SPRING 2015

emphasis

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

Blood samples initiative supports future research hope

Hundreds of pulmonary hypertension patients take part in a world-leading research programme

PHA UK Lottery launched

Play the charity's new fundraising prize draw

15th anniversary celebration

Take a look back at 15 years of PHA UK

Fundraising roundup

A whistle-stop tour of fundraising across the UK

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Professor David Kiely talks about his 20 years working with PH patients

Family matters

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Green Leaf Crew

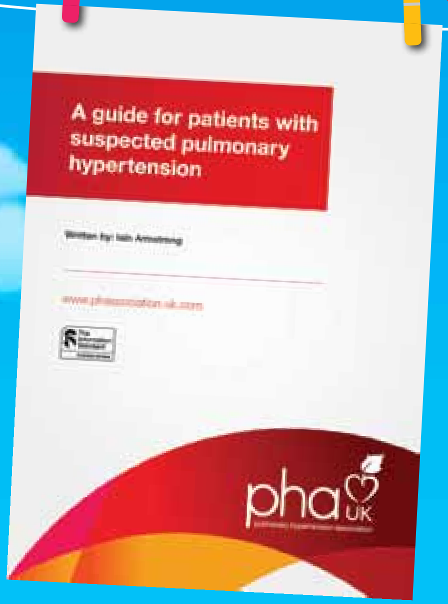
Meet Mason Lewis, plus cartoons and apps for kids

Emotional well-being and PH

Clinical psychologist Emma Offord on dealing with anxiety

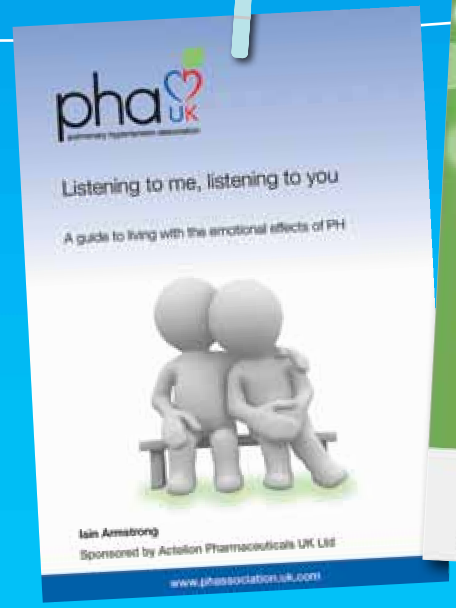
WELCOME TO YOUR NEW LOOK EMPHASIS MAGAZINE

Free support & advice...


A guide for patients with suspected pulmonary hypertension

Written by: Iain Armstrong

www.phassociation.uk.com


Listening to me, listening to you

A guide to living with the emotional effects of PH

Iain Armstrong

Sponsored by Actelion Pharmaceuticals UK Ltd

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It matters to me

Carl Harries and Iain Armstrong


Clinical trials and the future of pulmonary hypertension treatment

Written by: Iain Armstrong


How to feel in control of your breathing

A guide for people who are breathless

Written by: Dr Janelle Yorke

Senior Lecturer, University of Manchester

www.phassociation.uk.com


Signposting for potential benefits

2014/2015

By Shaun Clayton

www.phassociation.uk.com

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

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This magazine is printed on paper from sustainably managed sources

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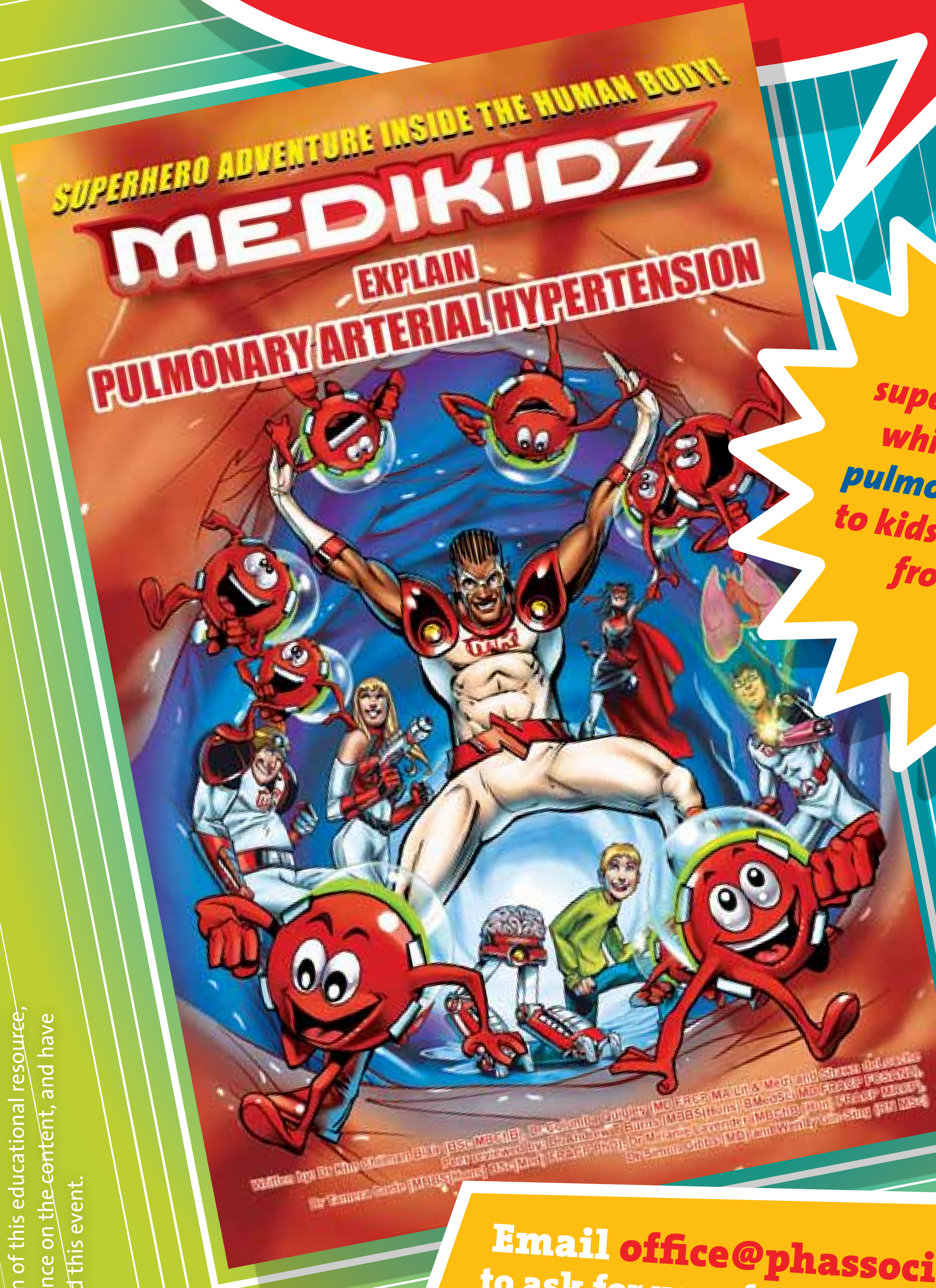
Superheroes to the Rescue!

Limited edition superhero comic books which aim to explain pulmonary hypertension to kids are now available from the PHA UK office.



Email office@phassociation.uk.com to ask for your free copy while stocks last!

Actelion Pharmaceuticals UK Ltd sponsored the production of this educational resource, with no influence on the content, and have also sponsored this event.

Welcome

Welcome to your new look Emphasis magazine. We have decided to revamp the publication as part of our 15th anniversary year and hope you like what you see.

With our bright new format, we'll continue to provide updates on important research and development work being carried out to help us to better understand pulmonary hypertension and develop new treatments – and hopefully one day - a cure for the disease.

Plus, we'll continue to include advice and information from a range of experts to help people living with the chronic condition – and, of course, we'll share your news, stories and experiences.

In this issue, you can read about how hundreds of volunteers are contributing blood samples to a Biobank which will provide vital data for future research into the progression of PH.

Clinical psychologist Emma Offord gives us an insight into the many emotional challenges which can be presented by PH and consultant pharmacist Neil Hamilton looks at some of the ways to help you to remember to take your medication.

In our new Family Matters column, we hear from Suzanne Calder about how her family has dealt with her daughter's diagnosis of PH. And, Mason Lewis becomes our first volunteer to answer the Green Leaf Crew's new questionnaire.

Turn to the centre-spread for a reminiscent look-back over our first 15 years, highlighting some the things we have achieved together. We'd welcome your feedback. There are lots of opportunities to get involved in future magazines, as well as keeping up-to-date via our website, Facebook and Twitter profiles too. So please keep in touch.

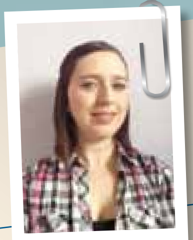
Iain Armstrong

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

> *"Turn to the centre-spread for a reminiscent look-back over our first 15 years."*

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.



Invitation to take part in online survey

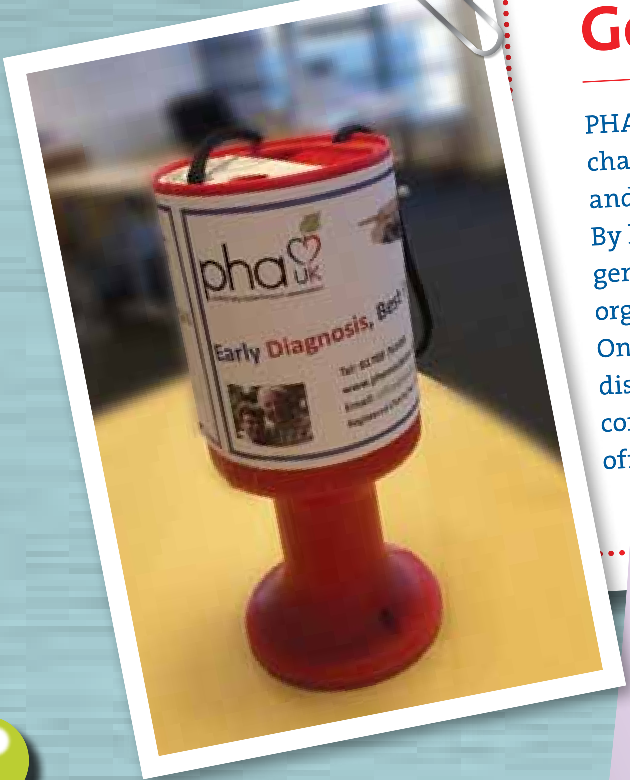
Dear PHA UK members,

My name is Emma Cole and I am looking for volunteers aged 18 and over, both male and female, to take part in research into what affects the lives of patients with pulmonary hypertension. My research is titled 'Hope, optimism and quality of life in patients with pulmonary hypertension'. It aims to provide people with a better understanding of what can affect life with an ongoing illness, so that future researchers might be able to test ways to improve the lives of people with PH. The psychological implications of having PH are not well researched so I would be very interested to know how you feel about your condition.

The research involves simply completing a short online survey that should take no more than 15 minutes. The questionnaire asks people simple questions to assess how PH affects their quality of life. Taking part is entirely voluntary and all responses are entirely anonymous. All information will be treated in confidence. You can find the online survey by going to the PHA UK website and clicking on the direct link to the survey on its front page. If you'd like to find out more please call 0114 225 3983 and leave a message for either myself or Katie Cutts who is my research supervisor. Thank you for considering taking part in this research.

Emma Cole
Health Psychology Masters Student,
Sheffield Hallam University

The deadline for completing Emma's survey is the end of June so please do act soon if you would like to get involved in this important research initiative.



Get collecting

PHA UK collection boxes are an easy way to raise money for the charity, and can be found in hairdressers, waiting rooms, shops and community halls across the country.

By leaving your box in a well-used location you not only help us generate much-needed funds, but also raise awareness of the organisation and its cause.

On average we receive around £20 from each collection box we distribute. If you would like to display a collection box in your community please get in touch with the PHA UK office via office@phassociation.uk.com or call 01709 761450.

Collection box hints and tips

- *Make sure your collection box is in a prominent spot and doesn't get buried, lost or forgotten*
- *Remember to pop your collection box out at events such as coffee mornings and concerts*
- *Encourage people to empty their coppers into the box - every penny counts and you'll be surprised how it adds up!*
- *When you have finished raising money, or your collection box is full, just empty the box and send us a cheque, made out PHA UK, for the total amount you have collected*
- *If you have any questions about raising money with a collection box please contact PHA (UK) on 01709 761450 or email office@phassociation.uk.com*

Giving in memory

Thank you so much to all our supporters who have collected donations in lieu of flowers at a loved one's funeral.

Over £820 was donated to PHA UK by mourners at the funeral of ***Sara Hunt***, aged 21, of Gloucester, who died the day before Christmas Eve last year. And, more than £350 was raised and donated to the charity by the family and friends of ***Margaret Cother***, of Worcestershire, in celebration of her life. There are many more. Whatever the amount raised, we really appreciate this way of honouring someone's memory by supporting the work of PHA UK. These personal donations help us to continue campaigning for better diagnosis and treatment for people with PH and greater awareness of the condition. If you would like to support the charity's work by giving in memory of a loved one, please post your donation to Helen Crabtree, PHA UK, Unit 2, Concept Court, Manvers, Rotherham, South Yorkshire, S63 5BD. You will receive a personal letter of thanks to confirm receipt of your gift.

