SPRING 2017

emphasis

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

Gardening as therapy

How it can help you feel better

APPEALING AGAINST PIP & ESA DECISIONS

Specialist advice inside

Putting a positive spin on it

DJ Will Acres shares his PH story

LIVING WITH PH

The early research findings

Life on wheels

A guide to mobility scooters

PLUS...

your letters, appealing PIP decisions, planning for summer holidays, and much more!

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**

Contents

pha UK
Influence. Hope. Integrity.

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Living with PH...

Regular Features...

This magazine is printed on paper from sustainably managed sources

Welcome

Welcome to the spring edition of Emphasis, where we start the new year with our largest PH family ever – 3,500 members and counting!

Together, our voices are stronger, so it's fantastic to see so many people affected by pulmonary hypertension joining PHA UK. Membership is free so if you know anyone who would benefit from being part of our network, do let them know.

This issue of Emphasis features 52 pages packed with news, features, guides and real-life experiences.

We share the headline findings of last year's Living with PH survey, and will be revealing more about this major piece research over the next few months.

PH affects people of all ages, and this issue highlights the experiences of 21-year-old student Will and 82-year-old Cynthia, who have both kindly shared their stories.

We're embracing the lighter evenings and promise of warmer weather with a special feature on how your garden can help you feel better, and a Turn2Us guide to challenging PIP and ESA decisions aims to help you get what you deserve when it comes to financial support. Let us know how you get on.

Plus, consultant pharmacist Neil Hamilton is urging PH patients to plan ahead for summer holidays - so if you've got something booked, or your thoughts are turning to sunshine, turn to page 32.

It's great to see so many of you contacting us with your news, views, ideas and stories. You'll find a selection of your letters in Emphasis Exchange and if you want to get in touch too, drop us a line at editor@phauk.org.

We always like to hear from you.

Iain Armstrong

Iain Armstrong
Chair of PHA UK
editor@phauk.org

We're embracing the lighter evenings and promise of warmer weather

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.

HOW TO STYLE YOUR VELETRI PUMP

PHA UK member Jane Robinson has been making bags for her Veletri pump and says they have received the seal of approval from the team at the Hammersmith Hospital where she is treated. Jane wrote to us to say they are very simple to do, are comfortable to wear and fit on the NHS belt. The pattern can be adapted to other sizes too.

Here's Jane's step-by-step guide to making your own Veletri bag:

1. *Cut a copy of the template in pelmet vylene. Keep the original!*
2. *Using two pieces of fabric right sides together, draw around the template on one wrong side and machine stitch a quarter of an inch away all the way round, leaving an opening at one end. Trim the corners and turn inside out.*
3. *Insert the template and sew up the opening.*
4. *Machine stitch a quarter of an inch from the edge all around to firm up. Fold into shape.*
5. *Sew on a Velcro strip and two D-rings using tape loops. Sew up sides by hand.*

If you would like a copy of the template, Jane is happy for you to call her on 01452 812590

A new keyring designed to help people manage their anxiety has been launched by our charity partners Anxiety UK.

The keyring, known as ***Calm Keys*** has been designed with five miniature information cards which outline coping techniques including affirmations, distractions and breathing exercises. There are also support numbers and wellbeing tips. To order your own set of Calm Keys, visit **www.anxietyuk.org.uk** and search 'Calm Keys'.

21st APRIL 2017
NATIONAL TEA DAY

Time for tea

On 21st April, Britain will come together for National Tea Day, so why not use the opportunity to have a drink and a chat with loved ones? Talking about PH and how it makes you feel helps others understand the condition, and is all part of raising awareness.

You could even plan a tea party to mark the day, and invite friends and family over for cake, a cuppa and to find out more about PH. We can help by sending leaflets, posters, or a fundraising pack – just drop us an email at office@phauk.org

be food smart
change4life

CHANGE4LIFE LAUNCHES NEW 'BE FOOD SMART' APP

Change4Life, a society-wide movement that aims to prevent people from becoming overweight, has launched a new 'Be Food Smart' app available through the Apple App Store and Google Play Store.

The app is designed to help families make healthier food and drink choices, encouraging people to think more about how much sugar, saturated fat and salt they consume.

By using the app to scan the barcodes of food items, users can quickly see what's inside. The app also includes lots of simple hints and tips for healthier choices, plus food detective activities for children and fun mini-mission ideas for the whole family. Search **'Change4Life'** to discover a whole range of ideas to help keep your family healthy and happy.

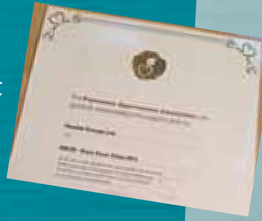
Social Media Round-up

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

Paula Joanne Burns I've just completed my assessment at the Freemans hospital, huge thank you to Professor Corris and his team... I now have a thorough understanding of my condition and a forward plan that gives me hope.

@alicetj (Alice Taylor-Gee)
My #ReasonToRun the #LondonMarathon is @PHA_UK - to help find cure for daughter's heart & lung condition

LouBLou Thank you for sending this for the fundraising we did at work. So proud of my colleagues for the support.



@maritess_mt (Tess Dunn)
Received my emPHAsis mag today! All signed up for conference, so glad it's taking place weekend after returning from honeymoon!! @PHA_UK

Michael Stephenson Just realised it's 3 years today since my little 'un was diagnosed with PH... what a journey.

@RBandH (Royal Brompton and Harefield Foundation Trust)
Read about benefits of singing as therapy in the @PHA_UK magazine talking about our own #SingingForBreathing

@wgigsing (Wendy Gin-Sing)
Great to be part of the Danish annual PAH Nurses meeting sharing experience from the UK @EuropePHA @PHA_UK

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

Emphasis **exchange**

YOUR LETTERS

"I'm delighted to say that the cake sale was a huge success"

I have suffered from PH for the past ten years and having been critically ill in July last year with sepsis, I returned to work after a four-month recovery. My colleagues on the eye unit at the Royal United Hospital (RUH) in Bath - where I work two days a week as a staff nurse - organised a charity cake sale when I returned, to increase awareness of pulmonary hypertension and raise some money for PHA UK.

I'm delighted to say that the cake sale was a huge success, and thanks to everyone's generosity in baking cakes and giving up their free time we raised an impressive £315. My story was also published as a press release on the hospital's website.

I've attached a photo - I'm the one on the right!

Kind Regards,

Andrea Murphy

"I now plan on doing something every year to raise money in my mum's memory"

I'm writing to you with a cheque for £500 from the company I work for, Ernst and Young, which is their matched funding for my 'Dry October' – where I gave up alcohol and coffee and raised over £1,000. I raised the money in memory of my mum, Rukiye Mehmet, who died from PH in April 2016.

Giving up alcohol and coffee was a huge challenge for me as I start the day with a triple shot latte and enjoy a glass or two of wine from Wednesday onwards! With that in mind, it was no surprise that my friends and family helped me raise that amount of money.

I now plan on doing something every year to raise money in my mum's memory – who knows, I may even do a run of some sort! This disease is not well known and I hope that by highlighting my fundraising efforts on my social media pages is not only helping me raise money, but also raise awareness.

The photo shows my mum at her birthday meal in September 2015. She had just survived internal bleeding while on holiday in Cyprus and actually came back to the UK looking and feeling better than she had done in years. Sadly, this new lease of life lasted a few weeks before the illness took its toll again, but it was lovely to see her dressed up that night and able to walk unaided to her birthday meal.

Kind Regards,

Mrs Hanife Ormerod

A bake sale held at Katie's workplace, Jisc, helped raise both funds and awareness of PH.

"I have come on leaps and bounds and I am living a normal life."

In July 2015 I was diagnosed with idiopathic primary pulmonary hypertension after nine months of experiencing serious symptoms. I was told I shouldn't have children, which, after recently trying for a baby, was the biggest heartbreak of my life.

I have looked into many ways of having children; these include adoption, egg harvesting and even going ahead regardless. It is a lonely place to be when every woman in their thirties around you is pregnant or has small children and no one will ever understand this pain unless they go through it themselves.

Fast forward to November 2016 and I have come on leaps and bounds and I am living a normal life. I have reduced my medication to minimal levels, I am active and even tried out for the local rowing team in the summer!

The ways I have tried to become healthier include mainly eating a vegan diet which has helped me lose weight naturally, receiving acupuncture, kinesiology, reiki and undertaking regular meditation. It all may seem very 'hippy' but I put my success down to these and having a positive mindset.

What does coming close to death teach us? For me, I realised I was putting too much time, energy and worry into my corporate role as an events and marketing manager. In the big world out there, what was I doing to contribute to humanity?

I also realised I was not dedicating enough time to my friends and family and activities which bring me joy. Therefore, I am now training to become an acupuncturist and naturopath, which will see me open my own practice in order to help and support others more than I ever have in the past.

I am also a member of the local Buddhist community and Theosophy Society, which has fully supported me throughout this and totally changed my mindset towards life and even death.

My top tip is this - just because something can kill us, it doesn't mean it will. Everyone has hurdles in life, this is one of them. You can and will keep going!

Thank you,

Katie Somerfield

YOUR LETTERS

"We had an amazing day"

I have great pleasure in enclosing cheques for the grand sum of £1766.40 – the fantastic amount raised from the Chesterwood show jumping and pony sports day, which was held for the 12th year running.

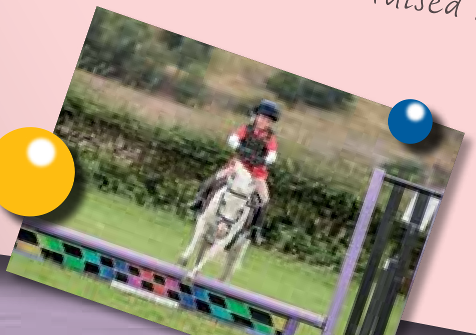
We had entries into each of the show jumping 'handy pony' and games classes, with lots of new faces, which was great to see.

Jackie and Josie Brown again very kindly donated a jump which they had made, showing the PHA UK logo. It is given to the person who they thought most deserved it – whether their pony has been naughty, whether their riding improved over the course of the day, or just for having a big smile on their face. The very lucky recipient this year was Sarah Willey. Thank you very much to all sponsors and helpers, without whom the show couldn't go ahead. A special mention must go to Jools Howard from High Plains who generously donated some Woodland Ride vouchers. Kate Marsden of Sought After Photography also very kindly took photographs during the day.

A massive thank you must also go to my sister Suzie Pigg for organising the show and to Graeme for allowing us on his land – plus Brenda, Ellen and their team for the gorgeous food. We had an amazing day and over the years the show has now raised the amazing sum of £17,760.97.

Many thanks again to you all,

Sheena Robinson



"WE WOULD LIKE TO THANK EVERYONE FOR THEIR GENEROSITY"

Over a year has passed since Alana Smyth and I ran a dinner dance, auction and raffle in La Mon Hotel in Belfast. This was to raise awareness of pulmonary hypertension, along with raising some vital funds for PHA UK.

A fantastic crowd of 360 people were in attendance for a five course meal, followed by dancing to Johnny Brady and his band. Everyone was extremely generous at the raffle and auction and in total we raised £10,200. From this, we donated five CoaguChek XS warfarin machines to the PH clinic in the Royal Victoria Hospital in Belfast, which left £8,705 for PHA UK.

Both Alana and I were diagnosed with pulmonary hypertension; Alana in 2014 and me in 2006. Since Alana's diagnosis, she has received a lung transplant and continues to respond well to her new lungs. Pulmonary hypertension is therefore very close to our hearts, and raising vital funds to help find new medications is very important to us.

We would like to thank everyone for their generosity in giving raffle prizes and auction items, along with donating their money in the run-up to the event and on the night. Without them all we would not have raised this fantastic amount.

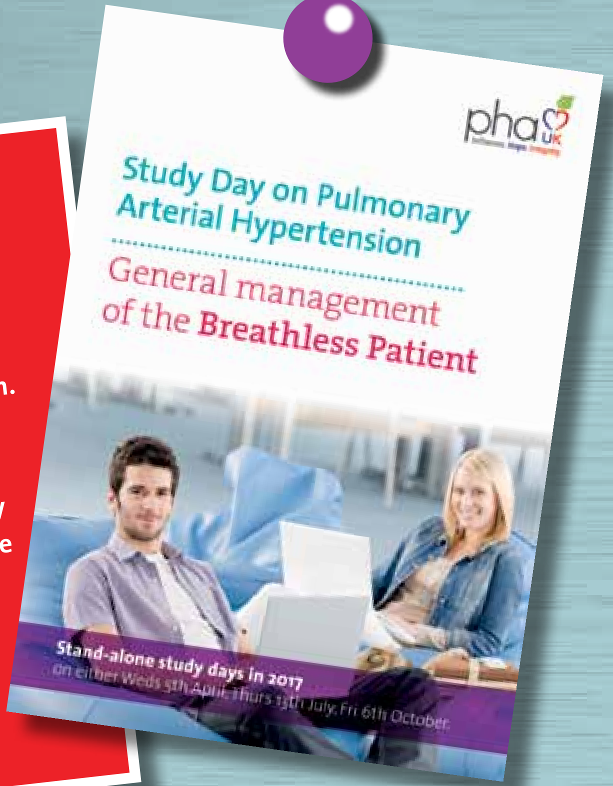
Thank you very much,

ALLY WHAN

NEW SESSIONS FOR PROFESSIONALS

In 2017, PHA UK will host a series of educational sessions designed to help medical professionals learn more about pulmonary hypertension. The sessions, titled 'Management of the Breathless Patient', will run at the PHA UK Resource Centre in South Yorkshire and will cover topics including rehabilitation, the circulatory system, epidemiology of PH, associated conditions, the WHO functional class of PH and the basics of the benefit system.

