SUMMER 2015

emphasis

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

Going for a spin this summer?

The benefits of cycling for people with PH

More advice on benefits

PHA UK's new partnership with welfare experts Turn 2 Us

Impact of living with pulmonary hypertension

First in-depth research into the long term impact of PH on patients and families completed

The Interview

Yvette Flynn looks back on her career working with children with PH

Put it in writing

A closer look at creative writitng as therapy

Going the extra mile

Meet some of our dedicated fundraising runners

Let's get physical

Carol Keen on the importance of gentle exercise

What is PH?
How can it be identified?
How can it be treated?

GPs, doctors, nurses and healthcare workers across all disciplines can learn more about pulmonary hypertension through PHA UK's medical education programme.

'Pulmonary Hypertension - diagnosis and management'

This flexible e-learning resource incorporates text, video and interactive tools to develop knowledge and skills. It can be self-managed with online assessments.

The course can be taken as part of personal career development and gains a certificate on completion. Or, it can be studied as a module worth 20 points as part of a degree or masters course. PHA UK worked with Edgehill University for this accreditation.

To find out more contact
education@phassociation.uk.com
or visit **www.paheducation.co.uk**

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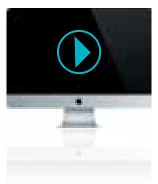

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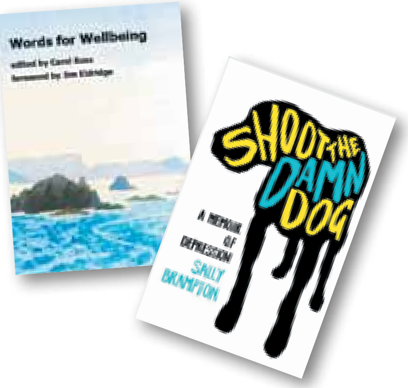


Find out about a useful new app that helps you keep a track your alcohol consumption. **Page 8**

This magazine is printed on paper from sustainably managed sources

PHA UK ANNIVERSARY 15 YEARS 2000 2015

It's going to be *PHantastic!*

Arrangements for PHA UK's 15th Anniversary Celebration at the end of October are well underway.

The 'PHantastic' event will provide an opportunity for patients, carers, families and PH professionals to come together to share experiences, learn more about the latest developments in PH treatment and care - and to enjoy themselves.

Topics to be included are:

- Exploring past, present and future therapies
- What treatment options are out there?
- Diagnostic tests, what do they show?
- Developing self-management skills
- The transition from child to adult care (GOSH)
- Developments in stem cell research.

And the line-up of confirmed speakers includes:

Dr Iain Armstrong,
Chair of the PHA UK and nurse consultant, Royal Hallamshire, Sheffield

Professor Paul Corris,
Professor of thoracic medicine, Freeman Hospital Newcastle

Dr Simon Gibbs,
Consultant cardiologist, at Hammersmith Hospital London

Dr Shahin Moledina,
Consultant paediatric cardiologist, GOSH

Professor Janelle Yorke,
Professor of nursing at the University of Manchester

Professor David Kiely,
Consultant respiratory physician, Royal Hallamshire

Dr Daniel Reed,
Research associate, of the National Heart and Lung Institute, Imperial College, London.

There will be an informal 'welcome' reception dinner and family film show on the Friday with seminars, presentations and fun activities all day Saturday.

Sunday will provide time to relax and enjoy the Heythrop Park Resort facilities and surrounding attractions such as Blenheim Palace, Cotswold Wildlife Park and the picturesque Cotswold villages of Burford and Chipping Norton.

The event will be held at Crowne Plaza, Heythrop Park in Oxfordshire from Friday 30th October to Sunday 1st November.

Everyone who has already expressed an interest in attending is being sent more information and a formal invitation directly by our event organisers CFS events. Places are limited but don't worry if you can't make it, a full report will be included in your next issue of Emphasis. ●

The 15th Anniversary of the PHA will be celebrated with a spectacular fireworks display and themed 'magical dream circus' gala dinner on the Saturday evening.

Welcome

Welcome to the summer edition of Emphasis. We had a fantastic response to our new-look publication last time, and I'm sure you will again find plenty of interest in this issue.

This magazine is packed with ideas to inspire you to get active and creative. We have a special focus on cycling and take a closer look at the new power-assisted electric bikes that are now available on the market.

Clinical physiotherapist Carol Keen encourages us all to embrace exercise as an important part of both rehabilitation and long-term health management.

And we consider the therapeutic benefits that creative writing can bring to people coping with a long-term health condition like PH.

In the news, you can read all about our new partnership with welfare and funding experts Turn2us. This charity's free online service is now available to PHA members who want to find out what support may be available to them.

Professor Janelle Yorke announces that our hugely important study into the long-term impact of PH on patients and families is now complete; and this pioneering research is set to provide us with key insights in to the effects of living with PH.

Plus, it never ceases to amaze me what lengths people go to, to raise money and awareness in support of our PH community. Turn to our bumper feature about running and meet just a few of those people who go the extra mile for PHA UK.

With much more news, interviews, expert advice and shared experiences, we hope you'll find this a great read. Don't forget we'd love your feedback and ideas.

Iain Armstrong

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

> *"Carol Keen encourages us all to embrace exercise as an important part of both rehabilitation and long-term health management."*

Emphasis *exchange*

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

STEM CELL RESEARCH GUIDE

A new stem cell research guide for patients, commissioned by the PHA, has been published by Dr Daniel Reed, a post-doctoral research scientist at the National Heart and Lung Institute, Imperial College London.

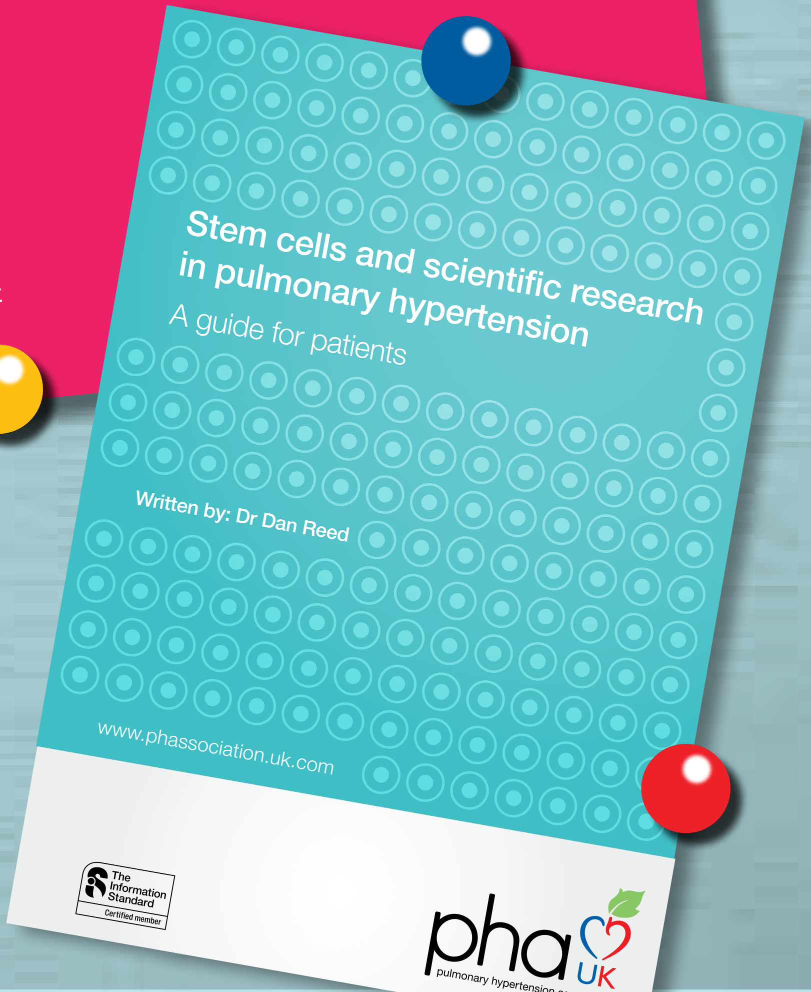
Called 'Stem cells and scientific research in pulmonary hypertension' the book addresses stem cell therapy, and the ongoing research using blood vessels made from stem cells; which is valuable for research into PH.

Stem cells can be useful to test for new treatments for PH and could be used to assess individual patients and work out the best treatments for them. The guide explains the biology of stem cells, stem cell therapy and how stem cells are used in laboratory research into PH.

Free copies of the book, and accompanying DVD, are available from the PHA, telephone: 01709 761450 or email: office@phassociation.uk.com

Dan said: "I have been touched by the stories that patients and families affected by PH have shared with me, and the interest expressed in my research.

"For me, this really highlighted the importance of good communication between scientists and patients with PH, and this became something I wanted to get more involved in."



Stem cells and scientific research in pulmonary hypertension

A guide for patients

Written by: Dr Dan Reed

www.phassociation.uk.com

WIN-WIN WITH THE PHA UK LOTTERY

Have you signed up to play the PHA UK Lottery yet? For as little as £1 a week you can enter the prize draw for cash prizes of between £5 and £25,000!

And every time you play you raise vital funds to support the work of PHA UK – 50p of every £1 comes directly to the charity. The remaining is used to provide the prizes and cover administration costs.

PHA UK chair Iain Armstrong said: "Our new fundraising lottery is designed to be a bit of fun for everyone who signs up to play - and a valuable new source of regular income for the charity. Every week, the PHA UK will gain extra funds via the draw and someone will win a cash prize too, so it's a win-win."

The PHA UK Lottery is organised through the Unity Lottery, a national organisation that runs charity lotteries for hundreds of charities across the UK.

To sign up and play, please go online at www.unitylottery.co.uk select PHA UK from the list of good causes and sign up using direct debit. You'll be posted a letter of confirmation with your six digit lottery number.

If you prefer to sign up by post – that's easy too. Just contact Helen at the PHA UK office on 01709 761450 and she'll post you a form to complete.

Winners will be contacted automatically when they win, so you don't have to check your numbers on a Saturday night!

PHA UK LOTTERY • PHA UK LOTTERY •

Social Media Round-up

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

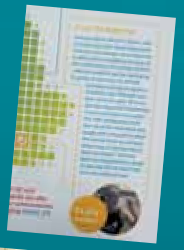
@WintonCC Winton Sports - Clegg Cup Champions 2015. In memory of Kirsty Phillips and support of @PHA_UK.

@roeanthony33 **@PHA_UK** the new emphasis magazine for the 15th anniversary is fantastic well done to the team

A big thank you to Jennifer McConnell, Gillian Mulraney, Donna Hunter and Jill Gallacher who completed the Great Womens 10k Glasgow Run and have raised £2132.33 for us. Well done ladies.

@Dr_N_Butcher As usual I'll run the GNR15 in memory of mum for @PHA_UK because those suffering from this life threatening condition need our support

@C2Perform My story in the Pulmonary Hypertension Association magazine. Thanks @PHA_UK! #fundraising #Triathlon



We're on set with this rowdy lot!! The PHA UK are making patient materials for the upcoming website redesign.

@NikkiRuss69 I'm fundraising for Pulmonary Hypertension Association UK using @ JustGiving. Check out my #JustGiving page

@dan1287 Looking forward to meeting students at Kings School, Macclesfield on Monday – on behalf of the @PHA_UK #engagement

Follow us on Twitter **@PHA_UK** *and like our page on Facebook at* **www.facebook.com/PULHAUK**

Free app to keep track of alcohol

Now that summer is upon us it's easy to be tempted by a cooling glass of white wine or an ice-cold beer.

But if you're worried about overdoing it, there's a useful new lifestyle app to help you track your alcohol consumption and keep an eye on the number of units and calories you are consuming.

The free Drinkaware app, from the UK's leading alcohol education charity, helps you to set goals to moderate your drinking and can be downloaded onto smart-phones and tablets.

It includes information about the health benefits of cutting down; support and motivation, including regular and personalised feedback; and a new 'cost-tracking' feature which enables you to see how much you have saved by cutting back.

There's also an extensive database of alcohol brands for accurate tracking, which helps you find your drinks quickly and easily.

If you're taking medication, such as Warfarin, it's always a good idea to drink in moderation. Reducing your alcohol intake also has a number of feel-good benefits. This easy-to-use app helps you understand the impact of your drinking, and supports you to change your habits for the better.

To find out more visit **www.drinkaware.co.uk/app.** to download the full app for free go to the App Store or Google Play.

Northampton Meet Up

A Northampton woman would like to meet other people with PH living in her area.

Sindy Banga was diagnosed with PH in October 2014 and is keen to meet others with the condition to share experiences and support. Sindy said: "Having PH impacts on confidence and certainly your social life. So, meeting others with the same condition may allow us to organise informal events that take into account our symptoms and the condition, for example walks that don't go too far.

"Given that PH is a relatively rare condition, it can be difficult to find others with the same condition."

If interested please contact Sindy direct via e-mail on sindy.banga@northampton.ac.uk

Exhibition tells PH stories

A recent visual arts exhibition in Sheffield offered a snapshot of what life is like for people with pulmonary hypertension.

The microstories exhibition invited audiences to reflect on the realities of living with a long term health condition.

Medical student Julia Goddard interviewed patients at the Royal Hallamshire Hospital PH Centre and created a series of real life stories – between just 200 and 300 words - which describe how people live and cope with their condition on a daily basis.

Julia said: "The exhibition provided an opportunity for people to read the microstories and respond in their own way. Everyone has a different response to living with an illness and individual ways of coping. The microstories provide an opportunity for people to relate to elements of the story but also, importantly, to share their own experiences. I hope that those who attended the exhibition enjoyed it, and found reading the stories interesting and useful."

The content of the stories varied from receiving a diagnosis and waiting to go home from hospital, to the coping strategies of humour, faith and burying your head in the sand.

