

WINTER 2016

emphasis

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

MEET THE PH BLOGGERS

Read their Christmas messages

Hitting a high note

How singing can help in the management of pulmonary hypertension

PRESCRIPTION CHARGES

An update on the campaign to extend exemption

Life after surgery

Elizabeth Cullen shares her story

PHfriends forever

How PH patients Priya and Alex help each other

Merry Christmas
.....&.....
HAPPY NEW YEAR
TO ALL OUR PH FAMILY!

Join us free today
and be part of a 3,500
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



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This magazine is printed on paper from sustainably managed sources

Conference is coming!
See enclosed form and p49 for details

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.



Welcome

Welcome to the winter edition of Emphasis. This issue marks the end of 2016, and what a year it has been.



So many of you have shared your stories with us and we're grateful to everyone who has contributed to Emphasis – which is your magazine. 2016 saw 500 new people join PHA UK, meaning we now have well over 3500 members. And this large community of patients and professionals really helped to get behind our first ever PH Awareness Week in November. Thank you to everyone who helped to spread the word and start conversations. We're also hugely grateful to everyone who has supported PHA UK through fundraising over the year, including the small selection on page 16. We couldn't do what we do without you. The message in this issue is all about positivity. In a special feature, some popular PH bloggers share their Christmas messages, and reveal how writing helps them cope with the

condition. Perhaps the festive season may inspire you to give it a go too. Plus, police officer Elizabeth Cullen shares her journey from diagnosis to surgery, and back to the beat in Ireland. And Alex Walker and Priya Mistry explain how their friendship helps them both manage family life with PH. Many of you may be thinking about making healthy new year resolutions – if so, take a look at our features on pages 26 and 28 for inspiration. We're now looking ahead to 2017, and especially to our conference in May. We hope to see many of you there.

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

The message in this issue is all about positivity.



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.

BARBARA'S BOOKS MAKE BUCKS...

In the Summer issue of Emphasis, we brought you news that writer Barbara Shrubsole was planning to hold a launch of her new book, 'Literary Allsorts', in aid of PHA UK and in support of her friend Sharon Pile, who has PH. After raising over £1,000 she sent us this overview of the event:

"The fundraising event in Bath proved to be a great success. Between 80 and 100 people came and listened to a short history of how the book came into being, and a detailed account read by Sharon about her daily experiences, both day and night, as she copes with the challenge presented by pulmonary hypertension. It would be true to say that most people learned something about a previously unknown condition. Tea and cake was enjoyed socially and a considerable amount of money was raised on the day. This sum has continued to increase with further sales and now we are able to announce that the total raised for PHA UK is £1,003. Sharon also has a few more books that she hopes to sell at a local event."

Barbara is pictured with Sharon, signing books at the launch.



PH IN YOUR POCKET

Our new 'pocket guide to PH' is helping people spread awareness about the condition by presenting the facts in a compact, portable way.

The dinky booklets, which fit in the palm of your hand, are ideal to carry in a handbag or back pocket, and fold out into a full-size leaflet packed with information about PH. To obtain a free copy, email office@phauk.org

Remembering Joan

Linsan Horridge lost his wife Joan to PH five years ago, and every year on what would have been their anniversary, he donates £100 to PHA UK. They would have been married 57 years in 2016.

Thank you Linsan for your kind donations.

Email support for PHA UK members

PHA UK members are now able to access free email support to help with issues around anxiety. As part of our partnership with mental health charity Anxiety UK, members can email phauk@anxietyuk.org.uk for advice on how to deal with feelings of stress, anxiety, and anxiety-based depression.

The email service is in addition to the dedicated helpline for PHA UK members. Call **0844 332 9010** for telephone support from Anxiety UK.



Social Media Round-up

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

Edd Evans-Morley Night two of the Side Streets Festival is about to start. Thanks for the info and promo material for this fundraiser.



Catherine Makin Thanks PHA UK - I've won another £5 on the lottery, all for a good cause

@wginsing (Wendy Gin-Sing) Patients, doctors, pharma and nurses together debating the care of PAH at the ESC meeting in Nice @EuropePHA @PHA_UK



@PlussSW (Pluss South West) Some more excellent entries for our #halloween #bakeoff! Well done Team #exeter. This month's charity is @PHA_UK



@maritess_mt (Tess Dunn) Thank u @theofficialscd for my new car sticker! More ordered already! #invisibleillness #pulmonaryhypertension #mobility @PHA_UK



@helpmybreathing (Luke Howard) Off to Newcastle for Prof Corris festschrift to acknowledge his huge contribution to PH and Lung Transplant @UniofNewcastle @PHA_UK @lunguk

@AnxietyUK Nice morning for a meeting with our partners @PHA_UK at their shiny new offices!



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

Dear Emphasis,

"I completed the Isle of Wight 100k endurance walk to raise money for PHA UK and hit £1168, with an additional £516 raised by students that I teach at Bullers Wood School, who did a sponsored run. The walk around the island was a fantastic experience and I would recommend it to anyone who is up for a challenge.

My lovely mum Moira Thow was diagnosed with PH 14 years ago. As is the story with so many others she was misdiagnosed for a number of years.

Despite facing the many challenges that PH threw at her she always remained positive. Moira made the most of what she could do and failed to dwell on the things that she could no longer do.

She continued with her amazing handiwork and this included knitting socks to sell for PHA UK, woollen squares for Salvation Army blankets, baby jumpers to go to Africa, and cardigans, jumpers, hats and gloves for the growing grandchildren, in addition to items for competitions. She would read, complete crosswords, Sudokus and jigsaw puzzles; her mind was always kept active.

Moira was looked after by the team at the Gartnavel General Hospital in Glasgow and my family will always be grateful to them all for the support given to her. The challenges she faced with the condition can all but be forgotten against the amazing care shown by the team of professionals who she came in contact with.

Moira had trained as a nurse so the daily act of making up her mix for the Hickman line was done with care and precision - she never complained about this onerous task. To watch her struggle to perform daily tasks was never easy, however I always came away from a visit full of admiration and respect for someone who never gave up, and who made the absolute best of what she had.

The support shown by PHA UK was a great comfort to Moira and all our family, which is why I chose to raise money for them. We have witnessed first-hand the advances in treatments for this condition and will continue to raise funds for PHA UK in the future. I ask that you put your thinking cap on and come up with a plan for a fundraising event yourself. Moira was my inspiration, what is yours?"

Marie Hemmings



Marie's Mum, Moira.



DID YOU KNOW....?

The revamped PHA UK website has a 'read aloud' function, meaning those who find it difficult to read can listen to the information on screen. Plus, the website translates into 60 different languages, making it accessible to people from around the world. Take a look at www.phauk.org



Reforms to ESA assessment

People with serious health conditions who claim sick benefits will no longer be required to prove they are still ill every six months. Department for Work and Pensions secretary Damian Green has announced that those with severe, lifelong conditions will not have to go through reassessments to keep their payments. Employment support allowance (ESA) will now continue automatically for those who have a lifelong illness or severe health condition with no prospect of improvement. The testing process, which includes reassessing the conditions every six months, has come under intense criticism for failing some of the most seriously ill and disabled.

Mr Green said:

"If someone has a disease which can only get worse then it doesn't make sense to ask them to turn up for repeated appointments. If their condition is not going to improve, it is not right to ask them to be tested time after time. So we will stop it."

The criteria is yet to be drawn up with health professionals but people with congenital heart conditions, as well as those with autism and illnesses such as severe Huntington's are likely to qualify for continuous payments without reassessment.



Department for Work & Pensions



Shopping centre raises money in support of young **Stanley**

A shopping centre in Aylesbury has raised over £7,000 in support of five-year-old Stanley Smith, who has PH.

Friars Square shopping centre raised £6,292 from Christmas grotto ticket sales last year, which they have donated to PHA UK. The centre's maintenance and management teams also raised an additional £1,400 that will go to the Smith family to buy specialist equipment for Stanley.

Stanley's mum Karen said:

"We're really touched by the fact that the team raised money especially for Stanley. It will go towards some of the specialist equipment he needs, like a dry suit for swimming which has to be made to measure to cover Stanley's Hickman line. Stanley loves splashing about in the water so he will be able to start swimming lessons soon. He also needs a bigger buggy as he gets worn out quickly."



SUPPORT PHA UK WHILE YOU DO YOUR CHRISTMAS SHOPPING

If you do your Christmas shopping online, buy it through a special website and you'll pay the same – but PHA UK will get a donation too. Instead of going directly to an online store, simply go to www.easyfundraising.org.uk and access the store through there instead. This tells the shop you came through Easy Fundraising, and after you have bought your item (which will cost you exactly the same), they will give you a cash reward that, with the click of a button, you can turn into a donation for PHA UK.

To sign up, visit www.easyfundraising.org.uk and when prompted, type **PHA UK**.

easyfundraising
.org.uk



Welfare training day for PH professionals

This summer saw PH health professionals from centres across the country gather at the PHA UK resource centre to learn more about welfare benefits.

The 'Welfare Training Day', organised by PHA UK and delivered at their centre in Sheffield, was presented by welfare support charity the Child Poverty Action Group (CPAG) and focused on the

range of benefits available to people with PH. It included coaching around PIP, ESA, housing support and the appeals process.

Shaun Clayton of PHA UK said: "We organised the day in response to feedback from PH professionals who told us they are increasingly being asked for advice and support from patients on issues around welfare benefits, and would like to help as much as possible. The training day aimed to equip them with knowledge, and also help them signpost patients to experts where necessary."

Following successful feedback, further training days will be organised in the future.

**CHILD
POVERTY
ACTION
GROUP**

New regulator for fundraising activity

The Fundraising Standards Board, the body that used to regulate fundraising activity in the UK, has now formally closed. Charities, including PHA UK, are now regulated by the **Fundraising Regulator**, which was set up following the Etherington review of fundraising self-regulation (2015) to strengthen the system of charity regulation and restore public trust in fundraising.

As an independent regulator, their role is to set and promote standards for fundraising practice, recommend best practice guidance and take remedial action where necessary. They also adjudicate complaints and operate a fundraising preference service to enable people to manage their contact with charities.

Shaun Clayton, director of membership support at PHA UK, said: **"We believe it's incredibly important that charities maintain ethical and transparent fundraising practices. As such, we welcome the role of the Fundraising Regulator and are committed to adhering to its standards."**

You can read the Fundraising Regulator's code of fundraising practice online at www.fundraisingregulator.org.uk



STILL NEED TO SORT YOUR CHRISTMAS CARDS?

Our Christmas cards are not only beautiful, but they raise money for PHA UK too. Snap yours up now for just £5 for a pack of ten (including postage) and if you write them quickly, you'll be able to get them out before the big day. Visit the 'shop' section at www.phauk.org or call us on **01226 761450**. Pictured are three of the five designs available.



MEET the PH Bloggers



Putting pen to paper (or finger to keyboard) helps these PH patients in many different ways. We asked them why they blog, and what they would like to say to Emphasis readers this Christmas...