Free places for medical professionals are available.
For more information please email ***office@phauk.org***


Study Day on Pulmonary Arterial Hypertension

General management of the **Breathless Patient**

Stand-alone study days in 2017
on either Weds 5th April, Thurs 13th July, Fri 6th October.

Family fundraising

Thank you to the family of Henry Ross, who have raised almost £6000 for PHA UK in his memory. Henry's wife Adrienne and sons Mark and David set up a JustGiving page and say the messages of support from family and friends have been comforting.

Mark said: *"We shouldn't have been surprised with the response, but it was even more overwhelming than we anticipated. My father was an incredibly selfless and community oriented individual. After over 40 years of social work, teaching, community service and charitable work, we found that family, friends and acquaintances near and far were only too happy to make a donation to PHA UK in his name.*

"My father received incredible care from the PH centre at the Newcastle Freeman Hospital and we are very grateful to Professor Corris, nurse Rachel Crackett and the rest of the team there."

PUTTING A POSITIVE SPIN ON IT

When 21-year-old DJ *Will Acres* was diagnosed with PH, it took him by surprise. But with the help of his music, family and friends, he's making the most of every moment. >>>

It was traipsing through the mud at Glastonbury festival in June 2016 that made Will realise something was seriously wrong. Struggling to keep up with his friends, and with pains in his chest, he went straight to his GP and 12 weeks later was diagnosed with idiopathic PH.

"My diagnosis initially hit me very hard", he said, "as within three months it felt like my life had changed inexplicably. I felt a wave of emotions, all in such a short period of time – devastation, fear of the unknown, but also the determination to tackle this condition head on."

A few weeks before going to Glastonbury, Will, who lives in London, noticed his voice becoming weaker. Initially it was dismissed by his doctor as straining of his vocal chords from shouting too much at clubs and gigs.

But when there was no improvement, and after his experiences at the festival, Will was referred to his local hospital for tests.

When PH was suspected, he was transferred to the team at the Royal Brompton Hospital, who confirmed the diagnosis of idiopathic pulmonary hypertension.

> ***"My diagnosis initially hit me very hard…as within three months it felt like my life had changed inexplicably"***

As a student studying a degree in music production, and regularly performing as a DJ at clubs and events in London, the diagnosis has forced Will to change his lifestyle.

He said: *"PH has had a huge impact on my life, however I am determined to minimise that impact as much as possible. Drinking is a big part of student life and I used to take part in drinking regularly when going on nights out. I now barely drink and when I do I will only have a couple of drinks maximum; often just one. However, this has barely affected me as I make a point to still have as much fun with my friends as possible, without alcohol. In all honesty cutting out booze has been great and I've never felt better."*

Will also makes a conscious effort to be as active as possible and uses an activity tracker to try and achieve 10,000 steps a day. He is currently working on a music album for his final university project and continues to DJ, keeping aware of his physical limitations.

Will said: *"There is nothing better than playing to room full of people who are having a great time. I try not to let my diagnosis get in the way of music. When writing it I'm sitting down so don't feel any effects of PH at all. However, when I'm playing a set, I'll often need to make sure I'm not going over the top with dancing around too much, as this can lead to me feeling breathless. I also try to avoid lifting heavy objects such as amplifiers for long periods of time. "*

Will says the support he has received from family and friends has made a big difference to his mental outlook, and believes relationships have been strengthened since his diagnosis. Those around him have organised fundraising activities for PHA UK and Will is planning to host his own charity gig this year.

He added: ***"It may seem very bizarre, but in a way my outlook on life has changed for the better since being diagnosed with PH. I'm far more grateful for everything I have and the opportunities I have been given throughout my life so far. I find myself living in the moment rather than clogging my mind up with anxieties and self-doubt."*** ●


Will and cousin Sarah


Will with family

Will's advice for **other young people** diagnosed with PH:

> ***"My best piece of advice is to not give up on your dreams and what you love, as having music is something that has kept me going through thick and thin. It's helped me to escape the world when I've needed to, and also provided me with drive to keep going no matter what life throws my way. Make the most of the opportunities you are presented with regardless of having PH. Most of all, don't stop having fun - go out and grab life by the horns!"***

You can find out more about Will's music by searching **Will Acres Music** on Facebook, or following him on Twitter, **@WillAcresMusic**

Fundraising roundup

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

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


£1,160 RAISED

Phil's family fun day

Phil Bower held a family fun day at his local club in Manchester to raise money in memory of his wife. Patricia died in September 2015 and the event at Cadishead Conservative Club, which included live music, face painting and a bouncy castle, raised £1160. Phil said: "The highlight of the day for me was being on stage thanking everyone for participating."

Team effort for Will

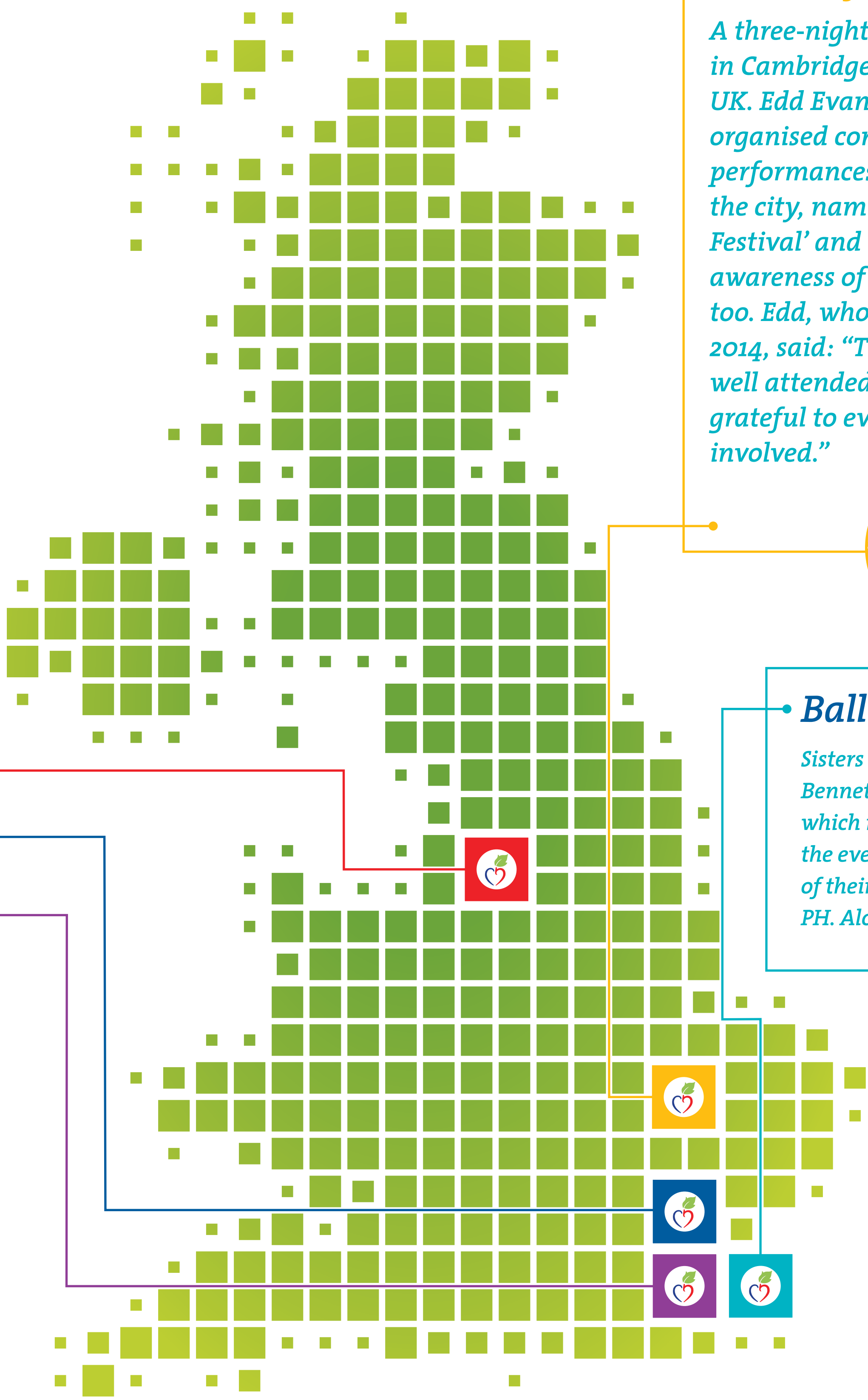
Lea Acres organised a coffee and cake day in support of her son Will, who has PH. She held the event at home, raising £400 for PHA UK and £364.70 for the Brompton Hospital, where Will is treated. Lea said: "Knowing that the team at Brompton and PHA UK are supporting us is such a comfort and definitely helps, so we held this event to say an initial thank you. Our family and friends attended and have been so incredibly supportive, of which we are so grateful." St .James' Primary School in Emsworth, where Lea works, also raised £180 from a collection and her local community fundraising group, Funderbirds, raised £320 from a raffle. A collection by family friend Maureen Lord raised a further £100. You can read more about Will and his experiences with PH on p13.


£1,000 RAISED

Barn Dance success

With the help of family and friends, Stephanie Wolfe from Faversham organised a barn dance in support of her 24-year-old son Alex, who was diagnosed with PH last summer. Stephanie's daughter Rebecca sourced the band for free and the night of fun and dancing raised over £600. Stephanie said: "The whole family invited friends and a thoroughly fun evening was had by all. Alex was even able to join in the Ceiledh dancing!" Stephanie's other daughter Florence is taking on a marathon in Vienna next year, with half of her sponsorship being donated to PHA UK. Good luck Florence!


£660 RAISED



Festival for funds

A three-night entertainment festival in Cambridge raised over £300 for PHA UK. Edd Evans-Morley and his friends organised comedy, music and theatre performances at the Red Bull pub in the city, naming the event 'Side Streets Festival' and using it to help raise awareness of pulmonary hypertension too. Edd, who lost his wife Natalie to PH in 2014, said: "The event was a lot of fun and well attended and we're very grateful to everyone involved."


£344 RAISED

Ball raises bucks

Sisters Danielle Barham and Natasha Bennett held a fundraising ball in Kent which raised £2500. 150 guests attended the event, which the girls held in support of their young nephew Stuart, who has PH. Along with other events organised by friends, a grand total of £5795.02 has been raised for PHA UK. Danielle said: "Our gorgeous little nephew was diagnosed in 2015 and had a double lung transplant in September last year. Thank you to everyone who helped us raise this money." The girls are planning more fundraising events for 2017.


£5,795 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

Life on wheels

Charlotte Goldthorpe looks at how mobility scooters are giving some PH patients back their independence, and considers what you need to take into account when making the decision to climb on board.

Image supplied by www.sunrisemedical.co.uk

Using an electric scooter can make a great deal of difference to your quality of life, enabling you to get around independently.

Like most vehicles though, they don't always come cheap, with prices ranging from £400 for basic models, up to over £5,000 for top-of-the-range machines. It's also possible to buy them second-hand.

The good news is there's a charity scheme which can help people who are receiving the highest rate for the mobility component of their Disability Living Allowance (DLA).

Motability, which has affiliations with many motorised scooter retailers across the UK, enables people to get mobile by exchanging their allowance to lease a mobility scooter, car or powered wheelchair. PHA UK can also sometimes provide small grants to assist with equipment like mobility scooters.

> *"...a scooter gives me a feeling of independence rather than being a burden...it's fun"*

PH patient Gill Luck started using a scooter after using a wheelchair. She said: ***"I felt like an invalid when having to use a wheelchair, whereas a scooter gives me a feeling of independence rather than being a burden. It's fun and lots of family and friends want to have a go. I still have to use a wheelchair in some situations but can accept that."***

Gill opted for a lightweight model as it is often loaded into her husband's car when they go out and about.

She added: ***"In having a lightweight one you obviously compromise on distance range and stability. If you want a bigger, more stable one you might have to install a hoist into your car and have a bigger boot. It is worth researching the options fully. My first scooter was second hand but I did eventually buy one, once I had become used to using one, ascertained how much I used it and what I used it for. My Dad now has my old one and loves it too."***

GETTING INSURED

Over the past few years it has been argued that it should be compulsory for those driving mobility scooters to be insured. However, as it stands, there is no such law. Owners of mobility scooters are advised to get insured to cover themselves in the event of an accident, theft or damage to their scooter.

There are a number of mobility scooter insurance companies on the market including Fish Insurance, Surewise.com and Blue Badge Mobility Insurance. When filling out the details for insurance, generic questions such as name, address and the type of scooter you own will be asked.

There are usually three types of insurance to choose from. These are:

- **THIRD PARTY ONLY**
  This protects other people, vehicle and property in the event of an accident that was deemed to be your fault.
- **THIRD PARTY FIRE AND THEFT**
  This covers you for the above, plus fire or theft of your own scooter.
- **COMPREHENSIVE**
  This will cover you for all of the above, plus damage to you and your own vehicle/ property which is caused by you.

No matter where you are or what you are doing, accidents can and do happen. Through being insured, it will eliminate the fear of facing a costly legal battle if anything was to go wrong, or having to pay for a new scooter, and give you piece of mind when out and about on your scooter. >>>

Gill out and about on her lightweight scooter

Life on **wheels**

RULES OF THE ROAD *(and pavements!)*

The Highway Code sets out rules for the use of mobility scooters on roads and pavements.

