbed and could find a comfortable place in my mind.

In my opinion, if anyone is interested in practicing meditation for the first time, Headspace is the perfect place to start."

Record response to survey

We've had an amazing response to our 2016 Living with PH survey – more than ever before. Almost 600 people shared their experiences and we'll be reporting on the results soon.

This was a vital piece of research into what it means to have PH in the UK today and it will be used for years to come to make sure we are heard loud and clear in future debates about NHS policy and spending reviews.

The research is already attracting interest from key influencers within the NHS PH services, so if you filled in the survey, you've already helped to make a difference.

At PHA UK we are committed to representing the interests of people with PH, their families and carers, and the survey findings will also help us to decide our own future priorities about what issues to campaign upon; what research to invest in and what services we need to support to best meet their needs.

This survey was focused on PH patients using adult PH services and was open to all adults with pulmonary hypertension – PHA UK members or not. A separate survey dedicated to children and young people with PH will be organised in future. The Living with PH survey is now closed and the team are busy compiling all the responses. The results will be made available soon – so watch this space.

We're very grateful to everyone who took the time to fill in the survey. Thank you for adding your voices.

A BIG THANK YOU!

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  

Striding out for Shona

Jo-anne Magee and four friends from Belfast completed the Belfast Marathon Walk in memory of their friend Shona McFarlane, who had PH. The eight mile walk took place alongside the Belfast Marathon, and followed part of the route. Jo-anne said: "We promised Shona before she died that we would do something for PHA UK and we are over the moon with the £2,878 we have raised from the walk, which we called 'Shonafest' in her memory. I know she would be very proud of us all."



£2,878
RAISED

Kieren's cycling sportive

Kieren Hanogue from Leeds cycled the hills of North Yorkshire in the 112 mile Etape du Dales sportive, raising £819 in support of his friends, who lost their baby girl Erin to Pulmonary Veno-Occlusive Disease. Kieren's wife has also raised money by completing the Great North Run and the pair organised a sponsored walk at the school they work at. Kieren said: "The Etape du Dales was the perfect challenge to raise further money and awareness and as a family we will continue to support the work of PHA UK."



£819
RAISED

Rock'n'Roll run for PHA UK

Ahmed Yaseen took on the Rock 'n' Roll marathon in Liverpool to raise funds after his colleague Emily was diagnosed with PH. Along with his winnings from a Euro 2016 sweepstake (he picked Portugal!) Ahmed has raised over £350 for PHA UK. He said: "I really wanted to help as soon as I found out about Emily being diagnosed with the condition. I am extremely moved by her level of courage and determination and I wanted to make a positive difference."



£350
RAISED

Team Heartbeat's Total Warrior

Northumbria University student Jamayal Khan joined family and friends to take part in a 12k Total Warrior challenge. Calling themselves 'Team Heartbeat', together they raised £500, in support of Jamayal's aunt Sam Khan, who is a Trustee of PHA UK. He said: "The challenge was tough but it was great to complete the course as a team. My aunt is an inspiration and we were pleased to be able to support PHA UK."



£500
RAISED

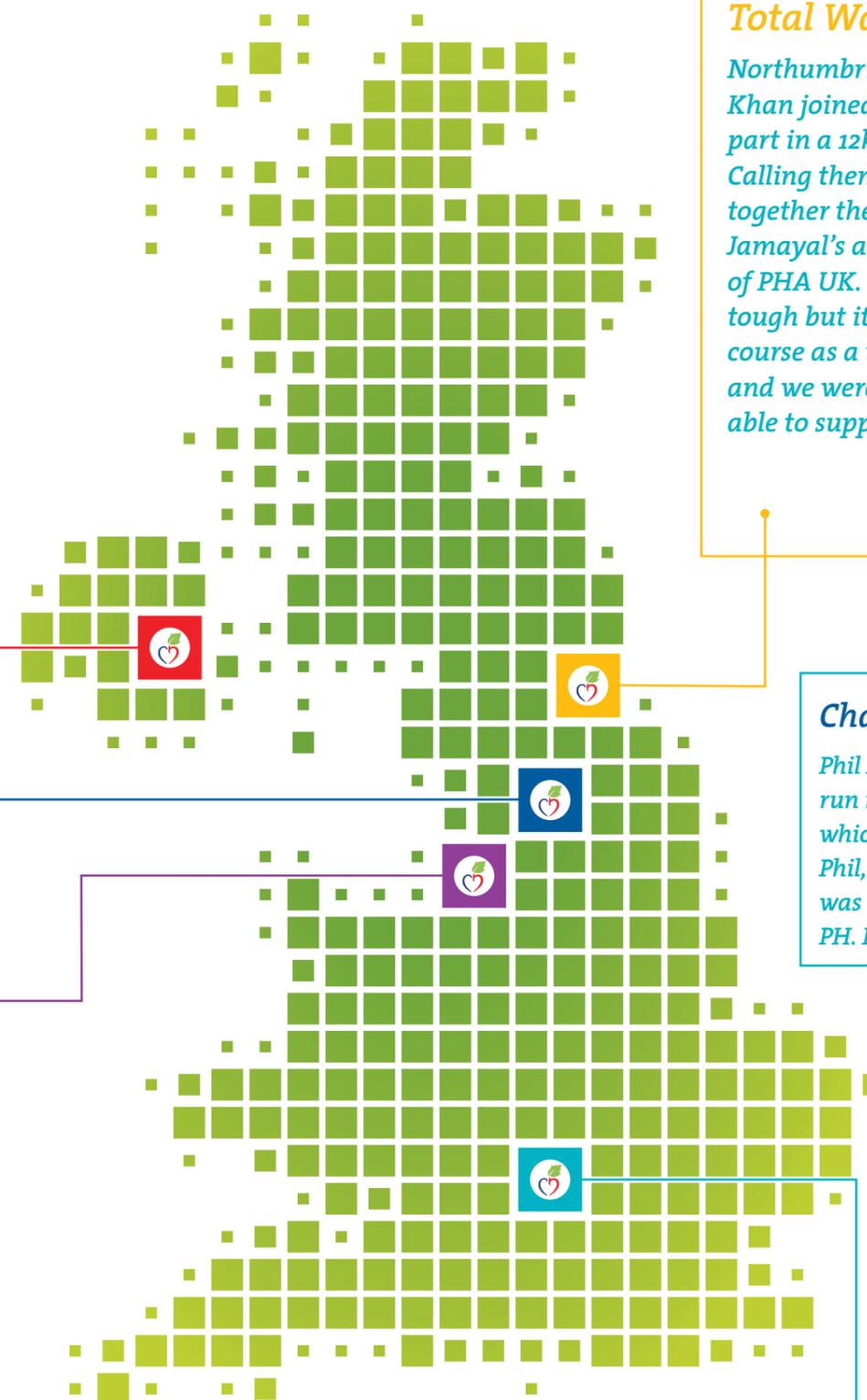
Challenge of a lifetime

Phil Marshall completed a moorland run in North Yorkshire of 110 miles, which took 28 hours non-stop to finish. Phil, who lives in Banbury, Oxfordshire, was inspired by his wife Sarah who has PH. His run raised almost £9,000.

Phil, who described his run as the 'challenge of a lifetime', said: "PHA UK were our lifeline when Sarah was diagnosed. With their help, we have learned to manage the disease, made new friends on their own journeys, and have become involved in research to improve treatments and hopefully develop a cure in the future."



£8,809
RAISED



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

KEEPING POSITIVE WITH PH



Mary Jane Lomer from Hampshire was diagnosed with PH 14 years ago, but refuses to let the condition hold her back. Here, she explains how she makes the most of life.

I had always been a bit breathless and had all the symptoms of PH. In 2002 I was diagnosed by Dr Simon Gibbs at Hammersmith and with the amazing quality of care from the PH team and a change of lifestyle, I have carefully limited my activities to suit my energy. This doesn't mean sit down and do nothing as I find resting for too long a period makes you feel worse. But I've learned not to accept two invites in one day! Sometimes being out of sorts can last for several days. However, thanks to the team at Hammersmith, my condition is carefully monitored by Dr Luke Howard and Dr Rachel Davies. They are accompanied by Clinical Nurse Specialist Wendy Gin-Sing, who has been like a gold thread through the years of my PH with her kindness and care. I can't thank them all enough for extending my life and helping me to continue enjoying my retirement and family life.

I am so lucky with my family who realise that I am not 'ill', but that I have a chronic lung condition which won't go away.

Together with my daughter Miranda and grandson Ted (pictured), who is four, we have just flown to France to stay with my son Chris, and as the flight was such a success I am soon to go back alone. This was another milestone as it was my first flight using oxygen.

Since my grandson was born, four days after my husband died, I have been driving to my daughter's house each Thursday to have what Ted calls a 'Granny Day'. This has given me a purpose, and I have been able to plan what I do with Ted to suit my condition at the time.

Belonging to a 'normal' group of people, not just a group with health problems, is very therapeutic. I have been a Women's Institute (WI) member since 1965 and everyone knows of my condition, and that I need to go home when the meeting hall gets hot and airless.

I also like to write. I recently published a book about my local area in Rowlands Castle, which I'm selling to raise money for PHA UK. I initially released 'Round and About Rowlands Castle' in 1988 and spent 18 months updating the book for its re-release. It was great fun to work on and helped to stop me thinking about PH. Painting has also been my life's pastime. I paint and sketch everywhere I go and many of the pictures in the book are by me.

I still get really bad episodes of feeling terrible, but I move about to stir up the oxygen. If I have done too much, I stop. I enjoy gardening, but if I get tired I ensure I sit down after a few jobs until the energy returns. I walk whenever possible but rest every so often. I know many people in my village, so I often stop to chat!

I have had a very exciting life and met many people living a more restricted lifestyle than I have experienced. So instead of saying 'why me?' I have always said 'mustn't grumble', as so many people are worse off than myself. ● ☺



Learning from the world at global PH conference

PHA UK have attended an international PH conference, where hundreds of people from over 40 countries gathered in America to learn from each other about research and treatment.



The International PH Conference was organised by the Pulmonary Hypertension Association, the American equivalent of PHA UK, and took place in Dallas, Texas, in June. The event marked the 25th anniversary of the charity.

Over 1500 people attended from around the world, with half of those attending made up of patients, caregivers and family members. Other delegates included medical professionals, researchers and medical students. It was the biggest turnout the conference has ever seen.

The three-day event included 25 medically led sessions, back-to-back scientific sessions from PH thought-leaders from around the world, and lots of opportunities for patients to network together.

Singer and musician Chloe Temtchine, who has PH and performs whilst attached to her oxygen canister, entertained the crowds with her latest single, 'Breathe'. And Rino Aldrighetti, PHA's first president and CEO, reflected on his 17-year career with the charity after announcing his retirement.

PHA UK chairman Iain Armstrong,

with trustee Kay Yeowart and her husband David, a former trustee, attended the conference on behalf of PHA UK. Kay and David's son Lewis was diagnosed with PH in the 1990s and the family travelled to the USA to seek treatment for his condition.

Kay, who then helped set up PHA UK in 2000, said: "It's very important to keep links with associations from around the world, as we all have the same challenges, but it's interesting to see how they are dealt with in different countries."

