AUTUMN 2017

emphasis

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

MOVE MORE

Physical activity and pulmonary hypertension

IT'S BACK!

PH Week returns in November

Financial support for carers

Navigating what's available

PLUS...

PH services in the spotlight, your news and experiences, special interviews and much more!

"I feel happier than ever"

Cover star Selina's inspiring story about living with PH

LIVE BETTER WITH PH

QUALITY OF LIFE WITH PH

The results from our largest ever survey

#BreathlessNotVoiceless

Could you support us by playing our PHA UK Lottery?

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

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

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

So how does it work? Each week PHA UK Lottery players are allocated a six-digit number and the winning numbers are selected every Saturday. Cheques are then posted to winners directly – there's no need to check your numbers or make a claim yourself.

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

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

Signing up is simple!

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

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

> *"I play because I like to know the money is going to a charity that's close to my heart… and to my lungs!"*
> **Darren, Glasgow**

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

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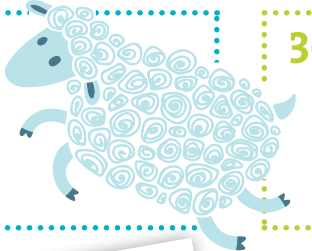
Influence.
Hope.
Integrity.

Latest News...

This magazine is printed on paper from sustainably managed sources

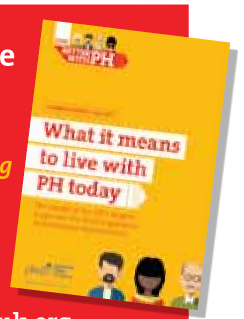
Living with PH...



Regular Features...

With this issue of Emphasis:

A summary of the results of the *Living with PH* survey.



For a free copy of the full report, email office@phauk.org or call 01709 761450

LIVE BETTER WITH PH

Welcome

Welcome to the autumn issue of Emphasis, where we bring you the results of our largest ever survey into what it's like to live with pulmonary hypertension.

> *"We need to shout louder, together"*

Last year, 563 people affected by PH shared their voices in our third major piece of research, ***'Living with PH'***, and a summary report of the results is attached to this magazine.

As an organisation, we take our steering from the lived experience of PH and the outcome of this research will drive our strategy over the next few years.

One really important finding is that ***60 per cent of people think pulmonary hypertension has a 'major impact' on their quality of life***, and we explore this further on *p16* of this magazine.

It's important the results do more than simply sit on the pages of a report – which is why we're using them to campaign for changes to public policy through our advocacy programme, ***PHocus2021***. I'd urge you to look at our new website, ***www.phocus2021.org***, to find out how you can get involved.

In these times of austerity, we need to make our voices heard. We're not asking for more – we're asking for what's fair for people affected by PH. We need to shout louder, together, and everybody has a story to tell – even if it's that nothing has changed! We can achieve so much more when many voices speak up about the same thing. We have lots of amazing supporters who run marathons and throw themselves out of planes to raise money to support our work, but every single person reading this, who is affected by PH, can help our work simply by sharing their experiences. So please - use every opportunity you get to make your voice heard and support us to help people ***live better with PH***.

Iain Armstrong

Iain Armstrong
Chair of PHA UK
editor@phauk.org

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.

Money *from music*

The family of a PH patient in Wigan are producing a music album with the aim of raising more than £1,000 for PHA UK.

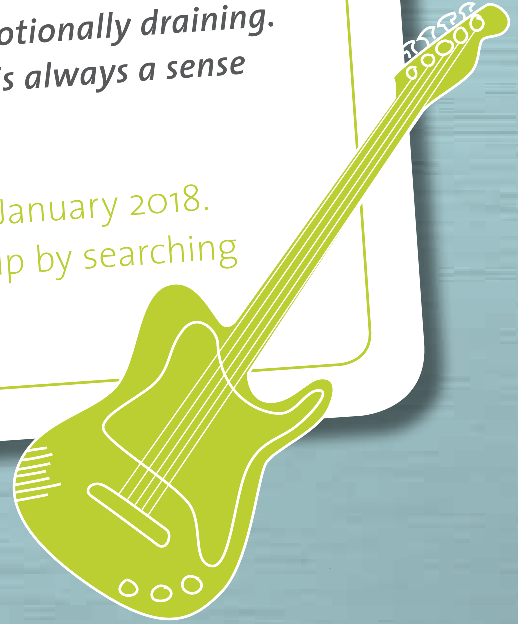
Brothers Thomas and James Jones are working alongside their dad Rob to create the album in support of their mum, Karen (pictured), who was diagnosed with PH in 2011.

The album, titled ***'Old Wives' Tales'***, will feature at least six songs, with the majority focusing on Rob's early memories as a child and his love for guitars.

Speaking about his mum's condition, Thomas, 26, said: ***"It's difficult for us as a family in a number of ways. It's hard to plan things around the illness as it can be so limiting and often unexpected.***

"We are often far apart from each other due to the distance of the hospital which can be very hard and emotionally draining. Visiting can involve lots of travel and there is always a sense of worry around the illness."

The album is planned for completion in January 2018. You can join the project's Facebook group by searching ***'Old Wives' Tales album***.



PH STUDY DAY SUCCESS

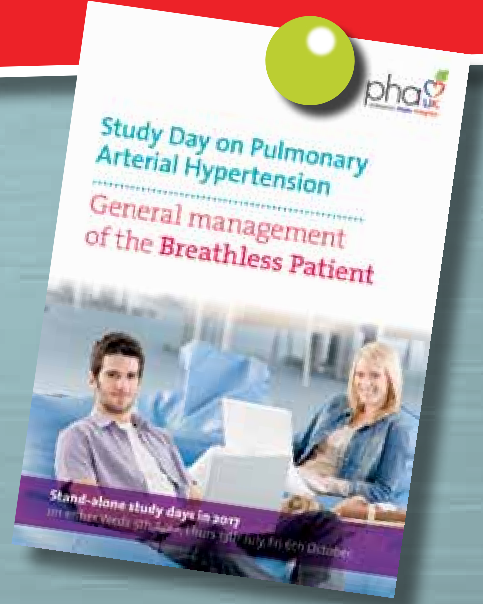
A series of study days organised by PHA UK to raise awareness of pulmonary hypertension amongst healthcare professionals have been so successful that another date has been added.

The stand-alone study days, titled 'General Management of the Breathless Patient', have been taking place throughout 2017 at the PHA UK resource centre in Sheffield.

Kicking off at full capacity in April, the second event ran on 13th July and the third session on 6th October is already booked up. Another session on 17th November has just been added to meet demand.

Between 30-40 per cent of people attending the first study days have gone on to sign up for the full medical education programme hosted by PHA UK in conjunction with Edge Hill University. 'Pulmonary Hypertension Diagnosis and Management' is split into four modules and can be used to gain 20 academic credits towards a degree or master's degree qualification.

To find out more about the study days or medical education programme, call 01709 761450 or email office@phauk.org



Social Media Round-up

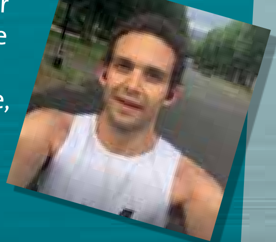
Here are some top tweets and popular posts from PHA UK's Facebook and Twitter

Kim Carpenter-Richards
Getting ready for the Furlong Fury for PHA UK. Wish me luck!

@smmhealthltd
Thank you @PHA_UK for informative Pulmonary Hypertension study day. Clinicians and public need to be aware of this often 'invisible' illness

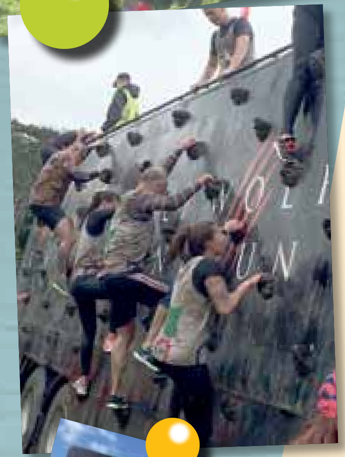
Lester Long
At Riley's Fish Shack, Tynemouth. Electric bikes rule, the only way to deal with CTEPH :-)

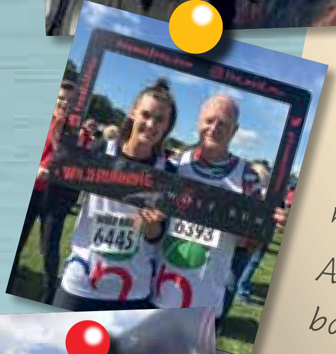
@AlexT
Morning 24km run - one for each hour of the day - make every one count! 1,697ft elevation through Highgate, Hampstead & Harringey for @PHA_UK

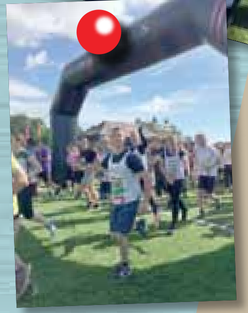


Debbie Nogre
"Where there is love there is life! And with a PH team as good as ours in the UK... There is hope"

@thisisgerty (Tina Pickering)
Friends for life... @maritess_mt thanks to @PHA_UK. Always a 'plus side' to PH. It lives with us, not the other way around







Dear Emphasis,

When my niece, Jess, told me she was going to take part in 'The Wolf Run' in Leicestershire to raise money for the PHA UK, I was totally overwhelmed. My nieces and nephews are a huge part of my daily life and an amazing support to me, and have long understood about my pulmonary hypertension, the complexities of the condition, and the importance of awareness and fundraising.

Jess is a proper 'girly girl' but was clearly prepared to tie her hair into a pony tail, pull on her trainers and test her strength and determination whilst competing in the 10k endurance challenge.

When Jess told the family about her plans, before she had even registered her place, a family 'team' had formed – consisting of my eldest nephew Jack, niece Claire, youngest nephew James and my brother-in-law Andy.

Jess was no longer taking part as a 'lone wolf' but now part of a pack, full of stamina and determination to run through overgrown woodland terrain, scramble under muddy army nets, and face nature's finest obstacles of fallen trees, lakes and mud pits.

At the end of the event, with mud splattered faces, wet aching bodies and swollen bruised knees, the event photographer took their official final photo, capturing their huge beaming smiles showing relief, admiration for each other, and a sense of achievement in completing the 'Wolf Run' as 'Team Jess'.

I for one couldn't be prouder of my family. Thank you Jess, Jack, Andy, Claire and James and everyone who sponsored them in raising an amazing £1,089 for the PHA UK. A job well done indeed.

Tina Pickering

CARERS REACHING 'BREAKING POINT' DUE TO LACK OF TIME OFF

Unpaid carers are reaching 'breaking point' as they struggle to take even a day away from care responsibilities for years at a time, research has found. 40 per cent of those who care for loved ones have not had a break in over a year, and 25 per cent had not received a single day away from caring in five years.

The report by the charity Carer's UK, called State of Caring 2017, found that carers most frequently listed access to breaks as one of three factors which could make a difference in their lives.

Carers who had not had a break in a year or more reported a deterioration in their health, both mentally and physically.

The research also charts a growing anxiety around the level of support that will be available against a backdrop of cuts to adult social care services.

Heléna Herklots CBE, Chief Executive of Carers UK, said: *"The need for an action plan from the Government on how they will improve support to carers is now urgent... getting some time away from caring to spend time with a partner, get to a medical appointment or just get a full night's sleep surely isn't too much to ask."*

THANK YOU!

The Lisburn Dairy Farm and West Belfast offices of the Northern Ireland Housing Executive held a coffee morning in memory of Ally Whan, raising £250. Thank you for your support.

Northern Ireland Housing Executive

Our Spring issue article about scooters got lots of you talking. Here are some of the stories you shared with us on our Facebook page.

Jayne Venables: *"If I give 24 hours' notice at my local station I can get on the train towards London, but I can't come back. The station has one entrance and exit and a bridge to get over, so I have to go to the next station and come back on myself – adding another hour onto the journey. Needless to say, I don't bother."*

Caroline Ryan: *"Just been reading the spring edition of Emphasis and enjoyed Sarah Marshall's write-up of using a scooter in London. I'd love to do what she did but even getting on a train at my local station is a battle. There is a big gap between the platform and the train and you have to ring the station and give 24 hours' notice for someone to be at our unmanned station with a ramp. Still no guarantee that anyone will turn up. Then we have to change trains onto the mainline and only one train a day comes in on the right platform to make an accessible train change. All others come in on another platform and need a metal set of stairs to mount to get over to the London bound trains. I can't use the steps and there's no lift, so it's totally inaccessible for me on a scooter or in my wheelchair. Our rail network needs to do more to make travel feasible for those of us with limited mobility. A great article Sarah!"*

Catherine Makin: *"I hired a scooter for my holiday in Cornwall at Easter. It was a bit of a hassle putting it into my car and it was heavy, but still I got around places that I haven't been able to since having PH."*

Joanne Kelly: *"I tend to get into all sorts of predicaments on my scooter Daisy. One day I decided to go exploring on Daisy up a winding lane which took me over the moor and as I turned to go back down I saw a farmer's truck coming. I panicked, went too fast over a speed bump, sent my oxygen tank flying in the air into the middle of the road, and was left with a tube dangling from my nose without anything attached. As the farmer passed by he tipped his flat cap with his mouth open – I bet he couldn't believe what he was seeing on top of the moor in the middle of nowhere. The sign at the bottom of the lane said: 'Go slow: walkers and horses' – not mad ladies on mobility scooters!"*

Big thanks to Charlie Young from County Durham...

...who travelled 126 miles on two wheels from Cumbria to Teesside on a coast-to-coast cycle challenge, raising £615.

Charlie's mum was diagnosed with PH in 2009 and he wanted to help raise awareness of the condition and help support clinical studies to find a cure.

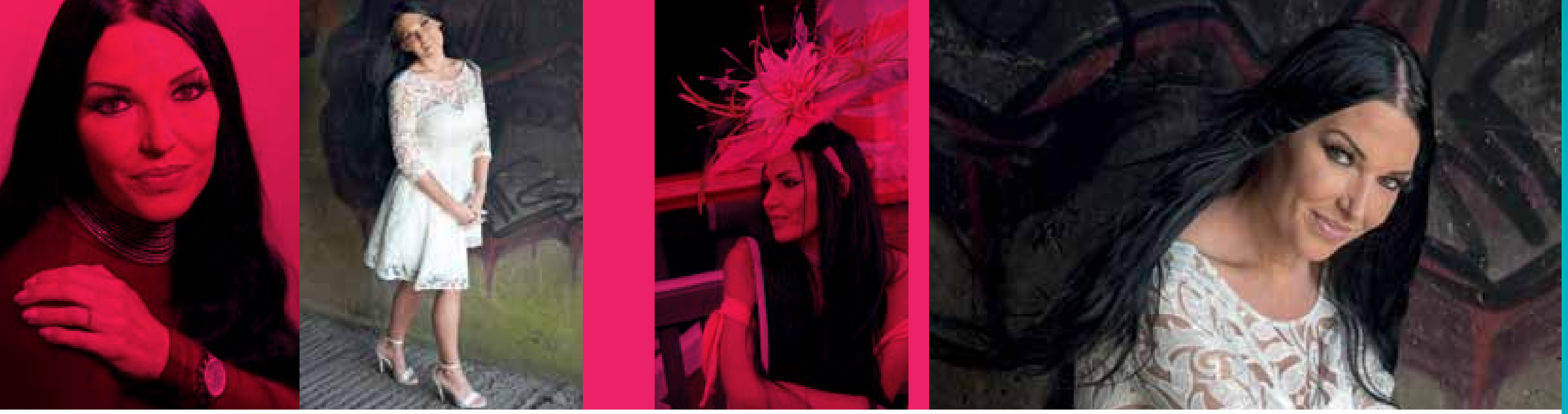
Before taking on the fundraiser, Charlie was a cycling novice and hadn't ridden more than a few miles.