Ian Sabroe, Honorary Consultant in Respiratory Medicine at the Royal Hallamshire Hospital and Professor of Inflammatory Medicine at the University of Sheffield, said:

"The event provided a wonderful opportunity to see how other people reacted to stories of illness. Many people responded and shared their own stories and reflections. We were inspired and encouraged to continue our research in this area, and have learnt valuable lessons about the value of stories in illness."

A Sheffield-based organisation called Ignite Imaginations, which creates arts activities in areas of need, worked with a group of young people to read through all the stories and create a series of artworks, including printed cushions, in response to them.

"Well, this don't seem right!"

"Well, this don't seem right!" Harry thought to himself as he walked to the station. He knew he was unfit but, all this breathlessness? It's only a 10 minute walk. Maybe he should speak to that doctor again, see what he thinks.

"Well, that's not quite normal!" Harry heard from the doctor. Funny how even someone he was seeing for his legs noticed his breathing. Harry thought to himself that he must mention it to the other doctor again. His breathing was getting a bit worse.

"Well, that's unusual!" from a different doctor this time. Apparently one side of his heart isn't doing so well, but it's strange, normally it's the other side of the heart that goes wrong. Someone's got to be different, Harry thought.

"Well, I think I'll refer you on," a doctor from a different department. He wondered to himself as he made his way home on the bus how he would get to this new hospital. It was a bit further away and he couldn't drive the distance any more. He'd talk to his sister, see if she was free.

"Well, we've got the results back." Not a disease that Harry had heard of before. But he understood what had gone wrong, understood what he needed to do. A long journey to get there though. And it isn't quite finished yet.

← One of the microstories

Get cycling this summer!

Cycling is the third most popular recreational activity in the UK with more than three million people riding a bicycle each month.

Taken steadily and on flat ground cycling can be a great way to get outdoors, reduce stress, lose weight and improve fitness. It can provide good low-impact exercise whatever your health condition.

As with any exercise, it is very important that if you have PH and want to take up cycling, that you check with you PH team first.

Then choose a good-sized, lightweight bike that suits you. See our separate feature on the new innovation of electrically-powered bikes too, if you'd like to consider that option.

Or, you can just try out cycling with a hired bike at one of the many cycle hire centres on trails across the UK.

There are many bikes available for people with challenging health conditions or disabilities. The Wheels for All initiative is a national project which provides advice, organised activities, training and specialist bikes for people of all abilities at several centres across the UK. Visit www.cycling.org.uk for more information.

Also, the National Cycling Charity aims to support more people to get cycling through a network of local development officers and Bikeability courses. For more information, please visit their website at www.ctc.org.uk

If you fancy getting in the saddle this summer, remember to keep safe and enjoy!

USEFUL CYCLING WEBSITES

www.getcycling.org.uk
Promotes cycling for leisure, transport, health, happiness and the environment; cycling events and advice on disability cycling – plus it has its own bike shop in York.

www.livingmadeeasy.org.uk
Offers practical advice on daily living equipment, including bicycles and tricycles for children and power assisted bicycles for adults.

www.cycle-route.com
Lists popular cycles routes across the UK with maps, lengths of the route and any landmarks or places of interest along the way.

www.sustrans.org.uk
Information about the National Cycle Network with suggested routes for families, foodies and culture vultures; road safety advice, bicycle maintenance and training advice.

Turn over for more useful tips and a personal cycling story

Pedal **Power**

Could a power assisted electric bicycle be for you?
Sally Brown investigates.

Getting the right amount of exercise when you have a diagnosis of PH can be a challenge. Cycling isn't right for everyone but it's a case of less pain and more pleasure since the introduction of power assisted electrical bikes.

Watching someone on a bicycle powering past you, travelling uphill, with relatively little effort can be surreal. You might find yourself thinking you need an eye-test. But no, it's not an illusion.

A power assisted bicycle really does take the puff out of pedalling and allows you to exercise without over-exerting yourself. And power-assisted, or e-bikes, are helping lots of people with a range of physical conditions get out and about.

Some e-bikes can travel at up to 15 mph and others have a more powerful motor which can take them up to speeds of 28 mph. The crucial difference between all of them and a small moped though is that they can all be pedalled without the use of the motor when wanted.

There are two main types of power assisted bikes:

An electrically assisted bike offers power on demand, even when you aren't pedalling, which is great if you're short of puff. The electric motor is activated manually using a throttle which is usually on the handgrip, similar to the ones on a motorbike or scooter. These sorts of bikes tend to be more powerful and you can either pedal them like an ordinary bike; use both the pedals and power-assist function or simply ride along using the electric motor alone.

The 'pedelec' (pedal electric cycle) is an e-bike which has a pedal-assisted electric drive system. They are very similar to normal bikes in that the electric motor is only there to provide extra power when needed, for example pedalling uphill. But you won't get any power assistance if you stop pedalling, so if you think you might struggle, get a more powerful bike with a throttle.

Power assisted electric bikes start at around £299 but you can pay as much as £6,000 so it's obviously an investment which requires some thought.

Electric bikes can be ridden along public roads as well as cycle trails and anywhere else that pedal bikes are allowed. In Great Britain, if you're 14 or over you don't need a licence to ride electric bikes that meet certain criteria, and they don't need to be registered, taxed or insured. But do check out the exact requirements at:
www.gov.uk/electric-bike-rules

Of course, if you don't fancy going electric but would still like a little help to get cycling, don't forget trikes can be a great help. They offer more stability so, with no wobbling to worry about, you can ride in a low gear without the danger of falling off. It is also possible to purchase specially adapted trikes with a lower, lightweight frame, making it easier to climb on board and pedal. There are even folding trikes which make storage less of a challenge and some brands do come with electric assist if that's what you prefer.

If you have PH and you want to take up cycling, or are thinking of purchasing a bike for someone who suffers from the condition, you must check first with your PH team. ●

Riding *high...*

One PH sufferer who has really benefitted from using a power-assisted bike is Sarah Colledge.

Sarah, who was diagnosed with PH on her 25th birthday, bought an electric bike four years ago. Her husband, Grahaeme, is a keen cyclist and they used to ride a lot together before Sarah developed PH.

Grahaeme suggested buying an electric bike after he'd researched them online.

But one of the issues with PH is the tendency to lose confidence in your own abilities and Sarah took a lot of persuading to have a go.

"I was really unsure at first as I had not ridden a bike in years, but the test run was a huge success. It was exhilarating and I couldn't stop smiling the whole time."

Sarah eventually purchased a Wisper 705 se, Battery 14ah 36v bicycle in 2011 and hasn't looked back since.

"Getting the bike was a life changing moment for me," said Sarah. "I can't walk too far and the slightest incline feels like I'm climbing Everest. I now do all my short journeys to town and doctor's appointments by bike, weather permitting. Having PH restricts what you can do so my bike symbolises 'freedom' and 'normality' for me."

Sarah's bike has a maximum speed of 15 mph and a range of up to 50 miles depending on level of battery use. She and Grahaeme use their bikes to cycle to local village pubs and out to Burghley House, Stamford, where they live, for picnics. They also cycle around Rutland Water and into town for coffee.

And the bike has done some travelling of its own, going with them down to Cornwall, The New Forest and further afield to Brittany in France.

"It's taken me up hills I could never dream of walking up, and without it I would have missed seeing the most amazing countryside, lakes and rivers," said Sarah. "It's truly magical and a lifeline to a world I wouldn't otherwise see. I'm eternally grateful to Grahaeme for pushing me to give it a try."

Sarah's e-cycling tips:

- Aim to get the best bike you can afford with a long range lithium battery.
- Do your research and think about what you want to do on your bike – is it for practical purposes like getting to the shops or for more long distance travel.
- Wear lots of layers! You can feel the cold with PH because you're not exerting much energy if you have the battery on full power
- Try to get a bike that has throttle assist. This allows you to do an uphill start purely using the battery with no peddling. (Sarah found this invaluable in Cornwall.)
- Do short journeys first to get yourself used to the bike and build your confidence if you haven't ridden for a while.
- Be prepared to expect some comments such as 'that's cheating'. Although, when they see you whizzing up a hill, most people say they want one.
- Be prepared to feel tired afterwards and you may feel slightly breathless whilst cycling uphill as you're still putting a little effort in.
- Consider buying a step through bike. It's much easier to get on and off.

Most of all enjoy the freedom and sense of achievement you have after a few miles of cycling. ●

Checking what financial support is available **in difficult times**

PHA UK has set up a new partnership with *Turn2us,* a national charity that helps people in financial hardship in the UK.

Turn2us provides a number of free services which help people to gain access to welfare benefits, charitable grants and other financial help, and these will soon be available via PHA UK's website.

Here Turn2us tells us more about how these services can help anyone with pulmonary hypertension (PH) and those who care for them, who may be struggling financially or are unsure of what support could be available.

Check your welfare entitlements

People can experience financial hardship at any time for many different reasons, and it is often an unexpected event that can have the greatest impact. We know that having a serious illness like PH, or caring for someone with PH, can cause financial difficulties and place a huge strain on household income.

Welfare support exists to help those affected by these issues, but awareness tends to be low and the perceived complexities of the system often deter people from accessing this vital help.

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

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

Penny is just one of many people that we have helped to access welfare support. When Penny's husband started experiencing mental health problems, he had to take leave from work. Then making things even harder, Penny's own long term health condition became worse and she too was forced to stop work.

Initially the couple's situation was manageable as Penny was receiving full sick pay in the first instance. However, over time this amount was reduced by half. With this being the only income coming into the household, the family started to struggle. Barely able to cover their absolute essentials including food, Penny didn't know what to do, and the stress started to mount.

After finding out about Turn2us from a friend, Penny used the Benefits Calculator and was pleasantly surprised to find out she was eligible for Working Tax Credit and Employment and Support Allowance. In total Penny receives £600 per month through these benefits – income she says took a lot of stress off the family at a very difficult time.

See if you're eligible for a charitable grant

There is generally low awareness of charitable grants, and research by Turn2us found that nine out of ten people on low incomes had no idea that this help exists.

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

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

> ***Turn2us has a free and easy-to-use online Benefits Calculator to check what welfare benefits, tax credits and other support you could be entitled to.***

One of the people who received help through grants is Matthew, a father of three and carer to his wife who has mental and physical disabilities. After he was unexpectedly made redundant, it took Matthew a while to find a new job. He managed to find part-time work, but on a very low income, the family started to get in to arrears with their mortgage, electricity and heating bills.

As their debts mounted, Matthew and his family knew they needed to get some help. After hearing about Turn2us, they tried the Grants Search and were successful in applying for an annual grant of £800 from a charity linked to Matthew's wife's former profession.

Matthew says: "I feel more positive as this money has made a big difference in paying off our debts. It's also allowed us to make little changes that make a huge difference such as brightening up our kitchen with a lick of paint which has cheered my wife up a great deal."

Other help available

Through its website, Turn2us also provides a range of information and resources on welfare benefits, charitable grants and other support services. This includes the latest information on planned changes to benefits and tax credits.

For those without internet access, Turn2us provides a free, confidential helpline on 0808 802 2000, open Monday to Friday 9am to 8pm. The charity's experienced advisers can carry out a benefits check and grants search to see what help you may be able to apply for.

Turn2us also works with a range of national and local organisations to reach more people in financial hardship. The charity trains and supports frontline workers including advisers, caseworkers and volunteers so that their service users can access the Turn2us website and find the help they're looking for.

In the last year alone, nearly four million people used Turn2us' services to find financial support. With survey data suggesting that estimated income identified through benefits and grants during this time totals over £101 million, the charity is showing more and more people that support is available through difficult times.

The free Turn2us Benefits Calculator and Grants Search will be available to use on the PHA UK website soon. For more information, please visit www.turn2us.org.uk ●

So, how are you feeling?

First large-scale longitudinal research study into living with pulmonary hypertension completed, Steph Pollard reports

THE FIRST in-depth research study into the long term impact of living with pulmonary hypertension has now been completed.

PHA UK and the University of Manchester have worked together on the 'IMPHACT Study' to monitor people's experiences of living with the condition over an 18 month period.

The study has focused on the emotional impact of the condition on both patients and their families and 185 volunteers diagnosed with PH and 41 of their primary carers have completed regular questionnaires. 25 of the patients also took part in interviews over a 12 month period.

Launched in May 2013, the research project finished at the end of June this year and its findings are due to be published this autumn.

Professor Janelle Yorke at the University of Manchester has led and overseen the project as its principal investigator.

Janelle said: "We are delighted to have completed this in-depth 18 month study which represents the first major piece of robust, independently verified research into the impact of PH ever undertaken in the UK, if not the world.

"We have asked people what it actually feels like to live with PH and be treated for the condition in order to pull together evidence which describes and demonstrates the true impact of PH on people's lives.

"The results will now be prepared into a report and shared widely via medical journals and healthcare conferences around the world.

"Every participant will also receive a copy. We'd really like to thank them too for taking part in this important study and sharing their everyday insights into living with PH."

Working closely with Professor Yorke, the research project was managed by nurse specialist Paul Sephton, seconded from Sheffield PH centre. He organised for the regular questionnaires to be posted to participants' homes and carried out face-to-face and telephone interviews to gather more personal contributions and comments.

Paul said: "In the past, PH was a condition which was treated with acute or palliative care, but over the past 15 years much better early diagnosis of PH and huge advances in medical treatment, has led to PH becoming a chronic – often life-limiting condition – for many people. Our research has investigated this relatively new experience of living with PH long-term and the challenges that it presents."

> *"The IMPHACT Study is PHA UK's most significant piece of research so far."*

Paul says the research study asked questions about all aspects of living with PH including quality of life issues, coping with invasive and complex treatments and adherence to prescribed medications. The research touched on coping with uncertainty, fatigue and psychological issues too.

A full report will be published soon, but initial findings reveal a real insight into living with the condition.