"It was great to speak to the medical professionals there, and to so many PH patients too. One of the standout scientific sessions for me was delivered by Professor Martin Williams from Imperial College London, who talked about personalising medication and the role of genetics in PH.

"It was also interesting to see how widely oxygen is used in America, and quite humbling to see the way patients don't let it hold them back. Watching Chloe Temtchine perform so beautifully, with her canister, was a special moment."

For David, the highlight of the conference was meeting so many patients, who were all happy to share

their stories and experiences.

He said: "It felt very much like a 'family affair', as there were so many people yet everyone was so friendly. It was really interesting to see how much treatments have developed, and great to see that the UK is keeping pace."

“It's very important to keep links with associations from around the world, as we all have the same challenges.”

Kay added: "The first American conference we attended was 17 years ago, shortly before we set up PHA UK, when there were one or two approved PH treatments available. Today, there are 14. There's been so much progress, and there are now so many more long-term survivors of the condition. It gives us a lot of hope for the future, and we all left the conference feeling very positive and enthused." ●

So you need a transplant..?

Transplants can be a life-saving option for people with PH – but what happens if you choose this treatment option? Here *Steph Pollard* talks through the process and, overleaf, two pulmonary hypertension patients share their transplant stories.

Every year, cardiothoracic surgeons at specialist centres across the UK transform and save lives through heart and lung transplants, sometimes performing 'heart and double lung' transplants – also called a combined transplant.

People with PH and those born with congenital heart disease are probably most likely to require a combined transplant and on average, only six are performed a year.

Several people with PH across the UK are currently on the transplant waiting list. In 2015, the National Audit of Pulmonary Hypertension recorded that three PH patients underwent transplants.

Usually, transplant is considered for PH patients when a range of oral and intravenous medical therapies have failed to alleviate their symptoms and protect their quality of life and their life expectancy. Transplant is put forward when their own diseased lungs, or heart and lungs, are assessed as 'severely damaged'.

There is then a great deal of discussion between patients, their PH consultant, PH team, other professionals such as their GP, family and loved ones. Transplant can often be an option for children with aggressive forms of PH and/or heart disease, but the decision always belongs to the patient and their family, and they may change their minds at any time in the assessment process.

NHS heart and lung transplant units include Harefield Hospital in Middlesex; Wythenshawe Hospital in Manchester; Freeman Hospital in Newcastle; Queen Elizabeth Hospital in Birmingham; Papworth Hospital in Cambridgeshire; and the Freeman Hospital in Newcastle and Great Ormond Street Hospital in London.

Consultant transplant physician Dr Colm Leonard of Wythenshawe's heart and lung transplant centre at the University Hospital of South Manchester said: "The transplant assessment process is handled with the highest levels of medical skill, care, communication and attention to detail at specialist centres like ours. To begin with, every patient referred to us undergoes a thorough series of tests to see if we would recommend that they are suitable for transplant."

These tests may include blood tests, urine tests, blood pressure tests, lung

and heart function tests, x-rays and CT and MRI scans.

The patient's consultant then discusses the transplant team's recommendations with them and if the patient decides to proceed, they are put on the transplant list. A transplant co-ordinator will then support them as they wait for donated organs that match their needs and their blood group.

It can mean a frustrating and frightening wait; and for some, sadly, the wait can be too long. We are all aware that some people die while on the waiting list, and campaigning is ongoing for more people to sign up as potential donors.

When a donated organ, or organs, which may be suitable for a particular patient do become available, everything can happen very quickly.

Dr Leonard says: "Our donor management team, made up of specialist nurses and doctors who are skilled in organ retrieval, goes directly to where the organs have been donated to assess them and ensure they are maintained in the best possible condition. If all goes to plan and the organs remain a good match for the patient, a transplant operation could happen within hours."

.....
“The transplant assessment process is handled with the highest levels of medical skill, care, communication and attention to detail at specialist centres.”
.....

Sometimes, something turns out to be not quite right with the organs or the patient is too ill for the procedure and the transplant is called off.

But if the patient and organs remain a good match, the operation is carried out immediately by a specialist surgeon, which can take several hours. A piece of equipment called a heart-lung bypass machine is attached to the patient throughout, and this keeps oxygenated blood circulating around the body. The operation is extremely complex but, put simply, the patient's organs are removed and new organs put in place and connected to existing blood vessels.

Patients usually stay in hospital for a few weeks afterwards. The organs are monitored to ensure they are working properly and to ensure the body does not reject them. The patients are helped to breathe and feed and manage post-operative pain as they recover too.

Dr Leonard says: "Following surgery, patients are cared for on our cardiothoracic critical care unit then transferred back to our dedicated transplant ward, where our highly-skilled transplant nurses continue to monitor and support their recovery."

When patients go home, they continue to have check-ups and tests as their progress is monitored, plus physiotherapy to strengthen the new organs – called cardiopulmonary rehabilitation. Another essential part of the recovery process is the taking of immuno-suppressants which are powerful medications designed to prevent our immune systems from rejecting and attacking the new organs as 'foreign bodies'. Sadly this is always a risk. To guard against this happening, transplant patients need to take immuno-suppressants for life.

Even when transplant patients have made a full recovery, they will still need regular check-ups. Dr Leonard says: "Patients do need to return for reviews, generally at the centre where they received their transplant. But, if all goes well, the frequency of visits reduces over time. We are conscious of travel issues but are often told by patients that they appreciate returning to the unit as the staff feel like an extended family to them!"

Having a transplant is certainly a major life event and the impact on patients and their families can be very wide reaching. With this in mind, units like that at Wythenshawe offer support services including appointments with social workers and psychologists, support groups and transplant buddy schemes. Patients are also offered advice on exercise and diet.

Every transplant experience is different, but all demand the highest standards of medical expertise, support and care. Read how having transplants transformed Jocelyn and Pauline's lives overleaf. And to find out more about the transplant process, talk to your PH team or visit www.nhs.uk and search 'Heart-Lung Transplant'.

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Read Jocelyn's and Pauline's stories.
.....

PAULINE'S STORY...

Pauline Ginn, aged 55, of Bolton, in Lancashire, didn't have to wait long for her heart and double lung transplant – she was put on the waiting list in January 2015 and underwent the life-changing surgery in April. It was a good job though, as she was in urgent need. Here Pauline tells us how an early match probably saved her life.

"When I was having the transplant assessment in January, I felt alright really; quite well. And as I went through the process, I had it in mind that a transplant was something that might happen to me in future, in ten years or so. I had no idea just how quickly my condition was going to deteriorate to a crisis point and that I'd need a transplant within weeks. Or that I'd get one!

I was born with a hole in my heart but doctors had thought it would close itself in time and it wasn't until I had a check-up when I was 23 years old that they discovered the hole had grown with me. The doctors said that I would not see 30 unless I had open heart surgery, which I did. Meanwhile my PH had got progressively worse as the hole was in the left ventricle, and the right ventricle was having to cope with all the work. The cardiac consultants at Wythenshawe Hospital referred me to the Royal Hallamshire in Sheffield when I was 42 years old and Dr Kiely confirmed my PH diagnosis. I was Dr Kiely's 100th patient! I know he has seen hundreds now.

After years of colds turning to pneumonia, and putting me on every PH treatment and IV therapy going, I was put on the list for a transplant last year.

It was shortly after that, that I got a severe chest infection, was rushed to intensive care and spent three months at the Royal Hallamshire, often in high dependency care. I was so weak. I had two pints of fluid removed from my body and another one and a half pints from my left lung. I'd lost so much weight I was reduced to five and half stone. I did look poorly, I was blue. They were really worried about me.

Eventually I was sent home on 24 hour oxygen and was in quite a bad state. Just three weeks later I got the call that a 'package' of heart and lungs had been donated that were a perfect match for me. I couldn't believe it. But one thing was for sure, the transplant was a necessity. It had to be done.

My consultant surgeon at Wythenshawe Hospital was Dr Venkateswaran and he is such a lovely man. I give him a hug and kiss every time I see him. I was his first heart and double lung transplant – but he didn't tell me that until afterwards! He'd observed five operations before tackling me and he hopes to carry out many more up here in the north in future. He has already carried out one more since mine.

I was in theatre for ten and a half hours and then in intensive care for five weeks and on the rehab ward for two weeks, but it has all turned out well. I am here with my family. That is the main thing. I'm not sure I would be otherwise. I was so very ill before and my lungs were in a terrible state.

We've had our first holiday in ten years in Spain this summer and I am so grateful to everyone – the donor and their family and all the medical staff – for this second life. One of the weirdest things is how much I miss everyone at the Royal Hallamshire Hospital as I don't have to go now! Part of rebuilding your life after such a dramatic operation is adjusting to all the changes like that, which you just don't think about beforehand."

Pauline with Dr Venkateswaran.



Pauline and family celebrating one year after transplant.



JOCELYN'S STORY...

Jocelyn Barker of Brixton in South London had a double lung transplant at Harefield Hospital in 2008 after a four year wait. Here, she tells her story:

"I was diagnosed with Idiopathic Pulmonary Arterial Hypertension in 1996, although it was then called PPH. I had been progressively short of breath after the birth of my second baby and when I finally decided to seek help, I had to go down the typical route of suspected asthma, panic attacks, or stress - which I knew weren't right.

Eventually I was diagnosed about a year after my symptoms began. I deteriorated slowly over the next few years on Warfarin and calcium channel blockers until an amazing new drug called Bosentan became available in early 2002. This really helped until the dreaded breathlessness broke through again. This became the pattern as we added more drugs, nebulised iloprost, sildenafil and finally subcutaneous treprostinil, but the slow deterioration just kept on.

In 2004 I had a few days at Harefield Hospital for a transplant assessment and was told I needed to go on the list straight away for both a heart and double lung transplant. We decided to live as normal a life as possible whilst on the list, and went on holiday abroad and for days out as usual.

It was difficult at times knowing that, however you rationalise it, I was waiting for someone's tragedy for my chance. Two false alarms and three and a half years later, in 2008, I finally received my new lungs. A heart and lung block wasn't going to be available in time and my heart looked as if it would recover once the pressure was removed, which it did. I spent ten days in intensive care and was home about a month after the transplant.

Despite some common experiences, the whole transplant process and recovery is quite individual. I was so grateful to have the chance to fight for



Jocelyn Barker.



Jocelyn and family.

my health, but it was tough when I was already exhausted from the severe PH. I did have a dark time when I felt I couldn't tell people how low and unwell I felt because everyone was so happy for me. Although for years now I have felt so, so grateful, happy and determined to make the most of all I have.

I love travelling and post-transplant I've done lots of it, including five weeks backpacking in South America. I've loved white water rafting, paragliding, cycling and just being able to walk everywhere.