Breathe easy...

A calming new app to help you relax through your breathing is now available for smart-phones and tablets.

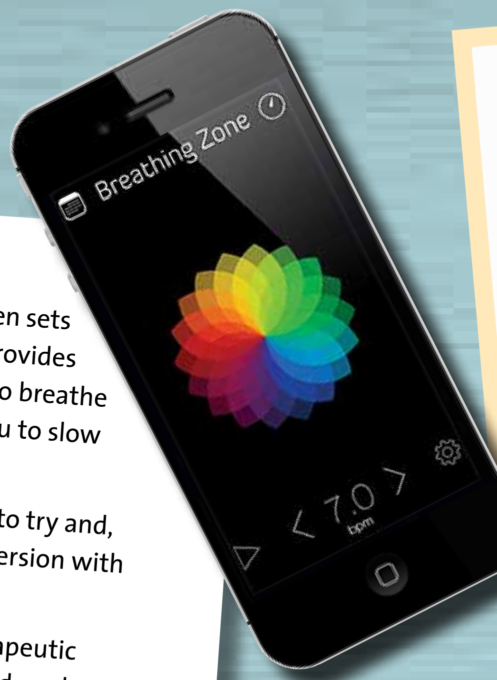
The Breathing Zone app talks users through simple breathing exercises designed to help reduce stress and anxiety and manage high blood pressure.

The app's developers say it is easy to use and there are no complicated settings or difficult breathing techniques. All you have to do is breathe in and out and follow the spoken instructions. Breathing Zone even uses your smartphone's microphone as a breathing analyser to assess your breathing rate and then sets you a reduced target to aim for. It provides a visual pulsating image on-screen to breathe along with which gradually helps you to slow down your breathing.

A free version of the app is available to try and, if you like that, you can buy the full version with additional features at low cost.

Clinical studies have shown that therapeutic breathing can help improve your mood, make you feel more relaxed and lower high blood pressure.

To find out more visit **www.breathing-zone.com** To download the full app go to the App Store (£2.58) or Google Play (£1.99).



Hello my name is...

A terminally ill doctor has launched a campaign to encourage hospital staff to say hello and introduce themselves properly to patients.

The *'Hello my name is...'* campaign has been launched by Dr Kate Granger, a young hospital consultant from Yorkshire who works in elderly care.

Kate became frustrated with the number of staff who failed to introduce themselves to her when she was in hospital receiving treatment for cancer.

Her experience prompted her to launch a national campaign reminding staff to go back to basics and introduce themselves to patients. She has already inspired hundreds of nurses, doctors, therapists, receptionists, porters and domestic staff.

Kate said: *"Saying hello and introducing yourself properly can be the first rung on the ladder to providing compassionate care and the start of making a vital human connection, helping patients to relax, and building trust.*

"I think the main messages from the campaign is about high quality communication and always treating patients as people with respect and dignity.

"I really hope my legacy will be exactly that, putting compassionate practice right at the heart of healthcare delivery every single day."

Feedback from patients across the country shows how vital basic communication is to them, saying that the smallest things make the biggest difference.

More than 80 NHS organisations – including over 400,000 staff who between them care for millions of patients – have backed Kate's initiative.

It has also been endorsed by prime minister David Cameron, health secretary Jeremy Hunt, the Countess of Wessex, Bob Geldof and Drew Barrymore amongst others.

Find out more, visit www.hellomynameis.org.uk and on Twitter #hellomynameis

SUPERHEROES TAKE ON PH

A superheroes comic book designed to explain pulmonary hypertension to kids is now available from PHA UK.

The full-colour publication has been produced by Medikidz, an international publishing company which has written award-winning comic books about a growing range of diseases.

In each book, its superhero characters take young readers on an adventure around their planet called Mediland, which is shaped like the human body, to explain how everything works and how an illness can affect it.

PHA UK's Dr Iain Armstrong has scrutinised and peer reviewed the pulmonary hypertension version of superheroes' comic adventure book.

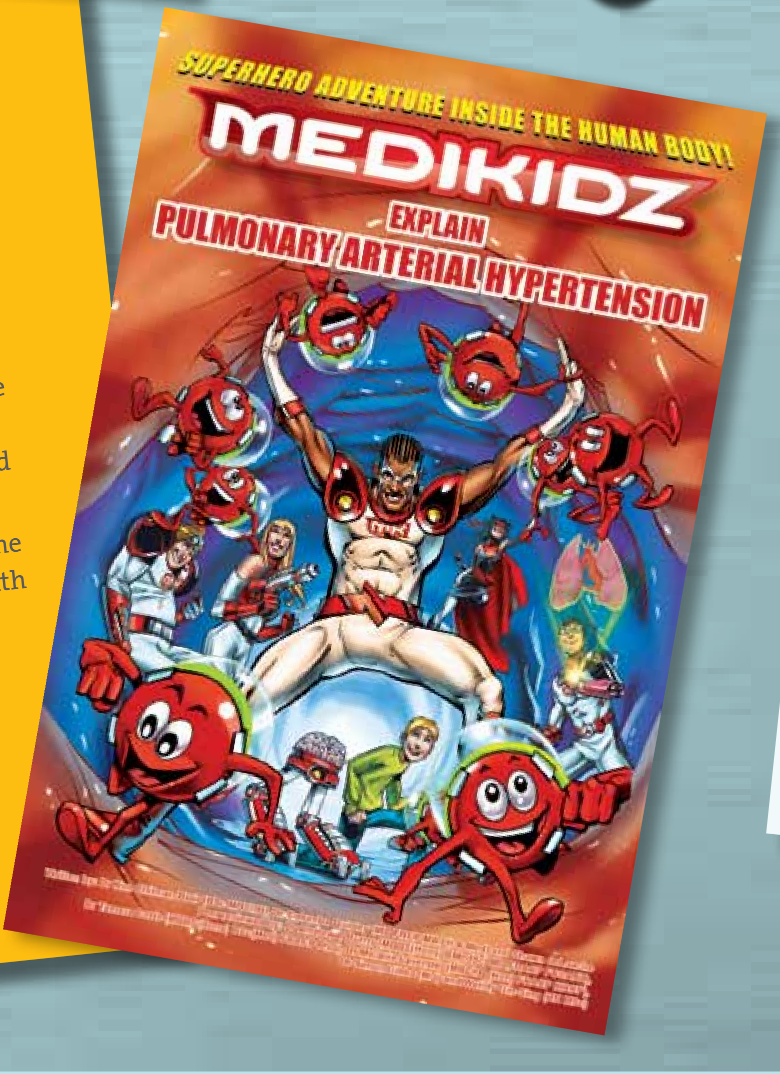
Medikidz was co-founded by Dr Kate Hersov who, after working in paediatrics, became frustrated with the lack of appropriate literature for her young patients. Her company is committed to helping young people understand what happens when people are diagnosed with serious illnesses.

Rachel Cruickshank of Medikidz said: "We believe that every child deserves access to medical information they can understand. It is our aim to create a global community of young people that are informed, empowered and health-aware.

"To date over 3,500,000 Medikidz comic books have been distributed across the world, helping young people to become more informed about a range of health issues from asthma and autism to bed-wetting and breast cancer."

Actelion Pharmaceuticals UK Ltd sponsor the production of this educational resource, with no influence on the content.

PHA UK ha 300 free copies of the PHA UK endorsed 'Medikidz explain Pulmonary Arterial Hypertension' to give away. If you would like a copy contact PHA UK on office@phassociation.uk.com



Family *celebration!*

For mum-of-two Laura Ling excitement is mounting for an incredibly special day.

Not only will she renew her wedding vows to husband, James, on the couple's seventh anniversary, 24th May. But Laura and James will also baptise their children – five-year-old Henry and 19-month-old "beautiful miracle" Rosie-May.

Laura was diagnosed with pulmonary hypertension while pregnant with Rosie-May and went through a very difficult time. Laura says she is indebted to the specialist PH team at Hammersmith Hospital, in London, and obstetrics staff at neighbouring maternity hospital Queen Charlotte's and Chelsea for ensuring a safe delivery.

Laura, 35, adds that planning for the family's big day - a church ceremony in Dover, where they live, followed by a reception at a country house – has helped her to get through the last couple of years.

"James and I had a civil ceremony when we got married but I wanted to do this and planning it kept me strong. Through everything, James has been my superhero and I can't wait to renew my vows to him. It will be such a special day and later in the year we are going on a 'family moon' to Orlando, Florida with the children."

Laura's health problems began about seven years ago when she was diagnosed with another rare condition called common variable immunodeficiency (CVID), which means she has low levels of antibodies, used to fight off infection, in her blood. She has to undergo infusions every two weeks.

While 23 weeks pregnant with Rosie, Laura developed breathlessness and swollen ankles, which she initially put down to the pregnancy. While having her infusion treatment, she had a CT scan of her lungs, but PH was missed and eventually she became so ill she could barely stand. Paramedics took her to hospital in Kent.

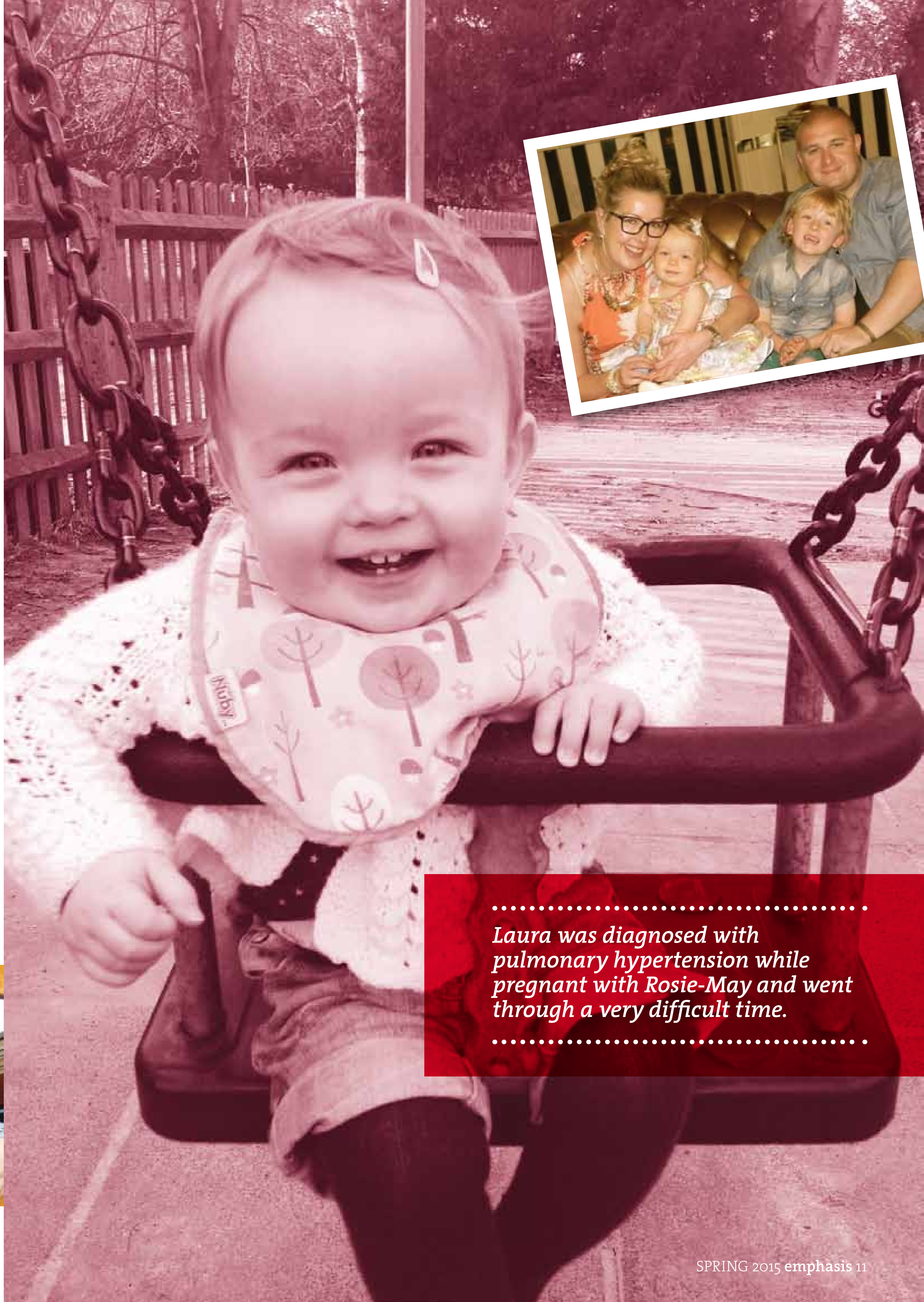
Later Laura was transferred to hospital in London. By now, she knew she had PH and was overwhelmed by what it meant. Her heart was failing and she was given the devastating news that continuing the pregnancy may threaten her own life. She was so ill that she was told that she may have to consider an abortion.

She recalled: "I couldn't believe what I was being told. I was away from my then three-year-old son and heartbroken does not begin to cover how I felt at the time.

"However, my anger over it made me more determined not to give up. I never let myself believe for longer than a split second that I would lose the fight and lose our daughter."