Emphasis shortlisted for award

We're proud to announce that Emphasis, your magazine, has been shortlisted for a prestigious communications award. We've made the final cut in the category of 'Best Publication' in the Chartered Institute of Public Relations (CIPR) Yorkshire and Lincolnshire PRide Awards, and we'll find out if we've won in November. Wish us luck!

CIPR PRIDE AWARDS 2017

CIPR CHARTERED INSTITUTE OF PUBLIC RELATIONS



"I FEEL HAPPIER THAN EVER"

Six years after being diagnosed with PH, *Selina Walker* from Cleveland has a changed outlook on life. This is her inspiring story.

"I was diagnosed at 26 after having a stroke at home while I was making tea for my children in December 2011, when my sons were aged seven and three. I had never heard of PH, but I put my trust in the team at the Freeman Hospital in Newcastle to help me live the most normal, positive life possible.

In a bizarre way, I feel grateful that I have been given a chance to have PH as it has completely changed my outlook on life. I have changed things I wasn't happy with. I have got out of bad relationships, got out of bad housing, and broken ties with toxic friends and family members.

I am happier and don't plod on through life anymore. If there is something I want, or something I want to do, I will do it. If there is somewhere I want to go, or something I want to see, I will do it. I may have to take a longer route around but I will get there in the end.

Having PH has made me realise that it is up to me to make me happy and I have joy in experiencing the little things. I feel a lot more grateful about everything, and everything I do have. I think sometimes the nice things can be lost in thinking of the bad things in life.

I know a lot of people suffer from depression when diagnosed with a life-changing illness such as PH. I also did for a short while but I began to work on increasing my self-esteem and self-confidence and I now feel happier than ever.

Sometimes I think that things are put in your path so you can prove to yourself that you are stronger than you think. In a way, I am glad that I have PH as I have a brand new view on my life and what I really want from it. I don't have time to feel down. I get up every morning, put make-up on, dress confidently and spray on some perfume. These little things make me feel ready to take on the day.

Having PH and its symptoms is just normality now. I have learned to live with them and I know that I will never be able to run in the kids' sports day races and that I will never be able to go rambling around the Lake District, but I am ok with that. I have hobbies that I enjoy such as reading, writing and learning new things. If I ever really want to go somewhere or do something I research if I can make any adaptations to what I would like to do, to make it possible..

My advice to other people diagnosed with PH is to live for the day.

If there is something you want to do, don't let the condition get in the way. In this day and age, there is usually a way that things can be adapted so that everyone is capable of doing them.

Don't think that your life is over or dwell on the negative sides.

We all get tired and frustrated with limitations from time to time, but don't let that be your main focus. Cut yourself some slack. If you are tired then rest, there is no shame in it. We are just helping our bodies repair so we can carry on being our awesome selves.

If there is help available, take it.

Especially for things that you know tire you out the most. For me, I know I would never be able to look after my garden the way I would like, so I have a wonderful friend that cuts my lawn and tidies up the hedge in the summer.

Take inspiration from other patients who are living happy, fulfilling lives.

There is much more to you as a person than your PH. I am still a mum, daughter, sister and friend and I live my life being as happy and as kind as I can be."

Counting sheep

Everyone needs sleep, but some people with pulmonary hypertension struggle to get the quantity or quality they need. *Mary Ferguson* finds out more.

Counting sheep

Regular inability to sleep can be frustrating and distressing, and have a significant impact on wellbeing and quality of life.

Struggling to drop off, tossing and turning and waking regularly are common problems experienced by many people with PH, with the resulting fatigue making day-to-day life difficult.

Why do we need it?

As a nation, sleep is something we simply don't get enough of. According to The Sleep Council, more than a third of people in the UK average less than six hours a night.

Generally, adults aged 18-65 require seven to nine hours and in this time, our bodies are able to replenish energy stores and make repairs, while our minds organise and store the memories of the day before.

The Sleep Council's ***Lisa Artis*** told Emphasis: ***"A good night's rest is essential to a healthy lifestyle - protecting you physically and mentally as well as boosting your quality of living.*** *Just one night of interrupted sleep negatively affects mood, attention span and cognitive ability."*

The consequences of not getting enough, she said, are serious. *"Each hour of sleep lost per night is associated with a temporary loss of one IQ point and chronic sleep debt can have a seriously damaging effect on our mental and physical health."*

Hampshire-based PH patient **Lorraine Dior** tries to counteract her lack of sleep at night by napping during the day. She said: ***"I sleep much better during the day than at night for some reason.*** *I go to bed between 10 and 11pm and often don't drop off until 4am. I'm then up again at 7.30am for the school run.*

"It's been going on ever since I was diagnosed with PH, so for over 20 years. I just put up with it, as I feel like I've tried everything."

Unlike Lorraine, ***Catherine Makin*** from Lancashire avoids daytime naps as it then affects her ability to sleep later on. She said: ***"Sometimes I end up tossing and turning all night, then when I've finally got over it, it's time to get up.*** *Some nights I can get to sleep really easy but end up waking early in the morning. It makes me feel frustrated and means that I end up resting longer and sometimes I have to cancel plans to go out with friends if I'm feeling too tired."*

Quantity vs Quality

Research conducted in 2016 found that the sleep quality, not quantity, is what makes a difference to the wellbeing of patients with PH.

The 'Sleep Quality and Quantity: Association with Quality of Life and Function in Patients with Pulmonary Hypertension' was funded by the PHA UK and forms part of the wider imPAHct cohort study. It involved 179 patients and found that the quality of sleep experienced by an individual affected quality of life, fatigue and function to a greater extent than the amount of sleep someone has.

Andrew Hargreaves, 40, has been struggling with his quality of sleep since his Hickman line was fitted last November. He said: *"When I try and sleep I toss and turn, only managing two or three hours at a time.* ***Concern about my line getting tangled keeps me awake*** *and it's become more of an issue over the last six months.*

"It's affected my quality of life because I find myself needing a 'power nap' more often now, and my poor wife's sleeping pattern has been knocked about as I'm always fidgeting. I can find myself to be very short-fused."

The 'Sleep Quality and Quantity' study concluded that the use of sleep questionnaires may be a simple method to identify patient difficulties and highlight those who need further investigation.

Other research, conducted in America, has shown that quality of sleep can be improved by having something worth getting out of bed for the next day.

Top: Helen Akers
Left: Andrew Hargreaves
Right: Catherine Makin

In July, scientists at Northwestern University in Illinois announced they had discovered that when people feel they have a 'purpose in life', they have better quality of sleep and fewer night-time disturbances.

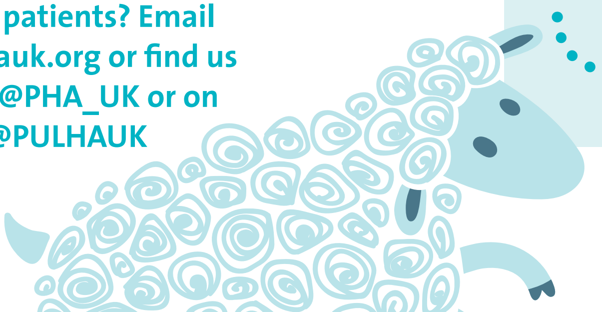
Despite all the research, many PH patients live day-to-day with the fatigue and frustration caused by disrupted or limited sleep.

It's a feeling familiar to ***Helen Akers*** from Chesterfield, who has struggled with her sleep since being diagnosed two years ago. She said: ***"I have awful, strong palpitations and missed heartbeats when I lay down.*** *It greatly affected my marriage as I kept the ex-husband awake and it's one of the reasons he is now my ex.*

"I have tried all kinds of things to help; meditations, audio, no phone at night, even strong sleeping pills - and still was awake all night. My life is affected so much by my sleep."

If you have concerns about your sleep, please speak to your specialist centre or GP.

Got any sleeping tips or experiences you'd like to share with other patients? Email editor@phauk.org or find us on Twitter @PHA_UK or on Facebook @PULHAUK



7 steps to better sleep

The Sleep Council offers the following advice for falling, and staying, asleep.

YOUR BEDROOM

The right environment will promote good sleep, which means a clean, tidy, peaceful and welcoming room. Your room should be completely dark and between 16-18° C (60-65° F).

YOUR BED

Avoid waking up with aches and pains by putting quality before price and investing in a comfortable mattress. Spend at least 10 minutes trying out the comfort and support levels before you buy!

YOUR LIFESTYLE

Switch off your technology a couple of hours before bedtime and avoid napping during the day and drinking alcohol or consuming caffeine before bed.

STRESS AND WORRY

Slow down your busy brain activity by placing your hand on your heart and listen for the beating. Breathe in deeply for four seconds, and then breathe out slowly. Repeat this until you can feel your heart rate slowing.

YOUR DIET

The best foods to promote good sleep include milk, cherries, chicken and rice, while fatty meat, curry and alcohol should be avoided. Avoid eating after 6pm.

EXERCISE

Try to exercise a little more or change the type of activities you do if you are struggling to get to sleep. Yoga is renowned for its relaxation and sleep benefits, while walking has been found to help people fall asleep more quickly.

RELAXATION AND OTHER THERAPIES

Make time to wind down and use relaxation techniques to prepare your body for sleep. Look up cognitive behavioural therapy (CBT) techniques, stimulus control using the 20-minute rule, and sleep restriction methods that can all help.

Visit **www.sleepcouncil.org.uk** for further advice

Quality of life with PH

The results of the *Living with PH* survey confirmed that, beyond doubt, pulmonary hypertension has a significant impact on quality of life.

Of the 563 people who shared their experiences, 60 per cent said that PH has a 'major impact' on their overall quality of life, with life expectancy, emotional and mental wellbeing and relationships all causing concern.

But although these statistics paint a challenging picture of life with PH, 45 per cent of respondents said the treatment and professional care they receive improves their overall quality of life 'a lot'.

The Living with PH survey also showed that patients rate improvement in quality of life to be more important than increased life expectancy when it comes to what they hope to gain from their treatment.

Professor David Kiely, Clinical Lead at the Sheffield Pulmonary Vascular Disease Unit, said: *"The results of the Living with PH survey, showing the very major impact on quality of life, reflects what many of us have witnessed over the years in lots of interactions with patients. Once again, the PHA UK and the UK patient population has provided very important information that will help us inform our practice as we look to a cure in the future."*

Measuring quality of life

Quality of life is now routinely measured when patients receive treatment for PH. Two disease-specific quality of life outcome measures are used by the UK specialist centres - EmPHasis-10, which was developed and supported through funding by the PHA UK at the University of Manchester - and the Cambridge Pulmonary Hypertension Outcome Review (CAMPHOR).

Natalie Doughty, Pulmonary Hypertension Clinical Nurse Specialist at Papworth Hospital, said:

"Assessing the effectiveness of our treatments in relation to improvement of quality of life is increasingly important to both patients and service commissioners, especially in light of the research by the PHA UK. I would certainly encourage patients to complete the questionnaires when asked to do so at their visit to their PH centre. The results are carefully scrutinised and compared to previous results for the individual patient, and these provide valuable insights into the effectiveness of our treatments over time."

EmpPHasis-10 consists of ten questions which address breathlessness, fatigue, control and confidence. The measure is now being used all over the world and an online version is in development.

> *It's critical to take quality of life into account when treating a patient for PH*

Dr Simon Gibbs, Lead Clinician and Honorary Consultant Cardiologist for the National Pulmonary Hypertension Service at Hammersmith Hospital, said: *"From a medical point of view, EmPHasis-10 is a systematic way of finding out about a patient's quality of life and in clinic, it enables me to see at a glance how a patient is doing. It's also a way of monitoring the change in quality of life over time. It's critical to take quality of life into account when treating a patient for PH. In chronic disease, you have to treat the whole patient, not just one medical condition."*

Professor Kiely added: *"Importantly, emPHAsis-10 allows us to measure the impact of PH on people's lives. And given that improved quality of life has been identified by patients and their families as being of critical importance, this will help us to assess the impact of many interventions - not limited just to drugs, but also including other forms of support and help such as pulmonary rehabilitation."*

60% of respondents said PH has a 'major impact' on their overall quality of life.

What does 'quality of life' mean to you?

Let us know what quality of life means to you by using the hashtag **#BreathlessNotVoiceless** on Twitter and Facebook.

The Living with PH survey also uncovered experiences of diagnosis, treatment and financial impact, which we will be exploring in more detail over the coming months. A summary of the survey results is enclosed with this magazine. For further copies, or to request the full report, please email office@phauk.org or call 01709 761450.

Hallamshire consultant takes on world's toughest mountain race

Charlie Elliot, a Respiratory Consultant at the Royal Hallamshire Hospital in Sheffield, recently completed the legendary Berghaus Dragon's Back Race in aid of PHA UK. Here, he tells us how he prepared both physically and mentally for the world's toughest five-day mountain race in Wales.

> "Each day at work I see how difficult it can be to live with PH."

"I first became aware of the Dragon's Back Race after watching a film documentary about it three or four years ago, thinking it looked like an epic undertaking and an adventure, but I never thought I'd be able to do it. Then in 2016, with the help of my fell running club the Dark Peak Fell Runners, I made it round the Bob Graham Round in the Lake District and the immediate question was - 'what's next'?

My mind went straight back to the Dragon's Back Race. Carpe diem, midlife crisis, whatever - I entered. I figured I may not make it to the end, but I would never know if I didn't put myself on the start line.