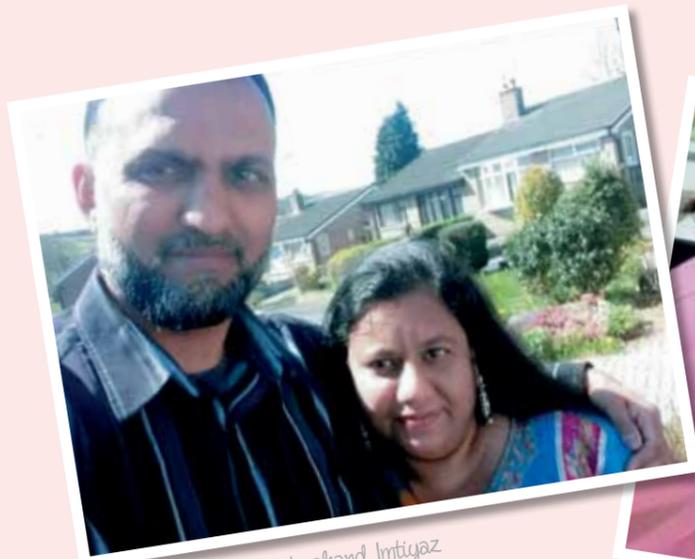
I do feel a responsibility to live a purposeful life and so work full time in various voluntary roles. There have been a few medical emergencies and for me fatigue is the most difficult symptom, but being busy distracts me from thinking about it too much and I build rests into the day. Now at eight years post-transplant there are more problems, but the team at Harefield are wonderful.

I would say the overwhelming emotion in the whole experience is gratitude, to the fantastic team at the Hammersmith Hospital's PH Centre who looked after me very well pre-transplant, to my donor and her family, to all my family, friends and church who have supported us all, and to the team at Harefield who continue to care for me. Just a huge THANK YOU."

Read Jocelyn's daughter's perspective on her Mum's transplant experience in our Family Matters column on page 34.

Living with PH in my community

Rukhshana's story



Rukhshana with her husband Imtiaz



Rukhshana with her son Amaan



In a personal account for Emphasis, 45-year-old *Rukhshana Khalifa* explains how she has struggled with her diagnosis in her close-knit community – and why raising awareness of the condition is important in all cultures.

“I was told I had asthma, but I started getting more breathless and tired and had to stop exercising, so my weight increased and I started to feel really depressed. I found it hard to tell my family and friends in the community what was wrong. People could see the changes in me but they didn't understand why, and neither did I at the time.

I think one of the problems is that in my community people tend to always be very busy and there is a culture of 'just getting on with things', so it's difficult to accept that someone feels ill but has no clear reason for it.

My friends laughed the first time I took a taxi to my work at a children's centre as I was unable to walk or catch the bus. They told me I should be walking as it would help me lose the weight. I just couldn't make them understand that something was happening to me.

A couple of times I collapsed at work but as I was fasting for Ramadan, people just assumed it was because of that. Eventually I had to stop going to work altogether as I could no longer run around after toddlers.

After being in and out of hospital for some time, in many ways it was a relief to be diagnosed with PH last year, as at least I knew what was wrong. But the problem was that no-one around me had heard of PH, so still didn't take what was happening to me seriously.

It seems to be really hard for my community to understand what this illness is. I've had family who have had cancer, and because everyone knows what cancer is, the community immediately accepted how serious it was.

But from the start of my symptoms my parents found it hard to understand and when I was diagnosed they wouldn't come to the hospital with me to talk to the nurses. Eventually they came, but they still struggled to accept the diagnosis. Although I think now it is slowly starting to hit them.

It could be that the lack of understanding, or wanting to understand, is the same in every community, but I find it all very frustrating. It doesn't help that from the outside you can't really tell there is anything wrong with me, apart from the weight gain and the swelling.

Having PH has affected how involved I am in my community.

For example, Muslim weddings are a big part of our culture and they tend to last for a full weekend, with all the focus on food and dancing. I now get too tired to attend them.

I do still see my friends sometimes and as time has passed since my diagnosis they seem to understand a bit more. I have had a lot of support in particular from my friend Shenaz, and from former colleagues at the children's centre.

I've given my friends leaflets about PH and encouraged them to read up about it, but still some people ask me why at the age of 45 I act like I am 80, and it really gets to me.

Really, it's only my husband Imtiaz and my 15-year-old son Amaan who understand what I'm going through. I feel like I can't explain my symptoms to anyone else. Imtiaz has been very supportive, as has my son. He is studying physics at school and likes to learn more about the disease. He often chats about it with his teacher.

I am aware though that all this is hard for them too. But I think men seem to find it difficult to admit when they are struggling – in any culture!

The support I have had from the PH centre at the Hallamshire in Sheffield has been amazing too. When I'm there, I feel like I'm spending time in a nest. I feel protected and I'm so grateful to them. And my faith as a Muslim has been a great source of support for me too. I've been praying a lot more since my diagnosis.

I have other ways of coping too. I have always been someone who likes to look glamorous so taking care of my appearance helps me to feel better about myself. However, that does make it even harder for people in my community to understand that I am ill.

It seems to be a cultural thing that women don't 'put themselves out there' but due to the lack of understanding I have experienced I really wanted to share my story with Emphasis and I would love the opportunity to spread awareness about PH further. ”

Rukhshana is backing **PH Awareness Week**, as she is keen for the Muslim community to understand more about her illness. Read more about how you can get involved on [page 26](#).

OXYGEN

AN ESSENTIAL GUIDE

Oxygen is vital for life - and oxygen therapy is part of everyday life for many people with pulmonary hypertension. Here *Kate Betts* takes a closer look at the life-supporting component of air and how some PH patients receive oxygen therapy.



Oxygen is needed by every cell in the human body and is used to generate energy through our respiration process in each cell. It really is vital to life.

It comes in to our bodies through the air we breathe into our lungs and moves around the body attached to haemoglobin in red blood cells. In pulmonary hypertension the walls of blood vessels in the lungs (the pulmonary arteries) are narrowed and thickened, making it harder for blood to flow through the lungs easily. Or the arteries may be blocked by blood clots, with the same effect on blood flow. This means the heart has to pump much harder to get enough blood through the lungs and then around the body. How much blood your heart pumps around the body is referred to as your cardiac output.

The oxygen level in your blood is usually measured in the clinic with a finger-tip sensor and is referred to as your oxygen saturation level. Normally, oxygen saturation levels should be between 96 and 98 per cent. You can still be breathless with normal or near normal oxygen levels because your cardiac output is low.

Sometimes in pulmonary hypertension, because blood cannot flow evenly through the lungs, the actual level of oxygen in the blood also drops. This can add to the problem of a low cardiac output and worsen breathlessness symptoms.

To counteract this for some people with PH, oxygen treatment is used to increase the amount of oxygen in the lungs and bloodstream. This is also known as home oxygen therapy. Not everyone with PH needs oxygen therapy and many will not need it all the time. It may be that oxygen therapy is only used at night when sleeping. This is because oxygen levels are usually lower in the blood at night. Whether or not someone with PH needs oxygen, and when they need it, will be agreed with health professionals after an assessment. The oxygen will be provided for free by the NHS at the person's home, where they will be shown how to use it by a specialist engineer.

The oxygen is supplied in a cylinder or an oxygen concentrator machine. Cylinders can be filled with compressed oxygen or liquid oxygen. Liquid oxygen is supplied in a large container, every

fortnight or so, and this is used to fill a portable cylinder, which is small enough to carry around.

Compressed oxygen is supplied in cylinders of various sizes, some which are small enough to be portable. They can be moved using wheeled devices or backpacks.

Air is about one fifth oxygen. The rest is mainly nitrogen. A concentrator takes in air and extracts the nitrogen from the air, leaving just oxygen. Patients given a concentrator, which is also sometimes called a convertor, compressor or condenser, are also given a back-up cylinder in case of a power cut. Concentrators tend to be given to people who need to use oxygen for many hours a day.

What is oxygen?

> Oxygen is a colourless, odourless, and tasteless gas.

> Oxygen is a chemical element that makes up 21 per cent of the air that we breathe. The other 79 per cent is mainly made up of nitrogen, with tiny amounts of carbon dioxide and other gases.

> Oxygen is vital to life, because every cell in the human body needs it to function.

> Oxygen comes in through the air we breathe into our lungs, where it is taken up by red blood cells and carried around the body in blood vessels.

> Oxygen was said to have been discovered by Joseph Priestley in Wiltshire in 1774, but others claim it was actually discovered a year or two earlier in Sweden.

The British Thoracic Society best practice guidelines say that using nasal cannulae (nose tube) is the preferred method of delivery for the oxygen; it is possible to eat and drink while using nasal cannulae; but for some a mask may be more suitable. Masks are useful for people who need higher flows of oxygen. Sometimes nasal cannulae can be uncomfortable and cause a dry, sore nose. But it is important not to use Vaseline or any petroleum-based product to relieve this, as they can be flammable. Health care professionals or pharmacists can advise on alternatives. There are some other precautions needed when using and storing oxygen, as it is a fire hazard. The NHS says for example never let anyone smoke while you're using oxygen; keep oxygen at least six feet away from flames or heat sources,



Dr Luke Howard

such as gas cookers and gas heaters; inform your local fire brigade that you have oxygen at home (although your supplier may do that for you); inform your car insurance company if you are going to transport oxygen in the car, and keep oxygen cylinders upright to prevent them being damaged.

There are lots of tests that need to be done by health professionals before they decide whether to prescribe oxygen. These include the simple finger-tip sensor that measures oxygen saturation and blood gas tests (from your wrist or earlobe). Sometimes measuring oxygen levels while walking and sleeping is required. Dr Luke Howard, Consultant Respiratory Physician at Hammersmith Hospital and Honorary Senior Lecturer at the National Heart and Lung Institute, Imperial College London said: "Oxygen therapy may really help some of our PH patients, but it is important for patients and carers to realise that oxygen will only really help breathlessness when oxygen levels are reduced. This is not usually true for our patients born with heart defects, where oxygen usually does not help.

"Many patients ask me if oxygen is addictive or worry that if they start it, they will get used to it such that the effect will wear off, but I always reassure them that this is not the case. We don't have any good evidence that oxygen therapy provides long-term benefit to their condition, unless patients have a diagnosis of COPD, so really we are giving people oxygen to help improve their symptoms and quality of life. This should reassure patients that if they don't feel better on it or don't want it, they are usually not harming themselves if they opt not to use oxygen. The only exception to this may be in patients to whom we recommend oxygen at night, for whom we'd say this therapy is more of a necessity." ●

For more information go to www.phauk.org/treatment-for-pulmonary-hypertension

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Let's talk about PH

It is nearly time for our first ever PH Awareness Week UK! Here's how you can get involved and get everybody talking about PH.

PH Awareness Week will take place from **Saturday November 19th until Sunday November 27th**. The aim is to help everyone affected by pulmonary hypertension to share their experience of living with the condition and raise awareness amongst friends, family, neighbours and health professionals across their community.

If you would like to join in, there are lots of things you can do. For example, you could engage in the big PH conversation on social media; invite your friends and neighbours around for a chat about PH; talk about PH at work, share your PH story with your local newspaper and radio station or write a letter direct to your

local GP practice or MP. Turn the page for the 'top ten things' you could do to get involved in PH Week 2016.