Serena Lawrence

Serena lives in Ontario, Canada and was diagnosed with Idiopathic Pulmonary Arterial Hypertension in December 2013. She blogs at www.phightorflight.blogspot.co.uk

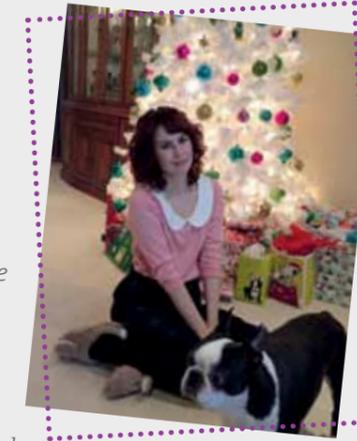
"This Christmas will mark three years living with pulmonary hypertension. I actually had my right heart catheterisation on Christmas Eve (Merry Christmas to me!)"

I started my blog, *The PHight or Flight Project*, in the spring of 2014 (several months after my diagnosis). Blogging has helped me connect with lots of other PH patients who understand what it is like to live with this disease.

It has also given me the opportunity to interview people with PH who have thrived for a long time, which certainly helps provide hope to me and other PH patients. I have spoken to people who were diagnosed and told that they had 24 hours to live - over 40 years ago!

Blogging has also helped me continue a bit of a career after retiring from my job at the age of 26. I've been able to do a lot of freelance writing and even have my own column called "Life with PH" with the American online news magazine *Pulmonary Hypertension News*, which I really enjoy doing. I'd love to write a book someday. When I was first diagnosed I needed supplementary oxygen 24/7. My best friend even had to push me around in a wheelchair when she

invited me to go to the mall. My mom had to help me change my clothes, I could barely shower. It was very humbling to go through that in my twenties. I am happy to share that I am doing better than doctors expected because I was so ill (between a stage 3-4) when I was diagnosed. I still get out of breath, but I've learned to pace myself. Sometimes slow and steady really does win the race. Last Christmas was the first Christmas I didn't need oxygen to decorate the tree. I even got a new one and decorated it all by myself!"



My message to Emphasis readers this Christmas:

"I've learned that a lot can change in a few years, and sometimes it can be for the better. Whatever you do, don't stop laughing or loving."

Gemma Cousins

Gemma lives in West Yorkshire and blogs at www.deepbreathgem.blogspot.co.uk. She was diagnosed with PH on New Year's Day 2014.



“I first fell ill in November 2013 after collapsing and finally had my diagnosis confirmed on 1st January, three months later.

I initially started to blog as I wanted to raise awareness of PH and what it is like to live with an invisible illness. I had been to an event where I experienced quite a negative situation with a member of the public, who thought I was ‘abusing the system’, as I didn’t look ill and yet was in the disabled area. It really affected me and it was this that pushed me into writing in the hope that the same thing wouldn’t happen again to me, or other people with invisible illnesses.

It was hard at first trying to explain all my feelings and trying to make my blog informative without being dull. But it’s been extremely therapeutic for me, and the support I have received from friends, family - and people I don’t even know – pushes me to keep writing. I find a lot of my friends want to know how I am doing, but don’t want to ask every time they see me. This way I can keep them updated without having to repeat myself to everyone, which is great!

My blogging has certainly helped my confidence. I have received such fantastic support that I realise people do genuinely care and I no longer feel like I am on my own with this condition.

Living with PH is a rollercoaster ride of emotions and sometimes you just want to run away and hide under the duvet. Writing a blog helps me with these emotions. It’s been great as well to read other people’s blogs who have PH as a lot of the time I can totally relate to how they are feeling and it makes me realise I am really not on my own with this.

You don’t have to be good at writing stories to write a blog. I’m dyslexic and find it hard writing what I mean but it’s not an English exam, you don’t get marked down if your grammar isn’t 100 per cent! I just find it a great way to be able to get

out my feelings as I find bottling up my emotions leads to more stress. Therefore, if you are reading this and think you would like to start writing a blog, do it. It’s honestly been the best thing for me.”

My message to Emphasis readers this Christmas:

“If having PH has taught me anything, it is to dream big, expect the unexpected, have a little bit of hope and if it’s meant to be it will all work out. Keep PHighting, stay positive and most of all have a merry Christmas and a happy New Year.”

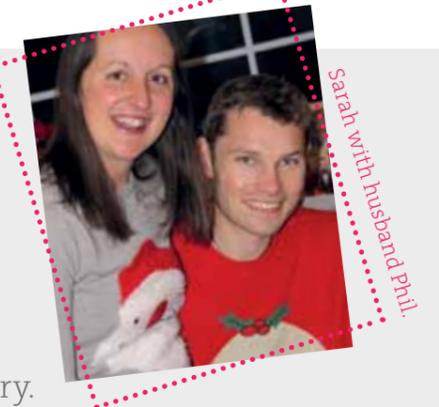


Gemma (centre) with friends.



Sarah Marshall

Sarah lives in Northamptonshire, and was diagnosed with PH in 2013. She attends the Royal Brompton Hospital and has been blogging at www.wecanadjustthesails.wordpress.com since January.



Sarah with husband and Phil.

“I blog most weeks, and originally started blogging as I wanted a record for myself of what life was like with PH.

Not long after I started my blog, I deteriorated and was put on the lung transplant list, so a lot has happened this year and I’m pleased I have written about it all. I also find that by writing down my thoughts and what is happening in my life, it makes me feel calmer - I find it very therapeutic. My friends tell me it has taught them a lot about living with PH and I like that it has spread awareness to people. They are more understanding now as they have a better grasp of my condition, and what I can and cannot do. I also love hearing from PH friends who have read

my blogs, as it makes me feel less alone when they say that my blog resonates with them.”

My message to Emphasis readers this Christmas:

“Keep positive, keep smiling and keep living your life. Yes, life changes when you get the diagnosis of PH, but you can still have fun, you just need to adapt to the new you. Merry Christmas everyone, I hope 2017 moves us closer to a cure for PH.”

Kathryn Graham

Kathryn lives in Hertfordshire with her husband and two daughters. She was diagnosed with pulmonary arterial hypertension in the autumn of 2010 and began writing her blog at www.kathryngrahamwriter.blogspot.co.uk shortly afterwards.

“I see my blog as a personal diary in many ways, but one with a mission and purpose to campaign about important issues close to my heart.

One thing I love about blogging is that you can write about anything and focus your blog in whatever direction you wish to take it. I love photography, wildlife and nature, cooking, travelling and spending time with my family and cocker spaniel Ted. I try and capture all these things that I love in my blog and it means there is always something interesting to write about, whatever is happening in my life. Blogging encouraged me to write my own book, ‘Life is for the Living’, which is about my PH journey from diagnosis through to the end of my first year post heart and lung transplant and tells of all those thoughts, feelings

and emotions that I went through as I encountered each step of the journey. It’s helping raise funds for charities close to my heart including PHA UK.”

My message to Emphasis readers this Christmas:

“I wish all my fellow PH patients and Emphasis readers a peaceful Christmas and hope that the New Year brings you all stable health. Above all, I hope there is more promise on the horizon for improved treatments, care and raising awareness of PH.”



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  

Paws for pounds

A sponsored dog walk in Midlothian raised £275 for PHA UK. Katherine Lang organised the ten-mile event in support of her sister Nicola McCulloch, who has PH. As well as four furry friends, lots of their family members took part, including Katherine's son Ben, pictured with dog Hollie. Katherine said: "It was quite a hard walk but everyone was very well behaved – humans included! Family and friends who could not take part in the walk, including Nicola, met us for lunch half way so everyone got to be involved."



£275
RAISED

Running in memory of Sarah

Vicki Ridge pounded the pavements of Warrington in the English Half Marathon, in memory of her friend Sarah Herron. Sarah had PH and died in October last year. Vicki, who raised £635, was given £250 towards her total from her employers at United Utilities. She said: "Sarah was a wonderful friend and colleague and with her anniversary coming up I wanted to do something in her memory. As PHA UK was very close to Sarah's heart it was the obvious choice for me."



£635
RAISED

Clare's sponsored swim

Keen swimmer Clare Quinton took to the pool and completed 22 lengths to raise money for PHA UK. Clare, who lives in Farnham Common, Buckinghamshire, was looking for a way to increase her fitness when a friend suggested swimming. She raised £870 through her sponsored swim, cheered on by her family. Clare, who was diagnosed with PH in 2000, said: "I really enjoyed the challenge and it just shows that you never know what you can do until you try."



£870
RAISED

Pedalling for PH

Neil Panton of Strichen in Aberdeenshire didn't let his PH hold him back when he completed a 66-mile bike ride around Loch Ness. He raised £1,800 by taking on the Etape Loch Ness cycle sportive, pedalling for almost five hours. He said: "Before I was diagnosed with PH seven years ago I was a keen runner, but I've since turned to cycling. I enjoy a challenge and wanted to raise money to help research into the condition. The event was certainly a challenge as there were a fair few hills!"



£1,800
RAISED

Insane Terrain

Rozita Ramli and colleagues at Greenvale AP (one of the UK's largest Potato suppliers) took on an 'Insane Terrain' 5km assault course, getting wet, wild and muddy to raise £1,240 for PHA UK, in memory of Rozita's father, Ramli Ismail. Rozita said: "At points when I was short of breath and wanted to stop, I pushed myself to keep going knowing what my Dad would have given to be able to do something as simple as walking up the stairs without getting breathless." Peter Coleman, Anna Williams, Paulo Silva, Bruno Alves and Harriett Fletcher joined Rozita in the challenge.



£1,240
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

Hitting the high notes

Breaking into a yuletide rendition of your favourite festive carol could be the latest weapon in the battle against breathlessness. *Melody Mills* (yes, that's her real name!) reports on the benefits of singing as therapy.

Whilst medical therapy continues to play a big role in supporting those with pulmonary hypertension, many patients feel they need further strategies to help reduce the life affecting severity of their symptoms.

The humble act of singing is now believed to be amongst the most powerful of these strategies – hailed by doctors and patients alike for its ability to reduce symptoms and boost general health and wellbeing.

If you're still left wondering whether exercising your larynx with your favourite song can really help you, scientific research appears to confirm the potential benefits.

A 2010 study funded by **rb&hArts**, the arts programme at Royal Brompton and Harefield hospitals, found some evidence to suggest that singing lessons may be of benefit for patients, but it was initially unclear whether it was the singing or the fact that patients were taking part in a group activity that was making the difference.

So under further research, patients attended either a singing class or a film club for eight weeks. The results were compelling.

All participants in the singing group reported positive physical effects in relation to their breathing after attending the singing group. In

particular, they reported being more aware of their breathing and how to control it more effectively. Participants felt that they had achieved something both personally and physically.

In comparison, those attending the film group felt that there had been little benefit in attending the group. In fact, they all asked to enrol onto the singing classes!

All participants in the singing group reported positive physical effects in relation to their breathing after attending the singing group.

But why did the study findings come out so clearly in favour of the singing? Well, learning to sing requires plenty of breathing and posture control. Even the world's most famous singers spend hours on techniques to control their breathing. It's only natural therefore that the benefits of vocal coaching should be felt by those suffering from breathlessness as well.

Then there's the obvious psychological benefits of singing in a

large group and achieving something as magnificent as making music together.

With the benefits of singing proven, a ground-breaking singing workshop for patients with PH, and also COPD, was established, benefitting hundreds of people living with breathlessness.

Royal Brompton and Harefield NHS Foundation Trust's Singing for Breathing is a flagship project which supports people living with chronic lung and heart conditions or who experience breathlessness. The workshops include relaxation techniques, breathing exercises and vocal exercises, as well as singing a wide range of songs – often chosen by the participants themselves.