I tried to be consistent with my training - putting in eight to ten hours of running per week. I missed many weekend lie-ins, and didn't have many lazy Sundays with the family, but I tried to minimise the impact on 'real life' - mostly running to and from work. Then, one morning I found myself in Conwy Castle at 6:30am surrounded by a Welsh male voice choir singing, it was such an amazing atmosphere! ***The challenge of the next five days was 315 km (just short of 200 miles) with a 15,500m climb.*** *Apparently it is roughly twice up Everest!*

I enjoyed days one and two the most, taking in the spectacular scenery. Tryfan, Crib Goch, Snowdon, the Moelwyns and the Rhinogs were amazing. Day three was the biggest test at 71km and in extremely hot weather. Day five was going great until about 10 miles or so from the end when I picked up a thigh injury. That made for a very slow and painful shuffle to the finish line. By this stage though, after almost five days, I was ready to crawl on my hands and knees to the finish line if that was what it would take. It was a slow and sore finish, but I made it and got my dragon.

I was anxious before the race that I might not finish. I didn't want to 'big it up' and get a lot of sponsorship then drop out mid-way through so I hatched a plan with Neil Hamilton (lead Pharmacist at the Sheffield Pulmonary Vascular Disease Unit). I set up a donation website and we decided that if I made it to day four Neil was going to go public with it. It seemed to work ok - he was an excellent press officer!

I finished the race in a time of just under 60 hours, coming in at 56th place, which I'm really proud of. To date I have raised over £1,400 and the money is still coming in.

It was the most difficult and crazy thing I have ever signed up to, but extremely worthwhile. *I hope in doing it I help raise awareness of pulmonary hypertension and the great work PHA UK do.*

Each day at work I see how difficult it can be to live with pulmonary hypertension, both in terms of the physical symptoms and the psychological impact.

I know the money raised will directly help people who are being treated for pulmonary hypertension and beyond that, their families. I hope it may also make some people that have never heard of pulmonary hypertension before, look it up and see what it is. Let's help spread the word!"

DID YOU KNOW...

The first Dragon's Back Race happened in September 1992.
It is now respected internationally for its 'toughest mountain race' status.
This year, over 220 people started the race, but only 127 finished it.

To sponsor Charlie please visit his **JustGiving** page
www.justgiving.com/CharlieElliot1

Me & my music

For PH patient *Chris Johnson*, 54, singing helps him to enjoy a good quality of life - despite the limitations of his illness. He spoke to *Mary Ferguson* at his home in Barnsley, South Yorkshire.

> "Singing is the thing I enjoy most out of everything now."

"I was diagnosed with PH 13 years ago, two years after I started experiencing symptoms. As a rule, I try to 'just get on with it', but the worst thing for me is the difficulties in walking around. I think you've got to try though. It's no good just sitting here and thinking 'I've got this condition, so I'm not going to do anything'. And singing really helps.

I first started singing when I used to babysit for my younger brothers and sisters. I used to put records on and sing Elvis and Buddy Holly to them – and when I started singing, they'd go to bed!

The first time I sang in front of a crowd was when I was watching a friend's band at a pub and they asked me to get up and sing a Rod Stewart song with them. It was 'The first cut is the deepest' and I joke now that if I undergo a transplant, I'll be singing that when they start!

I was eventually encouraged by a friend to get some equipment together, and he got me some regular gigs at a pub in Leeds, where I performed for about three years. I sang in lots of places before I started getting ill and I was determined to continue, although the singing I do these days is mainly at busker's nights or parties for friends and family. I couldn't cope now with the way it was before I was diagnosed; I did a lot more then.

Singing helps my breathing. I think when you're singing, you have to breathe differently – you have to take a lot in, so you're exercising your lungs a bit more as well. *It's hard to explain to people that although you have trouble with your heart and lungs, you can still get up and sing. They don't understand. One or two people have said 'how can you sing a song like that when you're ill'? But I just tell them I've got my own way of doing things.*

I sing a lot of country music, Elvis songs, and rock and roll. For some songs, you really have to take a lot of breath, but I can get a sneaky breath in here and there if I need to.

If I ever do feel a little bit 'off it', I'll just stick to singing some of the steadier ones. Rock and roll songs are quick, but they're short. You need more power for ballads, and they tend to be longer. I don't dance much when performing, which helps.

I've got no nerves or qualms about getting up and singing. A few years after being diagnosed I sang some songs at the PHA UK patient conference and that's the only time I've felt nervous!

I like performing anywhere, as long as people appreciate it. I like it when the audience are surrounding me, rather than there being a lot of space between us. I like them to be there, dancing in front of me. That's the best.

I get out and perform a couple of times a week these days. My problem is carrying all the heavy equipment, but I just get someone to help me. One of the lads from the venue will take the speakers and desk in for me. Some of the guys that go are older, so in turn I may help them too by carrying some of the lighter stuff. So, it's a bit of give and take really.

When I'm up there performing I really, really enjoy it. Singing is the thing I enjoy most out of everything now. It takes my mind off things, like an escape route."

> "I'd like to thank everyone who has helped me throughout my journey with PH, from Dr Kiely and the team at the Hallamshire Hospital, to everyone at the PHA UK."

Fundraising r£undup

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

£300 RAISED

Hamper raffle in Huddersfield

Zara Taylor from Huddersfield organised a raffle at her aunt and uncle's pub, The Traveller's Rest in Brockholes, in support of her grandma Janet Mitchell, who was diagnosed with PH seven years ago. The winner went away with a luxury hamper loaded with generously donated items, and second and third prizes were donated by her grandad. Zara said: "I want to raise as much awareness and money as I can with different events because if it wasn't for the doctors and nurses at the Royal Hallamshire Hospital in Sheffield, my Nan probably wouldn't be here today."

10k, cake and coffee

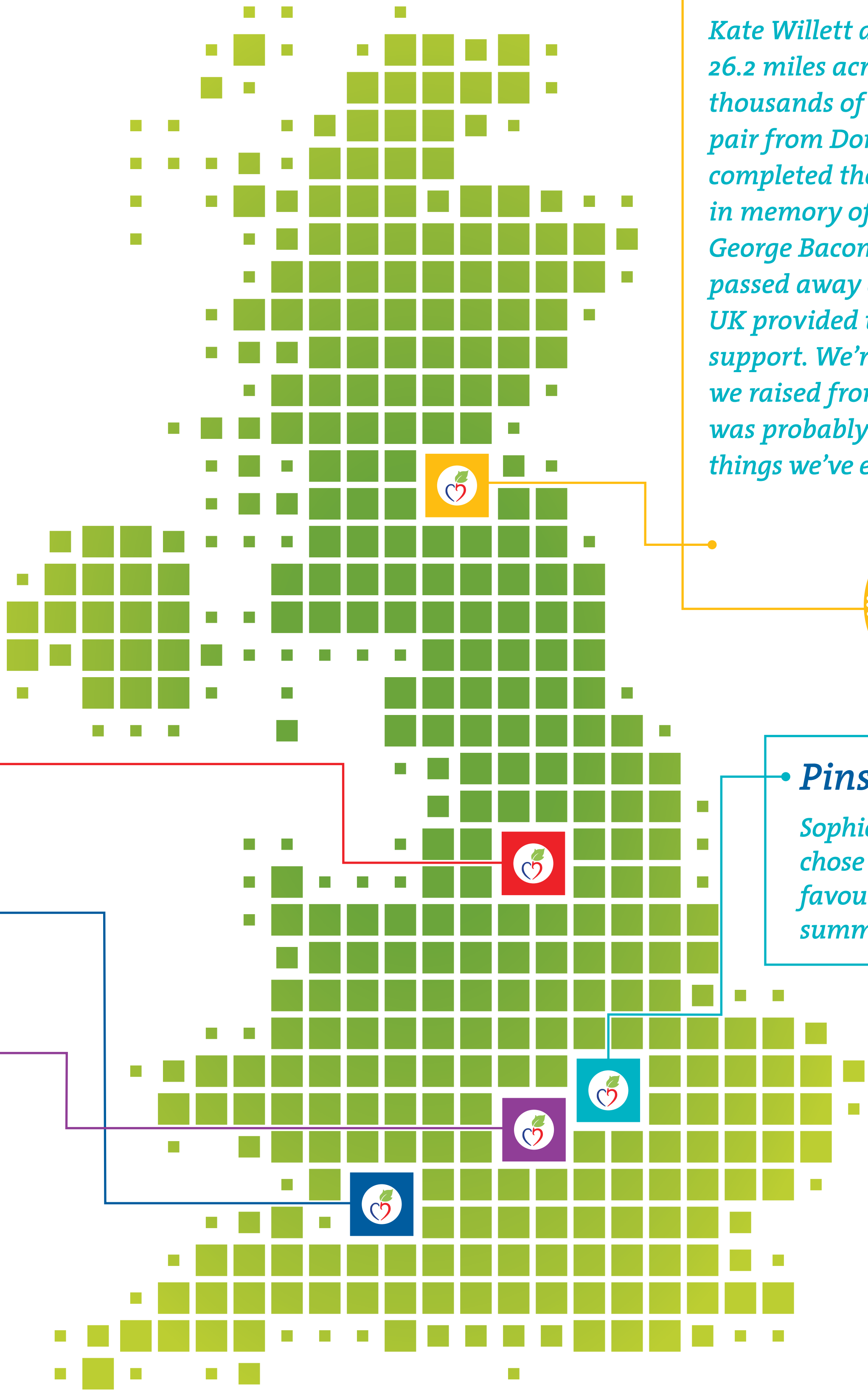
When PH patient Cliff Vaughan and his wife Pauline decided to enter the Bristol 10k, they chose to hold a coffee and cake day at their home in Wotton-under-Edge to generate money in lieu of sponsorship. Pauline made bags and cushions to sell alongside the cakes made by friends and family, and although Cliff was unable to take part in the race on the day due to injury, his wife, sister in law Helen and husband Mike completed the running event.

£400 RAISED

Tennis tournament serves up success

Elizabeth and Andrew Barr organised a charity 'American Tournament' at Olney Tennis club in Buckinghamshire to show their support for nephew Will Acres, who was diagnosed with PH in 2016. Players and spectators got to enjoy a sun-soaked afternoon of tennis, tea and a raffle, with the main prize an impressive home-made chocolate cake.

£703 RAISED



Scottish marathon success

Kate Willett and Jodi Savage took on 26.2 miles across the border to raise thousands of pounds for PHA UK. The pair from Doncaster and Edwinstowe completed the Edinburgh Marathon in memory of Kate's partner's brother, George Bacon. Kate said: "George sadly passed away a few years ago and the PHA UK provided the family with invaluable support. We're really pleased with what we raised from the marathon although it was probably one of the toughest things we've ever done!"

£2679 RAISED

Pins for PH

Sophie Chesson from Bedfordshire chose PHA UK charity pins as favours for her wedding this summer, in exchange for a donation of £30. On the big day, the favours were worn in memory of Sophie's friend Maddy Hardman, who had PH. Friends and family members are involved in an ongoing campaign to raise as much money as they can to support PHA UK to help others in Maddy's memory. So far, they have raised over £6000.

£30 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

Navigating the help available for carers

With high numbers of carers seeking support from Turn2us, we know that caring for someone can have a huge impact on personal finances. It can leave many struggling to make ends meet, so it is crucial that people receive all of the support that they are entitled to and eligible for.

Here is a summary of some help available and who might be eligible to apply.

Carer's Allowance

Carer's Allowance is money for people who spend at least 35 hours a week providing regular care to someone who has a disability. The person you care for must be getting a relevant benefit because of their disability, which in some cases has to be paid at a certain rate. You don't have to be related to, or live with, the person you care for to get Carer's Allowance.

If you get Carer's Allowance (or are entitled to it but do not get it because of Overlapping Benefit Rules) you will also get a Carer's Premium, an additional amount included in your means-tested benefit (Income Support, Income-based Jobseeker's Allowance, Income –related Employment and Support Allowance, Pension Credit and Housing Benefit).

Carer's Credit

Carer's Credits mean carers can be 'credited' with national insurance contributions to help them qualify for other benefits which they may not otherwise have been eligible for if their caring responsibilities prevented them from being able to work and pay national insurance contributions in the normal way. You must be 16 or over but under state pension age, and caring for someone for at least 20 hours a week in order to receive it.

Income Support

If you and your partner, if you have one, are on a low income, not in full-time work, and you fit into a specific category then this could help you. Income Support is a means-tested benefit which helps people who do not have enough to live on. It is only available for certain groups of people who do not get Jobseeker's Allowance or Employment and Support Allowance and are not in full-time employment. Carers and lone parents with children under five are common examples of claimants who can claim Income Support.

You must usually be 18 or over but under Pension Credit age (some 16 and 17 year olds can get Income Support).

Universal Credit

Universal Credit is a means-tested benefit for people of working-age who are on a low income. It is replacing six existing means-tested benefits: Income Support, Income-based Jobseeker's Allowance, Income-related Employment and Support Allowance; Housing Benefit; Child Tax Credit and Working Tax Credit. Universal Credit is paid on a monthly basis. Entitlement is worked out by comparing your basic financial needs that the government says you need to live on with your financial resources.

Universal Credit is being introduced gradually. Whether you can claim depends on where you live and your personal circumstances. It has been rolled out nationally to all single jobseekers without children for new claims. It is gradually being rolled out to all claimant types of working age making new claims (apart from families with more than two children), but this is still only occurring in certain areas currently.

In addition to benefits, there is a range of other help that you might be eligible for.

Pension Credit

Older people who are disabled or carers may also qualify for Pension Credit to top up their income.

Further help

In addition to benefits, there is a range of other help that you might be eligible for.

Housing costs

Housing Benefit is money to help you with your housing costs if you are on a low income. It can help with rent and some service charges.

Localised Council Tax Support schemes provide help for people on low incomes with their Council Tax bill. While Discretionary Housing Payment is a payment you may receive at the discretion of your local authority which can help towards housing costs. You can only get it if you are entitled to Housing Benefit or the Housing Costs element of Universal Credit.

If you are on certain benefits, you may be eligible for a Cold Weather Payment if the weather in your area falls to 0° centigrade or below for seven days in a row. If your electricity supplier belongs to the Warm Home Discount scheme and you're getting the guarantee part of Pension Credit, you will automatically get an annual discount off your electricity bill. Many other people on certain benefits may also be eligible for this discount but will have to claim.