Chair of PHA UK Iain Armstrong said: *"Lots of people tell us they can feel very frustrated about how little some of the people closest to them within their own communities, workplaces and families know and understand about what living with PH means – and how they never seem to get around to sitting down and having a conversation about. That is what PH Awareness Week is all about - reaching out to everyone and helping people seize the opportunity to 'Talk about PH'."*

Visit the 'PH Week section' at www.phauk.org

Email us on PHWeek@phauk.org

Call PHA UK on 01709 761450

TEN GREAT WAYS TO GET INVOLVED...



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"Let's talk about PH"



**PH
AWARENESS
WEEK
2016**

Ten things you can do in PH Awareness Week



1

#LetsTalkPH

Whether you use Facebook, Twitter or Instagram, include the hashtags **#PHweekUK** and **#LetsTalkPH** in your social media posts and help spread the word online. Follow and share PHA UK's social media posts. Share your own news, stories, photos and experiences. Join the conversation and let's get PH trending!

2

Put the kettle on – invite people to come and talk about PH

Invite friends, neighbours and relations around for a cup of tea and a chat about PH. We've designed some invitations you can download from our website at www.phauk.org. And you can also email us on PHWeek@phauk.org or call **01709 761450** to request some copies of our new **'PH pocket guide'** AND a cuddly PHA UK hippo! Share a photo of your new friend on social media with the hashtag **#HippoInTheRoom** to show everyone you're encouraging conversations about PH!



3

Talk to your local media

Tell your local newspaper, radio station and TV news channel about your story and how you are supporting the UK's first ever PH Awareness Week. You can contact them direct – they are always looking for human interest stories. There is a press release template you may like to use available to download from our website and some tips on contacting the media on **page 38** of this magazine!

4

Spread the word at work

Do you have an internal newsletter or e-bulletin? Would you like to ask if you can include an article about your PH story as part your support for the UK's first PH Awareness Week? Use our template article at www.phauk.org if you like.

5

Write to your GP or local hospital

PHA UK has a special offer on our PH medical education programme during PH Week. Could you write to your local practice or hospital and let them know about this flexible e-learning course all about the diagnosis and treatment pulmonary hypertension? There is a template letter you can download from the website. Please help us to invite more GPs, hospital doctors, nurses, pharmacists and healthcare workers across all disciplines to sign up and learn more about PH.

6

Write to your local MP

It's always a good idea to keep politicians and policy makers informed about PH! Why not send a letter to your MP telling them about our first PH Week and about your experience of the condition, how it is treated and where you go in the NHS for that treatment. MPs are interested in their constituents' lives. Help them to make well informed decisions about healthcare and welfare services in the future. Download our template MP letter from the website. And let us know if they reply!



7

Take on a fundraising challenge

Supporters of PHA UK are all-year-round fundraisers! But you may also want to hold a fundraising event or take on a challenge during PH week and make the most of spreading the word. How about a sponsored swim, run, walk or bike ride? Or a sponsored silence, knit-a-thon or bake-off. Contact PHA UK on **01709 761450** for a fundraising pack.

8

Get blogging

If you already write a blog, include an entry about PH Week and link to it from your social media accounts using the hashtag **#PHweekUK**. If you don't yet blog, our awareness week could be the perfect time to set one up. After all, writing is great therapy!

9

Tell teacher

If you have children with PH, you could use PH Week as an opportunity to see if you could pop in the staff room and talk to more teachers and classroom support staff about the condition and how its symptoms affect your child. You could also ask if you could put a poster up on the school noticeboard.

10

Increase your own knowledge of PH

The more you know about PH, the more you'll be able to tell other people. Have a look at the materials available from **PHA UK's Resource Centre** and via our website, or connect with other PH-ers on Facebook and Twitter. And thank you for reading your Emphasis magazine. If there are any subjects you'd like us to cover in future issues please let us know editor@phauk.org



Let's talk about PH

PH
AWARENESS
WEEK
2016
19th-27th Nov

A handy new pocket guide to PH

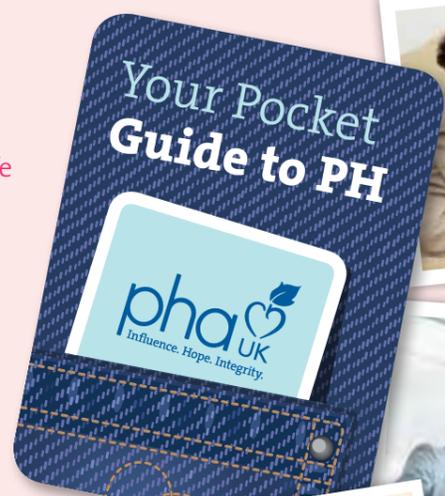
We've produced a new pocket guide to PH which will be launched during PH Awareness Week 2016. The z-card-style leaflet is a handy little tool to carry around and give people to read about pulmonary hypertension, its impact on people's lives and the aims of PHA UK.

Chair of PHA UK Iain Armstrong said: *"We hope the PH pocket guide will help people with PH pass on a little more information about PH and what it is like to live with the condition. Reading it with friends, family and other members of their community may also help to spark discussions about their experience of PH and how it affects them."*

To request copies of the **'PH Pocket Guide'** please call us on 01709 761450, email PHWeek@phauk.org or write to PHA UK Resource Centre, Unit 1, Newton Business Centre, Newton Chambers Road, Thorncliffe Park, Chapeltown, Sheffield, S35 2PH.

Talking Points about PH – a handful of facts for PH Week 2016!

- Around 7,000 people are diagnosed with pulmonary hypertension in the UK.
- Symptoms of PH can include shortness of breath with just a little exercise such as climbing the stairs; feeling tired or dizzy; swelling around the ankles, arms or stomach; fainting; and chest pain.



- Pulmonary arterial hypertension is a rare condition which responds to highly advanced treatment. It affects two to four times more women than men.
- Pulmonary hypertension can be caused by a build-up of blood clots in the pulmonary arteries over time. This is called chronic thromboembolic pulmonary hypertension (CTEPH)
- PH affects people's ability to carry out basic tasks and get around. Living with the condition can also have a significant impact on emotional wellbeing.



Support day brings patients together in Scotland

PH patients in Scotland came together for a support day organised by the Scottish Pulmonary Vascular Unit (SPVU), based at the Golden Jubilee National Hospital in Glasgow.

Just under 100 patients and carers attended the event, which included educational talks and workshops.

The day, which takes place every two years, was put together by SPVU clinical nurse specialists Karon Carson, Rachel Thomson and Val Irvine, and was sponsored by PHA UK.

Attendees at the event, which took place at the Golden Jubilee Conference Hotel, took part in workshops that covered topics including travel, oxygen, breathlessness and diversion therapy.

“...it was especially good for patients to come together and meet others with PH.”

Talks were delivered by PH professionals including research scientist Dr David Welsh, and Yvette Flynn - one of the founders of the Great Ormond Street Hospital PH service for children, who now works on development projects for PHA UK.

A question time session enabled the audience to put their PH queries to an

expert panel, and a special workshop designed to support carers was delivered by SPVU research nurse Val Pollock.

Throughout the day, delegates were also able to enjoy complementary therapies including massage, Reiki, reflexology and nail treatments.

Karon Carson, clinical nurse specialist, said: *"The purpose of the day was to provide support and education for patients and their carers and overall, feedback from the event has been excellent."*

"Everyone seemed to learn something and it was especially good for patients to come together and meet others with PH. Funding for these types of events is always an issue so we're very grateful to PHA UK for their support."

Shaun Clayton, director of membership support at PHA UK, said: *"It's really important that PH patients and their loved ones have the opportunity to share their experiences with others so we were very pleased to be able to support the SPVU to deliver their event."*

The Scottish Pulmonary Vascular Unit was founded at the Western Infirmary in Glasgow in 1990. Its next patient support day is planned for April 2018. ●



How to make the most *of your pharmacist*

Senior pharmacist *Neil Hamilton* explains why a pharmacist is a great source of health advice and support – all without an appointment.



Pulmonary hypertension is a condition best managed by experts in specialist centres, isn't it? Yes, and no. I can't praise the UK specialist centre network highly enough - it is the envy of the world for the quality of care provided for those living with PH.

However, even those patients with very advanced symptoms requiring inpatient stays are only in hospital for a fraction of their year. The rest of the time they are at home, often some distance from their PH centre, with their friends and family. It is during this time that being able to get good advice locally is vital.

I am sure that everyone will have, at some point, tried to get an urgent appointment to see a GP and struggled due to sheer demand. In addition, however helpful your centre is, sometimes telephone advice is not the answer. I wonder how many of you have turned to your local pharmacist in this situation?

As well as your GP, district nurse or community matron, a pharmacist is another health expert you can turn to for advice and support - and the great thing is you don't need an appointment. Pharmacists are highly-trained healthcare professionals who can answer questions about lots of health conditions.

As well as in large high street pharmacy chains (such as Boots and Lloyds), there are pharmacists in every independent chemist, supermarket

pharmacy, and increasingly in GP surgeries - not to mention hospital pharmacies.

It may be that they haven't come across much pulmonary hypertension before, but crucially all pharmacists will know where to look for advice and information regarding your very specific PH medication. They will also be very familiar with all the other more commonly prescribed medicines you take for other conditions.

If you have any questions about your medicines, you can walk into any local pharmacy and ask to see the pharmacist. Practically speaking, this is helpful because you don't need an appointment; pharmacies are sometimes open outside of GP surgery hours - for example at weekends or in the evening; and many pharmacies now have private consultation rooms.

As well as getting information and reassurance from your pharmacist, some also offer free repeat prescription collection and delivery services.

Don't just take my word for it – I am biased after all! In the NHS Strategy document published last year, entitled 'The Five Year Forward View', NHS England Chief Executive Simon Stevens outlined how we need to "make far greater use of pharmacists: in prevention of ill health; support for healthy living; support to self-care for minor ailments and long term conditions medication review in care homes; and as part of more integrated



local care models".

Dr Jill Loader, Assistant Head of Primary Care Commissioning (Pharmacy) at NHS England also recognises their value, saying; "Pharmacists are highly qualified health care professionals, training for five years to become experts in medicines and in giving health and wellbeing advice. They are often available during evenings and at weekends. They give respected advice to many other health care professionals and for some patients they are the first port of call. However, many people are unaware of all the services a modern pharmacy can provide."

With all this in mind, overleaf is my guide to getting the right support and advice when you decide to go to see your pharmacist. >>>



1. Getting the most out of your medicines

You can ask your pharmacist about any prescription or over-the-counter medicines you're taking. This is especially useful if you have concerns about side effects, if you're worried about not taking your medicines correctly, or if your medicines don't seem to be helping much, for example.

To help you understand the medicines you take, if you're in England, Northern Ireland or Wales (though not Scotland), you can ask for a free 20-minute consultation called a Medicines Use Review. This is a great chance for you to ask questions about your medicines; learn more about the medicines you take and how they work; discuss any worries you might have; or ask for help to overcome any problems you may be experiencing, such as difficulties taking your medicines or side effects.

If you live in England and you've been prescribed a new medicine for the first time for asthma, COPD, type 2 diabetes, hypertension, or antiplatelet / anticoagulant therapy, you can also ask your pharmacist about the New Medicine Service.