In 2008, Singing for Breathing, a charity-funded initiative, was one of just two such projects in the country but there are now more than 50 Singing for Lung Health classes nationwide, with more springing up all the time. **rb&hArts** has continuously delivered workshops for almost a decade, supporting hundreds of people through vocal coaching.

Karen Taylor runs Singing for Breathing workshops at Brompton and urges anyone experiencing breathlessness to give singing a go.

She said: "If I had a pound for every time someone told me they couldn't sing,

then I'd be a very rich woman. I always try to encourage people to give it a try. There's something magical about singing in a group – it's so obviously beneficial to general health and wellbeing, but it also makes it easy to make friends with like-minded people.

"The emphasis of the workshops is on taking key elements from how professional singers develop and exercise their vocal chords to prepare the body for singing, and tailoring them to benefit people experiencing breathlessness.

"The types of songs we sing are really varied from chart hits like 'Something Inside So Strong' to classic songs like 'Summertime' and musical numbers like 'Oh What A Beautiful Morning'.

"We regularly seek feedback on the workshops and know that 95 per cent of attendees feel happier after a workshop and nine out of ten report feeling physically better. Nearly all say that the workshops teach them something useful about their breathing."

Jay Dowle, 65, is an example of someone who says they have benefitted both physically and emotionally from singing.

Jay, who has been receiving specialist care for emphysema for the last six years and has attended the workshops for 15 months, said:

"There's something so incredibly spiritually uplifting about singing in a group. People sing in all aspects of life, often without really thinking about it – whether it's at the football, at church or even on a political rally. For all of us in the group, the nature of our condition means we are able to do less and less in our everyday lives, yet through singing we have all discovered something we can do really well.

Breathlessness can strike me at any time with no warning, including when I am in public. It's embarrassing and frightening and the tension and panic it generates only serves to make the problem worse. I used to feel certain that I was going to die and would regularly need to attend hospital, but now I've found a way to cope better by using the breathing exercises I've learned at the workshops."

Jay and the rest of his class took part in a Christmas concert at a local church last year, which was a big moment for the group. This year the singers are preparing for two 'Carols by Candlelight' services at a local church.

If you are interested in taking part in the Singing for Breathing workshops around Brompton, they take place on Mondays in Harefield (Village) Library, 11.15am or Tuesdays at 11am in Fulham Wing at Royal Brompton Hospital.

Sessions are free, but a donation is welcomed. For more information, visit www.rbht.nhs.uk/about/arts or contact the arts team directly on 0207 352 8121 ext 4087, or email arts@rbht.nhs.uk

To find singing opportunities close to your area, talk to your PH team, ask at your local GP surgery, or visit the British Lung Foundation website, on www.blf.org.uk/support-for-you/singing-for-lung-health/join-a-group



Read Sonia Campbell's and Chloe Temtchine's singing stories overleaf.





“The feel good factor is immense”

Sonia Campbell was diagnosed with PH in 2005, after first becoming ill on holiday in South Africa. She endeavours to stay active as much as possible, and has attended Singing for Breathing workshops for more than four years. Sonia said:

“

The feel good factor is immense. The singers who have led the sessions are so diverse and enthusiastic. They are integral to the success of the group. The breathing exercises are the most important thing for me. They have helped me to manage my breathing in an enjoyable way. The workshop gives my day a structure and allows me to meet like-minded people. I also like that the sessions I attend take place in hospital, because I see it as a key part of my treatment. All the singers benefit so much from what we do there.

”



Singing with

YouTube sensation *Chloe Temtchine* doesn't let her PH stop her performing – she just takes her oxygen tank 'Steve Martin' along for the ride.

With her affectionately-named oxygen canister by her side, New-York based *Chloe* has performed in front of thousands of people in America, including at the International PH Conference in Texas earlier this year.

PHA UK Trustee Kay Yeowart, who attended the conference, chose her performance as her standout moment from the event, saying: **“Watching Chloe perform so beautifully, with her canister, was a special moment.”** Chloe struggled with her symptoms for five years before being diagnosed with PH. Speaking to the website *xojane.com* in 2014, a year after being told she had idiopathic pulmonary hypertension, she described how she found herself struggling to catch her breath on stage. Months later, she was about to hit a high note in one of her songs when she had a severe coughing fit.

After spending time in a critical care unit, where she was eventually given a diagnosis, Chloe was told she needed to rely on an oxygen tank for the rest of her life.

She said: **“With one paralysed vocal cord, ulcers all over my throat, and my new sidekick made of tin, I wondered how in the world I would be able to sing again.** But I decided that symptoms were only symptoms, and that I had a choice to either let them rule me or to live my life as well as I could, despite them. I looked at my tank and he looked at me, almost as if

to say, 'I am your friend. I'm only here to help you. We can go everywhere together. It will be a lot easier with me around. Don't you worry; I will supply you with the air that you need.'

Steve Martin is often dressed for the part when on stage with Chloe, with a bowtie, ribbon and sometimes even a hat.

Speaking to *Niji Magazine* in 2015, she said: **“I hear from many people with PH that they are both embarrassed and ashamed to go out with their oxygen tanks.** At first, I felt the same way. But once I truly understood how much my body was struggling and the value of oxygen, I made my tank my best buddy.”

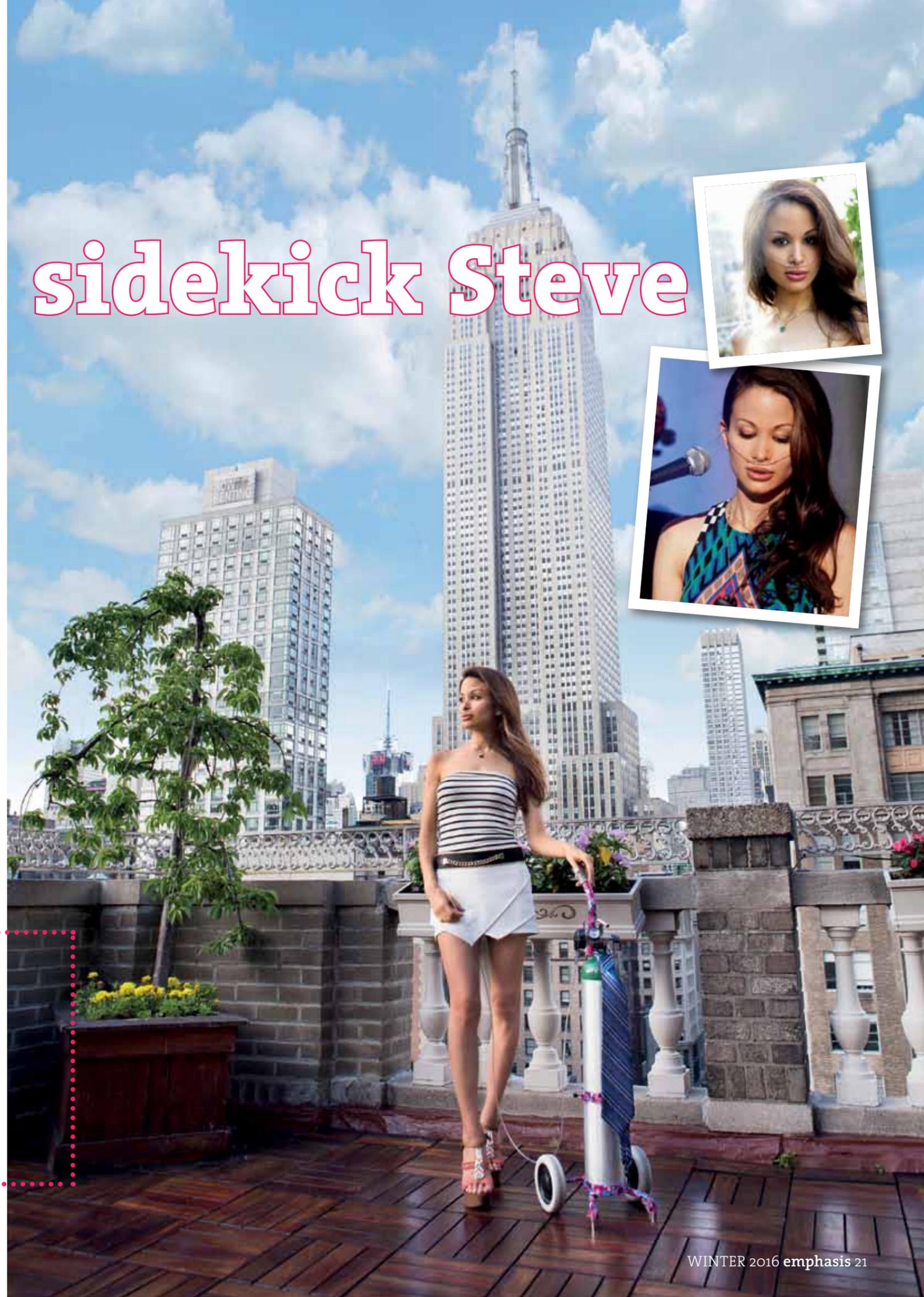
Chloe campaigns to spread awareness of PH in America, and half of the proceeds from her latest single, 'Breathe', are being donated to the Pulmonary Hypertension Association USA.

To watch *Chloe's* new music video for 'Breathe', visit www.breathlessnothopeless.com

To find out more about *Chloe*, visit www.chloetemtchine.com

You can follow her on Twitter [@chloetemtchine](https://twitter.com/chloetemtchine)

sidekick Steve





Financial help for children & young people with PH

Living with pulmonary hypertension can be challenging, and it's not made any easier by money worries. If your child has PH, or you are a young person with PH, welfare benefits and other support could be available to help you manage financially.

This support isn't paid automatically so it's important to find out what you could be eligible for and make a claim. This guide from the charity Turn2us, who work in partnership with PHA UK, takes you through what support could be available, and how to access it.

Welfare benefits

There is a range of welfare benefits available to people living with an illness or disability. Which benefits and how much you can get depends on your circumstances. You can use the free Turn2us Benefits Calculator at phauk.org to check which welfare benefits and other support you may be entitled to in your situation. It is important to claim your entitlements because they can help you access other benefits and other forms of support.

Disability Living Allowance

Disability Living Allowance (DLA) is money for disabled children under 16

who have additional care needs – for example they need more help with washing, dressing and personal care than other children of their age, or mobility needs – they need more help or supervision moving around than other children of their age. If your child is over 16, has a disability and is not currently claiming DLA, they may be able to claim Personal Independence Payment (PIP) instead.

DLA is made up of a care component and a mobility component and depending on your child's needs, they may qualify for one part or both. The care component is paid at three different weekly rates depending on how much care is needed – the higher rate is £82.30, the middle rate is £55.10 and the lower rate is £21.80. The mobility component is paid at two weekly rates, the higher being £57.45 and the lower being £21.80.

DLA is a non means-tested benefit which means it does not matter what savings or income you have. The decision to award it will be based on how your child's condition impacts on

their day to day life.

If your child starts to receive DLA, you may become eligible for other benefits, for example Carer's Allowance. You may also get extra in benefits such as Housing Benefit and Child Tax Credit.