Laura was put on a high dose of steroids, to which she responded, and was transferred to the care of the PH team at Hammersmith's with Queen Charlotte's obstetricians taking over looking after her unborn baby. In addition to the steroids, she was put on Bosentan and Sildenafil.

She was then told an abortion would be just as dangerous as continuing with the pregnancy, which brought huge relief as it was "an unimaginable decision to have to make." >



Laura was diagnosed with pulmonary hypertension while pregnant with Rosie-May and went through a very difficult time.

> *“I find it incredibly challenging trying to raise two children and live with PH. On a bad day, I find it hard to move, on a good day, I’m doing Zumba in the living room.”*

> *As well as being a busy wife and mum, Laura is now back in her part-time job as an officer of the UK Border Force.*

At 30 weeks pregnant, Laura, was allowed home with weekly visits to the hospital. By then she had also developed gestational diabetes.

Preparing for the birth, Laura knew the risk PH posed to both her and her baby. There was a high risk of her or Rosie-May not surviving the birth. Laura was readmitted to hospital at 36 weeks.

A week later, staff induced labour. A 12-strong medical team, James and Laura’s mum were present when healthy Rosie-May Florence, named after her three great-grandmothers, was born, weighing 5lbs 7 ozs.

Laura said: *“All in all, it went very well. It was a natural birth and the team around me were fantastic. I honestly felt like royalty, they treated me so well and I’ll be eternally grateful.”*

After spending three days in intensive care, Laura was transferred to a ward and discharged a week after the birth. As well as being a busy wife and mum, Laura is now back in her part-time job as an officer of the UK Border Force, where she has worked since she was a teenager. Her last echocardiogram showed that the right side of her heart is moderately impaired. She is undergoing ablation treatment to correct an irregular heart rhythm.

She said: “I find it incredibly challenging trying to raise two children and live with PH. On a bad day, I find it hard to move, on a good day, I’m doing Zumba in the living room. But I always think to myself that although things could be better, they could be much worse.”

In addition to support from her family and friends, Laura says fellow PH patients she has met online have helped her through, especially Hollie Sassienie, who was in the same situation a year beforehand. Laura and James keep in regular touch with Hollie and her husband Daz and meet up.

“It helps knowing I’m not alone,” said Laura. ●

Roll up Roll up!

PHA UK LOTTERY • PHA UK LOTTERY •

Join the PHA UK Lottery

A new PHA UK lottery has been set up to raise thousands of pounds for the charity, and give one lucky winner a week a bumper cash prize.

The lottery initiative will be launched this month and you can sign up now to start playing for as little as £1 a week. Every Saturday a winner will receive a cash prize which could grow to as much as £25,000!

At the same time, the initiative will bring in a welcome weekly boost of funds to support the PHA UK's work.

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 charity draw and someone will win a cash prize too, so it's a win-win really."

The PHA UK lottery has been set up through the Unity Lottery online platform which helps hundreds of UK charities run their own weekly draws to raise money for their good causes.

It is easy to play – you can either sign up online or fill in an application form to send through the post. (See our step-by-step guide opposite for more details)

Participants can play for as little as £1 per week. 50p of every £1 you play is guaranteed to go straight to PHA UK, and the remaining money is used to provide prizes and cover administration costs.

The amount of money you can win each week depends on how many people have entered that week's draw. The more people who enter – the bigger the prize.

PHA UK chair Iain Armstrong said: "We're really hoping this will prove a popular new initiative for the PHA UK community.

> *"Our new fundraising lottery is designed to be a bit of fun...and a valuable new source of regular income for the charity."*

"We don't charge a membership fee to join PHA UK and this is an alternative way for people to support the charity on a regular basis if they'd like to – as well as enjoy taking part, with the chance of winning cash prizes for themselves and their families.

"The more people who enter the lottery, the more we raise for the charity and the bigger those cash prizes will become."

We'd love to hear from PHA UK lottery winners in next issue of Emphasis magazine! If you'd like to celebrate your win with us, please e-mail editor@phassociation.uk.com *or call Shaun on* 01709 761450.

STEP-BY-STEP GUIDE

HOW TO ENTER THE PHA UK LOTTERY

- To become a PHA UK Lottery player simply go to www.unitylottery.co.uk (or follow the link on PHA UK's website)
- Click on the 'Play Now' button and then select PHA UK from the list of charities.
- This will take you to the PHA UK lottery page from where you can join by either downloading an application form to post - or sign up for a direct debit.
- You'll be given a six digit lottery number – which is yours to keep as long as you choose to play.
- Every Saturday a winner will be drawn and a prize cheque will be posted direct to their address – (so winners don't have to do anything to claim)
- The size of the prize depends on how many people have entered the lottery that week!
- Please note, you must be 16 or over to enter.
- See www.unitylottery.co.uk for more information or call the PHA UK office on 01709 761450 for advice.

Vital research into blood samples **offers future hope**

The Pulmonary Hypertension Biobank is an important research initiative which aims to help us better understand the development of the disease and bring about new treatments which could reverse PH rather than solely fight its symptoms. Here, Deborah Wain finds out more from *Dr Allan Lawrie*.

Have you had a blood sample taken for research purposes? If so, you're not alone. Hundreds of pulmonary hypertension patients are taking part in a world-leading research programme aimed at bringing about new treatments for the disease.

The Pulmonary Hypertension Research Biobank is a growing store of blood products which are being analysed by scientists to better understand the basic biological workings underlying the development of PH.

The collection, held at the University of Sheffield Medical School and the Royal Hallamshire Hospital, includes 900 samples taken from 400 patients since it was set up in 2009. Where the study is unique is that it gathers samples from patients from before their diagnosis and over the longer-term as they undergo therapies.

Dr Allan Lawrie, who leads the team behind the research, believes it will lead to breakthroughs in treatment in the future as tools the scientists use for analysis become ever more sophisticated.

The Biobank was established through close collaboration between the Department of Cardiovascular Science at the university, the National Institute for Health Research Clinical Research Facility, and the Royal Hallamshire's Pulmonary Vascular Disease Unit – the UK's largest PH centre.

Patients are asked for their consent to take part in the study on their first clinic visit and, if they agree, the first blood sample is taken during the right heart catheterisation test. Subsequent samples are collected at least once a year. One patient involved from the start has provided samples at 11 separate visits.

Tens of thousands of pieces of data have been accrued which are then merged to highlight patterns.

On its arrival in the laboratory, located adjacent to the PH centre, the blood is processed into different components before being put in frozen storage at -80C and then analysed to address questions about the progression of PH and the disease's response to treatments.

Tens of thousands of pieces of data have been accrued which are then merged to highlight patterns.

One key area of focus is identifying biomarkers – biological properties or molecules that can be measured – and identifying new targets for drugs. There has been significant progress looking at the role of a specific protein.

Four out of ten patients at Sheffield have participated in the research as not everybody is suitable.

The age of patients ranges from early 20s to 70s and they live as far afield as Liverpool and Birmingham. Blood taken from those patients who do not go on to be diagnosed with PH also provides valuable information.

Allan said the resource is shared with other scientists nationally and internationally in the drive to develop treatments that can reverse PH rather than solely fight symptoms.

He said: "Because lung tissue from transplants has become increasingly rare, we're using blood as a model for what's happening in the lungs. We've built up a huge resource by approaching the Biobank in a systematic way and maximising the strong position of UK centres to access the 'treatment naïve' - patients who haven't started treatment.

"By sitting clinical and biological data alongside each other we've learned so much already and understand much more about how the disease works. Although new treatments have so far come from pharmaceutical-driven research, research from the academic community is starting to filter through.

"Because PH is such a rare and diverse disease, we need to keep adding to the Biobank. We're hugely grateful to the many patients who are giving us their blood for research and want them to know the importance of it. We can't say when it will be but there's no doubt there will be improved treatments coming through from this research."

"Because PH is such a rare and diverse disease, we need to keep adding to the Biobank."

The programme, which involves a team of research nurses, scientists, data coordinators and students, costs over £75,000 a year to run. Initially the Biobank was funded through a National Institute for Health Research Biomedical Research Unit. Since 2012 costs have been met by the British Heart Foundation (BHF) from a study researching novel biomarkers. It's hoped funding can be secured from BHF for the next five years.

Allan would like to set up a patient panel to feedback findings to patients and find out ways the patient experience can be improved further. Anyone interested in taking part should contact Allan at a.lawrie@sheffield.ac.uk ●

ALWAYS
BEING THERE

Suzanne and John Calder's daughter Sarah was diagnosed with pulmonary hypertension at the age of 25. Here, Suzanne tells us about the family's difficult journey...

I don't think we took it in straight away. It was a very big shock, especially to Sarah, and to be told this on her 25th birthday as well. The doctor told us about the medication they would put her on and then, the cruellest blow, that it would not be wise for Sarah to have children because of the risk involved. I can't explain the feeling that you have at the time. We felt worried, angry that this has happened to our daughter, but we tried to be strong for Sarah and her husband Grahaeme. This is our family's story."

Shortly after Sarah was born in 1974 the doctor discovered a problem with her heart, and advised us to take her to a specialist at Cheltenham hospital. My husband John and I immediately panicked but after a year of tests they finally concluded that it was a heart murmur.

Sarah grew up a normal healthy child and when she reached 18 she needed another check-up on her heart murmur. We were told that the right side of her heart was enlarged but that there was nothing to worry about. Looking back now, I often wonder if this had been checked further would the doctors have found more, but of course in those days I do not think they had even heard of PH.

Sarah went on with her life, going out to work and socialising. She met Grahaeme and they moved to Oxfordshire where she started going to the gym every week. But a couple of times she rang me to say how tired she was getting all the time. When Sarah caught an infection, which she could not shake off, she went to see her doctor who told her it was just a cold.

The place where she worked had stairs which she was finding difficult to climb. She decided to see another doctor and on that day she was late and had to hurry up a hill to get to the surgery. He could see how out of breath she was and did a quick examination, listening to her heart and checking her nails (which were tinged blue) and her lips which were also blue.

Following two weeks of tests at the John Radcliffe Hospital in Oxford, we were all in the room when the doctor told us about this very rare and serious illness called Pulmonary Hypertension (PH). What shocked us the most was the doctor saying it was an incurable illness.

Sarah was put on medication in a tablet form, and later sent to Papworth Hospital for more tests which revealed that she did have a hole in the heart after all, however this was actually helping her PH. She was put on another medication, Iloprost, which had to be injected into a nebuliser and inhaled seven times a day. Learning how to mix the medication made us all feel we were helping in some way.

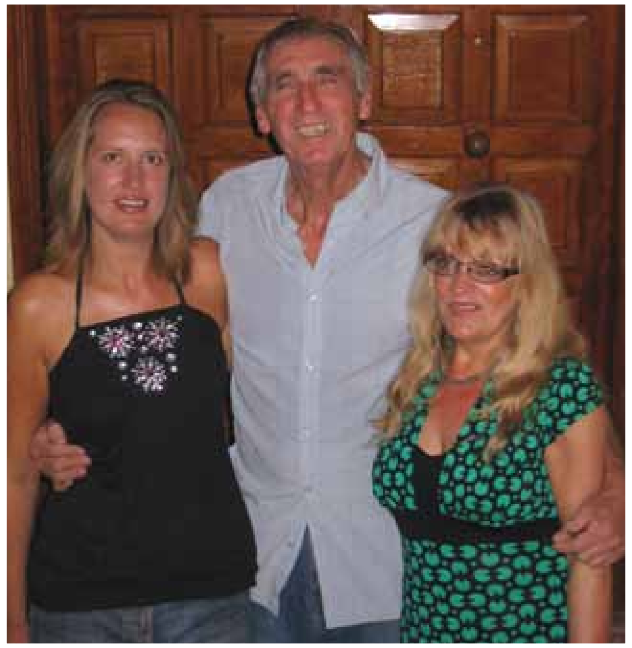
As this illness is progressive Sarah has had to give up a lot of things that she used to do, like going to the gym, dancing and cycling but she did not let her illness dominate her life. She decided to give up working full time and started to take on courses like sewing and writing.

Sarah was put on Bosentan about ten years ago, which she was very happy about, especially as it helped her through her wedding day. She has been on one drug trial and done a few things for PHA UK trying to raise awareness and funds. She now goes cycling as she and Grahaeme bought an electric bike which is great for her especially going up hills. She also does Pilates and tries to walk as often as she can.

Sarah has had this illness for 15 years. She is now 40 years old and has learnt to live with it very well. She has oxygen every night and uses a mobile oxygen machine, which she can take away with her at weekends and on holiday.

I believe that the best thing any parent can do with a child who has PH is to hope that they grow up with a positive attitude, change their life style if necessary and make changes to help their illness. Above all it's important for them to have loving family and friends around them whenever they need them.

John and I have learnt a lot about this illness from going to PHA conferences and keeping in touch with the PHA UK, but above all we have learnt from Sarah to stay strong and be positive. One day there will be a cure, but until such time we carry on with our lives and will always be there for our lovely daughter, of whom we are very proud. ● ”



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

Emotional well-being

Clinical psychologist Emma Offord talks to Steph Pollard about dealing with the emotional challenges of PH

Living with pulmonary hypertension does not just have a physical impact – many aspects of the condition, its consequences and treatments can also have a significant impact on people's mental health and emotional well-being.

Dr Emma Offord is a clinical psychologist attached to the PH team at Papworth Hospital in Cambridge. In this role, she has one day a week dedicated to working with PH patients and has supported more than 150 people over the last two and half years.