This is very relevant to patients with PH as so many will be prescribed medicines from these categories, especially inhalers and anticoagulants (blood thinners). This free service is a chance to work with your pharmacist during the first few weeks of taking your new medicine to have any questions answered and to iron out any problems you're experiencing.

2. Inhaler technique

Your pharmacist can check that you're using your inhaler(s) in the best way possible to ensure your medicine is effective in helping you to manage your asthma well.

Even if you started the inhaler in a hospital bed, there's a chance you haven't been shown how use it correctly. Like any tool for any job, inhalers will help you best if you are an expert in the technique of using them. In addition, there are so many different types to learn.

Think your inhaler technique is fine? You might be surprised. Even if you've been using the same inhalers for years, you might have developed some bad habits with your technique. Lots of people aren't getting the full benefits, and a few tweaks to how you're using your inhaler may make all the difference.

If you have several inhalers and you aren't sure what they all do and why you need the different ones, ask the pharmacist.

3. Need to manage your weight?

If you are retaining fluid, this could be a sign that your heart is struggling due to the high pressure in the lungs. Fluid does not always build up around the ankles but will make your breathlessness worse. Fluid weighs heavy, so keep an eye on your weight as this will be a good marker of fluid retention. Talk to your pharmacist about your diuretics, how much is advisable to drink and tips to get back to normal weight.

4. Worried about side effects?

If you're worried about side effects and it's putting you off using your medicines exactly as you have been prescribed, you could be putting your health at risk. Why not chat to your pharmacist about any side effects you're worrying about or experiencing, and get advice on how to reduce or manage them?

5. Get help to stop smoking

Have you decided to, or are you struggling to, quit smoking? Chat with your pharmacist to help work out a plan to make it easier. They will be able to advise you on the right products to try, as well as give you information on local quit-smoking courses and services.

6. Regular blood tests or monitoring

Several important medicines prescribed for PH patients need to be monitored closely with blood tests. This may not have been well explained to you, or you may be concerned about the results and what they mean. The pharmacist will be able to explain what tests are needed and why.



.....
“Pharmacists are highly qualified health care professionals, training for five years to become experts in medicines and in giving health and wellbeing advice.”

In reading through this article, you may have already decided to go and have a talk to your local pharmacist. Maybe you are still unsure how you could start the conversation, in which case here are a few suggestions for things you could find out:

- What does this medicine do?
- How will this medicine help?
- How long will it take for the medicine to work?
- How long will I need to use this medicine for?
- How and when should I take this medicine?
- Should I avoid any other medicines, drinks, foods or activities when I'm taking this medicine?
- What should I do if the medicine doesn't agree with me?
- Can you check my inhaler technique?
- How can I give up smoking?
- What's the best way to lose weight?

It's important to be prepared. In order to provide good quality advice, your pharmacist may ask you a few questions about your symptoms to ensure you get the best possible advice. So it may be worth taking a few minutes to think about the following questions before you go:

In the past few weeks:

- Have you been prescribed a new medicine that you don't know

much about?

- Have you started something that you are worried is not suiting you?
- Have you been given any advice about your medicines in the past?
- Have you put on weight lately? How much? What is your usual 'dry' weight?
- Have you had any change in symptoms recently (reduced exercise capacity, chest tightness or breathlessness)?
- Has your breathlessness interfered with your usual activities (for example housework, leisure time, work)?
- Have you felt dizzy or light-headed?
- Do you keep a symptom diary?

To summarise, the pharmacist is under-used and under-valued by lots of the population. Taking advantage of the skills and services offered by your convenient local pharmacy is a part of the NHS plan for the coming years.

Whilst telephone advice is always available between appointments at PH specialist centres, this is not always appropriate or the best way to deal with problems.

So next time you have a medicine-related query, or next time you collect a prescription, why not take the time to have a chat with the pharmacist there. You'll be glad you did – and you may even wonder why you hadn't done so before! ●



LET'S TALK ABOUT LIFE

Hope Barker's mum, Jocelyn, developed PH after the birth of her daughter – and when Hope turned 13, she saw her mum undergo a double lung transplant. Here, Hope shares her family's experience – and thanks another family for their brave and selfless act in donating their loved one's organs.

“There were two false alarms before it actually happened. In these situations you can go as far as being prepared for the operating theatre before the doctors realise that something is wrong with the donor's body. Those organs, then, are not transplantable and the patient goes home and carries on waiting. That's just the nature of the game. The first time, I was twelve years old. My dad and brother Caleb went to the hospital with my mum and I, too young to join, was left with friends. It was the middle of the night and I sat up until the sun rose reading *Utterly Me*, Clarice Bean. The second time I am told I went to the hospital with my parents. Although almost a year had passed since the first incident, I have no memory of this. It finally happened in May 2008. We had said goodnight and gone to sleep, we thought that morning would come as always, and it did; except on this morning my mum wasn't with us, she was lying on a hospital bed receiving a new pair of lungs. Statistics show that at the end of December 2015, there were 6,635 people on the transplant waiting list in the UK. That means that right now, as you read this, there are over six thousand mothers, fathers, brothers, sisters, daughters and sons living with the reality that 'tomorrow' might not come. Of course, transplantation isn't the magical cure for these people. If we consider lung transplantation alone, just over half of those who undergo the procedure will survive a further five years. Even before that you have the arduous recovery in Intensive Care Units, the suppressed immune system that can result in hospitalisation for common infections, and the mental strain on both the patient and their family. You learn to take nothing for granted, and whenever you go to sleep you are reminded of what 'good night' could really mean. All of that, though, is worth it

because, for as little time as you get before your body rejects the foreign organs, it's still more time that you get to live. This is where the really tricky part comes in, and this is the part that nobody wants to talk about, because for my mum to live, somebody else had to die. Katie was in her mid-forties and was a perfectly healthy woman leading a perfectly normal life. We don't know how she died but we know it was instantaneous and unexpected, probably a brain aneurism or something similar. This is how people who are able to donate their vital organs usually die – it means the rest of the body is largely unaffected and is viable for transplantation. Katie's parents have sent us photographs of her, and have written a few letters to my mum over the years. I can't begin to imagine their pain and I will never stop thanking them for the sacrifice they made for us – because it is a sacrifice. Even if you are signed up to the donor list your relatives can opt out for you at the last minute, and many do. It seems an impossibly cruel question to be faced with at such a difficult time in your life: "Hi, your daughter is dead, can we have her heart/lungs/retina/skin/kidneys (the list goes on) please?" Yes, it is cruel, and I know I'm biased but I can't help but see the necessity of it and of transplantation in general. Organ donation isn't something we are taught about in school, it's not an issue that we discuss regularly and that is the problem. While 90 per cent of people say they support organ donation, just 33 per cent are on the NHS Organ Donor Register. That leaves us with 57 per cent of the population who are happy to donate their organs, but may end up not doing so for absolutely no reason at all. In 2015 we saw the number of organ donors fall for the first time in 11 years. Less people are donating their organs than ever and that's because we aren't talking about transplantation.

Nobody wants to talk about death, nobody wants to think about what's going to happen to their body when they're gone but the truth is, it's selfish not to. Most people I try to discuss the issue with sweep it aside with a non-committal, "oh yeah, I've been meaning to do that." I suppose if it hadn't happened to me, I probably wouldn't care either. We all have our own lives, our own problems, and we all mean to get round to it eventually – but that's not enough. In the past few months we have been reminded of what we can do as Wales formally introduced the opt-out system. This is a system by which everybody is automatically registered to be a donor and those who have an active problem with it can choose to opt out. This is something my mum and I have been campaigning for and talking about for years and it makes perfect sense. Nobody is forcing you to donate, nobody will make you do anything against yours or your family's wishes but it eradicates that fundamental laziness.

I don't want to change the world, I don't expect this article to enter into parliamentary discussions (as much as I would like it to), all I want is for people to fill out a two minute form and register as an organ donor, to talk to their family and make them aware of their wishes. To stop saying they'll get round to it, stop saying they'll do it tomorrow, and if they've already registered then stop thinking they've done enough. We all need to talk to our friends, talk to our family and let them know they can do it too. I know that nobody wants to talk about death, so why don't we talk about life, because that's what your donation could mean for somebody.

If you would like to share your family's PH story, please email editor@phauk.org



Hope's article was first published in the University of Warwick's student newspaper, The Boar.



PH patients reassured in wake of services review

Patients at the Royal Brompton Hospital in London are being reassured that PH services will continue as normal, following the results of an NHS England review into cardiac services.

This summer, the Royal Brompton Hospital was told controversially that it may have to stop providing complex heart care to patients with congenital heart disease because of concerns over standards. This is despite it being one of the largest and best performing units in the country.

PH specialists from the hospital, along with PHA UK, have reassured service users that whilst the news is unsettling, the PH service, which works closely with the Adult Congenital Heart Disease (ACHD) unit will continue to run as normal until a final outcome is agreed.

Last year, NHS England established a set of standards that it wanted hospitals to meet to ensure both child and adult patients with congenital heart disease got high quality care.

In July, bosses at NHS England announced which Trusts are not meeting the standards and which need to close services and transfer care elsewhere. They said that subject to consultation, which could include talking to the wider public, they would work with Royal Brompton and Harefield NHS Foundation Trust to safely transfer CHD surgical and interventional cardiology services to appropriate alternative hospitals.

University Hospitals of Leicester NHS Trust, which doesn't provide specialist PH services, has also been told the same.

The announcements caused anger amongst hospital bosses, and Robert Craig, chief operating officer at Royal Brompton and Harefield NHS Foundation Trust, expressed concern that there could be a knock-on effect to its PH services.

“We owe it to our patients to keep the services together and complete.”

In an official statement he said: *“Threatening to withdraw services from one of the largest and most successful centres in the country seems an absurd approach... Some adult services such as the nationally-designated pulmonary hypertension service would also be adversely affected because of their inextricable links with congenital heart disease services.”*

PHA UK has written to Robert Craig to offer its support in any ongoing consultations.

Iain Armstrong, Chair of PHA UK said: *“At this stage, it's too early to tell whether*

the announcements from NHS England will have a detrimental effect, if any effect at all, on PH services at Brompton. However, PHA UK is offering its full support to the hospital, and patients should feel reassured that the services will continue as normal during the time it takes for consultations to take place.”

Dr Stephen Wort, clinical lead for PH at Royal Brompton, and Carl Harries, clinical nurse specialist in PH at Royal Brompton, issued the following statement to Emphasis: *“This is an unsettling time for patients and staff of the Adult Congenital Heart Disease and PH services here. However, we have been in this position before and we are determined to fight this, as we have done in the past. More than anything, we owe it to our patients to keep the services together and complete.*

“Each nationally designated PH service is slightly different in their experience and expertise; ours is based on the inextricable relationship of congenital heart disease and PH, stretching back to the days of luminaries such as Paul Wood. We cannot let this priceless knowledge and know-how be dismantled.”

Look out for updates to this story on the PHA UK website and our social media channels. All information is correct at the time of going to print. ●



Save the date!