Personal Independence Payment

If you're over 16 and have difficulty or need help to look after yourself and/or to get around because of your PH, you may be able to claim Personal Independence Payment (PIP). PIP is available in England, Scotland and Wales. If you live in Northern Ireland, you may claim Disability Living Allowance (DLA) instead.

PIP has two parts – a daily living component and a mobility component. Each component has two rates of payment, a standard rate and an enhanced rate. Which components you get and which rates they are paid depend on how you score in the medical

assessment, a healthcare professional assesses your ability to do daily living activities like cooking, eating, taking medication, washing and dressing and your ability to get around outdoors. Points are awarded based on how difficult you find each activity. These points determine how much you might receive.

As well as scoring points, at the time of the claim, you will need to have had the same (or more) difficulties or needs for the past three months, and expect to have the same (or more) difficulties or needs for the next nine months. An exception to this is if you are transferring on to PIP from DLA.

Most awards of PIP are for fixed periods. When your award expires, you will have to re-apply and be assessed again, in case your needs have increased or decreased over time.

Employment and Support Allowance

If you are unable to work because of sickness or disability and you do not get Statutory Sick Pay, you may be able to claim Employment and Support Allowance (ESA). You cannot usually receive ESA if you are in relevant education or you are a full-time student, however you may claim whilst studying if you receive DLA or PIP.

You must have "limited capability for work" to get ESA. You will be asked to attend a medical assessment where a healthcare professional assesses your capabilities. It is important that you attend the medical assessment and keep submitting your sick notes (often called fit notes or Statements of Fitness for Work) to keep your claim in payment.

There are two types of ESA. Contributory ESA is available to people who have paid enough national insurance contributions within a certain time. The amount you get is just for you and it doesn't depend on your income. Income-related ESA is available to people whose household income and savings are low enough. The amount you get is for you and your partner (if you have one) and depends on how much income and savings you both have. Some people get both types of ESA, for example because they are a couple but only one of them has

paid enough National Insurance to get Contributory ESA. The rates of ESA depend on your age, whether you live with a partner and how you score in the limited capability for work assessment.

Benefits for students

If you are aged under 20 and in full-time relevant education, you cannot usually claim benefits. Relevant education includes full-time courses such as AS and A levels, NVQ and SVQ level 3 and below, and BTEC. However, if you are receiving DLA or PIP, are a parent or you live away from your family, you might be entitled to some benefits.

If you are in full-time advanced education, you cannot usually claim benefits. Advanced education includes degree or postgraduate courses, courses above A level or advanced GNVQs. However, if you are a lone parent, you care for a disabled person or you are under 21 and live away from your family, you could be entitled to some benefits. Income from a student grant or loan can affect your welfare benefit entitlements.

If you are studying part-time, you could be entitled to some benefits.

The rules around benefits for students can be complicated, so you should seek advice from a local adviser – you can find one in your area using advicefinder.turn2us.org.uk. There is also further information about benefits for students at turn2us.org.uk/Your-Situation.

Charity grants

If you're struggling financially, it's also worth checking if you may be eligible for help from a grant-giving charity.

The free Turn2us Grants Search, available at phauk.org, features over 3,000 charitable funds that give grants and other support to individuals in various different circumstances. The Grants Search also includes details of each fund's eligibility criteria and how to apply.

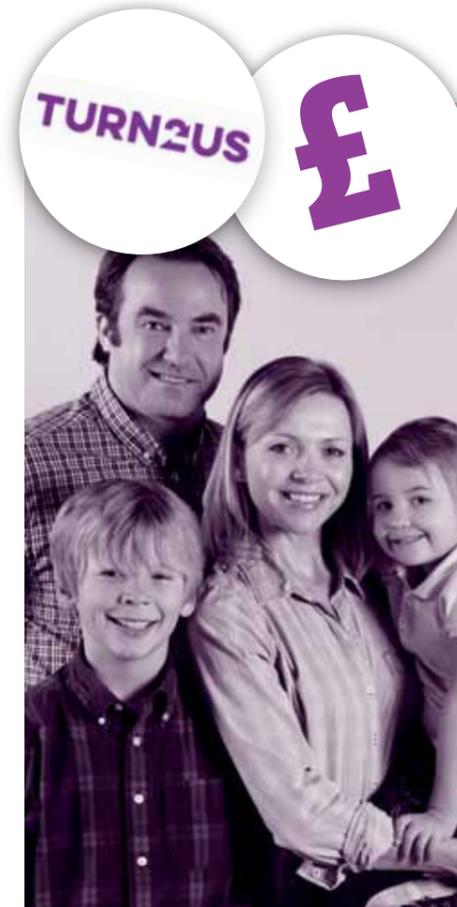
There are funds available to help people in financial hardship, people who have specific illnesses or disabilities.

Grants may be able to help with bills and other living expenses, education costs, or for one-off essential items.

Further information & help

Other support may be available for children and young people living with PH, including help with health and travel costs. You can find further details on the 'Ill, injured or disabled' section of the Turn2us website at www.turn2us.org.uk/Your-Situation.

You can use the free Turn2us Benefits Calculator and Grants Search at www.phauk.org



GOING BACK ON THE BEAT

Police officer *Elizabeth Cullen* was diagnosed with PH in 2007 and underwent a pulmonary endarterectomy to save her life. Nine years on, 37 year old Elizabeth, who lives in Ireland, reflects on her journey to surgery, and the difference it has made.

“Looking back, it seems my ill health started in November 2006. I remember I had really bad pains in both shoulders but eventually they went away.

I used to do beat patrol as part of my work as a police officer and began to notice I was getting more breathless trying to walk around. I just thought I needed to get fitter (despite cycling to and from work on a daily basis) so I tried some new sports like rugby and jujitsu. I was still breathless but thought as my fitness grew my breathlessness would improve.

I worked over Christmas that year and went back to my home town of Sligo to celebrate the new year with family. At home I began to feel much improved. My breathlessness went away. I came back to Fermanagh, where I live, by bus and as I walked towards my friend's car with my bags,

I almost collapsed. I just thought I was having an asthma attack and so I took my inhaler and took it easy that day. I had an early night hoping I would feel better in the morning. But the next morning I struggled to shower and could not finish ironing my uniform. I called in sick to work and made a doctor's appointment, and went to the surgery still struggling to walk.

“...as I walked towards my friend's car with my bags I almost collapsed.”

The doctor told me she suspected I had a blood clot in my lung and fought to get me admitted to hospital.

Hospital took a chest x-ray and booked me for a CT scan the next day. I began to google my symptoms (I wouldn't recommend it!) and convinced myself I was having a panic attack as all the symptoms fitted.

The next day, after my CT scan results came through, the hospital made a big fuss and sent me in an emergency ambulance with a doctor and nurse to Belfast. I had blood clots in both lungs.

At Belfast City Hospital they advised that they would give me drugs to dissolve these

clots. Unfortunately, these drugs did not work. Luckily for me this hospital had, in the previous year, referred a patient to Papworth with the same condition as me and they made a very quick referral for me.

In January 2007, Papworth confirmed I had PH and at the time, I had no idea what it was. After lots of visits and meetings, eventually I was deemed a suitable candidate for a pulmonary endarterectomy. I had the operation in October 2007.

In the months before the surgery I was advised to take it easy – instead I bought a house and learned to drive! I also attended my friend Patricia's wedding and was annoyed I couldn't dance more. I couldn't wait for surgery as I was gradually getting worse.

When I came round from surgery I was in lots of pain, but not in my chest. Instead I had severe nerve damage and nerve pain in my feet and coccyx. I have permanent nerve damage but I can do almost everything I used to be able to do, and am back at work. I am unsure of the long term implications for me as a result of this nerve damage but if I had not had the surgery, I would have died.

I felt like my lungs were fully healed five years after surgery. I now play sports and lead a full and active life. I will take Warfarin forever but I consider this a small price to pay.” ●



Earlier this year, Elizabeth trekked 34km across the west of Ireland to raise £378 for PHA UK.

“I have always wanted to raise funds for PHA UK as I got a lot of support from them and their members whilst I was sick, and post-surgery. The Sligo Camino challenge, a 34km trek in my home town of Sligo, was one of the hardest things I have ever done in my life. I had sore legs from the start but because the charity is so close to my heart I battled on and managed to finish it. Thinking of other people with PH spurred me on and I was so proud to finish the walk for them. My friend Patricia who did the walk with me was also a great support.

I had never done anything like this challenge before. I had walked a few kilometres but not that far, and not over mountains. Even so I think I will do it again next year - perhaps I'll do a bit more training though!”

HAPPY NEW YEAR!

Are you making any resolutions?

It's that time of year again when some of us like to make a resolution or two to improve our lives, be more healthy, eat well or give up a bad habit. But how many of us keep them? To help you achieve your

personal goals this year, here are some excellent tips from *Professor Richard Wiseman*, of the University of Hertfordshire, which he's shared via the **NHS Choices Live Well** website.

1 **Make one resolution** and channel your energy into changing just one aspect of your behaviour.

2 **Don't wait until new year's eve** to make a resolution – give some thought to what you want to achieve beforehand.

3 **Avoid previous resolutions** if you can – start a fresh challenge.

4 **Don't run with the crowd** and go with the usual resolutions – think about what you really want to do.

5 **Break up your goal** into a series of steps – take it one step at a time.

6 **Tell your friends and family** – they are more likely to support you to succeed.

7 **Draw up a list** of what benefits you'll get out of achieving your goal – regularly remind yourself of these to motivate you.

8 **Give yourself a small reward** whenever you achieve a sub-goal /make progress.

9 **Log your progress** and make it concrete – for example, keep a journal, fill in a computer spreadsheet, cover a noticeboard...

10 **Expect to revert to old ways** from time to time – treat any failure as a temporary setback rather than a reason to give up altogether.

Visit www.nhs.uk/livewell for more help, information and advice.

HAVE AN 'APPY NEW YEAR...

Resolutions may involve nothing more complicated than joining your local library, signing up to a stop smoking support group or taking regular walks in your local park. But if you live your life on your smartphone or your tablet... there are lots of techy tools which can now help you change your lives a little for the better in 2017 (if you have PH, always talk to your GP and PH team before embarking on any new exercise routine.)

Eat well and lose weight

As much as it is a cliché to lose weight for the New Year, it can still be a very worthwhile resolution to make! And there is loads of support available online these days. A 12 week plan to help you succeed has been published by the NHS Live Well website and this includes a 'meal mixer' tool to help you plan and prepare meals.

www.nhs.uk/LiveWell/Loseweight/Pages/Loseweighthome.aspx

If you use Instagram, you can also follow 'From Paleo to Atkins' and connect with lots of other people trying to lose weight and get fit. Get inspired and motivated!

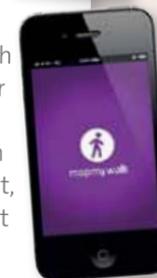


Take more exercise

My Fitness Pal is a great little app, available on iPhone and android, which can help you track your calorie intake and monitor your activity levels as you undertake your new personal fitness programme.

Map my walk is another brilliant free tool which you can use to show how far you've walked – or jogged - and how much energy you've exerted. You simply press a button to start and a button to finish – the app then gives you your step count, a map of your route, the speed you completed it and calories burned.