Grants

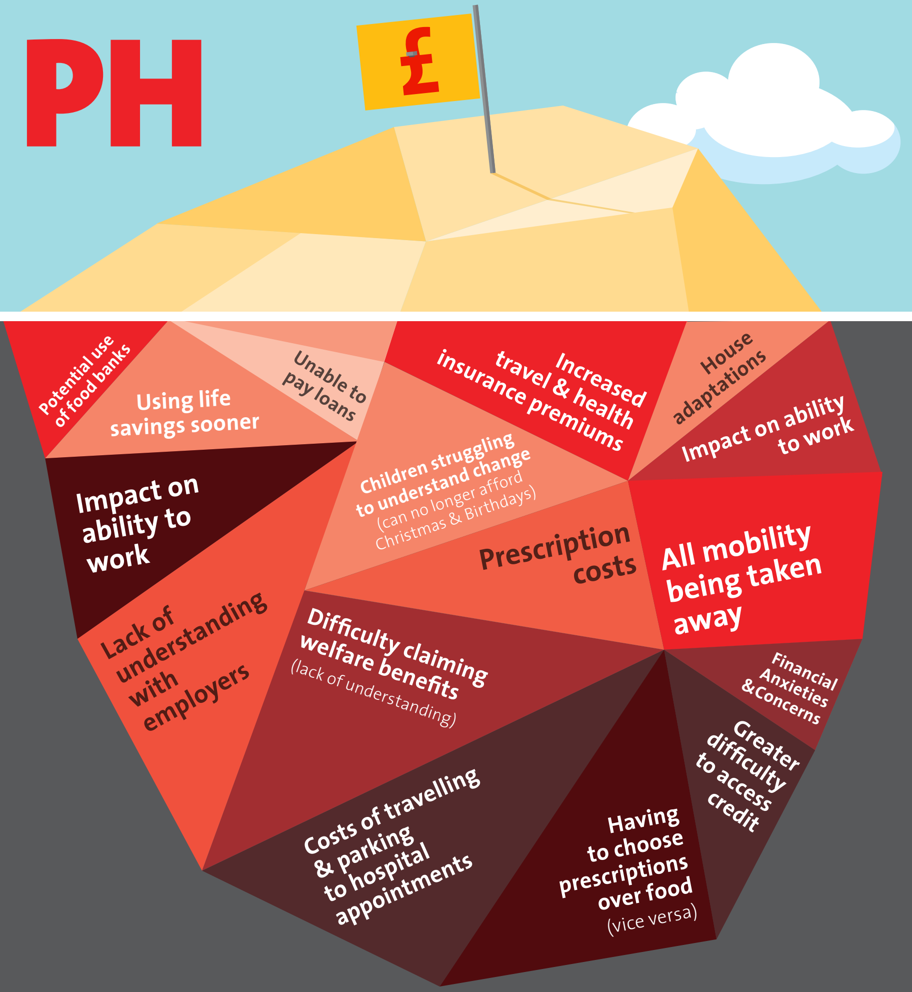
Charitable funds give grants to people in financial need who meet their eligibility criteria, using a sum of money that the grant-giving charity has set aside for this purpose. They are run by charities or organisations (such as energy companies) that have grant giving as part of their aims and objectives.

If you don't think that you are receiving all of the help that you are entitled to or eligible for, the Turn2us website has a Benefits Calculator to find out what welfare benefits and tax credits you could be entitled to and a Grants Search tool to find out if you might be eligible for support from over 3,000 charitable funds, as well as a range of information and resources to help people in financial hardship.

Turn2us can also provide direct financial assistance through a range of specific funds that are managed directly by the charity, including the Elizabeth Finn Fund which supports people from over 120 different professions and its new Turn2us Response Fund.

For more information, please visit www.turn2us.org.uk

A deeper look at **the hidden costs of PH**



Living with a chronic condition like pulmonary hypertension can have a knock-on effect on family finances and personal purse-strings – impacting overall wellbeing and quality of life.

63% of those who responded to the Living with PH survey said that financial worries had an impact on their lives, and the same number said the condition affects their ability to attend work or education.

At the PHA UK offices we receive daily calls from people worried about their work situation, battling the benefits system, or struggling to get by. And you've been telling us about your concerns on social media too, with problems including the costs of travelling to hospital appointments, dealing with a benefits system that doesn't understand PH, and rocketing electricity bills linked to having to use an oxygen machine.

We're digging deeper to uncover the full picture when it comes to the financial impact of pulmonary hypertension, to bring these hidden costs to the surface and push for change.

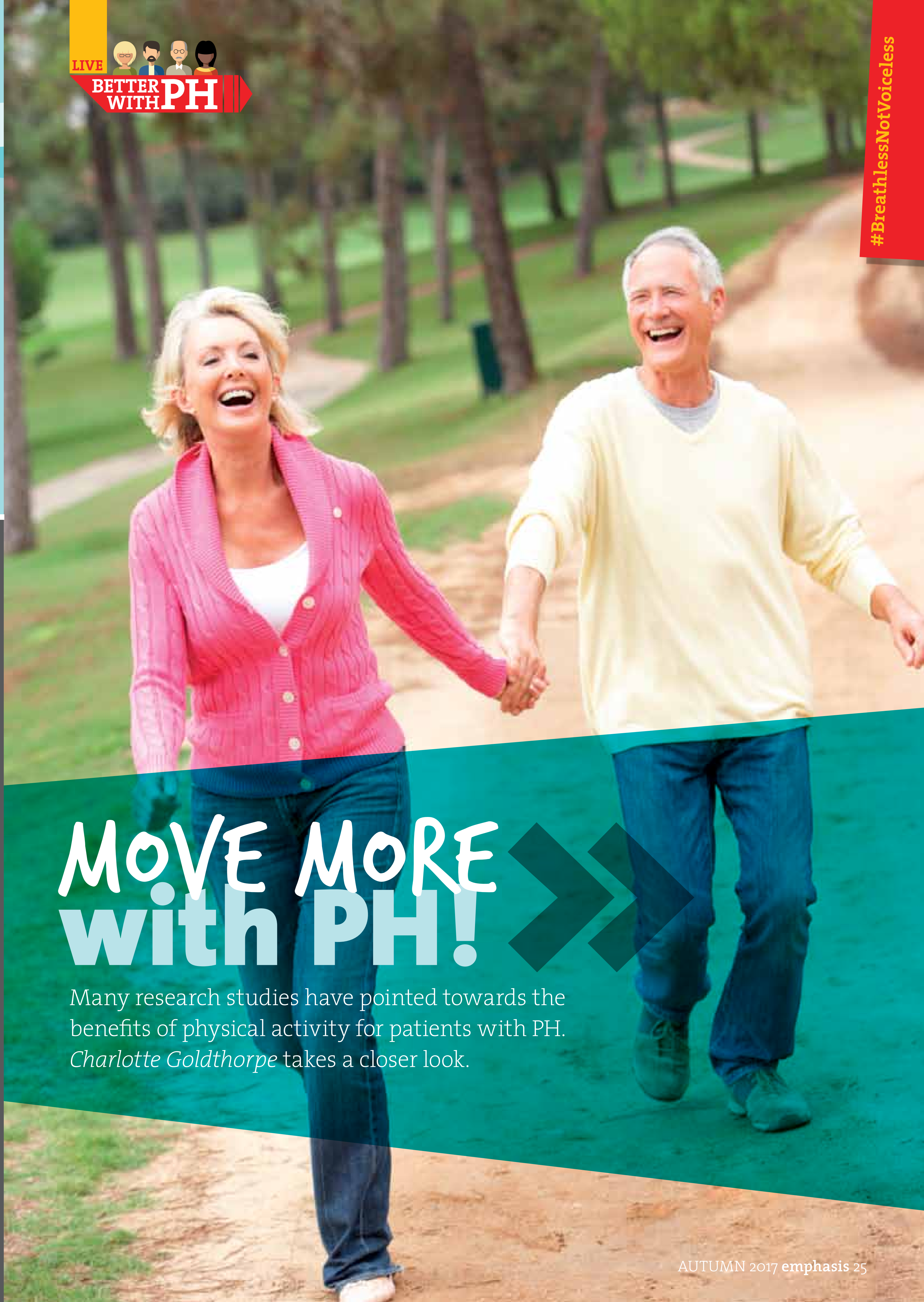
And we really need your help.

We're currently putting together a survey, which will be posted to everyone who filled in the Living with PH questionnaire and said they would be happy to be contacted for further research. But to really make an ***impact***, we need as many of you as possible to add your voices to this ***vital piece of research***.

Please - let us know if you can help us by emailing office@phauk.org with your name and postal address. You can also call us on 01709 761450.

If you're struggling with your finances, you're not on your own. Financial hardship charity Turn2us offer advice and support and can be contacted via their website: www.turn2us.org.uk You can also access their free grants search tool and benefits calculator at www.phauk.org

#BreathlessNotVoiceless



MOVE MORE with PH!

Many research studies have pointed towards the benefits of physical activity for patients with PH. *Charlotte Goldthorpe* takes a closer look.

MOVE MORE with PH!

We all know that moving more is good for our general health and wellbeing, and now physical activity is becoming increasingly recognised as a self-management technique to help people manage the symptoms of PH.

When conducted under specialist supervision, moderate and regular exercise in pulmonary hypertension is both safe and beneficial. It's even thought that patients with severe PH can see improvement from exercise because toned muscles use oxygen more efficiently than flaccid muscles.

At the PHA UK patient conference earlier this year, **Professor Paul Corris**, Director of Cardiopulmonary Transplantation and the Northern Pulmonary Vascular Unit in Newcastle, described how exercise training has become an increasing focus for clinicians as a supportive treatment for PH.

He said: ***"There has been a huge change in the way at which we look at exercise and PH. Although we need to be cautious and ensure patients warm up and don't undertake sudden severe exertion, we now encourage exercise because it is good to improve muscle function in PH and some patients will even benefit from exercise training programmes.***

"There is currently an interesting research exercise programme being led out of The Scottish Pulmonary Vascular Unit in Glasgow, inspired by a pioneering programme in Germany, which is trying to quantify how much added health gain there is for patients who exercise. Trials are really the lifeblood for us going forward in terms of improving what we can do for you."

Dr. Luke Howard, Consultant Respiratory Physician at Hammersmith Hospital, also considers exercise training as a method of treating the symptoms of PH.

He said: ***"It's hard to exercise when you have PH and it's hard to keep your muscles strong when you're undergoing medical therapy. However, research has shown that on average people who go into exercise studies improve their***

six-minute walking distance by 72 metres – that's nearly double the effect of any drug. In other words, exercise, which is cheaper than any drug, can do more for your six-minute walk test, which is why it is so important.

"Physical functioning, general health, mental health and emotional wellbeing all tend to improve through exercise training which contributes to a better quality of life for patients."

The benefits of exercise are not just physical - it can also have a positive impact on your mental health. According to The Royal College of Psychiatrists, exercise affects dopamine and serotonin levels in the brain, which affects your mood and thinking.

For some people, moving more can help relieve symptoms of depression and anxiety in ways that medication and talking therapies cannot. In fact, according to NHS Choices, 'if exercise were a pill, it would be one of the most cost-effective drugs ever invented'.

PH patient **Joseph Short** was advised by his consultant to take part in low impact exercise, having struggled with physical activity for 11 years. After kayaking until his mid-forties, he contacted his local canoe and kayak club and under Paddle-Ability, a scheme designed to help people with disabilities, they accepted him as a member.

He said: ***"Kayaking has helped build up my cardio and respiratory functions and cardiac tests show positive results. It hasn't been an easy road but the last two years I've concentrated on something other than my PH and approaching 63 I feel alive again."***

Anne Danks, who has been living with PH for four years, said: ***"I was initially warned not to do serious exercise, but due to my improved symptoms I now visit the gym most mornings and do an hour on the stepper. It's very good for stress management and general fitness."***

Carol Keen, Clinical Specialist Physiotherapist in Pulmonary Hypertension at the Royal Hallamshire Hospital, is currently investigating the benefits of physical activity for patients with PH in a new role funded by PHA UK.

She said: ***"We are keen to encourage our patients to become more physically active as we know that it can benefit them. In the past, it's only been patients admitted to the ward who have seen physiotherapists, and getting more active might not be their priority at that time.***

"As well as talking to patients and seeing how they can build more activity into their lives, we are looking at referring more of our patients into exercise services local to them, including pulmonary rehabilitation classes. It's early days yet, but we are keeping a track of how our patients get on to see if it makes a difference to them.

"My advice is that during exercise you should be a little bit out of breath, but still able to hold a conversation, and to stop if you feel dizzy or experience chest pain."

It's important to always consult your specialist before embarking on a new exercise regime.

We asked members of the PHA UK Facebook page how they stay active with pulmonary hypertension...

"I try to walk 5,000 steps a day, cycle using an electric bike and go to pilates or yoga classes once a week." **SARAH COLLEDGE**

"It's all been small steps and taking little leaps here and there, but it's been so worth it for me and I would definitely recommend it." **GEMSY ELIZABETH**

"I was diagnosed with IPAH in February, since being on my medication it has given me the ability to do more than ever. I stick to low intensity but it still makes me feel great!" **KATE LEWIS**

"Swimming has been really helpful for me!" **KAREN HAGERMAN MOSELEY**

"I walk and attend an aqua fitness class once a week – it helps me." **LOU CHADBUR**

"Our nine-year-old daughter has PH and has recently started gymnastics once a week and loves it!" **KELLY BRAND**

Why should you MOVE MORE?

- To feel better
- To make the most out of the treatment you are on
- To be able to do more
- To feel less breathless
- To gain a better quality of life – now and in the future
- To benefit your relationships with family and friends
- To improve your mood

Walk this way...

HERE ARE CAROL KEEN'S SEVEN TOP TIPS FOR MOVING MORE:

1. ***Start with a short walk*** – perhaps to the first lamp-post on your road and back again. The next day, try to make it to the second lamppost, and so on.
2. Think about how many ***'active days'*** you have each week. Could you add one more?
3. If you have a ***mobile phone that counts your steps, or a Fitbit***, then measure how active you are for a week. Can you increase that by 5 per cent the next week? And the week after that?
4. ***Build it in to your daily life*** – walk to work, get off the bus a stop earlier, use the upstairs toilet, take the stairs or park the car a bit further away from the shops than usual.
5. Lots of local councils organise ***walks for health*** – have a look and see what there is near you.
6. ***Walking with friends or family*** can help to keep you motivated, but make sure they go at your pace.
7. If you have children, why not ***walk them to school?***

Thomas Cook apologises

to PHA UK member over lost oxygen

Thomas Cook has apologised to PHA UK member *Jean Knapp* after she had to abandon her dream holiday.

THE Sun
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AIRLINE AIR RAGE Pensioner with 'life-threatening' illness escorted off plane during 70th birthday trip after Thomas Cook 'lost her OXYGEN cylinder'

Jean Knapp was travelling to Rhodes from Gatwick with her husband Raymond

Mail Online

Tearful pensioner says she was 'made to feel like a criminal' after being escorted off a plane at Gatwick when Thomas Cook lost her oxygen cylinder ahead of her 70th birthday holiday

- Jean Knapp planned to go on holiday to Rhodes, Greece, with her husband
- When she boarded the plane cabin crew asked her if oxygen tank was necessary
- She said airline lost it and she was forced to cancel holiday, leaving her in tears

By ISOBEL FRODSHAM FOR MAILONLINE
PUBLISHED: 11:05, 4 July 2017 | UPDATED: 15:22, 4 July 2017

Jean, who has lived with PH for 11 years, had planned to travel to Kefalonia, Greece, with her husband Raymond from London Gatwick for a holiday to celebrate her 70th birthday - and had received clearance from Hammersmith Hospital to fly with oxygen.