Emma says: "As part of the PH medical team, it is my role to explore the potential impact of PH on people's emotional health and their quality of life. Individuals' lives are affected in a number of ways, for example, loss of self-confidence, concerns about work or studies, giving up the things they enjoy, the impact on their relationships and their hopes for the future.

"As well as identifying difficulties associated with PH, my job as a psychologist is to explore how an individual might like their life to improve alongside their condition and help them to develop new and existing skills towards desired changes.

"At Papworth, we recognise the clear psychological and emotional challenges of PH, related to adjusting to the initial diagnosis; or learning to balance the restrictions of the condition and its treatments with living a meaningful and active life.

"Some people struggle with the changing perception of their identity and sometimes body image as they start treatment with, say, a Hickman line; use a wheelchair to conserve their energy or require daily oxygen.

"Some young women and their partners have to work through the fact that it may not be possible to have children.

PHA works in close partnership with Anxiety UK and funds access to a level of free support through this charity dedicated to helping people deal with anxiety.

"Others with PH have gone through overwhelming experiences such as frequent episodes of breathlessness when they are out and about or alone at home – fear of this happening again can cause tremendous anxiety.

"Still others face the prospect of complex surgery, intrusive therapies and of course some have to mentally prepare for transplant.

"The condition can also transform relationships and we can support patients and their families to deal with that too."

Emma says: "Typical problems can range from simply feeling low to being more deeply depressed. People may feel anxious, worried, angry, afraid or experience panic attacks. I talk to patients about a very wide range of issues prompted by PH."

Emma makes an assessment of people's needs and either offers support and therapy herself or refers patients on to support based closer to a patient's home.

Her referral reports then help to outline the impacts of PH to those who may not be so familiar with the condition and its treatment. Emma often refers patients through Anxiety UK which has a network of qualified and competent psychologists and counsellors across the country.

PHA works in close partnership with Anxiety UK and funds access to a level of free support through this charity dedicated to helping people deal with anxiety. PHA UK will fund the first session of any course of therapy a PHA UK member opts to take through Anxiety UK. Plus, there is a free Anxiety UK helpline for PH patients on **0844 332 9010**.

Emma, who previously worked in paediatric mental health at Great Ormond Street Hospital, recommends the support offered via Anxiety UK.

"The relationship with PHA UK works really well and it is good to have a network of professional therapists across the country to refer patients on to for support.

"Some people still do struggle to ask for help or admit feelings of vulnerability when they are going through so much with their condition.

"Some people can find it helpful to cope with the changes to their life by challenging the physical and social restrictions. This can be a useful strategy, in terms of continued independence and confidence; however, it can also be exhausting and not always manageable. We encourage people to balance their health with their abilities and to seek support to maintain their independence. Sometimes therapy can make a really positive difference to their lives by addressing these issues." Emma uses a range of therapeutic approaches, including narrative therapy.

Emma says: "This approach encourages individuals to step away from a dominant story about their life and identity defined by their health condition, towards a preferred untold story with more possibilities for a meaningful and enjoyable life."

She also uses mindfulness to help tackle anxiety and regain a sense of physical and emotional calm; plus cognitive behavioural therapy (CBT) to help people tackle their worries and develop more helpful thought processes and perspectives. ●

Anxiety UK is a leading charity which works to relieve and support those living with anxiety disorders by providing information and support. The organisation provides a dedicated free helpline for PHA UK members if they are feeling depressed or anxious and need someone to talk to. If a person with PH would benefit from face-to-face therapy with a professional, this can also be arranged and PHA UK has committed to fund the first counselling session for members who use this service.

To speak to someone about how PH is affecting you or a loved one, please call 0844 332 9010 or visit www.anxietyuk.org.uk

What is anxiety?

Anxiety is the feeling you have when you think that something unpleasant is going to happen. It is completely normal and something that all human beings experience from time to time. The word 'anxiety' is often used to cover a broad range of experiences and is linked with emotions such as fear and worry. It can become so severe and intense at times that it becomes debilitating and starts to restrict daily routine and life as a whole. People often experience physical, psychological and behavioural symptoms when they feel anxious or stressed. Some of the most common physical symptoms of anxiety are difficulty in breathing, hyperventilation, palpitations, increased heart rate, chest pain, dizziness, feeling sick, dry mouth and shaking. A number of these physical symptoms are also symptoms of PH, which can be particularly difficult for sufferers. One of the things people most commonly do, when faced with a situation which makes them feel anxious, is to avoid it. Although avoiding situations may give immediate relief from the anxiety, it is only a short term solution. As anxiety can affect individuals in many ways the methods for treating it can also vary and include guided self-help, exercise, counselling to cognitive behavioural therapy (CBT). An individual is usually offered self-help in the first instance, followed by more intense interventions, such as talking therapy or medication.

Fundraising roundup

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

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

£13,830 RAISED

Jumping at the chance to raise money

Sheena Robinson and her sister Suzie Pigg have raised an incredible £13,830 over the last ten years, through the annual Chesterwood Showjumping and Pony Sports Day, held near Hadrian's Wall in Northumberland. Sheena, who has PH, is very proud that the whole family is involved. "I used to ride but, these days, I've handed over the reins to my 13-year-old daughter Harriet and my nieces Ella, who's 10, and Nancy, 5." The show even includes a dedicated PHA fence.

PHA hogs sharpen knitting skills

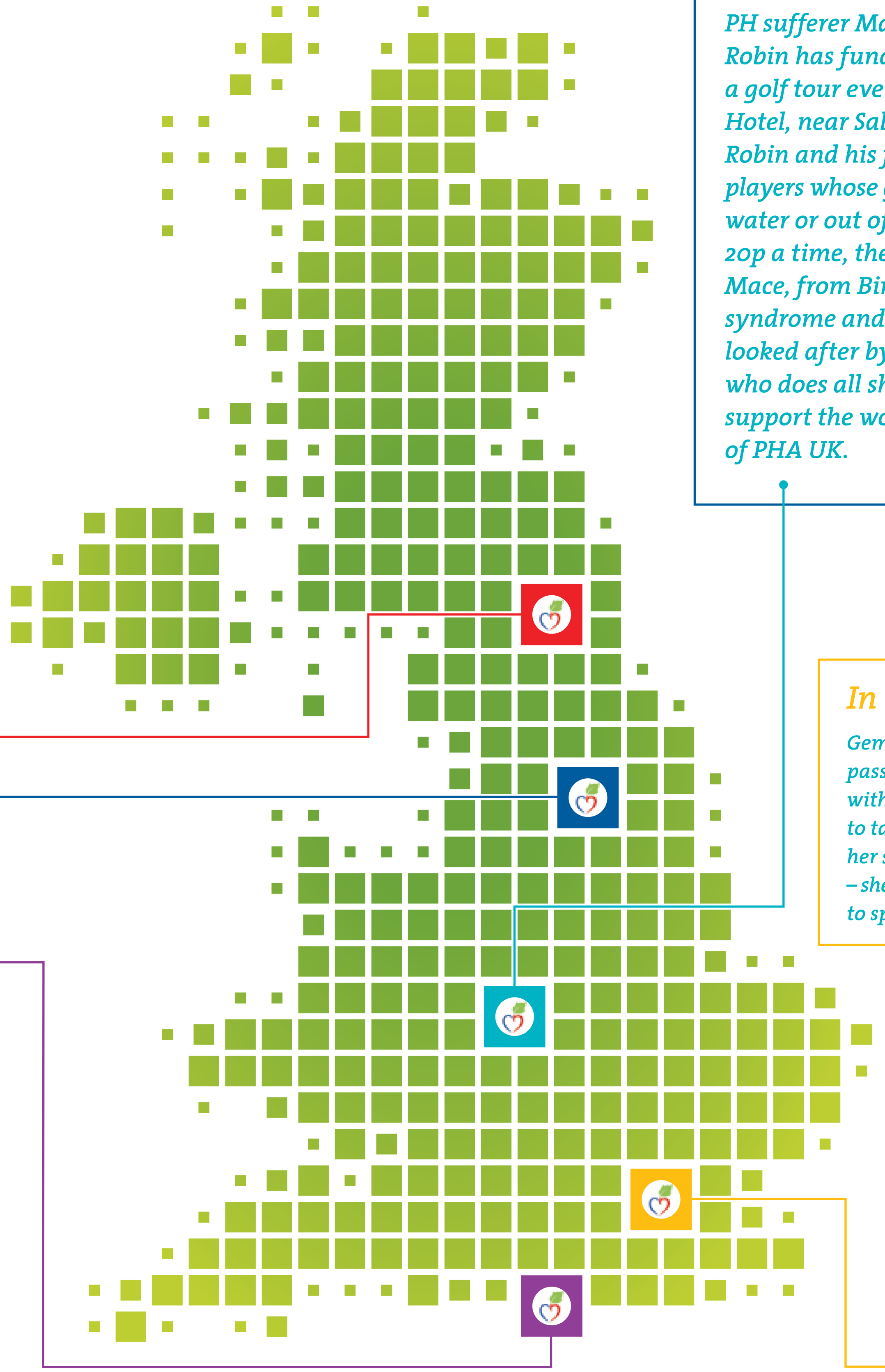
Since losing her mum, Margaret Boyle, to PH in 2011 Michelle Todd of Wetherby wanted to do something to raise money for PHA UK. Having inherited her mother's knitting needles she asked her aunty to teach her the basics. "Initially I made some Easter egg cosies which were really popular with friends and colleagues and raised £140 which was match-funded by my employer Lloyds Bank," said Michelle, aged 49. She then took on a rather prickly knitting challenge when her husband spotted a pattern for hedgehogs. She produced a range of 'PHA Hogs' and struggled to keep up with demand at Christmas. In total Michelle has raised £640 and is now planning this year's knitting challenge – fluffy PHA owls.

£640 RAISED

On your bike – around the Isle of Wight

When Alice Parker's father and uncle announced that they were going to cycle around the Isle of Wight to raise money for PHA UK, she didn't want to get left by the wayside. Alice, 21, who lives in Surrey and whose younger brother has PH, joined forces with her boyfriend Oliver to tackle the 80 mile route - a total of 5,000 feet of climbing. "It took us two days and on the second day I got a puncture just after stopping to admire The Needles," said Alice. "After that my chain kept coming off whenever I changed gear, but I managed to finish the ride." Alice's sponsored adventure raised £765 for PHA UK.

£765 RAISED



A 'hole' lot of money

PH sufferer Mace McConnell's Uncle Robin has fundraised for PHA UK through a golf tour event at Hunley Hall Golf Hotel, near Saltburn, North Yorkshire. Robin and his friends decided to penalise players whose golf balls landed in bunkers, water or out of bounds. By fining everyone 20p a time, they raised an amazing £400. Mace, from Birmingham, has Down's syndrome and a tracheostomy and is looked after by his mum Maureen who does all she can to support the work of PHA UK.

£400 RAISED

In at the deep end

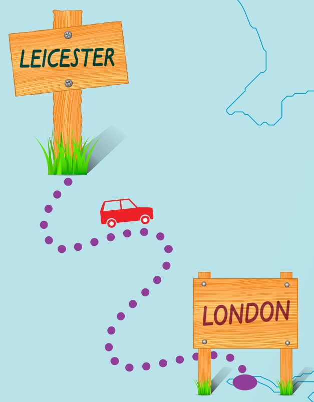
Gemma Elliott-Wetton's father, who passed away after being diagnosed with PH, had always encouraged her to take part in triathlons because of her swimming and running abilities – she just needed to get her cycling up to speed. So Gemma, 26, started training and signed up for a triathlon near Windsor last year. Gemma said: "It was a glorious day and I had family and friends there to support me. I felt really good until the run at the end which was tough, but I crossed the finish line in two hours 41 minutes which was 20 minutes faster than my target." Gemma, from Buckinghamshire, raised £2,565 and felt she had truly done her father proud.

£2,565 RAISED

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

Catherine's Wish

Meeting BBC celebrity Chris Evans has been just one highlight in Catherine Dunphy's busy diary.



For Catherine Dunphy, who turned 12 in February, there has been a lot to celebrate in recent times. She's started high school, twice abseiled off a viaduct during a school outdoor pursuits weekend and taken up yoga. But the real highlight came when she was invited to the London studios of Radio 2 to meet one of her favourite celebrities, breakfast show star Chris Evans.

Diagnosed with PH as a toddler, Catherine, from Leicester, was in and out of hospital but, since the age of seven, her condition has stabilised on combined oral therapy.

She still struggles with the debilitating effects of PH, but is very determined and aims to do everything her school friends do.

Mum Kim Sutherland said: "Catherine's amazing. She never complains. She's a happy girl and our approach is always to get on with life as far as we can."

As a new-born, Catherine's breathing was laboured, but initially medics thought her throat was the issue.

At 18-months-old she underwent a routine bronchoscopy – a test to view the airways – but it left her in intensive care. PH, however, was not picked up.

> *"Yoga has helped to improve Catherine's posture and aid her breathing, and she's now started Pilates."*

It wasn't until a year later when a heart consultant at Leicester's Glenfield Hospital referred Catherine to Great Ormond Street Hospital that she was finally diagnosed.

It's now recognised that Catherine has a condition called 'patent ductus arteriosus'. A duct which usually closes at birth remained open and caused an excess flow of blood to her respiratory system, causing damage to her lung bed. This may be the cause of her PH.