'Class 2' vehicles are those with an upper speed limit of 4mph and are designed to be used on pavements. 'Class 3' vehicles are those with an upper speed limit of 8mph and can be used on the road as well as the pavement. However, they must not travel faster than 4mph on pavements or in pedestrian areas.

They also must not be used on motorways, or on dual carriageways where the speed limit exceeds 50mph.

For the full rules, visit **www.gov.uk**

Do you use a mobility scooter?

If you would like to share your experiences, (good or bad!), or if you have any advice for others, please email **editor@phauk.org**

ME AND MY SCOOTER

We took to Facebook to ask what you thought about using a mobility scooter. Here's what some of you said.

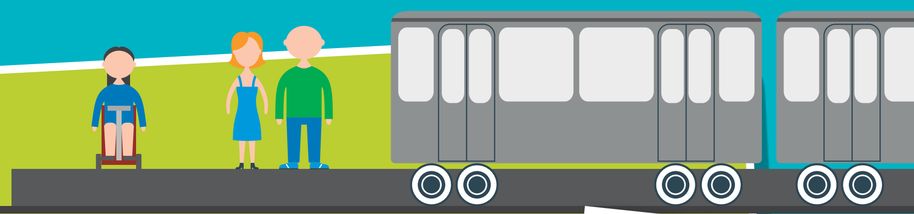
JANE TAYLOR: *"I can look around whichever shops I want, without having to be pushed. I feel less of an invalid and even managed to go up and down hills in Cornwall. I wouldn't be without mine now."*

PAULETTE ROBINSON: *"I used one for years and loved it! It gave me my freedom back to go shopping, walk my dog, go to the library and travel on a train."*

MARK KINGSTON: *"I did feel so self-conscious when I first used mine, but soon got used to it as it gave me so much more freedom to visit places I otherwise would miss out on."*

VESTA POULSTON: *"I've recently bought a Smartie from Monarch Mobility which I'm really pleased with. It folds down with a remote control to the size of a smallish suitcase and you can pull it along when folded."*

JAYNE VENABLES: *Love mine. It means I can have independence when shopping - I don't have to ask to stop at each thing I want to look at. I can also use it to see my friends locally; I'd have to ask for a lift otherwise."*



Braving the underground **on my scooter**

Earlier this year, Northampton-based PH patient *Sarah Marshall* visited London with her scooter and oxygen. In a special blog post, she shared how she got on.

With additional needs, catching the underground is complex. Every stage has to be planned carefully. Luckily my friend Madi, who travelled with me for a girly get-together, lives in London so researched our journey, and even emailed Transport for London (TFL) to double check. They sent back a helpful route description.

Shockingly, only around 25 per cent of stations on the underground are classed as accessible. Furthermore, half of those 'accessible' stations are not actually suitable for wheelchairs, due to 'the gap' between carriage and platform.

The majority of fully wheelchair accessible stations are on the outskirts; there are very few in the centre, in fact just four in Zone One. This suddenly restricts the number of places that disabled people can easily visit in London. It also makes our journeys longer and complicated as we can only change tube lines at fully accessible stations. The UK is one of the most disabled friendly countries in the world, yet the centre of our capital city is off limits if you need wheels to get around.

For our trip, a direct route was not possible, and we had to meander. Even after going the long way around, the nearest accessible tube stop to our final destination was 2.5 miles away, so we had to catch a cab for the last part of the journey. Getting from Ruislip to our destination at The Langham Hotel in Marylebone for an able-bodied person involves one train, and takes half an hour. As a disabled person, it took two different tube lines, a taxi, and took us over an hour.

Each station had a wide barrier for me to enter and exit without trouble. The trains on the Central line were wide and empty, with disabled bays so my scooter didn't cause a blockage in the carriage.

One of the trains on the Jubilee line was very busy, but luckily my fellow passengers were very accommodating, and didn't push or moan at me despite my scooter taking up a lot of floor space in a narrow compartment. And happily, not one person looked at me in alarm or panic when they saw I was using flammable oxygen in a train!

As I was unable to use the escalators, we had to keep looking for lifts to get us from one platform to the next, or to the street. Luckily, they were all fully signposted, so easy to find, but it did add extra time to the journey, and wasn't as easy or quick as running up the escalators like the rest of the passengers.

> ***"Braving the underground was an accomplishment. Maybe this will be the first of more train journeys."***

In the end, there was only two incidents in the whole of the journey. On one outgoing train, there was a raised gap between train and platform: we managed to lift the scooter off safely, but it wasn't ideal, and I couldn't have done it on my own. We were surprised as it was a fully accessible station from carriage to street.

However, in some older stations, only sections of the platform have been updated and made accessible, and although clearly signposted, we'd not noticed. We didn't make that mistake twice! We also made a faux pas by deliberately exiting at an inaccessible station; the nearest one to Madi's house. Luckily my husband met us at the platform, so retrieved my scooter from the train, and carried it down the 50 stairs to the street, as there was no lift.

Braving the underground was an accomplishment. Maybe this will be the first of more train journeys. ●

You can follow Sarah's blog at **www.wecanadjustthesails.wordpress.com**

Could you *encourage blood donors?*

Save a life
Give Blood

Donating blood saves lives and improves the health of others. One in four of us will need to receive blood at some point. Unfortunately, if you have PH then you can't give blood, but you may like to encourage others to do so? If someone is unsure about donating for the first time, here is a step-by-step guide to what to expect.

① **Over 6,000 blood donations are needed every day** in order to treat patients across England and it's estimated that 200,000 new donors are needed each year. Giving blood is simple and many people would not be alive today without the generosity of volunteer blood donors.

② **Most people aged between 17 and 65 are able to give blood,** but everyone is advised to consult a doctor before registering. If you are able to give blood, you can find your nearest blood donation centre at www.myblood.co.uk You can book an appointment online or over the phone and you'll then be sent a Donor Health Check questionnaire to fill in – this is designed to make sure you can become a blood donor and your blood is safe to transfuse to patients.

③ **On the day, you will be greeted by someone at the blood donation centre** and seated in a waiting room until your name is called. In this time, it's important to have plenty to drink and read through a pamphlet you're given about the donation process. You'll then be called to a private health screening, where a donor carer will confirm your identity and ensure it's safe for you to donate. You'll be taken through your donor register questionnaire and give a small sample of blood to check your iron levels. Once both you and your donor carer are happy, you'll be taken to another waiting room before being invited to a donation chair.

④ **Once you are comfortable,** the nurse will apply a blood pressure cuff to your arm to maintain a small amount of pressure and the needle is then inserted into your arm. Your chair is then tilted back and your blood donation will begin. You'll be asked to clench your fists or tense your buttocks to maintain blood pressure during the donation.
It will usually take between five and 10 minutes.

The feeling of donating blood can be a little strange, especially if it's your first time, but there is always someone nearby, so if you feel uncomfortable, you can let a member of staff know very easily and they can help. Once complete, a nurse will sit you upright in your chair and apply a plaster on your arm.

⑤ **A selection of free drinks and snacks are available** and you'll be encouraged to relax and have tea and biscuits for at least 15 minutes. Also try to book your next appointment before you leave!

Visit the NHS Blood and Transplant website at www.blood.co.uk for more information.

Living with PH 2016 Survey

The early results

Thank you to everyone who took part in the *2016 Living with Pulmonary Hypertension survey,* designed to gain information on the patient journey and how PH impacts on daily living.

We received 563 responses and have been able to compare results with similar surveys carried out in 2007 and 2010. The average age of participants was 59, and the average age at diagnosis was 53. 70% of participants were female.

KEY FINDINGS

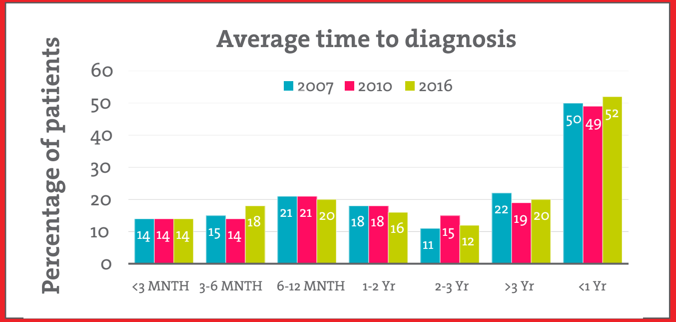
- *48% of respondents waited over a year for a diagnosis after first experiencing symptoms.*
- *46% of patients had their symptoms for over six months before going to see a doctor.*
- *32% of patients were admitted as an emergency because of their symptoms.*
- *40% of patients saw four or more doctors being diagnosed.*
- *Both time to diagnosis and the number of doctors seen before diagnosis remain as good, or slightly better, than reported in the two previous surveys.*
- *Since being diagnosed, 48% of patients see a specialist at least every six months, and 87% see a specialist at least every 12 months.*
- *46% reported their overall quality of life has improved 'a lot' and 62% think the support they receive is excellent. 26% think it is good.*
- *92% of patients said they thought it was better to travel to a specialist PH centre rather than to be under the care of a non-PH specialist at a more local hospital.*

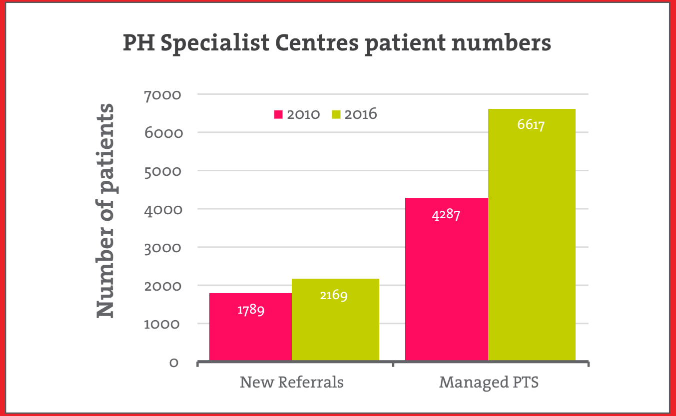
This survey found that care of patients with PH is perceived as good or excellent and patients were keen to travel to specialist PH centres for their care. Compared with the previous survey in 2010, the percentage of patients seeing more than three doctors before diagnosis was reduced, possibly suggesting an increasing awareness of pulmonary hypertension amongst physicians.

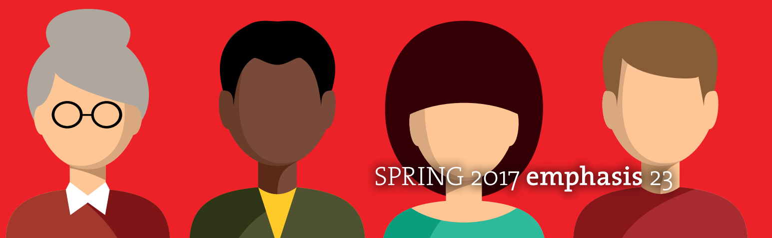
However, a large percentage of patients had symptoms for more than six months before seeing a doctor, which has hardly improved since previous surveys.

As earlier diagnosis of patients results in better long-term survival, we will continue to work to raise awareness of pulmonary hypertension in the UK.

Thank you to everyone who took part in the survey. More details about the results will be made available soon. ●







My life changing challenges

Asha Sagoo from Leicester is determined to raise awareness of pulmonary hypertension, and shared her story during PH Week to help others understand what it feels like to live with the condition.

Asha with her family

Asha and husband Bob

"My journey to diagnosis was not an easy one. I'd been coughing and getting breathless since February 2014 but I just assumed it was due to me getting old, putting on weight and lack of exercise.

Nevertheless, I underwent various tests at my local hospital but nothing was detected. Consultants thought it may be due to a lung infection called sarcoidosis, however I was lost in follow-up and this was never treated. I just assumed I was on the waiting list to be seen.

On the morning of 21st December 2015 I felt severely breathless, fatigued and dizzy, and I couldn't get out of bed.

When I tried, I realised I wasn't going to make it - shivers ran up from the bottom of my legs and although I wasn't in any pain, my oxygen levels were dropping and my body was shutting down. The only thing I could vaguely remember was the sound of my children playing outside my room, all excited about the Christmas holidays.

Just before collapsing on the bed I managed to whisper a call-out to my then eight-year-old son Ryen, who ran in and somehow managed to phone his dad at work, and then an ambulance, telling them that mummy wasn't very well. By then, I had passed out.

My kids were terrified. I was put on an oxygen machine in the ambulance and as they were driving me away I managed to get a glimpse of them through one eye - my son's face had gone pale white like he'd seen a ghost, and this is an image that will haunt me for the rest of my life.

***Tests at Leicester Royal Infirmary revealed I had a substantial blood clot very close to my heart,** which was too dangerous to operate on, so I received blood thinning injections and was hooked up to oxygen and a heart monitor.*

*For two weeks, I wasn't allowed to move off the bed in case the clot burst or travelled anywhere else. **My children spent their Christmas holidays visiting me in hospital every day.***

On 5th January 2016 I was discharged from hospital but my symptoms continued.

> ***"I have full faith that one day a cure for PH will be found..."***

I couldn't climb my stairs anymore at home, my coughing increased dramatically and I couldn't even find the energy to shower or wash my hair. I also put on a lot of weight from fluid retention in my ankles, face, feet and tummy, gaining 1.5 stones over two months. I couldn't even lift my legs to put my trousers on.

Recognising something was wrong, my respiratory consultant referred me to the PH centre at the Royal Hallamshire Hospital in Sheffield, where I was quickly diagnosed with pulmonary hypertension.

I had never even heard of this illness, nor knew anybody with it.

Months passed and I was put on eight different medications to slow the illness. I thought I was getting better and slowing the illness down, so as it was the first PH Awareness Week in November, I decided to try and raise awareness and money for PHA UK by walking a quarter of a mile every day, which had previously felt impossible.