Couch to 5k is another fantastic NHS programme available via the www.nhs.uk/livewell website that's been designed to help people get off the couch to running five kilometres or 30 minutes in just nine weeks. Some of our PH fundraisers have used this one. If it suits you – give it a go.



Write a Blog

Some people find writing a cathartic process and a blog a fantastic way to share your knowledge, interests or experience. Some people really find it helpful to blog about living with PH (see page 13). You can use a free online platform called WordPress to set up a blog: wordpress.com/create/



Electronic cigarettes *the lesser of two evils?*

With the New Year a key time for people thinking of kicking the habit, senior pharmacist *Neil Hamilton* considers the benefits of e-cigarettes when it comes to stopping smoking.



We will all have seen the use of electronic cigarettes (e-cigarettes), or 'vaping' becoming more common. Indeed, estimates suggest these are now used by over 2 million smokers in the UK. There will be multiple reasons why people choose vaping over cigarette smoking and in this article I will explore some of the issues and what the scientific evidence tells us.

The use of e-cigarettes is justified by some as a cleaner alternative to cigarettes. It is well documented that tar, carbon monoxide and other impurities found in cigarettes and cigars may be responsible for some of the harmful effects of smoking, such as lung cancer. E-cigarettes contain no tar; the fluid inside is called e-liquid and is usually made of nicotine, propylene glycol, glycerine, and flavourings. Other than the nicotine itself, it is quite possible that these are harmless

programmes and assistance through GP surgeries and local pharmacies. Although prescriptions are still available, unfortunately the funding for support initiatives has fallen dramatically since 2012, which may explain the similar timing of a fall in 'quit rates'.

A recently published research article in the British Medical Journal (BMJ) by a group from University College London aimed to explore the role played by e-cigarettes in smoking cessation. They looked at data on about 1200 smokers between 2006 and 2015. The group found that e-cigarettes were positively associated with the success rates of quit attempts, in that using e-cigarettes will likely reduce the amount of quitting attempts an individual needs. The study found that the use of nicotine replacement therapy (NRT) on prescription (such as patches, gum or inhalators) was



year old smoker may expect to gain nine life years compared to someone who continued to smoke.

Quitting smoking will be a necessity for anyone being assessed for transplant, which may affect some patients with pulmonary hypertension. Currently in the UK, transplant candidates must be without nicotine for at least six months before being enrolled onto the active waiting list. This applies to tobacco, e-cigarettes and also prescription nicotine replacement products. Whilst the evidence post lung transplant is less clear, it is also known that resuming smoking after heart or kidney transplants increases complications and chances of rejection.

“Quitting smoking will be a necessity for anyone being assessed for transplant, which may affect some patients with pulmonary hypertension.”

As health professionals, the message is very clear that we encourage all smokers to quit if at all possible, however a lifelong non-smoker will have no personal experience of the challenge of quitting. Evidence such as the BMJ study tells us that e-cigarettes are playing an increasingly common part of quitting attempts, but that successful cessation will be down to many factors- not least a huge amount of will power!

ingredients; however, there is currently no requirement for the contents to be guaranteed as with a medicinal product.

Public Health England recently undertook a review of the evidence for e-cigarettes, the results of which can be found via the NHS choices and BBC websites if you would like more information. **However, the findings were largely positive, suggesting them to be '95 per cent safer than smoking cigarettes.'** It is speculated that with tighter regulation over their manufacture, e-cigarettes could be prescribed on the NHS as a smoking aid in the future.

Currently the NHS provides smoking cessation aids on prescription such as inhalators, gum and patches, together with access to smoking cessation

negatively affected by e-cigarettes, presumably because some people preferred to use an e-cigarette to NRT. Unfortunately the study could not find a link between e-cigarettes and rates of successful attempts to stop smoking.

In the year 2014-5, smoking rates fell by one per cent, which suggests that something in the UK's tobacco control policy is working, but it is unclear how much of this decrease is due to e-cigarettes. The growth in e-cigarettes may have reduced the uptake of NRT, but across the board, the UK saw 32.5 per cent of the eight million smokers attempt to quit in 2015. It is not to be underestimated just how addictive nicotine is and how difficult it would be to quit. However, it is also important to remember the health benefits to smokers of quitting. For example, a 40-

If you are one of the UK's eight million smokers, perhaps one of your New Year's resolutions could be to quit smoking. Advice and support is on hand through your local pharmacy and GP surgery, even if this is not as well publicised as in the past. Encouragement and moral support will be readily available from your PH centre too. Good luck!

ME & MY JOB

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

NAME: Alan Greenhalgh.

PLACE OF WORK: Freeman Hospital, Newcastle upon Tyne.

JOB: I am the research nurse for Pulmonary Hypertension.

HOW LONG HAVE YOU WORKED WITH PH PATIENTS? I started this role back in February 2014 so just under 3 years.

BEST THING ABOUT YOUR JOB: It is exciting to know that taking part in research helps in the development of new drug therapies, trials existing therapies in alternate ways and patient groups, and in turn see how they benefit and improve the quality of life for our patients. Working with an amazing team, together, we support our patients both now and into the future. And of course, thank you to our patients, without whom we would not be in a position to take part in clinical trials.

FIRST THING YOU DO WHEN YOU GET TO WORK: Sit down, power up the computer so that I can check my emails, sift through the calendar and generally prepare for the day.

WHAT'S ON YOUR DESK? I have my computer, study protocols, diary, endless pieces of paper that just don't seem to have a home to go to, and today, the all-important piece of homemade Rocky Road courtesy of my fellow research nurse Debbie.

PROUDEST MOMENT AT WORK: I guess my proudest moment has simply been the opportunity to be involved in Pulmonary Hypertension research and to observe how medications that have gone through the trial process have finally become a treatment option available to our patients.

WHAT DO YOU LIKE TO DO OUTSIDE WORK: My days of nightclubbing until the wee hours are gone. A nice pint of beer on a Friday after work goes down a treat. Catching up with friends is also a must. My more reserved pastimes include gardening, history and photography, being a member of both English Heritage and The National Trust allows me the chance to get out and about and combine all three. At home I do like to potter in the garden as I find it quite relaxing.

KEY DEVELOPMENTS YOU'VE SEEN FOR PH PATIENTS: One of the key developments would be the introduction of a specific therapy for patients with Chronic Thromboembolic Pulmonary Hypertension (CTEPH). Research has provided that opportunity to develop a new drug, trial it, evaluate its effectiveness, and then see it become licenced for use. Globally there are new ideas on the horizon – developing exercise training programmes specifically for PH patients for example.

TEA OR COFFEE? I am a tea drinker and I have to have it black – tea bag in cup, hot water and leave the tea bag in. Simple, no fuss. Thanks to my work colleagues I never seem to be short of a hot brew at hand.

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



PHriends forever

Alex Walker and Priya Mistry are both 32 and live ten minutes away from each other in Leicester. They also both have pulmonary hypertension and were diagnosed just a few months apart, but until earlier this year had no idea that each other existed. After a chance introduction, the pair now enjoy a special friendship and overleaf, they share their stories...





Alex Walker “”

“I was finally diagnosed with PH in August 2011. I say finally as my symptoms started way back in January 2008. I had been complaining to my local doctor at the time of swelling, breathlessness, pressure behind my eyes and passing out every time I went up the stairs at home. The doctor had told me that he believed I was suffering with anxiety and panic attacks and that I should slow myself down and look into breathing techniques – and that maybe yoga would help!

This went on for a number of years and I had got used to the fact that I just had to take my time. Having an 18-month old little boy also made me think that maybe I was just exhausted. So trying to eat right, be organised and get early nights is what I did.

“It’s great having someone to compare symptoms and feelings with...”

In 2011 my partner Ben, son Finnley and myself moved into a new house. I literally couldn’t do anything by this time without feeling breathless, dizzy and basically just wanting to sleep. Every bone in my body ached, I had a cough that used to make me sick, I seemed to have put on a lot of weight and my back was so painful too.

One Sunday morning we woke up and I felt so poorly Ben told me enough was enough and he took me to our local A&E department. From there I decided I wasn’t going home until someone had told me what was going on with my body.

I was eventually transferred to the Royal Hallamshire and after my diagnosis was confirmed, I attended every six months or so and seemed to become stable. I began chatting to other people and learned of local pulmonary rehab sessions that you can attend if referred by your GP.

I got my doctor to refer me to a session in Leicester and after six weeks, in my last session, the physio came over to me with



Alex with her partner Ben, and her son Finnley.

the telephone number of a girl with the same condition, and suggested I give her a call. I couldn’t believe it, and rang Priya later on that evening to introduce myself. We decided to meet for a coffee later on that week.

We probably chatted for an hour or so during that first meet-up before I had to dash off on the school run, but decided to arrange another meeting with our other halves so that we could all meet and share our experiences.

We all get on really well and Priya and I meet up whenever we can to go for lunch or a meal out. We are in touch over text or WhatsApp most days and it’s great having someone to be able to compare symptoms and feelings with, and know that they totally understand where you’re coming from.”

Alex’s family and friends are taking part in a ‘Wolf Run’ in April 2017, to raise money for PHA UK. You can support them via www.justgiving.com/fundraising/Alex-Walker32

Priya Mistry “”

“I was diagnosed with idiopathic primary PH in January 2011 after two to three months of feeling breathless whilst going upstairs or walking around town. I put my symptoms down to becoming unfit due to changing jobs which meant I was driving more than walking.

I also became very unwell with a virus and had a persistent dry cough for almost a month, trying every possible remedy over the counter and two courses of antibiotics. It kept me up overnight and interrupted my working day and conversations at home. It got to the point where I was having to write things down on paper to converse with my family.

My feet and legs started swelling up and my GP sent me for an urgent chest X-ray. I was rushed into hospital as an emergency with a potential pulmonary embolism.

“It was reassuring to hear someone else with a very similar story.”

Like Alex, I was referred to the Royal Hallamshire and I visited them every four months. Although we may have been attending at similar times, we never crossed paths there.

In passing conversation, my nurse mentioned late last year that I might benefit from pulmonary rehabilitation and I saw my doctor who referred me for this. When I went for an initial assessment, I was told by the physio that there was another young girl from Leicester who has PH and was undergoing the rehab programme and that he would like me to meet her. I couldn’t believe it, especially as I was told the majority of people attending rehab are elderly, with COPD or emphysema.

My rehab was put on hold due to other reasons, but I was very keen to meet Alex and asked the physio to kindly pass my number onto her. To my pleasant surprise, Alex rang sooner than I thought and we exchanged stories over the telephone. It was shocking to hear someone else of the same age living in the same city, diagnosed in the same year! We were both shell-shocked, but in a good way. It was reassuring to hear someone else with a very similar story.

When we met for coffee we were both a little nervous yet excited at the same time. It went well and it was nice to find we were on the same wavelength. Meeting up with our partners too has really helped the four of us out.



Priya with her husband Alpesh, and her parents Usha & Sushil.

Alex and I are constantly in touch over the phone and our friendship has developed over the course of the year. We share information on symptoms and side effects and how we both deal with PH at work and at home.

I have a blue disabled badge and have to put up with horrible comments from the general public. PH is an invisible condition and I want people to know how rare and life-threatening it is.

Alex and I help each other out by telling one another if we hear anything about research or treatment and enjoy meeting up for lunch or dinner.

We have both adapted to living with PH and together are understanding the condition more and more.”