Catherine's PH diagnosis came shortly after Kim had given birth to son Jon and, like many patients or family members, she had never heard of the condition. It was a bewildering and traumatic time.

Catherine was put on Bosentan and then, as medical data suggested she was getting worse, also Sildenafil. She was repeatedly hospitalised with chest infections and respiratory problems.

Kim, a self-employed garden designer, remembered: "Catherine's prognosis wasn't very good. It was all very hard and bleak for that first four years."

However, since the age of seven, Catherine has, said Kim, "done brilliantly". Her PH has been re-categorised from 'severe' to on the 'severe/moderate' border.

Although she can't walk far, Catherine doesn't miss out on activities, and takes part, if need be, with the help of Kim. For example, during Halloween 'trick or treating' she hitched a car ride with her mum.

Catherine has been on all her class outings, including the adventure weekend in the Peak District when she surprised everyone with the abseil.

She uses oxygen but generally not during the day.

Yoga has helped to improve Catherine's posture and aid her breathing, and she's now started pilates. The family has also sought alternative therapy for Catherine in the form of acupuncture and reflexology, which they say has also helped her.

Asked for her thoughts on having PH, Catherine said: "I don't mind missing PE when it's cold and wet but I'd like to be able to run with my friends."

Catherine, who has a pet dog called Seven, loves animals and is interested in following a career working with them.

The youngster's visit to the BBC was organised through the charity "Wishes for Kids". Accompanied by Kim and Jon, now aged nine, she had a full day out in London including a ride on the London Eye and trip to toy shop Hamley's.

Kim said: "Catherine met Chris and other presenters on his show. He was lovely; really warm. Catherine loved the experience."

While Catherine was once visiting PH specialists every three months, her visits are now down to once a year, although she's checked at Glenfield's cardiology unit each month.

Kim expressed her appreciation to healthcare staff, including the "dedicated" PH team at Great Ormond Street and also to PHA UK. The family have greatly enjoyed taking part in family weekends.

Kim added: "We're very grateful for the fabulous treatment and support and for the fact that Catherine is doing so well." ●

We are
15 years young!

PHA UK ANNIVERSARY
15
YEARS
2000 2015

PHA UK is marking its 15th anniversary in 2015. Together, we have achieved an enormous amount over the last decade and a half. We have worked to promote better awareness of pulmonary hypertension; support the advancement of new and improved treatments and therapies and support those affected by the disease. There is plenty more to do, but here are just a few highlights along our way so far....

Our amazing journey begins...

2000
PHA UK registered with the Charity Commission

2000
PHA UK helpline staffed by volunteers introduced

Sept 2001
First national PHA UK conference held in Derby

2002
First pulmonary hypertension impact study undertaken

Nov 2002
Government's All Party Committee for Pulmonary Hypertension formed

April 2004
First PHA UK family weekend held in Chester

2004
PHA UK delegation attends international PH conference in Miami

April 2006
PHA UK hits its first 1,000 members

Dec 2006
PHA UK delegation visits No 10 Downing Street to ask for political support against potential funding cuts for PH drug therapies

2007
PHA UK takes on its own office and small staff in Rotherham, South Yorkshire

Spring 2007
NICE decision to no longer recommend funding for PH drugs is overturned, in a large part due to PHA UK campaign

2011
Understanding and Living with Pulmonary Hypertension' publication gains recommendation of British Medical Journal (BMJ) which recognises high quality patient information

Nov 2011
First students taken on to PHA UK's Medical Educational Programme

March 2012
First issue of the Emphasis magazine published

Jan 2013
PHA UK and University of Manchester begin an 18 month longitudinal ImPAHct research study exploring exactly what it is like to live with PH, both for the patient and their families

June 2014
PHA UK founding member Kay Yeowart awarded MBE for her services to those affected by pulmonary hypertension

Sept 2014
PHA UK is the only UK health charity to take a stand at the European Respiratory Society's Congress in Barcelona, which attracts 20,000 health care professionals

> *"The PHA UK have been absolutely brilliant. If you've got a problem you can just pick up the phone. And at the family weekends you get to meet other people who are in the same position as you, which makes you feel as if you're not alone."*
> **Maureen, mum of Mace McConnell, Birmingham.**

> *"If you look back fifteen years, there were a couple of treatments on the market, but now we have a lot more oral agents available, which are preferable forms of treatment for many patients. And new developments are happening all the time."*
> **Paul Sephton, charge nurse at Sheffield Royal Hallamshire Hospital**

> *"Since I joined the PHA they have done a great job in helping me whenever I have phoned or emailed them, they really have made what was a very difficult time, easier."*
> **Sandra McEwan of Flamborough**

> *"PHA UK is an amazing association. They work so hard for patients, from the research that goes on in PH centres to the material they produce to help people come to terms with a serious diagnosis. It's not easy to set up a charity representing people with a rare disease that affects relatively small numbers but the team is very focussed on helping its members, both patients and carers."*
> **Carl Harries, clinical nurse specialist at Royal Brompton Hospital, London**

> *"The support and information provided to me by the PHA UK...provides me with much needed information and, just as importantly, reassurance."*
> **Nigel Willetts of Bath**

Special 15th Anniversary EVENT

A celebratory weekend event is being held to mark PHA UK's 15th anniversary year. The family-friendly conference will take place at Heythrop Park in Oxford on 30th & 31st October and 1st November.

PHA UKs 15th anniversary event will feature a programme of talks and workshops about PH led by high-profile speakers – as well as social and leisure activities for all ages.

Chair of PHA UK Iain Armstrong said: "As it's our 15th year, we wanted to do something a little different by combining our two annual flagship events – the conference and the family weekend - into one.

"Our celebration weekend will be a family friendly conference where children are more than welcome. We will have our usual conference programme with a range of expert speakers talking about the latest developments in PH – plus activities for families as well. We see it as an occasion for patients, families, carers and PH professionals to come together, share experiences and enjoy themselves."

PHA UK events have always provided an opportunity for adults and children with pulmonary hypertension and their families to meet other people in the same circumstances.

Past events have been very successful with many people feeding back how much they have learned; and with many lasting friendships having been made.

Heythrop has been used as a venue by PHA UK before and it is felt that its large grounds and excellent conference facilities will offer opportunities for both serious discussion and relaxation this year.

The programme of speakers for this event is being prepared and will be announced in the next issue of Emphasis.

If you would like to attend the PHA 15th Anniversary Celebration Weekend please complete for form below and we will send you more details. Or, you can register your interest via our website www.phassociation.uk.com.

Places are limited, by the size of the venue, so please do respond as soon as possible via the slip below. We will then send you an official invitation and a chance to apply for a place – all bookings will be handled on a first come first served basis.

PHA UK 15th Anniversary Celebration Weekend

To be held at Heythrop Park in Oxford on 30th & 31st October and 1st November 2015.

Please send me more information about the above event:

NAME ....

ADDRESS ....

....

.... **TELEPHONE NUMBER** ....

E-MAIL (if applicable) ....

Please post this slip to: **Freepost, PHA UK**

CELEBRATORY WEEKEND
30TH OCT TO 1ST NOV 2015

> *"As it's our 15th year, we wanted to do something a little different by combining our two annual flagship events."*

the*interview*

Professor **DAVID KIELY**

in conversation with

Deborah Wain

Professor David Kiely has been working with patients with pulmonary hypertension for 20 years. He was appointed director of the Sheffield Pulmonary Vascular Disease Unit in 2001. The Sheffield unit is one of the largest PH centres in the world and assesses and manages all forms of adult PH.

David was given the honorary title of professor from the University of Sheffield earlier this year in recognition of what's been achieved in Sheffield in terms of the unit and research. He is involved in a large number of professional groups and chairs the UK and Ireland Physicians Group. David is married to Jane and has four teenage daughters.

Q. What prompted your original interest in PH?

A. *One of my first jobs was in respiratory medicine where we saw a lot of breathless patients and I enjoyed trying to work out why patients were breathless and seeing the improvements that drugs could make. I was encouraged to do some research with heart scans to measure the pressure in the lungs to try and understand what different infusions and drugs could do to the blood vessels in the lungs in healthy people and in patients with lung disease.*

In 2000 when I was looking for a consultant post very few people had any experience in PH, so I guess I was in the right place at the right time. I started working in Sheffield in 2001, which was a time of great change in PH. It was nice then to be involved in trials with drugs that worked on pathways I had been interested in during my research.

Q. What does your current role involve?

A. *I work in Sheffield as a doctor. The majority of my time is spent with patients with PH. A lot of what I do is asking people what limits them in their daily activities, doing tests to find out why people are breathless and thinking about ways of how to improve things. I spend a lot of time discussing different treatments with patients and their families and trying to help people adapt and plan for the future.*

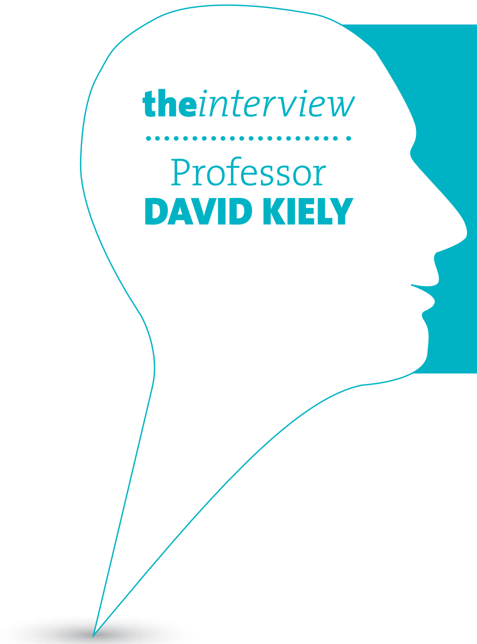
I'm also involved in research and teaching. In Sheffield we have a large Biobank where we take blood samples and perform scans at every visit then follow up patients over many years to try and understand why some patients get better on some treatments and others do not. With colleagues we're developing new ways of measuring how well the heart is working and what's happening to the blood vessels in the lung.

What's also very important is trying to develop and assess the effectiveness of new treatments for PH and I spend quite a lot of time with patients talking about clinical trials. We've been involved in a lot of studies over the last decade and it's been great to see many of the drugs that have been studied now being used to improve the quality of life of patients.

As part of my job I also spend time in meetings to try and plan how best to provide services and keep myself up to date. It's a busy but varied job and I'm lucky to meet lots of different people. It's humbling to see how patients and their families cope with PH and inspiring to see what fulfilling lives many lead.

Q. What developments have you seen during your time working with PH patients?

A. *Establishing national specialist centres in the UK is one of the most important developments. This has allowed us to understand more about this rare condition and help us to study new treatments by ensuring patients are seen by doctors and nurses who understand the problem. Over the last 15 years we've seen numerous new treatments licensed for PH and curative surgery for patients with chronic lung clots. We have also seen the development of powerful scanning techniques such as CT scanning and MRI which help us find out more about why*



the*interview*

Professor
DAVID KIELY

> *“I spend a lot of time discussing different treatments with patients and their families and trying to help people adapt and plan for the future.”*

people have PH. With the PHA UK, we’re also understanding more about the journey patients and their families are on and the importance of listening to patients. This has led to the introduction of help to support patients that does not involve drugs and surgery.
I can’t think of any other branch of lung or heart medicine where there have been so many new drugs and surgical treatments successfully developed over the last decade.

……

Q. What are you most proud of about the PH centre in Sheffield?

A. *I’m most proud of the courageous way our patients cope. For some, this may be managing to get out of the house and for others it may be going rock-climbing! I like to feel that we have played a small part in helping patients to achieve this. I’m also very proud of the staff, who take a great pride in what they do, will always go the extra mile and, importantly for a close knit team, respect the value of everyone’s role. I’ve never liked stuffy environments so I would like to think patients and their families find all our staff approachable and our unit welcoming.*
Sheffield has a long history in the PH field. Donald Heath who described the severity of changes in blood vessels in the lung in PH (a system still used today) was a medical student and junior doctor here in the 1950s when Sheffield was one of the first places to start measuring pressure in the lungs using heart catheters. I’m very happy that we have tried to continue the PH tradition in Sheffield and that our research involves the input of nurses, pharmacists, doctors, scientists, physicists, mathematicians, IT experts and engineers and it is focused on improving outcomes for patients, many of whom are active participants in research and inform what we do. We are trying to answer some big questions, which means we need to work with people with lots of different skills.