However, three days before the start date of my challenge, I was out shopping with my husband when I collapsed, and lost consciousness as I banged my head on the ground.

I spent PH Awareness Week in hospital undergoing further tests, but have since been able to complete the challenge and have raised £925 thanks to the support of family and friends, who I have kept updated via social media.

I will be undergoing a transplant assessment at The Queen's Medical Centre in Nottingham in March, and I am also now being treated for sarcoidosis.

The list for medication doesn't stop, however I have full faith that one day a cure for PH will be found and I'm determined that my children will never have to think of another Christmas without their mummy. ● "

MY EVERYDAY CHALLENGES

PH AWARENESS WEEK 2016

- Some days are worse than others
- Sometimes it means greasy hair days because it's too hard to wash my hair
- It means cancelling plans, no matter how badly I want to keep them
- My choices are stolen away like dancing, exercising and even walking
- I now have to plan for wherever I go and whatever I do
- Will I be able to go shopping? Will I be able to give my kids a shower?
- Sometimes it means just lying in bed, looking out the window and hoping tomorrow is a better day.

Whilst sharing her story during **PH Week**, Asha put together a poster detailing the everyday challenges she faces.

To support Asha during **PH Week**, her community spiritual centre held an event to raise awareness of the condition and funds for PHA UK. **The Centre of Oneness** in Leicester displayed educational materials and sold cakes and biscuits, and **raised £225**.

Remembering Allan Smith

Tributes have been paid to a key member of the Golden Jubilee Hospital pulmonary hypertension team who passed away suddenly just before Christmas.

Allan Smith, senior clinical pharmacist at the Scottish Pulmonary Vascular Unit (SPVU), was involved in a cycling accident on 18th December.

Described by his colleagues as 'highly regarded' and 'a kind and generous teacher', Allan played an important role in respiratory medicine. As well as working as a specialist pharmacist at the SPVU, he also worked alongside Strathclyde University as a practice teacher and a visiting lecturer, and was frequently asked to talk about the pulmonary vascular work he was undertaking at conferences and meetings of fellow pharmacists and medical staff.

In a tribute from the seventh-floor team at the hospital, read at his funeral, Allan was described as 'well humoured and upbeat', with colleagues recalling his legendary banana loaf and his tales of the adventures of his cat, Mungo. *"We are suffering an irreplaceable loss"*, read the tribute, *"but we continue to focus on what an incredible legacy of respect and achievement he has left behind."*

Following a suggestion at his funeral that Allan be remembered through little things, his colleagues at the SPVU threw a snowball in his memory, and took a stone from the site of the first hospital he worked at, placing it in a park near the outreach clinic in Aberdeen that they often walk to. They have also pledged to remember Allan through the care of their patients, and in the words of colleague Colin Church, *"there is no doubt that Allan will be greatly missed by all who knew him."*

"Allan was the mainstay of the pharmacy service to the SPVU since it was formed in 1998. He did his job with a calmness and competence that will be extremely difficult to replace. Allan was always an important source of information for the SPVU on the role of drugs and their interactions and unfailingly provided prompt replies in relation to therapy queries. His became an opinion the SPVU trusted implicitly and we miss him immensely. Allan was without doubt a gentleman and a scholar."

Professor Andrew Peacock
Director of the PH service
at the Golden Jubilee Hospital

"Allan was one of the first pharmacists to develop a specialist interest in pulmonary hypertension in the UK and probably the world. His wealth of knowledge and experience in the field has influenced and enriched all of us who learned from him. We will all remember his hugely likeable personality and sense of humour. I speak proudly on behalf of the members of the PH Professionals Group when I reflect how we feel privileged to have known and worked with Allan. The PH community has tragically lost one of its most gifted colleagues".

Neil Hamilton
Consultant Pharmacist at the Sheffield Pulmonary Vascular Disease Unit and Chair of the PH Professionals Group. ●

Allan with his wife Gillian.

At his funeral, Allan's close friend Walter spoke of his love for hill walking and skiing.

KNOW ANYONE WHO WANTS TO GET MUDDY FOR PHA UK?

As part of the official *'Tough Mudder Charity Family'*, we're inviting people to take part in the iconic obstacle race for FREE with one of our exclusive charity fundraiser places.

Raise vital funds for PHA UK while completing Tough Mudder's 10-12 mile mud and obstacle course, designed to drag participants out of their comfort zone and test their physical strength, stamina and mental determination. In some locations, half-length versions of the course are available too.

In return for a free place, all we ask is for participants raise a minimum of £300 in sponsorship to help us continue our work.

Focusing on teamwork and camaraderie, this year there are also some exciting new obstacles including the 'Augustus Gloop' – a towering vertical tube with gushing water to climb up, and the 'Funky Monkey' – a series of revolving monkey bar wheels.

We only have limited fundraiser places available. To take part please contact PHA UK on office@phauk.org or call 01709 761450.

Tough Mudder events are held across the country:

LONDON April 29th, May 6th & 7th, Sept 16th, 23rd & 24th
MIDLANDS May 13th, 20th, & 21st
SCOTLAND June 17th & 18th
YORKSHIRE July 29th & 30th
SOUTH WEST August 19th & 20th
NORTH WEST Sept 9th & 10th

You can find more location information at www.toughmudder.co.uk

What shall we *do this summer?*

Consultant pharmacist *Neil Hamilton* is encouraging PH patients to plan early for their summer holidays this year.

If you're anything like me, then once Christmas is over, you start to think about the summer holidays; where to go and what to do. After all, we all need something to look forward to.

I recently booked up our family holiday for August and although that may seem a long way off now, the hectic nature of daily living means that time soon passes! By planning well in advance you have time to consider and prepare for the most important factor in having a great holiday - taking good care of yourself.

Looking after yourself is crucial and for anyone taking medication, making sure you have supplies for your trip is just the start. Most people will receive repeat prescriptions from the GP every month. Lots of surgeries now have the option to order repeats online if you have access to the internet. This convenience, coupled with your local pharmacy collecting and dispensing your prescription may save lots of your time and effort - but all this may require a few days notice. GPs are increasingly busy so don't leave it until the last minute to put in your request, especially if you have a plane to catch!

Likewise, if your PH medication is delivered to you, let your homecare company know in advance so they can adjust your delivery dates accordingly. They may need up to five business days' notice, and they won't have vans in all postcode areas every day. Just make sure you have enough of everything for your trip, and if you need blood tests doing, they may need to be brought forward too. Depending on where you are going and how you plan to travel, you may need a list of all your medicines to take with you.

If you are prescribed one of the prostanoids, given as an intravenous or sub-cutaneous infusion, or nebulised, you will need all the ancillary items too. If you are flying, check with the airline or tour operator about the rules for carrying sharps with you. Don't leave it too late!

> “Don't leave it until the last minute to put in your repeat prescription request, especially if you have a plane to catch!”

If you use oxygen, it is likely that your oxygen provider will be able to provide extra for the holiday. Get in touch and find out what they can do for you. If you plan to fly, check with the airline regarding any charges before you book.

Once you have sorted any regular medication, trips away may also mean that you need some other treatments, just in case the need arises. By this, I mean medicines such as anti-histamines for allergies or skin reactions, travel-sickness for the journey, sunscreen and even refilling the first aid kit.

Anti-histamines are an essential for most people to give some relief from bites, stings and other allergic problems. They are relatively cheap to buy in from your pharmacy and have very few interactions with other medicines. Some (of the better ones!) may cause drowsiness, so always check with the pharmacist especially if you want to drive, or have a few drinks whilst taking them.

Nobody likes to feel sick but travelling, especially by ferry, can give people a lot of bother. A small one-off dose of a travel-sickness tablet may be just enough to make the journey a far more pleasurable experience. These again are very unlikely to clash with your regular medications, but for peace of mind always ask at the pharmacy counter if you are in any doubt.

If you are unfortunate enough to not only feel nauseous, but suffer a stomach upset too, maintaining hydration and salts will be crucial. It is possible to buy rehydration sachets containing salts and electrolytes which are dissolved in water. Obviously those of you taking water tablets will be increasingly susceptible to dehydration in this situation and would be well advised to ask for medical help if symptoms persist for more than a couple of days.

I'm based at the Hallamshire Hospital in South Yorkshire and 'Sunny Sheffield' is not a nickname to be taken too literally! However great the city is, and however beautiful the Peak District on the doorstep is, I don't think many folk would come to visit us expecting to get a tan. I'm sure that's the reason that lots of people go abroad for their holidays and why sunscreen is vital, so we can enjoy some sun without the fear of getting burnt.

Unfortunately, there are some medicines that make the skin more sensitive to the harmful effects of the sun's UV rays. Amongst the medicines commonly prescribed for PH patients are amiodarone, nifedipine, diltiazem, furosemide and some antibiotics. There are plenty besides these too, and again I would always advise you check whenever you are unsure. Obviously if you are taking a 'photosensitising' medicine, depending on the strength of the sun it may be sensible to avoid direct sun altogether, maybe cover up, but at the very least apply a high factor sunscreen or even a sunblock. You can't be too careful.

> “There are some medicines that make the skin more sensitive to the harmful effects of the sun's UV rays”

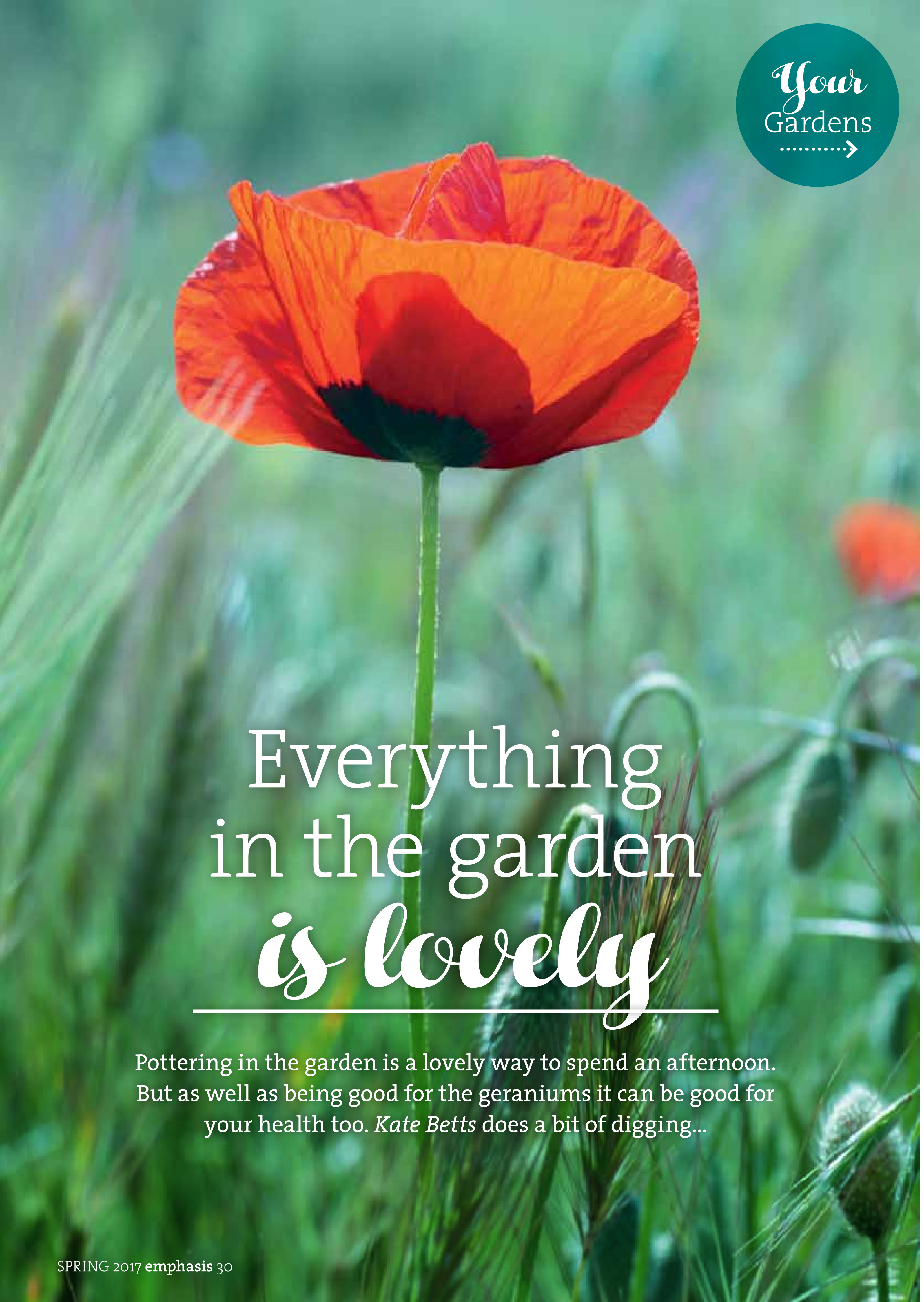
Luckily our family first aid kit hardly ever sees the light of day - which is great news until the one day when you need it, something important has expired or been left open too long. It may sound obvious but do keep a regular check on the dressings, creams and anything else in your first aid pack. Sterilised product's expiry dates indicate when the sterility will be lost by, and if a bottle has been open too long its contents may be ineffective. The same applies to tubes of cream, which may also lose sterility and effectiveness over time. Try not to get caught out!

My holiday medicines reminder wouldn't be complete without mentioning travel insurance. After all, if despite all your best efforts something does go wrong, or you still feel unwell, you need up-to-date travel insurance with adequate cover for peace of mind. In order for the policy to cover you, be sure to tell the company all about your existing medical conditions. Failure to let them know in advance may affect any claim you want to make. Contact the PHA UK office for details of insurers that are particularly helpful if one of your party has PH.