She said: *"Hammersmith were really efficient and emailed me back the same day. I then received an email from Condor, part of the Thomas Cook group, confirming that I would be able to fly."*

However, despite receiving confirmation from Thomas Cook that an oxygen tank would be made available, the pair were unable to fly and were forced to abandon their holiday.

Jean said: *"I was totally devastated – it was a special birthday and I had been planning the trip for months. We were just told to get off the plane and go home.*

"I paid £200 for the medical clearance (MEDA) forms for Condor, part of the Thomas Cook group, and they told me they'd received the forms and would contact me on June 20.

"Then I received a letter from Thomas Cook confirming that the oxygen cylinder would be on the flight. It was even on my boarding pass.

"I said can I have my oxygen now please, and it was not there. We were belted into our seats and nobody could find it.

"Then they took me to the front of the plane and asked if I could travel without it, but I told them I couldn't because I'd be at risk of a heart attack.

"We were given no support and no apology at the time - we just felt so isolated."

Jean and Raymond were forced to make the six-hour journey back home to Andover - missing their dream holiday and Jean's 70th birthday celebrations.

Thomas Cook has since apologised to Jean and refunded the cost of the holiday. A spokesperson said: *"We are sorry that we let Mrs Knapp down. Due to an aircraft change at short notice, we were unable to provide the additional oxygen on board.*

"Clearly this is not acceptable and we have investigated to make sure it doesn't happen again. We have fully refunded Mrs Knapp's trip and offered a gesture of goodwill."

Jean said: *"I wanted to share my story so other PH patients are aware of what I went through and to raise awareness of oxygen policies on airlines.*

"I followed all the correct procedures, but still my oxygen was not made available.

"Every airline has a different oxygen policy document within their disability policy which can be confusing. I would urge all PH patients to check and double check, and even ring up a week before you fly to make sure your oxygen tank will be on board.

"It was later revealed to us that Titan Airways which is operated by Thomas Cook does not carry oxygen on board, however my medical forms slipped through the net. Had we been alerted to this sooner we would have had time to rearrange our holiday, but sadly, we weren't informed until the very last minute. I sincerely hope this doesn't happen to another PH patient."

Since coming to terms with what happened to her, Jean and her husband have decided to go away next year and have ordered supplies from portable oxygen equipment provider, Pure O2. Jean said: *"They are a wonderful company and I have been able to book a shoulder oxygen bag to meet my needs."*

According to a recent report by the European Lung Foundation (ELF), a lack of reliable information about airline oxygen policies was found to be the main obstacle to patients with a lung condition when flying. ●

Pulmonary hypertension care ***goes under the microscope***

The UK's specialist PH centres are undergoing a 'peer review' process to ensure they continue to provide world-class care. *Neil Hamilton*, Consultant Pharmacist at the Royal Hallamshire Hospital in Sheffield, explains.

When a patient is diagnosed with PH, it can have a massive impact on almost every aspect of their life. This impact also extends to family and friends who together will embark on the journey of living with the condition. Despite the best efforts of the PHA UK, pulmonary hypertension remains little-known - yet is every bit as serious as conditions like multiple sclerosis, cystic fibrosis or cancer.

As a result, you need to be reassured that whilst it may be statistically a rare disease, expert care is available to you 24 hours a day, seven days a week, 365 days a year at one of the UK's specialist centres. However, you may not be so reassured by me telling you that, because I work at one of those centres - so I would say that, wouldn't I? Perhaps you would feel more encouraged, if your own experiences up to now weren't enough, by hearing that these centres are currently undergoing a process of review. This process is aimed at improving standards further, and reinforcing the UK's position in providing care that is the envy of the world.

About the centres

Pulmonary hypertension is managed in the UK by a network of specialist centres. As many of you will already know, these are found in Newcastle, Sheffield, Papworth, and four in London - at the Brompton, Great Ormond Street, Hammersmith and Royal Free hospitals. Patients in Wales are referred to one of the centres in England for their care and there is also a centre in Belfast which is closely linked to some of the centres based in England. The Glasgow centre serves the whole of Scotland and despite being funded entirely separately, the team are very much part of both the UK Physicians and PH Professionals groups.

Unfortunately, these centres are not spread evenly across the country, but the reality of specialist care is such that centres cannot be opened overnight. The expertise and infrastructure takes years to grow. However, all the PHA UK research studies have found that patients are happy to travel for specialist care, provided the quality of care they receive is worth it.

This network ensures the highest standards of care for our patients. The network not only allows for optimal clinical care but also makes collaboration in research and recruitment to clinical trials really achievable.

Assessing the service

NHS England Specialised Services are the body within the NHS responsible for commissioning (paying for) the PH medicines prescribed to adults in England.

They have taken the decision not only in PH, but in a number of specialist clinical areas, to assess the current quality of the care provided - with the aim of raising standards even further. Representatives from each centre and the PHA UK met earlier in the year and agreed with NHS England a number of 'quality standards'. The centres must document their response to each of these standards, demonstrating exactly how they meet them.

In the coming few months, each of the centres will be the focus of a 'peer review' visit. This simply means that a team of clinicians, nurses, pharmacists and managers from one of the PH centres will visit another unit to see how they deliver care to their patients. All those undertaking a review visit have received special training in order to have the knowledge and skills necessary. The training was also vital in learning how to prepare our own centre for a visit.

> *"I am convinced that patients would not receive better PH care anywhere in the world."*

Involving members

As members of the PHA UK, a highly active and engaged patient group, you may be wondering where you come in. In a clearly positive step, NHS England has also recognised the vital role of patients in this peer review process.

Representatives of the PHA UK have been invited to take part in the training and visits to provide their unique and invaluable insight.

The first visit took place at the Royal Brompton in early July and the schedule continues throughout the autumn. As you would expect, the team undertaking the peer review visit will be different for each visit; but crucially, they will be made up of at least one clinician, one nurse, one manager and one patient. Pharmacists have also been included wherever available. The visits themselves are scheduled to last about half a day. The day may include a 'walk through' where the visitors are shown around the unit. The main focus of the visit is to discuss in detail some pre-submitted documents that the centres have been tasked to prepare in advance. In essence, these documents describe in some depth how the care is provided to the patients. The documentation includes an annual report, an operational policy and a demonstration of how the centre delivers each of the quality standards.

Following the documentation review, the visitors have the opportunity to meet with the team at the centre. This is the ideal opportunity to clarify, discuss and better understand any areas not fully evident from the paperwork.

The visit concludes with the composing of a report, initially for NHS England and for the centre being visited. With the primary focus on areas of good practice, the report will highlight all the positive aspects of the patient care. If there are any obvious deficiencies, an NHS England peer review report gives the hospital trust an extra lever to approach their managers for any additional resources needed in order to ensure they can meet the standards going forward.

Confidence in our care

It is vital to point out that although the peer review process is generating lots of work for us as we prepare for visits, the outcome can only be wholly positive for the patient experience at any one of our specialist centres. We cannot be oblivious to the challenging times in the NHS at the moment, but I am convinced that patients would not receive better PH care anywhere in the world. You don't need to take my word for it - the PHA UK will keep you all updated with progress from these visits and will communicate to you all the important outcomes. ●

If anyone wants to know more than I've covered here, I'm sure that your specialist centre will be more than happy to answer any questions that you may have.

Short story writing
delivers new insights into the impact of pulmonary hypertension

Research published by the *British Medical Journal Open Respiratory Research*, and funded by *PHA UK*, has delivered new insights into the impact of pulmonary hypertension for patients.

The new approach focused on listening to the stories of people who have PH, and then finding new ways of communicating what was learnt. To do this, one of the researchers, Julia Goddard, wrote short stories inspired by each person of around 200 to 300 words long, with the aim of encouraging discussion about the illness and helping researchers develop a deeper understanding of the effects of PH.

The research involved conducting interviews in a variety of locations including on the hospital ward and in patients' homes. In total, 12 patients (six male and six female) from the Sheffield Pulmonary Vascular Disease Unit took part in the study.

The stories highlighted very powerfully how PH affects people's lives. The discussions focused on time to diagnosis, impact of diagnosis, complexity of therapy, frequency of hospital visits, access to information and the reassurance of care delivered by an expert unit in a supportive 'family' environment. Many participants also spoke about changes in their illness day-to-day, which highlighted the need for healthcare workers to be sensitive to changing patient concerns.

Professor Ian Sabroe at The Sheffield Pulmonary Vascular Disease Unit, who was part of the team that carried out the research, said: ***"Qualitative studies like this allow us to really understand the impacts of PH. Through story development we can communicate the effects of pulmonary hypertension and in turn, highlight the clinical challenges for healthcare workers in caring for patients with the illness."***

Iain Armstrong, chair of PHA UK, and also involved in the research programme, said: ***"This is very accessible research for patients and their families, healthcare workers and researchers alike and I would encourage all members to download and read the study.***

"Story development is part of a holistic approach to understanding pulmonary hypertension and can help facilitate patient-focused discussion and interventions."

A recent study of Parkinson's disease revealed the value of using story analysis to illustrate the experience of receiving a life-changing diagnosis. The study reflected the need to adapt to changing circumstances in illnesses associated with nearly inevitable decline and with episodes of acute care and changes to therapy.

Iain Armstrong said: ***"This research highlights that paying close attention to the qualitative aspects of pulmonary hypertension can help in the management of the illness.***

"The impact of PH is not static and these stories indicate how patient and family concerns change over time. This has caused patients, family members, clinical practitioners and the public, to pause and reflect."

The full study is available to download for free at *http://bmjopenrespres.bmj.com/content/4/1/e000184*

The story below was inspired by one of the participants and reflects the relief she felt after being diagnosed with PH.

To finally get a diagnosis! Amanda has been waiting for it for months, for years even. She has been feeling ill, feeling exhausted, feeling unlike herself and not knowing why. The doctors told her there was nothing wrong, that she was fine, that had she thought about visiting a therapist?

But now she has the answer! The answer may bring up more questions than it answers but it explains the fatigue. It explains why she wasn't able to play with her kids, why she couldn't take them to school, why she couldn't help with their homework.

The diagnosis doesn't provide a cure, it doesn't mean all her problems are solved. But it helps many of them. They say the medications may just be for the symptoms but this is what she has been looking for. She feels normal again. She no longer has to go out in a wheelchair, feeling like an old woman. She can walk up and down stairs unaided. She can drive again. She has got her independence back.

The diagnosis is not an easy one and there are still many more challenges to face, but at least now she knows what she is facing. At least now she has some help. At least now she has a reason for it.

Andy smiles to himself as he sees the confused look on the doctor's face. He knows full well that this doctor, and probably most of the people on the ward, haven't heard of his disease, most people haven't. And Andy knows roughly what's about to happen next as well. There's a few ways that it can go, but it tends to follow a certain pattern.

The doctor may try and bluff his way through it. Entertaining, but obvious. They may look it up on their phone. Wikipedia has a lot to answer for. The preferred option is, however, that they ask.

After living with the disease for half a decade now Andy has a range of explanations at his fingertips. He has the one for younger children. He has one for when he's in a rush. He has one for his grandma's friends who are being polite and enquiring after his health. And, of course, he has one for doctors who admit knowing little about this rare condition.

It can become a little awkward if they don't ask. If they demand that he listen to them, that they are the doctor and they know more, that they understand what the ECG means. Andy may not know what each of the little squiggles on the page mean but he knows his ECG isn't going to look normal, isn't going to look like everyone else's. He could have told them this at the beginning as well, if only they had asked.

Several participants expressed their concerns about other care teams who either gave the impression of not listening to the patient, or being reluctant to contact the specialist centre for advice. The story above is an example.

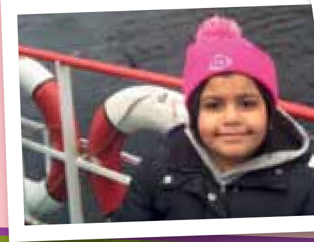
Green Leaf Crew!

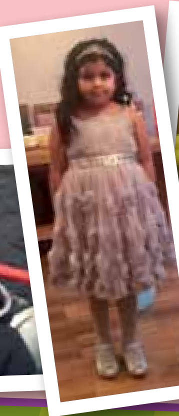
GREEN LEAF CREW Q&A

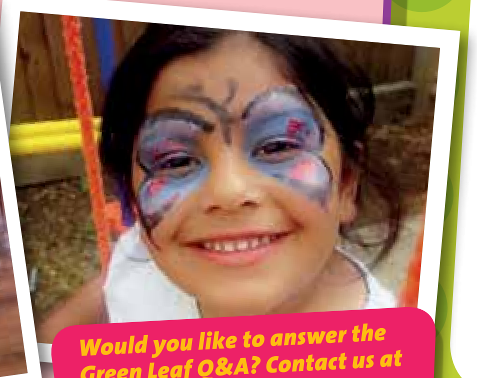
FATIMA HUSSAIN

Fatima Hussain is five years old and lives in Harrow with her Mum Shazia, Dad Omar and her four older sisters. Fatima was diagnosed with PH in February this year and is cared for by the team at the Great Ormond Street Hospital in London. These are some of her favourite things.

Q. What has been the best holiday you've been on?
A. *When I went to Dubai with my family.*
Q. Where would you like to go next?
A. *France because they wear funny hats.*
Q. What's your favourite subject at school?
A. *I love phonics the most.*
Q. If you could be any super hero, who would it be?
A. *Spider-Man so I can make pretty webs.*
Q. What's your favourite thing to do at weekends?
A. *Go to the park with my mummy.*
Q. What's your favourite sweet?
A. *Millions are the best.*
Q. If you could take a selfie with any celebrity who would it be?
A. *My mummy*
Q. What is your favourite TV programme?
A. *Lego friends.*
Q. Do you have a favourite film?
A. *Strange Magic.*







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

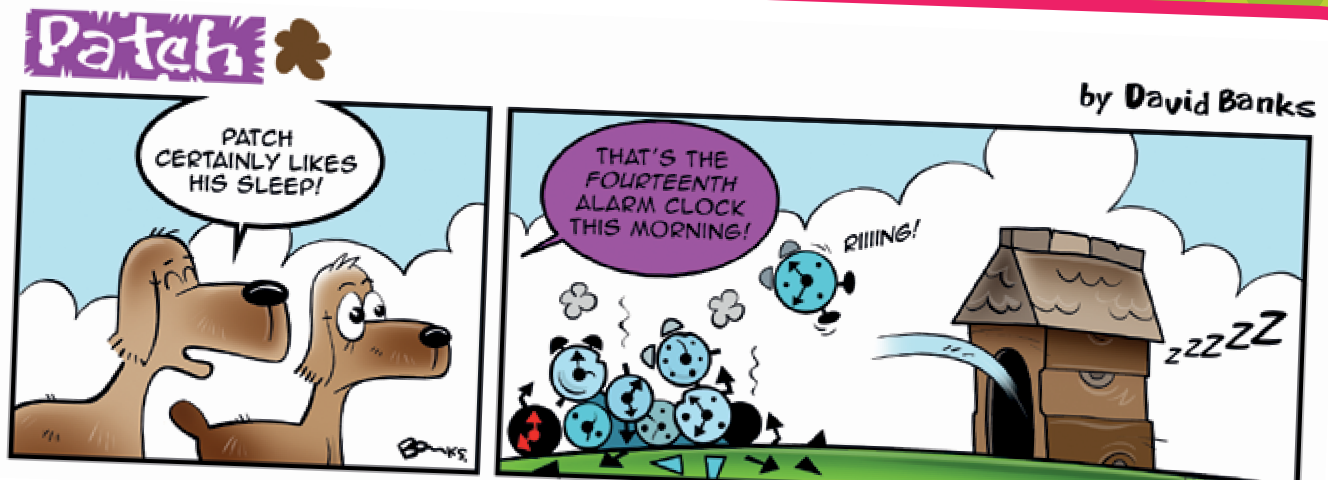
LOTS TO LOVE IN LONDON

IF, LIKE FATIMA, YOU TRAVEL TO GREAT ORMOND STREET, WHY NOT MAKE YOUR NEXT VISIT TO THE CAPITAL MORE FUN BY ENJOYING ONE OF THESE TOP TOURIST ATTRACTIONS ON OFFER IN LONDON?