Professor Janelle Yorke said: "Our initial findings show that many people live with daily experiences of being breathless and a having general lack of energy. Many people have developed a range of coping strategies to help minimise the impact that PH symptoms have on their lives but there is scope for health care professionals to work more closely with patients to develop self-management techniques.

"We have also learned a lot about how a diagnosis of PH and living with the condition can have a profound impact, not only on the patient, but also their family and wider social network.

"It is important that we learn from the stories told in this research and further develop support mechanisms for PH patients and their families."

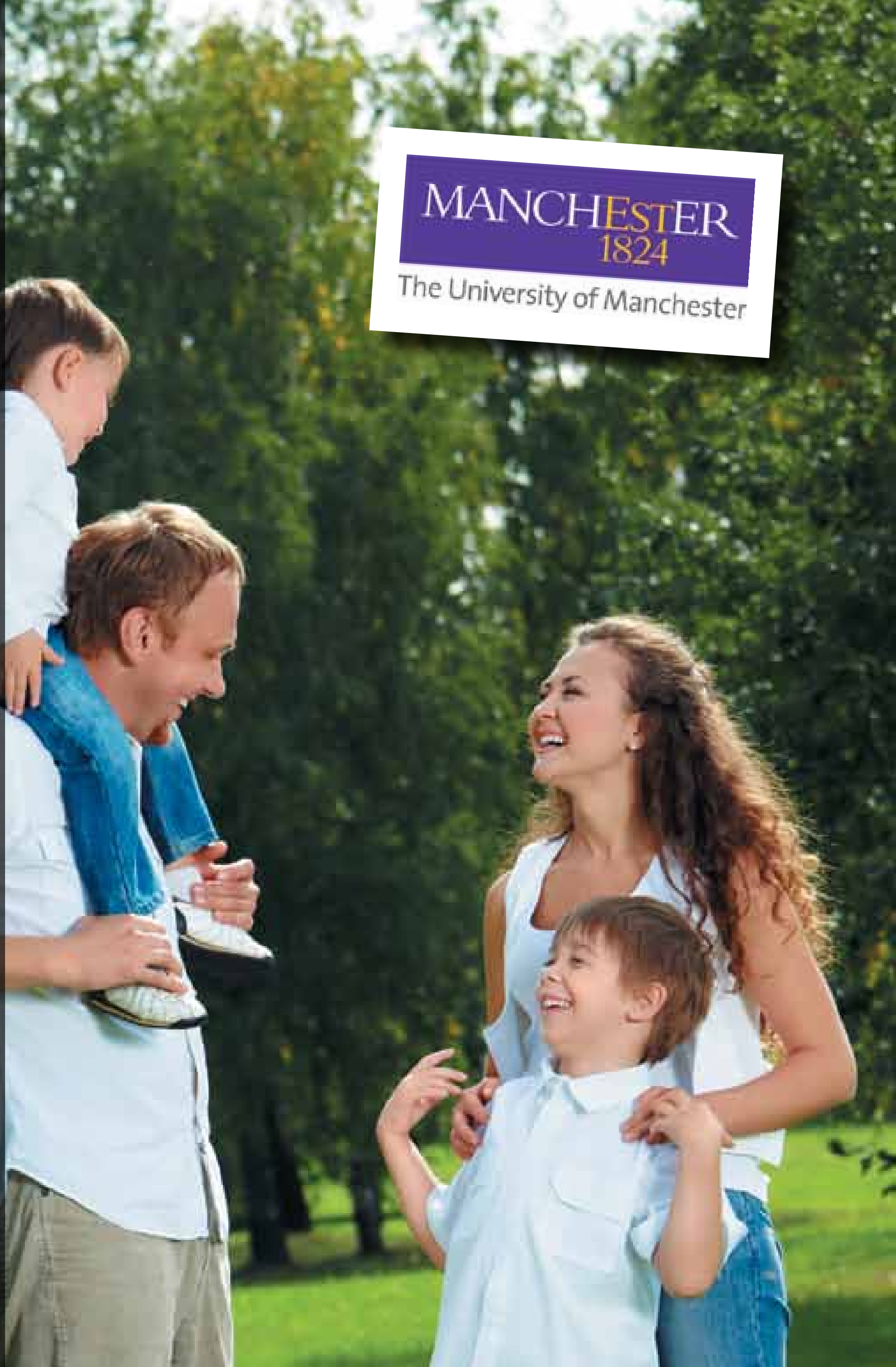
The IMPHACT research project was meticulously designed to comply with strict requirements for independent statistical analysis and was approved by the National Institute of Health Research. The significance, value and potential usefulness of its findings is very broad. For example, the research will provide strong evidence comparable with other long-term conditions. The evidence gathered may also prove useful to strengthen the political case for continued funding of PH drugs and treatments in future. Plus, the report may provide vital evidence to support individuals' applying for things such as personal independence payments and blue badges.

And, the study's findings will help the PHA UK review the services it provides to ensure they continue to meet the needs of its members.

Chairman of PHA UK Iain Armstrong said: "The IMPHACT Study is PHA UK's most significant piece of research so far and should help healthcare managers, politicians, the medical profession and the charity gain a better understanding of the impact of the condition on patients and their families. I am sure it will really help inform any future funding and development decisions about the way PH is managed and how individuals and their families are supported.

"PHA UK has been very proud to work closely with the University of Manchester, PH specialist centres and the volunteers themselves to deliver this vital research."

The £100,000 research project has been funded through the PHA UK, with some grant funding from Bayer. ●



MANCHESTER
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> *"We have asked people what it actually feels like to live with PH."*
>
> Professor Janelle Yorke

BUILDING CONFIDENCE BEATING BOUNDARIES

Toby Pettifor of east Sussex gave his dad and brother a shock when he collapsed in hospital, but despite a history of PH in the family, he has not been abashed and remains extremely positive. Here he tells his story...

"My name is Toby Pettifor, I am 24 years old. I am currently working in retail management. I have always loved my sport and music from a very young age. And in the later part of my life I have added socialising to that list.

I was diagnosed with pulmonary hypertension three years ago now and my deterioration was dramatic. I went from being able to push myself in the gym - 30 minutes on a cross trainer in the summer - to not being able to walk up small hills in the winter.

I had quit the gym late that summer, and being a typical stubborn man I refused to think that there was anything wrong with me, I just put it down to the fact that "my fitness has gotten bad after quitting the gym" but things only got worse.

It took my father, Roly, forcing me to go to the GP at Quayside Surgery in Newhaven, which kick started my diagnosis. They did an ECG, took one look at it and said that I needed to go to A&E at Royal Sussex County Hospital who admitted me to the hospital's cardiac wing. One week later, they referred me to the Royal Brompton Hospital. At every stage they were all fantastic it has to be said.

So began my time with the guys at the Brompton. They did some more tests and gave me my diagnosis of primary pulmonary hypertension. Which, in a weird way, was a relief because subconsciously I did know something was massively wrong, I was just too stubborn to admit it. You know what us men are like.

But on the other hand it was incredibly daunting, and not just because of what the road ahead would entail, but because my mother also suffered from this condition, and she passed away in 1995 waiting for her heart and lung transplant when I was four years old. But that was because not much was known about the condition and how to treat it back then.

Luckily for me medicine has come a very long way. After my diagnosis and whilst they were deciding which route of treatment they wanted to go down I accidentally forced their hand.

One day on the ward I walked a matter of 20 yards and collapsed, and awoke on the floor to a team of nurses and doctors all looking at me with concerned faces. I always laugh that my brother, John, and father were also there that day and at this moment could only see a load of people crowding around me on the floor making all sorts of fuss. By this point I was fully conscious and joking with the nurses but they couldn't see that, only my legs, so they must have been assuming the worst. Poor them.

After the hysteria had died down and I was happily lying back in bed laughing with my father and brother about the whole thing, the doctors and specialist nurses came to visit. They explained that it was either the condition or low blood pressure, due to it being a very warm day and because I had been lying down all day. But we all decided that it wasn't worth the risk, so we decided to go right ahead with getting me onto the IV pump for treatment.

So I was started on Epoprostenol. I had a torrid time of it when I was going up in doses. The side effects were not pretty but with the reassurance that the higher I go the better in the long run, we ploughed on. I went up to 20.

My amazing specialist nurses taught me everything about how to care for the line, and how to make up my drugs and quite frankly had the patience of saints. I was due to be discharged soon, but that was unnerving because I had the realisation that all this work the nurses were doing to take care of me, soon I would have to do myself. And so followed a torrent of questions: "How am I going to do this/that" etc. Then the day came for my release six weeks from the day I walked into my local GP's practice, which is remarkable testament to all three, my GP's practice and both hospitals.

But then came the scary part, which was to look after my IV pump and medication myself, but within a few months it became like anything else in a routine. It was second nature and most of that "torrent of questions" you just answer yourself as you get back to normality.

But the really testing part is finding your boundaries. Because I was quite severe, I mean not being able to walk 20 yards, we were contemplating everything: "Was I going to be able to walk up the three stories of stairs in the house?", "Was I going to be able to go back to work?" So I just took it in baby steps and took it all one day at a time, and slowly built myself back up.

Then it was time to go back to work. The company I work for was really supportive and we built up from a few three-hour shifts per week, gradually back up to full-time. Since then I have settled back into my old life, and haven't really found any boundaries. I played competitive football, although didn't push myself too hard. I have flown to Canada and went on a stag do to Lanzarote. I have got a promotion at work, and I'm looking for my next one, hopefully sometime this year.

Just recently my line got infected, and back at the Brompton they took it out and, before they put in my new line, they talked about the possibility of me going on to oral medication and coming off the pump, which again got me thinking about my life and my capabilities. In the end, I decided that the pump has enabled me to get back to my normal life, and has done me the world of good, given me confidence beyond belief.

Looking back, if I hadn't have had that fall in hospital, we probably would have gone down the oral route first, so, in a weird way, I am thankful for that fall because it forced our hand to go on to the pump. And I am thankful for that, because although at the beginning it was a lot to get my head around, the confidence and quality of life it has given me is incredible, not to mention the wonders it has done for my heart. And I can truly say that I own my condition, not the other way around.

Thank you to all the team at the Brompton, especially Carl Harries and Lisa Parfitt, also my family, especially my father Roly, who have all just been amazing in making it so easy to adapt and for their continued support. And also you beautiful lot for reading my story ● "

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

The benefits of exercise

Research has shown that people with pulmonary hypertension can benefit from exercise. For example, one study looked at patients doing an exercise programme with physiotherapists and found that it increased how far they could walk and how much they were able to do for themselves. Here, physiotherapist Carol Keen talks to Deborah Wain about the benefits of getting active.

Carol Keen is lead therapist in specialised medicine at the Royal Hallamshire, part of Sheffield Teaching Hospitals NHS Foundation Trust. Her role involves delivering physiotherapy to in-patients with PH. She also leads a team of physiotherapists and occupational therapists working in the hospital.

Carol first began working with people with PH in a critical care setting when they were among patients with a range of conditions who were very unwell. However, for the last two years, she has been directly involved with PH patients through the Sheffield PH Centre. This has meant getting to know patients better and seeing them improve and leave hospital.

Carol says that most patients can benefit from physiotherapy regardless of the severity of their condition because what's offered is "very variable and adaptable" and tailored to the individual needs of patients.

She says: "It might be some breathing exercises and relaxation to help when they are short of breath, or we may get people up and walking. We can get patients doing exercises on the bed, in their chair or by the bedside. For our more able patients we can give them weights to exercise with or maybe get them working on an exercise bike."

Patients are assessed by discussing what they can normally do, what they can't do, as well as what it is that's limiting them. The physiotherapists explore what patients want to achieve and set goals. Treatment plans are then established to help patients towards these targets.

"We try to focus a lot on function – trying to get people to achieve goals that will make a real difference in their daily lives – to walk without help, to be able to go round the shops, to get upstairs, or to walk the dog," comments Carol.

Physiotherapists work closely with doctors and nurses to identify who might benefit from their help. A patient might be seen just once, or the physiotherapists might work with some patients for several weeks if they are on the ward for a long period of time.

Carol explains: "There are lots of ways in which we can help. For some patients who are very unwell with their breathing or with a chest infection, we can help them to manage this and feel better. We may be able to help them to relax and control their breathing so that they don't feel so anxious about it.

"For patients who have become very weak or out of condition, perhaps because they have been unwell or very short of breath for a long time, we can help them to get stronger and get moving again.

"If patients are with us for a long time, we can work with them to maintain or improve their strength or activity while they're here, so that they're better prepared when they go home.

"Finally, as patients are preparing to go home, we work with them and their families to make sure they have everything in place, and can manage everything they will need at home, such as equipment or care to help with everyday tasks. We might refer them on to services closer to home to offer ongoing support. To plan for this, we work closely with the occupational therapists, nurses and other members of the team."

For some PH patients, there can be psychological barriers to overcome in becoming more active.

Carol explains: "It can be hard for patients who are often short of breath to appreciate that they can get fitter, and that sometimes it's okay to get a bit out of breath as this means that they're 'training' and that it will lead to improvement.

"Also, lots of patients will have lost confidence in what they can do as they've steadily declined over a prolonged period of time. It can help to start with small steps and build up activity slowly.

"Equally, when patients do start to make gains that they perhaps didn't expect, it can have a very positive impact on their outlook and confidence."

Currently, Carol and her colleagues only see in-patients, although she says they would like to see a change enabling them to also see out-patients in the future.

Of the rewards of her job, Carol says: "I come across some very determined patients, and it's really valuable to work with them and see change. Also, I think that there is a lot of potential to develop physiotherapy in this area and I'm really enthusiastic to look at what more we can do to support patients and families."

To this end, Carol is about to start a research programme, funded by the Chartered Society of Physiotherapy, looking at what physiotherapy is currently provided for PH patients across the UK.

The aim of the study, to run over 18 months, will be to identify what works well for which groups of patients, what gaps there might be in services and what barriers professionals might need to overcome to provide better physiotherapy to patients.