So to conclude, I hope I haven't sounded like I'm nagging! Everyone deserves a holiday and everyone should look forward to having a great time with friends and family. This will be so much easier with a bit of planning in advance so you can all stay healthy while you are away.

Your local pharmacy or PH centre pharmacist will be very happy to advise you regarding your specific prescription and how that works alongside holiday medicines.

Whatever you end up doing and wherever you go, have a wonderful time!



Your
Gardens

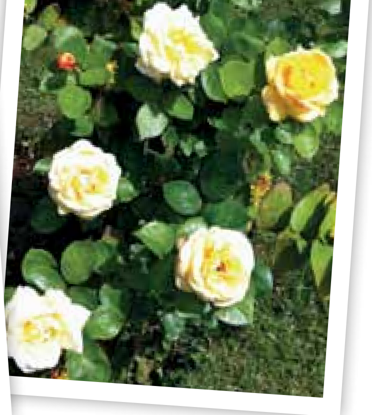
Everything in the garden *is lovely*

Pottering in the garden is a lovely way to spend an afternoon. But as well as being good for the geraniums it can be good for your health too. *Kate Betts* does a bit of digging...

Kay Yeowart's garden, East Sussex

Christine Bank's garden, Somerset

Simon Dean's garden, Bradford



Steph Pollard's garden, Yorkshire

Gardening doesn't have to mean digging a trench to plant potatoes, it could just be growing a window box full of herbs or tending to a collection of colourful flowers in pots. The trick is not to overdo it.

It is commonly held that gardening helps both physical and mental health. According to researchers in the Netherlands every ten per cent increase in exposure to green space translates into an improvement in health equivalent to being five years younger!

And a study in the UK, published in the Journal of Public Health, showed allotment holders benefit from better mood, self-esteem and other indicators of well-being after a period of gardening.

But you don't have to go for a big vegetable patch. Even the humble house plant has been credited with reducing pain. Research by Kansas State University found that putting plants in the hospital recovery room for patients who had operations including appendectomy and thyroidectomy led to a reduced perception of pain and less use of painkillers compared to patients in a recovery room with no plants.

Nearly 90 per cent of homes in the UK have gardens and they cover about a quarter of a typical city. So for most people it literally is a form of therapy on the doorstep.

As well as the health benefits of gardening itself there are the outcomes of all the work; pretty flowerbeds, tidy lawns, and sculptural shrubs and trees to look at, rose petals and jasmine blossoms to smell. And maybe some nice fruit and vegetables to eat.

But getting out into the garden can be quite a challenge, especially if there are steps and uneven paths. So to keep the garden manageable it is worth thinking about the layout and, if necessary, creating paths that are suitable for a wheelchair or mobility scooter, or perhaps putting in handrails. Also it may be worth researching which plants need less care and attention than others. Having a garden that gets out of control easily can be stressful.

Raised beds are a good way to reduce the need to keep bending up and down. They can be at different heights, including high enough to reach from a wheelchair – or just a chair.

There are garden tools and accessories designed to make gardening easier, such as lightweight spades and forks, gripping aids and kneeling stools. And what about a bench? It's a great place to sit and admire the work you have done and plan next season's produce.

Keeping warm while outside is also important. Wrap up well when it's cold and do not stay outside for too long. Use plenty of layers and even thermals if necessary.

Thrive, the national charity which helps people with a disability or health condition to start or continue gardening, says it is important to do some simple bending and stretching exercises before starting any activity. The gentle exercises will loosen up muscles and make strains less likely. On cold days, it might be worth waiting until the air warms up before starting or only working in areas of the garden that are sunny.

The charity also advises sticking to one job at a time, having regular breaks, moving equipment around the garden in relay fashion, taking a chair out first, then the tools, and, most importantly, stopping work before getting too tired.

As with all activity there are risks everyone needs to think about. The Royal Horticultural Society suggests precautions to minimise the risks, such as wearing gloves for most gardening activities, only potting-up with compost in a well-ventilated space and wearing a mask when using anything which may create dust. It's also important to make sure tetanus jabs are up to date and always wash hands after gardening and especially before eating.

> *As well as the health benefits of gardening itself there are the outcomes of all the work; pretty flowerbeds, tidy lawns...*

A report by the influential think-tank the King's Fund earlier this year concluded that gardening is good for people of all ages and urged the NHS to consider more "social prescribing" of gardening activities. This is where the NHS literally pays an organisation like a local charity to offer gardening or other activities from dance classes to knitting groups and cookery clubs as a form of therapy to help keep people healthy.

In Newcastle for example one charity takes people fishing to help them get out and about and meet others.

Research in Rotherham carried out by Sheffield Hallam University has shown that 'social prescribing' of various activities like gardening for people with physical or mental health issues led to Accident and Emergency attendances reduced by 21 per cent and hospital admissions down by nine per cent.

So it's official, gardening is good for you. David Domoney, an ambassador for Thrive and co-presenter of ITV show 'Love Your Garden' with Alan Titchmarsh, puts it simply: *"It's amazing how much sense of well-being and happiness the sight of a simple plant can bring."*

For more information visit **www.thrive.org.uk** and **www.rhs.org.uk** ●

European study finds **lack of reliable information on airline oxygen policies**

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.

The ELF carried out a survey with patients and healthcare professionals to help improve the practicalities of travelling by air for people with a lung condition and to build up a clearer picture of the current situation they face when planning a trip abroad.

A total of 96 people responded to the patient survey from 18 countries worldwide – 75 per cent being patients themselves and 25 per cent being relatives or carers of someone who needs to travel with oxygen.

A key finding published by the ELF stated that nearly 20 per cent of patients find a lack of reliable information from airlines the main barrier when travelling. In addition to this, 12 per cent said bringing their own portable oxygen concentrator (POC) on board the aircraft was a significant barrier. 11 per cent also claimed that planning the journey and organising the logistics behind travelling abroad, coupled with the physical impact of the journey itself, may cause them further fatigue and stress.

As part of the study, the ELF surveyed 196 healthcare professionals from 57 countries, most working in secondary care. 16 per cent of respondents were from the UK and several respondents came from Portugal, the Netherlands and Spain.

22 per cent of the healthcare professionals surveyed agreed there was a lack of information on travelling with oxygen and that this was a key obstacle when patients plan a trip abroad. 20 per cent also reported that the importance of respiratory assessments is often underestimated, and said they had experienced difficulties accessing a local protocol or a screening tool.

The results of the survey were presented at a workshop held at the ERS International Congress in London. Participants included healthcare professionals, patients, representatives of patient organisations and representatives of industry (POC providers). Together, they discussed how to improve the practicalities of travelling by air and the steps required to carry out these changes.

Next steps

Both healthcare professionals and patients have stressed the need for a standardised certificate, which can be easily recognised by airlines and easy to understand by those not medically trained.

In 2017, the ELF will work towards a standardised certificate template which will be different for adults and children, be specific about the condition of the passenger, contain information on any accompanying person or escort and be specific about the oxygen flow rate.

The ELF will also work towards guidelines and protocol for the assessment of fitness to fly for patients with a lung condition, an information sheet on POCs and a list of commonly accepted POCs.

The present report and any outcome of the workshop will be published online on the ELF website in the section dedicated to air travel with a lung condition **www.europeanlung.org**

TAKING OXYGEN ON BOARD

The European Lung Foundation offers the following advice to people travelling with oxygen:

- Check with airlines which portable oxygen concentrator (POCs) are allowed
- Check battery requirement – consider the time you will spend at both airports
- Check on the airport map where plugs are located or contact the airport directly
- Bring information about your POC with you (instructions and warranty)
- Arrange assistance at the airport/airline both at home and at the destination airport
- Ask to be boarded and to disembark first or last

Are you flying abroad this year?

Check out consultant pharmacist Neil Hamilton's advice on planning ahead for holidays on ***page 28***

*“With some adjustments, you can live **a happy and fulfilled life**”*

Cynthia Croughton from Hertfordshire was diagnosed with pulmonary hypertension aged 70, and 12 years later, she still enjoys an active life. She shares her inspirational PH journey with Emphasis.

“***Although I was only diagnosed with PH much later in life, I've had problems with my lungs since I was eighteen months old, when I developed pneumonia following a bout of measles. Later on I can remember becoming out of breath just walking up the hill to the train station on my way to work in London.***

That said, I have always loved sport and played netball, tennis, badminton and occasionally squash when I was younger. I was always out of breath, of course, but after a while I developed little ploys to get my breath back – tidying up the tennis balls at the back of the court, or bouncing the ball a few times before serving.

It wasn't until 2004, just after my 70th birthday, that I realised something had changed. I was first referred to a cardiologist who said the problem was my lungs. A chest specialist sent me for a CT scan which revealed both lungs were full of blood clots; I was admitted to hospital straight away and started on Warfarin. Despite this I had further bouts of pulmonary emboli in 2005 and 2006, and it was not until a second opinion was sought that I was referred to Hammersmith Hospital's Pulmonary Hypertension Service in February 2007. It had taken five doctors two and a half years to properly diagnose PH.

In a way, it was a relief to find myself in a hospital where doctors and nurses were showing me such care and explaining all I needed to know about my illness. During the past 12 years I have gradually become more breathless more quickly on exertion, which has restricted my walking and activities. But I have a stairlift and use a stick, or sometimes two. I can still drive and have a Blue Badge but most of all I have a very supportive husband and family, many kind friends, and neighbours offering help too.

Being a member of PHA UK is a huge support and encouragement and *I realise how fortunate I am to have had such an active and contented life for so long.* ***Others are not so lucky, because PH is not an old ladies disease. I have had to learn patience and to be thankful for the many things I still enjoy. So to anyone newly diagnosed I would say, don't be despondent; there is so much help out there so please accept it. Then with some adjustments you can live a happy and fulfilled life.***”

> *“Being a member of PHA UK is a huge support and encouragement.”*

New guide to financial support **for you & your family**

PHA UK has put together a financial benefits guide to help you negotiate the minefield of benefit entitlement and receive what you deserve.

Having pulmonary hypertension, or being a caregiver for someone with PH, can present many financial challenges and working out what benefits you may be entitled to is not always easy. This is why we've developed a guide to help you navigate potential support, whatever your situation.

Bringing benefits to life

The new benefits guide has been brought to life with scenarios based around common real-life situations, to make it easier than ever to identify what you may be entitled to.

Top tips and benefits calculator

Top tips from our director of membership support Shaun Clayton feature throughout the guide, and you'll also find useful information about our handy benefits calculator, brought to you through our welfare charity partner, Turn2Us. The calculator, which is available by visiting **www.phauk.org**, flags up all the benefits that are likely to be applicable to you, plus information on how to apply for them.

The WHO Functional Class

The financial support you receive will depend on many factors, including how severe your condition is and how much it affects day-to-day life for you and your family. The section of the guide on the World Health Organisation's (WHO) Functional Class explains more about this to help you.

Important definitions

When making your application it's important to take into account some key words that governing bodies will look for when reviewing an application. In the guide, you'll find important definitions so you're well-prepared when you come to fill out your application.

Appeals process

It's very common for people with PH to have to go through an appeals process if their initial application is rejected. The process is broken down into three sections within the guide. See the following article (right) for more detail about appealing. ***If your application is turned down initially - don't give up.*** ●

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Financial support:
What could my family and I be entitled to?

A PHA UK guide to navigating potential support, ***whatever your situation.***
Shaun Clayton

Having pulmonary hypertension (PH) or being a caregiver for someone with PH can present many ***financial challenges***, and working out what benefits you may be entitled to is not always easy.

The financial support you receive will depend upon many factors, including how severe your condition is and how much it affects day-to-day life for you or your family.

We have put together this guide to help you negotiate the minefield of benefit entitlement and get what you deserve.

If your application is turned down initially, do not give up. Sometimes you need to challenge decisions to get what you are entitled to.

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The WHO Functional Class

It is important to remember that all welfare entitlement applications are based on something called ***functionality*** (this is what you can and can't do on a day to day basis). It has little to do with the condition an individual is diagnosed with, such as Pulmonary Hypertension.

Instead, it focuses on things like being able to go up a normal domestic flight of stairs at home, washing and dressing in the morning, carrying out a basic supermarket shop, or cooking a meal. 'Functionality' looks at how your symptoms can cause restrictions on a regular basis, but not necessarily all the time.

SHAUN'S TIP... *The WHO functional classes **MIGHT be able to help you define YOUR functionality**, however if it doesn't then do not worry. These are only to guide you if you find them helpful.*

Just because one person with PH is entitled to a particular benefit it doesn't necessarily mean that everyone will be, as all applications are looked at on a person-by-person basis. With that in mind, to help with your applications, it may be useful to understand the definitions of the 'WHO functional classes'. This is the class system created to define the severity of an individual's symptoms and how they impact on day-to-day activities.

WHO Functional Class 1: This is defined as *"Patients with Pulmonary Hypertension but without any resulting limitation of physical activity. Ordinary physical activity does not cause; breathlessness, fatigue (tiredness), or activities that can cause chest pain, dizziness or even black outs."* So this would describe you if you do not suffer from the above symptoms when doing 'ordinary physical activity' - such as climbing a flight of stairs, doing the dishes, bathing and cooking (not going for a run or going to the gym).