1) ENJOY THE HUGE COLLECTION OF BUSES, TRAINS, TRAMS AND SUBWAY CARS AT THE LONDON TRANSPORT MUSEUM
2) BOOK A TOUR ROUND ONE OF THE MANY FAMOUS SPORTS STADIUMS IN THE AREA, INCLUDING THE NATIONAL STADIUM, WEMBLEY.
3) TAKE IN THE SIGHTS OF LONDON ON THE LONDON EYE
4) VISIT THE SEA LIFE AQUARIUM, WITH 17 THEMED ZONES TO ENJOY
5) CHECK OUT THE ANIMALS AT LONDON ZOO, WITH HABITATS INCLUDING TIGER TERRITORY AND PENGUIN BEACH.
6) VISIT HAMLEYS STORE AND ENJOY SOME OF THE FINEST TOYS IN THE WORLD.

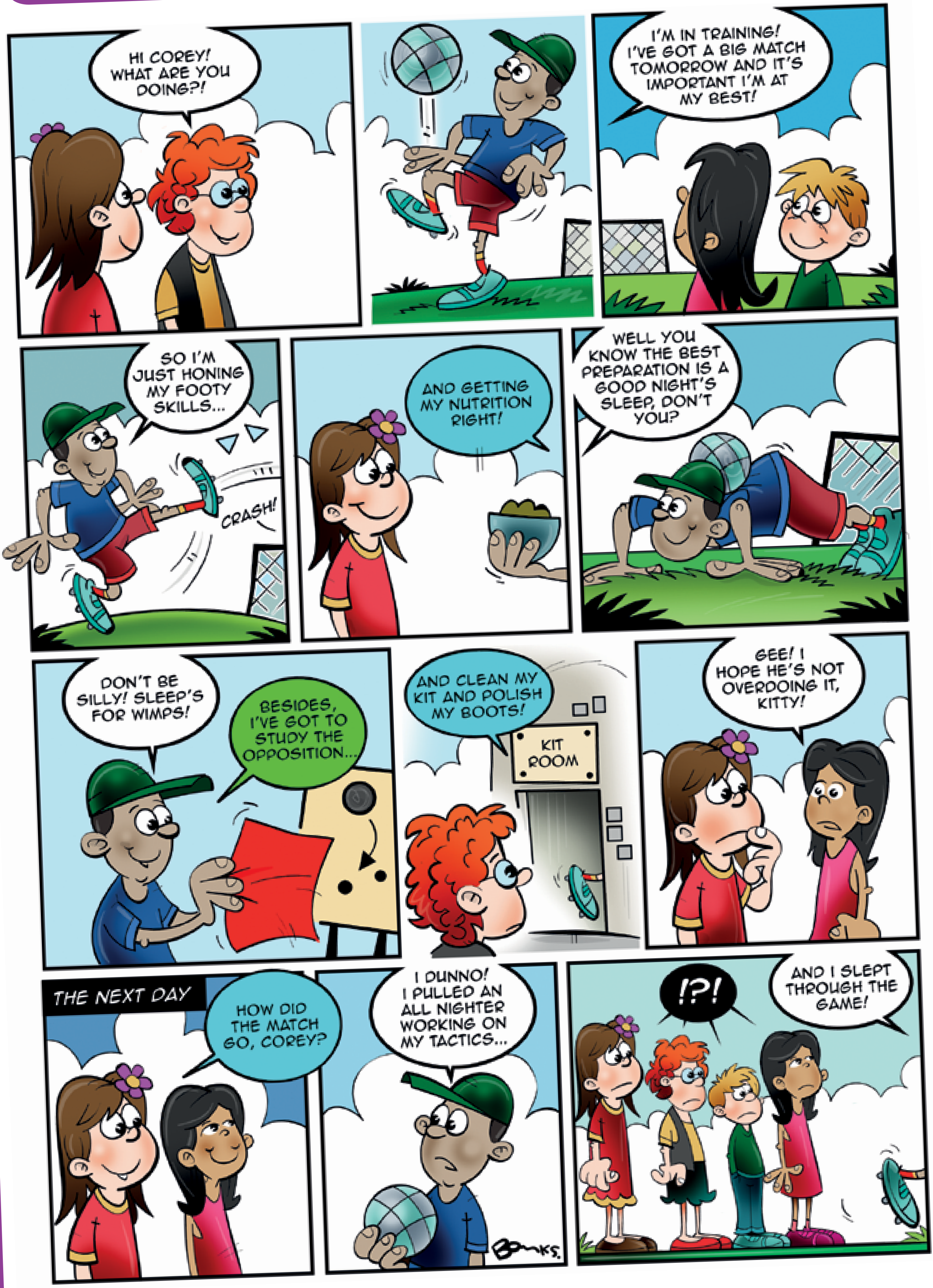
Patch

by David Banks



The GREEN LEAF CREW

BY DAVID BANKS



MY BODY, MY FIGHT, MY HOPE FOR MY LITTLE BOY

Jo Martinez's eldest son Zack, six, was diagnosed with Eisenmenger Syndrome and pulmonary hypertension at the age of two and under the care of Great Ormond Street Hospital, he started receiving medication a year ago. 12 months on, Jo is doing everything she can to help raise awareness of PH and fundraise for drug research, including losing three stones and overcoming a knee injury to take part in her first triathlon. Here, Jo shares how she keeps motivated to push her body to the limits and how she strives to offer Zack a normal and happy childhood.

*"**Since Zack started taking his medication I desperately wanted to do something to fundraise for drug research as the threat and fear of the inevitable became more real.***

A few years ago, I raised money through a pound for pound challenge (£1 for each lb lost), losing 44lbs and raising over £4,600. This spurred me on to take on my next challenge, but this time it would be harder, which meant improving my general fitness, overcoming a knee injury and losing some post-baby weight.

I have three kids who require a lot of running around and carrying up and down the stairs. I just felt unfit and wanted to be 'fit for purpose', 'fit for mumming about'! And what better motivation than fighting to raise money for drug research for my gorgeous little man who will need more medication as he grows up.

> "My mission in life is to give my three children a happy, normal childhood..."

I was completely petrified of taking part in a triathlon. I am a good swimmer, so I knew I could do that part easily and jogging was my 'go-to' exercise while my children were small. However, I needed to get my fitness levels up to train properly, so I joined a gym and started working on my running and weights and general cardio.

As I got more into the exercise, I started to think that one day I could actually attempt a triathlon. Even if it took all day, it would still be an achievement, right? So I signed up for the Ringwood Results Triathlon in April 2017 - a 600-metre swim, 28-mile bike ride, and a 9km run through the New Forest in Dorset.

I pushed myself every day for a year, clocking on average ten hours of full-on exercise each week to get me into shape. Then, as the triathlon got closer, I practiced more lengthy swims, and transitions between the bike and running - nothing feels as bad as that jelly numb feeling in your legs and feet when you come off the bike and have to go straight into a run!

Every run I went on I would think of Zack's little lungs gasping for breath and how he is challenged on a daily basis to do the simple things that we all take for granted. Every time I woke up aching and wanted to put off getting my butt kicked again in the gym I pushed myself to do it; because all I have to help save my boy is my body, my fight, my hope and my determination.

My mission in life is to give my three children a happy, normal childhood where they can climb trees, have water fights and build sand castles, and although Zack is on sildenafil and has restricted ability when it comes to cardio activities, he is happy.

Sometimes I feel like a swan paddling away under the water to do things to help make the idyllic lifestyle happen (like piggy backs up the stairs and shoulder carrying when we have gone off on a scooter mission and can't scooter any more), but I guess most mums feel like that.

I desperately want to find a treatment that will help Zack lead a happy and normal life and one day avoid a double lung and heart transplant. This drives me to want to push my body to its limit to raise vital funds and awareness of this serious condition.

The hard part of Zack's diagnosis is that no one seems to know or understand what it is or how hard it is for him. He looks like a perfectly normal little boy on the outside. He doesn't generally get very poorly because he has Eisenmenger Syndrome which is not as aggressive as primary pulmonary hypertension. However, the more severe stuff will be to come.

I find that awareness of the condition is a challenge and find it very hard to explain to people in a few words what he has and how it affects him. Often I get blank faces, then heartfelt sympathy, which is hard to deal with because it is such a serious issue. But how do you react when someone tells you about a terrible condition that will affect a child every day of their life? It's very hard to know how to respond.

> "Every run I went on I would think of Zack's little lungs gasping for breath and how he is challenged on a daily basis to do the simple things..."

What makes everything seem that bit easier is having a supportive family who understand Zack's illness. My brother even took part in the triathlon to support us and in total we raised over £1,300.

Since completing the triathlon a few of the mums at school are now more in the loop but it's bittersweet because as much as I want people to understand, I also don't want anyone to treat him differently.

Our most recent drama is that Zack's classroom next year is up two flights of stairs. Anyone with PH or supporting someone with the condition knows this will bring its own challenges.

All Zack needs at the moment is a full and happy childhood so he's able to try new sports and activities, but for those around him to understand his limits and that he will need a rest to recoup and to not make a big deal of it when he does. I have found everyone has been good at this so far.

He recently joined Beavers which has enabled him to take part in so many activities. It has been such a relief to find a hobby for him that suits his personality so well.

Zack's happiness motivates me to continue to find new ways of fundraising for PHA UK and I've already booked my place in a half marathon and have also applied to do the London Marathon next year. I wouldn't call myself a runner and recently hurt my back, so I'm not sure how this will go, but I believe it's always worth working towards something. Plus Zack wants me to get another medal for him to play with!"

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

GET INVOLVED!

PH
AWARENESS
WEEK
2017
20th-27th Nov

After the success of our first ever PH Awareness Week last year, we need your help to make the second an even bigger success!

This year's PH Awareness Week will take place from **20th to 27th November 2017** and our aim is to give people a voice by creating a platform for you to share your experiences of living with PH.

There are many ways to get involved with PH Week 2017 to help raise awareness amongst your family, friends, neighbours and health professionals. For example, you could support the campaign on Twitter and Facebook; invite your friends and neighbours to chat about PH over coffee and cake; talk about PH at work to inform your colleagues; share your PH story with your local newspaper and radio station; set up a blog, or write a letter to your local GP practice or MP.

For more information, visit www.phauk.org

Five top tips for raising awareness on social media during PH Week 2017

① Follow PHA UK on Twitter and Facebook for all the latest updates and tag us in your posts. Find us at **@PHA_UK** on Twitter and **@PULHAUK** on Facebook.

② Use one or both of the campaign hashtags in your Tweet or Facebook post - **#BreathlessNotVoiceless #PHWeek2017**

③ Try to use an image or link to the PHA UK website in your post. This increases the chance of shares, retweets and likes.

④ It's ok to politely ask people to retweet or share your content. Usually this is done at the end of a post in a shortened form e.g. **'Plz retweet'**

⑤ Search for the campaign hashtags in the search bar to view the conversations during PH Week.

Don't forget to use the hashtags **#BreathlessNotVoiceless** and **#PHWeek2017**

Scotland ***says 'no'*** to selexipag

Pulmonary hypertension patients in Scotland have been denied the opportunity to benefit from new treatment after the *Scottish Medicine Consortium (SMC)* decided not to fund the drug selexipag.

The decision, announced in July, was made in relation to patients in functional class III, who would otherwise be considered for treatment with inhaled iloprost.

The SMC said the evidence of the clinical and economic benefits of selexipag was "not robust enough".

Pauline Harrison, a PHA UK member in Inverness, spoke out about the decision on BBC Scotland. She said: *"Instead of looking at the benefits, they are looking at the cost first. And I'm sorry, but you can't put a price on a life."*

"Disappointing"

PH professionals have also expressed their dismay at the decision. Dr Martin Johnson, Consultant Physician at the Scottish Pulmonary Vascular Unit, said: *"It is disappointing to us and our patients that we have not been given approval to prescribe selexipag.*

"This medication has efficacy proven in a large clinical trial, has been licensed in the USA and Europe and is already being used by my colleagues in other countries. There is no other oral prostacyclin pathway agent available to us in the UK and this mode of drug delivery, oral, has distinct advantages for patients over the current alternatives, such as nebulised."

Iain Armstrong, Chair of the PHA UK, described the decision as a 'huge blow'. He added: *"It is vital that those affected by PH have access to new treatments that could improve their ability to engage in the normal day-to-day activities that most of us take for granted. There may be a significant number of patients with PH who can't use the currently available prostanoid treatments and for these patients, selexipag – an easier to manage, oral treatment – could help to keep them well and out of hospital for longer."*

Fighting back

In response to the decision, the PHA UK wrote an open letter, printed in an influential Scottish newspaper, which called on the Scottish Government to revisit the decision in order to help patients enjoy a better quality of life.