We're delighted to announce that the PHA UK Conference will return to the **Heythrop Park Hotel in Oxford** on 13-14 May 2017.

Iain Armstrong, Chair of PHA UK, said: *“We had overwhelmingly positive feedback from the last time the event was held at Heythrop Park, in 2015, and look forward to seeing everyone there again in the spring.”*

The PHA UK Conference is now to be held every 18 months meaning there will be a spring conference one year followed by an autumn conference 18 months later and so on.

Iain said: *“As we have increased the production of Emphasis to four issues a year, and with the ever-growing use of social media to keep our supporters connected and informed too, we've made the decision to run our conferences every 18 months.”*

More details to follow in the next issue of Emphasis – keep your eyes peeled!

Please note that we are NOT taking expressions of interest or bookings for places until later in the year.



PHA UK and Brexit A MESSAGE FROM YOUR CHARITY

“The summer referendum that decided Great Britain should leave the European Union became commonly known as ‘Brexit’. And whether you were on the remain camp or leave camp, we can all agree that it is going to have a profound effect on the UK for generations to come. In July, PHA UK Chair Iain Armstrong and director Shaun Clayton attended a workshop, run by the Directory of Social Change, around how charities could mitigate any potential risk to the sector caused by Brexit.

Whilst there, we heard a lot of ‘big’ charities express concern that £200m of EU funding would diminish, and that they would need to become more inventive to raise funds for themselves –

Being a small charity is often seen as a weakness, however, as we have always said at PHA UK, our size makes us strong.

which included paying more attention to their memberships. Advice given included ‘attempt surveys’, ‘listen to your membership’, ‘try having the small charity mentality’ and ‘build

trust’. But for PHA UK, your charity, these are things that we’ve already been doing for years. We are not limited to one single large, lone donor, or a single source of funding. Instead, we rely on thousands of individuals supporting us with their own individual acts of kindness.

Being a small charity is often seen as a weakness, however, as we have always said at PHA UK, our size makes us strong. After all, we’re 3,500 voices moving forward together - and with this, anything is possible. Thank you for your continued support.”

The team at PHA UK





HOW TO GET YOUR PHANTASTIC STORY INTO THE LOCAL MEDIA

PR expert and former journalist *Kate Betts*, of Capital B Media, explains how you can promote your PH story to the local media.

So you are organising a fundraising night or doing a sponsored run for PHA UK and you want to raise as much money as you can; or your loved one has just been diagnosed and you wish more people knew about the condition. But how do you go about it?

One great way to let people know is by getting coverage in the local media. Local newspapers, radio and TV are always looking out for stories about people in their "patch". They love stories about real people, because we all love reading or hearing real life stories.

Before you contact the media you need to think 'have I got a story'? They need a 'hook' to run the story; a reason people will want to read it. For example it might be quite difficult to just get them to run a feature on PH if you can't supply them with someone to talk about having it. Or if the fundraising event is very low key (eg. a cake stall at a fair – a very tasty fundraiser but not necessarily a headline story!). Your story needs to be

a 'human interest' story and provide the media with someone to interview and photograph – or be an interesting event or achievement – the more quirky or impressive the fundraising activity the better!

Putting together a press release

The best way to tell the media about your story is to write a press release. A press release is basically just your story written down. Nothing fancy. It tells a reporter what's happening, where, when, how, why and who is involved. You can simply write your press release in an email – and give a phone number at the end so they can call you back with any queries. Have a look at a story in a newspaper and see how they are written; that's how you want to write it.

The press release also acts as a source of news for TV and radio stations. They obviously can't use the press release in the same way as a newspaper, but it gives them the complete story and saves you having to explain it on the

phone again and again.

Some people might say that you can get journalists interested by telling the story on social media and this can work. But while social media is another great way to raise awareness and get your story out there, don't rely on it as way to alert journalists. Firstly it's a bit like them finding a needle in a haystack – they have literally got to find your tweet or Facebook post from among the millions out there. And even if they do they will have to track you down to tell them the rest of the story. And journalists are busy people. So it's much better if you just send a press release straight in to their inbox telling them the complete story. You can find email addresses and phone numbers for the news editors and reporters either inside your local newspaper or on the websites of the paper, radio station or TV programme.

If you are organising a sponsored event send the media a press release beforehand - and after. That way you

have two chances of getting coverage. Wherever possible send a photo too. Photos need to be of people, looking at the camera, as sharp and bright as possible - and at least 300kb big. Attach them as jpegs to the email. Don't embed them in the email or any document.

And once you have sent the press release and photo it really is a waiting game. They might ring you up to ask you more, or they might just run the story. The newspaper won't tell you if they are going to run it or not. So you will need to buy the paper for a few days to check if they do. You can also check online to see if they have used it.

Talking to the media

After you've sent out your press release, the local radio or TV station might ring you up and ask for an interview. That's brilliant and your chance to talk about what you are doing and why it is so important. Do check what they want. They might just want a 'soundbite' to use in a radio news bulletin or a TV package, or they might want a live four minute interview. Whatever they want, you may be surprised how little air time each interviewee gets; so try to be concise, don't get bogged down in detail, just tell your story as well as you can.

Do prepare what you are going to say. Remember the reason for doing the interview is to make people aware of what you are doing, but more importantly to make them aware of PH (and PHA UK). So, and this is especially true of a live radio interview, you must keep 'name-checking' pulmonary hypertension and PH.

If you are doing a radio interview about a particular fundraising event do bear in mind that out



Have a look at a story in a newspaper and see how they are written; that's how you want to write it.

of the 100,000 people listening perhaps a dozen will come to the event, everyone else wants to know things like 'what is PH?', 'how is it diagnosed?', 'how does it affect people'. So use the interview to raise awareness generally and be careful not to get lost in the detail of the event.

As a former local radio producer, I heard hundreds of interviews that told us lots about the event (what time it started and finished; the exact details of what was being sold/ auctioned / produced; and who was helping out or sponsoring it etc) and very often they forget to namecheck the charity or tell us anything about what the charity does or what the condition or issue was that the charity raised money for. The result: an entertaining interview for the radio

station, which they will love; but a missed opportunity for you to promote awareness of PH or PHA UK.

Go for it!

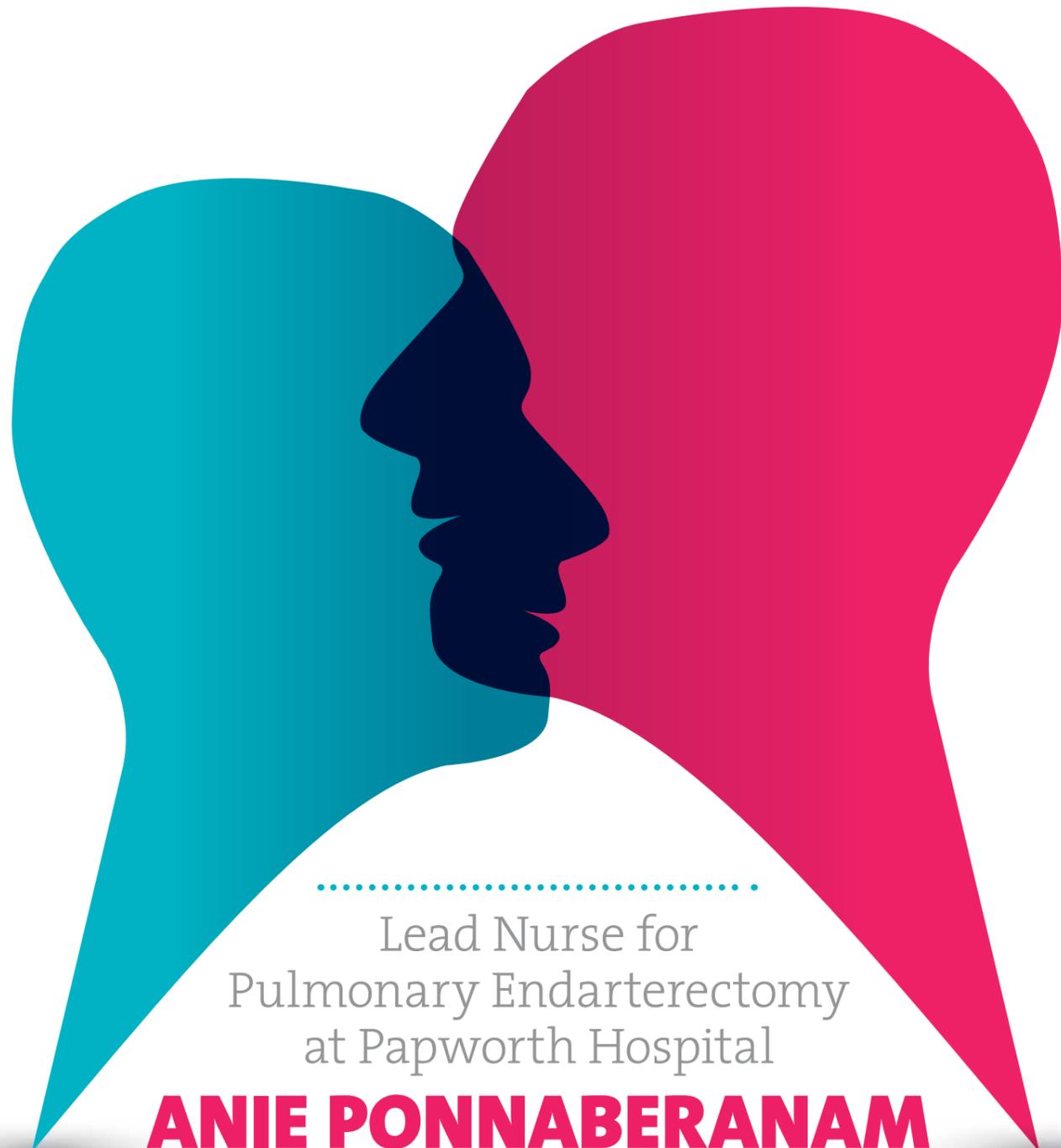
Ultimately, when you're thinking about telling the media your story, remember that they want to hear from you. The majority of journalists are nice people (honestly, I used to be one!) and they will be interested in what you have to say, and pleased that you got in touch. Don't be afraid to pick up the phone, or send an email.

So get out there and do what you can to raise awareness. With PH Week coming up in November there's never been a better time.

Turn to page 25 and visit www.phauk.org to download a free template press release, which you may find useful if you're thinking of contacting your local media during our first PH Awareness Week. ●



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theinterview
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Lead Nurse for
Pulmonary Endarterectomy
at Papworth Hospital

ANIE PONNABERANAM

=====
in conversation with
Mary Ferguson

Anie is the lead nurse for the Pulmonary Endarterectomy service at Papworth Hospital, a national service to treat patients with Chronic Thromboembolic Pulmonary Hypertension (CTEPH).



She trained in India and has been a nurse for the past 31 years, holding roles in various clinical specialities in the Middle East and the UK. Anie joined Papworth Hospital in 2006 as a staff nurse and has been promoted several times during her employment. She worked as a nurse specialist for PAH and has held the lead nurse post for the National Pulmonary Endarterectomy service since 2010. She has extensive experience in this field, coordinating the patient pathway from other centres and other countries. Her role includes education and support for patients and families, and communication with healthcare professionals around the country.