SHAUN'S TIP... *It's important to note that in your clinic letters you may find you have been assessed to be in a functional class you do not agree with. When completing your application, describe the functional class **you feel you fit into best**.*

WHO Functional Class 2: This is defined as *"Patients with Pulmonary Hypertension resulting in slight limitation of physical activity. They are comfortable at rest. Ordinary physical activity causes undue breathlessness, fatigue (tiredness), or activities that can cause chest pain, dizziness or even black outs."* This would be one of the classes that the majority of patients with PH would fall into. This would describe you if when 'at rest' (sitting, laying down or standing still) you have no symptoms of breathlessness etc., however when carrying out 'ordinary physical activity' (for example climbing a flight of stairs, shopping, or making the bed) you do suffer from any of the above symptoms. – (For example; Paul struggles with the stairs, needs a break after going up and down them.

SHAUN'S TIP... *Always remember that these applications should be based on your worst day and not your best. What can you **reliably and frequently** do?)*

WHO Functional Class 3: This is defined as *"Patients with Pulmonary Hypertension resulting in marked limitation of physical activity. They are comfortable at rest. Less than ordinary activity causes undue breathlessness, fatigue (tiredness), or activities that can cause chest pain, dizziness or even black outs."* This, like class 2, is the other class that the majority of patients with PH would fall into. This would describe you if when 'at rest' (sitting, laying down or standing still) you have no symptoms of breathlessness and so on, but can have difficulty doing general day-to-day activities such as household chores. You may have to take breaks while carrying out daily living activities (climbing a flight of stairs, walking to the shops and so on) - For example; Niamh has difficulty with the stairs but also can only walk on the flat on the way to shops without experiencing any dizziness.

SHAUN'S TIP... *Don't forget that if you have another condition with PH, for example if rheumatoid arthritis affects your needs or you suffer with depression, make sure that these are incorporated into your application. **Don't just focus on your PH.***

WHO Functional Class 4: This is defined as *"Patients with Pulmonary Hypertension with inability to carry out any physical activity without symptoms. These patients manifest signs of right heart failure, breathlessness and /or fatigue, which may even be present at rest. Discomfort is increased by any physical activity."* This is the most severe class of PH. It describes how the patient may suffer from symptoms even at rest (for example when sitting down) and will suffer from severe symptoms whilst doing any activity, no matter what it is. (For example, Dave cannot climb a flight of stairs like Paul without experiencing a high burden of symptoms. And unlike Niamh, Dave cannot walk to the shops at all without serious dizziness.)

The main symptoms of PH

PH affects people's abilities to carry out basic tasks and get around. People with this condition often look well at rest and it's only through a simple activity such as climbing the stairs that they may experience symptoms.

How can I find out how much I can claim?

We have teamed up with welfare charity **Turn2Us** to offer a very useful Benefits Calculator, accessible via our website, which flags up all benefits that are likely to be applicable to you, plus information on how to apply for them.

You simply need to fill in your personal details and circumstances. The calculator will even take into account where you live, and identify local benefits such as discretionary housing benefit or emergency funds.

To access the tool, which is completely free, visit www.phauk.org and search 'benefits calculator'.

You can also find out about any additional help that may be available to you from charitable trusts by visiting www.phauk.org and using the 'grant search' tool, which has also been developed in conjunction with Turn2Us.

Another great source of information is the section on illness, injury or disability on the Turn2Us website, accessible via www.turn2us.org.uk. Click 'your situation' along the top and select the relevant option.

It's always worth contacting your water and energy providers to explain your situation and discuss your bills. Many companies run a social tariff scheme.

Your local Citizen's Advice Bureau is also a useful source of information. You can also access its services online at www.citizensadvice.org.uk and clicking the 'benefits' section along the top.

If you want to know more about individual benefits the PHA UK have produced a publication called **'Signposting to potential benefits'** to help, please contact **office@phauk.org** for a free copy.

Appeals process

SHAUN'S TIP... ***Don't be afraid to appeal!*** *Most applications are turned down for no good reason. The people reviewing your applications are all trained in one area - how to say no! The system is stacked against us, but staggeringly around **80 per cent** of people who appeal eventually get what they deserve.*

It's very common for people with PH to have to go through an appeals process if their initial application is rejected. The process is broken down into three sections:

MANDATORY RECONSIDERATION
This is where you request that your application is looked at again by the same organisation that reviewed it in the first place. In essence, you're asking them 'are you sure you made the right decision'?

APPEALS APPLICATION
This is a more formal process that requires you to send either a letter or an application (dependant on the benefit) to the Department of Work and Pensions (DWP), expressing your dissatisfaction with the initial outcome of your application. Tell them that you're not happy and would like to push this matter further.

REVIEW PANEL
Unfortunately, in some cases, your application may need to be pushed this far. If the outcome to your appeal is not to your liking then you can ask that your application be reviewed by a panel of trained medical professionals (in many cases this is the first time your application will be looked at by a medical professional). People often tell us that it's at this stage they finally feel like they are being listened to and understood.

To request your free copy of the financial benefits guide, please contact **office@phauk.org**

Appealing against PIP & ESA decisions

Claiming Personal Independence Payment (PIP) or Employment and Support Allowance (ESA), is not always a straightforward process. Here, our charity partner Turn2us helps you decide when you should challenge a decision and how to do it.

PIP is only awarded to about half of the people that claim it and nearly 40 per cent of all ESA claimants are told that they are fit for work. Lots of people have to challenge the decision to refuse their benefits and then appeal to Tribunal to get what they are entitled to.

It's not easy to deal with a decision that you're not entitled to benefits. It can leave you feeling stressed, disbelieved and unsupported. It can also affect your health, especially when it leaves you worse off financially.

1. The Decision Letter

When you are refused PIP or ESA, you will receive a letter from the Department for Work and Pensions (DWP) confirming the decision. This is called the 'decision letter'. You usually have one month from the date of the decision letter to ask the DWP to change their decision.

If you're not sure whether the decision is right, you may want to check the rules for PIP or ESA and whether you qualify. These are helpful websites for checking if you qualify:

www.c-app.org.uk has easy-to-use questionnaires for PIP and ESA. When you have completed the questionnaire, it tells you whether you are likely to qualify, and which answers are important. You can use the checklist of important answers to see if the DWP has considered all of those facts.

www.benefitsandwork.co.uk has self tests for PIP and ESA. When the DWP assesses your entitlement to PIP or ESA, they award points for each activity listed in the rules. The Benefits and Work self tests tell you how many points you may score for each activity. You can use the results to compare how many points you think you score against how many points the DWP awarded you.

2. Mandatory Reconsideration Request

To ask the DWP to look at their decision again, you must request a 'Mandatory Reconsideration'.

If you think the DWP made the wrong decision, you have to ask them for a Mandatory Reconsideration within one month of the date on your decision letter. If you ask for a Mandatory Reconsideration later, the DWP will not look at their decision again unless they accept that you have a good reason for the delay.

The best way to ask for a Mandatory Reconsideration is to write to the DWP at the address on your decision letter.

Make sure you include:

- *'Mandatory Reconsideration Request' at the top*
- *Your National Insurance number*
- *Today's date*
- *Date of the decision*
- *Why your request is late (if it is)*
- *Which part of their decision is wrong and why.*

You can request mandatory reconsideration over the phone, but a letter is the best way of making sure your request is processed. You may be able to get help to write the letter from a local benefits adviser, which you can find on **www.advicefinder.turn2us.org.uk**.

Your letter does not have to be detailed. A short letter is better than no letter.

If you can, include more detail in >>>

Over 60 per cent of appealed PIP decisions and 58 per cent of appealed ESA decisions are changed by the Tribunal.

your letter. For example, if you think the DWP did not award you enough points for a particular activity, tell them how many points you think you should have received. You can give details about what happens when you do that activity or try to do it. You can give them evidence to prove what you say, for example medical letters or records, or a letter from someone who helps you.

The DWP tries to deal with Mandatory Reconsideration requests within two weeks of receiving them. If you don't hear anything after two weeks, you may want to call them to check they have received it. Remember to keep a record of your call.

When the DWP looks again at their decision, if they think that the decision was right, they will try to telephone you to see if you have anything else to tell them. If they can't get through to you or what you tell them doesn't change their mind, they will not change the decision.

If you tell them that you have more evidence to send to them, they will give you more time to submit it before they look at the decision again.

3. Mandatory Reconsideration Notice

The Mandatory Reconsideration Notice confirms whether the DWP has changed their decision. Once the DWP has considered all of the information they have, they will issue a Mandatory Reconsideration Notice. You will receive two copies.

Don't be put off if the DWP does not change their decision at this stage. The DWP only changes a small proportion of challenged decisions themselves (13 per cent for PIP and 10 per cent for ESA).

If you are still unhappy with the DWP's decision, you can appeal to Tribunal. Success rates at the appeal stage are much higher. Over 60 per cent of appealed PIP decisions and 58 per cent of appealed ESA decisions are changed by the Tribunal.

You cannot appeal to Tribunal until you have received your Mandatory Reconsideration Notice.

4. Appeal to Tribunal

The Tribunal is independent of the DWP. They will look at all of the information the DWP has and everything that you tell them and then decide whether the DWP's decision is correct according to the rules.

Appeal Form

The appeal form is an SSCS1 form. The easiest way to get a copy of the form is to do an internet search for 'SSCS1' and download the form from the **www.justice.gov.uk** website. You could also get a copy from your local Citizens Advice Bureau or another benefits adviser or charity.

You have to submit your appeal form within one month of the date on your Mandatory Reconsideration Notice. If you submit your appeal later, the Tribunal will only consider it if you have very good reasons for the delay and your appeal is submitted within 13 months of the date on the Mandatory Reconsideration Notice.

When you complete the form, make sure you:

- *'Complete 'Section 5: About Your Appeal' with details of which activities you think the DWP scored wrong and why you think you should have been awarded more points*
- *Say you want to attend a hearing unless you can provide lots of documents to tell your story for you (it is better to attend a hearing, if you can, as this gives your appeal the best chance of success)*
- *Sign the form*
- *Include one of the copies of your Mandatory Reconsideration Notice.*

Submit your appeal by posting your completed SCCS1 form to the Appeals Centre using the address on the form. They will send you a letter to confirm they have received your form. This letter will have your Tribunal Reference number on it. You can check the progress of your appeal by calling **0300 123 1142**.

A copy of your appeal will be sent to the DWP by the Tribunal Service.

Evidence

Within four weeks of receiving a copy of your appeal, the DWP will send you and the Tribunal all the paperwork about your claim. This is their evidence. It is a good idea to read their evidence, if you can, and make a note of anything that you do not agree with.

You can submit evidence too. It is best to send it with your appeal form but you can send it later. Put your Tribunal Reference number on any papers you send to the Tribunal separately to your appeal form.

Good evidence to submit includes:

- *Sick notes and prescriptions*
- *Medical records from your GP*
- *Letter from friends or family who help you saying how they help you, how often and what would happen if they didn't.*

When the Tribunal decide your entitlement to PIP or ESA, they award points for each activity listed in the rules. Documents which show how much help you need to carry out the activities are the best evidence to prove that you should be awarded more points.

Hearing

You will receive a letter from the Tribunal Service at least two weeks before the hearing confirming the date, time and place.

You can take someone with you to the hearing, and if you have any more evidence, you can take that too.

When you arrive, the clerk will greet you and explain what happens next.

When you go into the Tribunal, you will see a panel of two people for an ESA appeal or three people for a PIP appeal. They will introduce themselves and explain what happens next. Each of the panel takes turns to ask you questions about your health and how it affects your ability to do things for yourself. Remember to tell them about your worst days as well as your best days.

You can take a break at any time during the hearing. At the end of the hearing, you will be asked if there is anything else you want the panel to know before they make a decision. You may want to tell them about things you disagree with in the DWP's evidence.

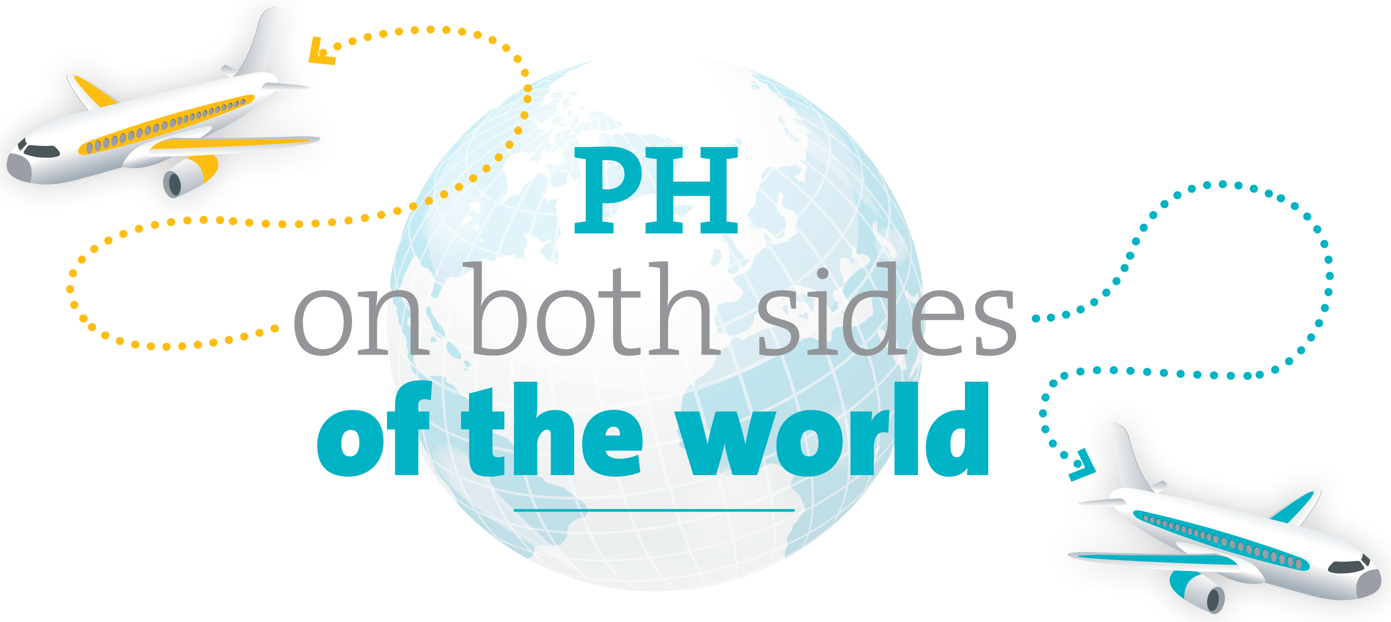
You will be told the Tribunal's decision on the day of the hearing unless the panel think it will take a long time to make a decision. Whether they make the decision on the day, or later, you will receive the decision in the post. A copy of the Tribunal's decision will also be sent to the DWP.