The letter, produced under the umbrella of the PHA UK's advocacy programme PHocus2021, was signed by Iain Armstrong and two consultants from the Scottish Pulmonary Vascular Unit at Glasgow's Golden Jubilee National Hospital. It was published in The Sunday Herald in July. You can read the letter in full at **www.PHocus2021.org**

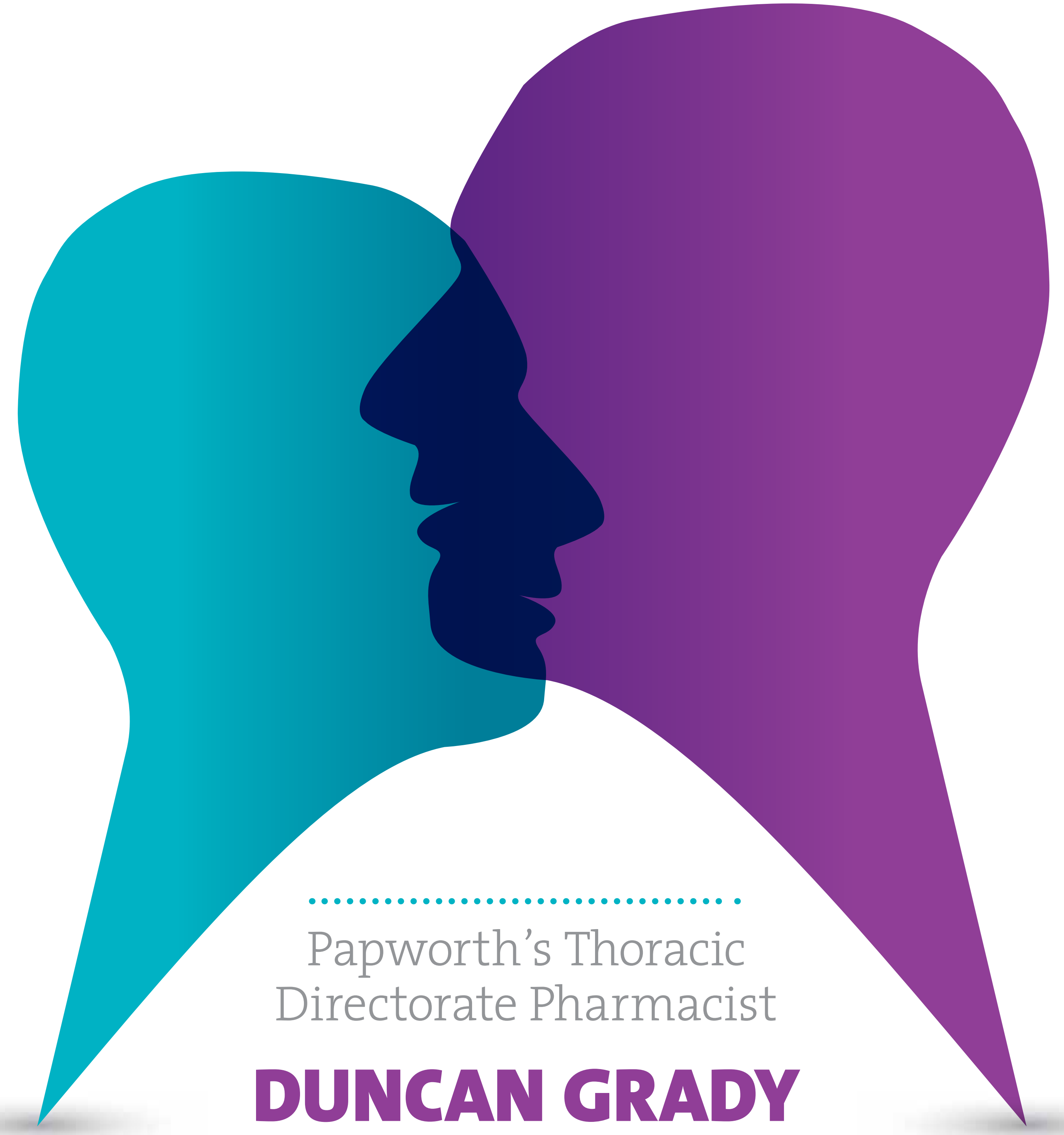
2021 PHocus

PHocus2021 is a five-year programme spearheaded by the PHA UK, campaigning for changes to public policy to make life better for people with PH. The brand new website is now live at **www.PHocus2021.org**


Breathless, not voiceless. It's time to turn up the volume for PH patients.

Our 4 aims for positive change...

*the*interview



Papworth's Thoracic Directorate Pharmacist

DUNCAN GRADY

in conversation with

Deborah Wain

Duncan Grady is Thoracic Directorate Pharmacist at Papworth Hospital NHS Trust, in Cambridge. Born and raised in New Zealand, Duncan obtained his pharmacy degree from Otago University, at Dunedin, and worked at Christchurch Hospital as a junior pharmacist covering general surgical and medical wards before moving to the UK.

Initially, Duncan planned to stay for just two years and work all over the country as a short-term locum hospital pharmacist. However, his first locum job was in Cambridgeshire, at Addenbrookes Hospital, encompassing haematology and oncology, and lasted for two years. He then moved to Papworth Hospital covering maternity leave. By the end of the year he had "grown to love the place" and took a permanent position as a respiratory pharmacist. Duncan has now been at Papworth for 13 years and working with pulmonary hypertension patients is the main part of his job. He has recently finished a Master's degree in Advanced and Specialist Practice from the University of Bath.

Q. What initially sparked your interest in respiratory pharmacy?

A. *I fell into respiratory pharmacy by accident. Prior to joining Papworth, I had been working covering oncology, haematology and bone marrow transplantation and had become very interested in those fields. Respiratory wasn't 'on my radar' as an interesting topic but as with anything, once you start reading more about it and deepening your understanding of a disease area, the more interesting it becomes. The biggest pull to respiratory though was pulmonary hypertension. The team at Papworth were very welcoming and the disease area just grabbed me as being utterly fascinating – a real mix of cardiology, respiratory and rheumatology. I also liked the investigative sleuthing required to get to the diagnosis and the holistic approach to treating patients with breathlessness by considering all the potential reasons for being breathless and optimising as many of those reasons as possible.*

Q. Please can you tell us more about your current role?

A. *My main role at Papworth is being the clinical pharmacist for the PH team but I also cover patients with interstitial lung disease (lung fibrosis) and some lung cancer patients. When other pharmacists are away I also look after patients with chronic lung infections (bronchiectasis and cystic fibrosis). I spend most of my time seeing in-patients and trying to join the PH team doctors on their ward rounds, helping them to choose the most appropriate medicinal treatments for our PH patients. I am a trained independent prescriber and enjoy using these skills to benefit patients.*

Q. Are patients surprised by how much contact you have with them?

A. *Patients in hospital don't always fully understand what clinical pharmacists do. Some of them think I'm only interested in getting them new supplies rather than talking through what to expect from new medicines, how to manage adverse effects and prevent drug interactions that could prove harmful, but most are very pleased to have a pharmacist available to ask (many) questions of.*

Q. Are any two days the same?

A. *No two patients are the same so I guess that means no two days are the same either!*

Q. What major developments have you seen around PH?

A. *I've been involved in PH for many years and I've seen a dramatic change in the medication available. From one licensed therapy for which we had to fight for funding...*

>>>

the*interview*

Thoracic Directorate Pharmacist
DUNCAN GRADY

> *“My favourite part of the job is talking to our patients. It is an absolute privilege to work with them to improve their health.”*

to now multiple agents and nationally agreed funding streams. The patient population also seems to be older these days with more concurrent diseases to consider, which adds to the challenge of treatment but is also what makes my job interesting.

Q. What's the most rewarding aspect of your job?

A. *My favourite part of the job is talking to our patients. It is an absolute privilege to work with them to improve their health. They often teach me a great deal about how well and how fast the medicines work, what the most relevant side effects are and what benefits they make to their lives. Learning from their real-life experiences makes us all much better practitioners.*

Q. What excites you going forward?

A. *I'm a pharmacist so I have to say the potential for new drug therapies! It is reassuring to see that there are new medicines coming through the pipeline and that pharmaceutical companies are still putting resources into researching new treatments. Some of the older medicines for PH are beginning to lose their patent so prices are due to come down. I am hopeful that decreases in costs might mean that the NHS can afford to give more patients upfront combinations of therapies.*

Q. Is there plenty of interest in this area of specialism in pharmacists entering the profession?

A. *There is certainly interest in pulmonary hypertension from the students and junior pharmacists who visit or work at Papworth – especially once they see what we do and get taught more about the disease. It is a fairly niche area to get into though with only a few specialist centres, so there are only a small number of hospital pharmacy jobs nationwide that include PH. However, there is definitely more to do. Not all the UK specialist centres have a specialist pharmacist yet and the disease area would benefit greatly from more awareness amongst health professionals. The message is getting out though - I have recently managed to get a PH case study incorporated into a clinical diploma for pharmacists studying with the University of East Anglia, and the PH Professionals group help run regular study days for interested health professionals.*

Q. What has been the focus of your recent academic work?

A. *My Master's research topic was investigating and measuring patient adherence to specialist PH medicines. Adherence was relatively good on average but at least one in ten patients struggled with taking their medicine on a regular basis. More needs to be done in helping recognise and support these patients so that they can get the most health benefit out of their PH medicines. The research has now been submitted to a scientific journal and will hopefully be published in the next few months.*

Q. And finally, how often do you get back to New Zealand these days – is the UK home now?

A. *The UK is home now. I haven't been to New Zealand for many years, mostly because of the ever-increasing cost of travelling and the fact that various people come over and visit relatively frequently. However, my wife and I are currently in the planning stages to take our children on a four-week tour of New Zealand in early 2019. I can't wait!* ●

These people gave me something to live for.

When *Raymond Maule* was diagnosed with PH, he found support in an unexpected place. Here, he tells Emphasis how his local women's rugby team have helped him accept his condition and live a full and happy life.

I was born with Eisenmenger's Syndrome, and a few years ago was diagnosed with having PH. The last few years have been some of the most difficult of my life.

The family moved from Bradford to Leeds where I came under the care of the heart and PH unit at the Leeds General Infirmary (LGI).

Life was becoming difficult to handle. I had coped all my life with having Eisenmenger's, but when I was informed that I had PH, life took a dramatic downturn. Knowing that this was a serious illness with no cure, I became despondent, and without hope.

The staff at both the Sheffield Hallamshire Hospital and the LGI took me under their care and their help gave me a huge lift.

> **I fought back, and loving the game of rugby league, I found a local club where I could go and watch the games.**

I fought back, and loving the game of rugby league, I found a local club where I could go and watch the games. That club was West Leeds ARLFC, and at that time only the women's open age team were playing the winter game.

This was last December, and I managed to see two games before they had a break until February, when I began watching the games on a regular basis. I am an avid writer and photographer, and I took my camera along and took photos of the games.

I was able to share these photos on the clubs' Facebook site and over time, I was 'adopted' by the team. Since then I have never looked back.

When the women's side finished for the season, the younger end began their seasons, and I have since been adopted into those age groups and teams. They have all embraced me as a person, and learned about my illness, the restrictions this causes, and much more. These people gave me something to live for and I now look forward to the games and events at the club.

> **More than just a rugby club, these are very special people and have embraced me as a person despite my illness.**

All the teams look upon me as the club's photographer, although my main team is the women's and girls' team. Last season the women won the Women's Rugby League Association First Division Championship, and in June they celebrated their achievement with a presentation and awards evening. I was invited along to take photos and received a huge surprise when I was named the 'Club Person of the Year' and received a lovely trophy.

Having learned of my illness over those months, the girls also made the occasion special by holding a raffle and collection for the PHA UK - another surprise.

More than just a rugby club, these are very special people and have embraced me as a person despite my illness. They have helped me through some of the darkest times of my life, providing hope, and a feeling of being wanted and loved. ●

#BreathlessNotVoiceless

IN THE NEWS


Claire was filmed attending one of her regular hospital appointments.

LIGHTS... CAMERA... ACTION..!

In June, PHA UK member *Claire Jones* appeared on the Channel Five programme 'On Benefits', to talk about her determination to keep on working.

Despite living with PH since 2013, Claire, who lives in South Wales, continues to work part time as a piano tuner. The programme highlighted how she manages working life alongside her condition, claiming £300 a month in Personal Independence Payments (PIP) to help with the running costs of her car.

When she had a phone call from researchers out of the blue last September, Claire was initially unsure about whether to take part. She said: *"At the time I didn't really want to do it. I'd heard of the programme and seen bits and pieces, but it wasn't something I was a fan of. Once they heard about me having a rare condition and working in quite an unusual job they really wanted me to take part, and they convinced me to do it."*

Filming took place over four days in November last year. A crew interviewed Claire both at home and whilst out on the road to visit piano tuning clients, highlighting how important her car is to her work and her life. They also filmed Claire's long-term partner Malcolm.

"I was worried about it simply because I didn't know what they were going to show," she said. *"I shared my worries with the film crew and they reassured me it would be ok. Overall, it was a good experience. I don't think I would actively seek out another opportunity to go on TV now I've done it once, but I'd certainly consider it if I was approached again."*

'On Benefits' showed Claire unpacking boxes of medication and popping to the shops for cat food – highlighting the difficulties that some people with PH face taking on everyday tasks. Although she drives her car to and from the shop, it shows her struggling up the path back up to her front door.

The programme also followed Claire on a visit to the Bristol Heart Institute for her outreach clinic, where she was filmed undergoing her walk test and talking to a cardiologist.

She said: *"I do wish they'd featured more about my PH as one of the reasons I decided to go on the programme was to raise awareness of it. They filmed me mixing my medications for my IV line and explaining what PH is - which I thought I did quite a good job of - but they chose not to show those bits."*

Claire invited friends and family to watch the show with her when it aired in June.

"It was strange seeing myself on TV. I cringed at my voice and my accent, but I suppose everyone is like that aren't they! The crew told me to avoid social media for the first 48 hours after the programme aired but I looked anyway and it wasn't too bad and my family all told me they were proud."

In the programme, Claire is described as 'determined not to be a burden on the system' by continuing with her part time work as a self-employed piano tuner. It ended with Claire telling the camera: ***"I'd probably be quite within my rights to sit on my bum all day and do nothing. But that's just not who I am. I choose to come out to work and I love my job, I really do. I still enjoy it like I did when I started."*** ●

Thank you to everyone who raises awareness of PH through the media. Please share your stories with us by emailing **editor@phauk.org**

Let's get Quizzical

Getting friends and colleagues together for a quiz night is a great way to raise money for PHA UK – and lots of fun too! It's also a perfect fundraising event for the autumn and winter months, when sponsored runs and walks can lose their appeal in the cold. Here's our guide to organising a night to remember.

CHOOSING A DATE & LOCATION

Decide on a date and venue, such as a pub, local hotel, social club or village hall. Ensure that whatever venue you choose, there is enough space for guests and easy access to food and drink.

ARRANGING A QUIZ HOST

Pick someone who is entertaining, funny and will get the crowed interested. Make sure there are a variety of questions and ask the host to explain a bit about PH and why you're raising money.

GETTING OTHERS INVOLVED

Invite friends, families and colleagues and help them understand why it's important they support your event. If you've arranged to stage the event at a pub, for example, make sure those who are regulars are aware of the quiz night. Also, make it clear what the maximum number of people there can be in one team is.

TICKET PRICES AND PRIZES

Cover the cost of your event in the ticket price, and add a few extra pounds to go towards the fundraising total.

Ask local businesses to donate prizes, clearly explaining what they will be used for. If you have more prizes than you need, you could carry out a raffle on the night to raise even more funds.