……

Q. What positive developments are giving you hope for treatment advances in the future?

A. *We’ve made a lot of progress over the last 10 to 20 years but finding a cure or trying or prevent the development of PH will require a huge effort from patients, healthcare professionals, industry, researchers and others. The fact that the world is becoming a smaller place and people are working more closely and sharing information and ideas will ensure we continue to make progress. I think the past is often the best guide to the future. Everything points to major progress in the years ahead.*

……

Q. What does the professorship mean to you?

A. *It’s important for our PH centre within the university that we’re recognised, so we can get additional funding. In that sense, having a professor title can be helpful. We’re very lucky that the university is supportive of what we do and we are hopeful that over the next few years we may be able to develop a large Pulmonary Hypertension Research Institute. Personally the professor title just re-enforces the opinion of my family that I’m turning into an old fart!*

……

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

A. *The PHA UK is one of the reasons that we’re able to provide the care for patients that we do. They are involved in a lot of work behind the scenes lobbying MPs and working with NHS commissioners to make sure PH is on the radar. They also work very closely with healthcare professionals and patients and have produced wonderful materials, books, newsletters, videos, internet resources and educational courses that we use every day. I’ve known the association’s Kay Yeowart and Iain Armstrong and several patients who are on the PHA UK committee for many years and have witnessed at first hand all the great work they do.* ●

Tai chi…

help relieve anxiety

Most people have heard of tai chi's benefits for physical health, but what you may not have heard is that it can also be beneficial for improving mental health too…

by Fiona Anderson
www.taichiinstructors.co.uk

Fiona Anderson

Tai chi…

help relieve anxiety

I myself used to suffer from such severe anxiety that when I first started tai chi, it was six months before I could speak to the chief instructor. At that time I used to find it hard to practise anything because I was so stressed about being watched and that stress increased exponentially if any one of my instructors gave me the most gentle helpful hint to improve – all I could take in was how I wasn't perfect.

I persisted with tai chi because I felt myself getting healthier physically (after years as a couch potato). After a while I began to notice that I was becoming calmer and more able to take in the gentle corrections from my kind and patient instructors. I was still very anxious, but not anything like the same stress-out level of anxiety.

Now, 7 years later I am a happy confident person not only in tai chi but also in my life generally. How did tai chi help me achieve such relief and freedom from anxiety?

Well, it's a whole host of things that tai chi gives you, working together:

- *Focus on the physical actions of the body*
- *Achieving something through persistence*
- *Staying in a new environment through persistence*
- *Being in control of your own progress*

Let's take those one at a time:

Focus on the physical actions of the body

Mental health conditions are all worsened by the relentless spiral of negative thoughts, reinforcing each other and taking you downwards. Having something physical to focus on (e.g. how to place your feet correctly) means that your mind is taken out of the thoughts and into the physical focus instead.

Since learning tai chi involves learning one correct placement (of foot or spine or hand, etc) after another, this means your mind has a series of physical things to focus on in sequence. Practising just a short small sequence of movements over and over is necessary to learn them with your body as well as your mind, so it's integral to tai chi to be taught how to learn in this way.

This means your mind is getting regular and intense practise in how to focus on body parts rather than thoughts, taking you out of that negative spiral of thoughts and giving you some much needed relief from them.

Achieving something through persistence

When I started tai chi, I had no idea that it was even possible for me to be good at any sport; I just wanted to do something unthreatening.

Just doing the movements in the tai chi class then practising them at home on my own meant I was feeling physically better, so I kept on with it. My instructors kept telling me to relax, it didn't matter if I got it wrong, what mattered was that I should keep trying, as I was learning how to learn.

I took ages to learn any small sequence, while some others powered ahead. But as my instructors all told me, everyone needed to learn at their own pace and all that mattered was trying to practise with a sincere heart. After a long while I had learnt my way through 54 of the 108 sequences. This was amazing to me. I'd always had such a negative self-image with regard to sporty achievements. I can't begin to describe the feeling of achievement!

Persistence is the key to progress and progress means you feel better about yourself; then your anxiety about yourself lessens. Just stick with it and don't worry about where you are and one day you will have achieved something you thought was not possible at all.

Staying in a new social environment through persistence

As I mentioned earlier, I couldn't talk to my Sifu (chief instructor) for months on end at the beginning. I also had severe anxiety about talking to others in a social situation. But talking to people wasn't actually required. I could just drink tea and listen to others in the tea breaks. I was just one of the students, among all of us just sitting there, some drinking tea, some chatting, all being accepted as being part of the class.

Just keeping going there, doing my training, drinking tea, becoming part of the group, over time helped me relax. After a while, I learnt how to talk with the other students. We all had the tai chi to talk about, so no artificial seeking a topic. These days, I can crack a joke, or sit quietly listening to others, or rabbit on myself. I am no longer anxious about being in company. Tai chi helped me relax in a non-threatening environment, helping me see that I was accepted for being myself and didn't have to do anything to justify being present. This helped me feel far less anxious in social situations and far more relaxed generally.

My previous anxieties about whether people liked me, or how I could make them accept me have all gone, as I began to realise what mattered was how I could feel more relaxed in myself, for myself.

Being in control of your own progress

What's really great about tai chi, is that it doesn't matter what the pace of your progress is because there is no end goal. All you need to do is concentrate on what you're learning at that moment; to concentrate on learning that action; on repeating it over and over again; to take it into your body memory as well as your mind memory. You are told quite clearly from the start to relax into learning just what you're on then and not to even think about getting to some goal.

I used to worry a lot about people watching my lack of progress, but as this message was reinforced over weeks and months, I started to stress less about my very slow learning and began to relax more. It was a lovely feeling once I understood it was perfectly fine for me to be slow, to be a klutz, to be unfit. And to my surprise, as I relaxed about being this way, then I began to slowly improve, to slowly become less klutzy, to slowly become less unfit, to slowly become able to take in more.

My instructors told me, "Don't worry about where you are. Don't compare yourself to others. Just look at how far you've come since you started. Compare yourself now to yourself then and be happy at your progress". This is what I tell my students myself these days too because as you relax into celebrating yourself now and then, you feel much better about yourself, you lose all that performance anxiety and you can just be happy about what you're doing. Then one day you'll notice with surprise how far you've come – all due to relaxing into being yourself.

Relax and you will progress at your own pace. It's the relaxation that helps you achieve. Stressing about trying to achieve goal slows down your progress. Practise for the sake of practising and you will get there, without worrying about getting there!

This article first appeared in Anxiety UK magazine

In summary…

Tai chi teaches you to relax about being yourself, about being in various situations, about your progress, about everything really.

As you learn tai chi you learn about being kind to yourself, then you become ever more relaxed and can take in more, both in tai chi and in everyday life.

Your feeling of self-worth can increase through tai chi and this helps you relax into accepting help, rather than being anxious about needing it or about what people think of you.

Relaxation is the key to tai chi and learning tai chi means learning how to relax. Learn how to enjoy your life more; how to enjoy the moments, one at a time, until those moments turn into longer chunks and you can relax into being yourself, for yourself. ●

Making life a little easier **with your medicines**

Concordance – what's it all about? Senior pharmacist ***Neil Hamilton*** explains the latest techniques to help PH patients take their prescribed medication.

Concordance, and sometimes adherence are terms that have become more commonplace health language in recent years, often referring to patients taking their prescribed medication correctly. Previously people may have used the term compliance but this has rather fallen out of favour. Concordance is defined in one of the largest medical dictionaries as being;

> *A negotiated, shared agreement between clinician and patient concerning treatment regimen(s), outcomes, and behaviours; a more cooperative relationship than those based on issues of compliance and noncompliance.*

The word itself has its roots in Late Middle English: from old French (concordant) and from medieval Latin (concordantia), both meaning 'being of one mind'.

It is the sense of a shared agreement which explains why the phrase "compliance" has become less popular, as we move away from the idea that Doctors tell patients what to do and patients have no say in their own management. This old way of thinking is commonly being replaced by patients and healthcare professionals agreeing on the best plan. Whilst the teams at the specialist centres have the knowledge and clinical training, nobody knows you like you do, and the best idea on paper may not be realistic for everyone.

With this in mind, one of the most obvious forms of non-concordance is noted when patients fail to take their medicines exactly as prescribed. There is little research data available specific to Pulmonary Hypertension , but in other long-term conditions, concordance has been found as low as 50%. This means that only half of all patients involved in the project took their treatments exactly as prescribed. This seems surprisingly low, and it would be very interesting to understand what the figure is in the UK and even more helpful to find out why it is not close to 100%. I know that the PHA is doing some work on this so watch this space...

The specialist treatments for PH are expensive and whilst paying for this should never be your concern, the NHS would much rather be paying for a treatment that you will take as prescribed rather than one for which your doses are often late or worse still, missed. With this in mind, there are several options available to patients who, for any reason, are serially 'forgetful' (as opposed to those who consciously decide to take their medicines different to how it is prescribed).

Despite seemingly obvious advantages to using any of the MDS systems, again there is little evidence written in the literature to support their widespread usage.

Royal Pharmaceutical Society's guidelines require that healthcare professionals make sure patients understand their treatments in order to manage them safely. This means ensuring patients have enough information and have the mental capacity and the physical capability to take medicines from their original packs wherever possible. This becomes more of a challenge with an ageing population with multiple diagnoses and hence increasing numbers of medicines to remember and take correctly. Any compliance aid has resource and time implications, which need to be justified in each case. Whilst it acknowledges the importance of compliance aids, the preferred option is medicines dispensed in their original packs. Not least because these ensure all the patient information leaflets are present.

However, as with any part of the agreed management plan, careful consideration of the best way to take the medicines (usually tablets) is absolutely vital. I suspect that some reading this will realise straight away that one of these compliance aids would be helpful, and some will know just how useful they are already from their own experience.

What I hope is that after reading this, everyone gives an extra thought to how they manage their treatment. If you don't or can't take medication as prescribed, the first people to discuss with are your GPs or the team at your PH centre. It is vital that those looking after you know what you're doing so that you receive the best care and advice. After all, if you are taking more (or less) than your doctors think, your own health might be at risk. Don't be afraid to tell them as there will nearly always be a solution that works for everyone.

If you think you'd benefit from any of the compliance aids mentioned, have a chat with the team at your local pharmacy or your centre. They will be arranging them for you so can best advise on what is possible to make sure you get the best possible aid for your circumstances. ●

The phrase "compliance aid" is still used for all of these reminder systems. These range from very simple to more complex ideas:

Medication reminder charts - a chart prepared by the pharmacy with details of the names of each medicine prescribed, dosage, times of day to be taken, potential side effects and any other special instruction, for example with/after food.

Medication administration records (MARs) – used in care/nursing homes for staff to record a signature next to the dose of medication administered to the patient. These tend to have less in the way of additional information.

Monitored dosage systems (MDS) – for example Dosette, NOMAD, Venalink. These may be self-filled boxes containing each day, or each dosage times' tablets. They can also be obtained from the local pharmacy. It is worth checking with your pharmacy if they provide this service if you think you would benefit from it.

Electronic reminders – the newest and unproven, but there are apps available for smartphones, tablets and computers which can prompt or remind patients when their next dose is due. These are in addition to the simple alarm or reminder functions already installed on the devices. Either way, using technology can be very helpful to aid the memory!

The specialist treatments for PH are expensive and whilst paying for this should never be your concern, the NHS would much rather be paying for a treatment that you will take as prescribed rather than one for which your doses are often late or worse still, missed.

Emma's **story**

Cardiff Mum looks back on seven years that changed her life.

> *"Rhiannon is brilliant and helps me a lot around the house, with things like getting the laundry out of the washing machine."*

A Cardiff mum's life has changed dramatically since she first started suffering from symptoms of pulmonary hypertension seven years ago.

Emma Llewellyn-Bishop, 35, of Cardiff, tells us that what she's learned through her experience of coping with the condition is to always "listen to your heart".

It took two years for Emma to be given a definite diagnosis of PH and since then, as well as being a single mum to Rhiannon, she has had to deal with adjusting from being extremely fit and active to needing to use a mobility scooter to get out and about. Then her mum Sheila, who had moved in to support her, sadly died a year ago.

Emma says she has had lot of well-intentioned, but conflicting, advice from others but feels the best way forward is to trust yourself.

She said: "It's really hard and, especially when I was first diagnosed, I felt at times that I couldn't cope. People tell you to do things this way, or that way, but at the end of the day you're living with your decisions and you know what's right for you. You need to listen to your heart."

As a young woman, Emma was a dance student and an au pair and then worked as a head groom at a busy stables, looking after show jumping horses. She also was a regular user of her local gym. In fact, she rarely visited her GP.

All of that changed in 2008 when Emma began suffering from breathlessness and felt "like her insides were being crushed". Her condition worsened and she knew there was something seriously wrong when even her duvet felt "heavy".

Another problem with the rhythm of her heart meant that she was eventually admitted to the University Hospital of Wales' cardiology unit, but it took months before she got any answers as to what was causing her loss of breath and blackouts.

It wasn't until she was referred to the specialist PH centre at London's Hammersmith Hospital that a provisional diagnosis of PH was confirmed. The news came as a relief in the sense that she felt, "it wasn't just me," but understanding the potential effects of the condition was a lot to deal with.

Eventually unable to get upstairs at home, Emma needed to move in to adapted accommodation with a stair lift.

Emma's current treatment regime consists of taking Sildenafil and Macitentan, plus medication for water retention, and she uses oxygen daily. She relies on her mobility scooter to take Rhiannon to and from school, an hour away, and taxis if she needs to go further afield. She would love to learn to drive but can't afford to.