If you have been refused PIP or ESA, it could be harder for you to make ends meet. You may have to make do on less money unless or until your appeal is successful. Make sure you visit the Turn2us website **www.turn2us.org.uk** to find out about other help.

Turn2us can help you to find:

- *Benefits adviser near you to help challenge a PIP or ESA decision. Use **www.advicefinder.turn2us.org.uk***
- *Other benefits you may be entitled to. Use the Benefits Calculator on **www.phauk.org***
- *Charities that can help you with grants that you don't have to pay back. Use the Grants Search on **www.phauk.org***
- *Immediate help for people who are really struggling. Search **www.turn2us.org.uk** for 'Emergency Assistance'.*

Turn2us is a charity that is passionate about fighting UK poverty. Find out more about their work at ww.turn2us.org.uk, or on Facebook or Twitter @turn2us _org



PH on both sides of the world

Joanne Kelly, who now lives in Lancashire, spent four years as a pulmonary hypertension patient in Australia before moving back to the UK. Here, she discusses her experiences at both ends of the globe.

“I was born 46 years ago with a rare congenital heart defect called ***transposition of the great arteries***, and was one of the first babies to receive the new ‘**mustard procedure**’, which involved redirecting blood flow to ‘revamp’ the heart.

The procedure meant that babies with the condition were able to live near-normal lives and I went on to marry and have two beautiful children of my own.

Five-and-a-half years ago, my husband was offered a job over in Adelaide, South Australia, and along with our daughters aged 17 and 20, we took the opportunity to make the move.

Up until this time I was very active and, despite my limitations, quite fit. I worked full-time, rode horses, walked for miles and led an ordinary life. We walked for hours during weekends in Australia, admiring the scenery and animals this beautiful country had to offer. I also started a very physical job as a housekeeper in a busy hotel in the city, and life was good.

Almost overnight though, this changed. I began feeling very tired and achy, couldn't walk as far, and wanted to sleep most of the day. Sensing that something was wrong, I went along to my local GP who then referred me to a rheumatologist for tests.

Eventually, I started on medication for fibromyalgia, but continued to decline until a point where my GP said ‘enough is enough’ and sent me to an emergency department at hospital. From this point, life as I knew it changed.

Diagnosis

After a 12-day stay in hospital I received the news that my heart was failing due to the congenital heart disease and consequent heart operations I had undergone. I was advised that because my heart had been made to work in a different way, it had become very tired.

I was in shock as I hadn't been to a cardiologist in 18 years. *I have since found out that most ‘mustard babies’ (those who received the procedure I had), had been seeing one every year of their lives. Somehow, it seemed, I had got lost in the system.*

And so I started seeing a lovely cardiologist based in the city's main hospital, who specialised in adult congenital heart disease and had previously worked in Birmingham's Adult Congenital Heart Disease (ACHD) centre.

After seeing him every three months for three years he wasn't happy that my symptoms weren't improving. ***My shortness of breath and exercise intolerance were getting worse, and so was the fatigue.***

My cardiologist fought tirelessly for me to find out why, and eventually he decided to trial me on Sildenafil, which enabled me to start to walk a bit further and improved my breathlessness.

He also decided to do a heart catheter with exercise, where I moved my legs in a scissor movement as a catheter was placed through an artery in my arm. It was then, a year after moving to Australia, that I was diagnosed with pulmonary hypertension.

I began seeing a lung consultant to measure oxygen levels on a six-minute walk test, and he concluded that I would benefit greatly from oxygen, which was another big lifestyle changer for me.

In Adelaide, PH is treated under a PH specialist cardiologist, *but I stayed with my original cardiologist and the two liaised together. The lung specialist oversaw the oxygen level side.*

I was started on a higher dose of Sildenafil, Macitentan, the blood thinner Waferin, and also my oxygen. I hired a mobility scooter as I lived on a hill, didn't drive and so was unable to take daily trips out or do the shopping. I felt useless, but the mobility scooter and oxygen gave me a new lease of life.

Moving back

Around this time, we decided to move back to the UK for work and family reasons, but also because of my health and fear of the unknown. ***It was a very hard decision and a huge upheaval; so much harder than moving out to Australia when I was fit and healthy.***

Since moving back to Lancashire I have noticed many differences in terms of both medical treatment and in people's attitudes.

I cannot fault the care on moving back to the UK - I was quickly sorted out with oxygen, medication and appointments at Birmingham ACHD centre *(I was referred there rather than Sheffield because of my congenital issues, and the two centres liaise closely together.)*

However, in Adelaide, I was used to having my next appointment made on the same day I attended the hospital, which gave me a sense of security.

I do sometimes feel that because of the UK's fantastic specialist PH centres, some GPs and hospital departments feel they can ‘pass the buck’ onto them – which can make me feel like I've been left out on the washing line, with no idea when my next appointment will be.

In Adelaide, the GPs worked closely with the specialists, phoning them during my appointment if they needed advice or were concerned.

I haven't experienced the NHS as a chronically sick person before, but I do feel the differences in care between Australia and the UK are vast in terms of patient support.

Changing attitudes

I find the attitudes of people in general in the UK differ to Australia too. Over here, we tend to be less accepting of people who have disabilities, or who use mobility aids.

I get a lot of stares when I am out and about on my scooter and have become more self-conscious since moving back here. I feel like this country needs more education about the needs of the chronically sick, in order for people to become more accepting of those who are different.

To be honest, support within inner communities for those with long-term illnesses is lacking in both countries, but the PH associations in Australia and the UK are both good.

The weather in Australia helped me because it's basically summer and spring all year round. I found the hot weather days quite a lot harder on my breathing, but it was a small price to pay for the sunshine.

Since moving back, I have noticed both differences and similarities between the two countries. With its fantastic specialist centres, I feel that the UK leads the way in terms of facilities and knowledge - but my experiences of support and social attitudes in Australia have been better.”

Since moving back to the UK, Joanne has set up her own charity to support people living with chronic illnesses. Chronic Illness Support for All UK (CISFA UK) aims to support adults through advice, care packs, chaperone services for medical appointments, meet-ups and community support groups. To find out more, search Facebook for CISFA UK or contact Joanne on **joannekelly41@yahoo.co.uk**

Diet, inflammation and mental health

Nutrition expert *Sarah Dash* explores how eating non-inflammatory foods may ease symptoms of anxiety, stress and anxiety-based depression.

Systemic (or chronic) inflammation is different to the redness and swelling that appears after you cut your finger. We can't see this low-level autoimmune response, and it's a prolonged reaction to a persistent problem, like disease or environmental stressors (think pollution or smoking). Instead of a quick response to an obvious intruder, systemic inflammation is a slower, continuous burn, like a cindering fire. Chronic inflammation can damage and disrupt biological systems and tissues, and this increases risk of disorder in both the body and the brain.

There are many foods and nutrients that are particularly good at 'tidying up' the inflammation in our bodies - you've perhaps heard them advertised as antioxidants or 'super foods'.

> *Chronic inflammation is important because it has been shown to be linked to brain function and mood.*

While there's no quick fix, there are many foods that can, and should be incorporated as part of a healthy overall diet. For example, fish, rich in omega 3s, and vegetables and whole grain cereals, packed with fibre, are known for their anti-inflammatory properties.

On the other hand, unhealthy foods (like 'fast foods' or sugar-laden lollies) can increase inflammation, likely through the health of our gut. A junk food diet can contribute to a weakening of the gut barrier that prevents food particles from leaking out into the bloodstream, where, obviously, they do not belong. Because these food particles are out of place in the bloodstream, off go the alarm bells of our inflammatory response. When poor quality foods are a part of our daily diet, the body maintains this low level of alarm, and we know this to be a risk factor for mental health.

Chronic inflammation is important because it has been shown to be linked to brain function and mood. In animals and humans, injection of 'pro-inflammatory' molecules has been linked to symptoms and behaviours like fatigue, withdrawal, and depressed mood – also features of common mental disorders. Also, people with higher levels of inflammatory markers in their blood have been shown to be more likely to develop depression in the future.

What goes on in the gut, as well as the inflammatory response that might follow, can disrupt the processes in the brain that help regulate our mood. For the health of your belly, body and brain, aim to avoid heavily processed foods, and instead rely on a range of colourful, fibre rich foods. ●

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.

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Green Leaf Crew!

GREEN LEAF CREW Q&A

STANLEY SMITH

Stanley Smith is five years old and lives with his mum and dad in Buckinghamshire. Diagnosed with PH as a baby, Stanley was fitted with a Hickman line in 2015 but it doesn't get in the way of him having fun. Here, he shares his favourite things with Green Leaf Crew.

Q. What's your favourite thing to do at school?
A. *Drawing with my friends.*
Q. What's your favourite thing to do at the weekend?
A. *Flying my plane with Daddy at the park.*
Q. Do you have a best friend?
A. *My best friend is Morgan, we love playing Hot Wheels together and both love monster trucks.*
Q. What's your favourite biscuit?
A. *I love all varieties of chocolate biscuits.*
Q. What's your favourite thing to have for tea?
A. *Fish fingers and chips.*
Q. If you could meet any famous person in the world, who would it be?
A. *The Queen, because everyone wants to meet her.*
Q. What do you like to watch on TV?
A. *SpongeBob Square Pants.*
Q. If you could have any superpower, what would it be?
A. *To fly like Iron Man.*

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

SPRING RAINBOW SMOOTHIE

CELEBRATE THE RETURN OF THE LONGER DAYS BY MAKING THIS HEALTHY LAYERED SMOOTHIE.

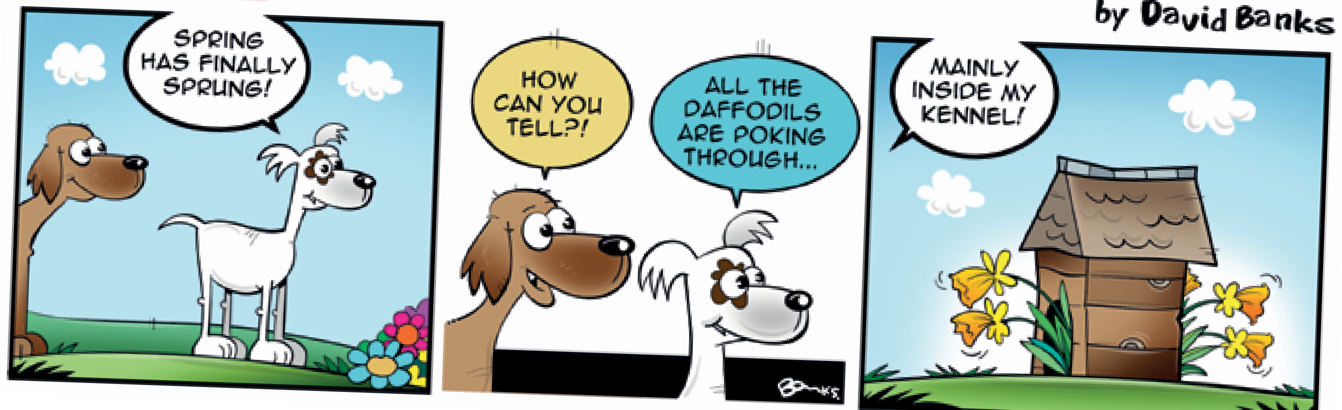
INGREDIENTS:
¼ CUP OAT FLAKES
1 BANANA, JUICE OF 1 ORANGE, 1 KIWI
¼ AVOCADO, ½ MANGO, ¼ CUP RED BERRIES
CINNAMON, SWEETENERS, 1 CUP WATER

METHOD:
1. BLEND OAT FLAKES WITH BANANA, WATER, ORANGE JUICE AND CINNAMON. ADD SWEETENER AT THIS POINT. DIVIDE THE MIXTURE IN THREE EQUAL PARTS.
2. ADD KIWI AND AVOCADO TO THE FIRST PART AND BLEND UNTIL SMOOTH. POUR INTO A SERVING GLASS.
3. COMBINE MANGO WITH THE SECOND PART, BLEND AND POUR INTO THE GLASS OVER KIWI MIXTURE.
4. BLEND RED BERRIES WITH THE THIRD PART AND POUR ON TOP OF MANGO MIXTURE. ENJOY IMMEDIATELY.

THIS RECIPE AND IMAGE IS TAKEN FROM WWW.DIETTASTE.COM WHERE YOU'LL FIND LOTS MORE DELICIOUS SMOOTHIE RECIPES.

Patch

by David Banks



The GREEN LEAF CREW

BY DAVID BANKS

the*interview*

Consultant Respiratory Physician at Hammersmith Hospital

LUKE HOWARD

in conversation with

Mary Ferguson

Luke Howard is Consultant Respiratory Physician in the pulmonary hypertension unit at Hammersmith Hospital. He also runs the hospital's exercise physiology service and is an honorary senior lecturer at the National Heart and Lung Institute, Imperial College London.