Priya is taking on a special walking challenge to raise money for PHA UK, to support research, treatment, and ultimately, a cure. You can support her via www.justgiving.com/fundraising/PriyaMistry1984



TAKING IT DAY BY DAY

Bunty Cloy's husband Bobby was diagnosed with PH in January 2016 and the last few months have been full of ups and downs for them both. Here, she shares how they support each other, with help from family and friends.

“Bobby and I live on a farm in beautiful Dumfries and Galloway surrounded by picturesque countryside. We have been married for 56 years and have one daughter and two sons who over the years, presented us with seven grandchildren, and at the last count we now have eight great grandchildren to add to the fun. From the beginning of 2015, Bobby's health began to deteriorate quite quickly – he was experiencing chest pains, shortness of breath, falling and feeling faint on exertion. After many visits to our GP he was eventually referred to the consultant cardiologist at the Dumfries and Galloway Royal Infirmary (DGRI) in July 2015, and they told us they thought Bobby had PH. This condition was something totally unknown to us and we had no idea what lay ahead. Our next appointment was with the respiratory consultant, again at DGRI. Three months later, while on a weekend away with family, Bobby was admitted to hospital in Edinburgh when he collapsed after walking just a few yards. The following week we went back to the DGRI who immediately started him on oxygen therapy during the night and when he was moving around in the daytime. At this time, he was referred to the Scottish Pulmonary Vascular Unit (SPVU) at the Golden Jubilee Hospital in Glasgow. We attended there in late November and it was decided to admit him in January 2016 for further tests. Unfortunately, late at night on 28th December 2015, Bobby was again admitted to DGRI after having a heart attack. A week later he was transferred to the Golden Jubilee where extensive tests on his heart and lungs were carried out and in January 2016, we finally had an Idiopathic Pulmonary Hypertension diagnosis. Because of all the stress of Bobby's health deteriorating rapidly the previous year, in a strange way it was a relief to have the

diagnosis, but we also had a great fear of the unknown and worry about whether the doctors would be able to help him. Bobby's condition has brought huge changes to our day-to-day lives. He is now on oxygen therapy 24/7 and uses his nebuliser seven times a day. He was a very sociable man and a great supporter of our local community, being president of two bowling clubs and a founder member of a boxing club. Sadly these are pastimes he is no longer able to enjoy. Earlier this year Bobby was invited to Dumfries and Galloway Sporting Awards ceremony when he was presented with a trophy for his services to boxing over many years. As you can

“In a strange way it was a relief to have the diagnosis, but we also had a great fear of the unknown.”

imagine, it was a very happy and proud night for all the family. We do our best to support each other day by day. I try to encourage Bobby to do what he can for himself so he still feels he has a bit of independence. We now have a level access shower fitted and this has been a tremendous help and has given him more confidence with his washing and dressing. Towards the end of last year, due to his heightened anxiety levels, he frequently became unwell at night when preparing for bed and it was a very stressful time for us. Bobby gets frustrated at not being able to carry out general household tasks but does his best to help in any way he can. He makes a great cuppa and it's always much appreciated.

Although our family have all moved away from the area, they are still very supportive, travelling down and taking us to numerous hospital appointments when required and telephoning and visiting frequently. We also have a good circle of friends who are only too willing to help out should we need it. While Bobby was in hospital for a few weeks during the summer and the garden was in need of attention, our friends very kindly stepped in to tidy it up. We take each day as it comes and don't plan too far ahead after all the ups and downs of last year. But I'm really happy to say that after some changes to his medication, Bobby's general health is much more stable. He can now enjoy pottering around in his new greenhouse, a gift he received from the family for his 80th birthday. We have had to make a lot of adjustments to our lifestyle over the last 18 months. We enjoyed weekends away with friends and trips up the country to visit our daughter and sons and their families. Unfortunately, some of their homes are not easily accessible for Bobby, so these visits are no longer an option for us. Our nearest supermarket is 15 miles away so going shopping is a bit of a marathon, for example making sure we have enough oxygen and nebuliser meds with us, and having to watch the clock all the time. On the plus side, Bobby now has an electric scooter which has given him the freedom on a good day to get out and visit our local country gardens and walks, which

have always been a great part of our lives with our children, grandchildren and great grandchildren. After reading the leaflets we were given when Bobby was diagnosed we decided to become members of PHA UK and we feel the information we have received since then has been beneficial in helping us to have a better understanding of PH. It is a steep learning curve and I want to know as much as I possibly can about how I can help, and if there are things I can do better for him. In April we attended the Patient's Day at the Golden Jubilee, which was supported by PHA UK, and we both found this to be a reassuring experience. Meeting and talking to fellow sufferers helped Bobby to realise he is not alone on this journey. I attended a workshop for carers and for the first time I felt I was talking with people who truly understand what it is like living with PH. Our sincere thanks go to the SPVU team in the Golden Jubilee and the Queen Elizabeth University Hospital for all their expertise and support and making us feel like we matter. It's of great comfort to us to know that should we have a problem, we can pick up the phone and someone will be there with some words of wisdom and reassurance. ● ”

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



Feed your feelings.

Research increasingly shows that depression and anxiety can be helped or hindered by what we eat. Here, mental health expert *Sarah Dash* explores how food can affect how we feel.



Sarah Dash is an academic working in the field of mental health. She is studying for a PhD and works with a team at Deakin University in Australia in its Centre for Innovation in Mental and Physical Health and Clinical Treatment.



Whether we're reading about it, shopping for it, preparing it or eating it, food is a big part of our day-to-day lives. While everyone's got to eat, I've always found myself particularly interested in food; not only the joys of preparing and eating it, or learning how it fuels us physically, but also about how food makes us feel. My questions about food and nutrition are shared by many health researchers - for example, if I improve my diet, will my mood improve? It's not until fairly recently that science had begun to provide the answers.

My interest in food and mood (and if I'm honest, warmer weather) led me to the University of British Columbia in Vancouver, Canada and then Australia, where I've spent the early stages of my academic and working career exploring the relationship between diet and mental health. I began my PhD in 2014,

Studies from around the world have shown what many of us suspected; diet is important to mental health.

working with leading Nutritional Psychiatry researcher Associate Prof Felice Jacka at Deakin University in Melbourne, Australia. Felice has been researching the relationship between diet and mental health for the past decade, and has been a very key investigator in uncovering what we now know is a clear association

between the quality of our diet and our mental health.

Many of us intuitively understand the food-mood connection (think comfort food or a celebratory meal), yet the scientific evidence in this area has somewhat lagged behind conventional wisdom. In the past decade or so, however, there have been many studies from around the world that have consistently shown what many of us suspected; diet is important to mental health. For example, studies from Spain, Norway, Australia and the US have all shown that following a healthy, 'traditional' dietary pattern, consisting of the foods we know to be good for us (colourful fruits and vegetables, whole grains, legumes and healthy fats) is protective of your mental health. The unfortunate, and perhaps unsurprising news is that the reverse appears to be true as well; unhealthy, processed 'junk' foods are not only bad news for our waistlines or hearts, but for our mental health too.

The burden of common mental disorders touches us all on some level; whether we are medical professionals, carers, relatives, or affected personally. While traditional treatments like medication or therapy are life changing for some who experience depression or anxiety, many are looking to incorporate other methods of mood management. A good quality diet, for example, is an important and practical way to promote mental health. Not only is our diet something that is relatively within our control (unlike, say, our genetics), it's something we're already doing

multiple times a day – eating! Now that the scientific evidence has 'caught up' in supporting the diet-mental health link, it's important to think about ways that we can encourage healthy, good quality diets for the prevention and treatment of common mental disorders.

The burden of common mental disorders touches us all on some level.

It's an exciting time to be a nutritional psychiatry researcher! Science is beginning to uncover the ways that we might use 'food as therapy' to prevent and perhaps even treat common mental disorders. As we continue to learn how to keep our bodies and brains as healthy as possible, it's important that the findings of new research are shared and talked about in a way that is useful, easy to understand, and gives us the tools to protect our mental health from the comfort of our own kitchens. ●



Are you struggling with stress or anxiety?



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

- Dedicated helpline service 0844 332 9010
- Email support via phauk@anxietyuk.org.uk
- Assessment and therapy provision for those who need emotional support
- Training and resources for PHA UK professionals and members

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

Feeling lonely this Christmas?

Call 0800 4 70 80 90

The Silver Line is the only free confidential helpline in the UK dedicated to supporting older people suffering from loneliness and feelings of isolation.

The helpline, which is available 24/7 and open all year around, provides information, friendship and advice to anyone in need, particularly those in their 70s and older.

It may be particularly helpful for people during these dark winter months and at Christmas, which can be a particularly hard time of year if you feel lonely.

The Silver Line's specially-trained volunteers take hundreds of calls from individuals each month. Some just need a chat, and others are helped to get in touch with local community groups and services which offer companionship, support and social opportunities close to their home. Silver Line can also offer regular befriending calls.

The confidential service can also provide vital support to anyone suffering abuse and neglect.

Dame Esther Rantzen set up The Silver Line in September 2013, following on from the success of ChildLine, which has been a first point of contact for children who feel they have no-one else to turn to since 1986.

Esther, aged 76, said it was her own experience of loneliness that prompted her to create the helpline to support those feeling similar. In just three years, Silver Line has received more than one million calls and recruited more than 3000 volunteers.

“We know that feelings of loneliness and isolation can be all too common among older people in today’s fast-paced modern society”

Esther said: “I knew there was a need for the helpline but to answer one million calls in such a short space of time is desperately sad. Calls to the helpline increase almost every week as we uncover the epidemic of loneliness among some of our



oldest and most vulnerable people.”

Chair of PHA UK Iain Armstrong said: “We know that feelings of loneliness and isolation can be all too common among older people in today’s fast-paced modern society – with families living far apart and communities not always being very well connected across generations.

“We also know from our own members that when an older person suffers from a long-term health condition like pulmonary hypertension these feelings of isolation can be exacerbated. It can be much harder to get out of and about and find people to talk to about their feelings and day-to-day experiences.

“We hope PHA UK and its wider community of mutual support helps all older people in need of a little human contact. And it is also good to know that a service like Silver Line exists and that there is a number to call if any older person is feeling lonely and needs to talk to someone at any time.”

Call The Silver Line on **0800 4 70 80 90**.
To find out more visit www.thesilverline.org.uk
To make a donation to support the work of Silver Line, please visit www.thesilverline.org.uk/donate/



A great BIG thank you..

...to everyone who got involved in our first ever **PH Awareness Week!**

From 19th to 27th November, the PH community worked hard to raise awareness of the condition on social media, via their local press, and through encouraging conversations with family and friends.

Some of you wrote to your MPs, and helped us to let medical professionals know about our education course. You helped us display posters, and got people talking online using the hashtags #PHweekUK and #LetsTalkPH.

Alex Walker got in touch with her local paper, The Leicester Mercury, to share her PH story.



Catherine Makin wrote to her MP and got an official reply wishing her luck with her coming treatment.



Patient **Pauline Ginn** delivered a talk at the Bolton Cardiac Society about PH and transplants, and received some lovely flowers as a thank you.

To coincide with PH Week, **Angela Cran** launched a special blog to talk about how the condition has affected her family. www.angelacran.wordpress.com



We'd love to know what you thought about the week, and whether you have any feedback for next year. Email editor@phauk.org.uk to share your views.