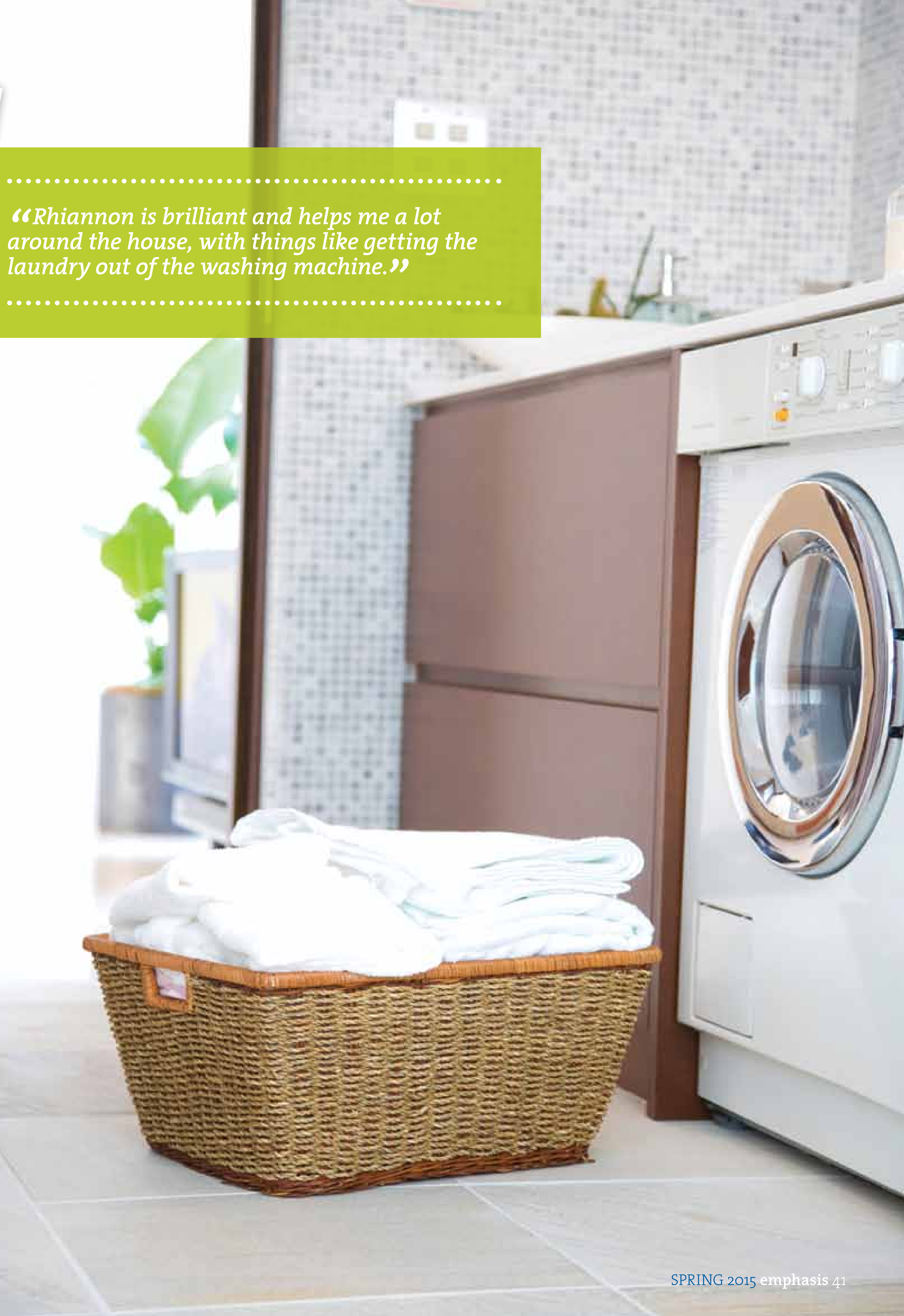
Of her daughter, who turned seven in January, she said: "Rhiannon is brilliant and helps me a lot around the house, with things like getting the laundry out of the washing machine. She keeps me going. I want to see her grow up."

Also a support to Emma are PHA UK and the friends she's made, and is regularly in touch with, through the online forum.

The charity Marie Curie has also helped her access reflexology treatment and assisted in other ways.

Emma says, because she "looks well" she has sometimes had unkind reactions from people while on her scooter but has learned to shrug the negativity off.

"I don't worry about what other people think," she said. ●



Green Leaf Crew!

GREEN LEAF CREW Q&A
MASON LEWIS

Mason lives in Warwickshire with his mum Rebecca, dad Steven and big sister Indianna. Diagnosed with PH at nine-months-old, in 2011 at the age of four, he became the smallest person in the UK to have a lung transplant. Now, aged eight, Mason is the first person to answer our new Green Leaf survey!

Q. What is your favourite biscuit?
A. *Any! But especially Mom's bourbons, I always find where she's hidden them.*
Q. Where do you like to go on holiday?
A. *I like the seaside but we went to Euro Disney last year which was great!*
Q. What superpower would you most like to have?
A. *I like climbing so maybe flying would be cool.*
Q. What is your favourite food?
A. *I like sausages.*
Q. What's your favourite fun thing to do?
A. *I like jumping on the trampoline. My sister is good at gymnastics and she tries to show me stuff.*
Q. What famous person would you most like to have a selfie with?
A. *I've done it! It was with Mickey Mouse.*
Q. Who is the most famous person you've already met?
A. *Apart from Mickey Mouse - Emma Bunton, who was at the Disney Store in Oxford when I went on a Great Ormond Street Hospital trip.*
Q. Do you have a big ambition, a wish or a dream?
A. *I'd like to go to Disney again.*

Tell us a joke:
Q. *What happened to the frog's car when it broke down?*
A. *It got toad!*

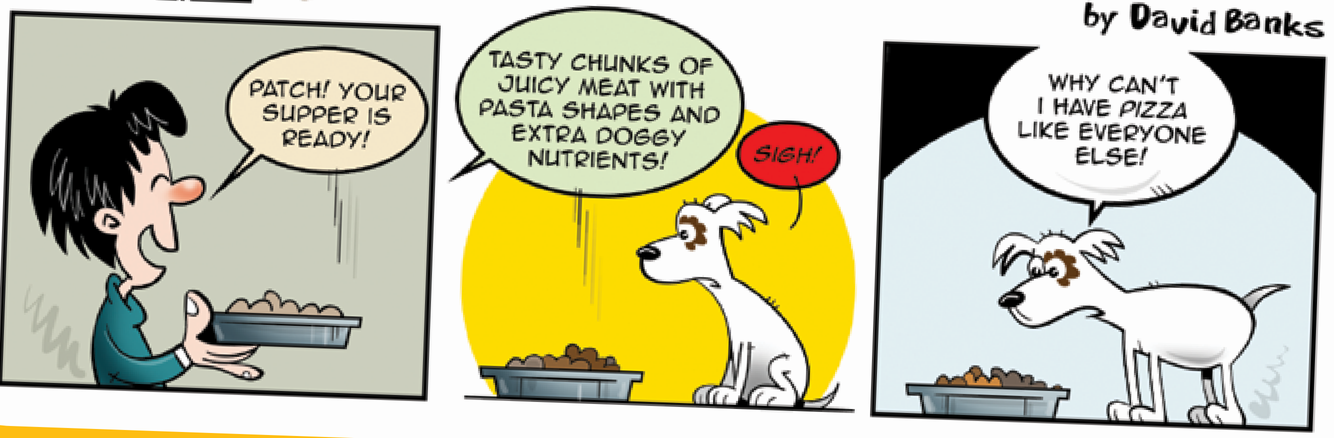
Would you like to answer the Green Leaf Q&A? Contact us at editor@phassociation.uk.com

Amazing Anatomy!

Have you heard about a new app which can take you all around the human body and show you how it works?
'My Incredible Body: For Kids' provides 3D anatomical illustrations, animations and explanations all about our organs, tissues and body systems.
There are sections on the brain and nerves, digestion, the lungs and breathing, our bones and skeleton, kidneys and urine, muscles, circulation and the heart, as well as seeing, breathing, smelling and touching.
With plenty of 3D good graphics, what's not to like!
The app won a 2014 Parents' Choice silver award too and is compatible with iPhone, iPad and iPod touch, and optimised for iPhone 5. It requires iOS 7.0 or later and is available from the App Store. For Android, it requires 2.3 and up, and is available from Google Play.

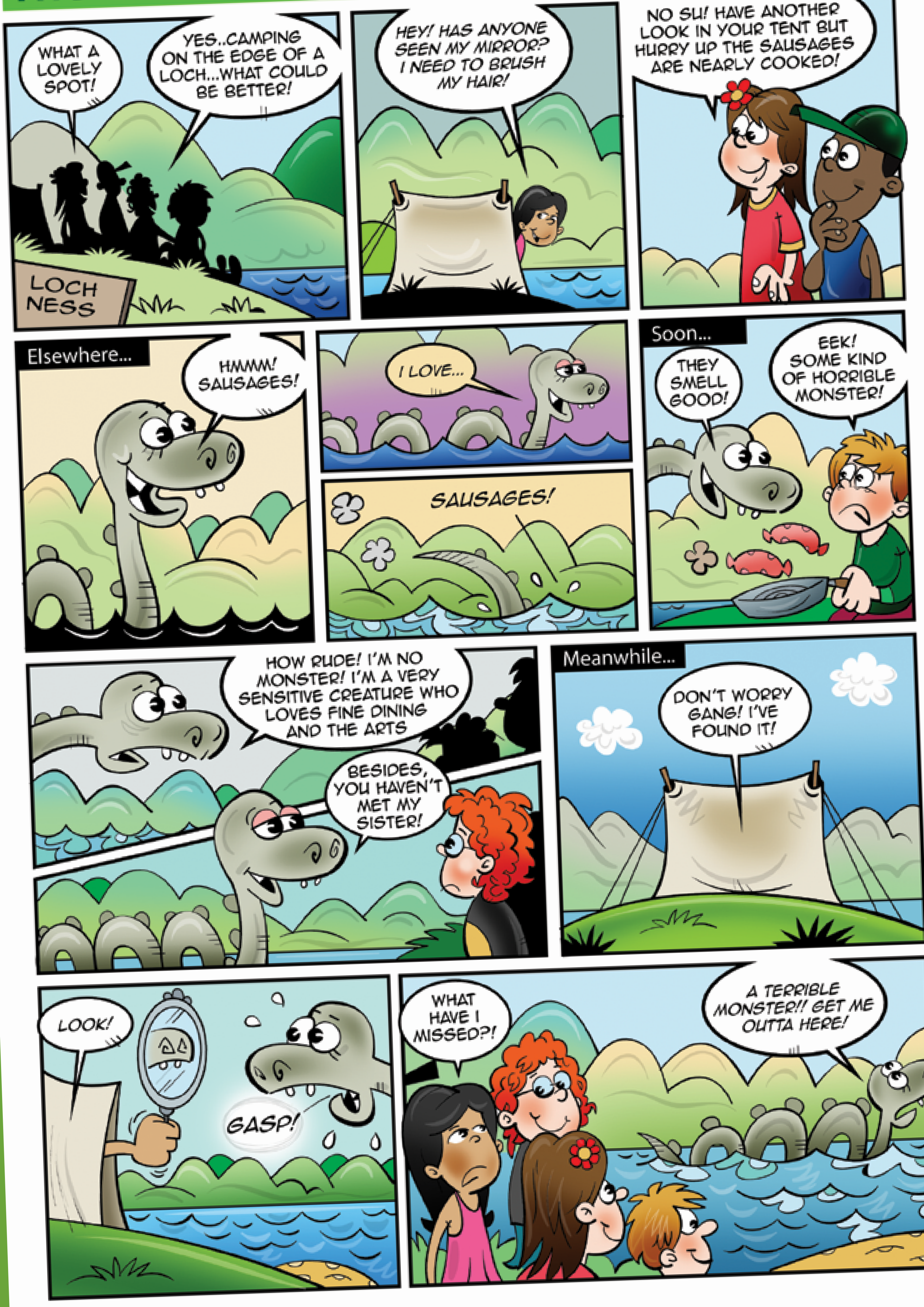
Patch

by David Banks



The Green Leaf Crew

by David Banks



FREE New Booklet Launch

Benefits **booklet**

A new booklet to help people navigate the benefits system has been published by PHA UK.


PHA Benefits Advisor
Shaun Clayton

This is the first time the charity has produced a bespoke guide to benefits for people with PH, their families and carers.

'Signposting for Potential Benefits' has been written by the charity's benefits advisor Shaun Clayton.

The free booklet looks at several aspects of the welfare support system such as the Personal Independence Payment (PIP); Employment and Support Allowance and Carer's Allowance.

It offers practical tips and advice based on research and the experiences of other PHA UK members.

Shaun said: "The booklet was put together in response to the many calls we take at the office asking for advice and support with applications for benefits.

> ***"We hope it will give people a little extra help to understand the system and claim what is due to them. We'd welcome feedback from members and, if the booklet proves useful, we plan to update it and reproduce it in future too."***

Shaun attended Government-recognised training provided by the Child Poverty Action Group (CPAG) on the Personal Independent Payment after it was introduced two years ago. This PHA UK publication was produced in collaboration with CPAG experts too.

To get a free copy of Signposting for Potential Benefits, please e-mail **publications@phassociation.uk.com**

Your Benefits Questions Answered

Benefits **Advisor**

With Shaun Clayton

It has been clear from phone calls to the office and questions asked on social media that benefits is an area of great concern for people affected by PH, whether they're suffering with the condition themselves or have a loved one who is.

That is the reason we have produced our new free booklet for members called 'Signposting for Potential Benefits'.

Since early 2014 we have been developing a deeper understanding of the benefit system at PHA UK and one thing has become clear, it's not perfect. Unfortunately though, it is what we have to work with.

One thing we would always say is, when it comes to making a claim for any benefit always seek advice, whether that is simply by surfing the internet or making calls. There are no silly questions, so please don't be afraid to ask.