Luke sits on national and international committees and guideline groups for pulmonary hypertension, pulmonary embolism, oxygen therapy and air travel and lectures around the world. He has an active research programme in Pulmonary Hypertension and Exercise Physiology, and decided on a career in PH back in his medical school days.

Q. Tell us a bit about your career pathway - did you always plan to go into medical sciences?

A. *Yes I did. At an early age, my best friend convinced me it would be a good idea to become doctors together. We both went to medical school, but interestingly he now works in the City! I distinctly remember being in the college library revising for an exam, when I came across one page in the medical textbook about pulmonary hypertension. That is when I decided on pulmonary hypertension as a career.*

Q. Can you tell us about your research programme in PH and Exercise Physiology?

A. *We have a strong research track record at Hammersmith and one of the things I have always been interested in is how certain conditions manifest themselves during exercise. After all, this is when patients get symptoms. My hope is to understand better what goes wrong during exercise and to link this in with our research aims at Hammersmith, so that we can use this understanding to better evaluate the effect of current and new drugs. I also have a strong interest in the development of new therapies in the early phase of testing. At the moment, I am particularly focused on the use of intravenous iron in pulmonary hypertension and a very exciting development, which is pulmonary artery denervation.*

Q. What inspires you in your work?

A. *I like to feel that our team can provide a complete approach to patient care. There is always much more we can do, especially with limited budgets, but I want patients to feel that they are getting the best care in terms of cutting-edge therapies as well as a compassionate and caring approach. I come to work to aim to support patients when they need it, help them make the best choices, encourage them to live as people, not patients, when they are well enough to do so, but also support them and their families when there is nothing more we can offer.*

Q. What achievement are you most proud of in your career?

A. *I am very proud of being where I am right now. I have a great job, supported by a wonderful set of colleagues. I am working in a fast-moving field of medicine which has gone from being able to offer next to nothing 20 years ago, to now being able to offer hope and a genuine improvement to quality of life and life expectancy. I work in a fantastic institution which supports innovation and lateral thinking and I have the amazing opportunity to travel the world to listen to others in my field as well as impart what knowledge I can. For me, to get to this position in my career, gives me great satisfaction and pride.*

Q. What are your thoughts on how far treatment of PH has improved over the last decade or so?

A. *It was not much over 10 years ago that we only had the prostacyclin therapies for treatment of pulmonary hypertension. These could only be given intravenously or nebulised. We now have a range of oral medications which are far more accessible to patients and have made a genuine...*

>>>

the*interview*

Consultant
LUKE HOWARD

> *“The first thing that strikes me when I talk to people around the world, is that we have a system in the NHS which is the envy of many.”*

change to their lives. We have gone from a situation where we used to manage decline to a philosophy where we treat early and aggressively to help people lead normal lives in many circumstances. This means we can now focus on much more than just drug therapies and start to encourage people to exercise and focus on aspects of their mental health. Previously this would have been seen as mere gloss on a dire situation, but now it has almost become an integral necessity in patient management. We are now in it for the long game!

Q. You’ve lectured all around the world. How do PH services in other countries compare to those in the UK?

A. *The first thing that strikes me when I talk to people around the world, is that we have a system in the NHS which is the envy of many. The aspect of the care we provide which is most coveted is our centralisation in specialised services. This brings a wealth of experience within each pulmonary hypertension centre. We may not have complete access to all the therapies we want at all times, but it is clear that our outcomes are just as good, if not better, than many others around the world. It is also clear that in some countries where the diagnostics are extremely advanced, access to medication is equally restricted. While I think we could do more with increased access to therapies, we are clearly doing extremely well with what we have. We punch above our weight in terms of our research output and with the current research structure that we have, we can go on to be even more successful as a national service.*

Q. How do you relax when you’re not working?

A. *Good question - with five children, I rarely get the opportunity to ‘relax’! But the highlight of my week comes on Saturday evening when I cook up ‘Daddy’s Chilli’ while listening to the Craig Charles Funk and Soul Show, and then sit down with the family for some lively chat and a very decent bottle of red wine. We like to walk a lot as a family and have been known to do the odd geocache here and there. Occasionally, I will dust off my flute or get in the queue for the piano. Failing all of that, I relax with a Kentucky bourbon whiskey and a single ice cube.*

Q. If you could help people understand just one thing about PH, what would it be?

A. *The internet can be a terrible place. If you are diagnosed with pulmonary hypertension, and you read the internet, you may feel like giving up. People need to understand it is not a death sentence. I think we are only a few years behind HIV in terms of what we can achieve and what people need to understand (to answer your question) is that there is now genuine hope for patients. Moreover, doctors who may have qualified many years ago, will still remember primary pulmonary hypertension as something nothing could be done for. When they see a breathless patient, they need to think of pulmonary hypertension and encourage patients to travel to specialist centres care where they will receive treatment, and care, from teams of expert nurses and doctors who are passionate about what they do.* ●

US & OUR JOBS

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

NAMES: Michaela Sellers and Mark Graves.

PLACE OF WORK: Royal Hallamshire Hospital, Sheffield.

JOB TITLE: We both work as Medicines Management Technicians (MMTs).

On the ward, we are responsible for making sure that all medications prescribed are supplied on time for you. We see everyone as soon as they are admitted, daily throughout their stay and then we will ensure that we have medication supplies ready for your discharge. This helps prevent delays when you are ready for home. The MMTs in the office handles queries and questions from patients, carers and other healthcare professionals. We will co-ordinate the homecare prescriptions and also check all the blood results for people on medicines like bosentan, ambrisentan and macitentan.

HOW LONG HAVE YOU WORKED WITH PH PATIENTS? Michaela: 8-9yrs. Mark: 6yrs. So between us, over 14 years!

BEST THING ABOUT YOUR JOB: Getting to know the patients and making a difference to their quality of life. The variety involved with the job and the number of patients in the service stops us from getting bored.

FIRST THING YOU DO WHEN YOU GET TO WORK: This depends on if we are in the office or on the ward. Whoever is in the office will check for urgent emails, voicemails and homecare prescription requests. When we're on the ward, we will see all the new admissions and organise medication for any planned discharges for the day.

WHAT'S ON YOUR DESK? We share a desk and on it you'll find post-it notes, telephone and headset, pens (Michaela is a pen magpie,) two clementines, a banana (new year new diet,) coffee, mug, hand cream, Sellotape, stapler and a hole punch. There are also usually lots of prescriptions waiting to be signed, then posted or faxed to one of the homecare companies.

PROUDEST MOMENT AT WORK: There is not one big moment but we are both proud to work for the NHS as a whole and also to see the growth of the PH service in Sheffield. We work very hard to sort all our patients' medication issues out throughout their time in the service even when they are at home.

WHAT DO YOU LIKE TO DO OUTSIDE WORK: Michaela: Theatre, cinema, wine, pub, spending time with friends and family, generally socialising, and holidays at home and abroad.

Mark: Cycling, camping, cars, Formula One, gym, beer, pub and spending time with my wife and 16-year-old daughter.

KEY DEVELOPMENTS YOU'VE SEEN FOR PH PATIENTS: The introduction of Riociguat, Macitentan and Ambrisentan. Graseby pumps being converted to T60 pumps. The development of the clinical pharmacy team which is an integral part of the multidisciplinary team on the PH unit here.

TEA OR COFFEE? Michaela: Coffee with milk but no sugar. Mark: Black coffee.

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

PHA UK 2017 Conference

Hurry!
TIME IS RUNNING OUT

There is still time to register your interest in attending the PHA UK Conference Weekend at the Heythrop Park Hotel in Oxford.

Attendees can look forward to a ***buffet dinner and cinema night*** on arrival, before the ***full-day educational programme*** on Saturday, delivered by pulmonary hypertension professionals and experts in both adult and pediatric areas, including ***Dr Shahin Moledina***.

During break-out sessions, we will be providing a ***crèche*** with activities for children such as ***arts and crafts***. Stalls including a ***jewellery stand*** and ***tuck shop***, and a ***stress-busting massage area***, will also be available.

The conference dinner on Saturday evening will have a 'pirate' theme and children (and adults too!) are invited to attend in fancy dress. Entertainment will include a ***magician***, ***disco***, ***raffle*** and a ***'quiet' room*** with ***live musicians.*** The weekend is designed to be ***relaxing and enjoyable*** and a way for PH patients and relatives to meet others and ***share their experiences***.

There are ***only 130 places available***, and places will be offered on a first come first serve basis once application forms are received. We look forward to seeing you there!

If you are interested in coming along please contact:

Daisy Stewart, *CFS Events Ltd, Mindenhall Court, 17 High Street, Stevenage, Herts SG1 3UN or call 01438 751519* ***as soon as possible***.

In your Summer issue of Emphasis...

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

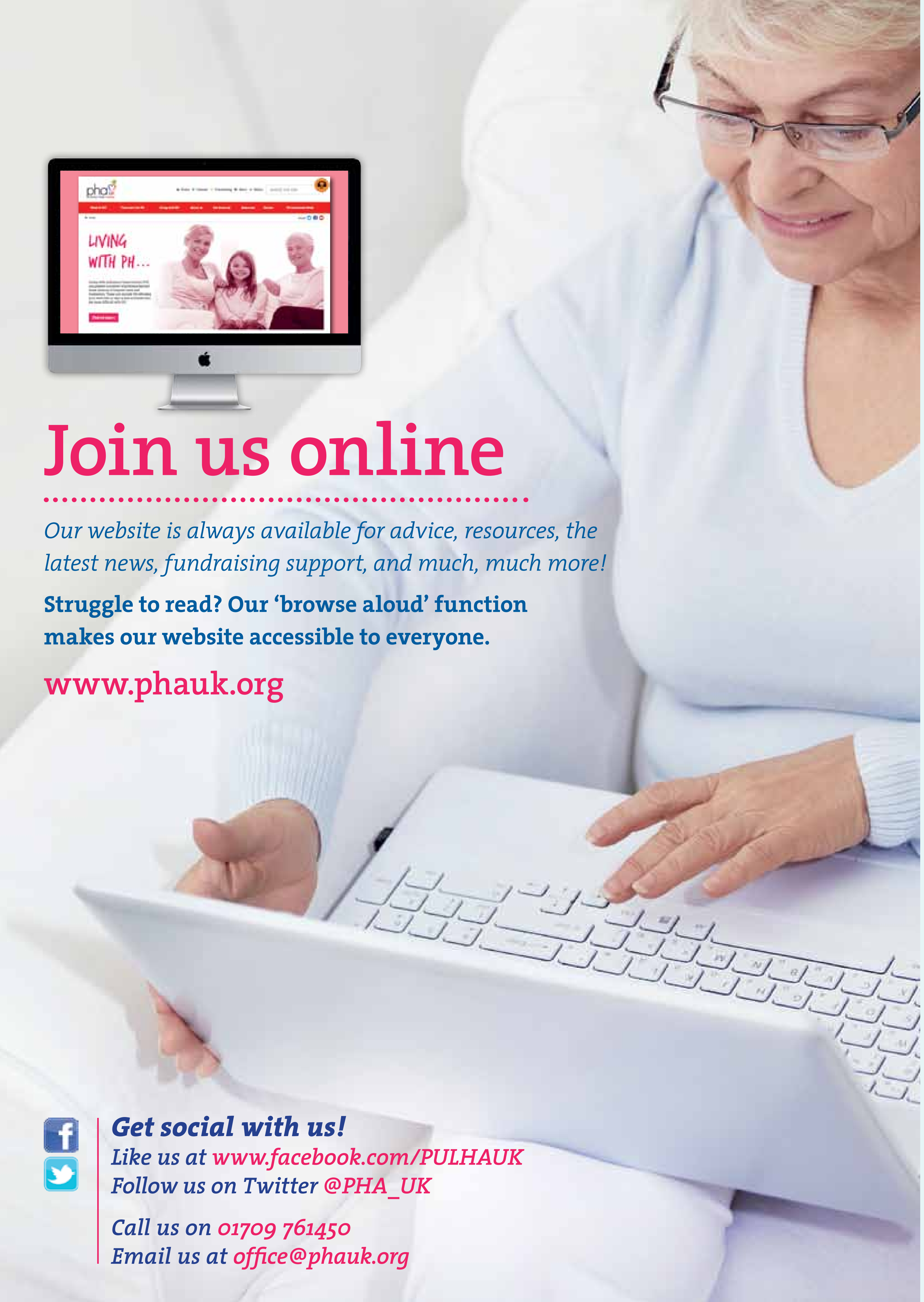
- *Electric bikes* – new technology is making pedal power accessible.
- *All about alcohol* – enjoying it safely and responsibly.
- *Research special* – all you need to know about getting involved.

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.



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Our website is always available for advice, resources, the latest news, fundraising support, and much, much more!

Struggle to read? Our 'browse aloud' function makes our website accessible to everyone.

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Email us at office@phauk.org

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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

Turn2us

PHA UK has joined forces with Turn2us, a national charity that helps people in financial hardship in the UK. The charity aims to help people in need access support; and provides a range of information and resources on welfare benefits, charitable grants and other services via its website: **www.turn2us.org.uk**. Through our partnership with Turn2us, PHA UK members can also use the Turn2us Benefits Calculator and Grants Search on our website at **www.phauk.org**

Do we have your correct details?

Please email us on **office@phauk.org** if any of the following apply to you:
- Are the details incorrect on the mailing you've just received?
- Have you moved house recently?
- Has your contact number changed?

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