This issue of Emphasis went to print at the beginning of PH Week, but here's a snapshot of what happened in the first few days. For further information on what went on, please see our social media pages.

Tracey Barnes encouraged her local health centre to display the new PH pocket guide – and even persuaded two doctors there to sign up to the PHA UK medical education course too!

PHA UK Chair **Iain Armstrong** was interviewed on Somerset radio station Sedgemoor FM about PH. He was also interviewed by a national news agency and an article about PH made it as far as The Irish Examiner.



@AnaFanClubUK (Sarah) *This week is #PHweekUK to raise awareness of the disease that myself and 7,000 others in the UK deal with on a daily basis.*

@LukeMarinog (Luke) *Help raise awareness of Pulmonary Hypertension, a very serious condition that should be talked about more #PHweekUK*



Partnering for respiratory health

As well as launching our first PH Awareness Week, in early November, PHA UK partnered with Mediaplanet UK on their 2016 Respiratory Health Campaign.

The campaign included a special magazine supplement in the Guardian newspaper, where Sue Townsley, PHA UK Trustee, shared her PH journey. This is what was printed:

Pulmonary hypertension: Sue's remarkable journey

At 32, Sue Townsley was diagnosed with pulmonary hypertension – an incurable disease with a poor prognosis. Medical advances and determination have helped her reach 49.



“When I learnt I had pulmonary hypertension at 32 I was told my only hope was a heart and lung transplant” says Sue Townsley, from Coventry.

In pulmonary hypertension the walls of the arteries supplying the lungs thicken and stiffen or are blocked by blood clots causing breathlessness, fatigue, blackouts and heart disease. Life expectancy is around seven years.

“Just getting off a chair left me breathless but I refused to accept that I would not see my children grow up” says Sue.

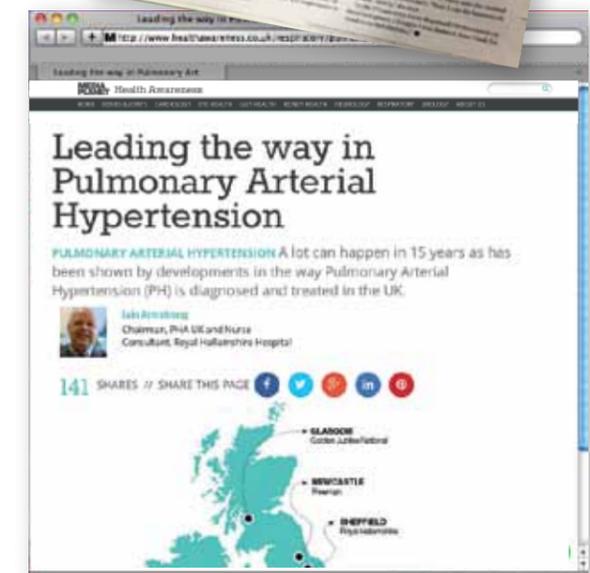
Sue was treated with Warfarin while awaiting a transplant, but got on to a trial that involved taking the vasodilator Iloprost as an inhaled vapour. *“I could go back to work part*

“Just getting off a chair left me breathless but I refused to accept that I would not see my children grow up.”

time” she says. After five years, she started on Slidenafil too. Finally, exhaustion forced her to leave and she started taking Iloprost intravenously. *“Now I can do housework and cook – slowly”* she says.

“In the 17 years since I was diagnosed PH treatment options have grown. I thought I was doomed. Now I look forward to my 50th birthday.”

The Respiratory Health Campaign also featured online and included an article on PH diagnosis and treatment developments in the last 15 years, written by PHA UK Chair Iain Armstrong. ●



Hope, optimism and quality of life...

Last year, *Emma Cole* invited *Emphasis* readers to take part in research around hope, optimism and quality of life with PH. In September, she showcased the results at the **European Respiratory Society (ERS)** international congress, and here she shares them with you.

Hi everyone,

Some of you may remember reading my invitation to take part in some research on hope, optimism and quality of life in the spring edition of *Emphasis* last year. Firstly, I'd like to say a big thank you to everyone that took part. I managed to collect lots of data which was really useful in helping to understand the factors that affect life with PH. Attending the ERS conference was a great way to get information out to doctors, nurses, researchers and other professionals from around the world, and hopefully helped to increase awareness and inspire others to undertake research in this area. Now I'd also like to take the opportunity to share some of the findings with you.

The data showed that there were significant relationships between hope and health-related quality of life and also between optimism and health-related quality of life.

More specifically, people that were found to have higher hope and optimism levels reported having better health-related quality of life than people with lower levels of hope and optimism. Age or gender did not seem to have any effect but people using oxygen reported themselves to be less hopeful than those that did not use oxygen. There were also a few differences between people with different types of PH but the reasons behind this were not fully understood. Hope and optimism are thought to affect health-related quality of life through differences in our thought processes and perceptions of our situation and goals.

People who are more optimistic are thought to be able to adapt better to challenging

situations and can adjust their hopes in situations that can't be changed.

Previous research has shown that quality of life is very important to people with PH and this study is the first step towards using health psychology to help people with the disease achieve their goal of a better quality of life. Now there is evidence to show that psychological factors such as hope and optimism are linked to health-related quality of life in PH, it may be possible for researchers to start looking at whether interventions could enhance hope and optimism levels and whether this creates an improvement in health-related quality of life for people with PH. Researchers could also study symptoms and physical well-being to see if similar links can be found and whether psychological interventions may have the potential to improve the physical aspects of the disease as well.

By taking part in research you are helping people to understand the factors that underpin the experience of living with PH.

The more we know, the better we can attempt to develop ways to help improve the lives of people with this condition. So once again, a huge thank you to everyone that took part and I hope you will continue to take part in research in the future.

Emma Cole
MSc Health Psychology



Hallamshire patients get together in Sheffield

The Sheffield Pulmonary Vascular Disease Unit Patient Day saw patients, carers and professionals all come together on 12th November.

PH patients who attend the Royal Hallamshire hospital in Sheffield gathered at the Hilton hotel in the city to meet fellow patients and learn from educational talks and workshops.

A talk about what tests tell us about pulmonary hypertension included a look at echocardiography, exercise testing and lung function and CMR. Experts Iain Smith, Andy Swift and Thanos Charalampopoulos presented on these topics, following an overview by the hospital's Consultant Physician and PH Lead, David Kiely.

.....
“It was great to bring everyone together and learn from shared experiences.”
.....

Jim Lithgow and Alex Rothman discussed research, including why it's important and what the Sheffield Pulmonary Vascular Disease Unit are doing - plus how research moves from

the lab to the clinic. During a buffet lunch, there was the opportunity for patients to visit four separate stations discussing various research studies.

The afternoon session looked at how the Sheffield PH service works together to maintain a centre of excellence, in a talk led by Charlie Elliot.

The day ended with question time, which saw patients put their queries to a panel of experts. The meeting was funded by the hospital charitable trust with support from PHA UK.

Iain Armstrong, Chair of PHA UK and Nurse Consultant at the Hallamshire, helped to host the event.

Iain said: “We realised it had been several years since we last got together in an informal setting, so this support day was well overdue. It was great to bring everyone together and learn from shared experiences, to see how best we can move our service forward over the coming years.”

Keep an eye out on future issues of *Emphasis* for news of upcoming patient events. You can also keep up to date by following PHA UK on Facebook and Twitter.

Here's what some attendees had to say about the event...

“My wife doesn't really tell me anything when she gets home, so as her carer, it was great to hear and learn things for myself.”

“We've really enjoyed it, thank you to everyone who put this on. As newly diagnosed we're finding out as much as we can.”

“A great mix of speakers, talking about different subjects... very educational.”

“A really worthwhile event. Very informative and a lovely friendly atmosphere. Thank you!”





Green Leaf

Crew!



GREEN LEAF CREW Q&A CHARLIE KEITH

Seven-year-old Charlie Keith lives in St. Albans, Hertfordshire, and was diagnosed with PH at just two months old. He lives with his parents Helen and Grant and little sisters Emma, who is four, and Olivia, who is two. Charlie wants to be a zoo keeper when he is older, and currently looks after his pet fish.

- Q. Do you have a favourite film?
A. *Star Wars: The Phantom Menace.*
- Q. If you could have any superpower, what would it be?
A. *Flying.*
- Q. What is your favourite part of Christmas dinner?
A. *Pulling the crackers and the chocolate log.*
- Q. Which famous person would you most like to have a selfie with?
A. *Luke Skywalker.*
- Q. What is your favourite thing to do at school?
A. *Art.*

- Q. What's your favourite thing to do at weekends?
A. *Play with my toy zoo animals and my monkey bingo game.*
- Q. Do you have a favourite snack?
A. *Chocolate biscuits, especially a Kit Kat.*
- Q. What do you like to watch on TV?
A. *Octonauts.*
- Q. Do you have a favourite animal?
A. *A zebra.*
- Q. What's the best thing about Christmas?
A. *Opening the presents, I'd really like more Playmobil animals this year.*