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Q. Could you tell us a bit about yourself and your career?

A. My first job in the UK was on the day ward at Papworth NHS Trust where PAH and post-op CTEPH patients were cared for. I was particularly interested in the PAH patients and was amazed to see them managing their own Intravenous Epoprostenol infusion pumps. Over time working on wards, I gained more confidence in caring for PH patients and I was so excited when I was offered an opportunity to cover maternity leave in the PH support nurse's office. Working in the office were both PH and PEA nurses and my role was mainly focused on PAH patients rather than the surgical patients. However, in 2010 I was appointed as lead nurse for pulmonary endarterectomy, leading the care delivery for the National Pulmonary Endarterectomy Service.

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Q. What does your role as lead nurse for pulmonary endarterectomy involve?

A. My responsibilities include providing support to patients and staff, and also healthcare professionals outside the organisation. My role involves co-ordinating, supporting and educating CTEPH patients and their families from the first referral for assessment of operability, to one year after surgery. Communication with a wide range of people inside and outside the organisation is key in supporting our patients. I work with patients and their families in the nurse-led clinic about the surgery, the recovery on the critical care unit and on the wards, and following discharge home. I am actively involved in the holistic assessment of care needs for patients both before and after surgery and I assist ward nurses in discharge planning, and in delivering telephone support and advice to patients after their discharge. Additionally, with support from our multi-disciplinary team pathway co-ordinator and referring centres, we follow the progress of our patients whilst on our

waiting list - for which I am also responsible for - to ensure that there are no unnecessary delays along their care pathway to surgery. And we participate in research and audits which allows us to identify areas for possible improvement and advances in treatment for CTEPH patients.

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Q. Can you describe a typical working day?

A. We have two nurses working in this service and we alternate between delivering care in the clinics and on the surgical wards. Additionally, we respond to all patient queries and offer telephone support. We contact patients to discuss scheduling a date for their surgery, and how they are managing their symptoms while waiting for surgery. We also ensure that their condition remains stable whilst on the waiting list and liaise with referring centres should any patient experience deterioration in their condition. We make follow-up calls to patients after surgery and contact the local GP, anticoagulation clinic or referring centres to help and support our patients appropriately. Our regular office activities include communication with referring centres, to update referrers on the progress of our patients.

.....
Q. How has the PEA service at Papworth developed during your time there?

A. Papworth has recently become the second largest PEA centre in the world and the number of referrals and surgeries are increasing year on year. We had 90 surgeries in the year 2009-2010 when I joined as a lead nurse and 178 surgeries in the year 2015-2016. In June 2013 we celebrated an important milestone - the completion of 1000 surgeries. And we operated on patient number 1500 in July this year. The success of the service is...

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“I am proud to be helping people who are in desperate need of this particular treatment.”

due in part to the increased knowledge of the condition and of earlier diagnosis by the referring centres around the country. The service has developed in other ways too. For example, a recent audit was conducted to identify any delay in patient discharges and an outcome of this piece of work was that non-clinical delays were identified and addressed appropriately to provide timely assessment of physical, psychological and social issues. We are also involved in a national audit tool called Patient Reported Outcome Measure, or PROM, which measures the patient expectation and experience of undergoing PEA surgery at Papworth.

Q. What are your thoughts on the development of treatments for CTEPH?

A. The demand for PEA surgery is increasing and the evidence persists in supporting it as the treatment of choice for patients with operable disease. A recent development in the treatment options available for patients with inoperable disease is the Balloon Pulmonary Angioplasty (BPA) procedure. Patients are considered for this course of treatment if their disease is considered inoperable, but suitable for angioplasty. I would like to see more awareness of CTEPH in tertiary services outside of our specialist PH referring centres, which might help patients in getting an earlier diagnosis and treatment. I would also like to see further developments in the education and awareness of GPs and other physicians in understanding and managing the care needs of patients following surgery.

Q. Last year you led a project to develop a new guide for CTEPH patients undergoing PEA - how has it been received?

A. Feedback has been very positive, with patients and relatives telling us they value them as useful guides to care and treatment and refer to them if they have queries. This also helps professionals by reducing the need for patients to contact the specialist centres seeking advice. I have also recently worked with the team here, and selected patients, to develop a DVD to inform patients and families about what to expect after surgery. PEA surgery is a major procedure and the recovery is not straightforward, so it is hugely important to have excellent

communication with patients and relatives. They need to understand the whole process of surgery and the different ways that patients can recover, and the different lengths of stay in hospital they may experience, as it varies from patient to patient. As we provide a national service, we are mindful that patients and their relatives are travelling from long distances from all around the country, and communication is crucial to prepare them adequately.

Q. What do you enjoy most about your job?

A. I am fortunate that I am able to get to know my patients personally and can support them through their surgical journey. It is inspiring to see the difference that surgery can make to a patient's quality of life and it is rewarding to see their progress following surgery. I work within a wonderful team where everyone pulls together to deliver excellent care and to achieve positive patient outcomes.

Q. What have you been most proud of in your career, and what inspires you?

A. I am proud to be the lead nurse for this pioneering national service and am proud of what we have achieved as a team. I am also proud to be helping people who are in desperate need of this particular treatment, to enable them to achieve an outcome that often completely changes their quality of life. Being a part of the national service inspires me a lot. Patients are so grateful for the smallest things that I do for them even though it is part of my job. It inspires me that within the short period of time working in the UK, I have progressed to such a challenging and prestigious position. I hope that I provide an example to my colleagues, and to the general public, of what someone arriving in the UK to work can contribute to the workforce and to society.

Q. PH awareness week will run in November. What is the key message that you would like to get out there?

A. I would like to raise awareness of the need for early recognition and diagnosis of causes of breathlessness, with early referral to specialist centres being key in realising the maximum benefit that patients with CTEPH can get. ●

Help with housing benefits

Benefits Advisor

With Shaun Clayton

We've had a lot of calls recently about housing benefit, and what you are entitled to when you have a diagnosis of PH.

If you are on a low income, perhaps because of having to give up work or work reduced hours, then housing benefit can help you with rent and some service charges. You can claim housing benefit whether you are working or not. To claim housing benefit, you must make rental payments to a landlord. Your landlord can be a private landlord, or a social landlord, such as a local authority or housing association. You cannot get housing benefit to help you with the costs of a mortgage. If you own your home, you may be able to get help with your mortgage interest if you are getting Income Support, income-based Jobseeker's Allowance, income-related Employment and Support Allowance (ESA) or Pension Credit.

How much can I claim?

The amount of housing benefit you will be paid depends on various factors, including the amount of rent you pay, the people who live with you in your household, and the amount

“It is important that you make your claim as soon as possible, otherwise you may lose out on payments.”

of any other earnings and / or benefits that you receive. It may be restricted by the local housing allowance rate in your area if you are a private tenant, and if you are a social tenant, it could be restricted by the number of bedrooms you have (sometimes known as 'bedroom tax'). It's important you notify the local authority of any changes to the circumstances in your household as soon as you can, so that your payments can be adjusted. Otherwise, you may have overpaid, which you'll then need to pay back later.

How do I claim?

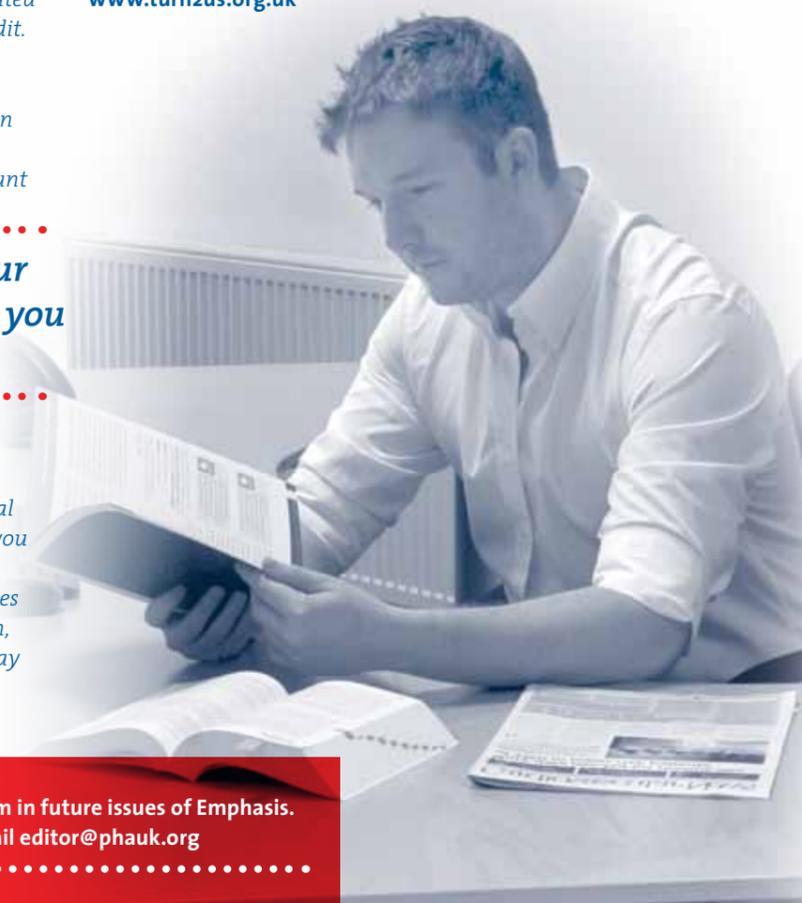
You can claim housing benefit from your local authority. You should be able to find contact details of your local authority housing benefit department from the internet, council offices or local libraries.

Council tax reduction

Council tax reduction (also known as CTR) is a rebate that can reduce your council tax bill and is for households on a low income, whether you are in or out of work. You can claim it at the same time as housing benefit.

Each local authority has its own CTR scheme so you should check with yours for the exact rules in your area. Contact details can usually be found on the back of your council tax bill. If you think you are entitled to claim either housing benefit or council tax reduction, it is important that you make your claim as soon as possible, otherwise you may lose out on payments. If your claim is turned down, or you do not agree with how much you are being paid, you can make an appeal against the decision by writing to your local authority. ●

Thank you to Turn2Us for providing some of the information in this article. To find out what benefits you may be entitled to, you can use their benefits calculator by visiting www.turn2us.org.uk



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@phauk.org



Green Leaf

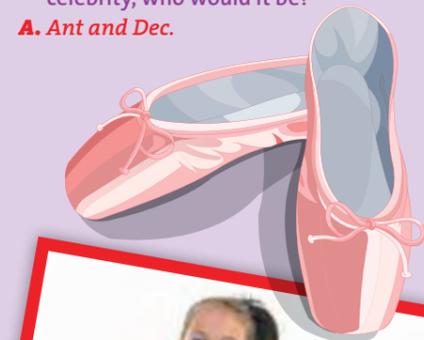
Crew!



GREEN LEAF CREW Q&A HANNAH WELCH

Hannah Welch is ten years old and lives in Dorset with her mum Donna, dad Colin and little sister Amy. They share their house with Bracken the dog and Diesel the cat. Hannah was diagnosed with PH in Spring 2011 and is a big fan of dancing. Here, she answers our Green Leaf survey.