It will have three elements - interviews with physiotherapists at specialist centres, a questionnaire to physiotherapists working outside the specialist centres and a patient focus group. Findings will be shared through the PHA UK.

Carol would like to find a patient willing to be part of the study's advisory group and invites other patients who would like to be involved to please contact her via Shaun Clayton at the PHA UK office on 01709 761450. ●

How can exercise help you?

Carol shares her advice on how to feel the benefits of being more active.

> What to do?

"The most important thing is to find something that you enjoy. Find something that fits in easily with your routines. What suits one person may not be right for someone else. Any form of activity has the potential to be helpful, as long as you're sensible about how much you do.

"Walking can be a really good way to become more active. You don't need any equipment and can do it anywhere. Depending on what you can manage, it might be a walk down the garden, along the street, in the park or further afield. Activities like yoga, Pilates or tai chi are good because they look at breathing as well as movement, which can be beneficial for people with PH. There was an article in the last edition of Emphasis about tai chi, and this edition is looking at cycling – see how other people have found it.

> How to start?

"Start small. If you don't really do anything at the moment, then start with just five minutes each day – walk to the bottom of the drive, or to the first lamppost on your street. Then see if you can get a bit further the next day. A park with lots of benches can be a good start – try walking from bench to bench and you can sit down to rest.

"If you already do something, could you do a little bit more? If you go swimming once a week, could you manage twice, or could you go a bit further, or a bit faster?

"Do you get the bus to the shops? Could you get off a stop earlier and walk the last bit? Could you park a bit further away from work and add an extra walk, or go for a walk in your lunch time?

"If you're uncertain about how much activity you should do, speak to your physiotherapist, consultant, nurse specialist or GP before you start."

> How to keep going?

"It can help if you can find someone to join you – going for a walk with family or friends, or joining a group activity. Have a look and see what is happening near you – here are some useful websites:
www.walkingforhealth.org.uk/
www.bhf.org.uk/heart-matters-magazine/activity

"Also, keep track of how well you're doing. It might help you to write it down, or if you're into technology then there are some great options to measure your progress.

"There are apps that let you see how far you have gone if you go for a walk or you can get a wrist band that tells you how many steps you have taken each day.

"Remember that you'll have good days and bad days. Don't be put off if you have some time where you don't do so well. Try and do what you can, and be sure to get back into it when you're feeling better. "

Think ahead *to beat the flu*

Senior pharmacist Neil Hamilton urges PH patients to look ahead to autumn and protect themselves against seasonal viruses.

Whilst most of us are only just going back to school or work after the summer holidays, September coming around means autumn and winter are not far off.

Beautiful countryside walks and colourful leaf drops are something to look forward to, but with them often comes a turn in the weather. For many people the colder weather brings concern over colds, flu and other illness.

As a result, this is the perfect time of year to plan ahead and think about how you can help defend yourself against the prospect of suffering a bout of the flu. You can do this quickly and easily by having the flu-jab vaccine.

I can tell you from personal experience that since I had full-blown flu once, booking in for an annual flu-jab has been a priority just as soon as my GP surgery has that year's batch in.

Flu is an extremely debilitating and unpleasant viral illness for the fittest in society and unfortunately those people with other conditions will fair even worse. Having pulmonary hypertension (PH) may not put you at greater risk of catching flu, but will have a far greater impact on you. Indeed your body may really struggle to fight it off and this will almost inevitably have an impact on your breathing.

There are very few reasons why you wouldn't be able to have it on medical grounds. The main exception is those of you taking medication that dampens the immune system (immunosuppressants such as mycophenolate or azathioprine).

The flu-jab is a very tiny dose of the flu virus so if your immune defences are down, the effect of the little dose is magnified. The other thing to note is that the vaccine itself contains egg proteins, so if you are allergic to eggs, just ask the clinic for the egg-free version. Other than these it should be pretty safe for everyone.

Not many people have reactions or side effects, but obviously as this is a tiny dose of the virus, some people feel a bit "fluey" for a day or two. This can often be easily controlled with a few doses of paracetamol if necessary.

Although flu jabs are the most common vaccine that most people have these days, it is possible to protect yourself against other nasty illnesses including pneumonia and shingles amongst others.

Pneumonia vaccine gives protection against serious chest infections, and may be recommended for "high-risk" groups, but not everyone would need one. These high-risk groups would include people aged over 65; those with kidney and liver problems, congenital heart disease, diabetes and those taking immunosupressants. If in any doubt, just ask your GP, nurse or pharmacist.

The shingles vaccine protects older people from developing this reactivation of the chicken-pox virus. You must be over 70 to be entitled to a shingles vaccine and it is a one-off jab with no repeat doses necessary. Shingles can be very painful and take some time to heal, so you may decide that a vaccine to help prevent an attack would be beneficial.

As with any treatment, these vaccines will not suit everyone and there may be unwanted side effects. However it would be very sensible for PH patients to discuss their options with their GP, nurse, pharmacist or specialist centre about any of these vaccinations that you think may be of benefit to you.

If you have access to the internet, there is lots of helpful information on these vaccines on the NHS website at **www.nhs.uk/Conditions/vaccinations/Pages/vaccination-schedule-age-checklist.aspx**

If you can't get onto the website, just ask a healthcare professional who will be more than happy to advise you.

I would suggest that fore-warned is fore-armed and with a bit of planning you may be able to save yourself the risk of nasty viruses this autumn and winter. Hopefully once you are prepared, you'll be able to look forward to leaf-kicking and snowball fighting! ●

Hold the Front Page for PH

When Anna Bowen was diagnosed with PH a year ago, like so many other people she had never heard of it. Now, thanks to her, a lot more people living in her community and beyond are that little bit more aware of the condition.

Anna, of Llandysul in Wales, contacted her local newspaper the Carmarthen Journal to tell them about the dramatic impact of her illness - and her family's efforts to raise money for PHA UK and campaign for more awareness.

Anna, aged 38, said: "I just decided to phone the paper and the reporters were really interested in our story. We ended up with a front page headline piece and more inside too, including a guide to joining the organ donation register. They looked at the PHA UK website for research and did fantastic job.

"The story was also top of the newspaper's website for two days so went national too. I also shared links to the coverage on Twitter and Facebook which got me in touch with friends of friends, answering questions and letting them know about the condition.

"I definitely felt famous for the day – and all for a good cause. I really wanted to get across the message that although we fight for every breath we are fighters. As a family we think positively and do everything we can to raise awareness and funds."

Anna, a former childminder, is married to Delme with children Mark, aged 14, Lucy, aged four, and Harry, aged 23 months. She was diagnosed with PH at Hammersmith in September 2014 after suddenly finding she couldn't run or tackle stairs without feeling out of breath. At the time she was training for a 10k race. Now the whole family is involved in races and hill climbs to raise money for PH.

ANNA'S HOODIES FOR SALE

As part of Anna's awareness raising campaign she has produced hoodies and polo shirts emblazoned with messages like 'I'm a PH Fighter' or 'My Mum is a PH Fighter' and 'My Friend is a PH Fighter' and even 'I'm a PH nurse'. If you'd like to buy a hoodie for £25 (with zip) and £22 (over head) or a polo shirt for £18, please contact Anna on **acbow13@hotmail.com** Every hoodie makes a £1 donation to PHA UK.

Thank you to everyone who raises awareness of PH through their local media.

Please do share your stories with us on Facebook and Twitter.

Run for your money

Would you like to pull on your running shoes and raise money to help fund more research and support for people with PH?

You can contact any marathon, fun run or cross country event direct to enquire about registering to run. Or, the PHA UK has a few free reserved places available.

*PHA UK places are up for grabs in the **Adidas Silverstone Half Marathon** which takes place at the historic motor racing circuit on March 13th 2016.*

*The popular London fundraiser – the **London BUPA 10,000k** race – has allocated our charity over 20 places for its May 30th 2016 race.*

*And finally, the **Tough Mudder** 10mile obstacle course is an option for the fearless and fun-loving. These events, held all around the country, are popular with groups of fundraising friends. PHA UK has 25 places available for 2016.*

All the PHA UK-dedicated places for the London Marathon 2016 have already been snapped up – the charity had seven but these tend to go very quickly!

Most people like to use the free 'Just Giving' website to help them attract quick and easy sponsors and donations. Visit www.justgiving.com to find out more.
PHA UK running vests, wrist bands and sponsorships forms are also available, while stocks last. Please, contact the office on 01709 761450 or office@phassociation.uk.com for more information about raising money by running for PH.

Dad joins kids *on school run*

Father-of-two *Tim Church* put in plenty of preparation when he decided to join his kids on a school run to raise money for PH, Sally Brown reports.

When Tim Church heard that his children were taking part in the oldest cross country race in the world, to raise money for PHA UK, he rashly decided to join them.

How difficult could it be to run ten miles, even if you are in your mid-forties and more used to playing real tennis than slogging through muddy fields?

The 2015 Crick Run took place on a beautiful spring day in March. This historic event begins in the village of Crick and ends in the grounds of Rugby School which both Tim's children attend. His son William, 18, and daughter Harriet, 14, had signed up, with Harriet taking part in The Barby Run, a 6.5 mile junior version of the race.

"It's been going for 177 years so it's rooted in tradition," said Tim. "I didn't want to let the children down, especially when they decided to use the run to raise money for PHA."

Tim's wife Louise had been diagnosed with pulmonary hypertension in 2002 and received a double lung and heart transplant in 2005. She sadly passed away in June 2006 at the age of 38.

"I'm sure Louise would have thought I was bonkers running 10 miles," said Tim. "I always hated cross country at school so it felt like a massive challenge. I'm not a natural runner so I started huffing and puffing around the country lanes of Suffolk to get fit."

Tim spent hours looking online at running shoes, warm up exercises and advice on carbohydrate loading as the day of the race grew nearer.

His training regime was inspired by NHS podcast 'Couch to 5k in nine weeks' which he listened to three times a week. Towards the end of his training he was tripling the distance he could run and had got up to 15 kilometres, just short of his 16k target.

"The woman who gives you instructions on the podcast is called Laura, so she sort of became my personal trainer," said Tim.

On the day of the race Tim ran alongside son William, who is a First XV rugby player.

"He barely broke into a sweat whilst I found the experience absolutely brutal," said Tim.

"It's one thing running on the flat but totally different when you're running uphill, across muddy fields and having to keep stopping to clamber over stiles and gates."

Tim was determined to finish the race because he knew that so many people were supporting his family and donating money to PHA.

His daughter Harriet was waiting at the final bend before the long finishing straight so she could finish the race with Tim and William. They received a huge cheer from all the pupils, family, friends and staff from the school.

"It was very emotional and I was really worried about breaking down at the end of the race," said Tim. "But I was so totally drained that if there were tears, they were tears of pain!"

It took Tim and William just over two hours to finish the race and he and his family have raised over £10,000 through the Justgiving website. He was particularly proud of Harriet who raised over £2,700 running in The Barby, having set herself a target of £500.

"Harriet is very open about what happened to her mother and she also raised £1,000 for PHA by putting on a fashion show at her previous school," said Tim. "William tends to keep things to himself a bit more, but doing the run together made the three of us stronger and more able to deal with the emotional side of things. It also allowed us the freedom to remember Louise very openly, nine years after she died."

Tim and his children are supported by his new wife, Alexandra, and they have become a close family unit again.

But what of the future running plans? Tim's not planning any half marathons just yet.

"I'm just so very grateful for all the support people have given us as a family since we lost Louise – and doing the run together in her memory was truly inspirational." ●

The free NHS 'Couch to 5k' podcast is a complete running plan for beginners. It's perfect if you're new to running because the plan is all about starting slowly and building up gradually.

What you get with Couch to 5k

- *Coach Laura will be there to help you every step of the way.*
- *Countdown timer that tells you how long you have left on a run.*
- *Option to use your own playlists.*
- *A progress wall so that you can record how well you are doing.*
- *Tell your friends how you're getting on through Facebook, Twitter and by email.*
- *Rate your run – keep a Couch to 5k diary.*
- *Valuable tips and advice for new runners.*
- *Real stories from other runners.*

Go to www.nhs.uk/Livewell/c25k to find out more.

Run for your wife

When Sarah Marshall collapsed with PH, husband Phil was soon pulling on his running shoes to raise awareness and cash for the cause, Dan Church reports.

Phil Marshall was preparing for another ordinary day at work at his home in Charlton, near Banbury when his partner's life quite literally came crashing down.

"Sarah walked from the bedroom to the bathroom and just collapsed on the floor," said Phil, an agricultural bank manager.

"She was so weak and breathless she couldn't walk, couldn't speak properly and her legs were blue. I thought there was every chance that she was going to die."

Life changed overnight. After six months of illness and many tests, Sarah was eventually diagnosed with idiopathic pulmonary hypertension, in October 2013.

Very quickly after diagnosis, the couple decided they wanted to do something positive in response to this terrible experience.

Phil said: "I was actually sitting in the ambulance with Sarah, on a mad dash down the M40 to the Royal Brompton Hospital in London, when I came up with the idea of doing a series of runs to do something to help people like her."

Phil and Sarah launched their 'I Give You My Heart' campaign in 2014 which aims to promote the importance of organ donation and encourage everyone to sign up to the organ donor register – transplants often being an option for the most severe sufferers of pulmonary hypertension. Instead of asking for sponsorship money, the campaign asked people to sign up to join the organ donor register.

Phil began training for four profile-raising events in support of the campaign, starting with the Silverstone Half Marathon in March 2014 and then the Milton Keynes Marathon - though this one ended in drama. He crossed the finishing line in Milton Keynes just as he was told that Sarah was on her way to hospital again.

Sarah, a former primary school teacher, said: "I ended up in A&E because I got very out of breath, couldn't walk and became very weak. General illnesses like a sniffle or a cold can just wipe me out and I become completely exhausted and I can't move and can hardly breathe for a few weeks."