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

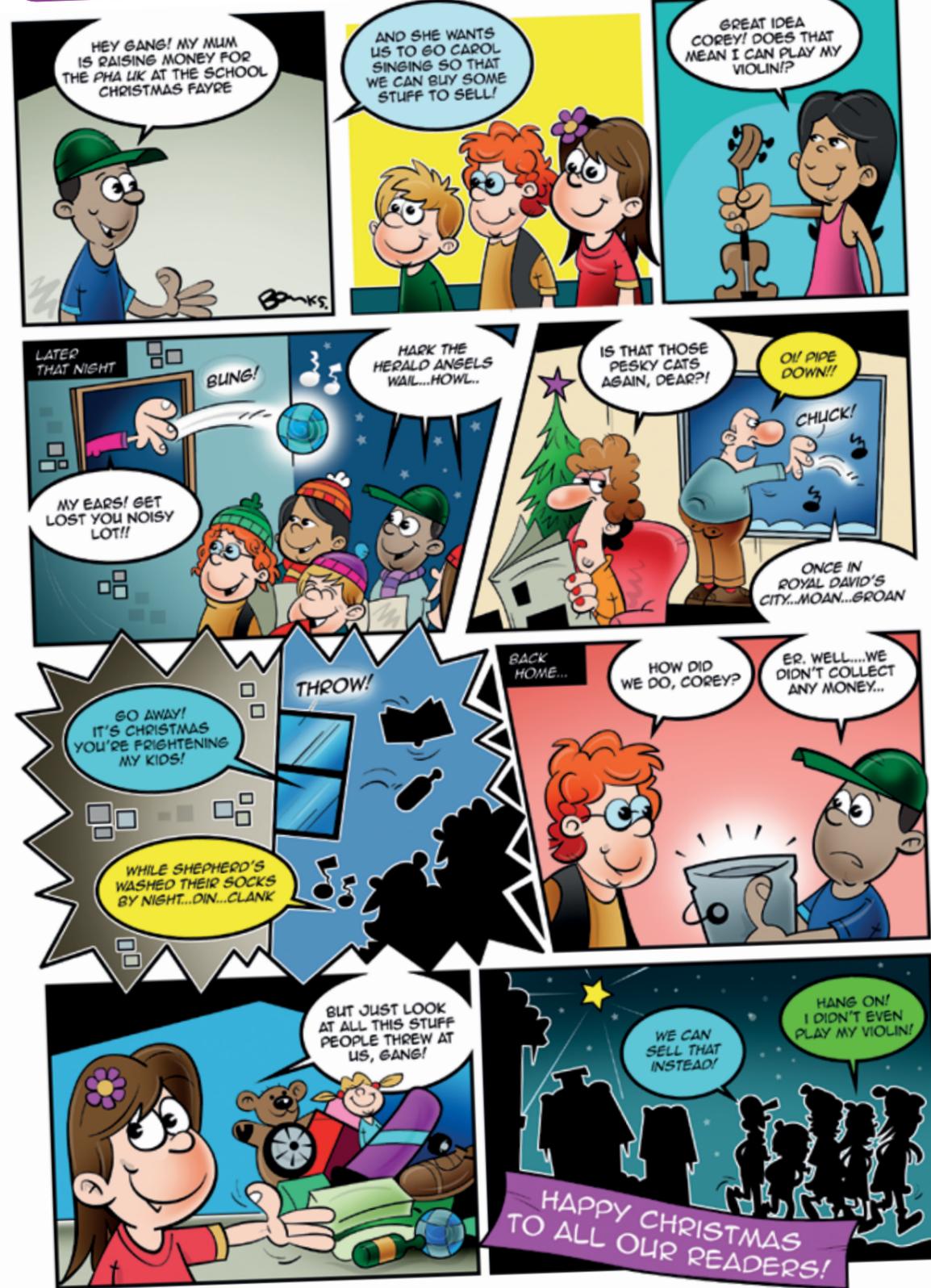
FAMILY FUNDRAISERS

Sporty siblings Lucy Bowen and Mark Hughes have both been busy raising money for PHA UK this year. Five-year-old Lucy completed 'Ironkids Wales', a fun run held alongside the adult Ironman event, and her 15-year-old brother Mark climbed Snowdon. He said: "I found it challenging but rewarding and the whole thing was amazing." The pair live in Carmarthenshire in South Wales and raised **£250** from their endeavours. They have been fundraising in support of their mum Anna, who has PH.



The GREEN LEAF CREW

BY DAVID BANKS



Patch



Campaign for free prescriptions

A campaign to extend exemption from prescription charges to all people who have long-term conditions is gathering pace. *Deborah Wain* finds out the latest.



The Prescription Charges Coalition is a group of organisations fighting for an end to “unfair” prescription charges for people with long-term medical conditions in England.

Research published in the Prescription Charges Coalition’s ‘Paying the Price’ report makes for worrying reading.

One in three people in England who have a long-term condition and have to pay for their prescriptions have not collected their medication due to the cost. Of these, three quarters report that their health got worse as a result with ten per cent ending up in hospital.

In April this year, the cost of a single NHS prescription increased by 20p to £8.40 – the latest of 35 hikes in a period of 36 years. Many with a chronic condition like pulmonary hypertension pay upfront for their medications through a pre-payment certificate (PPC) - the cost of a three month PPC was frozen at £29.10 and the annual PPC at £104. The Department of Health says the freeze will “ensure that those with the greatest need” are protected.

However, the Prescription Charges Coalition is campaigning for exemption from prescription charges to be extended to all people in England who have long-term conditions. It argues that the current system, established in 1968 and largely unchanged since then, is out-of-date and arbitrary.

The group highlights that in recent years, there has been a broad political consensus that the current system is unfair as some long-term conditions qualify people for free prescriptions whilst others don’t. The sense of unfairness has been made worse by the introduction of free prescriptions for all people living in Wales, Scotland and Northern Ireland. Some 90 per cent of prescriptions across the country are dispensed for free.

The Prescription Charges Coalition is made up of nearly 40 organisations. The long list includes Asthma UK, MS Society, Cystic Fibrosis Trust and Stroke Society.

It argues: “Our research, surveying thousands of people with long-term conditions, demonstrates that prescription charges are a major barrier to people taking their medicines effectively, leading them to severely compromise their health.

“This results in poorer quality of life, worse health outcomes, additional treatment, unplanned hospital admissions, decreased productivity and increased reliance on benefits.”

The majority of people adversely affected by charges are of working age as those in full-time education or aged over 60 are among patients exempt anyway. As it stands, the Government has no plans to make any changes to the list of medical conditions which qualify (see right).

Patients who want to add their voice to the campaign are urged to write to their MP asking them to make prescriptions free for everyone with a long-term condition like PH.

For more information, visit www.prescriptionchargescoalition.org.uk and follow the campaign on Twitter @PrescriptionCC. ●

PHA UK plans to join the Prescription Charges Coalition in 2017. Look out for future updates on the campaign in *Emphasis*.

The majority of long-term medical conditions do not entitle people to exemption from prescription charges but some conditions do. The following qualify for an exemption certificate:

- Treatment for cancer; this includes treatment for the effects of cancer, or treatment for the effects of a current or previous cancer treatment
- A permanent fistula requiring dressing
- Forms of hypo-adrenalism such as Addison’s disease
- Diabetes insipidus and other forms of hypopituitarism
- Diabetes mellitus, except where treatment is by diet alone
- Hypoparathyroidism (blood deficiency which can cause muscle spasms)
- Myxoedema (underactive thyroid) where thyroid hormone replacement is necessary
- Myasthenia gravis (abnormal weakness of certain muscles)
- Epilepsy requiring continuous anticonvulsive medication
- A continuing physical disability which means you cannot go out without help from another person.





Donna Welch and her daughter Hannah.

THE LITTLE GIRL WHOSE RARE CONDITION MAKES BREATHING A STRUGGLE

Donna Welch hit her local headlines when she started a crowdfunding campaign to help her daughter Hannah, who has PH, gain her own space in their small house.

Ten-year-old Hannah was diagnosed with PH in 2011, when she was just five years old. As a keen dancer, mum Donna has always wanted Hannah to be able to enjoy her own space – something she currently finds difficult in their two-bedroom home in Wareham, Dorset.

Hannah shares a bedroom with her little sister Amy, and the family hoped to raise enough money to create a loft conversion.

Earlier this year Donna launched a crowdfunding campaign, called 'Help for Hannah' to help raise the money needed to make the changes to the house.

Crowdfunding involves asking for a small amount of money from a large number of people, and online fundraising platform Just Giving now has a specific crowdfunding function, which Donna used to launch the campaign.

The Welch's story was published in two local papers – the Bournemouth Echo and Dorset Echo – with one running the headline: 'The little girl whose rare condition makes breathing a struggle'.

Donna told the journalist: "Hannah can't go to the park or play out on her

own with her friends like other children her own age because she is prone to fainting without warning due to her condition. She dreams of having her own space to escape."

Donna contacted The Dorset Echo directly via their Facebook page, and a reporter then interviewed her over the phone. The Bournemouth Echo contacted Donna after seeing the campaign on Twitter and conducted an interview via email.

“We've had lots of messages of support since the articles were published.”

Donna said: "Both journalists were very easy to communicate with and pretty much wrote the story up as I told it. We were a little worried things could have been taken out of context but we were very happy with the end results. We've had lots of messages of support since the articles were published and even a lovely letter and small cheque from an elderly lady who read about Hannah."



Unfortunately, the crowdfunding campaign didn't raise as much as the family hoped, so they are looking at additional ways to fund the loft conversion, including re-mortgaging their house. But every expression of support and donation kindly made by members of their community was appreciated.

Donna said: "Sadly the crowdfunding didn't raise much, but the campaign and the newspaper articles were definitely worth it as they helped us share Hannah's story, spread understanding of how PH affects her and raise awareness of this rare condition."

Thank you to everyone who helps raise awareness of PH through their local media. Please share your stories with us by emailing editor@phauk.org



Conference IS COMING!



We're gearing up for the next PHA UK Conference and we'd love to see you there.

Join us at the **Heythrop Park Hotel in Oxford on 13th – 14th May 2017** to meet fellow patients, hear from experts and professionals, and importantly, have fun. You'll find an 'expression of interest' form with this issue of Emphasis; please return to **Daisy Stewart, CFS Events Ltd, Mindenhall Court, 17 High Street, Stevenage, Herts SG1 3UN by 3rd February 2017**. You can also find the form online at www.phauk.org. There are only 130 places available, and we'll pick names at random from those who have expressed an interest. We'll let you know if you've been successful by **Friday 24th February 2017**.

In your Spring issue of Emphasis...

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

- **Gardening as therapy** – How it can help you feel better.
- **Living with PH** – The results of our major research into life with the condition.
- **The Interview** – In conversation with Dr Luke Howard, Consultant Respiratory Physician at Hammersmith Hospital.

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

You can get involved in Emphasis too:

- **Emphasis Reviews** - read a book, used an app or seen a film you think other readers may be interested in? Tell us about it!
- **Family Matters** - let us know if you'd like to tell us about your family's PH experience in our regular feature.
- **In the News** - let us know if you raise awareness of PH through the media.
- **Take the biscuit!** - and please get in touch if you'd like to answer the Green Leaf Crew Q&A.

We always love to hear from you – contact editor@phauk.org with any feedback or ideas.





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



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?

PHA UK AGM 2016

The PHA UK annual general meeting will be held at the Pullman St Pancras Hotel, London, on **Tuesday 6th December**. Please contact office@phassociation.uk.com for further information.

PHA UK Trustees

Dr Iain Armstrong, *Chairman*
Dr Tom Siddons, *Treasurer*
Kay Yeowart MBE, *Secretary*
Ms Sam Khan
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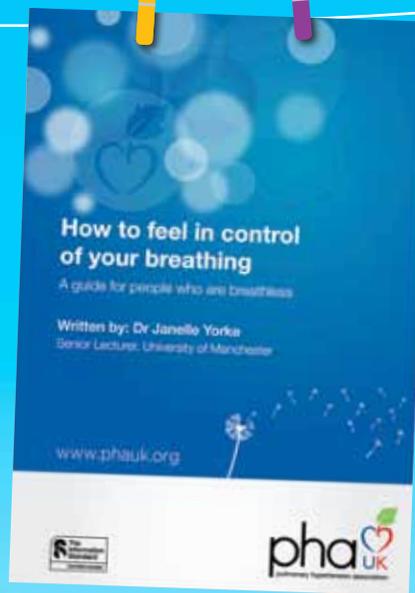
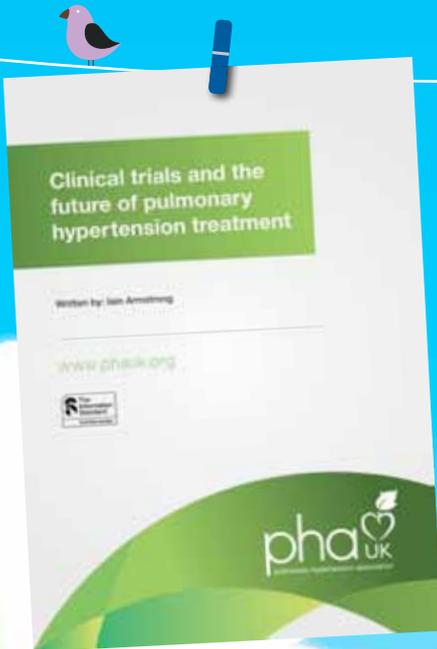
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