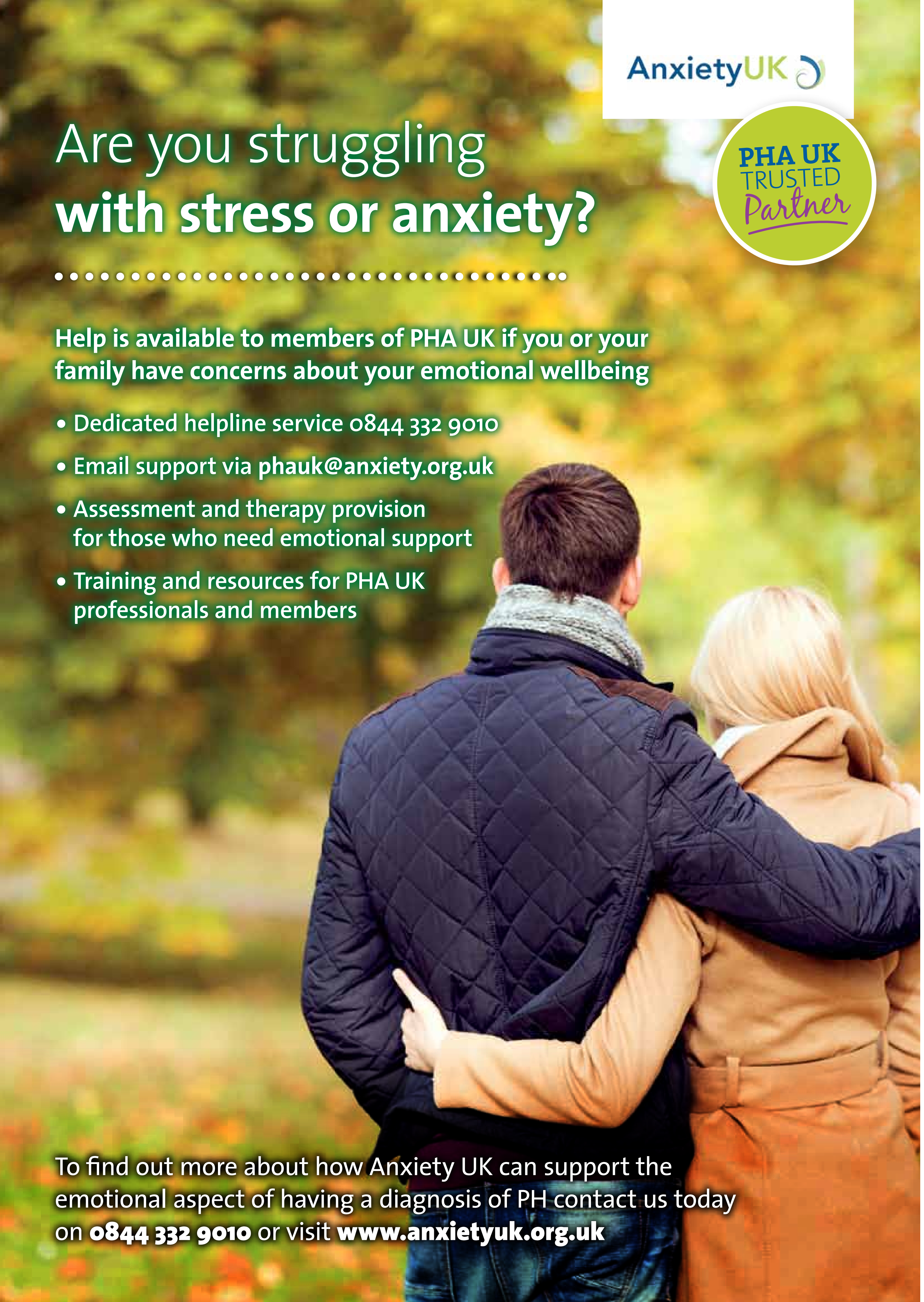
PROMOTION

Promote the event via social media and posters in your local shops and cafes, and, of course, at the venue the quiz will be held at. Get in touch with the news team at your local paper to let them know what you're doing, and why, and they may even be interested in running a story.

For a fundraising pack, or further advice on organising a quiz or any other event, contact the PHA UK office on 01709 761450 or email office@phauk.org
And don't forget to let us know how you get on!

DON'T FORGET TO INCLUDE QUESTIONS ABOUT PULMONARY HYPERTENSION IN THE QUIZ – IT WILL HELP GENERATE AWARENESS AND UNDERSTANDING TOO

PH Awareness Week 2017 *runs from 20th to 27th November and is the perfect time to get quizzical!*



How meals affect the mind

Nutrition expert *Sarah Dash* reports on a pioneering study that further links food with mood.

When I'm run down with a cold, I am quick to whip up a soothing bowl of chicken noodle soup. This advice was passed from my grandmother to my mother, from my mother to me, and it's an example of our understanding of 'comfort foods', and how what we eat can influence how we feel. The idea that what we eat can support our wellbeing is quite well accepted, but this is challenging to study in a scientific setting – after all, humans are more complex than mice in a controlled laboratory.

In the last decade or so, researchers around the world have conducted studies measuring what people eat, following them over time and assessing their mental health. The evidence from these studies is quite clear: what we eat is important to our mental health. What has been missing from the science of nutrition and mental health until now is the 'gold standard' of scientific studies – a randomised controlled trial, which aims to study the effect of a new treatment, while keeping other factors constant.

> *These findings are an important first step in thinking of new or additional ways we can improve mental health*

Earlier this year, researchers from Deakin University in Australia published the results of the first randomised controlled trial in diet and depression, called SMILES (Supporting the Modification of Lifestyle in Lowered Emotional States).

In the study, individuals with major depression were recruited from the community, and participants were randomly allocated to receive either dietary counselling, delivered by a clinical dietician, or a social support programme. Participants in both groups met with members of the research team over the course of 12 weeks, and those in the dietary intervention were prescribed a 'modified Mediterranean diet', comprising plenty of fruits and vegetables, legumes, whole grains, fish, nuts and olive oil.

At the end of the study period, those in the diet group had significantly greater improvements in their depression symptoms compared with those in the social support group, suggesting that a Mediterranean style diet may be beneficial in the treatment of depression.

It's important to note that participants in this study continued their usual treatment – medication or counselling – for the duration of this study. Traditional treatments are life changing for many, but this study provides preliminary evidence to suggest that diet may be an important part of the treatment of common mental disorders. While there's certainly more research required in this area, these findings are an important first step in thinking of new or additional ways we can improve mental health. ●

__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

References : Jacka FN, O'Neil A, Opie R, Itsiopoulos C, Cotton S, Mohebbi M, et al. A randomised controlled trial of dietary improvement for adults with major depression (the 'SMILES' trial). BMC medicine. 2017;15(1):23.

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ME & MY JOB

Helen Crabtree is Senior Office Administrator at the PHA UK, based at our Resource Centre in Sheffield. A key part of the small office team, Helen is often the first person you will speak to when you contact the charity.

HOW LONG HAVE YOU BEEN WORKING FOR PHA UK?: Five years now. I started as a receptionist and my job role has changed massively since then. Previous to this I worked within social services (both adult and children).

WHAT DOES YOUR JOB WITH PHA UK INVOLVE?: I cover all day-to-day aspects of admin work. I deal with new memberships, fundraising, and managing all incoming emails and telephone calls, as well as banking and so on. My job is different every day.

WHAT IS THE FIRST THING YOU DO WHEN YOU GET TO WORK?: I turn my computer and printer on, make a coffee and go through all the office emails.

WHAT'S ON YOUR DESK?: My desk is sometimes untidy - although I know where everything is! It's full of paperwork, often an empty coffee cup, and every stationary item you can think of.

WHAT DO YOU ENJOY MOST ABOUT YOUR JOB?: I love our office and the way I manage my own work load, and the fact I can bring my golden retriever Bella to work. I enjoy speaking to members and learning about their lives. I like being involved with fundraising from the start right to the very end. I try and stay in contact with our fundraisers and follow their journey along the way.

WHAT DO YOU LIKE TO DO OUTSIDE OF WORK?: I like spending time with my family. My daughter is 12 and my son is nine and we love holidays abroad and walking our dog. I enjoy socialising with friends, either going to the pub or going to see a show, and I'm also quite partial to a glass of wine whilst watching Game of Thrones or Love Island.

WHAT'S THE BIGGEST THING YOU'VE LEARNED ABOUT PH SINCE WORKING FOR THE PHA UK?: I've learnt it affects everyone differently, both physically and emotionally. No two people are the same. You can still have a good quality of life with the right mind-set and adjustments.

TEA OR COFFEE?: Coffee. Always black, with no sugar!

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

How we spend *your money...*

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

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

For fundraising support...
call the PHA UK office on **01709 761450**,
or email **office@phauk.org**

Source: Charity Choice (www.charitychoice.co.uk)

In your Winter issue of Emphasis...

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

Living with PH – readers share their stories.

PH Week round-up – a look back at our second awareness week.

Review of the year – what happened in the world of PH in 2017?

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.

Join our PH family for free today

Influence.
Hope.
Integrity.

Be part of a 3,500-strong national support network.

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

Join today and benefit from:

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

Being part of PHA UK also enables you to participate in important research, and our friendly office staff are just one call away when you need advice. Join our PH family and you'll be joining 3,500 members in a unique network of support and inspiration.

Join FREE today at www.phauk.org
call us on 01709 761450
email us at office@phauk.org
or simply fill in the form below and return to us.

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

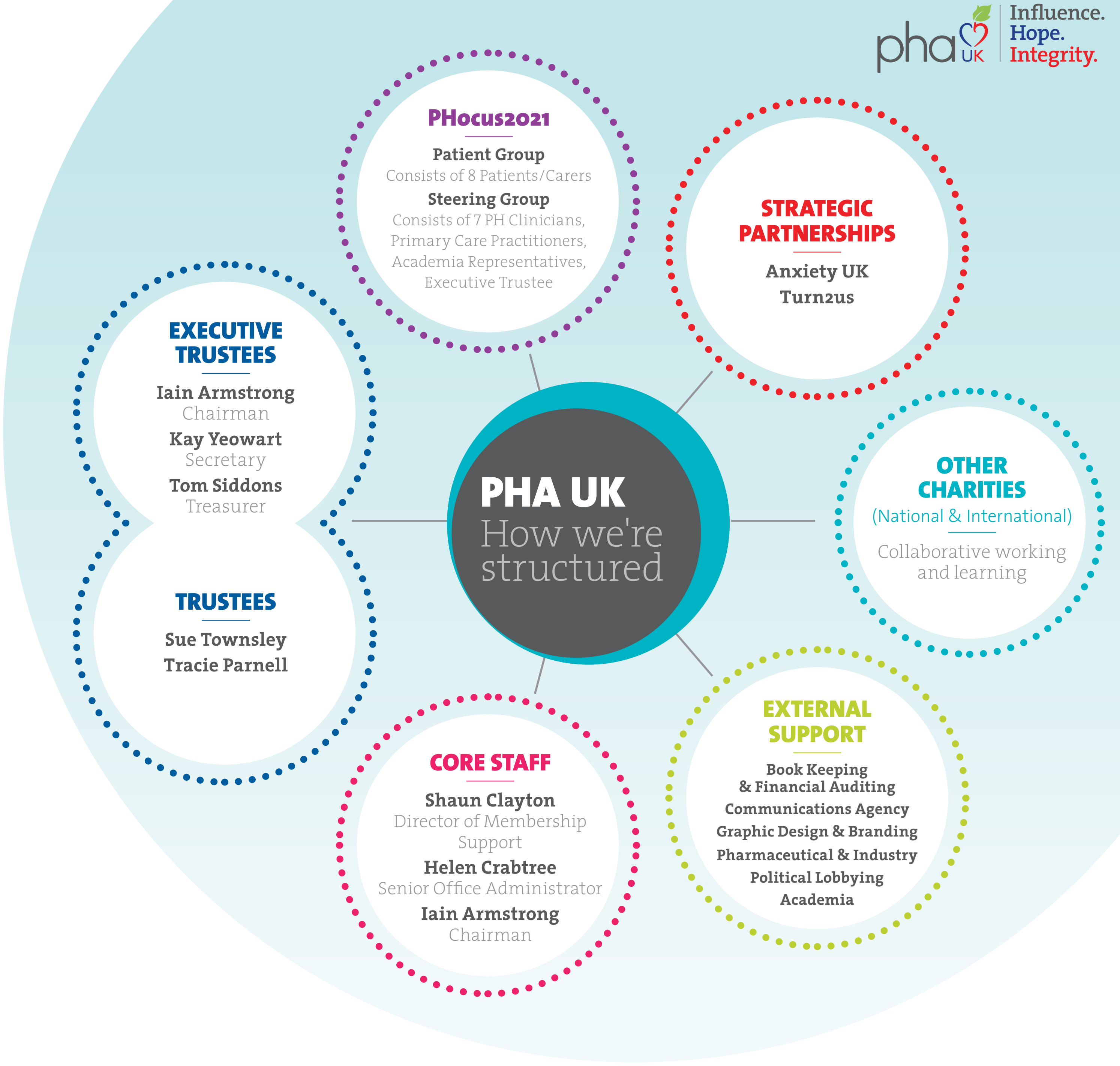
pha UK Influence. Hope. Integrity.

Name:
Address:

Postcode:
Email: Telephone:
Are you a Patient ☐ Carer ☐ Parent ☐ Medical professional ☐
Other (please state)

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

pha UK Influence. Hope. Integrity.



PHA UK
How we're structured

PHocus2021
Patient Group
Consists of 8 Patients/Carers
Steering Group
Consists of 7 PH Clinicians, Primary Care Practitioners, Academia Representatives, Executive Trustee

STRATEGIC PARTNERSHIPS
Anxiety UK
Turn2us

OTHER CHARITIES
(National & International)
Collaborative working and learning

EXTERNAL SUPPORT
Book Keeping & Financial Auditing
Communications Agency
Graphic Design & Branding
Pharmaceutical & Industry
Political Lobbying
Academia

CORE STAFF
Shaun Clayton
Director of Membership Support
Helen Crabtree
Senior Office Administrator
Iain Armstrong
Chairman

TRUSTEES
Sue Townsley
Tracie Parnell

EXECUTIVE TRUSTEES
Iain Armstrong
Chairman
Kay Yeowart
Secretary
Tom Siddons
Treasurer

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,
Thorncliffe Park, Chapeltown, Sheffield, S35 2PH
Registered Charity Number: 1120756

Anxiety UK

PHA UK works closely with our partners at Anxiety UK. To speak to someone about how you are feeling, call the dedicated PHA UK helpline on: **0844 332 9010** or email: **phauk@anxietyuk.org.uk**

Turn2us

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

Emphasis magazine is produced by PHA UK. Content by Capital B Media. Design by Creativesmith.

Free PHA UK publications for support & advice

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