Phil then entered the 85-mile Parish Walk on the Isle of Man in June 2014 following in his father's footsteps.

Phil said: "My Dad has always been involved with the Parish Walk and has completed it six times. It's a pretty big event. There are a lot of hills on the Isle of Man, so it's very tough. You're going all day and night and it took around 16 hours – nonstop! But I was very pleased to finish in fifth.

One of Phil's greatest achievements was taking part in the Grim Reaper 100-Mile Challenge last summer.

> ***"At the hardest point in our lives, the PHA were a lifeline for us. We wanted to raise some funds for them."***

"I wanted to set myself a test that would really push me as far as I could go and one hundred miles felt like a nice round number. I'd never run that far, so at the start I was worried about whether I'd be able to finish it. However at the 30, 40 and 50-mile marks the race computer showed that I was climbing up the places. Then I got to tenth place, then fifth and then third.

"I think it was around the 60-mile point that I actually took the lead. At this point, it's dark and you're not really sure how far behind anybody is. I thought I was going to collapse at one point, but I eventually got to the end and won."

Phil, who only took up running in December 2012, has certainly had some extraordinary long-distance running achievements and has attracted attention to his cause. Phil and Sarah's 'I Give You My Heart' campaign to promote organ donation in the UK receives lots of hits each week on Facebook and their website, and has signed up over 300 people on the organ donor list.

This year, Phil turned his attention to a big fund-raising run for PHA UK - the Thames Path 100-miler from Richmond in South West London to the centre of Oxford, which took place on May Day. This time Phil decided to ask people to sponsor him.

"At the hardest point in our lives, the PHA were a lifeline for us. We wanted to raise some funds for them, so they could continue their vital work supporting people with PH".

Phil managed to raise £4,650 for the charity through this sponsored run.

Phil, aged 31, still has further fund-raising plans for the future. He said: "I would still like to do the biggest and toughest event in Britain – the Spine Race. It's 268 miles along the Pennine Way which means crossing the highest peaks in northern England and into Scotland in the middle of winter."

Phil's passion to take on more running challenges goes hand in hand with his desire to do something positive for people with PH and generate lifelong memories for himself and Sarah.

"The fantastic thing is that Sarah seems to be improving all the time. She's 18 months into her treatment and from literally not being able to even lift her arm, she can now walk 300m on her own."

Sarah added, "It's so scary to be suddenly out of control of your own body. I would hate to be that poorly again. So, even though my life has changed completely, I'm very thankful that I'm alive and that I've improved so much. It's great to see Phil achieving so much through his running, turning this really difficult period in to something more positive. There are still a lot of things we want to do together. We intend to appreciate the life that we've got and live it to the full." ●

Aimee keeps *on running*

Athletic *Aimee Horn* raised an amazing £5,907 for PHA UK at this year's London marathon.

This was the second time Aimee had run the London Marathon – the first time was with her husband Steve, but that was before he was diagnosed with chronic thromboembolic PH (CTEPH).

Aimee said: "We used to run together and Steve did both the London and Paris marathons, but then he found he could manage less and less when he was training, and he knew something was wrong."

Steve was diagnosed with CTEPH in 2008 just one week before the birth of their daughter Maisie, now aged 7. He had an operation to remove blood clots on his lungs six years ago and is waiting for a second operation to tackle new clots now.

The couple, of Ruislip, West London, also have a son William, aged four.

Aimee said: "He was so fit and it was a real shock. The kids have never known him as that fit man that could run around.

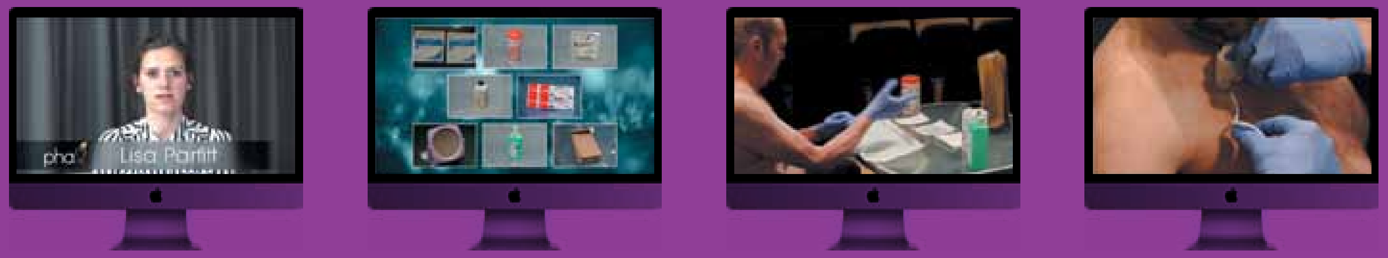
"I've carried on running partly because it helps me stay sane with all we have to cope with as a family. And I've run two marathons to raise money for PHA UK because it is very important to us to support further research into treatments for the disease."

Aimee, aged 38, managed to complete the London Marathon in three hours and 31 minutes this time, which was all the more impressive, given she had hurt her back just before the event and ran strapped up and on painkillers.

Her time was classed officially as 'good for her age' and earned her automatic places for the next two years if she wants them.

Aimee said: "That was good because it has freed up a valuable PHA UK-dedicated place for someone else to use.

"I'd urge anyone interested in running to raise money to support people with PH to give it go. And it is so easy with the 'Just Giving' website these days. People go online and donate the money and it automatically goes to PHA UK. Also a quick share on Facebook got me lot of new sponsors – and I had a lot of support from the school where I work too." ●



Showing how it's done

New short videos produced to help people get to grips with intravenous drug therapies.

A new series of video guides showing people with PH how to manage intravenous drug therapies at home is now available.

These teaching aides are to be used only with the direct instruction and supervision of highly skilled nurse specialist teams at PH centres.

PHA UK has worked with nursing staff and patients at four PH centres so far to produce a selection of short films showing people how to prepare and use their drug infusion equipment and how to clean and dress the access area around their intravenous line.

The 'how to' videos are now available to patients at the Royal Brompton in London, Great Ormond Street hospital for Children in London, Freeman Hospital in Newcastle and the Royal Hallamshire in Sheffield. They have been individually produced for the centres as each one uses a different model of intravenous pump and differing types of drugs.

Clinical nurse specialist at the Royal Brompton PH Centre Lisa Parfitt was one of those involved in filming.

Lisa said: "The short videos show real people with PH carefully going through the process of preparing their equipment, drawing up their drugs, beginning administration and all aspects of cleaning and care.

"They are designed to give patients, and any family members who may get involved too, that extra bit of confidence to handle these drugs at home.

"We explain and demonstrate how to manage these therapies first of course, but it is great that people can now also watch the DVD and take it away to look at as many times as they like."

A growing number of individuals with PH, including children, are using intravenous drugs to manage their condition. The therapy requires the drug to be pumped directly into their bloodstream through a Hickman or Goshong line.

Pumps differ in detail but all administer the drug almost continuously and cassettes of the medication must be replaced every 24 to 48 hours or so, dependent on the type of drug being used. The process may take ten to twenty minutes.

Everything, including the lines which usually feed into a person's chest area, needs to be kept extremely clean to avoid infection.

Lisa, who has worked in PH for eight years, said: "Intravenous therapy can be a challenge for people to get to grips with and to get used to psychologically too.

"We hope the videos will also help people being offered this therapy understand much more clearly what it involves so they can make an informed decision about taking this option.

"And we hope it will help people using IV therapy develop their skills and offer them reassurance. The films feature real people with PH, so they also help to show patients sitting at their own kitchen or dining room table getting used to their pump and line, that they are not alone in tackling this therapy."

PHA UK chairman Iain Armstrong said: "Intravenous therapy is an important long-term treatment option for some people with PH and we decided to fund this initiative to help people coming to this for the first time to understand how to look after and administer their drugs with confidence as quickly as possible. It is also a very valuable resource for people to watch before even making the decision to start these types of treatment.

"The videos will also be useful as a clinical training resource and a valuable addition to the extensive training and support available when considering or starting this type of treatment."

For more details, read about prostaglandins on the PHA UK website www.phassociation.uk.com or in the PHA UK Booklet Understanding pulmonary hypertension – Information for patients.

Iain added: "We'd like to thank all the nursing staff involved in filming at the Brompton, Freeman and Hallamshire Hospitals and especially the patient volunteers for sharing their time and experience." The PHA UK will work with any of the other PH centres in the UK that might wish to develop similar teaching and training resources. For patients interested in finding out more, please ask at your PH Centre. ●

Put it in writing

Many people find that creative writing can help to reduce stress and benefit their health and well-being. Here *Sally Brown* provides an insight into writing as a form of relaxation and therapy

Getting your thoughts down on paper is something that you can do at any time of day or night – and it can help you to deal with difficult emotions.

Research shows that writing about your feelings, or even recording your thoughts on a digital recorder or mobile phone, can really help to release the stress that exacerbates disease, which in turn can boost the immune system in a range of conditions.

American poet Allen Ginsberg said that 'to gain your own voice, you have to forget about having it heard.' Which is probably a good starting point if you have never tried to write before. Capturing your thoughts and feelings can simply be for your own benefit – don't start by thinking that you have to read it out, share it or perform to an audience. In that sense you will hopefully be more honest and write from the heart. Even writing something down and then throwing it in the bin, is a helpful way of expressing yourself at a time when you may feel angry, isolated or frustrated.

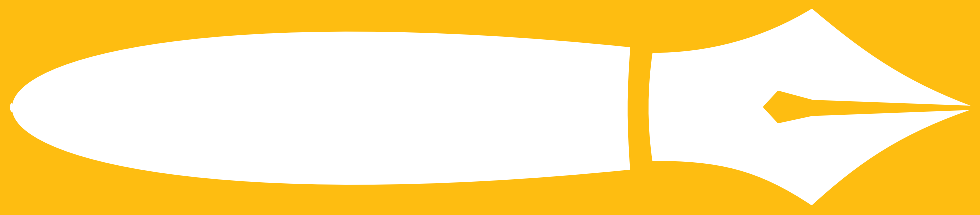
However, many people do get started with a creative writing class and it's worth having a look on the internet, or paying a visit to your local library, to see if there is anything in your area. Writing classes can be very supportive and can give you structure. Just having the discipline of attending a regular class encourages you to write each week, and you will usually have a choice of whether or not you want to share your work with others.

A class will also act as inspiration, giving you ideas on what to write about. It may be fiction, or it may be autobiographical, but it's amazing how a simple idea, such as writing about a memorable event from your past, or a special place that you like to visit, can result in a piece of writing that you want to develop and expand.

Writing can help make sense of the past, or the present, and it is strangely cathartic when other people take an interest and want to hear your story. The beauty of it is that there are no side effects, and it works well with people who are not always able to talk about how they feel.

Many writers suggest making a start by writing whatever comes into your head, for ten minutes every day. It may be the same word, over and over again, it may just be a list of names or a feeling, but the important thing is to get it down. Don't worry about grammar, or structure, just write. Eventually the more you do this the more focused you will become. Then choose something to focus on, for example think about how it felt to be a young child, and write about a particular object, place or person from your childhood. Or simply keep a record of your feelings throughout the day.

And whenever you feel angry or upset, writing can really help. Write those feelings down, get them out, put them down on paper – and who knows, five minutes later you might feel a whole lot better. ●



Some ideas to get you started...

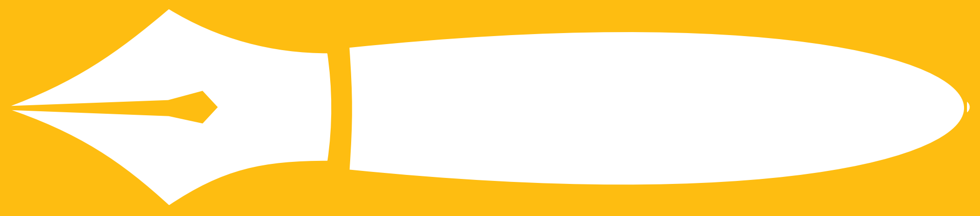
- Start by writing a description of something – it could be something you did on holiday, or out shopping, or just sitting at home. Use your senses to describe what you see, feel, hear, taste and smell.
- Think of a character - it could be you or someone you know, or completely made up. Write about what they like to do, what makes them happy, what makes them sad, their favourite food, how they feel about their appearance, or an important event in their life.
- Try writing a conversation between two characters – it could be friendly, it could be angry, frustrated or shocked. Make it relate to your main character and the event they are experiencing.
- Start with something dramatic – a car crashing, a door slamming, something being dropped on the floor, a child crying, a strange noise in the night – anything which grabs the reader's attention.

Any one of these ideas can make a good beginning to a piece of writing and you can pick the one which you find most interesting and develop it, or even combine all of these techniques into one piece.

More writing tips...

- Write for a minimum of ten minutes every day – it doesn't matter what you write!
- Remember it's ok to write for yourself – you don't have to share it with anyone else if you don't want to
- Join a local creative writing group – check the internet or call in at your local library
- Try and write regularly – get into the habit
- Always carry a note-book
- Keep a journal or diary, and record how you feel as well as what you have done
- Write a blog about your experiences and post it online – there are loads of websites to get you started – just google 'how to write a blog'

And remember, sharing what you have written can be very empowering but most importantly your writing is a means of self-expression and release – so go on, get scribbling...



Writing my life
Sara's story

A mother who lost her daughter, at the age of 21, to pulmonary hypertension is encouraging others to celebrate their lives through their writing.

Paula Hunt's daughter Sara loved writing. Sara was diagnosed with a heart defect at just four days old. By the age of nine she was told she had pulmonary hypertension and she went through two open heart surgeries before her 11th birthday.

But, more than anything, her mum said Sara wanted to achieve her dreams and pursue her love of dancing and writing.

Throughout her early years Sara had her heart set on becoming a dancer, and she took weekly lessons in ballet and tap near the family home in Gloucester. She adored the shows that her dance school produced - especially the costumes, the lights and the make-up.