- Q. What is your favourite biscuit?
A. *Chocolate digestives.*
- Q. Where is your favourite place to go on holiday?
A. *To our caravan in Devon.*
- Q. If you could have any superpower, what would it be?
A. *To be able to fly.*
- Q. What's your favourite thing to do at school?
A. *Laugh with my friends at breaks and lunchtime.*
- Q. What do you like to do at home?
A. *Watch TV.*
- Q. What is your favourite animal?
A. *Rabbits but I like all animals.*



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

- Q. What's your favourite meal?
A. *Spaghetti Bolognese.*
- Q. What is your favourite TV programme?
A. *Spongebob Squarepants.*
- Q. If you could have a selfie with any celebrity, who would it be?
A. *Ant and Dec.*

SWEET TREATS RAISE MONEY FOR PHA

Brother and sister Goby Watson, aged six, and Lucie Childs-Carty, aged 11, teamed up with their cousin Poppy Childs-Dixon, aged 10, to sell cakes for PHA UK.

The trio made the treats themselves and sold them on a stall outside their house in Darlington, raising £41. Goby and Lucie also had a casual clothes day at their school to help raise money and awareness.

Mum Lynsey Watson, who has PH, said: "The children are all so helpful to me, I couldn't ask for more." Well done Goby, Lucie and Poppy!



The Green Leaf Crew

by David Banks

Panel 1: A boy says, "MY MUM WANTS US TO GO AND TIDY MRS BUTTERCUP'S GARDEN DOWN THE ROAD." A girl replies, "GROAN!"

Panel 2: A boy says, "COME ON! IT'S REALLY OVERGROWN AND IT'S GOT TOO MUCH FOR HER..."

Panel 3: A girl says, "OOER! THIS MUST BE IT!"

Panel 4: A boy says, "WOW! THAT LOOKS LIKE HARD WORK!"

Panel 5: A boy says, "WELL, WE'RE NOT CALLED THE GREEN LEAF CREW FOR NOTHING!"

Panel 6: A girl says, "LET'S GET CRACKING!"

Panel 7: A girl says, "CLUT!"

Panel 8: A boy says, "SNIP!"

Panel 9: A girl says, "MOW!"

Panel 10: A boy says, "RAKE!"

Panel 11: A girl says, "PRUNE! TRIM!"

Panel 12: A girl says, "WEED!"

MUCH LATER... Panel 13: A boy says, "OH LOOK! IT'S MRS BUTTERCUP!"

Panel 14: A girl says, "I'M EXHAUSTED!"

Panel 15: An elderly woman says, "HELLO YOU LOT... THAT GARDEN LOOKS LOVELY. IF YOU HAVE A MOMENT... GLEAM!"

Panel 16: The elderly woman says, "YOU COULD DO MINE, WHICH IS NEXT DOOR!"

Patch

by David Banks

Panel 1: Patch says, "THIS IS WHERE I PUT ALL MY GARDEN WASTE!"

Panel 2: Patch says, "WHAT? IN THAT LITTLE SACK?!"

Panel 3: Patch says, "I GROW BONSAI TREES!"

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**



Have you ever wondered about the impact your diet has upon your mood? You may have eaten a heavy meal and felt sluggish, overeaten a dessert and felt sick, not eaten enough and felt tired and low in energy. The food we eat goes much further than just affecting our digestive system and our energy levels, our diet has a direct impact upon our mood – which can be both positive and negative.

Do you find that you are experiencing depression, feeling low in mood and lacking motivation? Ever thought that your diet may be a key contributor of this?

There are nutrients in our food that we require for our body and cells to function optimally. Our ability to focus comes from glucose which is found in carbohydrates, which is why guidance recommends a diet consisting of around 50% carbohydrate. Yet, what types exactly should we be eating? Wholegrains' as well as carbohydrates found in fruits and vegetables are important as they contain lots of vitamins and minerals.

When we don't get enough nutrients in our diet we can become deficient in certain nutrients and this puts us at risk of malnutrition related deficiencies which affects our physical and mental health.

So how exactly can our food influence our mood?

Foods actually have the ability to reduce anxiety, and those rich in magnesium and folic acid should be included in your diet. Foods rich in Folic Acid, include green leafy veg, spinach, lettuce, avocado, cabbage, bok choy, broccoli, salmon, green peas, shrimp, turkey, nuts and seeds, peanuts, sesame seeds, hazel nuts, cashews, beans pulses, lentils, chickpeas, black and kidney beans, oranges. Foods rich in Magnesium, include watercress, peppers, Brussel sprouts, cabbage, almonds, brazil nuts, oatmeal, long grain rice, yoghurt, baked beans, fruit, banana, kiwi, blackberries, strawberries, oranges, chocolate.

Foods can help to combat depression, so if you are lacking in any of these vitamins as well as vitamins B3, B6, C, selenium, zinc, omega 3 fatty acids, tryptophan, tyrosine, GABA you may find that you are suffering depression. Include wholegrains' and plenty of vegetables.

Try to get a balanced diet rich in fruit, vegetables, lean protein, meats such as oily fish.

Try this anxiety reducing tasty recipe that is rich in B vitamins and magnesium



Rocket Mushroom Risotto – serves 2

Ingredients:

- | | |
|-------------------------|------------------------------------|
| Extra virgin olive oil, | 30g parmesan, |
| 200g rocket, | 1 white onion thinly sliced, |
| 200ml white wine, | 2 garlic cloves crushed, |
| vegetable stock 1L, | 200g chestnut or button mushrooms, |
| Arborio rice 120g, | salt and pepper to taste |

Method:

Sauté garlic and onion in olive oil until soft and add sliced mushrooms until golden, add in rice for 2-3 minutes and then white wine until it is simmered off. Add in stock bit by bit for 30 minutes, or until the rice is cooked. 5 minutes before the end add in rocket and cover.

Serve with shaved parmesan and season.

≈ By Anna Daniels ≈

Reproduced courtesy of Anxiety UK



FRONT PAGE NEWS FOR NATALIE'S TRANSPLANT CAMPAIGN

A petition launched by PHA UK member *Natalie Kerr* to encourage organ donation has featured on the front page of a newspaper in her home county of Lancashire.

The Chorley Guardian ran a front page story about Natalie's campaign for all UK residents to be automatically placed on the organ donor register. It also included two pages inside, and another local paper, The Bolton News, featured the story too.

In the last issue of Emphasis, we described how Natalie received a double lung transplant in 2012, giving her more time to spend with her two children. She launched a petition in the summer that calls for all UK residents to be automatically placed on the organ donor register, rather than having to opt in. If the law was changed, it would give people the option to remove themselves if they wish.

The Chorley Guardian and Bolton News picked up on what Natalie was doing when they spotted her Facebook posts about the petition. They had both printed stories about her four years ago, when she underwent her transplant.

Natalie, who lives in Adlington, said: "I received phone calls from reporters at both papers and chatted to each one of them for a long time. They were really easy to talk to which I was so grateful for as it's not always easy for me to talk about what I went through when I was so poorly – it makes me

really anxious."

Since the stories were published, Natalie has seen an increase in people signing the petition and people have spoken to her about PH and what it is.

She said: "I'm really pleased that the articles have helped raise awareness of PH as well as spreading the word about my petition. Don't be afraid to tell your local papers about any fundraising or anything else you are doing about PH as it's a great way of spreading the word, and I have had a really good experience with it."

Natalie's petition is open until 28th October and if it reaches 10,000 signatures government will respond. If it reaches 100,000 signatures it will be considered for debate in Parliament. To sign the petition, visit the PHA UK website and follow the link.

See page 38 for our expert guide to raising awareness of PH through your local media.

Thank you to everyone who raises awareness of PH through their local media. Please do share your stories with us.



Cyberspace success for PHA UK

Visits to the shiny new PHA UK website have been high since its brighter and more welcoming design was unveiled in May.

The makeover of our online resource has made it easier for people to access from mobile phones, tablets and PCs, and statistics show that returning visitors are spending more time than before on each page.

PHA UK member Catherine Makin said: "Just had a little peek (at the new website) before work. Looks really good. I like the little tab that says 'I am.....' – as you can put in whether you are a patient with PH, family member, a carer, or professional, and it takes you to relevant information."

You can now also read back issues of Emphasis via the website, and keep up to date with the revamped online news area. A 'Browse Aloud' function allows the website text to be read aloud to you, in a variety of different languages.

Visit www.phauk.org and have a browse!

We would still welcome feedback or ideas of ways we can make our website even better for you. Please email office@phauk.org or call us on 01709 761450.



In your Winter issue of Emphasis...

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

- **Hitting a high note** – why singing can help you feel better and how to get involved.
- **Living with PH** – the results of our major survey into life with the condition.
- **Prescription charges** – the campaign to make them free for those with long term conditions.

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

You can get involved in Emphasis too:

- **Emphasis Reviews** - don't forget we'd like to hear from you if you'd like to share a review of a good book, app or film you think other Emphasis readers may be interested in.
- **Family Matters** - if you're interested in telling your family's PH experience in our regular feature, drop us a line.
- **In the News** - let us know if you raise awareness of PH through the media.
- **PH professionals** - tell us about your work with PH for our 'Me and My Job' or 'The Interview' features.
- **Take the biscuit!** - and please get in touch if you'd like to answer the Green Leaf Crew Q&A.

To get involved and to offer feedback and ideas, contact editor@phauk.org

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.phauk.org
call us on 01709 761450
email us at office@phauk.org**



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

Inside PHA UK

PHA UK Contact Details

Office hours: 9am to 3pm, Mon to Fri for general enquiries
Tel: 01709 761450
Web: www.phauk.org
Email: office@phauk.org
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.phauk.org

Do we have your correct details?

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

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

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

"Let's talk about PH"

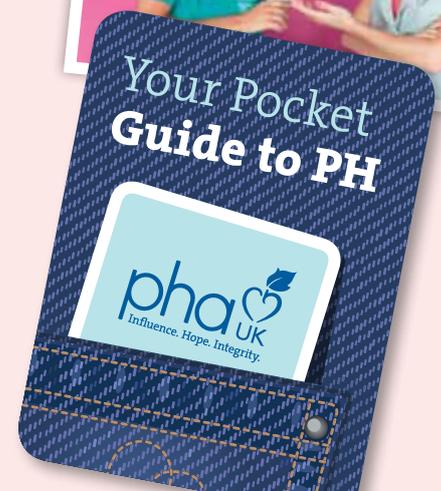
Get involved in the UK's first ever PH Awareness Week

Spread awareness of pulmonary hypertension and help more people understand what it is like living with the condition. Talk to friends, family, neighbours, work colleagues and members of your community about the impact of PH on your life.

Template letters, press releases, invitations and posters are available to download from www.phauk.org

Free copies of our new '*Pocket Guide to PH*' available from the PHA UK Resource Centre on 01709 761450 or PHweek@phauk.org

Join the conversation about PH on social media. Use the hashtags **#PHweekUK** and **#LetsTalkPH** to share your experiences and photographs.



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