And, once you've made an application do not be afraid to chase it up. People sometimes worry this will affect the outcome in a bad way – it won't and unfortunately, there can be delays, so if you feel that it is taking too long, give them a ring.

While filling in the application forms, people tell me they often feel that some of the questions don't accurately depict what they go through on a daily basis.

The problem is that most forms are composed of simplistic questions with tick box answers. It's all very black and white, and most conditions don't live in black and white, and PH is no different. Questions like "Can you climb the stairs?" with answers for you to tick ranging from 'yes no problem' to 'no not at all' don't allow you to say 'yes, but..'. And the more information you can provide them with the better. In this case, we suggest you tick the closest option but mention, maybe at the back of the form, that you have had to answer that particular question like that but a more accurate answer would be...." and then explain your situation. ***This way you have explained everything possible to the governing body.*** *Of course it is up to them whether or not to use all the information provided.*

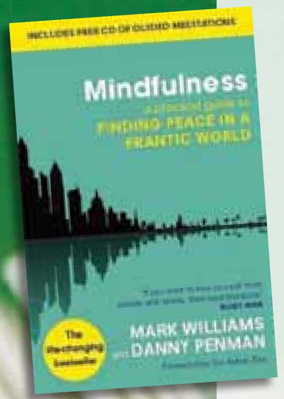
If you are initially rejected though don't be disheartened. Statistics show that within just one governing body, ATOS, there is a 90 per cent successful appeal rate, which is startling. Nine out of 10 people appeal successfully.

We'd like to support applicants to get their claim across as clearly as possible first time. There are many more tips in the publication, please email us on publications@phassociation.uk.com to get your copy.

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

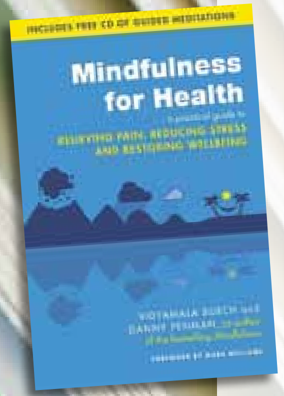
Would you like to join the Emphasis book club and review a book which may be of interest to other Emphasis readers?
If interested, please contact **editor@phassociation.uk.com**



Mindfulness: A practical guide to finding peace in a frantic world by Mark Williams and Danny Penman

I must admit, I was a little sceptical about the subject before I read this book. But, it's nothing to do with crystals and the like and won't turn you into a Buddhist. What it aims to do, is separate you from your worries, so you can think about them calmly and objectively. I loved one review I read which said it should be renamed, "How to cope with the rubbish that life throws at you".
Probably like many people, I had a vague idea of what meditation and mindfulness were, but didn't really understand them properly. This book explains mindfulness and its benefits very clearly. It helps us to understand how our minds work and how, in practical terms, we can rise above things, focus on the now and achieve clarity and peace of mind.
What seems to differentiate it from other books on meditation is that it also provides a very useful eight week programme of meditation which really gives you a sense there is something practical that you can do to bring about change. Eight guided meditations on an accompanying CD are well-scripted, easy to follow and progressive. Thankfully no panpipes, sweeping synthesisers, sounds of the ocean or wistful Californian voice-overs encouraging you to 'make parallel your chakra'! The recordings are every bit as good as the book - the content and style of vocal delivery are just right.
This is a well written, non-fluffy guide to help everyday people who are perhaps worried or stressed learn about and practice a different way of being. It doesn't patronise or over simplify - it's acknowledges the modern and often frantic life we lead. I would highly recommend this book. **Iain Armstrong**

Mindfulness: A practical guide to finding peace in a frantic world
by Mark Williams and Danny Penman, Little Brown Book Group, 2011, ISBN: 9780749953089



Mindfulness for Health: A Practical Guide to Relieving Pain, Reducing Stress and Restoring Wellbeing by Vidyamala Burch and Danny Penman

Mindfulness for Health makes mindfulness simple, practical and accessible. I suggest anyone living with a long standing illness or experiencing aches and pains caused by stress should take a look at it. It is no surprise the book is already a bestseller and won a BMA award last year - it is a well written, practical and credible with a clear scientific approach.
The author Vidyamala Burch's vast personal experience and expertise as a Mindfulness teacher is clear in the wisdom and clarity of the content. Her book strips away the more spiritual elements of meditation that many find off-putting, and roots its approach instead on sound, scientific evidence. It is packed with case histories which illustrate the benefits of mindfulness too.
The book includes an eight-week course, at the end of which you can continue with mindfulness yourself, mixing and matching the meditations that best suit you. Most of the things the course teaches you are common sense, but being made to actively readjust your attitudes each day really does begin to make a difference. The ten minute meditations on the accompanying CD are supportive and easy to use too.
Mindfulness for Health manages to deliver the essential skills and the theory. The technical aspects of meditation and neurobiology are communicated well, without obscuring the 'how to' aspects in the book. The result is a guide to applying mindfulness to both the prevention and management of chronic health conditions and potentially related stress. I'd highly recommended it to anyone with pain, stress or illness or who just wants to learn about mindfulness and how to apply it to daily life. **Iain Armstrong**

Mindfulness for Health
by Vidyamala Burch and Danny Penman, Little Brown Book Group, 2013, ISBN: 9780749959241

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In your next issue of Emphasis...

The next issue of Emphasis is due out this summer and we have planned features:

- Going for a spin – the benefits of cycling with practical tips and a special focus on electric bikes
- Put it in writing – a feature about the therapeutic effects of creative writing and one young woman's moving legacy
- Medical advances – a look back at the progress that has been made so far in tackling PH over the last 15 years

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

You can get involved in Emphasis too:

The Great PHA UK Bake Off - would you like to share recipes and photographs of your favourite fundraising cakes in a tasty summer feature about charity bakes and all things delicious. E-mail us your ideas and photos and we'll publish a selection.

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

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

To get involved with any of the above, please contact editor@phassociation.uk.com

Food for thought.

Using diet to help manage your stress levels

BY JEANNETTE JACKSON

Nutrition cannot 'cure' anxiety but feeling anxious in a body that is tired, sick or stressed can be a very different experience to feeling anxious in a body that feels vibrant, healthy and energised.

A diet rich in healthy, whole foods including complex carbohydrates can help you to feel calmer and satiated for longer, compared to when you eat high processed foods or sugary snacks.

This means your body is better able to support you through difficult times by creating a sense of stability at a core physiological level.

For example you may find your body's ability to 'recover' following a panic attack may be enhanced, or that you feel less exhausted after an attack than you currently do. You may also find that sleep becomes more restful, so that you wake more refreshed.

The food that you choose to eat not only helps to feed and fuel your body but it also has the power to either stimulate or inhibit your central nervous system. Food stimulates the release of neurotransmitters (chemical messengers in the brain) which in turn tell the body to feel relaxed, energised or sleepy.

We have the ability to somewhat manipulate the release of these neurotransmitters and thus initiate sense of calm, sleepiness or energy as we desire. By changing the way we eat we can change the way we feel because most neurotransmitters are manufactured by amino acids from protein foods we consume.

One important neurotransmitter is GABA (Gamma-aminobutyric-acid) which has an inhibitory effect on the central nervous system. It's role is to calm the body down and initiate a sense of peace within the mind and body. It is particularly useful following a fight or flight stress response within the body as GABA helps to 'mop up' the stress chemical cortisol and eliminate it through the urine. Cortisol is a glucocorticoid; a steroid hormone secreted by the adrenal cortex in response to a stressor and high cortisol levels are linked to anxiety and stress.

Foods rich in GABA include

- Bananas
- Beef Liver
- Broccoli
- Brown Rice
- Halibut
- Mackerel (particularly high source of GABA)
- Lentils
- Oats, whole grain
- Oranges, citrus fruits
- Rice bran
- Walnuts

GABA can help you to manage stress and maintain mental focus and so designing your own nutrition plan around these foods could help you counteract the chemicals released during anxiety and panic attacks.

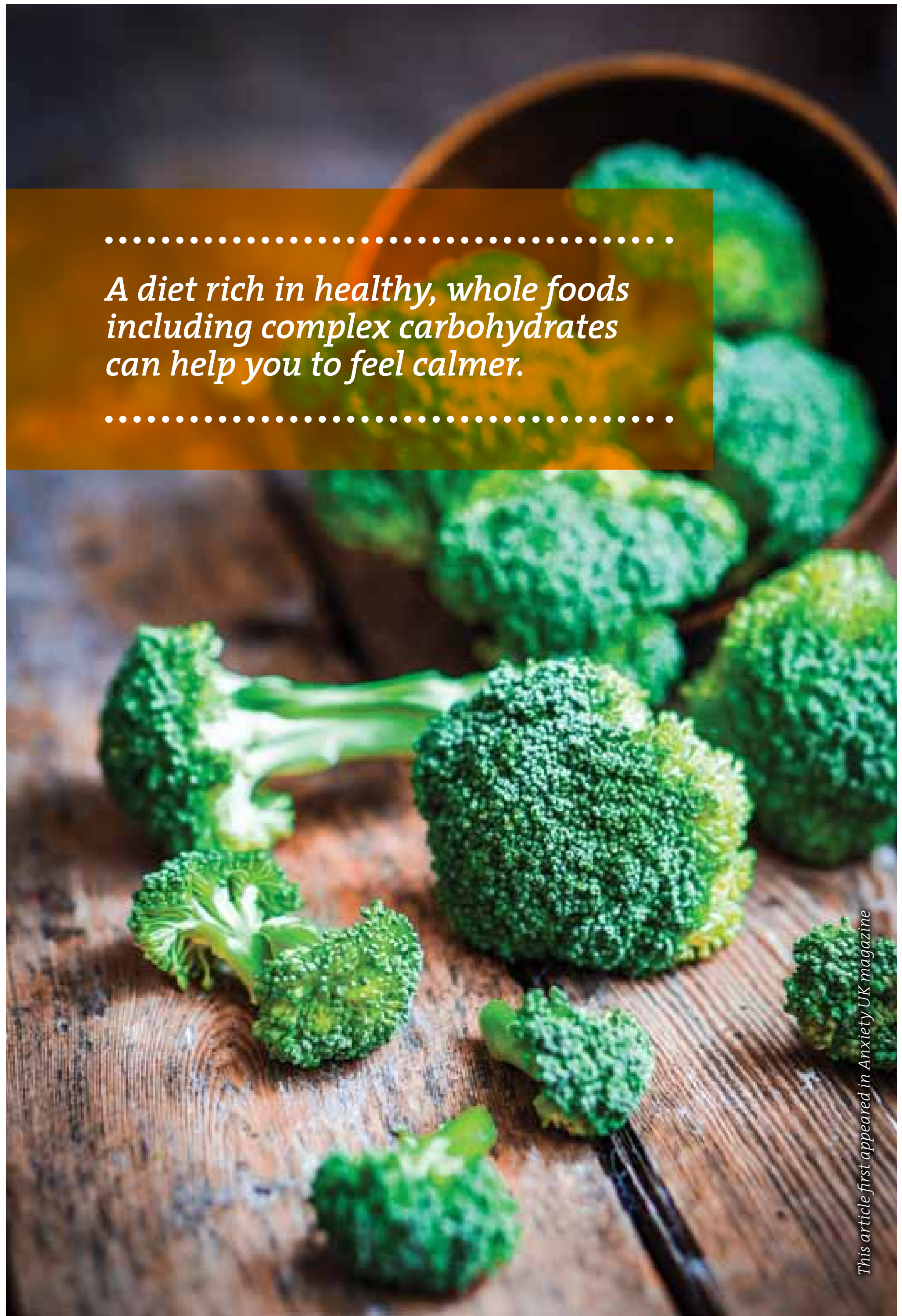
Limiting the amount of caffeine you drink will also help to ensure your brain and body aren't overly stimulated and green tea will make a superb substitute. Although it does contain some caffeine (approximately 35mg per 8oz cup) green tea also contains L-theanine which helps maximise the amount of GABA received by the brain, ensuring that the foods you eat have the impact you desire.

Another consideration in the quest to relax and calm the body is to combine GABA foods with low oxalate foods. Oxalates are a natural 'plant pesticide' and protect fruit and vegetables from infection or from being eaten. Many people can eat oxalate containing foods with no consequences, but for some it can exacerbate feelings of stress and tension as oxalates bind to minerals in the body, in particular magnesium, which has a calming relaxing effect in the body (also helps to reduce muscle cramps). When bound to oxalates the magnesium is less efficient as a muscle relaxer; making you feel more tense than you should be.

Foods high in oxalates include

- Almonds
- Brazil nuts
- Beetroot
- Blackberries
- Carrots
- Cashew nuts
- Celery
- Chocolate
- Cooked tomatoes
- Rhubarb
- Sesame seeds and tahini
- Sweet potatoes

These foods can still be part of a healthy varied diet - just limit their use and opt for high GABA foods instead. ●



> *A diet rich in healthy, whole foods including complex carbohydrates can help you to feel calmer.*

This article first appeared in Anxiety UK magazine

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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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Office hours: 9am to 3pm, Mon to Fri for general enquiries
Tel: 01709 761450
Web: www.phassociation.uk.com
Email: office@phassociation.uk.com
Address: PHA UK, Unit 2 Concept Court, Manvers, Rotherham, S63 5BD

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

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