Sarah wrote about her love of dance: "Dancing is the one thing that makes me feel like everyone else. I'm going to do it for as long as I can...it's what I do and I couldn't live without it."

Inevitably though, Sara's health interrupted her plans and, as a teenager, she received her GCSE results from a hospital bed having suffered a pulmonary embolism, which is a blood clot in the lungs.

With support from her family she went on to study A levels and started dancing again. She described those two years at school as the best years of her life. She found like-minded friends and was accepted to do a dance degree at Bath Spa University.

Sara managed to start her degree but, sadly, had to stop dancing due to ill health just two months into the course – only this time it was for good. Although she never ruled it out completely. "I will dance again one day, I'm convinced of it," she later wrote.

Over the years, through periods of physical limitation, writing became a vital part of Sara's life. She had always enjoyed writing, not particularly about herself but fiction.

She took notebooks away on holiday or on trips and would write about her surroundings and the people she met. She couldn't always run around like normal children so she would amuse herself quietly writing and drawing.

Sara also began to keep a blog which gave an incredible insight into how Pulmonary Hypertension affected her. She was influenced by a series of articles in a monthly newsletter from The Sommerville Foundation written by a psychologist born with heart disease. The articles offered an insight into how being ill throughout your childhood impacts your life. Seeing how helpful these articles were, made her want to write her own.

She wrote about going to university with a disability, how to survive in hospital, bravery, transplant thoughts and things that made her happy, such as new clothes, watching The Great British Bake Off and laughing with friends.

> "I weave my story as a choreographer weaves a dance, as a writer weaves a novel, as a director weaves a film. I have created it to be read and interpreted as any other piece of art is."

Sara also continued to write fiction. She didn't manage to complete her studies but her family were very proud to be able to collect a diploma on her behalf, awarded to students who complete two thirds of their degree.

Her brother Jon, 25, who is a creative writing graduate from Bath Spa University, accepted the award at a Graduation ceremony at Bath Abbey in July, alongside Sara's very proud parents, Paula and Phil.

Her mum Paula says she was always optimistic: "Sara never complained despite being in pain and confined to the house. She started writing to help others cope with the disease but I think it really helped her as well and she received great feedback, particularly from people who had read her blog."

Sara wrote an article for PHA-USA about the challenges of being on the waiting list for a heart lung transplant. The article was also published in her local paper, The Gloucester Citizen.

But it was through fiction, poetry and life-writing that Sara realised her talent. She had deep thoughts, a lively imagination, and sharp observational skills. She wrote; "I found out I'm actually quite good at writing - who knew? I knew I loved it and it turns out I'm not half bad.

"You can't just live in a hole surrounded by your illness, you have to get up and carry on as if nothing is wrong and hope that it won't be. Life goes on. I like the quote; 'Everything will be alright in the end, and if it isn't alright, then it's not the end' ".

Paula says Sara lived life to the full, pursued her dreams, challenged how other people related to her disability and kept smiling throughout.

Above all she used her love of the arts to express herself, to tell her story and leave a lasting legacy.

Paula thinks it's only fitting to allow Sara to have the last word:

"It would mean a lot to me if you all took a moment to appreciate the ability to walk and to breathe, and to live with the prospect of time stretching out in front of you. Not to feel sorry for me but feel good about your own lives. And maybe if you're deciding whether or not to buy those diamond shoes, this might give you the push to go for it. You only live once!"

Read Sara's blog at thegirlwithheartdisease.blogspot.co.uk

Green Leaf Crew!

GREEN LEAF CREW Q&A
RUBY TALLIS

Ruby aged 7 lives in Leamington Spa with her mum Tanya, dad Steve and sister Erin, aged 8. She was diagnosed with PH at the age of four and now manages her condition with daily medication, including Epoprostenol through her Hickman line. Here, she answers our Green Leaf survey!

Q. What is your favourite biscuit?
A. *Chocolate chip cookies.*
Q. Where do you like to go on holiday?
A. *Disneyland.*
Q. What's your favourite fun thing to do?
A. *I like playing with my friends and mucking about! I love my scooter and trampoline.*
Q. What football team do you support?
A. *Aston Villa. My big sister Robyn, who is 16, plays for Aston Villa Under 17's, and we go to all her matches.*
Q. Do you have a hobby?
A. *Taekwondo and swimming.*
Q. What is your favourite food?
A. *I love tacos.*
Q. What superpower would you most like to have?
A. *I'd like to be invisible when I want. So when people are mean to me I can disappear.*
Q. Who is your favourite singer or band?
A. *Katy Perry and Taylor Swift.*
Q. What is your favourite and least favourite thing to do at school?
A. *I am interested in learning about rabbits. I like all topic work. I don't like having to write a long story.*
Q. What famous person would you most like to have a selfie with?
A. *Meghan Trainor.*
Q. What's your favourite TV show?
A. *Britain's Got Talent.*
Q. Do you have a big ambition, a wish or a dream?
A. *I'd like to meet Amanda Holden.*

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

Best foot forward

Having PH doesn't stop Hannah Welch from Dorset practising her fancy footwork.

Hannah, aged nine, was diagnosed with PH when she was five, but still manages to take part in regular freestyle and cheerleading sessions at the nearby Rhythm Mix Dance Academy. So she was jumping for joy when her friends decided to help raise money for the PHA through the Academy's annual dance showcase. Gemma White and Lucy Manston, who run the Academy, were both delighted with the outcome. "The children sold raffle tickets, PHA merchandise and programmes and raised £563 in total," said Gemma. "It was a brilliant show and Hannah was able to perform in six dances with her class. She is a little star."

The Green Leaf Crew

by David Banks

Fundraising r£undup

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

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

Every little helps

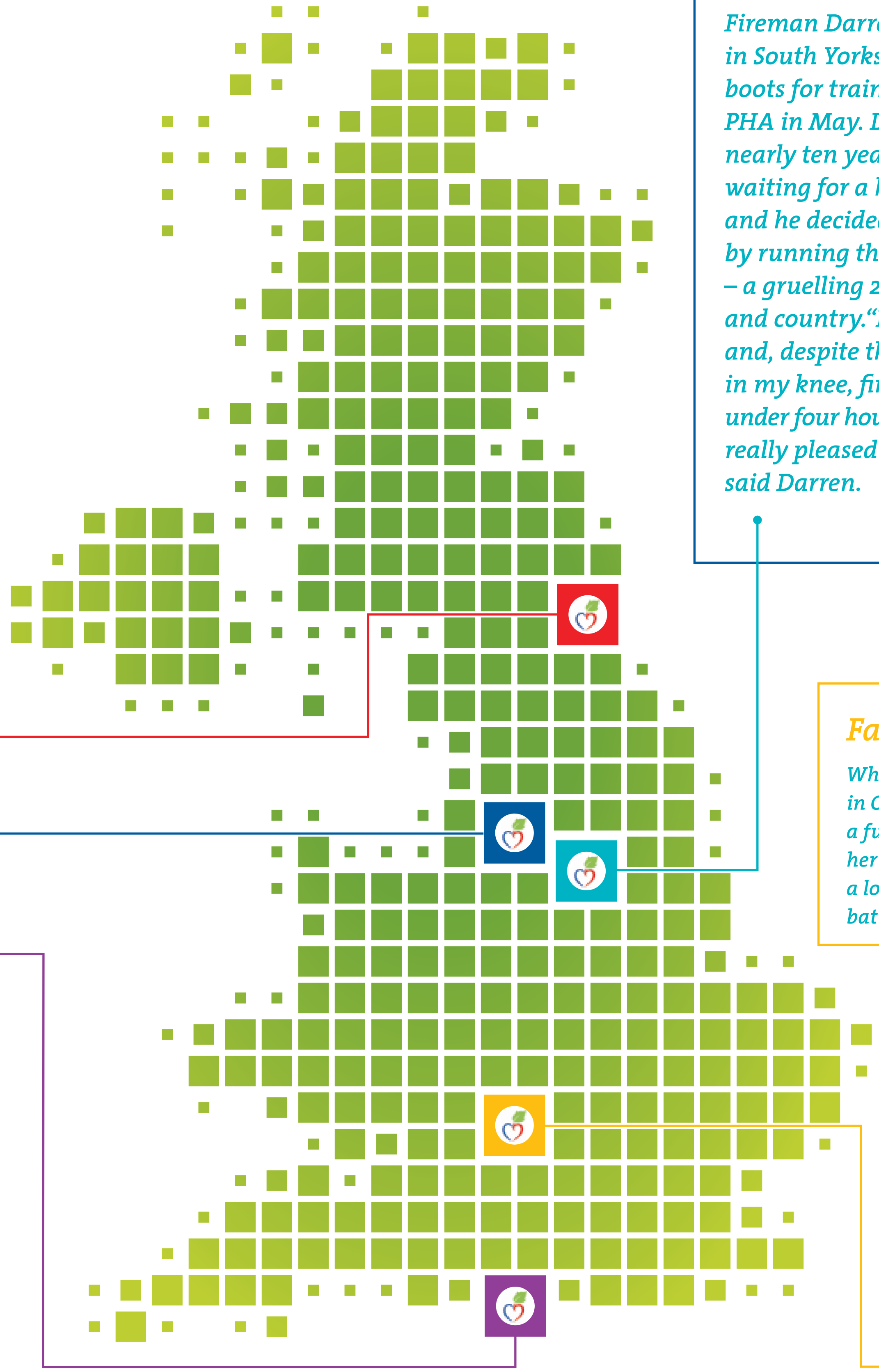
Sisters Pamela Greaves and Janice Hooper know that every penny counts when it comes to raising funds for the PHA. Since Janice's daughter Rebecca lost her fight to PH five years ago they have been collecting small change through the filling station business in Annitsford, Northumberland, where they work. "It amounts to around £15 per month" said Janice. "But over the years it all adds up." They have donated around £550 since 2012. Family and friends have helped with activities too, such as the coast to coast cycle ride and donating money in lieu of ruby wedding gifts. "Rebecca used to fund raise by selling hand-made cards," said Janice. "So I'm sure she would be proud of what we've achieved."

Coast to coast adventure

Simon Williams and Andrew Littler took to their bikes to raise over £3,000 for the PHA in support of Pauline Ginn, the wife of one of their employees, who has PH. They were joined by six other colleagues of Pauline's husband Terry, from Accident Exchange in Warrington, and completed the gruelling 230 mile Coast to Coast bike ride from Southport to Hornsea. "We had a few punctures and got lost a couple of times," said Andrew. "But overall it was brilliant and we celebrated by jumping, fully clothed, into the North Sea when we'd finished."

Collecting at leisure

A leisure park in Hampshire has nominated the PHA as its chosen charity for the year, in support of one of its regular holidaymakers. Everyone who knows Lauren Dean from Hoburne Naish Holiday Park wanted to do all they could to help, when they heard she'd been diagnosed with PH last year. The Park has collection boxes on reception, in its shop and bars and organises fund raising events such as fun days, bike rides and a recent staff bake-off. They have had generous cash donations from their customers, holidaymakers, and holiday-home owners and have raised £2,300 for the PHA since January.



Over the border

Fireman Darren Monette, from Swinton in South Yorkshire, swapped his safety boots for trainers to raise money for the PHA in May. Darren's father passed away nearly ten years ago, aged 59, whilst waiting for a heart and lung transplant, and he decided to mark the anniversary by running the Edinburgh Marathon – a gruelling 26.2 miles through town and country."I put a lot of training in and, despite the damaged cartilage in my knee, finished the race in just under four hours which I was really pleased about," said Darren.

Family fundraiser

When Natalie Collyer from Witney in Oxfordshire decided to organise a fundraising walk in memory of her sister Lynsey Pegram, she got a lot of support. Lynsey lost her battle with PH in March 2014, aged 36, and Natalie wanted to mark the anniversary with a five mile walk around Blenheim Palace, a much-loved location which they visited regularly when they were little. "In the end there were 35 of us, including Lynsey's husband Joss, and lots of family and friends," said Natalie. "Blenheim Palace kindly waived its entry fee and we raised over £1,500 as a result of the walk."

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

Helping an anxious child *not to worry*

Amanda tells how she helped her daughter overcome her phobias and anxiety.

My daughter Tabitha, now aged 11, was what we affectionately call a born worrier. Originally a tiny premature baby she is a sweet earnest and expressive child, usually anxious to please.

At seven she was a great eater with a varied and interested appetite. Then in 2011 she complained of a sore throat after a potato went down the wrong way. Thinking nothing of it at first, we noticed over a period of weeks that she was making a terrible mess of the table at mealtimes – crumbs and tiny bits of food all over the table and floor.

Separately I noticed that when sitting next to her (not at mealtimes) she seemed to be swallowing "noisily". Steadily, and then quite dramatically, her food consumption went dramatically downhill and she started to leave much of her food and lose weight rapidly.

We talked to her about it endlessly, got medicine for the continuing sore throat, tried all the usual praise and reward techniques and eventually spoke to the doctor, health visitor and school, most of whom were a bit unhelpful, suggesting it was a just phase or even attention seeking. This didn't seem to add up as, if anything, Tabitha seemed more and more upset about the increased attention she was receiving.

Going out of my mind with worry I searched online but all results seemed to focus on other eating disorders and this felt like she was phobic, not about the effects of food, but on the actual act of eating. By chance I hit upon Anxiety UK's website and phoned up the helpline and spoke to an incredibly calm, reassuring and knowledgeable woman.

She was able, in a matter of minutes, to understand the problem and explained that children who are anxious about eating often develop a clenched teeth method of swallowing that will only allow a small amount of food to go down. Unfortunately swallowing in this way is extremely difficult and actually causes throat pain which compounds the problem. I tried it (while on the phone with an empty mouth) and realised this was exactly what Tabitha had begun doing – not just during mealtimes but all the time.

It was like a light was switched on! The lady on the helpline also explained a route to addressing this, by taking baby steps, advising me to go right back to weaning basics, beginning with totally smooth pureed food. Significantly she explained how important it would be to Tabitha to know there was a plan, to feel that we were working towards a goal and that (at 7) "mummy was on top of it".

She was also so empathetic and supportive to me in my tearful state and helped me understand a pattern of behavior with Tabitha that had first presented when she was barely 2, and had made her quite poorly after avoiding going to the toilet because one time it had hurt. Immensely encouraged I put the plan into place straight away, explaining to Tabitha our target and our interim goals. We started on soup for a couple of days and then bravely put five very soft tiny pasta star shapes in her soup.

We progressed every couple of days with a target that, when she was ready, she and I would put on our best dresses and go out for a big Chinese buffet meal. To my amazement, just under three weeks later there we were tucking into spare ribs and crispy wontons. There's more good news to this story.

A couple of years later a new anxiety presented itself when the news was full of stories about missing children. We found that suddenly, over a period of weeks, Tabitha was coming down every ten minutes after going to bed and asking for drinks, food, attention.

Again we talked to her carefully and she explained that she was frightened about kidnap. Endless conversations, reassurances from myself, my husband, grandma etc seemed to make no difference and in fact she seemed to be getting worse… reluctant to go into any room alone, running in and out of the bathroom to "minimise the danger".

I was aware that this was again rooted in what seemed to me to be an irrational anxiety, but I was unsure how to address it. I again phoned the Anxiety UK helpline - as they had been so helpful before – hoping to get advice on how I would go about finding a local counsellor who might be able to help. Again a very helpful colleague listened sympathetically and gave me some incredibly useful advice and this has been the key to everything we have since done.

They explained that by endlessly explaining to an anxious child all the logical reasons why her fears are groundless, we are in fact compounding her fears – her fight or flee instinct was telling her "ok – they've explained why there's nothing to worry about, but I still feel scared – so there must REALLY be danger"….!

Instead, we followed the pattern we had used for her food phobia and introduced some baby steps. I asked her if she would feel better knowing that I would come to check on her in bed, she said yes. I bought her a new clock and suggested that on the first night I would come and check on her every half an hour. She immediately got it and said "and tomorrow you will come every 45 minutes?" I was so delighted that she realised how we were going to address it and explained that once we had got up to a couple of hours, I would start varying the times slightly – with her target being to be safe in the knowledge that at some time during the night mummy or daddy would come and check on her.

Again – amazing success – within a couple of weeks her anxiety was dramatically reduced and her fear of going into rooms alone seemed to disappear alongside her disturbed sleeping patterns. But the best thing about all of this is what she's done with this knowledge.

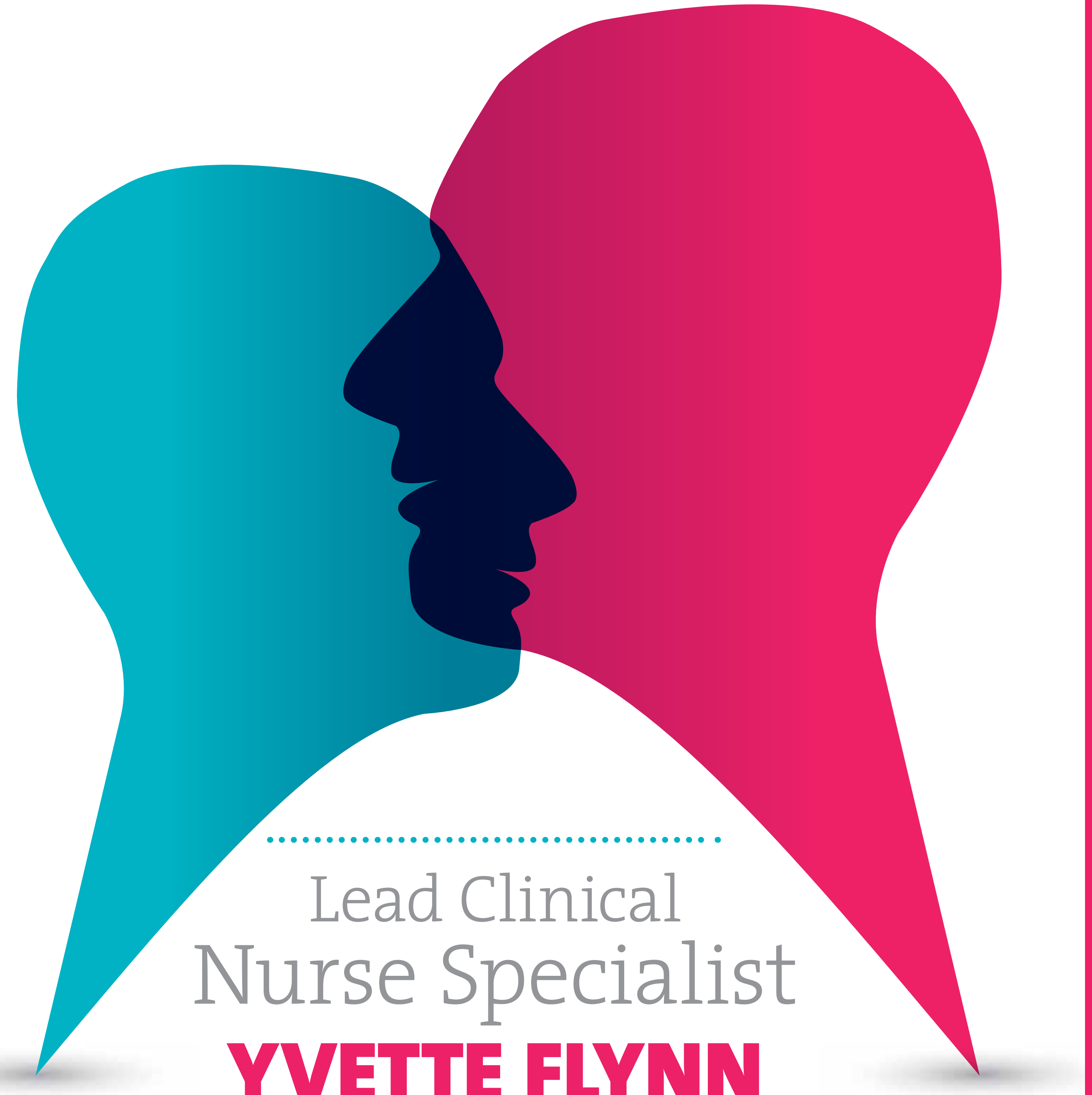
We had a long chat about the difference between "normal" worry (day to day stuff which can be immediately eased by reassurance or action – "have you filled in my form for the school trip") and what we call "silly worries" (the house will get burgled/ burn down etc), which get out of hand and turn into big monsters in her head.

We then traffic-lighted them as a way of her explaining that initial reasurance is not helping. Since then we've faced a couple of new anxieties head on using this approach and amazingly she has come up with her own baby steps / plan to facing her fears, resulting in incredibly quick and effective resolution. She's also keen to chip in with some really practical and informed suggestions when other mums are overheard talking about their children's fear of the dark etc.

I think Tabitha will always have a tendency towards worry but she seems to have equipped herself with a coping strategy that works, whatever the worry is. At 11 she is growing in confidence, popularity and humour and is approaching her imminent SAT tests next week, and looming entrance to secondary school, calmly and happily. I'm so proud of her and so grateful that I was able to access help for her (and me!) when she was young enough to trust me completely and learn some of these coping techniques.

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

the*interview*



Lead Clinical Nurse Specialist

YVETTE FLYNN

in conversation with

Steph Pollard

Lead clinical nurse specialist Yvette Flynn is one of the founders of the Great Ormond Street Hospital pulmonary hypertension service for children and young people which was established in 2002.

She retired from the GOSH PH team and the NHS earlier this year but it is not goodbye from Yvette as she is now working part time on development projects for PHA UK. Yvette has also now returned to her home county of Lancashire, where she lives with her partner Mick and enjoys working on her new allotment.

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

A. *I did my nurse training in Preston and worked for my first year on an adult orthopaedic ward, before I got the chance to move to a 90 bed paediatric unit, which I grabbed with both hands. I worked there for seven years and truly loved it but then got restless and went abroad to nurse children in Saudia Arabia and the Arab Emirates. This was a fantastic experience, but after three years thoughts of home brought me back to the UK. I then worked in paediatric intensive care at the John Radcliffe hospital in Oxford for eight years, before moving to GOSH in 1996, such a long time ago! This is where I got my first junior sister post on the neonatal intensive care unit (NICU). I worked there for four years, then when I hit 40, I decided to take a little break from the NHS and try something different for a while I joined the French medical gasses company "Air Liquide" as an area manager. Interestingly, they now supply oxygen to some PH patients in the UK. I worked for them for a year, and it was fun to be suited and booted instead of in "scrubs" and see the NHS from a very different aspect. As with all my jobs, this was a great experience that I've been able to pull on over the years. But then, I decided to go back to the NHS.*

Q. How did you originally get involved in PH?

A. *In 2002, I was back working in the NICU at GOSH and still looking for a new challenge, but within the NHS this time. Then I heard Professor Haworth was setting up a new GOSH service for children with PH across the UK and I was delighted to be asked to join the team as the clinical specialist nurse. I knew pulmonary hypertension had been recognised for over 150 years but therapies were limited and mostly ineffective. Although I had much to learn I had experience of the limitations of treating preterm/neonatal and paediatric patients with PH so this was an amazing opportunity to make a unique difference for these children and their families.*

Q. What did your role at GOSH involve?

A. *I worked with children and families on every aspect of pulmonary hypertension and how we might reduce its impact on their lives. The service was developed from the outset with family/child involvement so that we could deliver an effective focused service providing accurate and trust-worthy education about PH, medications and options as well as practical delivery of therapy. I was given the responsibility of making services in the community aware of a child with PH too; providing information about the disease and medications to them and also supporting these services to work with us to provide a shared care service across the UK. To this end, I helped set up eight care clinics across the country to ensure this shared care approach. This means that once there is a confirmed diagnosis and therapy commences, patients can have their regular clinic appointments nearer to home and only need to attend GOSH when they require specialist investigation or therapy. The shared care paediatric cardiac clinics continue today and the service involves a GOSH consultant, clinical nurse specialist and local cardiologist attending clinics in each of the centres every 2-3 months.*

Q. What key developments in PH treatment and care have you seen over the years?

A. *Well we started out in a lab-turned-office the size of a handkerchief in GOSH which we shared with five other lab staff. It was so small that if anyone needed to leave the room we all had to stand up! We moved from there into our current bigger office - although the children who visit us would still probably say it's a squeeze.*

More seriously at the start of the paediatric PH service in 2002, children were being seen close to their home with little expertise or experience. This has changed dramatically and patients are referred from all over the UK to the paediatric PH service at GOSH. In the early days, we only had life-long intravenous therapy or an oral calcium channel blockers to offer which was a very limited choice with limited outcomes. But since the introduction of other oral drugs and better knowledge of IV therapy this has greatly improved longer term outcomes for children.

There has also been a great deal of improvement in diagnosis. The right heart catheter is an essential diagnostic tool for all PH patients but, unfortunately, unlike in adult services, it is not possible to carry out the procedure under local anaesthetic for

> *"The clinical nurse specialist is often the first port of call in the PH team and is very much an ambassador for the PH service."*

children - general anaesthetic is required. Over the years, our understanding of how PH patients behave under anaesthetic and techniques at GOSH have improved dramatically so that this experience and its safety has significantly improved and risks reduced. Dr Moledina, PH clinical lead at GOSH, has also been working closely with the MRI consultant Dr Muthurangu towards replacing the cardiac catheter investigation with an MRI scan which does not require anaesthetic or sedation at all and is therefore of very little risk to the patient.
Individual care packages and processes for patients starting IV or oral therapies have also been improved and quickened considerably.

Q. What is PH specialist nursing?

A. *The clinical nurse specialist is often the first port of call in the PH team and is very much an ambassador for the PH service. They provide all aspects of education, practical support and day to day advice in dealing with PH. For example, we have developed a unique care package for IV therapy patients which involves home, school, community and hospital visits to make sure everyone is confident in their support of the child. We try to see every patient at each clinic and on every admission to GOSH and provide access to the PH service via phone, email and letter ensuring the best possible support and access to the PH team.*

Q. What were you most proud of about your work at GOSH?

A. *We have been able to build a PH service that provides children in the UK with all the therapies that are available worldwide. And I am proud to have been involved in building a unique nursing service for children with PH, through which we can support them and their families in ways that are not available in other countries - for example, the shared care model with community teams providing that vital support on their door step in conjunction with the PH team at GOSH. We have developed a very visible and accessible service that is effective, reproducible, sustainable and can be carried forward with the evolution of PH therapies and care packages.*

Q. How have you been involved with PHA UK over the years?

A. *PHA UK has supported me and my work in many ways. For example, when GOSH needed a second PH nurse, PHA UK funded the post for two years until the NHS was able to take it on and make the post permanent. This was direct support and recognition of the work I was doing in a rapidly growing service. I have attended many PHA UK family weekends and also organised two weekends for teenagers funded by PHA. I have always been supportive of the charity's work too and encourage all the families to join.*

Q. What does your current work with PHA UK involve?

A. *I am pleased to be involved in lots of projects with PHA UK. I am currently working with PHA and GOSH to develop a DVD for parents to help them prepare IV Epoprostenol. I'm involved in plans to carry out a survey of families about the impact of living with PH on the family life which aims to gather evidence which will help the PHA identify how they might further support them. I'm working with our partner Anxiety UK to develop more specific PH information materials for parents and teenagers. And I'm working on an important longer term project to set down with GOSH a more defined process for the transition of teenagers to adult services. I already have many teenagers in the PH service who would like to be involved in this important piece of work. Another project is to work with Dr Moledina and the PH team at GOSH to develop an additional medical/nursing education program in PH.*

Q. What contribution does PHA UK make in the fight against PH?

A. *In the early days the PHA rallied patients and their families to storm parliament demanding that all therapies should be available to all people with PH. Without their commitment and presence I am sure what is available now to the PH community would be significantly different. The PHA are always ready to support the nine NHS PH centres in order to improve the journey and outcome patients. They have created a community to which we can all belong; have a bigger voice and share our experience, joys and sadness.*

Q. Do you have a message for the PH service on your retirement?

A. *It was a huge decision for me to retire from the service, but when the children are walking faster than you in the six min walk test, it must be time to hang up your PH trainers! I have grown so much along with the children and their families and treasure every moment I've spent with them. I have been humbled by their strength and character. It has been an absolute honour that over the years they have taken me into their lives and trusted me to take them on the PH expedition and try, with their help, to fight for, develop and deliver what they need. I certainly miss being in the centre of the service now, but I am content in the knowledge that all the children and families are in very safe hands with Dr Shahin Moledina and the GOSH PH team who will take this already world recognised service, to greater heights in and I wish them every success in this magnificent task. I am so delighted to be invited by PHA to work with them on projects to continue improving life in the PH community because this affords me a link to all those families I have worked with. It's not goodbye from me but cheerio and I'll keep in touch.* ●

Benefits **Advisor**

With Shaun Clayton

Over the past few months we seem to have had a number of phone calls to the office from PHA members over 65 asking advice about what support is available for them.

When someone is within working age there is a whole range of potential benefits; personal independence payments (PIP), employment and support allowance (ESA) and so on. But it can be a bit of a shock when you get to retirement age and find you no longer qualify for these working age schemes.

Some people may also find themselves involved in a transitional period with their established support through disability living allowance (DLA) at this age. A lot of people don't realise the DLA benefit generally only relates to people of working age.

What happens when you go past 65?

Whatever situation you find yourself in, there is a support avenue for you to go down. There is a benefit called 'Attendance allowance' and to claim this you must be over 65, not currently receiving DLA or PIP and have been living in Great Britain for at least two out of the past three years.

Attendance allowance, like most benefits nowadays, comes with a higher and lower component based on the functionality of the person applying.

Unfortunately though, unlike DLA and now PIP, there is no 'mobility' side to attendance allowance, unless you were already receiving it from a prior application, then it will simply roll over.

Pension credits may also be available to you – these top-ups are income-related and aim to support people who, through their health and disability, may not have been able to contribute into an employment-based pension.

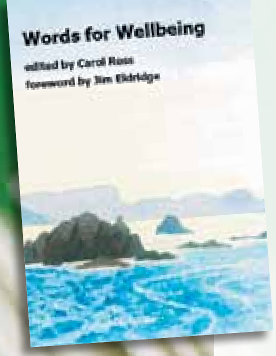
If you want to know more about pension credits in particular - and other support for post-65 - I would heavily suggest that you contact Turn 2 Us. If you are looking for help to navigate the rough welfare waters, they are an excellent new source of help for PHA UK members. They have both a telephone helpline and online help that will do a tailor-made search for anyone looking to know more about what is available to them, both in terms of benefit support and available grants. Please see their feature on pages 14-15.

And as always, if you want any more information about benefits please do contact the office publications@phassociation.uk.com and request a copy of our 'Signposting for potential benefits'.

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

BookReview

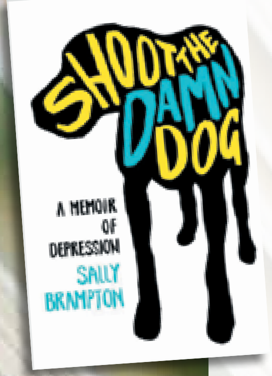
Would you like to join the Emphasis book club and review a book which may be of interest to other Emphasis readers? If interested, please contact **editor@phassociation.uk.com**



Words for Wellbeing edited by Carol Ross

This is a 'how to do it' book as well as a quick short read style of book. You can read it from cover to cover, or dip into when you have a few moments. It is ideal for when you are waiting for an appointment or a bus. You can just as easily pick it up and turn a few pages over a coffee. It offers practical help on how to write down your feelings and experiences. It shows different techniques on how to write about your own story or stories - even for those who have little time to spare. This is a very readable and stimulating book that I recommend to anyone who is thinking about starting to write a journal or write creatively. It is a collection of 14 chapters interconnected with poems, short prose and illustrations and there is something in it to appeal to most. I think it may motivate you to try something new and see if writing and art have therapeutic value for once you get beyond the "I can't" or "I'm rubbish" thoughts! I do offer this review with a little warning though as Words for Wellbeing may be a little bit out of some peoples 'comfort zones', but if you are open to the idea of therapeutic writing, it's a brilliant book choice. **Iain Armstrong**

Words for Wellbeing
edited by Carol Ross, published by Cumbria Partnership NHS Foundation Trust, ISBN: 095728490X



Shoot the damn dog – a memoir of depression, by Sally Brampton

Ok, deep breath, - let's talk about depression. Or, to be more accurate, let's read the very personal story of a successful journalist who suffered so severely that she was unable to write anything for four years. Sounds grim? Well depression is never an easy subject but Sally Brampton writes with such insight that you find yourself being carried along by her experience of psychiatrists, mental health units and what makes a good therapist.

It's all about the people she meets, the experts she encounters and the help she receives from unexpected quarters too. Crucially it is the support of her best friend, and one particular journalist who encourages her to write about her breakdown, that leads her to recovery.

For Sally writing about her experiences gives her a sense of relief and acceptance – her writing becomes a form of therapy in itself, as we have discussed earlier in this magazine.

Many of us have been there, or know someone else who has. And unfortunately there is still a stigma surrounding mental health. As one of Sally's fellow depressives says: "Sometimes I wish I was in a full bodycast with every bone in my body broken. Then maybe people would stop minimising my illness because they can actually see what's wrong with me. They seem to need physical evidence.'

Sally tells her tale with wit, compassion and ultimately optimism. From the depths of despair she learns to live and love again, to accept herself for who she is and to look back on life's more difficult experiences and learn to 'let it be'.

If you've ever experienced long periods of sadness, or been addicted to alcohol or drugs, then this is a book for you. It doesn't sanitise or cut corners, but it does shine a light on the darkness and shows that, with love and support, there is a better way forward. **Sally Brown**

Shoot the damn dog
by Sally Brampton, Bloomsbury Publishing PLC, ISBN: 978-0747572459

Join us online...

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

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The Information Standard
Certified member

In your next issue of Emphasis...

The next issue of Emphasis is due out before Christmas and we have planned features about:

- The PH National Audit – we talk to its founder and lead clinician Dr Simon Gibbs and ask, what's it all about?
- All going swimmingly – we take a closer look at the benefits of swimming for people with PH. Do you like a swim?
- Stem cell research into PH – Dr Daniel Reed provides a patients' insight into this important research for the future.

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

You can get involved in Emphasis too:

Emphasis Exchange and Reviews - don't forget we'd like to hear from you if have news to share or if you'd like to review a book, app or film you think other readers of Emphasis may be interested in.

Family Matters - if you're interested in telling your family's PH experience in our regular feature, drop us a line.

Take the biscuit! - and please get in touch if you'd like to answer the Green Leaf Crew Q&A.

To get involved with any of the above, to offer feedback and ideas, contact editor@phassociation.uk.com

On your marks, get set...bake!

It's that time of year again. Time to dig out your mixing bowl, dust off your Kenwood mixer and get baking! With The Great British Bake Off back on TV soon we've been challenging you to send in your favourite summer recipes. And it seems that cupcakes are a firm favourite of PH fundraising bakers! Hopefully the following recipes will inspire you...whether it's about cooking for pleasure, feeding the family or fundraising.

Shani's top tips

Shani Fernando has been putting her baking skills to good use recently, cooking up some delicious summer creations to raise money for the PHA. Her absolute favourites are chocolate fudge cake and carrot cupcakes but novice bakers beware – Shani has a few top tips to help you get the recipe right:

"Make sure you use light brown sugar, not dark brown sugar, when you are making chocolate fudge cake, otherwise it burns really easily. And measure out your ingredients, or it can go badly wrong!"

Shani also recommends getting a friend to help you: "If you're trying to bake in bulk it can be a bit daunting, so when my friend Emma offered to help me it was a big relief - especially as she makes the most amazing rice crispy cakes." Shani, aged 24, was diagnosed with PH as a nine month old baby and is currently on the heart and lung transplant waiting list.

Shani and Emma raised £110 selling cakes at Emma's workplace and the money is being used to fund a Sports Day Fête at her old primary school in aid of the PHA. The fête takes place on Saturday 22nd August at St James The Great RC Primary School in Thornton Heath, near Croydon.

Shani's favourite recipe: Carrot Cup Cakes

Ingredients:

175g light muscovado sugar
100g wholemeal self-raising flour
100g self-raising flour
1 tsp bicarbonate of soda
2 tsp mixed spicezest
1 orange
2 eggs
150ml sunflower oil
200g carrots,
grated orange
coloured sprinkles, to decorate

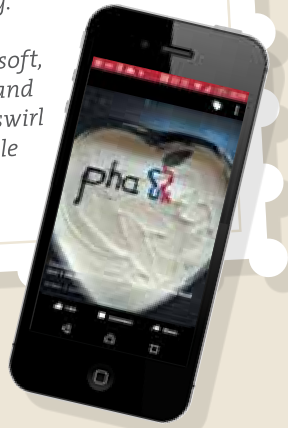
For the icing:

100g butter, softened
300g soft cheese
100g icing sugar, sifted
1 tsp vanilla extract

Method:

Heat oven to 180C/160C fan/gas 4 and line a 12-hole muffin tin with cases. In a large mixing bowl, mix the sugar, flours, bicarbonate of soda, mixed spice and orange zest. Whisk together the eggs and oil, then stir into the dry ingredients with the grated carrot. Divide the mixture between cases and bake for 20-22 minutes until a skewer poked in comes out clean. Cool on a wire rack before icing.

For the icing, beat the butter until really soft, then beat in the soft cheese, icing sugar and vanilla. Use a palette or cutlery knife to swirl the icing on top of the cakes, then sprinkle with decorations. ***Enjoy!***



Cupcake King

Home-baked goodies sold out in 15 minutes at a bake sale in aid of PHA at a secondary school in West Wales. Mark Bowen, aged 14, whose mum Anna has pulmonary hypertension, baked a selection of cupcakes for the sale and he and his classmates at Ysgol Gyfun Emlyn raised an amazing £150 in quarter of an hour.

Mark said: "We sold them at break and the other kids went mad for them. The cupcakes all went very quickly."

The cake sale brings Mark's personal PH fundraising total, through sponsored events and activities, to £450.

Karen's vegan cupcakes

PHA member Karen Farminer regularly gets the baking trays out – which can be a bit of a challenge if you are vegan and don't eat dairy products like eggs, milk and butter.

Here is Karen's recipe for yummy vegan vanilla cupcakes...

Ingredients for the cupcakes:

2 1/4 cups plain flour
1 3/4 cups sugar
2 tsp baking powder
1/2 tsp bicarbonate of soda
1/4 tsp salt
1 1/2 cups almond or soy milk
1/2 cup vegetable oil
1 tbsp lemon juice
2 tsp vanilla extract

For the frosting:

1/2 cup dairy-free margarine or virgin coconut oil
4 cups icing sugar, sifted
3 tbsp almond or soy milk
1 1/2 tsp vanilla extract
Food colouring (optional)

Method:

Preheat the oven to 180°C and line two muffin tins with medium paper liners.

Sift the flour, sugar, baking powder, baking soda and salt into a large bowl. In a separate bowl, whisk the almond or soy milk with the oil, lemon juice and vanilla. Make a well in the centre of the flour and pour in the liquids. Whisk vigorously until well-blended (the batter will be quite fluid). Pour the batter into the paper-lined muffin tins, filling the cups two-thirds.

Bake the cupcakes for about 25 minutes, until a tester inserted in the centre of one comes out clean. Let the cupcakes cool in the tin, and then remove before frosting.

Beat the margarine with two cups of the icing sugar until blended, then beat in the almond or soy milk and the vanilla. Add the remaining two cups of icing sugar and beat until the frosting is smooth and fluffy. Pipe or spread the frosting onto the cupcakes and store at room temperature.

The cupcakes will keep in an airtight container for up to two days.

NOTE: While many cake and cupcake recipes call for a fair bit of sugar, this recipe does require more than the average. The sugar adds more than just sweetness here. Since the recipe is egg-free, the sugar also adds moisture and tenderness. With less sugar, the cupcakes would be dry and crumbly.

Fundraising bake off

Summer's a great time to organise a bake sale in aid of PHA. You can ask friends and relations to help and that way you get a wider variety of cakes to sell, with everyone producing their favourites.

If possible make up smaller portions so that people don't have to buy a whole cake which can be expensive. And use pretty paper plates to display scones, fairy cakes and brownies. Don't forget to cover them with cling film to keep them free from insects and greedy little fingers on the day – and price everything up clearly so that people know what they have to pay, without having to ask.

For more advice in a fundraising booklet contact the PHA office on 01709 761450 or office@phassociation.uk.com

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

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

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

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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**

Do we have your correct details?

Please email us on **office@phassociation.uk.com** if any of the following apply to you:

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

Contact a friend

Kathy Davis: Kathy regularly meets with other PH-ers who live in the Portsmouth area of Hampshire. If you're interested in meeting up with this small and friendly group, just contact Kathy on **02392 365760** or email her at **davik7hmd@ntlworld.com**

Jocelyn Barker: Jocelyn's friends support group is still going strong in London and meeting on the first Wednesday of every month between 10am and 1pm. Anyone is welcome, but it's best to call Jocelyn first in case the date has to change (Although this rarely happens) on **0207 738 7085** or email **jocelynab@gmail.com**

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Join the PHA UK Lottery today!

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

Please note, you must be 16 or over to enter.